

# **CQC inspections and regulation of Whorlton Hall: second independent report.**

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## **1. Terms of reference**

In the summer of 2019, following a televised Panorama programme showing abusive care of people with learning disabilities and/or autism in Whorlton Hall (an independent hospital in the north of England), the Care Quality Commission, CQC, requested an independent review of its inspections of Whorlton Hall. Professor Glynis Murphy was appointed to conduct the review, for which the terms of reference were to:

1. Consider and report to the Board of the CQC on the regulation of Whorlton Hall between 2015 and May 2019 and form a view as to whether the abuse of patients that had been identified could have been recognised earlier by the regulatory or inspection process;
2. Make recommendations for how CQC can improve its regulation of similar services in the future, including in relation to:
  - The way risk is considered in these settings, such as when planning inspections;
  - Inspection methodology and practice, and the monitoring of services, in order to increase the likelihood of detecting of harm or abuse, or the risk of harm or abuse;
  - The protection of the human rights of service users;

- Any other aspect of the regulatory process, including the way in which CQC works with other agencies, where lessons can be drawn from the experience of Whorlton Hall.
3. The Review will limit its recommendations to those actions which can be taken immediately and do not require changes in legislation.
  4. The Reviewer will present the Report to the CQC Board for publication, and will complete the review as soon as is practical.

The first report relating to this review was presented to the CQC board on March 18<sup>th</sup> 2020 and has been available on the CQC website since that time. The findings and recommendations of that review are summarized below.

## **2. Could the abuse of patients have been recognised earlier by the regulatory or inspection process?**

None of the CQC inspectors saw punitive or abusive behaviour by staff at Whorlton Hall (though three did say they felt uncomfortable and uneasy in the service). The MHA reviewer from CQC, whose job it was to liaise with service users, also said s/he did not have concerns about the service. Moreover, a large number of professionals went to Whorlton Hall, who were not employed by CQC, including the local GP, representatives of the Local Authority and the CCGs who were placing residents there. In all, the local CCG, who had counted the visits found there were 37 over the previous 9 months to May 2019 (excluding GP visits), and none of these visiting professionals recognized that abusive behaviour was going on, even though they spoke to staff and service users. In addition, there were two advocates who were regularly working in Whorlton Hall, one day per week, over a period of years, who had close contact with service users and yet did not see abusive and punitive practice in place. During inspections, service users generally said that they felt safe and they liked staff, and it appeared that they were not able to describe the cruel behaviour of some staff.

In hindsight, CQC began to consider the issue of a 'toxic culture' and how to detect it. Paul Lelliott, head of CQC mental health at the time, drew up a paper alerting inspectors to the characteristics of a toxic or 'closed' culture. He listed a series of aspects of services that could be considered 'red flags', including many of the characteristics of Whorlton Hall. Nevertheless, if inspectors had been aware of such 'red flags', the question remains could they have detected abusive practices?

Where there is a small group of devious staff who deliberately mislead both those engaged in inspection and regulation processes, as well as MDT members, advocates and carers, it is very difficult to detect their actions, especially when service users are very vulnerable and have limited communication skills.

### **3. Recommendations from the first review for improvements in the future**

The following recommendations were made, taking into account CQC processes, the events and inspections of Whorlton Hall, and the interviews conducted through the review. The recommendations were limited to the terms of reference for the review.

**Recommendation 1:** CQC should consider displaying data, for each service, in a user-friendly way, on abuse allegations, complaints and concerns (coming into CQC via NCSC and other routes), alongside data on mandatory staff training, staff turnover, sickness rates, use of agency staff, restraints and segregations. These data should be easy to access, chronological, and graphical, and allow inspectors and MHA reviewers to prepare and plan inspections, and to become aware of 'red flags' indicating failing services.

It may be that CQC could also mine the rich source of data that it already has, on a large number of services, to provide evidence of a series of statistically significant performance indicators to assist staff in detecting 'red flags' for failing services (by, for example, conducting a regression analysis of the extent to which variables listed above influence outcome).

**Recommendation 2:** For high risk settings which provide hospital services for people with learning disabilities and/or autism and complex needs, CQC should consider using only unannounced inspections, and should include evening and weekend visits. Alongside this, CQC should require Provider Information on a regular basis, every 6 mths (previously these were linked to up-coming inspections), so that PIRs do not signal imminent inspections. All inspections should produce ratings, including focused inspections, and action plans by the provider should not be a sufficient reason for rating a service as 'Good' when it would otherwise be rated as RI. Inspection reports should be published more quickly (with a month to six weeks of the inspection) so that providers can improve services faster and inspectors can better plan re-inspections.

**Recommendation 3:** CQC should take abuse allegations, safeguarding alerts and whistleblowing events extremely seriously and recognise that they are probably the tip of the iceberg. They should work closely with other agencies on these issues (LAs and CCGs) and should consider these data as a whole for services, and examine their trends over time (rather than just seeing them as a series of individual cases). The relationship owner should access the relevant data (see Recommendation 1) for a service on a regular basis, and work with the Local Authority to ensure there is a proper response to these. Repeated retracted allegations should be very carefully investigated. Where allegations of abuse are escalating, the Local Authority should consult with CQC about increasing its inspections and surveillance (see Recommendation 5)

**Recommendation 4:** In all inspections, CQC should prioritise in-depth service user interviews, in private (i.e. without staff from the service that is being inspected), and inspectors should receive training in alternative and augmentative communication tools such as Talking Mats. They should also ensure that as many carers as possible are spoken to, about their views of the service, and inspectors should spend more time observing in the lounges and day rooms to ensure they have seen the every day nature of the service. There are a number of observation tools that could be used.

**Recommendation 5:** Where the information about a service indicates that it is at risk of failing its service users (see Recommendation 1 and 3 above), for example, if it repeatedly has RI ratings or if its data on restraints or abuse allegations are at worrying levels, CQC should consider conducting a 'level 2' inspection. Level 2 inspections should include more time in the service spent observing and interviewing service users, as well as staff surveys (to be returned to CQC, not to the provider), and interviews with staff who left the service after only short periods. CQC should also consider whether it is possible to rate the atmosphere and/or culture of services and should trial such a measure in inspections. In addition, in a level 2 inspection, CQC should consider whether the importance of detecting abusive behaviour by staff, merits the use of CCTV or other covert surveillance, despite the ethical issues these methods raise.

**Recommendation 6:** CQC should not register services like Whorlton Hall, that are very isolated, in unsuitable buildings, with out-of-date models of care (difficult for families to access, high numbers of unqualified staff, poor provision of activities, low numbers of qualified nurses, and insufficient MDT presence). They should not allow expansion of such services that already exist and should consider how best to alter those that they have already registered.

## 4. Progress by March 2020

Some of the courses of action recommended above were already being considered by CQC when the first report on Whorlton Hall was presented to them in March 2020. For example:

- In relation to recommendation 1, regarding data collected, CQC had started to develop such methods and was trialling the *Insight tool* which provided much of what is needed in terms of tracking abuse allegations, staffing issues, and restrictive practices in services.
- In relation to recommendation 4, regarding observations in services, CQC was considering observation tools that could be used and one (SOFI) was being trialled.
- With respect to recommendation 5, regarding rating service culture and use of CCTV, CQC was beginning a number of meetings to consider this, together with the ethical issues such methods raise.
- Finally, for recommendation 6, regarding registration, CQC Registration was drafting a new set of guidelines *Right Support, Right Care, Right Culture* to guide future registrations, and is considering how to reduce out-dated service models that already exist.

## 5. Progress since March 2020

CQC has been undertaking a variety of strands of work since the time of the first independent report on Whorlton Hall. In particular there have been three large pieces of work of relevance to this second report: the review of restraint, seclusion and segregation; the closed cultures work; the development of a tool for rating support plans. These are briefly described below.

### 5.1 Restraint, Seclusion and Segregation Review

In October 2018, the Secretary of State for Health and Social Care asked CQC to carry out a review of autistic people, and people with a learning disability and/or mental health condition who were subject to restrictive practices. Over 120 settings were visited including a variety of hospital provisions (such as NHS and independent sector rehabilitation wards and low secure units), and social care settings, group homes and children's services. Over 400

questionnaires on restrictive practices were completed, and a sample of care plans assessed, medication for some cases was reviewed, as were costs of placements. The final report *Out of Sight: Who Cares?* was published in October 2020.

Most people subject to restrictive practices (like restraint, seclusion and segregation) were autistic; many had a learning disability as well, some had mental health needs. A history of abuse and trauma was very common, and some people had been moved between settings many times, with no clear plan for their move back to the community. Autism diagnosis often came very late and services in the community also came too late and/or did not meet people's needs. In hospital settings, there were many breaches of people's human rights in their current placements, with a culture of restrictive practices, and frequent restraint, segregation and seclusion often being seen as the only options. There was frequently a high staff turnover, poor staff training, high agency staff use, lack of understanding of people's autism and specific needs, poor care plans (which were often generic), and a lack of therapeutic activity. People were sometimes not allowed to see family members, and did not always have advocates; when they did have these, they were not always of good quality. There was often poor use of de-escalation techniques, and a high use of restraint, including prone restraint, handcuffs and belts, and frequent use of prn for rapid tranquilisation. Seclusion and segregation conditions were often used as long-term strategies, and at times were not in line with the Mental Health Act Code of Practice (e.g. they frequently did not allow access to toilets/bathrooms, outside space, and the person's own possessions). There was often poor recording of the use of restraint, segregation and seclusion, and no plan for re-integration. Community-based settings did better than hospital settings on all of these issues, as did children's homes. There were 17 recommendations, including for NHS England, commissioners, community-based teams, providers, and some for CQC (such as ensuring that human rights and positive cultures were included in their Key Lines of Enquiry, not rating providers as Good or Outstanding if they were using prolonged seclusion or over-using restraint, ensuring providers were working to reduce their use of restrictive practices, increasing unannounced or evening/weekend visits, and improving how CQC listened to people and their families). Many of these were reminiscent of recommendations in the first independent review of Whorlton Hall inspections (see section 3 above). The findings will be returned to later in this report.

## **5.2 Closed Cultures**

CQC has had a stream of work examining Closed Cultures since 2019. This workstream was begun by Paul Lelliott (lead for mental health) following the uncovering of abuse at Whorlton Hall, and has continued to develop since then. The most recent report '*Identifying and*

*Responding to Closed Cultures: Guidance for CQC Staff* includes sections providing details on:

- Risk factors for developing closed cultures (such as staff not seeing people as equals; residents not being able to speak up)
- Warning signs of a closed culture (such as poor staff skills and poor training; restrictive practices)
- Potential impact on human rights and equality (Human Rights Act 1998: articles 2, 3, 5 & 8; and the Equality Act 2010)
- How to identify a closed culture (speaking to people who use the service, and family members; examining whistleblowing, complaints and allegations)
- What actions should be taken (such as prioritising care reviews, undertaking unannounced inspections, etc).

CQC staff have now been trained in how to recognise closed cultures and the Closed Cultures work has also included an extensive discussion of the use of overt and covert surveillance in detecting abuse. This will be returned to later in this report.

### **5.3 Quality of Life Tool**

During the Restraint, Seclusion and Segregation review, a panel of CQC staff and two advisors (Sandy Toogood and Louise Denne) from the Positive Behaviour Support Academy (see <http://pbsacademy.org.uk>) reviewed a number of individual PBS plans (and found them to be frequently of poor quality, see above under 5.1). They subsequently suggested that they develop a tool so as to assist CQC inspectors in rating PBS quality, and obtained a grant to fund this work. The tool focuses on Quality of Life outcomes and it has recently been reviewed by the Closed Cultures group. The group thought it was very long, and it has now been somewhat shortened and is going to be trialled by inspectors shortly.

The 4 sections with their 17 questions have been retained (see below for details). In the full tool, there are examples of good and poor practice, and inspectors are advised to seek information from observations, interviews with staff, service users, staff and families, and documentation for each:

- *Section 1 (9 questions): Is there a planned programme for each person that focuses on their quality of life?* (questions in this section are about the environment; staff knowledge of the person; engagement in meaning-full activities; choice and control for service users; safe, consistent, predictable environment; whether behaviours that

challenge are supported effectively; commitment to reducing restrictive interventions; effective practice leadership; staff training)

- *Section 2 (3 questions): Are planned programmes relevant to each person's needs?* (questions here are about the match to current needs and future preferences for each person; evaluation of outcomes for each person and review; whether the person and families are involved in the support plan)
- *Section 3 (2 questions): Is each person's programme at the right intensity?* (questions here are about programme intensity; and staff knowledge of the protocol)
- *Section 4 (3 questions): Is there a balance of programmes and support plans for each person across settings and over time?* (questions here are about balance across multiple programmes; whether support is seamless across services for the person; does the plan reflect planning for the future).

#### 5.4 Changes made already by CQC in response to recommendations

Almost immediately after the first report on Whorlton Hall was presented to CQC (in March 2020), the corona virus pandemic led to a national lockdown. Initially CQC had to suspend its routine inspections and it has since made a number of changes, as part of its 'transitional' new methodology, to improve its inspections and implement the recommendations of the Whorlton Hall independent review for high risk settings for people with learning disabilities and/or autism and complex needs. These change are summarised in the following Table.

**Table 1 showing recommendations and progress so far**

Recommendation in the first report	Details	Progress to date
1. Improve data display and analysis	a. For each setting inspected CQC should display data such as abuse allegations, complaints, levels of staff training, staff turnover, staff sickness levels, use of agency staff, restraints	Dashboards have been developed that show volumes and patterns of abuse allegations, complaints to CQC and concerns for Adult Social Care (ASC) locations, and for Independent health



	<p>&amp; segregations</p> <p>b. Regression analysis to identify statistically significant performance indicators for inadequate services</p>	<p>(IH) mental health.</p> <p>There is a dedicated programme on developing new 'indicators' which incorporate closed culture risk factors (such as staff turnover). New indicators will be available in Intelligence dashboards from January 2021.</p> <p>Options for how to make this accessible and how it can support decision making is underway (for February 2021).</p>
<p>2. For high risk settings, unannounced visits and evening and weekend visits should be used.</p> <p>Make inspections less predictable, provide ratings even from focused inspections and present faster reports.</p>	<p>a. Unannounced inspections and evening and weekend visits</p> <p>b. Decoupling PIRs from inspections</p> <p>c. Ratings from all inspections, including focused ones</p> <p>d. Faster inspection reports, following inspections</p>	<p>a. More unannounced inspections and evening and weekend visits being conducted</p> <p>b. Social care PIRs already annual. Independent hospitals not yet (due to COVID).</p> <p>c. Where there is a closed culture this will trigger faster pace inspections that can produced changed ratings</p> <p>d. Local Improvement Groups working towards this. New strategy also</p>

		expected to help.
3. Closer working with LAs & CCGs over abuse allegations & safeguarding concerns	<p>a. More liaison with LAs &amp; CCGs over investigations of abuse allegations</p> <p>b. Identifying and ensuring retracted allegations investigated</p> <p>c. Rising rates of concerns and allegations to trigger liaison with LAs and CCG and focused inspections</p>	<p>a. Improved current information sharing with NHS England for high risk hospital settings. Social care to follow.</p> <p>b. New system of provider information will ask for 'withdrawn complaints' and the outcome of these.</p> <p>c. Abuse allegations &amp; complaints now displayed on dashboard. Relationship owner will rapidly liaise with LA.</p>
4. Interviews and observations with service users & family carers	<p>a. Interviews with service users should be prioritised in inspections and should be in safe places</p> <p>b. Inspectors should be trained in alternative and augmented communication e.g. Talking Mats</p> <p>c. As many family carers should be interviewed as possible. These should not be selected by the service</p>	<p>a. Mental Health Act reviewers conducting on-line extended interviews with patients, staff, carers and advocates.</p> <p>b. Inspectors trained on closed cultures (and implications for what SUs and staff say). Also trained on Talking Mats (latter being trialled from end of November by inspectors).</p> <p>c. See a. above. Info from MH reviewer shared with Inspection teams</p>

	<p>being inspected.</p> <p>d. Direct observations in day rooms should always be conducted, to get a feel for everyday experiences for service users</p>	<p>d. SOFI-1 tool being used at times; training on SOFI-2 underway. New QOL measure about to be tried out (see later for details).</p>
5. 'Level 2' inspections of services at risk of failing	<p>a. Criterion for 'risk of failing' to be developed</p> <p>b. More time in the service, interviewing and observing service users</p> <p>c. Rating of culture or atmosphere of the setting</p> <p>d. Staff surveys (to be returned directly to CQC, not via the service manager)</p> <p>e. Access to CCTV records or similar</p>	<p>a. Closed Cultures document will be used to signal if a service is failing</p> <p>b. Closed Cultures assessment used to guide inspection and new QOL tool being trialled</p> <p>c. See above</p> <p>d. Not completed</p> <p>e. No powers under RIPA for intrusive covert surveillance. See later for discussion.</p>
6. Registration	<p>a. Out-dated models of service should not be registered anew (i.e. out-of-area, isolated from the community being served, low nursing numbers, poor MDT provision, high numbers of unqualified staff, poor provision of</p>	<p>a. New guidance published: <i>Right Support, Right Care, Right Culture</i> (published by CQC 8/10/20), making clear what will and will not be registered by CQC in learning disabilities and autism services.</p>

	<p>activities).</p> <p>b. Out-dated models of service that already exist should not be allowed to expand</p> <p>c. CQC should consider how to encourage those those already registered to improve</p>	<p>b. &amp; c. The new guidance will improve how ratings &amp;/or enforcement can be used to alter services that are already registered, so as to transition to up-to-date models of care</p>
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## **6. Research evidence**

In addition, to its work on the recommendations in the first report, CQC asked Prof Murphy to conduct a systematic review of the international research evidence in relation to the detection and prevention of abuse in services. This is described below and a shortened version of the review paper is included in Appendix 1 (the full references are in Appendix 2). As part of this work, two half-day workshops were run for CQC in October 2020, with the main researchers from the systematic review each presenting their work and discussing it with CQC staff (the workshop timetable is given in Appendix 3 to illustrate its contents).

There are already systematic reviews in the published literature for older people and children (Dong, 2015; Timmerman & Schreuder, 2014); this review has therefore been confined to research literature relating to adults with intellectual disabilities and or autism in residential services, both hospitals and social care settings.

A systematic search of this published literature on abuse and people with learning disabilities and/or autism, in residential services, was conducted using 7 databases and a range of systematic search terms (see Appendix 1 for a shortened version of the article). The PRISMA flowchart showed that over 15,000 potentially relevant empirical papers were returned from the searches; some were duplicates and were removed. Many did not contain empirical data, or related to older people, children or adolescents, so were removed. Finally, 48 articles remained and their quality was rated using the MMAT (mixed methods assessment tool). The studies and their findings are summarized below (see also Table 1 of the research paper in Appendix 1). Full references to the literature found are given in Appendix 2.

### **6.1 Background and early prevalence studies**

Many western countries have experienced similar difficulties to those in the UK, in relation to abuse in services for vulnerable people. Early reports about institutional abuse in the UK (e.g. in Ely hospital in 1967) were mirrored in other countries, and they gradually fuelled a widespread deinstitutionalization movement in the US, UK and Europe, in which it was initially assumed that community living would solve the problem of institutional abuse. Needless to say, this was a misguided belief, and reports of abuse continued to arise, causing much debate about how to detect and prevent abuse.

In 1975 in the USA, Congress mandated Protection and Advocacy offices for those with developmental disabilities, in recognition of the fact that they had unique difficulties in having

their service needs met. State developmental disability services could only receive federal funding if they had a Protection and Advocacy office, and it had to be independent of the disabilities services office. Zuckerman et al (1986) were asked to examine these Protection and Advocacy offices to see how they were involved in investigations of abuse and neglect. A questionnaire was sent out with 13 questions about the state's definition of abuse and neglect, staff size, investigations of cases of abuse or neglect, staff time taken in such cases, other staff involved, successful strategies, barriers to success, steps to preventing abuse, funding, and suggested changes. Directors from 43 (83%) of the states responded and they reported that they allocated an average annual budget of \$254,000 to Protection and Advocacy offices. However, this varied massively across states with some budgeting \$1.2 million and 13 states budgeting less than \$100,000. Most states reported that they found their budget inadequate, and they commonly involved staff outside the Protection and Advocacy offices to help investigate cases (including volunteers). Over 50% of states investigated service level abuse as well as individual cases, and most worked both independently on some cases, and jointly with other agencies (eg law enforcement or social welfare agencies) on other cases. In part this joint working was because the Protection and Advocacy agencies had no right to access client records unless requested to do so by a resident (this was considered a major barrier). Protection and Advocacy offices worked mainly by carrying out investigations and making recommendations, or by investigating and then negotiating for changes. Litigation was used relatively rarely (10 of 43 offices). In response to the question about steps to preventing abuse, the most common strategies recommended were staff training, closing institutions, strengthening laws around abuse, and increasing legal access to residents.

Despite the existence of Protection and Advocacy Offices in the USA, cases of abuse continued to arise, especially in residential settings, and in the 1980s researchers such as Furey, for example, argued that there was a relative lack of research in relation to the abuse of people with learning disabilities in such settings. She showed that 81% of all 944 cases of substantiated abuse against people with learning disabilities, in Connecticut, over a 5 year period, had occurred in various kinds of residential settings (Furey & Haber, 1989) and yet she could find no research on group homes, only a few studies in large institutions. Furey et al (1994) later analysed the relative rates of abuse in different types of settings: institutions, group homes, family homes, supported living and adult placements. She found the highest rates of abuse in institutions and group homes (and on average approximately 1% of these settings reported abuse over 5 years). Rusch et al (1986), also in USA, compared people with learning disabilities who had been abused to those who had not been abused and reported that challenging behaviour was a vulnerability factor (along with poorer verbal skills

and several other indices). Meanwhile, Marchetti & McCartney (1990) found male direct care staff were proportionately more likely to be perpetrators of abuse, and female direct care staff were proportionately more likely to report it.

Some research focused on one kind of abuse only, and a number of studies reported on sexual abuse in the 1980s and early 1990s, both in the UK, USA and Canada. Prevalence rates for sexual abuse amongst adults with learning disabilities varied considerably, ranging from 8% to over 50%; the highest figure was obtained by an interviewer in a day centre, someone already known to participants, talking to each of a group of people with learning disabilities directly (lower figures resulted from surveys). One of the best known surveys was that of Turk & Brown (1993), who surveyed a region in the SE of England (general population 3.6 million people). They reported an incidence rate of 60 new cases per year of sexual abuse of adults with learning disabilities. The victims were mostly women (approx. 70%), living in residential services of one kind or another (approx. 70%), and of varying levels of disability. The vast majority of alleged perpetrators were men (98%), many of them staff, and about 40% were other service users. Police were involved in about half of the cases but very often there was no action taken against the alleged perpetrator. The abuse mostly came to light through victim reports (68%), suggesting that the figures were probably the tip of an iceberg (since many people with learning disabilities have severe communication difficulties). Their second survey produced similar findings (Brown, Stein & Turk, 1995), as did Beail and Warden (1995).

## **6.2 Safeguarding, Adult Protection, and Serious Case Reviews**

A series of studies have examined evidence from safeguarding and adult protection registers, to examine levels of abuse allegations, the sources of such allegations, and the outcomes of investigations. They have confirmed that people with learning disabilities can and do make substantiated allegations of abuse, though these are relatively rare. Typically, it seems that the majority of allegations come from residential settings (as opposed to family homes), and in a considerable proportion of allegations, staff were the alleged perpetrators of abuse, but other residents and family members were also sometimes alleged to have been the perpetrators. All studies have reported that although a proportion of allegations are confirmed, a sizable proportion are not confirmed or are undecided.

In the UK, early studies of adult protection referrals (n=397) in SE England suggested people with learning disabilities were particularly at risk, compared to other care groups, though more so for sexual abuse than financial abuse (Brown & Stein, 1988). Brown and

Stein's (2000) later study investigated six months of adult protection referrals across 10 different local authorities in England and they found major variations in what was considered abuse, in what records were kept, and in which cases intervention was thought to be warranted. Ten years later, in a large study of over 6000 adult protection referrals, across all care groups, from two local authorities, over a number of years, researchers (Cambridge et al, 2010; 2011; Mansell et al., 2009; & Beadle-Brown et al., 2010) reported that the majority of referrals, for all care groups, were for people in residential care, as opposed to those living alone or with families, and that about half of all referrals concerned older people, while those for people with learning disabilities constituted 32% (those for people with mental health needs numbered 3% and others 6%). Given the overall numbers of people with learning disabilities (less than 2% of the general population), compared to the numbers of older people, the researchers concluded that people with learning disabilities were *proportionately* more likely to be the subject of adult protection referrals than other care groups. For cases involving people with learning disabilities, multiple types of abuse were most common (33% of cases), followed by physical abuse and sexual abuse (29% of cases and 17% of cases respectively), while financial abuse was less common (7%), as were other types of abuse, such as neglect (6%). Alleged perpetrators were mostly staff (46%), and other residents (26%), though some were family members (23%). Both men and women were alleged perpetrators, but for sexual abuse 91% of cases involved male perpetrators. Rates of adult protection referrals increased consistently across the years that were studied, and out-of-area placements seemed particularly likely to result in abuse. Over all care groups, abuse was confirmed in 41% of cases, discounted in 18% (i.e. considered not to have occurred), and there was insufficient evidence to judge in 39%. Fyson & Kitson (2012) reported a somewhat lower level of 'not determined' cases (20%) in their study of adult protection cases (there were no clear correlations of this 'not determined' decision with demographic variables (such as age or gender) or with the type of abuse, or where it took place, or with involvement of the police). However, one of the worrying aspects of Fyson & Kitson's study was that they found that the investigations were often conducted by professionals who did not know the individuals in question, which they considered probably made investigations more challenging and possibly less accurate. Moreover, Fyson (2015) found that safeguarding managers were not always able to define the outcomes of safeguarding enquiries (namely 'substantiated', 'not substantiated' and 'not determined') correctly.

As regards perpetrators, several studies from the US, have reported similar proportions of staff and other residents allegedly involved in abuse to studies in the UK. For example, Ramsey-Klawnsnik et al (2008) and Ramsey-Lawnsnik & Teaster (2012) in a prospective study of 429 Adult Protection cases of alleged sexual abuse across 5 states in the US, found 40%



of cases related to those with developmental disabilities (the remainder related to those with mental health needs, physical or sensory disabilities), with overall, 44% of the alleged perpetrators being staff; 24% were other residents. Only 18% of cases were substantiated and this was more common when other residents were the alleged perpetrators (65% of substantiated cases) than when staff were involved (19%). This was perhaps because staff were better able to hide what they doing, and/or that staff were perhaps more reluctant to report on each other. Similarly, Ahlgrim-Delzell and Dudley (2001) found in their study of abuse of people with learning disabilities, in a single state in the US (in a class action law suit), that of the 158 allegations of abuse, only about 20% of allegations were confirmed, and those against staff were less often proven (18% of cases accusing staff were confirmed), than those against other residents (49% of cases accusing other residents were confirmed). The reason for the low rate of substantiated cases was later investigated by Ramsey-Klawnsnik et al (2012) and by Abner et al (2019), in a series of logistic regressions of the Ramsey-Klawnsnik et al data. The former, having interviewed investigators, pointed out that while many investigators were very experienced, around a quarter had had less than one day of training. The latter found that the best predictors of successful confirmed cases were: the victim having verbally disclosed; the victim having been injured; a report of the case had been made within 3 days of the incident; and a resident being the alleged perpetrator.

There is of course a risk that people can be falsely accuse of abuse and a small qualitative study by Rees & Manthorpe (2010) asked 13 managers of services (for people with learning disabilities and challenging behaviour), and 10 of their direct care staff, who had been falsely accused, about their experiences. Most of the managers could detail positive experiences of the *No Secrets* guidance (Department of Health 2000) on their service, in uncovering abuse by family members, by staff and by service users. Nevertheless, managers also found a number of difficult issues in Safeguarding investigations, especially the frequently protracted length of investigations, a relative lack of expertise in investigators, lack of understanding of the needs and difficulties of service users, the intimidating nature of the process and the variation between different authorities in the way policies were implemented. Many also worried that staff were considered 'guilty until proven innocent'. All managers found the investigations very disruptive, some wondered whether it would not be better for investigations to be internal, and a number felt the investigations had a negative impact on client care. Some managers considered that for some clients, making allegations was a learnt behaviour and an unwarranted way of punishing staff. As for the staff who had been accused but were later exonerated, they complained about having no information about what they were accused of, about the protracted nature of the investigations, feeling very distressed, stigmatised and unsupported, angry with their employers and feeling that they

wanted redress. They also worried that some clients had learnt to make false allegations, and that this was not taken into account.

In a related study, Hussein et al (2009) investigated the use of the Protection of Vulnerable Adults (POVA) list. This was set up following the Care Standards Act of 2000 and its aim was to provide easy access to information about unsuitable employees for the social care sector, though the onus was on employers to refer 'unsuitable' staff, to make pre-employment checks and to pay for such checks. In 2005, the Department of Health commissioned Hussein et al to conduct a study of the POVA scheme and they provided basic details of the 5,294 referrals over a two year period (2004-2006), and more detailed records relating to 298 referrals for in-depth study. Hussein et al (2009) found that about 75% of all referrals to POVA followed investigations by employers, and there were a number of other organisations involved at times, such as Social Services departments (informed in 58% of cases), Adult Safeguarding (informed in 25% of cases), the police (involved in 51% of cases, particularly those involving financial or sexual abuse), and the CSCI (precursor to the CQC for social care). Of the 5,294 referrals, 58% were closed and the referred person was not added to the POVA list; 28% were on-going; and 7% (363 individuals) were added to the POVA list. In 9 out of 10 cases, processing took less than 3 mths and these were often cases that were removed at the pre-provisional stage. If they proceeded, cases frequently took a long time to get to a decision (e.g. many took more than 9 mths); the longer they took, the more likely they were to be confirmed. A very small number (n=37) were taken to appeal. The study suggested that the POVA list was resulting in the removal of unsuitable people from 'caring' roles, but that the vast majority of staff referred were not added to the POVA list. Moreover it seemed that better coordination between the various agencies was needed.

The POVA scheme was later up-dated, following the Safeguarding Vulnerable Groups Act of 2006, and the lists for children (POCA and 'list 99') and adults (POVA) were combined into the vetting and barring system. In 2012 it was again up-dated and became known as the Disclosure and Barring scheme. It had three levels: basic (involving a search of the Police National Computer for details of current convictions, the certificate only revealing unspent convictions and conditional cautions); standard (involving checks through the PNC for details of spent and unspent criminal convictions, warnings, cautions and reprimands held by Police) and enhanced (a check against the PNC of all spent and unspent criminal convictions, warnings and reprimands, together with checks against adult and children's barred lists where applicable).

Where very serious harm or death of a vulnerable adult occurred, regardless of the outcome of Adult Protection proceedings, Serious Case Reviews were required (these were originally established by the Children's Act 2004). These reviews were commissioned by local Adult Safeguarding Boards and Manthorpe and Martineau (2015) conducted a documentary analysis of 75 Serious Case Reviews<sup>1</sup>. They found them very variable but extracted three themes:

- Staff relationships: The theme of distortions of power and control among people with learning disabilities and staff 'in charge' featured strongly in many of the SCRs. Care managers and social workers often seemed to be absent or invisible.
- Family and carers: in a number of reviews, there were difficult relationships between social care professionals and family carers, who neglected and /or abused their relatives. At times, the vulnerable adults (some of whom later died) became invisible because they stopped using services, and care professionals did not visit the family homes.
- Biography and chronology: Most of the people who came to serious harm or died were known to services. However, there was often a dispute about their diagnosis and /or the degree of their learning disability, such that many had not received the services they needed

In a later study, Aylett (2016) examined 114 Serious Case Reviews, 32% of which concerned people with learning disabilities. They found, like Manthorpe and Martineau that the reviews were very variable in the quality and in the quantity of information provided. Of the alleged perpetrators, 46% were paid care staff, and the abuse took place in residential homes in 38% of cases. The themes in the executive summaries were as follows:

- Poorly co-ordinated assessment across agencies (including risk assessment and determination of mental capacity) (74)
- Inadequate information sharing and recording practices (40)
- Inconsistencies in understanding and application of concepts in Safeguarding Vulnerable Adults policy (35)
- Ineffective application of the principles of the Mental Capacity Act (26)
- Vulnerability inadequately recognised and responded to especially in circumstances of service refusal and self-neglect (23)

The most commonly recommended actions were as follows: providing staff training and developing competence (134); reviewing and improving policy, procedure and guidance (64);

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<sup>1</sup> At the time of Manthorpe and Martineau's study these reviews had no statutory basis; they do have now (as required under the 2014 Care Act) and are termed Safeguarding Adult Reviews.

facilitating information sharing and communication within and across agency (57); developing effective governance systems (48); holistic multi-agency assessment, planning, monitoring and review (36); develop dynamic risk assessment and risk management by assertive outreach to vulnerable adults (30); and engaging with a wide range of agencies and interests in Safeguarding Vulnerable Adults (23).

### **6.3 Families of people with learning disabilities**

Extremely few research studies appear to have asked families about their experiences of reporting abuse. However Bright et al (2018) recruited seven participants who were family members (all women, mostly mothers) of people with learning disabilities (all of whom were in residential services of one kind or another). All the participants had experience of raising concerns about the services, and in qualitative semi-structured interviews they were asked to describe their concerns and their subsequent actions. Three themes and 8 subthemes were noted following analysis using IPA:

- The nature and importance of concerns:
  - ‘the little things’ - examples included their relatives wearing someone else’s clothes, community activities not occurring, sleep patterns and diet not attended to, and more seriously, inappropriate use of restraint, or assault by another resident.
  - ‘understanding the person in their context’ – for example, poor understanding of their relative’s past experiences and how they showed their feelings
- Relationships between families and staff
  - trust and mistrust – there were high levels of mistrust especially if staff seemed to be covering up concerns
  - communication and information sharing – this was considered very important, and was made more difficult by poor records and multiple staff to talk to
  - effective and trustworthy management – good managers were not always available and their qualities didn’t always ‘filter down to staff’
- The process of raising concerns
  - the process itself was considered complex, frustrating and lengthy, requiring much time, energy and assertiveness
  - responsiveness – families felt staff were often not responsive and were defensive when concerns were raised
  - how it feels – families felt in a constant state of worry and uncertainty about when the next concern would arise, a feeling of constant vigilance

Bright et al recommended services should ensure that one person is allocated to each family so that they do not have to tell multiple people about their concerns; that services should

encourage family contact (and contact between families); that they should involve families in training for staff; and that they should consider simplifying complaint procedures.

#### **6.4 People with learning disabilities themselves**

Several studies in the systematic review have reported interviews with people with learning disabilities, for example, about what they seek in staff who work with them. Kroese et al (2013) reported that people with learning disabilities, who also have mental health needs, when interviewed said that they wanted staff who have a genuine interest in people to work with them, staff who were gentle, warm and approachable, with good communication skills, staff who 'listen to you and not judge you', and *not* staff who 'just do it for the money'. Kroese et al felt that those interviewed were well able to distinguish staff who really cared about them, from those who did not. In another study Kroese and colleagues (Jones & Kroese, 2006) interviewed a small number of service users about restraint procedures (all had experienced restraint). They could describe what it involved and knew why it was used (eg. to 'stop .... people getting hurt') but only half of those interviewed felt it actually helped them to calm down. They could suggest other better ways to calm them down (e.g. 'Talk to you. Restraint makes me more violent'), and several described frankly abusive incidents where staff taunted or encouraged them to be aggressive or self-injurious, and staff seemed to have 'enjoyed it' (the restraint).

A number of studies have investigated whether people with learning disabilities can act as service evaluators (see also the review by Kroese et al, 1998), and it is clear that this is often possible, provided the questions are put in an open-ended way and are simply worded, accompanied with pictures and, if yes/no questions are used, they are only given afterwards to double check opinions. Some researchers have also asked people with learning disabilities directly about adult safeguarding issues: about whether they know when the behaviour of others is risky or abusive, and how they protect themselves. In Hollomotz's (2012) study, 29 individuals living in various types of settings (family home, group homes, supported living) were interviewed using a semi-structured interview format, alongside three vignettes about abuse/ risky behaviours (one involved an unwanted hug, one an unwanted sexual touch, one an invitation to a stranger's home). Almost all of the adults interviewed recognized the risks in the vignettes and could name strategies that would protect the person involved. They were able to go on to discuss risky situations they had found themselves in (including sexual assaults and domestic violence) and could describe how they coped with them, some using very assertive behaviours, others seeking help from staff or social workers. Disappointingly, they said that some staff were dismissive of their reports, advising them to ignore perpetrators and/or taking no action themselves, implying a level of

tolerance that would not be shown in the wider community. Hollomotz concluded that such slippage in standards of behaviour was unwarranted and she also proposed that adults with learning disabilities needed more support and training to make their own reports of abuse.

### **6.5 Direct care staff detecting abuse**

Care work is widely recognized as both rewarding and at the same time stressful for direct care staff, who are most often women and usually poorly paid. Baines and van den Broek (2017) argued that the work represents a balance between care, coercion and control, with the latter two aspects rising as resources are reduced and managerialism is increased.

One of the many tasks of care workers is to be aware of abuse, and studies of the views of direct care staff have indicated that they are aware that people with learning disabilities are at greater risk of abuse than other people. Moreover, direct care staff generally have strategies for what to do if they suspect abuse, reporting to senior managers being the main strategy (Allington, 1992). However, several studies of direct care staff have found they struggle to define abuse, beyond physical and sexual abuse (Taylor & Dodd, 2003; Parley, 2010; Fyson & Patterson, 2019). They tend not to think of bullying, neglect, psychological and institutional forms of abuse, and rarely mention the Human Rights Act 1998. They often had inappropriate strategies for dealing with abuse, such as talking to the abuser, or not reporting it due to 'confidentiality' issues (Taylor & Dodd, 2003).

Early studies from the US suggested that certain kinds of direct care staff in residential settings were more likely to be involved in incidents of abuse, and others were more likely to report abuse. For example, McCartney & Campbell (1998) in a study of nearly 500 confirmed cases of abuse across 6 states, found newer staff, male staff, those on afternoon & evening shifts, and those previously reported in abuse incidents, were more likely to be involved in perpetrating abuse. Those reporting abuse were younger staff, newer staff and had more recently received in-service training on preventing abuse.

Some researchers have interviewed direct care staff directly about their experiences of providing care and about the differing standards of care in different settings. Hutchison & Kroese (2015), for example, interviewed a small number of direct care staff, inviting them to talk freely about their experiences of working in residential care, with specific emphasis on exploring any changes and differences in care practices they had encountered. The qualitative analysis indicated three themes: the degree of positive relationship reciprocity; value congruence and intrinsic motivation; experiences of environmental and organizational constraints. As regards relationships, one of the most important issues was the extent to

which they felt valued and empowered by more senior staff, as opposed to being disregarded and made to feel powerless and worthless. Feelings of working in a collaborative team, as opposed to being an isolated worker, having positive relationships with service users, and seeing service users and staff as equals were also considered important aspects of relationships, when a direct care worker. Feelings of congruence with the role of direct care worker, sharing the values of the service, and finding satisfaction in the daily work were also noted as important, as were the extent of leadership and staff training, and the degree of integration between the service and the outside world, with more isolated services being viewed much more negatively.

Meanwhile, Fyson & Patterson (2019) argued that the repeated scandals in care services for people with learning disabilities, may have been improving the detection of abuse but was not preventing the occurrence of abuse. They thought that since services seemed to be poor at detecting poor practice (and the slide from poor practice into abuse), it was important to find out what direct care staff understood to be poor practice, and to ask them what they would do if they encountered it. The first problem was the difficulty defining poor practice, since it is not defined in statutory guidance, such as *Dignity in Care* (2014) but is mentioned by Local Safeguarding Boards. However Fyson & Patterson pointed out that:

*'Local Safeguarding Adults Boards typically distinguish between abuse and poor practice by stating that abuse is something which requires a response under safeguarding procedures, whilst poor practice requires action by service provider organisations; this may help authorities manage the workload associated with responding to safeguarding alerts but is insufficient to guide residential care practice (Fyson & Patterson, 2019).*

They went on to interview 56 staff (home managers and direct care staff) across 14 community-based services for people with learning disabilities (some profit-making, some not-for-profit), asking them what they understood by the terms 'poor practice' and 'abuse'. They also asked them to identify which of these, if either, was happening in 9 vignettes of people in services, that were based on real events described by people with learning disabilities and their family members. Their main finding was that there was a lack of agreement between participants about the meaning of these terms, whether they were managers or direct care staff, from profit-making or not-for-profit services. All bar one participant had had adult safeguarding training and, in general, they could name specific forms of abuse (such as physical, verbal, financial, emotional, neglect), though few mentioned institutional abuse. Some understood abuse as about not being given a choice, or being treated with a lack of dignity or respect, and a few talked about 'good practice'

meaning 'doing as they would be done by'. Very few talked about abuse of power. As for poor practice, staff tended to see it as 'not following policies' and realized that it could result from a lack of training, poor management, and poor supervision, with new staff picking up 'poor practice' from staff already there. Most staff found it difficult to draw an exact line between poor practice and abuse (much as Taylor & Dodd, 2003 had found), saying there was an overlap, but some spoke about how poor practice could be an early indicator of abuse. There was a big range of opinions on the vignettes, as to which were 'ok', which 'poor practice', and which 'abuse'. The researchers concluded that:

*'Safeguarding training needs to support staff to understand abuse and poor practice not only as individual acts or omissions but also as a set of relational dynamics which can create and sustain either positive or abusive institutional cultures'*.

Despite the fact that staff are sometimes uncertain about the dividing line between poor practice and abuse, some do report their concerns, and the Public Interest Disclosure Act 1998 legitimised 'whistleblowing' as a way of protecting vulnerable people. This is how a number of cases of serious abuse have come to light: for instance, in the Longcare case, of extensive abuse of adults with learning disabilities in two very large care homes in Berkshire, several staff had reported their concerns but these were not taken seriously by police and local authorities for years. Abuse in Whorlton Hall also came to light through two whistleblowers, who eventually approached the media because they had been unable to persuade others to take action. It is difficult to know what proportion of whistleblowers are ignored by those to whom they report their concerns, and there are very few research studies of whistleblowers. However, Calcraft (2007) conducted six focus groups (with adult protection staff, social care inspectors, and trainers of social care staff), and interviewed 15 individuals, asking them about whistleblowing (they included social care workers who had reported concerns, and managers who had experience of responding to concerns). Whistleblowers reported that their experience was extremely distressing: they usually felt they had had no support from within their organisations, they often feared aggressive behaviour from those they reported, they were required to carry on working (while the alleged perpetrator was suspended on full pay), hence they sometimes suffered insults from other staff, and counter-accusations, and they received very little information about the outcome of any investigations. Understandably, some said they would not blow the whistle again. Many talked about how there was 'ingrained acceptance of abusive practices' in some services, and closed cultures, making some staff blind to the poor practice and abuse.

As Manthorpe (2001) noted, whistleblowing is not a step taken lightly and there are numerous sanctions that may be imposed on whistle-blowers to discourage them, in poor



services, including economic, anti-social and personally threatening consequences, such as:

- removal/reduction of overtime
- reduction of hours
- immigration fears
- dismissal
- not taking account of family commitments
- giving difficult tasks/work
- disciplinary action
- indications that family members will be threatened
- violence, intimidation and victimization
- counter allegations of abuse, or incompetence
- allegations of malevolence.

Since the early 2000s, there have been attempts to protect whistleblowers, including the introduction of a Statutory Duty of Candour (2014), meaning that providers must be open and transparent with service users about their care and treatment, including when it goes wrong, and the Fit and Proper Person Test (which requires that individuals who have authority in organisations that deliver care are responsible for the overall quality and safety of that care). Nevertheless Sir Robert Francis in his Freedom to Speak Up report (2015) found that the NHS culture did not always encourage or support workers to speak up, and that patients and workers suffered as a result. Workers felt that serious concerns they raised were sometimes met with a response that focused on 'disciplinary action against them, rather than any effective attempt to address the issue they raised'. They worried that they would be seen as disloyal, a 'snitch' or a troublemaker. The *Office of the National Guardian* and *Speaking Up Guardians* were created in response to recommendations in Sir Robert Francis' report (2015). His admirable 5 factor vision for how raising concerns in the NHS should work (page 91 of his report) was published in 2015, yet the Whorlton Hall scandal took place in 2019 and the whistleblowers would not have recognized Francis's vision.

## **6.6 Professional staff detecting abuse**

Services for people with learning disabilities typically have numerous contacts from visiting professional staff from local learning disabilities teams, such as social workers, community nurses and psychologists, and it is important to ask whether they can detect indicators of abuse.

Kroese and Smith (2018) interviewed 8 psychologists about their experiences of working with staff in residential settings for people with learning disabilities. The themes identified included the importance of developing a trusting and compassionate relationship with staff; engendering trust and being open and transparent with staff; the influence of the culture of the home and the resources; the need to stay alert to possibilities of bad practice and abuse, and the challenges of reporting such aspects of care. Psychologists, like other professional staff working with residential homes, may become aware of unhelpful attitudes of staff and of barriers created by the culture of the home, some of which may be indicators of abuse.

In an attempt to ascertain such indicators of abuse in residential services for people with learning disabilities, Marsland, Oakes & White (2007) interviewed 17 professional staff who had visited services where abuse was later proven or had almost certainly occurred (some family members were also interviewed and a number of 'files of concern' were analysed). Participants were asked about their professional role in relation to the service, what caused them to become concerned about the possibility of abuse, what deepened their concerns, and what they considered, with hindsight, to have been significant. Six themes emerged (each of these had multiple exemplars):

- The decisions, attitudes and actions of managers (such as the manager appears unable to change the way a group of strong/powerful members of staff are working; the manager of the home and/or organisation do not support members of staff who complain or act as whistle-blowers)
- The behaviours and attitudes of staff (such as restraint is used frequently and as a first option before other approaches are tried or members of staff lack skills in communicating with residents or interpreting the communication of residents).
- The behaviours of people with learning disabilities (such as residents show signs of fear, or talk about not feeling safe; residents behave very differently with different members of staff)
- Isolation (such as there is little input from outsiders and external professionals; staff demonstrate hostile attitudes to visitors who are treated as unwelcome or as intruders)
- Service design, placement planning and commissioning (such as agreed programmes or plans are not being carried out; members of staff or managers do not carry out recommendations made by external professionals)
- Fundamental care and the quality of the environment (such as there are no or few activities and things for residents to do; the home is in a poor state of repair or poorly furnished).

As Marsland et al (2007) commented 'popular models of abuse often appear to privilege the 'bad apple' model (Martin, 1984)', which puts the blame for abuse on one or two disturbed and deviant individuals. They add: 'While there is some legitimacy in this perspective .....it appears to offer an incomplete analysis of the reasons why individuals are abused'. White, Marsland et al (2003) remarked in their review of cultures that promote abuse: 'we are better able to respond to abuse which has already occurred than to protect people before they are abused'. They considered the issue of the prevention of abuse and suggested there were three levels of prevention: 'primary prevention, concerned with preventing the occurrence of abuse; secondary prevention, associated with the early identification of potential or actual abuse', and finally 'tertiary prevention, involving actions taken in response to established abuse, to reduce the likelihood of further abuse and to support those who have been abused'. The remainder of their review considered the factors that placed individuals at risk (which might allow prevention at the primary level) and the recognition of early indicators of abuse which might allow early identification of potential abuse (at the secondary level). They detailed the contributions of management; staff deployment and support; staff attitudes, behaviour and boundaries; staff training and competence; power, choice and organizational climate; isolation; service conditions, design and placement planning. Marsland, White and colleagues went on to create a guide for professionals in learning disabilities services (and older people services) of 'Early Indicators of Concern', taking into account all these factors (see <https://www.scie-socialcareonline.org.uk/identifying-and-applying-early-indicators-of-concern-in-care-services-for-people-with-learning-disabilities-and-older-people-the-abuse-in-care-project/r/a11G0000003CYfNIAW> ).

Interestingly, very many of the indicators of abuse described by Marsland et al were evident in Cambridge's account of the service where two people with severe learning disabilities and challenging behaviour were serially abused (Cambridge, 1999). Cambridge interviewed managers, direct care staff and professionals and they reported a series of difficulties, such as a closed culture (one saying: 'They were like a closed society, a law unto themselves. I got the instant impression of so much that was wrong'); the isolation of the service from outside scrutiny; ineffective staff supervision; inexperience and poor training amongst direct care staff; frequent cancellation of training; intimidation by abusive staff towards other staff; neutralization by abusive staff of moral concerns raised by new staff; lack of appropriate policies and procedures; non-compliance with the local learning disability team members' advice; poor coordination of concerns amongst such team members; poor oversight by commissioners; and a lack of support for whistle-blowers were all considered contributory factors.

## **6.7 Are there useful measures of organisational cultures that could detect closed or abusive cultures?**

Early recognition that general aspects of the social environment were important in services for people with learning disabilities started to arise in the 1960s and resulted partly from Goffman's work on institutions (Goffman, 1961). Moos and Hout (1967), for example, developed a measure of 'ward atmosphere', and found that this affected the satisfaction of psychiatric patients. It seemed to also relate to both lower levels of aggression towards staff, and better recovery. They argued that three aspects were important: relationships; treatment programmes; and systems maintenance. Later Moos (1987) developed a similar measure for use in prisons and secure facilities: the Correctional Institutions Environment Scale (CIES) and this has been used in secure services and prisons, but has rarely been employed in secure services for those with learning disabilities.

The original measure of Ward Atmosphere consisted of over 100 items and 11 subscales, though this was later revised to become the WAS-R, a shorter form with 82 items, each rated on a four-point scale (Røssberg and Friis, 2003). The revised Ward Atmosphere Scale (WAS) measured the following 11 aspects of the treatment environment: involvement, support, spontaneity, autonomy, practical orientation, personal problem orientation, angry and aggressive behaviour, order and organisation, program clarity, staff control, and staff attitude to expressed feelings. Subsequently, in Norway, Bakken et al (2012) used six of the subscales (involvement, support, practical orientation, order and organisation, angry and aggressive behaviour, and staff control) with 17 patients and 21 staff members in across two wards in a Norwegian hospital for the treatment of people with mild/moderate learning disabilities who also had mental health needs. Those with mild learning disabilities were able to complete the scale with some help but those with moderate learning disabilities were not able to do so because of the complex wording, even with help. For those who could complete it, scores showed that there was more involvement, more support, more order and organization, more practical orientation, and less staff control than in comparison wards in Norway for psychiatric patients. Staff and patients scored the scales very similarly.

Meanwhile, in the UK, Langdon et al (2006) examined ward atmosphere in two secure services (one medium secure, one low secure) for people with learning disabilities, using Moos's CIES. Eighteen men with mild learning disabilities took part, alongside 37 staff. The majority of the men were detained under the Mental Health Act and all of them had committed crimes (those who had committed more serious crimes such as rape or murder were generally in the medium secure unit), many also had mental health needs. All participants completed the CIES short form (revised edition), which consists of 36 items,

forming 9 subscales and three dimensions (Relationships; Personal growth; Systems Maintenance). The Relationships dimension comprised Involvement, Support and Expressiveness; the Personal Growth dimension comprised Autonomy, Practical Orientation and Personal Problem Orientation; the Systems Maintenance dimension comprised Order and Organisation, Clarity and Staff control. These are very similar to the subscales and dimensions of the ward atmosphere scale. The results showed that the men rated medium secure and low secure units differently on some subscales (Practical Orientation and Personal Problem Orientation), for both of which the low secure unit scored better than the medium secure unit. This implied that men thought low secure units supported them better to learn new skills and understand their problems better, perhaps partly a reflection of the greater freedom in the low secure unit to access the community. Interestingly, the men with learning disabilities rated both units higher than staff did on Involvement, Support, Personal Problem Orientation, while they rated Staff Control and Practical Orientation lower than did staff.

Another strand, of similar work, appeared in the 1970s, in the UK, in relation to the extent to which staff used institutional practices (such as block treatment, depersonalization, rigidity of routines, and social distance), as opposed to person-centred practices (see for example, King, Raynes & Tizard, 1971). Later studies of community-based group homes showed that in general they scored very low on such institutional practices. Nevertheless, it was recognized that there was wide variation in the quality of such homes, and it was clear that staff stress was a major issue. Moreover, aspects of staffing such as work overload, job variety, social support, feedback on job performance, job security, job ambiguity, staff morale, and staff turnover were found to correlate to staff stress and job satisfaction in services for people with learning disabilities (see Rose 1995). There was the beginning of a recognition of the importance of 'organizational culture' in services, where culture was defined as:

*'Culture: a pattern of basic assumptions invented, discovered or developed by a given group as it learns to cope with its problems of external adaptation and internal integration that has worked well enough to be considered valid and therefore to be taught to new members as the correct way to perceive, think and feel in relation to those problems.'* (Schein 1985; p. 9)

It has also been defined more briefly as:

*'How things are done round here – i.e. what is typical of the organisation, the habits, the prevailing attitudes, the grown up pattern of accepted and expected behaviour'* (Drennan, 1992).

Of course, if service culture related to staff stress and staff behavior, it was also likely to be a determinant of service quality, and attempts to relate the concept of service culture to service quality began to appear. For example, Gillett & Kroese (2003) used a measure called the Organisational Cultural Inventory (developed by Cooke & Lafferty, 1989). The inventory lists 120 statements for staff to indicate (on a five point scale) their degree of agreement, or otherwise, on the extent to which each statement was typical of staff behaviour in that organization. The scores added to produce measures of the degree to which the culture was constructive, or passive-defensive or aggressive-defensive, and it was designed to be appropriate for a whole variety of workplaces. Staff selected to participate were direct care staff from two residential units, one considered high performing (house A) and one low performing (house B), and which were otherwise comparable in size, location, resourcing, etc. A quality of life measure, COMPASS, was used to assess the quality of life residents (Cragg & Look, 1992) and, as expected, this was higher for house A. The OCI scores showed that House A was also higher on the constructive factor and lower on the passive-defensive and aggressive-defensive factors of the OCI, than House B. The researchers concluded that while the study was interesting, they would have liked a better measure of QOL (to include subjective and objective views) and a measure of culture that took more note of service user views.

Bigby et al (2012), on the other hand, developed their own measure of culture. They used ethnographic and qualitative methods to draw out aspects of culture in five group homes (each for 4 to 6 people) that were considered to be under-performing. The homes had rehoused people with severe disabilities when an institution closed and despite an improvement in home comforts and community presence, the homes still provided low levels of engagement in domestic and other activities, little community participation, and few relationships with non-disabled people. After over 200 hours of observations and numerous interviews, plus two rounds of analysis, the researchers concluded that there were 5 dimensions of service culture and they went on to confirm these in studies of three group homes that were considered good (Bigby et al, 2015; Bigby & Beadle-Brown, 2016). The five dimensions were:

- Alignment of power holder's values: Alignment vs Misalignment (exemplified by e.g 'Vision and mission are exactly what we live to' vs 'We're not going to do it that way')
- Regard for residents: Same as Other Citizens vs Otherness (exemplified by e.g. 'Like us' vs 'Not like us')
- Perceived purpose: Doing With vs Doing For (exemplified by e.g 'Its her choice' vs 'We look after them')

- Working Practices: Client-Centred vs Staff-Centred (exemplified by e.g. 'The guys come first no matter what' vs 'Get it done so we can sit down')
- Orientation to change and ideas: Openness vs Resistance (exemplified by e.g. 'Lets face it everyone can improve' vs 'Yes, but...')

Since then Humphreys, Bigby and colleagues (Humphreys et al, 2020) have developed these ideas into a measure of group home culture. They began by developing items which staff could rate (on a five point scale) that mapped onto the five dimensions of group home culture described above. They included items derived from descriptions of abusive environments in other studies too, such as Cambridge (1999) and Marsland et al's work (see above). An initial set of 359 items, were reviewed by the research team and then by a number of experts in the field, who whittled them down to 164 items. These were presented to 15 staff who had worked in residential settings, and following interview, ratings, and discussion, a final set of 86 items was collated. These were then tested in the form of a questionnaire with almost 400 direct care staff and front-line managers working in residential services. Following a very thorough statistical analysis, including factor analysis, and examination of factor loadings, 48 items were retained. These loaded onto seven factors (which had similarities to Bigby et al's five dimensions (see above):

- Supporting well-being (12 items) - the extent to which staff were enhancing well-being of residents
- Factional (8 items) - the extent to which there were divisions within the staff team that have a detrimental influence on team dynamics
- Effective team leadership (5 items) – the extent to which the house supervisor engages in leadership practices
- Collaboration within the organization (6 items) - the extent to which staff have a positive perception of organisational support and priorities
- Valuing residents and relationships (7 items) - the extent to which staff value residents and their relationships with them
- Social distance from residents (5 items) - the extent to which staff regard residents as fundamentally different from them
- Alignment of staff with organizational values (5 items) - the extent to which staff members values align with those of the organization

Bigby and colleagues are now trying the measure in Australian group homes to look at the extent to which the measure reflects quality of staff support.

## **6.8 What help can we get from CCTV or other surveillance?**

There are now a considerable variety of technological devices that may be of use in keeping people from harm. These include video and audio monitoring devices, motion sensors that can alert staff, tagging and tracking systems such as electronic tags for the ankle or wrist, that use the Global Positioning System (GPS). According to Niemeijer et al (2014), who have conducted research on the effects of these devices on care for older people and people with learning disabilities in the Netherlands, the Dutch Health Inspectorate estimated that '91% of residential care homes for people with dementia or intellectual disabilities were using some form of surveillance technology' in 2009. In theory this was expected to lead to reduced workload for carers, and more freedom and autonomy for residents, but some worried that it might also lead to fewer staff, reduced opportunities for relationships, and eventually to less training for staff in care (and more in technology). Moreover, there were Human Rights issues to consider, such as the right to liberty and security, under article 5, and the right to privacy and family life, under article 8 (Welsh et al, 2003). Yet, since mandatory confinement indoors was correlated to higher levels of aggression against staff, it seemed that technological solutions that gave residents more freedom and autonomy might be good for everyone (Welsh et al, 2003). Niemeijer and colleagues therefore set out to ask carers and residents in dementia services and learning disability services their opinions about the way technological devices were being used.

In one study, they engaged in 340 hours of ethnographic observations, as well as conversations and interviews with residents and staff, in 7 services for people with dementia and 6 services for people with intellectual disabilities (Niemeijer et al 2015). A range of technological devices were used in the services, mostly individually applied, and some appeared to promote resident autonomy: for example, electronic bracelets that automatically allowed some doors in the units to open, giving residents freedom to visit other units nearby, or to seek out quiet corners that they particularly liked. For some residents this seemed to mean that the ability to wander at will during the day helped them sleep better at night. For others, they sometimes became distressed, wondering where they had arrived at. Nevertheless, the very same devices that offered more freedom for some, were frustrating to other residents (who wanted to know, for example, why their bracelets did not allow them through the same doors). Some residents thought the bracelets were stigmatizing and refused to wear them; some appeared to want to wander less as they simply wanted staff to accompany them (and this would no longer happen), and some resented the camera in the communal hallway because they did not want to be watched. Niemeijer and colleagues concluded that at times the technological devices did indeed increase residents' autonomy, that some devices increased residents' privacy (as they could go where they wanted to),



whereas others (eg video cameras) decreased privacy. Moreover they argued that consent was a difficult issue, especially with the less obtrusive devices (such as GPS tags sewn into residents coats).

Niemeijer and colleagues also consulted nursing staff in the residential homes for people with learning disabilities or dementia, using the same ethnographic methods as above (Niemeijer et al, 2014). The themes that arose were:

- The importance of continuing to do rounds (in other words not just to rely on eg motion sensors at night) – the surveillance technology is an aid, not a substitute
- Alarm fatigue (sometimes alarms needed to be turned off for a while, as they were alerting staff unnecessarily, e.g. when a client got out of bed to visit the bathroom)
- Door locking (this seemed to continue, especially at night, even though it might have been considered unnecessary)
- Forgetting to take devices off (for example, when someone became less mobile, forgetting to take off their bracelet)

The nurses seemed to privilege proximity to their clients and safety of their clients over greater autonomy for clients, and in general tended to combine their old routines with the new technology, rather than replacing their old routines.

Finally, Niemeijer et al (2013) consulted professional carers and academics about the use of technological devices for older people and people with learning disabilities, using the technique of concept mapping. They investigated the way participants felt surveillance technologies should ideally be employed and six themes arose for its use:

- If it supports and enhances the capabilities of the client (safety and autonomy of clients should be improved; it should not be for cost saving purposes)
- It contributes to the reduction of other freedom restrictions/restraints (eg. allows more doors to be unlocked)
- It is based on a vision on its benefits and risks (with good procedural and technological underpinning)
- Staff are equipped to work safely with surveillance technology (they should feel safe with it and be well-trained in it)
- It is user friendly (and accessible to the client)
- It should suit the client (not the institution)

The themes were very similar for professional carers and academics, though the former considered safety of clients somewhat more and the latter considered autonomy somewhat more.

A similar, but more extensive list was provided by Godwin (2012) and discussed in Hayward (2017):

1. For whose benefit is the equipment being used? Consider who is the real beneficiary?
2. Whose definition of benefit is being applied? Would technology use primarily benefit the person, the carer or care organisation?
3. What are the potential effects of the technology on the wellbeing of the individual and his or her carer? Does it support the person's autonomy or simply reduce risk? How can a balance be struck, ensuring the wellbeing of both parties?
4. What are the actual or potential, active or passive detrimental effects of the technology? An individualised risk and wellbeing assessment is needed.
5. What are the costs and benefits (physical, emotional, psychological, ethical, and financial) of using technology, and to whom do they apply? Assistive technology may reduce carer stress, target care where needed and delay restrictions to lifestyle.
6. What is the real (not hypothetical) alternative to the use of this piece of technology? Consider the effect of technology on the person's future.

## **6.9 Conclusions from the literature review**

It is salutary to note that much research in this field consisted of small unfunded studies. No studies were found that measured 'risk' variables and followed large samples of services in a prospective way to determine the most important risk variables.

Early research on abuse in services for people with learning disabilities, which came mainly from USA and UK, tended to simply count allegations of abuse, often through adult protection referrals or similar processes. Typically such referrals, while sometimes resulting in decisions that 'confirmed' abuse in around half of cases (or fewer), were often 'undetermined', i.e. unable to be confirmed or disconfirmed in a proportion of cases. In all of the studies of allegations of abuse, police were involved in only a small proportion of cases.

Researchers looking at all care groups in these studies, consistently reported that people with learning disabilities and/or autism were more at risk of abuse than other groups, especially in residential services (as compared to the elderly, or those with mental health needs). The most common types of abuse for people with learning disabilities and/or autism

were physical and sexual abuse, with financial abuse and neglect much being less common. Certain characteristics seemed to make people especially vulnerable, such as having behaviours that challenged, and being female. It is likely that having no speech also makes people more vulnerable too, since they then cannot report abuse (and hence may not show up in the figures). All studies found abuse most often came to light through disclosure by the victim, by reports from staff and/or family members. There were some attempts to define the most likely kind of staff to report abuse and most likely staff alleged to be involved in abuse. Most likely to report abuse seemed to be new staff, female staff, and those who had had recent training on abuse. Most likely to be alleged to be taking part in abuse were new staff, male staff, and those who had previously been reported for similar behaviour. No research studies were found that investigated whether, for example, low empathy in staff members was a good predictor of alleged abusive behaviour.

Where staff and/or family were whistleblowers, against services, they themselves described the process of reporting abuse to be very stressful, partly because they were often ignored, partly because the processes were intimidating, partly because they worried for their own (or their loved ones) in the future, as they felt they were at the mercy of the staff against whom they were alleging abuse. There were a large number of sanctions that unscrupulous providers could impose on staff who spoke up. At times, it was other residents who were accused of abuse (about 25% of allegations seemed to be about other residents), and several studies found that such cases were more often proven to have occurred, than those alleged against staff, who may have protected each other, or been more successful at hiding what they did.

Professional staff, such as community learning disability team members (nurses, OTs, psychologists, speech therapists), who visit community-based services on receipt of referrals, and also work into Assessment and Treatment units and low/medium secure units, may become aware of unhelpful attitudes, or abuse, in some settings. A series of research studies reported the important aspects of services that such professional staff described, and the authors of one of these (Marsland and colleagues) drew up a list of early indicators of abuse, after interviewing people who had been into settings where abuse was later reported. These indicators fell into six categories:

- The decisions, attitudes and actions of managers (such as poor support for whistleblowers)
- The behaviours and attitudes of staff (such as a preference for restraint)
- The behaviours of people with learning disabilities (such as signs of fear)

- Isolation (few visitors, treated with hostility)
- Service design, placement planning and commissioning
- Fundamental care and the quality of the environment

Marsland and colleagues turned this into a guide for others to use as early indicators of concern and possible abuse. They commented that abuse rarely arose from a single ‘bad apple’ in a staff team: rather they were trying to capture a description of staff culture.

Awareness of such variables in hospital settings had of course arisen before, alongside the deinstitutionalisation movement. Measures of ‘ward atmosphere’ had been designed some years earlier, for use in hospitals and prisons, by Moos and colleagues in Canada. Several studies used these measures or similar ones to describe settings in hospitals or homes for people with learning disabilities and/or autism. However, the most useful work in this field has been conducted by Julie Beadle-Brown (in the UK) and Chris Bigby (in Australia). They used ethnographic methods to develop descriptions of the culture in community-based group homes that were considered poor and those considered good. The work has resulted in a well-researched measure of Group Home Culture (Humphreys et al, 2020), which measures 7 factors in the way such settings run:

- Supporting well-being (12 items)
- Factional (8 items)
- Effective team leadership (5 items)
- Collaboration within the organization (6 items)
- Valuing residents and relationships (7 items)
- Social distance from residents (5 items)
- Alignment of staff with organizational values (5 items)

Bigby and colleagues are currently using the Group Home Culture Scale in a study of the quality of staff support in Australia.

Finally, a few studies, mostly those by Neimeijer from Holland, were found which examined the use of surveillance technology in settings for people with learning disabilities (and in settings for people with dementia). The technology was being used largely to protect people’s safety at night (for example, cameras or movement sensors, monitored from a staff office) and /or to extend their freedom during the day (for example, bracelets programmed so that they allowed certain doors to open without staff assistance). Staff and residents found these mostly acceptable, provided they were very individualized and used to promote independence. There were no reports that we could find of research showing video technology had been effective in detecting abuse (see also Hayward, 2017).

## 7.0 Discussion and Recommendations

### 7.1 Discussion

CQC has made conspicuous efforts to implement the recommendations of the first independent report on Whorlton Hall, as shown in Table 1 (page 8-11). Despite the pandemic, which has made inspections difficult and has required policy changes, much has been achieved. However, the research reviewed above shows that much abuse comes to light as a result of service user disclosures and some also comes to light as a result of family members and staff whistleblowers, who both report the process of complaining to be distressing and difficult in a number of ways. The research studies reviewed suggest that staff are not always clear about what constitutes abuse and neither are residents with learning disabilities and/or autism. This means that providers should ensure there is training on abuse and safeguarding, not just for staff but also for the service users. Furthermore, the recommendation to do more interviews and observations with service users and family carers, and to ensure that as many as possible are interviewed, in secure places, using communication tools where possible, is especially important. Moreover, it highlights the need to make the process of making complaints and allegations as simple as possible, and Speak Up Guardians are clearly part of this.

The research literature indicates that people with behaviour that challenges are more vulnerable to abuse. They are also the people most likely to be restrained, secluded or segregated. The *Restraint, Seclusion and Segregation* review revealed that the quality of support given to many people with autism and complex needs was extremely poor, and contravened their Human Rights in a number of ways. Yet many of the hospital settings visited, in which these people lived, had been rated as *Good* or *Outstanding* by CQC (nearly 60%), as had 85% of the social care settings visited (see *Out of Sight: Who Cares?* P. 66). This suggests that Whorlton Hall was not the only place rated '*Good*' which was actually very poor.

One explanation for this is that CQC has become too 'process driven' and is not considering the outcomes for service users sufficiently, as McEwen, Bigby & Douglas (2019) have suggested. At times CQC inspectors seem to be missing closed and unhealthy cultures in settings that may seem on the surface, through their paperwork, to be adequate. This

suggests that CQC inspections needs to be more focused on observing what is actually happening to service users on their visits, and reinforces the need for thorough interviews of staff, service users and their families, as well as observations of relationships and activities in the settings that are inspected. Moreover, it suggests that CQC needs to become more outcomes driven and less process driven. It was clear from research that it is important for CQC to become more sensitive to the existence of closed cultures, and there are now a number of measures of culture that have been used in services for people with learning disabilities and/or autism.

Services are very keen to obtain ratings of 'Good' or 'Outstanding' from CQC and will go to considerable lengths to obtain such ratings, including (for example) checking that all their paperwork is in place and positive behaviour support plans are in place. This does not necessarily mean that such support plans are being followed. They may not even be understood by untrained or agency staff who may not know service users well. By adjusting the criteria for 'Good' and 'Outstanding', CQC has the ability to press services to improve in particular ways.

CQC has already started work on these issues, through its increasing focus on interviews (see Table 1, page 8-11), through its Closed Cultures workstream, and its work developing a Quality of Life tool (as discussed above in section 5.2 and 5.3). CQC is aware that where closed cultures have become embedded in services, it may be very hard to spot what is going on. For example, in a recent case of a service in Essex (Yew Trees), abuse was discovered through an analysis of video evidence collected by the provider, who alerted the CQC. Such evidence would be unlikely to be have been found by CQC inspectors alone, even wearing body cameras, on a visit, since it seemed that staff were covering up what was going on; so that they would probably have behaved differently in the presence of a CQC inspector, even if the visit were unannounced (much as seems to have happened in Whorlton Hall). This means that CQC must consider analysis of provider's and family member's video evidence, if they are to keep people safe from abuse. Such analysis is already within the RIPA rules, but CQC needs to consider whether it also needs to instigate surveillance itself, for the rare occasions where there seems no other way to ensure people are safe. The research to date suggests that surveillance can be done ethically provided it is person-centred, the least restrictive option, and done in the best interests of the service user, not the staff. The right not to be abused surely trumps the right to privacy.

## 7.2 Recommendations

It is recognized that CQC has worked hard to begin to implement the recommendations from the first report. Many of those recommendations from the first report will need to continue to improve and/or to be further developed, so as to be fully implemented:

1. The development of further quantitative indicators incorporating closed culture risk factors, such as staff turnover, frequency of restraints, etc, for the 'dashboard' on services for people with learning disabilities/autism and complex needs (to be added to the allegations, concerns and complaints data already on the dashboard)
2. The determination of a threshold of risk of abuse where more intensive (level 2) inspection is needed and/or where overt/covert surveillance might be justified
3. Unannounced and out-of-hours visits to high risk settings should increase further (these have increased a little but not by much)
4. More in-depth interviews with family carers (these have increased and should continue)
5. More in-depth interviews with service users, in privacy whenever possible (using communication aids, the latter being trialed from January 2021)
6. Implementation of the new registration guide *Right Support, Right Care, Right Culture*, now that it is published. Reports of a new large hospital setting (40 beds) for people with learning disabilities, to be run by MerseyCare, on the Maghull site are worrying. Such a service does not seem to fit the guidance.

In addition, in view of the evidence in this report, it is recommended that:

7. Services should not be rated as 'Good' or 'Outstanding' if they have used frequent<sup>2</sup> restraint, seclusion and segregation, as these are indicating that the service is not meeting the person's needs.
8. Services should not be rated as 'Good' or 'Outstanding' if they cannot show how they support whistleblowing and reporting of concerns (for example, they should train staff and those who use the service in what constitutes abuse; and what to do about it; they should have access to a Speak Up Guardian; and they should aspire to the good practice in the Francis report)
9. The Group Home Culture Scale should be trialed, to evaluate whether it helps inspectors determine which settings have closed cultures, and whether it assists in decisions about how to set a threshold for a more intensive inspection

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<sup>2</sup> What constitutes frequent should be discussed; it could be calculated from current average usage rates and targets could be set well below that rate

10. The Quality of Life tool that is already being developed should be trialled, to gauge whether it helps CQC move from evaluating process, towards evaluating more relevant service user outcomes

11. CQC should develop guidelines for when evidence of the quality of care (and the possibility of abuse) should be gathered from overt or covert surveillance. The former, overt surveillance, may include family member's material and/or provider's material and/or that gathered by CQC. The latter, covert surveillance, is likely to be very rarely justified but may be needed where there is a high likelihood that abuse is occurring (for example, repeated allegations of abuse) and no other way to gather the evidence.



## **Appendix 1:**

*N.B. This is a somewhat shortened version of the paper which will be submitted for publication shortly*

# **Detection and prevention of abuse of adults with intellectual and other developmental disabilities in services: A systematic review**

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## **Introduction**

Abuse is defined here as ‘a violation of an individual’s human and civil rights by any other person or persons’, and it can include physical, psychological, sexual, neglect or financial exploitation (Department of Health & Home Office, 2000). The high prevalence of abuse of people with intellectual disabilities is well-established, and has been documented in research from many countries, and not confined to particular cultures (e.g., Baladerian, Coleman & Stream, 2013; Brown and Stein, 1998; Horner-Johnson & Drum, 2006; Wacker, Parish & Macy, 2008). In one example, between 1998 and 2005, people with intellectual disabilities accounted for just under a third (32%) of adult protection referrals in two counties of England, although they were numerically only around 2% of the population (Mansell, Beadle-Brown, Cambridge, Milne & Whelton, 2009; Beadle-Brown et al., 2010).

Despite a number of scandals in the UK concerning abuse of people with intellectual and other developmental disabilities, from as early as 1967 (in the Ely hospital scandal), and

running through to the present day (e.g., Winterbourne View, BBC News, 2012; Whorlton Hall, BBC News, 2019), and despite increased public awareness (e.g., Channel 4, Under Lock and Key, 2018), relatively little research in the area has been conducted. Instead, research is related predominantly to children and elderly adults (e.g., Dong, 2015; Timmerman & Schreuder, 2014). Nevertheless, the abuse of adults with intellectual and other developmental disabilities is common, though due to the variability of methods of interviewing, definitions, and sample groups, the proportion of those who have experienced abuse varies widely. For example, depending on these variables, prevalence of sexual violence experienced by adults with intellectual disabilities is estimated to range between 10% and 80% (e.g., Turk & Brown, 1993; McCabe, Cummins & Reid, 1994; McCabe & Cummins, 1996; McCarthy & Thompson, 1997). Mansell et al. (2009) observed that the incidence of adult protection referrals was continually increasing, which was likely to arise partly from a growing alertness to such issues, and perhaps partly from worsening quality of care (for instance, increased levels of violence in service settings has been reported - Strand, Benzein & Saveman, 2004). Crime statistics in most countries do not provide a true reflection of these issues, as relatively few such crimes are reported to the police (for example, Myhill & Allen, 2002, found only 18% of incidents of sexual violence even in non-disabled people were reported to the police in England and Wales, and proportionally fewer reports are likely where victims have intellectual and other developmental disabilities). Therefore, the actual incidence of abuse is likely to be higher than reported figures suggest.

Consequently, adult protection has become an issue of central concern for UK service providers and policy makers (Lathlean et al., 2006). In the UK, several adult protection guidelines have been published, including *No Secrets* (Department of Health, 2000), *In Safe Hands* (National Assembly for Wales, 2000), and *Safeguarding Adults* (Association of Directors of Social Services, 2005). The vetting and barring scheme, Protection of Vulnerable Adults List, was established in England and Wales by the Care

Standards Act (2000) and introduced in 2004 to provide greater assurance about the quality of social care for adults. Employers of staff working directly with vulnerable adults in England and Wales, in registered social care services, have been required to refer employees (and volunteers) dismissed, or likely to have been dismissed, for harming vulnerable adults or placing them at risk of harm, to the Protection of Vulnerable Adults List. As a result of a public consultation on the review of the *No Secrets* guidance, new legislation to strengthen the local governance of safeguarding was announced by the government in its *Vision for Adult Social Care* (Department of Health, 2010). The government report 'No decision about me without me' (Department of Health, 2012) highlighted the need for the provision of good quality information to enable people to take part in decision-making and for the information to be available in accessible formats. In 2013, the government published the Francis Report detailing areas for improvement in healthcare, including a greater emphasis on prevention of abuse rather than reactive measures (Francis, 2013), and the Health and Social Care Act (2014) imposed a statutory duty upon local authorities to investigate all suspicions of abuse or neglect towards vulnerable adults in their area. Moreover, the Government's response to the abuse exposed at Winterbourne View was: *Transforming Care: A National Response to Winterbourne View Hospital* (2012), followed by the NHS-England document, *Building the Right Support* (2015). However, the targets proposed in these documents, to reduce the number of hospital beds for people with intellectual and other developmental disabilities in England, were not achieved by the end of April 2019. Most recently, the NHS Long Term Plan, published in early 2019, declared that the work of Transforming Care would continue. Alongside this, in 2018, the Secretary of State for Health and Social Care asked the Care Quality Commission to carry out a review of segregation and other restrictive interventions for people with learning disabilities

and/or autism, in in-patient settings and residential care, and CQC reported that service-users were not being offered high quality assessment, care and treatment. Staff working with this population often did not have the necessary skills for such work, and those involved in direct hands-on care were often unqualified.

Evidence suggests that, despite government efforts to reduce the occurrence of abuse and to promote the work of the Care Quality Commission (CQC) in monitoring, inspecting and regulating services, to make sure they meet fundamental standards of quality and safety, cases of poor practice and abuse continue to arise (e.g., Whorlton Hall, BBC News, 2019; Ivy Trees, BBC News 2020). In late 2019/early 2020, Murphy (2020) was asked to conduct an independent review for CQC following the abuse uncovered at Whorlton Hall. Findings suggested several actions might have led the CQC to detect abuse earlier including: (i) more unannounced visits, especially at evenings and weekends, (ii) the use of CCTV, or other overt or covert surveillance method, (iii) interviews of staff once they were no longer employed by the provider, (iv) more careful interviews with service users in conditions of privacy where they felt safe, preferably with the use of alternative and augmentative communication tools, and (v) more thorough interviews with all family carers. Six recommendations for how the CQC could improve practice were made. Recommendations related to: the ways in which provider data was used and shared with inspectors; the format of data for inspections and inspection reports; the handling of abuse allegations; the need to prioritise in-depth service user interviews, carer interviews and increased observations; the requirement for 'level 2' inspections (including increased time in the service, observations, and interviews), particularly where data indicated services were struggling; the use of CCTV or other overt/covert surveillance to detect abuse; and consideration as to whether it would be possible to rate the atmosphere and/or culture of services (Murphy, 2020). The final recommendation was that the CQC should not register or expand services that were very isolated, and/or in unsuitable buildings, and/or with out-of-date models of care (Murphy, 2020). One of Murphy's contentions was that a variety of indices of services could be monitored, which could act as 'red flags' to indicate that a service was

struggling to provide good quality care, and that such 'red flags' could trigger more in-depth 'level 2' inspections.

Subsequently, this systematic review was conducted to explore the ways in which abuse within services for people with intellectual and other developmental disabilities is detected globally. The aim was to address the following research questions: 'How is abuse detected within services for adults with intellectual and other developmental disabilities?' and 'How can we improve such detection?'

## **Aims**

The specific aims of the systematic review were to:

- Highlight the risk and protective factors for abuse of adults with intellectual and other developmental disabilities in such services.
- Identify any assessment tools or interventions to detect or to help to prevent abuse of adults with intellectual and other developmental disabilities in services.

## **Methodology**

### ***Design***

A systematic review of the research on the abuse of adults with intellectual and other developmental disabilities in services was conducted, incorporating quantitative and qualitative studies. Database and ancestry searches resulted in 48 articles that met the specific inclusion criteria. A data extraction template was used to record relevant information under the following headings: title, author, year of publication, country, sample, study design and methodology, study aims, risk factors for abuse, protective factors against abuse, barriers to detecting abuse, methods of detecting abuse,

tools/interventions to detect or prevent abuse, and external monitoring of services. The quantitative and qualitative findings are summarised.

### ***Search Strategy***

The final global literature searches in PsychINFO, PsychARTICLES, Medline, CINAHL Plus with Full Text, Criminal Justice Abstracts, SCOPUS, and PubMed (and ancestry searches) were conducted on 28<sup>th</sup> July 2020. Search terms used were “care regulation”, “care quality assessment”, “safeguarding”, “detecting abuse”, “surveillance”, “closed culture”, “neglect”, “mistreatment”, “maltreatment”, “learning disability service”, “intellectual disability service”, “autism service”, “residential care”, “residential facility”, and “skilled nursing facility”. Studies referring to children, adolescence, and elderly adults (all without intellectual and other developmental disabilities) were excluded, as well as those where the topic of the article did not relate to abuse perpetrated by professionals or staff, or quality of care within services. In addition, non-empirical articles (i.e., books, letters, reviews) were excluded, as were articles not written in English (see Figure 1). No limits were applied to year of publication or country in which the study took place.

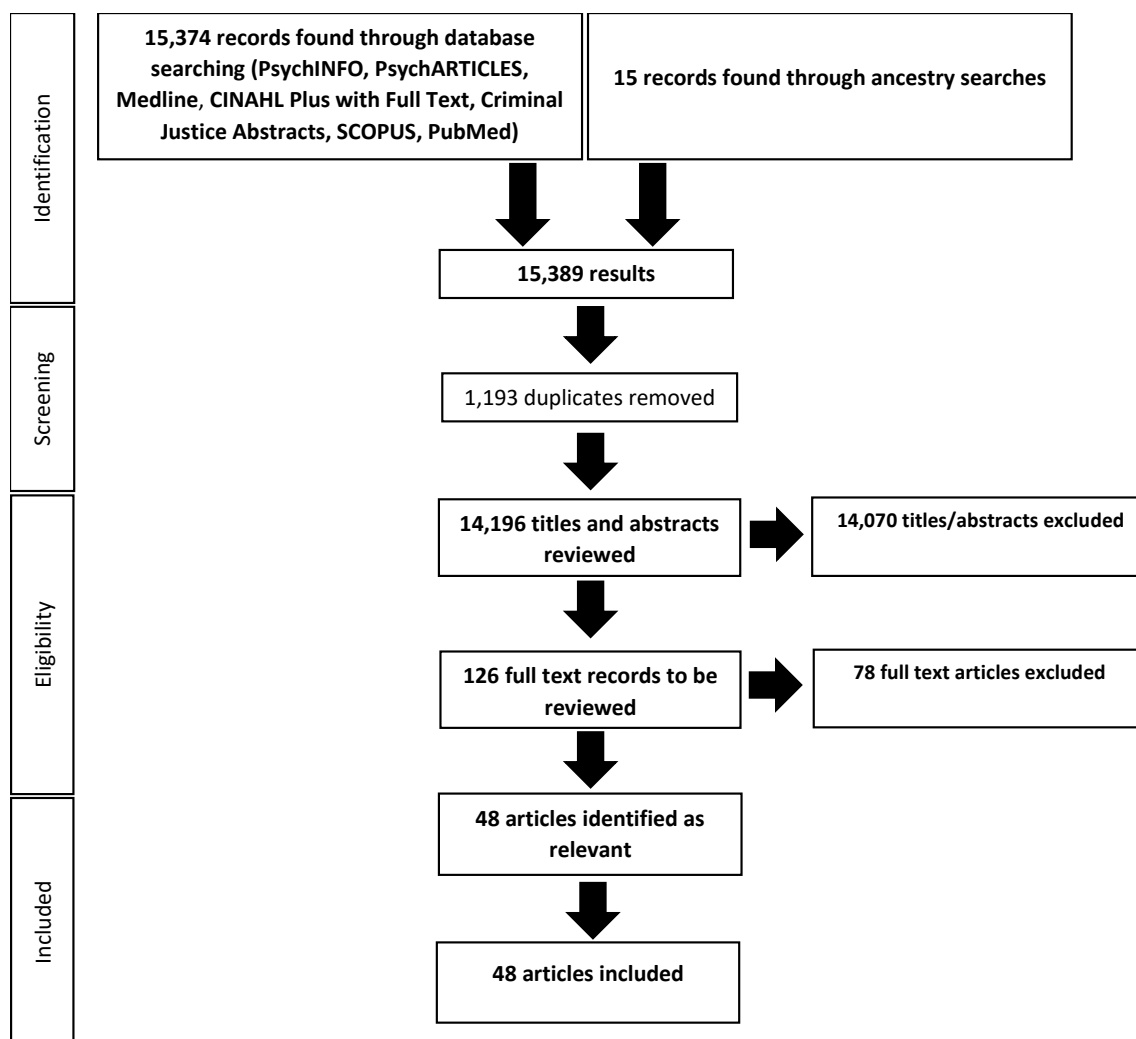
### ***Eligibility Criteria***

The current review aimed to consolidate and evaluate the current research on the abuse of adults with intellectual and other developmental disabilities within residential and inpatient services. Articles were reviewed to ensure they met the following inclusion criteria:

- Empirical research (i.e. published articles that refer to primary or secondary data that was based on direct observations, assessment, interview, survey, database, or documentary analysis).
- Written in English.
- The article related to the abuse of adults with intellectual and/or other developmental disabilities.
- The article related to abuse within services.

Articles were excluded if:

- They were a book, book chapter, magazine, letter, or review.
- The article related to the abuse of children, adolescence, or older people without intellectual and other developmental disabilities.
- The topic of the article did not relate to abuse or quality of care (i.e., the detection of abuse, prevention of abuse, assessment of abuse).
- The article related to abuse that had been perpetrated in the community rather than within residential services (e.g., abuse perpetrated by family carers).



**Figure 1. Prisma Flowchart of search results.**

### ***Identification of studies***

The initial search resulted in 15,389 papers. After duplicates were removed, 14,196 articles were included in the initial review of titles and abstracts. After the review of titles and abstracts, 14,070 articles were excluded, and 126 articles were identified for full text review. Following a further review of 126 full text articles against the eligibility criteria, 48 were included in the review – see Figure 1.

### ***Data extraction***



Table 1 provides a summary of the key characteristics of the 48 articles included in the review.

## **Results**

### ***Study Characteristics***

Twenty-eight of the 48 studies were conducted in the UK, five in Australia, one in Sweden, one in Norway, three in The Netherlands, nine in the USA and one across the UK and USA.

Twenty-one of the 48 studies used a qualitative study design, 15 used a quantitative study design and 13 used mixed methodology.

Authors of 12 of the 48 studies used interviews, 9 used self-report questionnaires/ surveys, 10 undertook documentary analysis, 2 conducted action research, 7 focussed on database analysis, 1 used concept mapping, 4 involved expert consensus/focused group discussion, 1 conducted a Delphi exercise, and 6 included participant observations.

Authors of 19 of the 48 studies recruited a sample of individual professionals (n = 1,246). Authors of a further 14 studies included a sample of adults with intellectual and other developmental disabilities (n = 3,614), and two studies recruited relatives of adults with intellectual disabilities (n = 10). The remaining 18 studies included 6 ethnographic field/action research studies within services, 5 documentary analyses of sources that referred to adults with intellectual and other developmental disabilities who had been abused within services, 1 study which included evidence from a literature review, team consensus process, and community partnership, and 3 studies whereby data was collected concerning reported cases of abuse from professional teams.

### ***Sociodemographic characteristics***

**Age.** Authors of 15 of the 48 studies reported the age of adults with intellectual and other developmental disabilities who had experienced abuse (n = 4,530; Mean = 37.8; Range = 0-100).

**Gender.** Authors of 11 of the 48 studies reported the gender of adults with intellectual and other developmental disabilities who had experienced abuse (n = 2,263), with findings suggesting 52.1% were female (n = 1,180), compared to 47.9% male (n = 1,083).

**Ethnicity.** Authors of four of the 48 studies reported the ethnicity of adults with intellectual and other developmental disabilities who had experienced abuse (n = 2,166), with findings suggesting the majority were Caucasian (n = 5925). Other ethnicities reported included African American (n = 54), and South Asian (n = 1). One of the more dated studies differentiated only between participants who were 'black' (n = 22) and 'white' (n = 78; Marchetti and McCarthy, 1990).

### ***Risk factors***

Authors of 31 of the 48 studies reported on risk factors associated with the abuse of adults with intellectual and other developmental disabilities within services, including victim characteristics, perpetrator characteristics, and organizational factors.

Victim characteristics associated with increased risk of victimization of abuse within services included: (i) service-user's gender, with females being more at risk of sexual abuse compared to males, (ii) more severe learning disability and communication difficulties, (iii) being known to services over time or since birth, (iv) an escalation of challenging behaviour, (v) previous abuse victimization, and (vi) having some reported involvement in an individual behaviour management programme or

being in receipt of a drug to control behaviour (e.g., Bigby, Knox, Beadle-Brown, Brown, Stein & Turk, 1995; Cambridge, Mansell, Beadle-Brown, Milne & Whelton, 2011b; McCartney & Campbell, 1998). In contrast, Marchetti and McCarthy (1990) reported that abused service-users were similar to the general resident population on basic demographic variables, but more of the abused residents had higher intellectual quotient scores and adaptive behavior levels. However, their findings focused only on confirmed cases of abuse and confounding factors were not accounted for in the analysis.

Individual characteristics associated with the perpetration of abuse included: (i) gender, with males more likely to perpetrate abuse compared to females, (ii) newer employees, (iii) previous perpetrators of abuse, (iv) staff's inability to cope with increasing stress or staff's inappropriate means of relieving stress, and (v) staff perceptions of, or attitudes towards service-users (e.g., Beail & Warden, 1995; Brown & Stein, 1988; Furey, Niesen, & Strauch 1994; Hollomotz, 2012; Marsland, Oakes & White, 2007; Turk & Brown, 1993). For example, beliefs that adults with intellectual disabilities are fundamentally different, they are 'too disabled', and 'have no skills' were a risk factor for abuse (e.g., Bigby & Beadle-Brown, 2016). Such beliefs may lead to experiences of inequality between staff and service users characterized by distortions of power and control (Manthorpe & Martineau, 2015).

Organizational risk factors associated with a higher risk of abuse within services related predominantly to managerial weaknesses, poor implementation of policy, and inadequate monitoring of services. Issues concerning inadequate monitoring procedures included a lack of outside monitoring visits and poor monitoring of service users placed out of area (e.g., Cambridge, Beadle-Brown, Milne, Mansell & Whelton, 2011a). Poor management was characterized by a lack of managerial support for staff,

negative relationships between staff and senior colleagues, a need for staff training, resistance to change, barriers to collaborative working (e.g., a lack of team meetings and reflective practice), and poor communication and/or engagement with the commissioning local authority and parents/carers (Allington, 1992; Hutchison & Kroese, 2016; Manthorpe & Martineau, 2015). Furthermore, a lack of community participation, repeated cancellations of appointments, poor quality care plans, and isolated or poorly maintained environments also characterized services where abuse had been reported (Bigby & Beadle-Brown, 2016; Cambridge, 1999; Marsland, Oakes & White, 2007). Organisations at increased risk of abusive practice showed evidence of poor processes for reporting concerns and minimal attempts to implement adult protection policies. Staff shortages, high staff turnover, and poor recruitment strategies further negatively impacted the quality of services and increased the risk of abuse (e.g., Manthorpe & Martineau, 2015; Marsland, Oakes & White, 2007; Parley, 2010).

Gillett and Kroese (2003), focused on the quality of life of service-users in low and high performing residential services for people with intellectual disabilities. Interesting authors found no difference in staff turnover or staff absence between the low and high performing service, however they did identify organizational norms of “confrontation and criticism”, “win against others”, “compete rather than co-operate”, “never making a mistake” and “the setting of unrealistically high goals” to be associated with the lower performing service. More recent research suggests organizational risk factors and norms can create a culture of abuse characterized by the absence of caring values, isolation, ineffective staff supervision, intimidation, a punishing regime, institutionalized practice, inexperience, anti-professionalism, barriers to disclosure, poor support for whistleblowers, deficiencies in service audits, staff collusion, poor inter-professional communication, poor recognition of staff skills, lack of clarity in care

management, difficulties in market management and service satisfaction (Cambridge, 1999; Marsland, Oakes & White, 2007; Rytterström, Unosson, & Arman, 2013; Taylor & Dodd, 2003).

### ***Protective factors***

Authors of 13 of the 48 studies reported on factors that protected against the abuse of adults with intellectual and other developmental disabilities within services. Protective factors included the service-users characteristics, the characteristics of staff, and organizational factors.

Protective characteristics of service-users included an ability to report information (i.e., communication skills), knowledge of their right not to be violated, control over their own safeguarding (i.e., knowledge of how to self-report a safeguarding concern), an understanding of social relationships, good coping strategies, and assertiveness skills (Ahlgren-Delzell & Dudley, 2001; Hollomotz, 2012).

Protective factors related to the characteristics of staff included: positive attitudes towards residents, acknowledgment and attendance to difference, recognition and respect for service-user preferences, intrinsic motivation, confidence to challenge bad practice, and having a positive relationships with senior colleagues whereby staff feel listened to and valued (Bigby, Knox, Beadle-Brown, Clement & Mansell, 2012; Bigby & Beadle-Brown, 2016; Calcraft, 2007; Gillett & Kroese, 2003; Hutchison & Kroese, 2016). McCartney & Campbell (1998) reported greater percentages of perpetrating staff in the 'newer' staff category (i.e., employed for no longer than one year) and fewer in the long-term staff category (employed for over five years) in comparison to a random sample of direct care staff. Interestingly, researchers also reported that a greater percentage of care staff who reported abuse were employed for less than five years.

These findings suggest other factors influence the likelihood of newer employees either perpetrating or reporting abuse, which require further exploration.

Protective organizational factors included the clear leadership of a manager whose values were aligned with those of other staff and the organization. Other protective factors included clear guidance at work, supervisors who worked alongside staff (e.g., modelling, monitoring and correcting practice), good communication, shared decision making, the embracing of new ideas and external visitors, good connections with the community, good relations with the safeguarding team, regular staff training, independent staff appraisal and supervision, a consistent use of disciplinary procedures for staff, support for whistleblowers, reflective practice, shared responsibility for practice quality enabling teamwork, and person centered working practices (Bigby et al., 2012; Bigby & Beadle-Brown, 2016; Calcraft, 2007; Cambridge, 1999; Furey, Niesen, & Strauch, 1994; Hutchison & Kroese, 2016; Jones & Kroese, 2006; Rees & Manthorpe, 2010; Rytterström, Unosson & Arman, 2013). Protective factors created a caring culture characterized as coherent, respectful, enabling for service-users, and motivating for staff. Arguably, the establishment of a positive culture that was operationalized and embedded through structures such as formal policy and processes protected against abusive practice.

### ***Barriers to detecting abuse***

Authors of 11 of the 48 studies reported barriers to detecting abuse within services for adults with intellectual and other developmental disabilities. A key barrier to the detection of abuse were a lack of awareness and knowledge amongst staff regarding what constitutes abuse and when intervention is warranted (Aylett, 2006). For example, evidence suggests neglect and financial abuse of adults with intellectual

and other developmental disabilities is frequently minimized and not reported (Brown & Stein, 2000; Taylor & Dodd, 2003). Arguably a lack of guidance may lead to differing thresholds for reporting abuse. Research conducted by Taylor and Dodd (2003) found staff were reluctant to report abuse if they had not witnessed the abuse themselves, if they felt there was a lack of evidence, if the service user had a history of making false allegations, if the service-user was suffering from poor mental health, or if they had concerns over breaking service-user confidentiality (Taylor & Dodd, 2003). In addition to a lack of physical or witness evidence to support allegations of abuse, cognitive deficits and associated communication difficulties of service users made allegations more difficult to assess and abuse more difficult to detect (Fyson & Kitson, 2012; McCartney & Campbell, 1998; Ramsey-Klawnsnik & Teaster, 2012; Turk & Brown, 1993).

Other barriers included a lack of inter-professional collaboration and expert consultation, inconsistent approaches to investigations, delayed reporting of abuse, delayed investigations, biased and leading questioning of victims by untrained professionals, lack of time to conduct a thorough investigation, and lack of resources (Ahlgrim-Delzell & Dudley, 2001; Cambridge et al., 2011a; Fyson & Kitson, 2012; Ottmann et al., 2017; Ramsey-Klawnsnik & Teaster, 2012; Zuckerman et al., 1986). Fyson & Kitson (2012) reported that the amount of time investigations took to complete led safeguarding to be perceived in a negative light by staff and highlighted apparent tensions between undertaking safeguarding work and fulfilling ongoing care management duties.

Using a Delphi exercise, Ottmann et al. (2017) sought the opinions of 249 disability services staff and managers working in child and adult disability services in Australia on the key barriers to effective safeguarding. Barriers included organisational issues (e.g., downgrading the severity of incidents, not investigating allegations of

abuse, unsatisfactory policies and practice guidelines, hierarchical processes, poor relationships and communication, lack of staff training, a culture committed to preserving the status quo), defective management practice, client issues (e.g., the limited capacity of and lack of support provided to people with disability), and external factors (e.g., a lack of resources).

### ***Improving practice to detect abuse***

In addition to the identification of protective factors identified, the current review highlighted several areas where practice could be improved to increase the likelihood of abuse being detected within services. Authors of 22 of the 48 studies made recommendations for how staff within services could improve practice to effectively detect abuse. Recommendations included the need for staff to observe, report and question the causes of any changes in the behaviour of service-users (e.g., increased anxiety, increased disruptive or aggressive behaviour; Turk & Brown, 1993), and to build relationships with service users' and their families, whilst ensuring they were aware of the process for raising concerns (Bright, Hutchinson, Oakes & Marsland, 2018; Hollomotz, 2012). Furthermore, staff should have a good knowledge of the service-users they are working with and ensure the service-user's interests are identified and prioritized through reflective practice (Bigby et al., 2012). Policies and protocols should be followed and immediate action taken by staff when abuse is reported, whereby information provided by alleged victims of abuse is documented, and relevant authorities are informed (Bigby et al., 2012; Ramsey-Klawnsnik & Teaster, 2012). Staff should receive regular unannounced visits by supervisors, regular clinical supervision and training (e.g., on topics including the relational dynamics of abuse, appropriate boundaries, patterns/signs of abuse, appropriate response to suspected cases of abuse)



to ensure they feel both supported and empowered in their role (Allington, 1992; Furey, Niesen & Strauch, 1994; Fyson & Patterson, 2019; Hutchison & Kroese, 2016; Marchetti and McCarthy, 1990; Ottmann et al., 2017; Ramsey-Klawnsnik & Teaster, 2012).

Service managers should look to build collaborative working relationships between professionals within their services, service-user families and external professionals (e.g., adult protection services) through effective communication, training, regular team meetings, and structured team building activities (Lymbery, 2005, 2010; Mickan & Rodger 2005; Rees & Manthorpe, 2010). In addition, managers should be supported of staff who report abuse. Knowledge of the Public Interest Disclosure Act 1998 would help to ensure staff who report abuse do not suffer detrimental treatment or victimization (Calcraft, 2007). Managers should be seen to act on concerns being raised and provide appropriate feedback regarding the investigation and offer opportunities for reflection on incidents (Calcraft, 2007).

Services need to be sufficiently open to outside scrutiny to increase the probability of abuse being detected and detailed advice is required for care staff about when and how to involve other agencies following an allegation of abuse being raised (Cambridge et al., 2011a; Hussein, Manthorpe, Stevens, Rapaport, Harris & Martineau, 2009). Recruitment strategies for new staff should include an assessment of intrinsic motivation to work in care and background checks (Hutchison & Kroese, 2016; Ramsey-Klawnsnik & Teaster, 2012). Bright, Hutchinson, Oakes and Marsland (2018) further suggested that involving families of service-users with intellectual and other developmental disabilities in the training and the recruitment of staff could help to increase understanding and empathy towards each other.

Most importantly, service-users themselves should be given more control and feel empowered to direct their own safeguarding by providing clear information about

what constitutes abuse and the safeguarding referral process (Hollomotz, 2012). For example, findings highlighted the importance of providing sex education and assertiveness training to people with intellectual disabilities to help with prevention and early detection of sexual abuse (Cambridge et al., 2011a; Turk & Brown, 1993). Additionally, service users should have an independent advocate who can notice and raise concerns on their behalf (Bright, Hutchinson, Oakes & Marsland, 2018).

### ***Tools to detect abuse***

Authors of 6 of the 48 studies referred to specific tools that could be used to aid in the detection of abuse within services for people with intellectual and other developmental disabilities, including surveillance technology, an assessment of culture, ward atmosphere and social climate.

Evidence from the current review suggested surveillance technology could contribute to the detection of abuse and autonomy of service-users, but only if it is set in a truly person-centered approach (Niemeijer, Depla, Frederiks & Hertogh, 2015). Surveillance technology should support and enhance the capabilities of the client, reduce restrictions, be based on a vision of its benefits and risks, involve staff who are equipped to work safely with surveillance technology, be user-friendly, and attend to the client (Niemeijer, Frederiks, Depla, Eefsting & Hertogh, 2013). A clear and well-formulated vision for the use of surveillance technology that is understood and supported by all stakeholders is imperative to successful implementation (Niemeijer, Depla, Frederiks, Francke & Hertogh, 2014).

Evidence also suggested the assessments of culture, atmosphere and social climate could also contribute towards the detection of abuse. Bakken, Røssberg & Friis (2012) in Norway examined whether adults with intellectual disabilities could reliably

rate the Ward Atmosphere Scale-Real Ward (WAS-R), a self-report questionnaire comprised of 82 items rated on a four-point scale measuring involvement, support, spontaneity, autonomy, practical orientation, personal problem orientation, angry and aggressive behaviour, order and organisation, program clarity, staff control, and staff attitude to expressed feelings. However, findings suggested participants required help to complete the questionnaire with the interviewer needing to reformulate difficult phrases or questions with double negation as well as provide practical examples of the content of the questions. Adults with moderate intellectual disabilities compared to those with mild intellectual disabilities found the items particularly challenging and they could not rate the questionnaire items reliably. In contrast, findings of a study conducted by Langdon, Swift and Budd (2006) showed the Correctional Institutions Environment Scale, a measure of social climate focusing on involvement, support, personal problem orientation, and staff control to investigate the staff and service-users' perceptions of the social climate within a low and a medium secure services for adults with intellectual disabilities, was valid for use within forensic services for people with intellectual disabilities. Furthermore, the Group Home Culture Scale, which measures seven dimensions of organizational culture in group homes, has acceptable content and face (Humphreys, Bigby, Iacono & Bould, 2020). The Group Home Culture Scale is a self-report staff questionnaire measuring the extent to which: (i) staff practices are directed towards enhancing the well-being of each resident, (ii) there are divisions within the staff team that have a detrimental influence on team dynamics, (iii) the house supervisor engages in leadership practices that transmits and embeds the culture, (iv) staff have a positive perception of organizational support and priorities, (v) staff value the residents and the relationships they have with them, (vi) there is little social distance between staff and residents, where staff regard the residents to be not

fundamentally different from themselves, and (vii) staff members' values align with the espoused values of the organization (Humphreys, Bigby, Iacono & Bould, 2020).

### ***External monitoring***

Authors of 15 of the 48 studies made recommendations for how external monitoring of services could be improved to increase the likelihood of abuse being detected within services. Recommendations included ensuring investigators have sufficient time, resources, supervision, access to expert consultation and appropriate training (e.g., on the risk factors for abuse) to ensure they are able to investigate a case thoroughly, promptly, and with as much information as possible (Abner et al., 2019; Ramsey-Klawnsnik & Teaster, 2012; Rees & Manthorpe, 2010). Furthermore, information concerning early indicators of abuse needed to be shared with professionals and family carers to enable them to identify and express their concerns. Likewise, information about early indicators was also required within the wider care system, so that commissioners, senior managers, and decision makers were equipped to recognize and respond effectively to such concerns (FMarsland, Oakes & White, 2007). Additionally, research protocols should be utilized to ensure researchers visiting services also respond systematically and effectively to disclosures (Sammet, Parish, Mitra, & Alterio, 2019).

More broadly, a review of adult protection record-keeping practices was recommended to ensure a more consistent and detailed approach across regions for adult protection case management and social work practices (Cambridge et al., 2011b; Fyson, 2015; Manthorpe & Martineau, 2015), as well as computerized recording and case management tools which aid, rather than hinder, effective practice (Fyson & Kitson, 2012). More specifically, Manthorpe & Martineau (2015) recommended the

monitoring of out-of-area placements and effective collation of concerns. Further, mental health services and practitioners should routinely engage and utilize mainstream adult protection-reporting arrangements (Cambridge et al., 2011a; Cambridge et al., 2011b). Other recommendations included unannounced inspections, and assessments of the culture of care providers (Halladay & Harrington, 2015). Further research is required that includes the development of observational tools and evaluation measures that can be used by researchers and regulators to better identify abuse within residential services (Bigby & Beadle-Brown, 2016; Hollomotz, 2012). It was recommended that facilities that fail to adequately protect residents, fail to train employees regarding resident abuse, or fail to respond appropriately to alleged abuse must be sanctioned and compelled to improve (Ramsey-Klawnsnik & Teaster, 2012).

## **Discussion**

The current systematic review aimed to highlight the risk and protective factors for abuse of adults with intellectual disabilities and other developmental disabilities, and to identify any assessment tools or interventions designed to prevent or detect abuse of adults with intellectual and other developmental disabilities.

This is the only review to date to provide a comprehensive summary of the global evidence related to the abuse of adults with intellectual and other developmental disabilities within residential and inpatient services. Several risk and protective factors have been highlighted relating to victim characteristics (e.g., severity of learning disabilities and associated communication difficulties), perpetrator characteristics (e.g., intrinsic motivation to work in care, ability to cope with increasing stress and perceptions of service-users), and organisational factors (e.g., poor leadership, staff shortages and/or high staff turnover, lack of reflective practice). However, to explain

abuse only in terms of single risk factors would fail to address the complex underlying structures of how abuse transpires (Conner, Prokhorov, Page, Fang, Xiao & Post, 2011). Crossmaker (1986) and Sobsey (1994), over 20 years ago, recognised the complexity of the issue when they concluded that the isolation inherent in institutional settings contributed directly to abuse. People resident in institutions are trained to be compliant and dependent and they are not empowered to defend themselves (Crossmaker, 1986). Further, the administrative structures and processes, such as ignoring the issue of abuse, the punishing or ignoring of reporters of suspected abuse, and imposing unrealistic policies and procedures contribute to an atmosphere in which abuse can become pervasive. Both Crossmaker and Sobsey reference the dehumanization and devaluing attitudes of staff towards residents as major contributors to abusive environments, and although their research occurred some years ago, it remains relevant today. Given the difficulties experienced by the UK government in implementing *Transforming Care*, it is perhaps unsurprising that the risk factors for abuse have largely remained consistent over the last thirty years. Findings of the current review therefore support recommendations made most recently following the independent review into Whorlton Hall (Murphy, 2020).

Authors of included studies make several recommendations for preventing and detecting abuse within care services, including: better supervision and training for direct care staff and investigators, better monitoring of out of area placements, increased inter-professional collaboration and expert consultation, regular unannounced visits by supervisors, CCTV monitoring, and more control given to service-users themselves so that they can direct their own safeguarding with the support of advocacy services. Despite self-referrals accounting for only 4% of referrals for adult protection (Mansell et al., 2009), and increased awareness being highlighted as

a protective factor against abuse, the current review failed to identify any empirically evaluated interventions aimed at reducing abuse. In addition, findings of the current review highlighted the relative paucity of research that has been conducted to devise and implement empirically validated, robust and reliable assessment tools for external investigators to utilise, to inform their overall assessment of a service. The effect of culture on service quality is a variable that has been highlighted but an area where little research has been conducted (Walsh, Olson, Ploeg, Lohfeld & MacMillan, 2010). The similarities between cultures in shared supported accommodation and institutions have been noted and more recently poor service culture has been identified as a risk factor for the occurrence of abuse (Hutchinson & Kroese, 2015). Some generic tools focusing on social climate and ward atmosphere have been devised and trialed in intellectual disability services (e.g., Langdon, Swift & Budd, 2006; Bakken, Røssberg & Friis, 2012). However, tools developed specifically for this population may prove particularly useful and echo the recommendations proposed in the most recent independent review of the CQC conducted by Murphy (2020). The current review identified only one such tool, the Group Home Culture Scale (Humphreys, Bigby, Iacono & Bould, 2020), which has not yet been standardized or sufficiently empirically evaluated.

### **Strengths and limitations of the review**

All studies identified were included within this review despite their methodological quality; this decision was made due to a lack of completed controlled studies. Furthermore, including both qualitative and quantitative data led to a more comprehensive and deeper understanding of the abuse of adults with intellectual disabilities and other developmental disabilities. However, the review suggested current research is largely of poor methodological quality, composed predominantly of

descriptive data, ethnographic field studies, or case study designs and/or small sample sizes. Only a minority of studies included a sample of people with intellectual and other developmental disabilities. Consequently, the validity and reliability of research findings is limited by the methodological limitations of the included studies. Furthermore, although the review highlighted the abuse of adults with intellectual and other developmental disabilities as a global issue, the majority of research has been conducted in the UK, therefore limiting our understanding of how abuse is detected in other countries.

### **Future research**

Further research is required to explore the connection between culture and abuse, and how cultures could be changed in a conscious way. Furthermore, a better understanding of how cultures impact on caregiving practice is needed. In addition, more research on high quality services is needed to identify further protective factors and share good practice. Lastly, empirically evaluated interventions to reduce the likelihood of abuse occurring in the future, and research to produce an assessment tool to detect abuse that is reliable and valid would be beneficial. Continued research in the area is critical to identify methods of preventing and detecting abuse of adults with intellectual and other developmental disabilities to increase the chances of early case identification and improve investigation and intervention techniques.



**Table 1 Brief details of all included studies**

<b>Article number, author, date</b>	<b>Title</b>	<b>Country</b>	<b>Study sample</b>	<b>Environment</b>	<b>Study design &amp; method</b>	<b>Study aims</b>	<b>Main Outcomes</b>	<b>MMA T Rating</b>
1. Abner, Teaster, Mendiondo, Ramsey-Klawnsnik, Marcum, Crawford & Wangmo (2019)	Victim, Allegation, and Investigation Characteristics Associated With Substantiated Reports of Sexual Abuse of Adults in Residential Care Settings	USA	410 reports of sexual abuse (61% females, mean age = 49.8)	Residential care	Quantitative (database analysis)	To identify characteristics of investigations of sexual abuse concerning vulnerable adults residing in facility settings that were associated with case substantiation.	18% of sexual abuse cases were substantiated. 51% of alleged perpetrators were facility staff compared to 25% who were residents. Cases that were substantiated were more likely to feature nursing home residents, older victims, female victims, and allegations of physical contact between the alleged perpetrator and victim.	4
2. Ahlgrim-Dezell & Dudley (2001)	Confirmed, unconfirmed, and false allegations of abuse made by	USA	1220 people with mental retardation who were part of a class action lawsuit in	State psychiatric hospital, mental	Qualitative (interviews)	To explore differences in confirmed, unconfirmed, and	A total of 1220 consumers were interviewed and 111 (9.1%) of these consumers made 158 allegations of abuse, neglect, or mistreatment. There	5

	adults with mental retardation who are members of a class action lawsuit		North Carolina. 111 reported an allegation of abuse, neglect, exploitation, or mistreatment during an interview for the Thomas S. Longitudinal Study between November 1996 and February 1998 (50 males, 61 females, aged 20-100, mean age = 41)	retardation centre, group home, nursing home, supervised living, family home, care home, other		false allegations of abuse made by consumers with mental retardation in regard to type of abuse and perpetrator.	were 85 unconfirmed claims (53.8%), 40 false allegations (25.3%), and 33 confirmed claims (20.9%) of abuse. Most frequent allegations were physical assault (39.9%), rape (20.9%) and mistreatment (18.4%).	
3. Allington (1992)	Sexual Abuse within Services for People with Learning Disabilities: Staffs'	UK	107 staff at both Health Authority and Local Authority services.	Day care and residential facilities	Mixed methods (questionnaire)	To ascertain the extent to which staff working with people with learning disabilities are aware of issues	32% of staff never discussed the subject of abuse in their work settings despite the fact that all felt people with learning disabilities to be at risk of sexual abuse, with 68% believing them to be at a higher degree of risk than	2

	Perceptions, Understandings of, and Contact with the Problem of Sexual Abuse					around the topic of sexual abuse.	other people.	
4. Aylett (2016)	Universal learning findings from an analysis of serious case review executive summaries	UK	114 serious case review executive summaries in adult safeguarding conducted between 2000-2012. In 28 cases (31.5%) the victim was characterised as having an intellectual developmental impairment.	Residential and community	Qualitative (survey)	To examine the conclusions and recommendations reported in executive summaries of adult serious case reviews to ascertain common and diverse themes which might support universal learning.	Analysis of the recommendation produced the following categories: provision for staff training and developing competence; reviewing and improving policy, procedure and guidance; facilitating information sharing and communication within and across agency; developing effective governance systems; holistic multi-agency assessment, planning, monitoring and review; develop dynamic risk assessment and risk management by assertive outreach to vulnerable adults; engaging with a	5

							wide range of agencies and interests in Safeguarding Vulnerable Adults.	
5. Bakken, Røssberg & Friis (2012)	The ward atmosphere scale for psychiatric inpatients with intellectual disability: A pilot study.	Norway	17 patients with mild and moderate intellectual disability and 21 professionals	Specialised psychiatric inpatient unit for adults with intellectual disability at the Oslo University Hospital in Oslo	Quantitative	The aim of this study is to examine whether adults with intellectual disabilities can reliably rate the Ward Atmosphere Scale – Real Ward (WAS-R).	Patients with mild intellectual disabilities were able to answer the WAS with some help, whereas patients with moderate intellectual disabilities had major difficulties with understanding more than half of the WAS items.	1
6. Beadle-Brown, Mansell, Cambridge, Milne & Whelton	Adult Protection of People with Intellectual Disabilities: Incidence, Nature and Responses	UK	1926 adult protection referrals recorded by the two local authorities between 1998 and 2005 (42% male, aged 17-100,	See Cambridge, Milne, Mansell, Beadle-Brown & Whelton	See Cambridge, Milne, Mansell, Beadle-Brown &	To report the key findings from a study of adult protection referrals collected by two English local	There was an increase in the number of referrals from 1998-2005. 67% of referrals were for a single type of abuse; most frequently physical followed by sexual. More abuse in residential care settings. Victims were	3

(2010)			mean age= 38.9)	(2011)	Whelton (2011)	authorities during 1998-2005 for people with intellectual disabilities.	most likely to be referred to adult protection by a member of staff and less likely by family. Only 5% of cases involved multiple perpetrators, which was significantly less than non- intellectual disabilities population. People with intellectual disabilities were more frequently abused by a man rather than a woman (52%). 46% of referrals related to abuse by staff/managers.	
7. Beail & Warden (1995)	Sexual abuse of adults with learning disabilities	UK	211 clients with a learning disability over the age of 16 referred to the Clinical Psychology Service over a 4-year period from 1988- 1991	Living at home, hospital residents, supported living in the community	Quantitative descriptive- Survey	To report a clinical study of reported or disclosed sexual abuse of adults with learning disabilities.	Abuse reported in 22 (25%) of cases. 86% self-disclosed abuse. Majority of alleged perpetrators were men (n = 19) and known to the victim (n = 18). Just over half the sample reported one perpetrator (n = 12) and multiple occasions of abuse (n = 13). The police were involved with a minority of	4

							clients (n = 5), however no-one was prosecuted. 17 clients suffered contact abuse and 1 suffered non-contact abuse.	
8. Bigby & Beadle-Brown (2016)	Culture in better group homes for people with intellectual disability at severe levels	Australia	Supervisors, direct support staff, 17 residents, and resident families across 3 group homes (aged 21-48, mean age = 36.5)	3 Group homes	Mixed Methods: Case study (observations and interviews)	To analyse culture in better performing services.	Several dimensions of culture identified in better care homes compared to underperforming care homes.	4
9. Bigby, Knox, Beadle-Brown & Clement (2015)	'We just call them people': Positive regard as a dimension of culture in group homes for people with severe intellectual	Australia	As above	3 group homes	Mixed methods: Case study (observations, interviews, and document review)	To analyse culture in better performing services.	Staff regarded residents positively, as members of a common but diverse humanity, and recognized sameness and difference. Staff provided care in the context of a relationship characterized by warm feelings, which for many extended to a deep emotional bond. Staff used both their own	4

	disability.						perspectives and their understanding of the resident's own perspective to guide their practice.	
10. Bigby, Knox, Beadle-Brown, Clement & Mansell (2012)	Uncovering Dimensions of Culture in Underperforming Group Homes for People with Severe Intellectual Disabilities	Australia	Staff and residents in 5 group homes (23 men and 3 women with intellectual disabilities, aged 34-70, mean age = 49).	5 group homes	Qualitative-ethnographic approach (field notes and interview)	To explore the characteristics and dynamics of the culture operating in five group homes that were underperforming in terms of community participation and engagement outcomes.	Five categories were developed, each of which represented the conceptualization of an element of the culture in the group homes: 'misalignment of power holder values with organisations espoused values', 'otherness', 'doing for not with', 'staff centred' and 'resistance'.	4
11. Bright, Hutchinson, Oakes & Marsland (2018)	Families' experiences of raising concerns in health care services: An	UK	7 relatives of people with intellectual disabilities	Residential care, supported living or attended	Qualitative (interviews)	To increase understanding of the experiences of families of people with intellectual	Three superordinate themes: the nature and importance of concerns, relationships between families and staff and the process of raising concerns.	4

	interpretative phenomenological analysis			respite care		disabilities when noticing and raising concerns in services.		
12. Brown & Stein (1988)	Implementing Adult Protection Policies in Kent and East Sussex.	UK	397 adult protection alerts logged between 1 July 1995 and the end of June 1996 by Kent and East Sussex Social Services Departments as adult protection. People with learning disabilities account for 3%.	Community, residential	Action research (mixed methods)	To report the extent and nature of adult protection cases dealt with by two Social Services Departments during a twelve-month period in 1995–6	Financial abuse experienced by 4% of people with IDD (n = 5), and sexual abuse by 33% (n = 44). Men featured as alleged perpetrators of abuse in 70% reports. Of the 397 initial alerts, 255 led to formal investigation and 84 to a case conference and 78 led to adult protection plans being put in place. Formal sanctions were taken in only 10 (3 per cent) of cases. Of the 397 cases overall, 91 (23 per cent) involved liaison with the police and 82 (21 per cent) with colleagues in the health service. There was a considerable range in reporting levels between and within both counties.	1



13. Brown & Stein (2000)	Monitoring adult protection referrals in 10 English local authorities	UK	Data was collected from 10 areas in England on 245 adult protection referrals during this six-month period in 1998 (n=79 with learning disabilities). 29 of the 79 people with learning disabilities were abused whilst in residential care.	Residential and community services	Mixed Methods (action research)	To ascertain whether and if so, how local authorities were generating and collating consistent data as the basis for evaluating their practice.	Data collated by social services departments varied from one area to another and many common problems were highlighted. The quality of information generated was partial indicating a lack of agreed procedures, poor recording practice and a lack of clarity regarding who is a 'vulnerable adult', what constitutes 'abuse' and when 'intervention' is warranted.	2
14. Brown, Stein & Turk (1995)	The sexual abuse of adults with learning disabilities: Report of a second year incident survey	UK	29 service managers/practitioners from 21 agencies who returned information on 109 sexual abuse cases reported in the area	Hostel, hospital, other facilities, or with their family	Quantitative-Survey	To conduct a UK incidence survey of the sexual abuse of adults with learning disabilities.	Of the 109 cases reported, 85 were proven or had enough evidence to suggest that sexual abuse was highly likely to have occurred. 53% of the 85 exposed the abuse themselves. Both women and men are at risk of being sexually abused. The largest proportion	3

			covered by the South East Thames Regional Health Authority for the years 1991 and 1992				of victims were in the severe to moderate ID categories (IQ 21-50). Over 60% of clients had additional problems. Perpetrators were predominantly men and usually known rather than strangers. Collaborative working between agencies was inconsistent, as were the actions taken by agencies following allegations of abuse.	
15. Calcraft (2007)	Blowing the whistle on abuse of adults with learning disabilities	UK	Focus groups conducted with adult protection coordinators, social care inspectors, and trainers of social care staff. Interviews conducted with 8 social care workers	Interviewees worked in day and residential care settings across the statutory, voluntary, and private	Qualitative (interviews and focus groups)	To explore the experience of whistleblowing on abuse in social care settings and look at how whistleblowing can help to protect people with learning disabilities from	The types of adult protection concern that people raised in the study included: inappropriate use of control and restraint, physical assault, rough movement and handling, deprivation of privacy and choice, verbal abuse, and sexual abuse. Themes that emerged included support for whistle-blowers, feedback for whistle-blowers, impact	4

			who had raised concerns about abuse in their workplace, 1 trainer and 6 managers who had investigated incidents involving whistleblowing on abuse or had experience of developing and implementing whistle-blowing policies.	sectors.		abuse.	on working relationships, organisational culture, and power, recognising and challenging abuse, closed teams and powerful individuals, negative views of whistleblowing, management, and organisational culture.	
16. Cambridge (1999)	The First Hit: A case study of the physical abuse of people with learning	UK	Professionals/staff (n=?)	Residential service	Qualitative: Case study (documentary analysis & interviews)	To describe the circumstances surrounding the physical abuse of persons with	Several risk factors surrounding the circumstances of abuse were reported including a culture of abuse that had a number of identifiable characteristics (e.g., isolation, ineffective staff	2

	disabilities and challenging behaviours in a residential service					learning disabilities and challenging behaviours in a residential service and the general findings of a related inquiry.	supervision, intimidation, institutionalised practice, inexperience, anti-professionalism, barriers to disclosure, poor support for whistle-blowers, deficiencies in service audit, poor inter-professional communication, poor ?? recognition skills, lack of clarity in care management, difficulties in market management and service satisfaction).	
17. Cambridge, Beadle- Brown, Milne, Mansell & Whelton (2011)	Patterns of Risk in Adult Protection Referrals for Sexual Abuse and People with Intellectual Disability	UK	Adult protection monitoring data collected by two local authorities (1857 referrals). Mean age 28.9 years, 42% male.	See Cambridge, Milne, Mansell, Beadle-Brown & Whelton (2011)	See Cambridge, Milne, Mansell, Beadle-Brown & Whelton (2011)	To compare referrals for alleged sexual abuse and other types of abuse for people with intellectual disability.	The annual number of referrals for sexual abuse for people with intellectual disabilities has increased over time. Sexual abuse was confirmed in just over a quarter of all referrals (26.4%). In 58.3% of referrals received practitioner input for 1-6 months, and the mean time referrals were open was 127.58 days.	2

18. Cambridge, Milne, Mansell, Beadle- Brown & Whelton (2011)	A study of adult protection referrals in two local authorities: an overview of findings for managers and practitioners	UK	6,148 adult protection referrals (all care groups??) recorded by the two local authorities between 1998 and 2005	46% of iDD referrals? were for people in residential or supported living, 32% for people living with a family and 17% for people living alone.	Quantitative (database analysis)	To report the key findings from a study of adult protection referrals collected by two English local authorities during 1998-2005.	63% of adults with intellectual disabilities had been referred for a single type of abuse. Physical abuse and neglect most frequently occurred in residential care. Large geographical differences in outcome of referral, likely related to local adult protection demands, resource availability, demographic and service characteristics, local competence.	3
19. Furey, Niesen & Strauch (1994)	Abuse and neglect of adults with mental retardation in different residential	USA	944 cases of abuse/neglect (excluding sexual abuse) over a 5 year period of adults aged 18-59 with mental	Group homes, community training, homes, own residence, institutions.	Quantitative (database analysis)	To examine the prevalence of abuse and neglect in residential settings for adults with mental retardation.	There was significantly more abuse and neglect in institutions than in the resident's own home. There was no difference between the rate of abuse in institutions as compared to the rate of abuse in group homes.	4

	settings		retardation.					
20. Fyson (2015)	Building an Evidence Base for Adult Safeguarding? Problems with the Reliability and Validity of Adult Safeguarding Databases	UK	14 safeguarding managers from Adult Social Care and Health teams.	Full range of adult social care specialist teams	Mixed methods: Case study (interviews and database analysis)	To evaluate adult safeguarding in one English local authority, focusing on how the adult safeguarding database was populated from case records and how the resultant data were utilised.	There was a significant increase over time in the number of adult safeguarding alerts received by the authority. An increase in workload had not resulted in increased resource allocation. Only half of the designated 'adult safeguarding managers' who were interviewed were able to correctly define the meanings of the recommended terms under which adult safeguarding outcomes are recorded.	4

21. Fyson & Kitson (2012)	Outcomes following adult safeguarding alerts: a critical analysis of key factors	UK	42 safeguarding alerts in one English local authority	All adult social care teams	Mixed methods (survey)	To report some of the findings from an evaluation of adult safeguarding in one English local authority.	15 cases resulted in a “substantiated” outcome, 18 cases a “not substantiated” outcome, 1 case was on-going, and 8 cases were recorded as “not determined”.	4
22. Fyson & Patterson (2019)	Staff understandings of abuse and poor practice in residential settings for adults with intellectual disabilities	UK	56 care staff and frontline managers working across 14 residential services in England	Residential services	Qualitative (Interviews)	To explore staff understandings of abuse and poor practice in residential services for people with intellectual disabilities.	Staff struggled to define either “abuse” or “poor practice”, focussing more on individual acts or omissions than on institutional practices. When faced with vignettes, staff demonstrated a lack of agreement regarding what constitutes either abuse or poor practice.	5
23. Gillett & Kroese (2003)	Investigating organisational culture: A comparison of a	UK	Staff groups from two matched residential units for people with intellectual	Small community-based residential	Quantitative non-randomised (cross-	To investigate organisational culture in small community-based	The unit with better quality outcomes demonstrated a more positive organisational culture. The lower performing group home had	3

	high and a low performing residential unit for people with intellectual disabilities		disabilities (n = 15).	services for people with intellectual disabilities	sectional study).	residential services for people with intellectual disabilities.	significantly higher scores for oppositional style (e.g., norms of confrontation and criticism). Competitive (e.g., norms of win against others and compete rather than cooperate), and perfectionism (norms of never making a mistake and setting unrealistically high goals). Reflecting a task rather than person orientation. No differences in turnover or absence figures were found between the two units.	
24. Halladay & Harrington (2015)	Scandals of abuse: Policy responses in intellectual disabilities	UK/USA	Two case studies (two scandals). In total, 46 different NYT stories and 14 secondary sources were identified for the New York case study. 90	Care homes	Qualitative (documentary analysis)	To compare two scandals related to the care of individuals with intellectual disabilities in the USA and the UK.	Both cases offered confirmatory support to extant theories of abuse, and to wider policy trends within intellectual disabilities.	3



			BBC television and radio stories, and 14 secondary sources for the UK case were identified.					
25. Hollomotz (2012)	'A lad tried to get hold of my boobs, so I kicked him': an examination of attempts by adults with learning difficulties to initiate their own safeguarding	UK	Adults with mild/moderate learning difficulties (n = 12 men, n = 17 women, aged 22-68)	50% lived with their parents/other family member, 25% lived in residential group settings, and 25% lived on their own/ with a partner.	Qualitative (interviews)	To highlight the resistance skills that are prevalent amongst some people with learning difficulties.	50% of participants reported an incident of physical or emotional violence. All participants knew of their right not to be violated or exploited. Most were able to identify risks and plan protective interventions in hypothetical scenarios. In most cases respondents described that risky situations are best handled by asking for assistance.	3

26. Humphreys , Bigby, Iacono, & Bould (2020)	Development and psychometric evaluation of the Group Home Culture Scale	Australia	343 professionals	Group homes	Mixed methods (literature review, expert review, cognitive interviews, exploratory factor analysis).	To develop the Group Home Culture Scale to measure the influence of organizational culture in group homes for people with intellectual disabilities on staff behaviour and residents' quality of life.	The scale measured seven dimensions of group home culture (supported well- being, factional, effective team leadership, collaboration within the organisation, valuing residents and relationships, social distance from residents, alignment of staff with organisational values). The content and face validity of the scale were acceptable.	4
27. Hussein, Manthorpe, Stevens, Rapaport, Harris & Martineau (2009)	Articulating the improvement of care standards: The operation of a barring and vetting scheme in social care	UK	5294 care staff referrals to the Protection of Vulnerable Adults list between 2004-2006.	All care settings	Quantitative (document- ary analysis)	To investigate the decision making of the POVA scheme and make recommendations for policy.	Almost all employers had undertaken inquiry and disciplinary processes prior to referring the staff member to POVA. In 6% of referrals there had there been no employer's investigation, in 77% employers' investigations had resulted in some form of disciplinary	4

							<p>action. 58% of referrals were closed and the worker not placed on the list. Referrals from residential care settings and those relating to financial, emotional or sexual forms of alleged abuse were more likely to be confirmed. Among referrals where a decision had been made, it took the POVA team an average of 5.8 months to be in a position to reach that decision.</p>	
28. Hutchison & Kroese (2016)	Making sense of varying standards of care: the experiences of staff working in residential care environments for adults with	UK	6 professionals	Residential care	Qualitative (interviews)	To describe the experiences of six care workers currently working in residential homes.	Three things were found to be important aspects of care workers experiences: degree of positive relationship reciprocity; value congruence and intrinsic motivation; and experiences of environmental and organisational constraints.	4

	learning disabilities							
29. Jones & Kroese (2006)	Service users' views of physical restraint procedures in secure settings for people with learning disabilities	UK	Service-users (7 males, 3 females) with mild learning disabilities who had been restrained at least once in the previous 6 months. Mean age 39.3 years.	2 secure residential facilities for people with learning disabilities	Qualitative (interviews)	To examine the views of service-users from secure residential facilities who are restrained frequently.	Restraint can lead to potentially abusive situations. Staff should try other approaches before restraining someone. Service-users were divided on whether restraint calmed them down and whether staff enjoyed performing restraint. Four participants indicated that they had experiences abusive restraint procedures. Two participants described incidents of improper and abusive practice that had been dealt with by appropriate bodies.	4

<p>30. Langdon, Swift &amp; Budd (2006)</p>	<p>Social climate within secure inpatient services for people with intellectual disability</p>	<p>UK</p>	<p>37 professionals and 18 service-users with mild/moderate intellectual disabilities and history of engagement in criminal offending behaviour.</p>	<p>Low/medium secure service</p>	<p>Quantitative- Between subject's design</p>	<p>To investigate the social climate of two different types of secure units ('low' secure vs. 'medium' secure) contained within the same facility for offenders with intellectual disabilities.</p>	<p>Service-users rated the units in a more positive direction than staff on some sub-scales of the Correctional Institutions Environment Scale (CIES): involvement, support, personal problem orientation, and staff control. Service-users rated the 'low' secure unit in a more positive direction than the 'medium' secure unit on practical orientation &amp; personal problem orientation. However, on selected sub- scales there were staff vs SU?? differences. The CIES may be a valid instrument for use within forensic services for people with intellectual disabilities.</p>	<p>2</p>
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31. Manthorpe & Martineau (2015)	What Can and Cannot Be Learned from Serious Case Reviews of the Care and Treatment of Adults with Learning Disabilities in England? Messages for Social Workers	UK	21 Serious Case Reviews	Range of services	Qualitative (document- ary analysis)	To investigate Serious Case Reviews for vulnerable adults where the person who was at risk of harm had a learning disability.	3 themes were identified (staff relationships, family and carers, and biography and chronology) resulting in the need for better care plans for people with complex needs, to monitor of out-of-area placements, and ensure issues of concern are collated.	4
32. Marchetti & McCartney (1990)	Abuse of persons with mental retardation: Characteristics of the abused, the abusers and the	USA	55 cases of confirmed abuse/neglect during a 33-month period in 4 state-operated residential facilities for persons with	Residential facilities	Quantitative (database analysis)	To analyse data from confirmed incidents of abuse in public residential facilities.	The number of confirmed incidents of abuse were relatively small, that. direct care staff members committed and reported most incidents of abuse (46%), and that most. Incidents of abuse occurred on the second shift	4

	informers.		mental retardation.				(11am-3pm). Although abuse also occurred frequently occurred (40%) on the first shift also (6-9am). Abused residents were similar to the general resident population on basic demographic variables, but more abused residents were in the upper IQ and adaptive behaviour levels. Abuse committers were more often males than females.	
33. Marsland, Oakes & White (2007)	Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential	UK	17 professionals from community learning disability teams, social services departments and voluntary sector agencies, and 3 family members who had been in direct contact	Residential and day services (including family home, residential home, own home, private hospital, NHS	Qualitative (interviews & file review)	To contribute to the prevention of abuse through the identification of 'early indicators'.	Physical, sexual, psychological, financial and material abuses, and neglect reported. Physical and psychological abuses were the forms of abuse most frequently reported. Many of the cases described involved multiple abuses, where individuals were abused in a variety of ways. Perpetrators of the abuses described	2

	settings		with services that went on to be identified as settings in which abuse of people with learning disabilities had occurred	service, specialised residential unit).			included staff members and other residents. Themes that emerged were: the decisions, attitudes and actions of managers, the behaviours and attitudes of staff, the behaviours of people with learning disabilities, isolation, service design, placement planning and commissioning, and fundamental care and the quality of the environment.	
34. McCartney & Campbell (1998)	Confirmed abuse cases in public residential facilities for persons with mental retardation: a multi-state study	USA	494 cases of abuse reported across 23 facilities people with mental retardation (63% male, mean age 34.94)	Large state operated residential facilities	Quantitative (documentary analysis)	To examine abuse incidents and the individuals involved in them in order to identify variables to be considered in the development of abuse prevention strategies for public residential facilities.	Neglect and physical abuse were the most common types of abuse. 89% of abuse was reported by facility staff members. Over 22 months, 494 cases of abuse were reported.	4



35. Moring, Parish, Mitra & Alterio (2019)	After Disclosure: A Research Protocol to Respond to Disclosures of Abuse and Sexual Violence in Research with Adults with Intellectual Disabilities	USA	Professionals	N/A	Mixed methods (literature review, team consensus process, community partnership)	To develop a protocol for responding effectively to disclosures of sexual violence from adult research participants with intellectual disabilities.	A research protocol was developed to ensure effective response following disclosure of abuse.	1
36. Niemeijer, Frederiks, Depla, Eefsting & Hertogh (2013)	The place of surveillance technology in residential care for people with intellectual disabilities: Is there an ideal	The Netherlands	9 professional carers, 2 intellectual disability physicians, 2 developmental psychopathologists, 8 academics, 4 personal coaches and 5 support workers.	Small-scale establishments and larger-scale residential care.	Mixed methods (concept mapping; brainstorming, prioritising, clustering,	To provide an overview of how surveillance technology is viewed by (care) professionals and ethicists working in the field, by	Surveillance technology in the residential care of people with intellectual disabilities should support and enhance the capabilities of the client, contribute to the reduction restrictions, be based on a vision of its benefits and risks, involve staff who are equipped to work safely, be user-	4

	model of application				processing by the computer and analysis)	investigating what the ideal application of ST in the residential care for people with ID might entail.	friendly, and attend to the client.	
37.	Niemeijer, Depla, Frederiks & Hertogh (2015) The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care	The Netherlands	A dementia special care unit of a nursing home. (included people with ID too???)	Long-term residential care facilities	Qualitative: Ethnographic field study.	To explore how clients in residential care experience surveillance technology in order to assess how surveillance technology might influence autonomy.	Two themes emerged: (1) coping with new spaces which entailed clients: wandering around, getting lost, being triggered, and retreating to new spaces and (2) resisting the surveillance technology measure because clients feel stigmatized, missed the company, and do not like being “watched.”	4
38.	Niemeijer, Depla, Frederiks, The use of surveillance technology in residential	The Netherlands	Same as Niemeijer et al., (2015)	Same as Niemeijer et al., (2015)	Same as Niemeijer et al., (2015)	To investigate how surveillance technology is actually being used	Five overarching themes on the use of surveillance technology emerged from the data: continuing to do rounds, alarm fatigue, keeping clients in close	4

<p>Francke &amp; Hertogh (2014)</p>	<p>facilities for people with dementia or intellectual disabilities: A study among nurses and support staff</p>					<p>by nurses and support staff in residential care facilities for people with dementia or intellectual disabilities, in order to explore the possible benefits and drawbacks of this technology in practice</p>	<p>proximity, locking the doors, and forgetting to take certain devices off.</p>	
<p>39. Ottmann et al. (2017)</p>	<p>Barriers and Enablers to Safeguarding Children and Adults within a Disability Services Context:</p>	<p>Australia</p>	<p>249 disability services staff and managers</p>	<p>NR</p>	<p>Mixed methods (Delphi)</p>	<p>To capture the views of disability services staff and managers regarding barriers and enablers to effective safeguarding.</p>	<p>Participants identified 170 items related to key barriers to effective safeguarding summarised as organisational issues, management practice, workforce development, client capacity building and contextual factors emerged. The knowledge and</p>	<p>4</p>

	Insights from an Australian Delphi Study						attitudes section of the Delphi survey highlighted serious gaps in the capacity of staff to identify basic risk factors, identify signs of abuse and neglect, respond to signs of abuse and neglect, and work with clients who experienced trauma as a result of maltreatment.	
40. Parley (2010)	The understanding that care staff bring to abuse	UK	20 care staff working within learning disability services (including 5 NHS employees, 5 local authority employees, 5 from the voluntary sector and 5 from the private sector).	NHS, voluntary and private sector	Qualitative (interviews)	To explore staff views relating to vulnerability and abuse of adults with learning disabilities.	Themes included interpretation of abuse, bullying, neglect, power, infringement of rights, right to liberty, right to have children. Physical and sexual abuse was readily identified by most informants. However, bullying, neglect and infringement of rights were less frequently identified. Some did not consider these to be abuse.	5
41. Patterson & Fyson	"I was gobsmacked": care workers'	UK	56 service managers and care workers across three types of	Residential & supported living services	Qualitative (interviews)	To explore how care workers, report their reactions and the	Participants invoked states of 'shock' and 'disbelief' to describe their response to the abusive practices	5

(2016)	responses to BBC Panorama's 'Undercover care: the abuse exposed': Invoking mental states as a means of distancing from abusive practices		service provider			interactional strategies they use to construct themselves as shocked and disbelieving, and thus as oppositional to the extreme practices in the programme.	presented in the programme.	
42. Ramsey- Klawnsnik & Teaster (2012)	Sexual Abuse Happens in Healthcare Facilities-What Can Be Done To Prevent It?	USA	28 personnel who had investigated cases of sexual abuse	Healthcare facilities	Qualitative (interviews)	To gather data that could help assist victims and hold perpetrators accountable in case of sexual abuse perpetrated against residents in healthcare facilities.	The amount of training the workers had received in conducting sexual abuse investigations varied considerably with 11% of investigators having had no formal training, despite over half reporting that sexual abuse is more challenging to investigate than other allegations.	4

43. Rees & Manthorpe (2010)	Managers' and staff experiences of adult protection allegations in mental health and learning disability residential services: A qualitative study	UK	13 managers from three services and ten care workers accused of abuse and later exonerated.	Residential services	Qualitative (interviews)	To consider the impact of adult protection investigations on managers of residential services and staff accused of harm or abuse, investigated and then exonerated.	Positive applications of adult protection recalled as well as the impact of false allegations. Many of the issues raised by the managers related to perceived inflexibility and their lack of discretion when applying policy.	3
44. Rusch, Hall & Griffin (1986)	Abuse-provoking characteristics of institutionalized mentally retarded individuals.	USA	80 abused retarded clients in residential settings and 80 non-abused clients	Residential setting	Quantitative-non randomized (Retrospective data collection from medical and	To examine the abuse-provoking characteristics of institutionalized mentally retarded individuals.	Six characteristics (social quotient, aggression, verbal ability, age, self-injurious behaviour, and ambulation) were significant in differentiating the abused from non-abused retarded individuals.	2

					program records)			
45. Rytterström, Unosson & Arman (2013)	Care culture as a meaning-making process: A study of a mistreatment investigation	Sweden	16 professionals	Community residential housing unit offering special services to persons with intellectual disabilities.	Qualitative: Case study (interviews, focus group, field study, document analysis)	To understand and explore institutional mistreatment from a care culture perspective.	Two different care cultures were identified: the service culture, which was need-oriented and emphasized freedom in care provision, and the motherhood culture, which was characterized by protection and safeguarding of the vulnerable residents.	4
46. Taylor & Dodd (2003)	Knowledge and attitudes of staff towards adult protection.	UK	150 professionals (33 males and 117 females), with various job titles including home manager, staff nurse, support worker, day service officer and	Mental health, learning disability, physical or sensory disability, older adult, or multiple	Qualitative (interviews)	To explore staff knowledge and attitudes towards abuse and the reporting procedures to further understand why abuse is not	Issues concerning staff awareness and attitudes towards abuse highlighted. Participants showed confusion and a lack of clarity over what they would consider abuse. Several beliefs emerged to explain why participants might not decide to report abuse (e.g., client confidentiality, risk making	3

			community care assistant. 14 participants worked with people with learning disabilities.	service user setting, or the police service.		reported.	things worse, doubt about whether the abuse had taken place, collusion).Lack of understanding for the procedure of how to report abuse.	
47. Turk & Brown (1993)	The sexual abuse of adults with learning disabilities: Results of a two year incidence survey.	UK	119 incidents of sexual abuse of adults aged 18+ with learning disabilities over 2 years	One large regional health authority (10 health districts, four social service districts, 5 joint social service/health districts)	Quantitative descriptive: Survey	To report the incidence of sexual abuse of adults with learning disabilities.	84 of the cases were proven/had sufficient evidence to suggest the sexual abuse was highly likely to have occurred. In a further 25 cases there was continued ongoing concern, in the absence of substantive evidence, that sexual abuse was occurring. Victim and perpetrator characteristics were identified. Most of the evidence was obtained from verbal disclosures of abuse, behavioural/psychosomatic change, and circumstantial evidence. In 27% of cases only 1 agency were involved in	4



							the investigation. No action was taken against the alleged perpetrator in almost half of cases (48.2%). Minimal support for the victim post abuse was offered in 71% of cases.	
48. Zuckerman, Abrams & Nuehring (1986)	Protection and advocacy agencies: National survey of efforts to prevent residential abuse and neglect	USA	State protection and advocacy agencies- Directors from 43 states.	State institutions and community based residential services	Mixed methods (survey)	To determine the involvement of protection and advocacy agencies in the investigation of abuse and neglect of persons with developmental disabilities in residential facilities.	Protection and advocacy agencies do play a role in abuse and neglect prevention, despite few staff members/resources having been allocated to investigations.	3

## Appendix 2

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### Appendix 3: Timetable for the workshops

#### Detecting and Preventing Abuse in IDD services: Two half-day workshops

Tuesday 13 <sup>th</sup> October (UK times)		
Date & time	Researcher	Title of presentation
1.45 pm	Prof Glynis Murphy, Tizard Centre, Univ of Kent & Mary Cridge, Deputy Chief Inspector, Adult Social care, CQC	A brief introduction to the workshop
2pm	Dr Andrea Hollomotz, Leeds University	Building resilience and an expectation of freedom from degrading treatment, through mundane interactions with staff
2.30pm	Prof Jill Manthorpe, The Policy Institute Kings College, London	Looking backwards, looking forwards; on having an inquiring mind
3pm	Dr Alistair Neimejer, Universiteit voor Humanistiek Utrecht	In search of good ethical care with surveillance technologies for people with learning disabilities
3.30pm	Dr Biza Kroese School of Psychology Birmingham Univ	Views from the inside and the outside: Asking residential staff and psychologists how to ensure good quality care
4pm	Dr David Marsland & Dr Caroline White Univ of Hull	Abuse in Care: early indicators of concern in residential services'.
4.30	Prof Julie Beadle Brown Tizard Centre, Univ of Kent	The need to design in quality: The role of engagement, active support and the SPELL Framework in promoting positive outcomes and detecting and preventing abuse
5.00	Finish	

<b>Wednesday 14<sup>th</sup> Oct</b>		
1pm	Prof Chris Bigby, LaTrobe University, Australia	Identifying differences in culture between poor and better group homes
1.30pm	Dr Lincoln Humphreys, LaTrobe University, Australia	The Group Home Culture Scale: development and findings
2pm	Prof Peter Langdon Warwick Univ	The value and importance of generating positive social climates and culture within secure services.
2.30	Dr Bakken National Advisory Unit on Mental Health in Intellectual Disabilities, Oslo University Hospital, Norway	Research on Ward Atmosphere – How can results be applied in clinical practice?
3.00	Tea break	
3.30	Prof Rachel Fyson School of Sociology & Social Policy, Univ of Nottingham	Staff understandings of abuse and poor practice in residential care
4pm	Glynis Murphy Tizard centre Univ of Kent	Discussion by all participants (GM will chair)
Close 5pm		

## Appendix 4

### Early Indicators of Concern in Residential Support services for People with Learning Disabilities

(Marsland Oakes and White, University of Hull).

This is a shortened version of the full document

#### The Early Indicators

There are six main areas to think about:

##### 1. Concerns about management and leadership

This is about the people who manage the home or service and other managers in the organisation. What are they doing, or not doing that gives you cause for concern?

##### 2. Concerns about staff skills, knowledge and practice

This is about the people who work in the home or service. What are their skills and practice like? What are they doing, or not doing that gives you cause for concern? This is not just people who work as care workers or nursing staff but also includes, for example, cleaners, catering staff and managers performing care tasks.

##### 3. Concerns about residents' behaviours and wellbeing

This is about the people who live in the home or service. How are they? Are they behaving in ways which suggest that their support is ineffective or inappropriate? Are there noticeable changes in people's presentation or their appearance?

**4. Concerns about the service resisting the involvement of external people and isolating individuals**

Are the people in the home or service cut off from other people? Is it a “closed” or an “open” sort of place? Does the service resist support from external agencies or professionals?

**5. Concerns about the way services are planned and delivered**

This is about the ways in which the service is planned and whether what is actually delivered reflects these plans. For example, are people receiving the levels of care which have been agreed? Are the residents a compatible group? Is the service clear about the kind of support they are able to deliver?

**6. Concerns about the quality of basic care and the environment**

Are basic needs being met? What is the quality of the accommodation like?