Symptoms of Abuse in Adults with Severe Learning Disabilities

Final Report to the Dept of Health

Ms Ali. C. O'Callaghan[1] & Professor Glynis H. Murphy

Tizard Centre, University of Kent, Canterbury, CT2 7LZ, UK.

and

Dr Isabel C.H. Clare

Department of Psychiatry (Section of Developmental Psychiatry),
University of Cambridge, CB2 2AH

---

[1] Correspondence

Any correspondence should be addressed to Ali O'Callaghan, the Tizard Centre, University of Kent, Canterbury, CT2 7LZ, UK. E-mail: a.c.o'callaghan@kent.ac.uk

SUMMARY

It is thought that people with a learning disability are particularly vulnerable to abuse. To date, however, research on the effects of abuse has focussed on people with mild learning disabilities. It is clear from such research, and from work on adults and children in the general population, that abuse can have profound and long-lasting effects. Much less is known about its impact on people with a severe learning disability. Such individuals often have extremely limited communication skills, so they may be unable to either understand or express what has happened to them.

This project report describes the methods we used to establish the effects and symptoms of abuse, as experienced by 18 adults with a severe learning disability; the results of the study are presented, together with three case examples. The adults experienced severe abuse of a variety of natures, in both residential care and day service provision. The majority of the alleged abuse perpetrators were staff known to the victim (only two were not staff members).

An initial interview was conducted with carers (mainly parents) of the abuse survivors, to find out background details, including details of the abuse. In following meeting(s), parents were asked about the symptoms their adult sons/daughters exhibited. Respondents were asked 22 questions, 17 of these referred to symptoms of Post-Traumatic Stress Disorder (PTSD), established from DSM – IV (American Psychiatric Association, 1994), while the remaining 5 questions focussed on other physical, psychological and behavioural symptoms not covered in the questions derived from DSM IV. In addition, parents were asked about the survivors' adaptive behaviours, using the Adaptive Behavior Scale (Nihira et al., 1993). For both the symptoms interview and the adaptive behaviour interview, the questions were asked with reference to three time points: in the 3 months immediately before the abuse was disclosed (time 1), in the three months immediately after the abuse was disclosed (time 2) and now/in the last three months (time 3).

The results showed that a very typical pattern emerged: abuse survivors had few problems or difficulties at time 1, major difficulties at time 2 and some recovery by time 3. This pattern was absolutely consistent for symptoms derived from the symptoms interview, for skills measured by the adaptive behaviour scales (ABS, Part I), and for challenging behaviours (measured by the ABS, Part II), though the degree of change varied somewhat for each symptom/behaviour.

In addition, it was found that, for this severe abuse, most alleged perpetrators were interviewed by the police and, in10 of the 18 cases, the alleged perpetrator appeared in court (with convictions in 8 cases). None of the abuse survivors appeared in court as witnesses (they did have severe learning disabilities so this is not surprising). Many abuse survivors were offered therapy, although this was often patchy, often after a major delay and sometimes only as a result of considerable battling by their parents. Few parents were offered help or therapy themselves, though most felt very traumatised, blamed themselves and described themselves as no longer able to trust people.

It was concluded that services have a long way to go, to improve the way they deal with abuse, particularly in relation to families. Services also need to consider how they provide therapy, both for the abuse survivor and the families of survivors.

Those seeking to document symptoms of abuse in people with severe learning disabilities should consider the traditional symptoms of PTSD but also need to examine other skills and behaviours. It seems that the changes in these over time are both alarming and consistent. They illustrate the very considerable burden on abuse survivors and their families over long periods of time.

INTRODUCTION

It is widely documented that both adults and children with learning disabilities have commonly been the victims and survivors of abuse (Brown and Turk, 1995 and Brown, 1999; McCarthy and Thompson, 1997; Churchill et. al., 1996; Walsh & Murphy, 2002). This abuse can take various forms, including sexual, physical, emotional, financial and the deliberate over or under use of medication (Brown, 1999). Research looking at those who perpetrate abuse against adults and children with learning disabilities, shows that the abuse is generally carried out by men and can include family members, care workers (at all levels of seniority), strangers and other men with learning disabilities (Brown et al., 1995). It is clear from research evidence that abuse has historically occurred in families, in institutions, in day and residential settings for adults and children with learning disabilities (Brown, 1999) and sadly continues to be a problem today (Murphy, 2000).

Remarkably few cases of abuse perpetrated against people with learning disabilities are ever prosecuted in the courts, either here or in other jurisdictions (Williams, 1995; Sanders et al, 1995; Brown et al., 1995; Luckasson, 1992). The reasons for this include the frequent failures of police, carers, health and social services departments in taking victims seriously and being aware of the possibilities of abuse, as well as the difficulties of obtaining evidence, especially from severely disabled victims. Charities, services and advocacy groups have taken steps towards abuse prevention; for example, VOICE, Mencap and Respond in their recently published report *Behind Closed Doors* (2001) documented some of the changes needed to increase adult protection, including changes in legislation to strengthen laws on sex offences. Criminal justice legislation for vulnerable victims recently enacted in England and Wales will hopefully increase the prosecutions in criminal court for abuse against people with learning disabilities. The Home Office report, *Speaking Up for Justice* (Home Office 1998), acknowledged the vulnerability of adults with learning disabilities as being based on the imbalances of power in their lives (in Murphy & Clare, 2001). The introduction in England and Wales of the *Youth Justice and Criminal Evidence Act 1999*, means that a range of special measures can be applied to support vulnerable victims (or intimidated witnesses) in court, including, for example, the use of video evidence.

In increasing numbers of cases of abuse, action is being considered in civil courts as well as in criminal courts (Holman, 2001). For compensation to be awarded in a civil court, it must be demonstrated that the abuse has caused the survivor psychological distress. Traditionally, this distress has been conceptualised in terms of Post Traumatic Stress Disorder (PTSD) according to an established psychiatric classification system (DSM–IV, American Psychiatric Association, 1994). The symptoms of PTSD, which have been well established in children and adults without learning disabilities (Joseph et al., 1997), include recurrent recollections, flashbacks and dreams associated with the traumatic incident(s), an exaggerated startle response, avoidance of thoughts, feelings and places associated with the trauma, feelings of detachment and estrangement, sleep problems, anger and depression and difficulty concentrating (Joseph et al., 1997; Muss, 1991; Yule, 2000). When the cause of the trauma is abuse, and sexual abuse in particular, the consequences include difficulties with intimate situations (Kennerley, 2000), successive fleeting sexual encounters (Yule, 2000) and self-harm (Boudewyn and Liem, 1995). However, with few exceptions (for example, Davison et al., 1994; Howlin and Clements, 1995; Sobsey, 1994), very little systematic information is available on the effects of abuse on people with learning disabilities and, in particular, on those with severe learning disabilities. It may be that people with severe learning disabilities experience rather different symptoms following trauma than do non-disabled (or mildly disabled) adults who can communicate their experiences and feelings through language.

This project aimed to look at the symptoms of abuse experienced by people with severe learning disabilities who have survived abuse. Traditionally, in investigations into symptoms of abuse, survivors would themselves be interviewed about the abuse and trauma (Joseph et al., 1997; Yule, 2000), often using a measure such as the self-report scale, the *Revised Impact of Events Scale* (Horowitz et al., 1979). The survivors of abuse in this project, however, would have been unable to respond to such questions, as they do not have the necessary communication skills to describe their experiences in a meaningful way to allow for an assessment of symptoms.

One of the few studies that has investigated symptoms and effects of abuse in people with severe learning disabilities is that of Howlin and Clements (1995). They examined the changes in behaviour of children with autism who attended a school where alleged abuse had occurred. The method employed in this study is based on an adaptation of Howlin and Clements'(1995) methodology, where parents and carers of children with autism were interviewed about the behaviour of the children at specific time points, in order to document behaviours likely to be the result of trauma.

METHOD

We planned to interview the carers of people with severe learning disabilities who had been allegedly abused, using:

- An initial interview, to gather basic demographic data
- A semi-structured interview, to examine the symptoms of abuse
- A standardised measure of skills and behaviour

We wanted to be sure that the symptoms interview included questions about all the symptoms that were relevant to people with severe learning disabilities, as opposed to just questions about symptoms that would be included in PTSD symptom lists for people without disabilities (see **Appendix 1, Table A** for the PTSD symptoms from DSM-IV). We therefore conducted some preliminary work, to develop this interview measure.

Preliminary work: Developing the Symptoms Interview

In formulating the types of questions to be considered in a symptoms interview, it was important to ensure that all possible relevant areas were covered. We therefore met with a group of ten adults with mild or moderate learning disabilities who were members of *Speaking Up!* (a self-advocacy group), who were keen to help us with the development of an interview. We were aware that participants were giving up their time and that the topic was a sensitive one, so great care was taken to seek potential participants' consent. All participants from *Speaking Up!* were paid for their time at the accepted rate. We also provided lunch for participants after the meeting, partly to thank them, but also to ensure that no one was unduly upset after the discussion of abuse (the lunch allowed time for participants to have a quiet word with us if they so wished).

We planned to introduce the topic of abuse to *Speaking Up!* , explain why we were interested in it and ask people to think about how abuse might make people with learning disabilities feel. We were concerned to encourage a general discussion of the topic and not to focus on personal experiences. However, we were aware that it was possible that, during the focus group, new disclosures of abuse might occur. Therefore, at the beginning of the session, we told those attending the group that, if they said that they were being abused or were in danger, we would need to talk to others about this (such as their care managers and/or the director of *Speaking Up!*). We also provided group members with an information sheet giving details of support groups, organisations and help lines for abuse survivors (including those who specifically work with people with a learning disability).

The topic of abuse was introduced by asking the participants to look at 3 pictures: one of a consenting couple cuddling and two of non-consensual interactions (a man hugging a woman, who is recoiling; a man stealing a woman's handbag). Following the discussion of these pictures, they were asked to discuss the different kinds of abuse and how people in the pictures (and other people) might feel. Then, members constructed an extensive list of the kinds of abuse and the sorts of symptoms and effects they might expect to find subsequent to abuse, in adults with severe learning disabilities. They were asked to think particularly about the symptoms which might be expected of men and women whose support needs were greater than their own. A summary of the areas/symptoms suggested by the self-advocates was later typed and returned to *Speaking Up!* for additional comments (see **Appendix 1, Table B**). The symptoms highlighted by *Speaking Up!* were then included within our final 22 question about symptoms (see Table 1 below and **Appendix 2**).

Table 1 The complete list of 22 question topics in the symptoms interview

Question no. in final symptoms interview	Code number in DSM-IV	Symptom description
Q1	B1	Recurrent and intrusive distressing recollections (such as thoughts or memories or images)
Q2	B2	Recurrent distressing dreams of the event (eg. nightmares, waking up crying and screaming)
Q3	B3	Acting or feeling as though the traumatic event were recurring (e.g. reliving or re-enacting the events, panic attacks, hallucinations, flashbacks)
Q4	B4	Intense psychological distress at exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event (e.g. people, voices, sounds, smells or objects that remind them of the event or particular times of day/night or fear of being touched)
Q5	B5	Physiological reactivity on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event (e.g. being ‘frozen’ to the spot, crying, sweating, change in breathing, trance-like state in response to cues/reminders)
Q6	C1	Efforts to avoid thoughts, feelings, conversations associated with the trauma (e.g. leaving the room when it is discussed, refusing to respond to any questions about the abuse, becoming agitated when crime or abuse is discussed or when it is on TV)
Q7	C2	Efforts to avoid activities, places or people that arouse recollections of the trauma (eg avoiding or

		refusing to see/go to certain people, places, activities)
Q8	C3	Inability to recall an important aspect of the trauma (eg. difficulty in remembering details of the events)
Q9	C4	Markedly diminished interest or participation in significant activities (eg. loss of interest in mealtimes, indoor/outdoor activities, remaining in bed or in one room for prolonged periods, loss of interest in people or world generally)
Q10	C5	Feeling of detachment or estrangement from others (eg. avoiding interacting with others, or avoiding sitting near others, difficulty trusting others, ignoring people, saying they want to get away)
Q11	C6	Restricted range of affect (eg. unable to show loving feelings or affection, lack of responsiveness to close family)
Q12	C7	Sense of a foreshortened future (eg not making plans, saying they felt their world had ended, saying they wouldn't live for long)
Q13	D1	Persistent high arousal – difficulty falling or staying asleep (eg waking frequently at night, walking around at night, taking a long time to get to sleep)
Q14	D2	Persistent high arousal – irritability or outbursts of anger (eg. destroying own property, lashing out, throwing objects, hitting, etc)
Q15	D3	Persistent high arousal – difficulty concentrating (on tasks they enjoy or activities or people)
Q16	D4	Persistent high arousal – hypervigilance (eg constant checking of locks on doors or windows, checking who is around, appearing fearful if others have to go out)
Q17	D5	Persistent high arousal- exaggerated startle

		response (e.g. seeming startled when someone enters the room, being ‘jumpy’ at home or in public)
Q18	N/A	Any self-destructive or self-harming behaviours
Q19	N/A	Unusual pattern of emotional behaviour (eg being very depressed, withdrawn or tearful)
Q20	N/A	Unusual pattern of physical illnesses (eg. colds, flu, diarrhoea, headaches, unexplained pains, increased seizures)
Q21	N/A	Other inappropriate behaviours (such as smearing faeces, wetting & soiling, excessive bathing, obsessive behaviours (like hoarding), inappropriate sexualized behaviour)
Q22	N/A	Needing unusual amounts of help on everyday tasks (eg on eating, drinking, dressing, bathing, cooking, leisure activities)

In addition to meeting with members of *Speaking Up!*, we met with two families of abuse survivors with severe learning disabilities, contacted through VOICE UK, who consented to be part of the study. During meetings with these two sets of parents, we went through a draft initial interview (regarding demographic data, details of the abuse and legal sequelae), in order to consider the appropriateness of the interview. Parents were asked to comment upon the interview form, the interview situation and to consider questions that they believed were missing. In addition to this initial interview, we left parents with a copy of our first draft of the symptoms interview (see below) to comment upon.

The main lesson learnt from working with self-advocates and parents at this stage was the devastating impact of the abuse, on both survivors and families.

Main study

Participants

The sensitive nature of the topic and the severe learning disabilities of the abuse survivors meant that we would have major difficulties interviewing the survivors themselves. In attempting to do so, we might also have caused considerable harm to the abuse survivors, especially as we were not funded to provide therapy (and not all survivors were receiving therapy). We therefore decided that interviews would be with parents/carers only, and we would not interview the abuse survivors themselves.

We were concerned only to approach carers/families were there was good evidence that abuse of the person with severe learning disabilities had taken place and therefore families were sought where cases had been reported to the police and/or gone to court. These turned out to be very difficult criteria to fulfil: 18 participants were finally recruited, through solicitors working in this field.[*]

Procedure

Families were approached by the solicitors to find out if in principle they might be prepared to take part and consent letters were then sent to the families. Three families approached by us declined and 18 agreed to participate.

Researchers subsequently met with parents/carers of the adult survivors of abuse on 2 - 3 occasions. This was generally at the family home of the parent/carer, although in a couple of cases interviews were held at the researcher’s place of work (the university), at participant's request.

Measures

1. *Initial interview*: the initial interview focused primarily on demographic information about the survivor; the nature and extent of the abuse; the legal consequences for the alleged perpetrator; and the support offered to and received by both the survivor and his/her family.

---

[*] Families were not approached if there was any suspicion that they themselves were possibly the perpetrators of abuse.

2. *Symptoms of abuse interview*: the final schedule comprised, first, a number of questions designed to elicit whether or not the survivor met the criteria under DSM-IV criteria for PTSD (see **Appendix 1, Table A**, American Psychiatric Association, 1994). To fulfil the diagnosis, the person must have experienced a traumatic event and experience at least 6 symptoms from the list, with at least one from B, 3 from C and 2 from D, to a degree which causes clinically significant distress or impairment.

   Five additional questions were also included, reflecting the ideas and information gained during the development phase (see above under **Preliminary work**) to elicit further psychological, physiological and behavioural symptoms.

   For each of the 22 questions, informants rated how often the symptom had occurred on a six point scale (from 'never' to 'extremely often, every day'). They also rated the degree of distress for each symptom on a four point scale (from 'none' to 'extreme upset, significant disruption to life').

   In order to document the impact of the abuse over time, the informants were asked about the survivor's symptoms at three time points: (i) *Before the abuse (time 1)* - in the three months before the informant learned of the abuse; (ii) *Immediately after the abuse (time 2)* - in the three months immediately following the discovery of the abuse; and (iii) *Now (time 3)* - in the three months preceding the interview.

3. *Skills and 'challenging behaviours'*: in order to assess the impact of the alleged abuse on the survivor's skills and 'challenging behaviours', the informants were interviewed in order to complete both parts of Adaptive Behaviour Scale (Residential and Community, 2nd Edition, Nihira et al., 1993). Again, the informants were asked about the survivor at the three time-points (as for the symptoms interview).

4. *Life events*: since it was possible that any of the survivors' difficulties reflected some incident(s) other than the abuse, information was collected on events in

the lives of the person with learning disabilities and his or her immediate family, using an adapted and extended version of the life events checklist from the Mini-PAS-ADD (Prosser et al., 1996). Informants were asked to date each event they reported so that we could establish its timing in relation to the abuse.

Reliability

The standardised schedule used in the study (ABS, part I and II) has well-established reliability (Nihira et al., 1993) and was not re-checked for reliability. However, we were concerned to establish the reliability of other data.

The lengthy nature of the interviews and the geographical spread of the informants meant that it would be difficult for two interviewers to be present at many interviews. We therefore proposed to informants that we tape interviews, so as to allow a second rater to code them, for reliability purposes. However, it was decided in the end that it would be inappropriate to tape interviews because of the anxiety shown by parents during interviews about where the content of the interviews would be going, who would have access to what was written, where interviews schedules would be locked and whether the interviewer was recording the interviews. In one case a carer was so anxious that the interviewer may have a tape recorder present, that she asked on 4 occasions whether the interviewer had a tape recorder with her. Of 3 parents/carers who were asked about whether they would be willing for the interview to be taped, all declined. It was therefore impossible to ask a second person to rate and score interviews based on taped recordings. Accordingly all reliability data resulted from interviews where two interviewers were present (17% of participants had two interviewers present, as well as both of the two pilot interviews). Percentage agreement ranged from 98-100% - see **Table C in Appendix 2**, for details.

The possibility of mailing out completed interviews for informants to check was also considered. However, this approach was rejected because of the degree of distress shown by informants in interviews – it was felt inappropriate to prolong this by contacting them again later with material they would need to check.

RESULTS

The participants

Families and carers were recruited through solicitors who were known to be dealing with cases of abuse against people with severe learning disabilities (see under **Method**). There were 18 participants with learning disabilities who had allegedly been abused; 17 families/carers were interviewed (since one person was the mother of two abuse survivors). Over 80% of participants came from London/south east England and all carers coded themselves as White British. Interview information was mainly provided by the mother or the mother and father of the abuse survivors. One sister also acted as informant. Only one carer who was not a family member took part.

In all, then, there were 18 abuse survivors with learning disabilities; 9 of the 18 were women and 9 were men. Their mean age at the time of the interviews was 30.8 years (s.d. 11.0).

Informants reported the abuse survivors as having severe learning disabilities in 16 cases and moderate learning disabilities in 2 cases (but see also the ABS results below). According to the informants, the causes of the abuse survivors' disabilities were genetic in 7 people (including 3 people with Downs Syndrome and 4 with other genetic causes); unknown in a further 7 people; perinatal (anoxia) in 1 person; post-natal in 3 people (meningitis in 2 and severe prematurity in 1). The abuse survivors also had a number of health problems, including mental health needs, epilepsy and physical health problems (see table 2). Of the 15 with health problems, 6 informants said these had started before the abuse and 9 said they had started after the abuse.

Table 2: Abuse survivors' disabilities and health needs (according to informants)

	Abuse survivors disabilities and health needs
Mobility	8 of the 18 had mobility difficulties (2 of these 8 were unable to walk unaided)
Hearing & vision	6 had hearing difficulties and 5 had visual impairments
Epilepsy	7 of the 18 had epilepsy
Autistic spectrum disorder	6 had been diagnosed as people with autism and 2 were considered to be on the autistic spectrum
Mental health needs	5 were receiving medication for the treatment of depression
Psychiatric admissions	None had had admissions to hospital for treatment of a psychiatric disorder prior to the alleged abuse; 3 had been admitted following alleged abuse
Other health needs	Asthma (4), Tourette's Syndrome (1), gastrointestinal/urinary/bowel disorders (3), pneumonia (1), overweight (1), underweight (4)

The Abuse

Only three of the informants initially heard about the possibility of their son or daughter having been abused as a result of immediate and direct contact from a professional (e.g. home manager or care manager or police). The remainder said that they had first realised that abuse may have taken place as a result of disclosure by the person themselves (1), symptoms in the person themselves (2), disclosure by another victim (1), disclosure by the media (3 cases), contact with them years after the abuse from a social worker or investigating team (3), or by some other means (5). The latter included being informed of abuse by neighbours of the home where the victim lived (1), receiving a letter from alleged abusers claiming their innocence (1), through the abuse survivor being found to be pregnant (1).

The abuse had occurred in long term residential placements in 9 cases, in respite homes in 7 cases, in day services in 1 case and outside services in 1 case. The mean age of the abuse survivors when the abuse started was 19.4 yrs (s.d. 9.0, range 7yrs to 37 yrs). For some abuse survivors the abuse was thought to have been short-lived; for many, it continued for years. The abuse was thought to have lasted for 1 or 2 nights in 4 cases, less than 6 months in 1 case, 1-3 years in 1 case, 4-10 years in 9 cases and for over 10 years in 1 case (for 2 people parents were unable to estimate how long the abuse lasted). The abuse had finished less than 3 years before the current interview in 5 cases, 4-5 years ago in a further 5 cases, 6-10 years ago in 6 cases and longer ago than that in 2 cases.

In all cases the abuse appeared to take multiple forms. Sexual abuse had occurred in 15 cases (including penetration in 9 cases), physical abuse in 9 cases (including being locked in a room or a cage, being pinched, burnt by cigarettes, kicked, slapped, hit/punched, being made to stand outside in the cold), emotional abuse in all 18 cases (such as threats against the safety of the person him/herself or family members), neglect in 11 cases (including not being washed or changed, being left when fallen, looking uncared for), financial in 6 cases (such as money and/or possessions being taken from the person) and over/under-medication in 2 cases. In the majority of cases (13) there was thought to be more than one perpetrator. Similarly there were thought to be more than one victim in almost all cases (15 of the 18), with 10 or more victims thought to be involved in 11 of the cases. The perpetrator was thought to have been a staff member in 16 cases, an acquaintance in 1 case and another person with learning disabilities in 1 case.

The physical consequences of the abuse included pregnancy and abortion (1 case), tests for sexually transmitted diseases (3 cases), bruises and loss of teeth (8 cases), visits to casualty (3 cases). The legal consequences involved police interviewing of the alleged offender in 17 cases. There were subsequent court proceedings in 10 cases and convictions in 8. The majority of parents still felt angry (13) or unsatisfied (2) about what happened to the alleged perpetrators, even where they were tried in court. Only two of the abuse survivors (one man and one woman) were asked to appear in court: in one case, the man attended court on the first day but was considered by the judge to lack capacity to act as a witness and so did not give evidence; in the other case, the woman did not actually attend court because it was eventually decided she too lacked capacity to be a witness. Only 3 of the parents/carers attended court (none to give evidence). In most cases (17), civil action was still due to be taken and in one case further criminal proceedings were also being contemplated.

In terms of the consequences for the abuse survivors' daily lives, 16 of the 18 moved placements following the abuse. Abuse took place in long-term residential settings in 9 cases and in 8 of these the abuse survivors moved placement (in the other case, the person did not move but the alleged abuser was suspended). Abuse took place in a respite care setting in 7cases and in all these the individuals stopped using the respite provision when it became clear that abuse had taken place (the home was subsequently closed). Three of those 7 abused in respite now receive care in a long-term residential facility and four are now at home with their families permanently (i.e. the families no longer use respite care). In the one case of abuse in a day placement, the abuse survivor moved. Finally, in the case of abuse involving an acquaintance (met through the local church), the abuse survivor did not move placement.

As regards therapeutic services, 12 of the 18 abuse survivors had therapeutic services of some kind following the abuse (some had several different services). Eleven had generic services (eg from their GP). Four people had services from their local community Learning Disability team (LDT) and 4 had specialist services (from an organisation specialising in post-abuse work. In terms of the types of therapeutic support that survivors received, 7 received psychiatric support (in 5 cases the treatment included medication), 4 received clinical psychology services, 8 received counselling and one received Art Therapy. According to the informants, some of these services were not useful (counselling in 3 cases, the GP in one case, medication in one case).

The parents themselves were rarely offered services of any kind: only 6 of the 18 had been offered any services and only 3 of these found the services helpful. Usually these services were from generic facilities, such as GPs (5 cases) or from organisations specialising in post-abuse support (5 cases). None received help from clinical psychologists, 4 received counselling and 1 received help from a psychiatrist. Not all of the parents wanted any services of course (n=2) and some parents felt distrustful of the services offered, especially when they came as part of an abuse inquiry which they felt was a ‘cover up’.

Most of the parents said they felt deeply changed by the experience of their son/daughter having been abused. In many families, there were multiple problems in relation to both the parents/carers and siblings. Of those interviewed, 15 said they now felt distrustful of people in general and 1 person felt distrustful of people in authority. Most parents/carers said they felt guilty (14 of the 18), often because they had placed the son or daughter (or sibling) in the residential care home or respite care home and/or because that they had not spotted the signs of abuse earlier. Some parents/carers felt the experience had caused them to develop mental health problems: 6 said they had become seriously depressed, 2 said they had a ‘breakdown’ and 4 said they felt ‘near breakdown’. Five had problems sleeping. Three felt they had developed personal problems as a result, such as alcohol abuse or excessive spending or over-eating, which they felt unable to control. Five said the experience had caused problems in their relationships with their partners and seven felt the experience had impacted negatively on siblings of the abuse survivor (in one case, an abuse survivor had later abused a sibling).

Parents had a number of pieces of advice for other parents, including not being too trusting of staff, i.e. recognising that abuse was a possibility (7 families), respecting the person with learning disability’s attempts to communicate about abuse (2 families), doing spot checks on placements and asking probing questions in placements (3 families), looking out for unusual behaviours in the person with learning disabilities, such as a sudden refusal to go to a placement or sudden soiling (4 families), trusting ‘gut feelings’ if worried about abuse or worried about particular staff members (2 families), ensuring services do police checks and make sure staff do not work alone (2 families).

Parents also had suggestions for how services could be improved, such as more spot checks and unannounced inspection visits (10 families), more qualified staff and staff training (9 families), better police checking and taking up of more references for staff before employing them (11 families), more open cultures so that whistle-blowing would occur (8 families), informing all families using a service when a case of alleged abuse had occurred (5 families). Two families also objected to the fact that abusive services would often re-open under a new name and two families even felt there was a case for having plain clothes police people on site in services. Almost all families felt services could react better when abuse was disclosed, for example, offering immediate help to the service user and family (11 families) being more communicative with families and ensuring better clinical services were available.

Symptoms interview data

There were 22 questions about symptoms of abuse (see Table 2). The Tables below show the number of abuse survivors who were said to suffer from each symptom at each of the three time points. For convenience the results are divided into those concerning recollections/reliving of the trauma (B1 to B5 in DSM-IV) in Table 3, those concerning avoidance (C1 to C7 in DSM-IV) in Table 4, those concerning increased physiological arousal (D1 to D5 in DSM-IV) in table 5 and the remainder (added questions, which were not in DSM-IV) in Table 6.

It can be seen from Table 3, Table 4, Table 5 and Table 6 that, typically, the abuse survivors had no or very few difficulties at time 1 (before the abuse); they had considerable problems at time 2 (immediately after the abuse was disclosed); their difficulties had somewhat abated by time 3 (at the time of the interview). The pattern is very predictable across symptoms, with a major shift in frequency of symptoms at time 2. There were a few symptoms, however, where the increase in symptoms at time 2 seemed less extreme: for example, symptom 12 (foreshortened future) in Table 4, symptom 15 (problems concentrating) in Table 5, symptom 22 (need for help) in Table 6. It is perhaps unsurprising that these symptoms showed fewer changes: all are difficult to observe in people with severe learning disabilities (in the first case (foreshortened future) because communication difficulties may mean it is difficult for the person to express their sense of the future; anyway; in the second and third cases, because people with severe learning disabilities often have concentration difficulties and need considerable help, throughout their lives).

For each symptom, information was also obtained on the level of distress (none, mild, moderate, severe and extreme) caused by the symptom, at each point in time (time 1, time 2, time 3). The results for levels of distress or severity of each symptom paralleled the results for frequency of symptoms almost exactly (see Tables D, E, F, G in the Appendix for details).

Table 3: Symptoms of re-experiencing the events (recollections, flashbacks, memories)

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q1 (recollections)			
Never/rarely	100%	35.7%	46.7%
Occ. /fairly often	0%	14.3%	20.0%
Very/extremely often	0%	50.0%	33.3%
Q2 (dreams)			
Never/rarely	88.9%	17.6%	70.6%
Occ. /fairly often	11.1%	29.4%	17.7%
Very/extremely often	0%	53.0%	11.7%
Q3 (flashbacks)			
Never/rarely	100%	29.4%	68.8%
Occ. /fairly often	0%	23.5%	6.3%
Very/extremely often	0%	47.1%	25.1%
Q4 (distress at cues)			
Never/rarely	100%	31.3	29.4%
Occ. /fairly often	0%	0%	23.5%
Very/extremely often	0%	68.7%	47.1%
Q5 (physiological response to cues)			
Never/rarely	100%	44.4%	61.1%
Occ. /fairly often	0%	5.6%	16.7%
Very/extremely often	0%	50.0%	22.3%

Table 4: Symptoms of avoidance

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q6 (leaving room if abuse mentioned)			
Never/rarely	100%	55.6%	41.2%
Occ. /fairly often	0%	5.6%	17.7%
Very/extremely often	0%	38.9%	41.1%
Q7 (avoiding cues)			
Never/rarely	100%	29.4%	41.2%
Occ. /fairly often	0%	0%	5.9%
Very/extremely often	0%	70.5%	52.9%
Q8 (unable to recall)			
Never/rarely	100%	84.6%	91.7%
Occ. /fairly often	0%	0%	0%
Very/extremely often	0%	15.4%	8.3%
Q9 (loss of interest in activities)			
Never/rarely			
Occ. /fairly often	100%	23.5%	50.0%
Very/extremely often	0%	0%	16.7%
	0%	76.4%	33.3%
Q10 (avoiding people)			
Never/rarely	100%	23.5%	35.3%
Occ. /fairly often	0%	17.6%	23.5%
Very/extremely often	0%	58.8%	41.1%
Q11 (restricted affect)			
Never/rarely	81.3%	31.3%	50.0%
Occ. /fairly often	6.3%	12.5%	12.5%
Very/extremely often	12.5%	56.3%	37.5%
Q12 (shortened future)			
Never/rarely	60%	21.4%	33.3%
Occ. /fairly often	6.7%	14.3%	13.3%
Very/extremely often	33.3%	64.3%	53.3%

Table 5: Symptoms of persistent increased arousal

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q13 (difficulty falling/staying asleep)			
Never/rarely	77.8%	23.5%	50.0%
Occ. /fairly often	22.2%	17.6%	16.7%
Very/extremely often	0.0%	58.8%	33.3%
Q14 (irritable/angry)			
Never/rarely	88.9%	33.3%	44.4%
Occ. /fairly often	11.1%	22.2%	38.9%
Very/extremely often	0.0%	44.4%	16.7%
Q15 (problems concentrating)			
Never/rarely	41.2%	23.5%	23.5%
Occ. /fairly often	23.5%	17.6%	29.4%
Very/extremely often	35.2%	58.9%	47.0%
Q16 (checking behav.)			
Never/rarely	100%	55.6%	61.1%
Occ. /fairly often	0.0%	0.0%	11.1%
Very/extremely often	0.0%	44.4%	27.8%
Q17 (exagg. startle)			
Never/rarely	100%	50.0%	50.0%
Occ. /fairly often	0.0%	11.1%	16.7%
Very/extremely often	0.0%	38.9%	33.4%

Table 6: Other psychological and behavioural symptoms

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q18 (self-harm)			
Never/rarely	88.2%	37.5%	56.3%
Occ. /fairly often	11.8%	12.5%	25.0%
Very/extremely often	0.0%	50.0%	18.8%
Q19 (emotional)			
Never/rarely	94.4%	22.2%	27.8%
Occ. /fairly often	5.6%	11.2%	27.8%
Very/extremely often	0%	66.7%	44.4%
Q20 (physical illnesses)			
Never/rarely	94.4%	61.1%	76.5%
Occ. /fairly often	5.6%	0.0%	5.9%
Very/extremely often	0.0%	38.9%	17.6%
Q21 (other inappropriate behav.)			
Never/rarely	94.4%	27.8%	38.9%
Occ. /fairly often	5.6%	0.0%	22.3%
Very/extremely often	0.0%	72.2%	38.9%
Q22 (need for help)			
Never/rarely	47.1%	23.5%	17.6%
Occ. /fairly often	35.2%	17.6%	29.4%
Very/extremely often	17.6%	58.9%	53.0%

A series of (non-parametric) anovas, using the Friedman test, were conducted to test for changes over time (time 1, 2, 3) in the frequency of each of the 22 symptoms in the symptom interview. A similar set of analyses was performed to examine changes over time (time 1, 2, 3) in the level of distress or severity for each symptom. The results are shown in Table 7. It can be seen that all the changes over time were statistically significant, with the exception of changes in the frequency and severity of inability to recall aspects of the abuse (Question 8), changes in the frequency of poor concentration (Question15) and changes in the frequency and severity of physical illnesses (Question 20).

Adaptive Behaviours

Carers were interviewed using the Adaptive Behaviour Scales (ABS), parts I & II, regarding their son's/daughter's skills and behaviours at the three time points (time 1 before the abuse, time 2 after the abuse and time 3 now) - see Method section. The raw scores for the ABS were added to provide domain scores and then factor scores in the usual way (see Nihira et al., 1993). There are 10 domain scores in Part I (independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, prevocational/vocational activity, self-direction, responsibility and socialisation). There are 8 domain scores obtainable in Part II (social behaviour, conformity, trustworthiness, stereotyped & hyperactive behaviour, sexual behaviour, self-abusive behaviour, social engagement and disturbing interpersonal behaviour). The five factors are made up as follows: the first three factors, Personal Self-Sufficiency (Factor A), Community Self-Sufficiency (Factor B) and Personal-Social Responsibility (Factor C) summarise adaptive behaviours in self-care, in the community and social behaviours respectively, from part I of the ABS. The last two factors, Social Adjustment (Factor D) and Personal Adjustment (Factor E), reflect maladaptive or challenging behaviours, from part II of the ABS.

The mean domain scores (and s.d.s) for time 1, time 2 and time 3, are shown in Table 8 (part I domains) and Table 9 (part II domains), together with the results of non-parametric analyses of variance. It can be seen that there are significant changes over time in 4 of the 10 domains from part I and in all 8 domains from part II.

Table 7. Significance of changes over time in frequency and severity of symptoms

Symptom (Q1 to Q11)	**Freq. of symptoms - chi sq (& p)**	**Level of distress/severity of symptoms - chi sq (& p)**	**Symptom (Q12 to Q22)**	**Freq. of symptoms - chi sq (& p)**	**Level of distress/severity of symptoms - chi sq (& p)**
Q1 (recollections)	16.3 (p<0.001)	20.0 (p<0.001)	**Q12 (shortened future)**	8.3 (p<0.02)	8.3 (p<0.02)
Q2 (dreams)	23.2 (p<0.001)	23.2 (p<0.001)	**Q13 (difficulty falling/staying asleep)**	16.1 (p<0.001)	17.8 (p<0.001)
Q3 (flashbacks)	19.6 (p<0.001)	22.5 (p<0.001)	**Q14 (irritable/angry)**	21.7 (p<0.001)	18.1 (p<0.001)
Q4 (distress at cues)	20.9 (p<0.001)	21.7 (p<0.001)	**Q15 (problems concentrating)**	5.2 (n.s.)	7.0 (p<0.05)
Q5 (physiological response to cues)	17.5 (p<0.001)	17.5 (p<0.001)	**Q16 (checking behav.)**	14.9 (p<0.001)	15.1 (p<0.001)
Q6 (leaving room if abuse mentioned)	15.8 (p<0.001)	16.7 (p<0.001)	**Q17 (exagg. startle)**	17.7 (p<0.001)	17.7 (p<0.001)
Q7 (avoiding cues)	24.3 (p<0.001)	24.2 (p<0.001)	**Q18 (self-harm)**	13.4 (p<0.001)	13.2 (p<0.001)
Q8 (unable to recall)	3.7 (n.s.)	3.7 (n.s.)	**Q19 (emotional)**	24.0 (p<0.001)	24.1 (p<0.001)
Q9 (loss of interest in activities)	21.0 (p<0.001)	21.1 (p<0.001)	**Q20 (physical illnesses)**	9.2 (n.s.)	7.9 (n.s.)
Q10 (avoiding people)	21.3 (p<0.001)	20.9 (p<0.001)	**Q21 (other inappropriate behav.)**	19.2 (p<0.001)	19.2 (p<0.001)
Q11 (restricted affect)	12.3 (p<0.002)	11.1 (p<0.005)	**Q22 (need for help)**	15.2 (p<0.001)	14.9 (p<0.001)

The mean factor scores (and s.d.s) are shown in Table 10, together with the results of non-parametric analyses of variance. It can be seen that there were significant changes over time for all factor scores. The pattern was always the same, with one minor exception. For the skills measures (factors A, B, C), higher scores indicate better skills. The abuse survivor's scores were highest at time 1, lowest at time 2 and somewhat recovered at time 3. The only exception was for factor A where the time 3 score was slightly worse than the time 2 score (though not significantly so). For the maladaptive behaviour/challenging behaviour measures (factors D & E), lower scores indicate better behaviour. Abuse survivor's scores were best (lowest) at time 1, worst (highest) at time 2 and somewhat recovered by time 3.

Table 8. Domain mean scores (and standard deviations) from ABS, part I, for time 1, time 2, and time 3.

Domain	Time 1 mean (& s.d.)	Time 2 mean (& s.d.)	Time 3 mean (& s.d.)	Friedman test – chi square (& p value)
Independent functioning (max. 118)	55.9 (25.7)	51.4 (25.8)	51.2 (23.2)	13.6 ($p = 0.001$)
Physical development (max. 24)	17.9 (4.8)	17.8 (5.1)	16.5 (5.6)	2.1 (n.s.)
Economic (max. 25)	2.6 (3.7)	2.4 (3.7)	2.5 (3.6)	1.2 (n.s.)
Language (max. 42)	15.5 (9.0)	13.3 (8.6)	14.4 (7.9)	4.3 (n.s.)
Numbers & time (max. 14)	3.2 (3.7)	3.1 (3.7)	3.2 (3.8)	0.4 (n.s.)
Domestic (max. 23)	5.2 (5.1)	4.4 (5.6)	3.9 (4.3)	1.9 (n.s.)
Prevoc/voc (max. 11)	2.0 (2.5)	1.6 (2.1)	1.9 (2.6)	1.4 (n.s.)
Self-direction (max. 22)	6.6 (4.7)	4.6 (4.1)	6.3 (4.6)	7.6 ($p<0.05$)
Responsibility (max. 10)	3.2 (2.5)	2.3 (2.2)	2.4 (2.0)	6.9 ($p<0.05$)
Socialisation (max. 26)	13.2 (5.4)	9.9 (5.3)	11.4 (4.5)	9.0 ($p<0.05$)

Table 9. Domain mean scores (and standard deviations) from ABS part II, for time 1, time 2, and time 3.

Domain	Time 1 mean (& s.d.)	Time 2 mean (& s.d.)	Time 3 mean (& s.d.)	Friedman test – chi square (& p value)
Social behaviour (max. 90)	2.3 (3.0)	10.7 (7.4)	7.5 (6.8)	18.6 (p<0.001)
Conformity (max. 66)	4.5 (2.9)	9.7 (4.8)	7.8 (5.2)	22.0 (p<0.001)
Trustworthiness (max. 60)	1.5 (2.2)	5.3 (4.8)	4.0 (3.7)	15.0 (p=0.001)
Stereotyped & hyperactive (max. 80)	2.4 (3.1)	4.3 (4.4)	4.2 (4.2)	10.1 (p<0.01)
Sexual behaviour (max. 15)	0.2 (0.7)	3.4 (4.9)	1.8 (3.1)	11.6 (p<0.01)
Self-abusive behaviour (max. 52)	0.9 (1.8)	5.4 (6.8)	4.1 (5.7)	15.9 (p<0.001)
Social engagement (max. 46)	1.2 (2.7)	10.6 (6.2)	6.6 (5.3)	22.6 (p<0.001)
Disturbing interpersonal behaviour (max. 70)	0.8 (1.2)	7.6 (8.9)	6.2 (6.8)	17.6 (p<0.001)

Table 10. Mean factor scores (and s.d.s) for factors A, B, C, D, & E from ABS

Factor	Time 1	Time 2	Time 3	Friedman test
A. Personal Self-Sufficiency	62.4 (20.8)	58.7 (22.2)	57.9 (21.5)	Chi sq 17.0 P<0.001
B. Community Self-Sufficiency	40.2 (28.4)	32.6 (27.3)	34.1 (22.9)	Chi sq 11.2 P<0.01
C. Personal - Social Responsibility	24.8 (13.2)	17.4 (10.8)	21.4 (11.3)	Chi sq 12.6 P<0.01
D. Social Adjustment	8.3 (5.5)	25.8 (15.0)	19.0 (14.1)	Chi sq 23.0 P<0.001
E. Personal Adjustment	3.9 (4.8)	13.3 (12.4)	10.5 (10.6)	Chi sq 16.2 P<0.001

Life Events:

The significant life events of the adults with learning disabilities and their parents were considered over the three time points. The results showed that the life events occurring in time 2 (where the symptom levels were at their highest) were not significantly higher than at time 1 or time 3 (see Table 11). In fact, at time one (before the abuse) a higher percentage of adults with learning disabilities had experienced the death of a first degree relative (33.3%), than at either time 2 (16.7%) or time 3 (16.7%). The pattern was similar for parents and carers. Likewise, death of other friends or close family members were not more prevalent at time 2 (see table) than at time 1 and time 3; in fact only one (5.6%) adult survivor or parent/carer experienced a death of a close friend or family member during this period, compared to 16.7% before the abuse (time 1) and 22.2% in three months preceding the interview (time 3).

Moving house was more prevalent during the abuse (time 2), or immediately after the abuse (time 3) than at time 1. However, movement of residence for the adult with learning disabilities and at times for their parents (particularly where the adult had returned to the family home), were often as a direct result of the abuse. Examples of this include adults who moved out of a residential home after the disclosure of abuse (which was common), or an adult who moved areas with their parents because there were too many triggers of the abuse in their previous home environment.

The frequency of relationship break ups, separation or divorce was not significantly higher at time 2 or time 3; in fact more relationship break ups occurred during time 1 (in the three months preceding the abuse). The number of adults with learning disabilities affected by alcohol, drug or problems with the law, also did not change significantly over the three time points. There were only two isolated examples of drug taking (adult with learning disability) and drinking excessively (parent/carer), both were said by informants to have been a reaction to the abuse.

The life event for which the frequency was greater at time 2, was in the category of major disasters. Two adults with learning disabilities experienced major flooding in their home, directly prior to the abuse disclosure (within days). The flooding was the reason that they went into to respite care (where they were subsequently abused).

The only other life event that varied between the time points was in terms of major successes. More major successes were experienced by adults with learning disabilities at time 3 (22.2%), compared with time 2 (5.6%) and time 1 (0%).

A non-parametric analysis of variance (Friedman test) was carried out for each of the life events for adults with learning disabilities, comparing events at time 1,2 & 3. There were no significant differences in life events across the three time periods.

Table 11. Significant life events affecting adults with learning disabilities (ALD) and/or their parents

	Time 1 ALD	Time 1 PARENT	Time 2 ALD	Time 2 PARENT	Time 3 ALD	Time 3 PARENT	Missing values
Experienced death of a first degree relative	33% (n=6)	33.3% (n=6)	5.6% (n=1) after the abuse	16.7% (n=3) after the abuse	16.7% (n=3)	16.7% (n=3)	5.6% (n=1)
Experienced the death of a close family member or friend	16.7% (n=3)	22.2% (n=4)	5.6% (n=1) during the abuse period	5.6% (n=1)	22.2% (n=4)	22.2% (n=4)	5.6% (n=1)
Serious accident or injury	22% (n=4)	11% (n=2)	5.6% (n=1) part of abuse + 5.6% (n=1) shortly after abuse	5.6% (n=1)	27.8% (n=5)	22.2% (n=4)	5.6% (n=1)
Serious illness of close friend, relative	5.6% (n=1)	0% (n=0)	5.6% (n=1) during abuse period	5.6% (n=1)	16.7% (n=3)	5.6% (n=1)	5.6% (n=1)
Move of house	5.6% (n=1)	5.6% (n=1)	16.7% (n=3) during abuse + 16.7% (n=3) immediately after abuse	11.1% (n=2) during abuse + 11.1% (n=2) immed. after abuse	27.8% (n=5)	22.2% (n=4)	5.6% (n=1)
Broke off a steady relationship	5.6% (n=1)	5.6% (n=1)	0% (n=0)	0% (n=0)		5.6% (n=1)	5.6% (n=1)
Separation or divorce of immediate family	16.7% (n=3)	11.1% (n=2)	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Alcohol problem	0% (n=0)	5.6% (n=1)	0% (n=0)	5.6% (n=1)- after the abuse disclosure	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Drug problem	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	
Serious problem with close friend/neighbour	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)	11.1% 9n=2)	16.7% (n=3)	
Unemployment	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Retirement from work	0% (n=0)	0% (n=0)	0% (n=0)	5.6% (n=1) after the abuse disclosure	5.6% (n=1)	16.7% (n=3)	5.6% (n=1)
Laid off or sacked from work	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Something	5.6%	0% (n=0)	5.6% (n=1)	0% (n=0)	5.6%	5.6%	5.6%

valuable lost or stolen	(n=1)				(n=1)	(n=1)	(n=1)
Problems with police	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Major financial crisis	0% (n=0)	0% (n=0)	0% (n=0)	0% (=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Sexual problem	0% (n=0)	0% (n=0)	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Death of pet	0% (n=0)	11.1% (n=2)	5.6% (n=1)	5.6% (n=1)	16.7% (n=3)	11.% (n=2)	5.6% (n=1)
Change of people/number in household	0% (n=0)	5.6% (n=1)	5.6% (n=1) during abuse period	5.6% (n=1)	11.1% (n=2)	11.1% (n=2)	5.6% (n=1)
Major disasters	0% (n=0)	0% (n=0)	11.1% (n=2) just prior to abuse (day before)	11.1% (n=2) just prior to abuse-(day before)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
Changes in friendships, losses or gains	5.6% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)	11.1% (n=2)	5.6% (n=1)	5.6% (n=1)
Major success	0% (n=0)	0% (n=0)	5.6% (n=1)	11.1% (n=2)	22.2% (n=4)	0% (n=0)	5.6% (n=1)
Other life events	0% (n=0)	0% (n=0)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)	5.6% (n=1)
No significant life events							

Case Studies

The impact of abuse was often devastating impact for both the survivor and the immediate family/carer of that person. We include here four case studies in order to illustrate some of the prevailing symptoms of abuse in this particular group of people. (Please note that pseudonyms have been used to protect the identities of the abuse survivors).

Case study 1

Carla is now twenty years old and has Down Syndrome. With at least ten other children attending the same respite facility, she was allegedly abused over a period of ten years, starting when she was 9 years old.

Though the local Social Services Department had begun an investigation into the alleged abuse five years ago, Carla's parents were only told of it three years later. Initially, they were advised not to be concerned as their daughter was not believed to be involved but that view changed as the investigation developed. It is now thought that she experienced repeated rape and other forms of sexual assault and that her silence was ensured through threats about her own safety and that of members of her family.

As might be expected, the impact on Carla was devastating. She had been able to use a few single words and some signs but all attempts at communication ceased. She appeared depressed and would spend long periods shaking, in a trance-like state, from which she was difficult to rouse. She tried to avoid all activities and places which, it was later learned, had been associated with her experiences, and if she was unable to do so, displayed extreme challenging behaviour, including soiling and aggression. For months, she appeared to re-enact what had happening, demonstrating explicit and specific sexual activity with dolls and attempting to masturbate in front of others.

The effect on Carla's family has also been devastating. Her parents blamed themselves for placing her in the respite facility and believed that they should have been much more alert for the possibility that the changes in their daughter were the result of abuse. Their trust in others, and of statutory authorities in particular, diminished. Whilst Carla has received psychiatric treatment and some counselling to help her cope with the consequences of her experiences, her parents have never been offered any support. At interview, they described themselves as almost overwhelmed by their feelings of anger towards the respite facility and guilt about their perceived failure to protect their daughter. Though Carla has now regained some of her signing skills, the effects on her of the abuse continue.

Case study 2

Graham is now aged 33 years and has cerebral palsy, as well as a severe learning disability. Ten years ago, he met the alleged perpetrator at a social event and got to know him over a period of time and visited his home. There, he was sexually abused on two occasions, and was threatened to ensure that he did not tell his parents.

After the abuse, Graham became terrified by certain noises, events, or objects which had never previously troubled him, such as loud noises, and seeing men together in intimate situations on television. He lost a great deal of weight and became tearful and withdrawn. He began to avoid certain places and then became anxious about going out at all. He was frightened by the thought of being left alone, even for short periods and in his parents' home, and started to shout and swear when it was time for him to go to bed.

Shortly after the abuse was disclosed, Graham's mother experienced severe depression and was described anti-depression medication; his father suffered a heart-attack. Graham was not offered any support initially but is on a waiting-list for long-term therapy from a specialist service providing treatment to people with learning disabilities who have been abused. His mother sought therapy for herself through her G.P.

Case study 3

Clare is now 37 years of age and has limited language skills. During the 1990s, she was abused over a period of eight years at a residential home for adults with severe learning disabilities. Clare's parents first became aware of the abuse when they were contacted by a relative who had read a newspaper article about police investigations into allegations of abuse at the home, involving a large number of residents.

Apparently, Clare experienced a range of sexual assaults, including touching, masturbation and penetration with objects, and was kicked and punched, threatened. On several occasions, she was locked in her room for days without access to clean clothes. Her money and possessions were taken. At the start of their investigation, Clare was interviewed by the police and was able, with difficulty, to provide a video statement. Subsequently, however, she became unable to speak about what had happened.

The impact on Clare was, again, devastating. She became depressed and was prescribed anti-depressants and anxiolytic medication. She seemed to experienced recurring flashbacks relating to the abuse during the day, and at night, she would wake up crying, apparently having had nightmares. She became distressed near men and very anxious in rooms where the doors were open. She began to self-harm, rubbing her fingers until they bled. Like Sally, she became particularly distressed in certain places, and would try to avoid them.

After Clare had been moved from the residential home, she was provided with counselling but this was discontinued after a year because she was unable to engage at all in thinking about what had happened to her. She received out-patient psychiatric treatment to reduce her anxiety but, nevertheless, her symptoms have remained so severe that, on several occasions, she has been admitted to hospital. She remains fearful of men and appears uninterested in everyday activities or the outside world.

Clare's parents have been extremely distressed by their daughter's experiences. They described how, at times, they have felt as if they would have a 'nervous breakdown' as a result of overwhelming, and long-lasting, feelings of anger and guilty. They feel unable to trust others, particularly those in authority. No support was ever offered but they feel they gain some support from an informal group for carers whose relatives were all abused at the home where Clare lived.

DISCUSSION

It is clear from the initial interview data and the ABS data that the abuse survivors included in this study had severe learning disabilities and often had health problems as well. It is likely, however, that the sample of abuse survivors included in this research is not a typical sample of abuse survivors with severe learning disabilities because:

- The participants were contacted through solicitors (i.e. there was the possibility of court action)
- All cases had been reported to the police
- The alleged abuse was mostly of a very serious and multiple nature.
- The sample seemed to be biased to White British participants (perhaps because people from ethnic minorities are not seeking advice from solicitors).

With these provisos in mind, the project demonstrated that, even with such allegedly serious abuse, few cases reach the criminal court and few convictions of alleged perpetrators result, as others have also reported (eg Brown et al., 1995). Moreover, it appeared from what informants told us that services still have a great deal to learn about how best to handle abuse, including how to inform parents/carers and how to support them. It appeared that it was extremely common for abuse survivors to move placement following alleged abuse, even though this is not considered good practice, since it results in major disturbance and disruption for the victim of the abuse at a time when they are very vulnerable.

The therapeutic services received by the abuse survivors were at best patchy. Parents and carers often told us that they had had to fight and argue with the ‘authorities’ to obtain any services for their sons and daughters; frequently the parents were also in great need of therapeutic help themselves but this was often not provided and/or not well suited to their needs. Parents and carers almost always reported themselves as feeling angry about what had happened and distrustful of services; many had stopped using services for people with learning disabilities because they felt they could no longer trust them. Parents were extremely traumatised themselves by their experiences but rarely offered support.

The parents/carers had a number of suggestions for other parents using services, such as ‘not being too trusting of staff’, being aware of the symptoms of abuse, respecting attempts by the person with learning disabilities to communicate what had happened to them, and doing ‘spot checks’ on services by conducting unannounced visits. They also had a great many suggestions for how services could be improved, including better staff training, more qualified staff, better police checking and reference checking for new staff, unannounced inspection visits, more support for whistle-blowers and more support and communication with families once abuse was suspected.

Parents’/carers’ reports of the behaviours and symptoms shown by the abuse survivors before the abuse was disclosed (time 1), immediately after it was disclosed (time 2) and now (time 3) were extremely consistent. In almost all cases, skills were best at time 1, declined by time 2 and recovered somewhat at time 3. These changes were statistically significant for 4 of the 10 ‘skills’ domains and all of the three ‘skills’ factor scores of the adaptive behaviour scale (part I, ABS, RC-2) – see Tables 8 & 10. Interestingly, the ‘skills’ domain scores that did not change significantly over time (for example, motor skills) were those predicted as not likely to change following abuse by Howlin and Clements (1995).

In terms of the ‘challenging’ behaviours of abuse survivors, these were very clearly worse at time 2, after the abuse had occurred, than they were at time 1, and they recovered somewhat by time 3. The changes in ‘challenging’ behaviours were statistically significant on all 8 domains and on both factor scores of the adaptive behaviour scale (part II, ABS, RC-2) – see Tables 9 & 10.

For symptoms of abuse, there were also very significant changes over time in the frequency of symptoms, with an extremely consistent pattern emerging of very few difficulties before the abuse (at time 1), major difficulties at time 2 (just after the abuse was disclosed) and some recovery by time 3 (the time of the interview) – see Tables 3, 4, 5, 6 & 7. The pattern for levels of distress (or severity) of each symptom was very similar (see Tables D, E, F, G in Appendix 3). On the small number of symptoms where there was little change, it seemed likely that the symptoms were difficult to spot or inappropriate for people with severe learning disabilities (such as difficulty concentrating).

The retrospective methodology we used means that the possibility that the reported difficulties were not related to the survivors' abuse cannot be completely excluded. However, careful comparison with the findings of the measure of life events did not indicate that other incidents in their lives could explain their symptoms. Similarly, it seems unlikely that informants were simply misguided about the level of their relatives' difficulties because of their own feelings: most of them described some alleviation in the symptoms of their adult child over time. We thought it very unlikely that parents/carers were exaggerating symptoms (otherwise we would not have found that some skills and behaviours did not change over time).

The three case studies described here are not the most extreme accounts that were reported during our interviews. Nevertheless, they make sober reading. Not surprisingly, given the range, duration, and severity, of their experiences of abuse, the impact on the survivors with severe learning disabilities and their families appears to have been profound and long-lasting.

From the informants' accounts of their relatives' symptoms, many of the abuse survivors would have easily meet the established criteria for a diagnosis of Post-Traumatic Stress Disorder (see Appendix 1, Table A). The implication is that these criteria provide a meaningful framework for examining the impact of abuse on men and women with severe learning disabilities, even when they have very limited, or no, verbal language or signing skills. However, the fact that there were also consistent reports of additional difficulties (as in Howlin and Clements, 1995), such as soiling (Carla), and self-harm (Clare) and loss of specific skills (for example, verbal language in Carla) or of a general regression to an earlier, less independent, stage of development (Graham), mean that our findings suggest that that questions relating to PTSD should be supplemented by items relating to skills and 'challenging behaviours'.

For all of the people described here, the investigations into their alleged abuse took place before the introduction of the current legislation (the *Youth Justice & Criminal Evidence Act 1999*) to support vulnerable or intimidated witnesses. Would their allegations would have been treated in the same way by the present criminal justice system? For example, now that it is possible for the court to accept unsworn evidence (s. 55), would *Graham* have been allowed to give evidence against his alleged perpetrator and what effect might this have had on the outcome? We cannot know.

In the meantime, practitioners seeking to examine the impact of abuse on men and women with severe learning disabilities for the court and for treatment need to assess both the symptoms and changes in the pattern of skills and 'challenging behaviours' of the survivor and the effect on siblings and parents.

ACKNOWLEDGEMENTS

We are grateful to the members of Speaking Up! (Cambridge) who participated in the focus group and to Mr. Craig Dearden and Mr. John Woodhouse for supporting this part of the project; to Miss Nicola Harney, Ms. June Raybaud, and VOICE (UK) for assistance in contacting the parents of survivors of abuse; and above all, to the parents themselves for sharing with us their experiences. The project was funded by the Department of Health; we would like to thank them for their support.

REFERENCES

American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition. Washington, D.C.: American Psychiatric Press.

Boudewyn, A.C. and Liem, J.H. (1995). Childhood sexual abuse as a precursor to depression and self-destructive behaviour in adulthood, *Journal of Traumatic Stress*, *8*, 445-459.

Brown, H., Stein, J. & Turk, V., (1995) The sexual abuse of adults with learning disabilities: a second incidence study, *Mental Handicap Research,* 8, 3-24.

Brown, H. (1999) Abuse of people with learning disabilities: layers of concern and analysis, in (Eds.) N. Stanley, J. Manthorpe & B. Penhale *Institutional Abuse: Perspectives across the life course*. London: Routledge.

Burgner T. (June 1998) *Independent Longcare Inquiry*.

Churchill, J., Craft, A., Holding, A. & Horrocks, C. (Eds, 1996) *It Could Never Happen Here: The prevention and treatment of sexual abuse of adults with learning disabilities in residential settings*, Revised Edition. Chesterfield: ARC & NAPSAC.

Davison, F., Clare, I.C.H., Georgiades, S., Divall, J. & Holland, A.J. (1994) Treatment of a man with a mild learning disability who was sexually assaulted whilst in prison, *Medicine, Science & the Law*, *34* (4), 346-353.

Holman A. (2001) In conversation with Nicola Harney. *British Journal of Learning Disabilities, 29,* 81-83.

Home Office (1998) *Speaking Up for Justice,* London, Home Office.

Home Office (2001) *Guidelines on the Implementation of the Intermediary Provisions of the Youth Justice and Criminal Evidence Act 1999.* London: Home Office Communication Directorate.

Horowitz, M., Wilner, N. & Alvarez, W. (1979) Impact of Events Scale: a measure of subjective stress. *Psychosomatic Medicine, 41,* 209-218.

Howlin, P. & Clements, J. (1995) Is it possible to assess the impact of abuse on children with pervasive developmental disorders? *Journal of Autism and Developmental Disabilities, 25,* 337-354.

Joseph, S., Williams, R. & Yule, W. (1997) *Understanding Post Traumatic Stress: A Psychosocial Perspective on PTSD and Treatment.* Chichester: John Wiley and Sons.

Kennerley H., (2000) *Overcoming Childhood Trauma: A self-help guide using cognitive behavioural techniques,* London, Constable and Robinson Ltd.

Luckasson (1992) People with mental retardation as victims of crime, in (Eds.) R.W. Conley, R. Luckasson & G.N. Bouthilet *The Criminal Justice System and Mental Retardation.* London: Paul Brookes Publishing Company.

McCarthy, M. & Thompson, D. (1997) A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities, 10,* 105-124.

Moss, J. (1998). Working with issues of sexual abuse, in (Eds.) E. Emerson, C. Hatton, J. Bromley and A. Caine *Clinical Psychology and People with Intellectual Disabilities*, Chichester: John Wiley & Sons.

Murphy, G. (2000) Justice denied. *Mental Health Care, 3,* 256-257.

Murphy, G. and Clare, I.C.H. (2001) Witnesses with learning disabilities. *British Journal of Learning Disabilities, 29,* 79-80.

Muss, D. (1991). *The Trauma Trap.* London: Doubleday.

Nihira, K., Leland, H & Lambert, N, (1993) *Adaptive Behaviour Scale – Residential and Community.* 2nd Edition. Austin, Texas: Pro-ed.

Prosser, H., Moss, S., Costello, H, Simpson, N, & Patel, P. (1996) *The Mini PAS-ADD.* Hester Adrian Research Centre: University of Manchester.

Saunders, A., Creaton, J., Bird, S. & Weber, L. (1997) *Victims with Learning Disabilities: Negotiating the Criminal Justice System.* Occasional paper no. 17, Centre for Criminological Research, University of Oxford.

Voice, Respond & Mencap (2001). *Behind Closed Doors; preventing sexual abuse against adults with a learning disability.* London: Mencap.

Walsh, P.N. & Murphy, G. (2002) Risk and vulnerability: dilemmas for women, in (Eds.) P. N. Walsh & T. Heller *Health of Women with Intellectual Disabilities.* Oxford: Blackwell Publishing Company.

Williams, C. (1995) *Invisible Victims: crime and abuse against people with learning difficulties.* London: Jessica Kingsley.

Yule, W. (2000) *Post-Traumatic Stress Disorders: Concepts and Therapy.* Chichester: Wiley.

Appendices

Appendix 1.

Table A: DSM IV diagnostic criteria for PTSD (American Psychiatric Association, 1994)

Table B: Responses and symptoms of abuse identified by members of *Speaking Up!*

Appendix 2

Measures used:

- Initial interview
- Symptoms interview
- ABS

Table C: Reliability data

Appendix 3

Tables D, E, F, G : changes over time in level of distress (or severity) for symptoms

Appendix 1

Table A: DSM IV diagnostic criteria for PTSD (INSERT PROPER REF)

DSM IV *diagnostic criteria for PTSD*

A The person has been exposed to a traumatic event in which both of the following were present:

1. the person experienced, witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others;
2. the person's response involved intense fear, helplessness or horror. *Note*: in children, this may be expressed instead by disorganised or agitated behaviour.

B The traumatic event is consistently re-experienced in one (or more) of the following ways:

1. recurrent distressing recollections of the events, including images, thoughts, or perceptions. *Note*: in young children, repetitive play may occur in which themes or aspects of the trauma are expressed;
2. recurrent distressing dreams of the event. Note: there may be frightening dreams without recognisable content;
3. acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations and dissociative flashback episodes, including those that occur on awakening or when intoxicated). *Note*: in young children trauma specific re-enactment may occur;
4. intense psychological distress at exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event;
5. physiological reactivity on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event.

C Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following.:

1. efforts to avoid thoughts, feelings or conversations associated with the trauma;
2. efforts to avoid activities, places or people that arouse recollections of the trauma;
3. inability to recall an important aspect of the trauma;
4. markedly diminished interest or participation in significant activities;
5. feeling of detachment or estrangement from others;
6. restricted range of affect (e.g., unable to have loving feelings);
7. sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life-span.

D Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more of the following):

1. difficulty falling or staying asleep;
2. irritability or outbursts of anger;
3. difficulty concentrating
4. hypervigilance;
5. exaggerated startle response.

E Duration of the disturbance (symptoms in criteria B, C, and D) is more than one month.

F The disturbance causes clinically significant distress or impairment in social, occupational or other important areas of functioning.

Table B: Responses and Symptoms of Abuse identified by members of Speaking Up!

Response to abuse/ identifiable symptoms	
Anger/ aggression at others/things	Feeling trapped
Avoiding certain people	Hitting yourself
Being very loud or quiet	Invasion of privacy/feel invaded
Body language: head down, not smiling	Jumpy and scared
Crying/ upset/sad	Loss of appetite
Depressed and withdrawn	Loss of people
Destroying things/property	Nausea
Difficulty in forgetting the abuse	Running away
Dislike of being touched	Self-blame
Drinking too much alcohol/ drugs	Sleep avoidance
Fear of being seen as a trouble maker	Sleep problems
Fear/anxiety	Staying in bed
Feeling alone	Suicidal feelings
Feeling guilty	Unable to concentrate
Feeling like they cannot trust others	

Appendix 2

Measures:

Initial interview

Symptoms interview (the time 1 interview is included; time 2 and time 3 interviews were the same but with different pre-ambles regarding the time being asked about).

Life events interview

Adaptive Behaviour Scale (ABS, RC-2)

Table C: Reliability data

Case number and name of interview	Percentage agreement	Identified different ratings: rater 1 (AOC)	Identified different ratings: rater 2 (GM or IC)	Comments
Case 1- initial interview	100% (54/54 responses were the same)	None	None	Answers to the questions were taken verbatim. Interviewers may have missed out one or two minor words, but there were no differences in ratings.
Code 7 – initial interview	There was agreement on all questions other than question 40 (53/54)- 98% of questions.	Question 40- did you as a parent/carer attend the court? - rated as a 'no' as the parent/ carer sat outside	Question 40- Rated as a 'yes' response AND noted that the parent/carer decided not to go in/sat outside.	There were some very qualitative responses, both interviewers had written responses verbatim. Where a different response was recorded (Q40)- for the database this was recorded as 'no'- since the parent/carer did not actually go into the court room.
Code 11 – initial interview	There was agreement on all questions, other than question 12 (53/54)- 98% agreement	Question 12- Detailed epilepsy as occurring 6-7 fits per day	Question 12- Detailed epilepsy as occurring 6-9 fits per day	Coded in database as suffering from epilepsy (fit frequency not required). There was agreement on all other responses, including on type of abuse, duration of abuse, consequences, help received etc.
Code 1- Symptoms interview – time 2 only	There was agreement on all questions. The frequency, duration and intensity of the symptom matched. Details on the type of symptom and/or effect also matched. 100% agreement	None	None	Slightly different terminology may have been picked up on at times, for example 'he can't say', rather than 'he can't tell you'. This resulted in no coding differences (eg. both the above were coded as 'don't know'.

Code 7- symptoms interview, time 1,2 &3.	100% agreement. Raters picked up on the same types of symptoms, frequency, duration of symptoms. All responses were the same between interviewers for each time point.	None	None	Reliability was only calculated for 10/22 questions as the second interviewer was not present for the final part of the interview.
Code 11- symptoms interview, time 2 only.	100% agreement for all response on type of symptom, frequency, duration and intensity of symptom.	None	None	
Pilot 1 & 2- initial interview	100% agreement between the two interviews on recorded responses	None	None	

Appendix 3

Table D: Level of distress as a result of symptoms of re-experiencing the traumatic events (recollections, flashbacks, memories)

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q1 (recollections)			
No distress	100%	25.0%	38.9%
Mild/moderate	0%	18.8%	27.8%
Severe/extreme	0%	56.3%	33.4%
Q2 (dreams)			
No distress	82.4%	23.5%	55.6%
Mild/moderate	17.6%	23.5%	33.3%
Severe/extreme	0.0%	52.9%	11.2%
Q3 (flashbacks)			
No distress	100%	23.5%	41.2%
Mild/moderate	0.0%	5.9%	35.2%
Severe/extreme	0.0%	70.6%	23.6%
Q4 (distress at cues)			
No distress	94.4%	23.5%	27.8%
Mild/moderate	5.6%	11.8%	27.8%
Severe/extreme	0.0%	64.7%	44.4%
Q5 (physiological response to cues)			
No reaction	100%	38.9%	50.0%
Mild/moderate reaction	0.0%	0.0%	22.3%
Severe/extreme reaction	0.0%	61.1%	27.8%

Table E: Degree of distress/severity of symptoms of avoidance

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q6 (leaving room if abuse mentioned)			
None	100%	50.0%	35.3%
Mild/moderate avoidance	0%	27.8%	53.0%
Severe/extreme avoidance	0%	22.2%	11.8%
Q7 (avoiding cues)			
None	100%	23.5%	23.5%
Mild/moderate avoidance	0%	11.8%	35.3%
Severe/extreme avoidance	0%	64.7%	41.1%
Q8 (unable to recall)			
No problem	100%	84.6%	83.3%
Mild/moderate problem	0%	0.0%	8.3%
Severe/extreme problem	0%	15.4%	8.3%
Q9 (loss of interest in activities)			
No problem	100%	23.5%	22.2%
Mild/moderate problem	0%	5.9%	38.9%
Severe/extreme problem	0%	70.6%	38.9%
Q10 (avoiding people)			
No problem	94.4%	23.5%	22.2%
Mild/moderate problem	5.6%	17.6%	38.9%
Severe/extreme problem	0%	58.8%	38.9%
Q11 (restricted affect)			
No problem	70.6%	33.3%	47.1%
Mild/moderate problem	23.5%	20.0%	23.5%
Severe/extreme problem	5.9%	46.6%	29.5%
Q12 (shortened future)			
No problem	41.2%	18.8%	29.4%
Mild/moderate problem	17.6%	12.6%	11.8%
Severe/extreme problem	41.2%	68.8%	58.8%

Table F: Level of distress/severity of symptoms of persistent increased arousal

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q13 (difficulty falling/staying asleep)			
No problem	72.2%	17.6%	41.2%
Mild/moderate problem	22.2%	17.6%	23.5%
Severe/extreme problem	5.6%	64.8%	35.2%
Q14 (irritable/angry)			
No problem	77.8%	29.4%	38.9%
Mild/moderate problem	22.2%	17.6%	44.4%
Severe/extreme problem	0.0%	52.9%	16.7%
Q15 (problems concentrating)			
No problem	29.4%	25.0%	17.6%
Mild/moderate problem	41.2%	25.0%	41.2%
Severe/extreme problem	29.4%	50.0%	41.2%
Q16 (checking behav.)			
No problem	100%	55.6%	55.6%
Mild/moderate problem	0.0%	5.6%	16.7%
Severe/extreme problem	0.0%	38.9%	27.8%
Q17 (exagg. startle)			
No problem	100%	44.4%	50.0%
Mild/moderate problem	0.0%	27.8%	27.8%
Severe/extreme problem	0.0%	27.8%	22.2%

Table G: Level of distress/severity of other psychological and behavioural symptoms

Questions	Time 1 (before abuse)	Time 2 (immediately after abuse)	Time 3 (now)
Q18 (self-harm)			
No problem	82.4%	35.3%	41.2%
Mild/moderate problem	17.7%	23.5%	35.3%
Severe/extreme problem	0.0%	41.2%	23.5%
Q19 (emotional)			
No problem	94.4%	22.2%	16.7%
Mild/moderate problem	5.6%	0.0%	33.3%
Severe/extreme problem	0.0%	77.7%	50.0%
Q20 (physical illnesses)			
No problem	77.8%	50.0%	52.9%
Mild/moderate problem	22.3%	11.1%	29.4%
Severe/extreme problem	0.0%	38.9%	17.6%
Q21 (other inappropriate behav.)			
No problem	88.9%	27.8%	33.3%
Mild/moderate problem	11.1%	11.1%	38.9%
Severe/extreme problem	0.0%	61.1%	27.8%
Q22 (need for help)			
None	29.4%	5.9%	0.0%
A little/some	47.0%	35.3%	53.0%
A lot/constant	23.5%	58.8%	47.0%