

# Designing Solutions for Improved Support within Health, Social Care and Criminal Justice for Adults with Learning Disabilities and/or Autism who Have Offended

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*Abstract: People with learning disabilities and/or autism encounter considerable challenges on the pathways through the criminal justice and/or forensic health systems. This article presents a thematic analysis of focused discussions between users, professionals and practitioners from health, social care and criminal justice. It is informed by the social model of disability, which dictates its focus on solutions for maximising the full and effective participation of disabled users. Informants raised key challenges, including indirect disability discrimination and risk averse practice, and evidenced innovative solutions. These include person-centred, multi-agency working, screening, information sharing, inclusive service design, nurturing sustainable key relationships and long-term community support.*

**Keywords:** autism; desistance; forensic social care; intellectual disabilities; learning disabilities; offender rehabilitation; personalisation; public sector equality duty; reasonable adjustments; social model of disability

## Foreword

Over a decade ago, when I published my review of people with mental health problems or learning disabilities in the criminal justice system (Bradley 2009) and at the time of the event described in this paper, we could not predict the unique situation we would find ourselves in now. Building on progress made and learning from our successes is challenging during a global pandemic.

The restrictions brought by COVID-19 have created difficulties in the lives of many people with learning disabilities and/or autism, who may struggle due to a break in routines, and many of the good practices

described in this paper are faced with additional challenges at a time when social distancing is a necessity. Person-centred working and bringing together multiple agencies to develop joint solutions requires repeat contact. Many people with learning disabilities and/or autism find it harder than others to participate effectively in online meeting formats. This creates new barriers to involving this group in the design and delivery of services.

Making time for training or to attend multi-agency planning meetings has become a luxury, as many desk-based staff across CJS and forensic settings are recalled to the frontline to respond to the Covid-19 crisis. We must guard against silo working and make extra efforts to maintain effective working relations for multi-agency cooperation and in our work with people with learning disabilities and/or autism.

It is encouraging to see the recent commitment by the Secretary of State for Justice to undertake a programme of work leading to better identification and support of people with neurodiversity, and I look forward to contributing to that work (gov.uk 2020). In addition, many frontline services such as Liaison and Diversion, Appropriate Adults and Intermediaries have continued to provide much needed support. To further improve the lives of people with learning disabilities and/or autism who have been caught up in the CJS or forensic settings we must ensure that learning from events such as this is built upon as we return to more 'normal' conditions.

The Rt Hon. Lord Bradley of Withington in December 2020



## **Introduction**

People with learning disabilities and/or autism who have offended encounter considerable challenges on the pathways through the criminal justice and/or forensic health systems in England and there is a growing body of literature that explains these challenges, which is explored shortly. These include the likely over-representation of people with learning disabilities and/or autism in the criminal justice system (CJS), experiences of inhumane or degrading treatment and a high incidence of reoffending. Sociological research into the causes for these experiences enables a focus on broader social issues, which act as ascendants to what are often seen as 'individual troubles', as C. Wright Mills (1959) would put it, such as persistent cycles of reoffending. This article uses the social model of disability (Oliver, Sapey and Thomas 2012) to achieve this objective. In short, this means that, instead of focusing on individual pathology, our focus is on how services and environments need to change.

The current literature and findings from this study suggest that health, criminal justice and social care do often not collaborate as effectively as they could when responding to the often-complex needs of people with learning disabilities and/or autism who have offended. This is why this article presents solutions, which were collaboratively developed by some of the most innovative users, practitioners and professionals from across

England. To set the scene, the introduction covers definitions and prevalence, disability equality and human rights issues, additional comorbidities and risks and existing evidence on effective solutions.

### *Definitions and Prevalence*

This article is concerned with individuals with learning disabilities, autism and co-occurring learning disabilities and autism. It mostly does not distinguish between these groups. Instead, the shorthand term ‘people with learning disabilities and/or autism’ is used. The World Health Organisation (2020) defines learning disabilities<sup>1</sup> as:

a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

The NICE (2016) guidance describes autism as:

a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. ... People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties.

Estimates about the proportion of autistic people who also have learning disabilities range from 15% to 84%, with a mean of 52.6%. Furthermore, around a third of people who have learning disabilities also have autism (Emerson and Baines 2010). People with autism have sometimes been wrongly diagnosed as having learning disabilities and vice versa. This has led to individuals falling through gaps in service provision. Such gaps were the driver for the ‘I Exist’ campaign (National Autistic Society 2002) and the motivator behind the Autism Act 2009 (Aylott 2011).

Autism affects 1.1% of the general population (National Autistic Society 2020). There are currently no reliable estimates about the number of autistic people in the CJS. Prevalence figures range from 2.74% to 26% (King and Murphy 2014). The proportion of people known to adult services as having learning disabilities is 0.6% although, as explained later, actual prevalence is likely higher (Hatton *et al.* 2016). Two separate studies estimated the prevalence of learning disabilities among prisoners at 7% (Mottram 2007; Murphy, Gardner and Freeman 2017b). Hence, despite the vague statistics, it can be concluded that people with learning disabilities and/or autism are likely over-represented in the CJS.

### *Disability Equality and Human Rights Issues*

The social model of disability makes a distinction between impairment and disability (Oliver, Sapey and Thomas 2012). Impairments are located at the individual level. The diagnostic descriptions of the labels ‘learning disabilities’ and ‘autism’ are presented in the previous section, and they describe how these impairments may affect individuals. However, impairments do

not have to become disabling. Disability only occurs when practices and environments are ill-equipped to respond to an individual's needs. For example, based on Oliver, Sapey and Thomas's (2012) distinction between disability and impairment, Hollomotz (2014) suggested the following distinction for people with learning disabilities seeking to access offending behaviour intervention programmes:

*Impairment*: Difficulties with literacy, with understanding complex words and abstract concepts and with applying learning from one setting to another;

*Disability*: Restricted learning opportunities, caused by information being provided in inaccessible formats, including the use of complex words and phrases, abstract concepts and a heavy reliance on printed text. (p.190, italics in original)

Disability can be overcome by designing interventions especially aimed at people with learning disabilities and/or autism, with their specific access and learning needs in mind.

In England, making such reasonable accommodations is a legal requirement. Here, we have a comprehensive equality and human rights framework. This includes international human rights instruments, such as the United Nations (2006) Convention on the Rights of Persons with Disabilities (CRPD), which promotes the human rights of disabled people. Moreover, the Equality Act 2010 prohibits unlawful discrimination on the basis of disability. This includes direct disability discrimination, which refers to 'less favourable treatment of a disabled person because of their disability compared with others who are not disabled', as well as indirect disability discrimination 'where a policy, practice or criterion is applied to everyone (or would be), but in fact puts (or would put) disabled people at a particular disadvantage when compared with others who are not disabled' (Equality and Human Rights Commission 2017, p.21). To prevent discrimination the Public Sector Equality Duty (Section 149 of the Equality Act 2010) requires that a public body is aware of equality issues when planning and enacting policy. With regards to disability, this means that they need to pay heed to the issue of reasonable adjustments (in Section 20).

In addition, under the Human Rights Act 1998:

it is unlawful for all public bodies and other bodies carrying out public functions as defined under the Act to act in a way that is incompatible with rights set out in the European Convention on Human Rights (ECHR). This obligation is both negative (that is, not to breach the rights) and in certain circumstances positive (that is, to take steps to guarantee the rights). (Equality and Human Rights Commission 2017, p.20)

The Human Rights Act 1998 includes the right to education (protocol 1, article 2), the right to a fair trial (article 6), freedom from torture and inhuman or degrading treatment (article 3), respect for private and family life, home and correspondence (article 8) and protection from discrimination in respect to these rights and freedoms (article 13). Identifying people with learning disabilities and/or autism in contact with the CJS is a first step towards complying with article 13. Without additional support this

population may have difficulties reading and understanding prison information and accessing the prison regime, including, as illustrated in the example that distinguished disability from impairment, offending behaviour programmes. In addition, a study by Talbot (2008) into the experiences of prisoners with learning disabilities and difficulties found that:

over half had been scared while in prison and slightly less than half said they had been bullied. None of the comparison group [without learning disabilities and/or autism] said they had been bullied. Prisoners were almost three times as likely as the comparison group to have clinically significant depression or anxiety. (p.vi)

They were also five times more likely to be subject to control and restraint and three times more likely to spend time in segregation, which contravenes article 3 of the Human Rights Act 1998. Once released without support to manage daily living, the likelihood for this group to be caught up in cycles of reoffending is high (Murphy *et al.* 2017a). In other words, this group requires assistance to achieve equal chances of success in community resettlement, which constitutes a positive obligation under article 8 of the Human Rights Act 1998 and links to article 19 in the CRPD, which covers living independently and being included in the community. In particular, article 19 states that disabled people should have access to a range of community support services, ‘to support living and inclusion in the community, and to prevent isolation or segregation from the community’.

#### *Additional Comorbidities and Risks*

The majority of people with learning disabilities who offend, especially those who committed sexual offences, have experienced significant adverse childhood events (Lindsay *et al.* 2010), which gives rise to the need for trauma-informed care. This ‘recognizes the role of adverse events in the development of high-risk behaviour and honours the subjective interpretation of trauma as a central component of the healing process’ (Levenson, Willis and Prescott 2016, p.353). Some people with learning disabilities and/or autism who have offended are diverted into forensic inpatient services. Here, Lunskey *et al.* (2011) found that compared with those without learning disabilities, people with learning disabilities exhibited more severe symptoms (including challenging and (self-)destructive behaviours) and fewer resources (such as personal social support). They were affected by additional disadvantages, resulting in increased risks, such as risks of exploitation or of becoming homeless. Doyle and de Villiers (2015) assert that although these risks ‘may not themselves constitute factors directly related to risk of re-offending they ... may act as barriers to successful interventions aimed at more clearly “criminogenic” risk factors’ (p.173).

In addition, alcohol or substance misuse problems affect roughly one-third of people with learning disabilities in prison or forensic inpatient care (Browning, Gray and Tomlins 2016; Chaplin *et al.* 2017). Although substance use appears similar in prisoners with and without learning disabilities, the former group are less likely to report this as an antecedent to their offences, if they are indeed able to make this link (McGillivray *et al.* 2016). Some people with learning disabilities and/or autism may have

additional difficulties with understanding dysfunctional behaviours and their consequences and services are ill-equipped to respond to these difficulties, as illustrated by their reduced completion rate of alcohol and drug treatment programmes when compared with non-disabled people (McGillivray *et al.* 2016). Williams, Kouimtsidis and Baldacchino (2018) also highlight higher risks of adverse health outcomes linked to problematic alcohol use. This may arise from systemic barriers in accessing health-care services and information (Emerson and Baines 2011; Walker *et al.* 2016). People with learning disabilities and/or autism also experience additional social consequences linked to substance and alcohol misuse, including exclusion from services (Williams, Kouimtsidis and Baldacchino 2018).

### *Improving Responses to People with Learning Disabilities and/or Autism*

Over a decade ago, Lord Bradley's (2009) review of people with mental health problems or learning disabilities (including autism) in the CJS outlined a range of recommendations. These include ensuring that the right support and services are available for people in contact with the CJS, provision of adequate community alternatives to prison, where appropriate, and improving care for people leaving prison; and progress has been made. Liaison and diversion services are now embedded across England. These seek to identify people with learning disabilities and/or autism when they first encounter the CJS (NHS England 2020). Evidence suggests improved health outcomes and a reduction of reoffending (Disley *et al.* 2016; Earl *et al.* 2017). Community Sentence Treatment Requirements provide alternatives to prison, and if eligible for, and consented to, use health services to address mental health, alcohol and drug issues (Department of Health and Social Care 2019).

Initially under the *Transforming Care* programme (NHS England 2017) and now as part of the NHS England (2019) *Long Term Plan*, efforts are being made to improve community services for those who display behaviours that challenge, including offending behaviours. Within prisons and probation, offending behaviour programmes written for people with learning disabilities are expanding (CSAAP 2020). The National Probation Service's (2019) *Health and Social Care Strategy 2019–2022* makes learning disability and autism priority areas. It aims to address health and social care related drivers of offending and commits to developing national toolkits for staff and to increase partnership working with local services.

Getting changes such as these off the ground takes time and the focus of this article is on further demonstrating the need for such change and that change is possible.

## **Methods**

The University of Leeds, the Prison Reform Trust and the National Autistic Society jointly organised a seminar in London in November 2018 to discuss solutions for improved support within health, social care and criminal justice for adults with learning disabilities and/or autism who have offended. This seminar was funded by the ESRC and it built on a similar seminar

held in May 2017, which has been summarised in a detailed briefing paper (Hollomotz and Talbot 2018). This article is guided by the written records from our second seminar. The Methods section considers sampling, the process of facilitating focused discussions, data processing and analysis.

### *Sampling*

Prior to the event we put considerable thought into framing and conceptualising what we aimed to get out of the day and how best to achieve this. Our aim was to encourage debates about effective and innovative solutions to help move practice forward. A purposive sampling strategy was key to achieving this aim. Delegates attended the event by ‘invitation only’. We aimed for maximum variation (Etikan, Musa and Alkassim 2016) by inviting representatives from across sectors, professions and regions of England. At the same time we employed a homogeneous sampling approach, which drew in candidates who shared similar traits (Etikan, Musa and Alkassim 2016), namely professionals with positive attitudes towards working with people with learning disabilities and/or autism, those who had a ‘can do’ mentality and who were in a position to make decisions.

The resultant group of 48 delegates consisted of eleven delegates from the criminal justice sector (prison, probation and police), nine from social care (public and third sector) and nine from health (learning disability nursing, psychology and psychiatry). Seven worked for advocacy organisations and four came from the legal sector (a solicitor, two prosecutors and a magistrate). In addition, we had Lord Bradley and two academics, including the first author of this article. Five members of the Working for Justice Group also attended. (Permission was given to use this affiliation and first names.) This group of people with learning disabilities and/or autism who have experienced involvement with the CJS has eleven active male members and one female member, who was unable to attend. To offset this, some of our practitioners discussed female service users. Of the five members who attended, two have autism and coexisting learning disability, and three have a learning disability. None have autism alone. None were from ethnic minority backgrounds. Hence, the findings in this article mostly reflect the experiences of white, (adult) men with learning disabilities or coexisting autism and learning disabilities.

### *Facilitating Focused Discussions*

The seminar was chaired by Lord Bradley, author of the Bradley (2009) report, who has spent many years advocating for the fair and humane treatment of people with learning disabilities and/or autism and those with mental health problems in the CJS. His presence and input as someone who had made change happen helped to frame the respectful, productive and solution-focused atmosphere which we were aiming for. The seminar was divided into two parts: first, the keynote panel of national leaders from health, criminal justice and social care reported on progress in their sector and their hopes for the future; second, the focus was on practice examples. There were 13 presentations of 10–15 minutes, as well as two structured

focus group discussions, which capitalised on communication between delegates in order to generate data (Kitzinger 1995). First, delegates deliberated ideas about the cause of the ‘problem’ and pet ideas about how to solve it. The second focus group concentrated on practice examples and personal experiences. To achieve a mix of backgrounds, delegates were allocated to five tables. Here, many delegates had roles (moderators, presenters of illustrative examples, note-takers) and were briefed ahead of the event and on the day, to ensure consistency.

In line with the principles of inclusive research (Walmsley and Johnson 2003) we sought to engage delegates with learning disabilities and/or autism in ways that were meaningful to them. Individuals were encouraged, with support, to prepare what they wanted to say in advance. In the role of presenters of illustrative examples four of the men were asked to speak for three to five minutes at the onset of focus group 2. (The one user who did not present at his table held the final speaker slot at the seminar.) After they spoke, the focus group asked questions about the personal history presented before discussing further illustrative examples offered by other participants. Moderators were briefed to encourage contributions by user delegates to mitigate against the risks of power imbalances. The five sets of table notes indicated that this was successful, as all featured substantive comments made by the users at focus groups 1 and 2. Moreover, the users named in this article have been supported to read, edit and elaborate on the points they raised by practitioners with whom they are familiar.

### *Data Processing and Analysis*

Despite our efforts for consistency some table notes were more detailed than others and some useful information may not have been recorded. To address this, the notes were sent to each corresponding table chair for checking. Some commentators were approached for further elaboration. The results feature some direct quotes from the table notes. Although these may already have paraphrased the original speaker, using these retains more authenticity than further paraphrasing would have done.

The written records from the event were imported into NVivo12. This includes table discussion notes, notes taken by the first author and one table note-taker during presentations and subsequent audience discussions, speaker’s power point slides, and a list of speaker’s ‘key messages’. (After the event each speaker was emailed to request their ‘key message’ in up to three sentences.) Next, a word cloud of the 40 most frequently used words across these written records was created, using a word frequency query of stemmed words of four letters or more. This means that, for instance, ‘police’ and ‘policing’ were combined into one word. These methods of data collection and intentions to use this information were made explicit on the day. At the same time the event adhered to the Chatham House (2020) Rule<sup>2</sup> to promote a free and frank exchange.

The data from the table notes and key messages were organised thematically in NVivo12. In line with the social model of disability (Oliver, Sapey and Thomas 2012) these themes focused on social and contextual



issues affecting individuals. Accounts of desistance were given much weight on the day and in writing up the findings. Maruna and Mann (2019) explain that such a focus can help to explore ‘individuals’ social contexts, embedded social networks and subjective interpretations as keys to understanding long-term life change’ (p.6). The first draft list of themes was influenced by the word frequency query. Thematic organising of the table notes and speaker’s ‘key messages’ resulted in 19 subthemes, including, for instance, education, autism awareness, housing, substance misuse and relationships. Further information from the presentations and subsequent audience discussion notes were included when it added to the existing themes. Finally, the subthemes were grouped into the four main themes that are reflected in the headings of the Findings section. The aim was to incorporate all table notes and ‘key messages’ in the Findings section. Only during the final stages of editing, to comply with the journal’s word limit and enhance flow, some notes were edited out, such as a discussion about preventing school exclusions. This is relevant, but it is not an offender intervention.

### Findings and Discussion

*Figure 1* presents a word cloud of the 40 most frequently used words across the written records of the event and as such it provides a snapshot of the findings and discussions to come. (Please refer to the Methods section for more detail.)

The bigger the words appear, the more often they were used, with the most frequent five words being people (179), need (158), services (157), support (155) and works (128). The five words with the lowest counts in the cloud were individuals (31), system (31), circles (30), living (28) and challenges (27). Terms like autism and the combined ‘learning disabilities’ should come as no surprise, given the subject matter of the event. The same goes for prison, probation, police, health and social care. Interestingly the words rights (33) and risks (34) received almost equal counts. Delegates were talking about support (155), with the word ‘punish’ receiving not a single count, even after the word frequency query in NVivo12 was raised to take account of single word occurrences. Instead, we used words like help (47), understanding (36), training (35) and sharing (32), which gives a flavour of the atmosphere of the seminar overall, as delegates discussed best ways for moving practice forward in partnership with users. We also discussed prevention. This is not included in the word cloud, as this word got only 21 mentions across the written records, but the qualitative data presented later on indicates that this was, nonetheless, a central theme. We discussed the importance of ongoing support, starting with more consistent screening (32) for both learning disabilities and autism and information sharing.

We heard many inspirational accounts, both directly from the five self-advocates and through practitioners. This article cannot present all. To give a flavour, one example is presented in *Box 1*. The key points raised by Graham’s case are discussed at relevant points throughout this article,



**Question:** *What got you to the point of being able to commit to running a group?*

**Graham:** A passion for helping in any small way that I can help. Sharing that common interest and pushing that forward. Peer support. It helped me, so I thought it would help others.

**Question:** *What was it that enabled a change?*

**Professional from KeyRing:** Graham was able to see a way out and so was motivated.

**Graham:** I didn't want to become that person that was always struggling, I'd had enough of muddling through, I wanted something good to happen. The choice came a few years into my support from KeyRing when I realised, I wanted my life to get better.

**Support worker:** A non-judgemental unconditionally positive model of someone sticking by you.

**Question:** *How to get a team who face verbal abuse etc to keep coming back?*

**Graham:** If you believe that someone can change, you need to stick with them until the end, whatever happens, until you see that change.

**Professional from KeyRing:** At KeyRing we had an exceptional team manager who was supportive, gave the team vision and was always available – this made the difference.

The findings are loosely organised to follow a 'journey' through the system: Prevention is followed by considerations about inclusive service design. Next, information sharing and consistency are discussed. Finally, key relationships and community support are discussed.

### *Prevention*

The term 'prevention' can refer to relapse prevention, which means preventing individuals from reoffending (for example, Keeling and Rose 2005). By 'reoffending', this article means to relapse back into behaviours similar to those for which a person had previously been in contact with criminal justice or other services. In addition, prevention can start much further upstream. The equality and human rights framework described earlier promotes equal opportunities. To achieve this within the education system, young people with learning disabilities and/or autism need to be identified and offered additional support. The relevance here is that a lack of educational attainments has been linked to social exclusion, which in turn has, in some instances, been linked to the development of problematic behaviours (Wheeler, Clare and Holland 2014).

Moving on into adulthood we know that in England the proportion of the population known to have learning disabilities drops from 2.5% among children and young people to 0.6% among adults aged 20–29 years (Hatton *et al.* 2016). Emerson and Glover (2012) claim that this highlights the existence of a 'hidden majority' of adults with learning disabilities. A senior representative from social care commented at our event: 'We give them no support in early adulthood and then are surprised when they show risky behaviour which sometimes ends up in them hurting themselves or other people'. Our delegates believed early identification, retention of

knowledge about a person as they transition from child to adult services and subsequent better support in early adulthood are pivotal. Guidance by Public Health England (2019) on collaborative approaches to preventing (re)offending in children aims to support just that. One delegate suggested that we should learn from people who were not known to adult services before encountering the CJS. Individuals and their families could advise what help could have prevented the offence.

Delegates provided a variety of examples of service gaps for people with autism who do not have learning disabilities. These gaps link to prevention, as without autism specific guidance, some people with autism are at risk of developing problematic behaviours. For example, a psychologist explained:

We get lots of panicky calls from the police and local authorities, typically about young men 16 to 17 years old, who have autism and have developed raving anxiety in tandem with their sexual development. There follows a long, detailed assessment but no offer of family therapy, meaningful employment, specialist education and/or help to integrate into society.

The second point links to an absence of appropriate interventions once problematic behaviours have been detected. The first point links to a lack of adequate information about sex and sexuality as a method to prevent problematic behaviours. Delegates emphasised the importance of appropriate information. For instance, an advocacy worker stated:

An autistic child may not make the link about how you get from forming romantic relationships to having sex and may well be behind their peers in experience of even friendships. So, unless completed in a specific way for autistic children, sex education may still not address risk issues.

A solicitor commented that common offences by people with autism he sees are cybercrimes, harassment and possessing indecent images of children. Mostly, family carers are not aware that these offences are happening and those committing the offences are isolated.

Department for Education (2020) guidance on sex education provides limited insights into how considerations about inclusive design should shape delivery. Thus, solutions have to be found in the specialist literature. For example, Asagba, Burns and Doswell (2019) explain that educators should avoid abstract and jargon language, use concrete examples of abstract ideas and be flexible in adapting existing published resources. Grove *et al.* (2018, p.315) discuss how curriculum and materials can be modified through the use of technology. Evidence further suggests that involving family carers in sex education can improve outcomes for young people with learning disabilities and/or autism (Asagba, Burns and Doswell 2019; Rooks-Ellis *et al.* 2020), while the use of peer educators has been received positively by adults (Frawley and O’Shea 2020).

### *Building Inclusive Services*

The National Autistic Society (2017) highlights that professional expertise and services are not always available for autistic patients in specialist



FIGURE 2  
*Holding Room*

learning disability services. In addition, a service gap remains for autistic people without learning disabilities. An advocacy worker asserts that learning disabilities professionals working in prisons and forensic services generally do not feel they have the skills or experience to work with this group. Hence, disability awareness training was welcomed across sectors. However, availability of training is not enough. It also needs to be of a quality that can make a difference and staff need to be able to access it. One study in a specialist learning disability hospital reported that staff lacked an understanding of autism, even after compulsory autism training (Chan *et al.* 2017). Some delegates reported that being released to attend training is challenging for wing- or ward-based staff who need to find cover for their shift. A self-advocate further adds that ‘training does not always shift entrenched “old school” attitudes’. One table discussed that training that involves users as educators can potentially have more impact. An external evaluation of such training provided by KeyRing found that ‘participants stated that their personal attitude towards people with learning disabilities had significantly changed for the better’ and training had increased their confidence in communicating with them directly about their needs (Burleigh and Vaughan 2018, p.22).

In addition to training, services need to be designed to meet the needs of people with learning disabilities and/or autism. Chief superintendent Jonathan Betts understands that the Public Sector Equality Duty encourages such a change in organisational culture. Betts helped to ensure that police processes, procedures and environments in Cheshire do not have a disproportionately unsettling effect on autistic suspects. To do this he ‘walked’ the experience of being brought into custody through the eyes of an autistic person. This led to several changes. For instance, the signpost ‘holding room’ (see *Figure 2*), might frighten a person who thinks in literal terms and does not like touch. This room has since been renamed ‘secure

waiting area'. This inexpensive example of a disabling barrier being removed has significant potential to reduce anxiety.

### *Information Sharing and Consistency*

Across the CJS – police, courts, prison and probation – there remains work to be done to ensure that people with learning disabilities and/or autism are routinely identified, and adequately supported (HM Inspectorate of Probation Criminal Justice Joint Inspection 2014, 2015; Talbot 2008). A probation officer reported that in her region three-quarters of those attending treatment programmes aimed at men with learning disability and/or learning challenges who have sexually offended have no diagnosis and no service involvement. Danny pointed out that people with learning disabilities and/or autism who are aware of their condition do not always want to disclose. Even once a person's support needs become known, our professional and user delegates explained that they are often unsure of whom to turn to for support.

At the time of the event there was no routine screening upon reception into prison. However, from April 2019 prisoners are screened for learning difficulties and/or disabilities on first reception into the educational services of all adult prisons across England (Ministry of Justice 2019b; Wakeling and Ramsay 2019). Prison and probation use IQ below 70 as the benchmark for 'learning disabilities'. They label those with IQ between 70 and 80 as having 'borderline intellectual functioning'. These groups are described as having 'learning disability and/or learning challenges' and they are entitled to additional support (Ramsay *et al.* 2020). This does, however, not include autism. Graham describes his autism diagnosis as a turning point, and this was reinforced by the other delegate with autism.

Delegates were concerned that once they leave prison and probation many people with 'learning disability and/or learning challenges' lose their entitlement under the more stringent criteria used by health and especially social care. Many people with autism and increasingly some individuals with learning disabilities tend to be excluded from community services, which have been affected by austerity measures over the last decade (Malli *et al.* 2018). For instance, between 2010–11 and 2017–18 local authorities in England lost about half of their government funding (National Audit Office 2018), but how this has been applied differs across authorities.

Furthermore, retaining knowledge about people's needs as they travel through the system is essential. One note-taker summarised a user's thoughts as follows:

A person should tell their story once and agree whether and how that will be shared with others (and why). Information should be shared along the justice pathway (police, liaison and diversion, court, probation, prison). Even better, one person should walk with the individual along this pathway.

Similar suggestions were made at our first event. We summarised this as a key person 'holding the story' (Hollomotz and Talbot 2018, p.21). However, the then new General Data Protection Regulation (European

Commission 2020) made delegates nervous about information sharing. In addition, they commented that knowledge is not routinely retained by courts. A solicitor was concerned that ‘too many times you start a case with an individual with complex needs and they have four or five judges’. One of the speakers presented the case of a woman who displayed destructive behaviours, which in the past led to frequent arrests and time spent in prison and hospitals. The complexity of these behaviours required a joint working approach between family, social care and community learning disability teams, police, ambulance, fire, probation and alcohol services, A&E liaison, the lawyer, the local MP and the courts. One judge understood the difficulties that inconsistencies in court responses caused. Since then, almost without exception, this is the only judge who deals with this woman. Essentially this means she has a ‘personalised’ judge. This contributes to a more consistent response to her behaviours, which have become less frequent and less severe. However, this solution is an informal arrangement. Hence, it is not offered more broadly to others who could benefit.

The updated quality standards of the National Institute of Health and Care Excellence (NICE 2019) on *Learning Disability: Behaviour that Challenges* includes the following quality statements: ‘Local authorities and clinical commissioning groups [will] jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability’. In addition, ‘people with a learning disability and behaviour that challenges [should] have a named lead practitioner’. Some delegates forecasted developments that may potentially help with information sharing. The NHS England (2019, p.52) Long Term Plan commits that ‘by 2023/24, a “digital flag” in the patient record will ensure staff know a patient has a learning disability or autism’. Following piloting this became available for wider use at the end of 2020 (NHS Digital 2020). The plan includes a move towards integrated care records across GPs, hospitals, community services and social care. However, the rise of electronic databases and flags used by different agencies increases risks around algorithmic bias and algorithmic discrimination (Obermeyer *et al.* 2019), which is why the lead practitioner ‘holding the story’ remains crucial. This practitioner could be one formal key relation for the individual when moving into the community.

#### *Key Relationships and Support upon Community Resettlement*

Box 2 shows quotes taken from Derek’s presentation. He co-presented with the director from his social care organisation. Derek speaks in detail about factors that enabled his resettlement, including being involved in discharge planning, key relationships, feeling secure and staff consistency.

**Box 2:** *The Journey to my Front Door*

**Derek:** I got into trouble when I was younger. I was sent by the court to hospital. I spent about 18 years in various secure hospitals. In high, medium and low secure services. I was discharged once, but it all went wrong, and I had to go back.

**The move: What helped?**

**Derek:** Having regular meetings around my discharge and being involved.

**Director of Derek's social care organisation:** Really involved. There was some real joint working going on. Not just people turning up for meetings.

**Derek:** Bridging work with the new service I was going to. Develop trust.

**Director:** The bridging and development was over a long period, this helped both of us start to develop trust and understanding.

**Derek:** This was done in a professional way and not in the way it was done last time I was discharged.

**Director:** I think it was important for Derek that he felt safe and looked after.

**My own front door. What helps?**

**Derek:** To me a good service keeps people such as managers and key staff for the long term, not constant change and people leaving. I need staff that respect me and treat me fairly. Staff who understand me and my needs and can help me when I am struggling.

At both events, professionals from across sectors emphasised that finding and securing housing upon discharge from hospital or release from prison was a major challenge. Derek's social care organisation arranged housing for him. Likewise, Graham and Danny received hands-on support by KeyRing. For instance, Danny was supported to complete housing application forms and to apply for the correct benefits. Danny thinks that without this help, he would have ended up back in prison.

To enable successful community resettlement, individuals need to establish positive social support networks. However, an advocacy worker shared that often community services do not want those who have committed offences, as they are worried about risk. In their lieu probation can offer structure and social contact for people. 'This is often the only social contact available and there is an associated risk that once the order ends, the person may well reoffend to get access to social contact again'. Moreover, disabled people are disproportionately excluded from paid employment (for example, McMahon, Bowring and Hatton 2019). Graham's volunteering work, leading a Lego group and offering peer support, is an example of a creative solution for establishing meaningful social roles beyond the restraints of paid employment and existing provisions.

Giving and receiving peer support was hailed as invaluable by all user representatives. As members of the Working for Justice Group they have given feedback on their experience of the CJS, supported the Bradley



(2009) report and been involved in several prolific projects, delivered awareness training and had their say at the House of Lords and the House of Commons (KeyRing 2020). Danny explains that the Working for Justice Group helped him to speak for himself to people in authority. He is proud that the group has had an impact on raising the importance of using more accessible versions of information and easy read within the CJS. Beyond this, Ian describes his support network in *Box 3*.

**Box 3:** *Ian's Support Network*

Ian is supported by Choice Support twice a week to keep his flat tidy, budget and manage his bills. He now feels more confident doing his own shopping, cooking and washing. With support he has been able to live independently for nearly ten years, having lived with his parents until he was 40 years old. During this time, he had several support workers, but he prefers continuity. Once every five weeks the Community Learning Disability Team help with wider issues; and Ian attends a peer support group aimed at recognising factors that can lead to offending. With all this support Ian has improved his ability to develop and maintain relationships, developed his social skills and become better able to manage his anxiety when things get difficult. This help in developing his independence, alongside finding a job that he enjoys and that suits him has enabled him to stay in the same job for 15 years and prevented further involvement with the CJS.

Two speakers at our event introduced Circles of Support and Accountability (COSA), which involve using community volunteers to support people who have committed sexual offences to safely reintegrate back into the community. The objective is that the volunteers become a social network who introduce their core member to various community-based activities (Wilson *et al.* 2007). For further information, please refer to the case study that was included in the briefing paper that summarised our first event (Hollomotz and Talbot 2018, p.21, box 5.5c). The idea of community mapping was also discussed at the second event: We heard about the liaison and diversion service in one area using its community link workers to find out about services, supports and amenities in the area.

A representative from social care reflected at our event: 'The diverse range of people in the room is illustrative of the need for integrated approaches'. This was illuminated by Graham's account (*Box 1*), who required a response to needs arising from learning disabilities, autism, mental health, alcohol misuse and offending behaviour. One delegate noted that 'just a couple of key relationships can have a massive impact on recovery journeys'. This includes the above discussed informal social networks and peer support, but also relationships with professionals. Derek emphasised that staff need to be respectful, but also understand his risks and support needs. In *Box 1* Graham mentioned that it was his alcohol worker who made the difference. Looking back, he values that she believed in his ability

to change, even when he did not. Graham also explained that his support team, despite facing ‘verbal abuse etc.’ did not give up on him.

Once these services are successfully set up, one representative from the CJS was concerned that services discharge people who are seen to ‘be doing well’. However, remaining incident-free is often reliant on having the right services in place that provide structure, safety and boundaries. One advocacy worker commented that ‘a well-managed need is still a need’. The positive case histories we heard on the day had in common that individuals received ongoing hands-on support. For example, Danny stated that what had made a difference in his resettlement were help with budgeting, bills and looking after himself.

### **Conclusion**

Behaviour change at the individual level is imperative for preventing future offending and there is an abundance of literature that explores how this can be supported, including many excellent articles in this journal. What this article adds is an exclusive focus on how professional practice can be optimised, as well as on how disabling barriers can be removed or overcome when people with learning disabilities and/or autism access services within the CJS and forensic health system. This is summed up well in one user’s key message: ‘People with disabilities can *do* things with support’. Designing solutions is not an easy task with quick fixes. This article demonstrates that there are often many complex issues affecting people with learning disabilities and/or autism and it rationalises why solutions need to be carefully planned around individual’s needs.

As we had the aims of outlining enabling practices and environments in mind from the point of project conception we were highly selective in our choice of delegates and brought together users, professionals and practitioners from health, social care and criminal justice who had a reputation for being committed towards pursuing the disability equality agenda and for making change happen. We also thought carefully about the focus of discussions and invited presentations and briefed speakers and facilitators accordingly. The fact that this was successful was reflected in *Figure 1* and its related discussion and is further summarised in the feedback below:

I found the whole day energising, including all presentations and table discussions. Sometimes it feels like we are trying to climb (and re-climb!) a mountain, just to embed respect and humanity in our work with this marginalised group, but seeing, hearing and feeling the will in the room was really uplifting! (senior representative from criminal justice)

Data processing, analysis and writing up of the findings were driven by the social model of disability, which acted as a lens that helped to prioritise what data to include and how to analyse and relate this to the existing literature. For instance, approaching the likely over-representation of people with learning disabilities and/or autism in the CJS through the social model of disability gives rise to several observations: first, needs not being identified and met early on in life can be linked to some people with

learning disabilities and/or autism slipping onto a destructive path. Once they come into contact with the CJS some individuals' needs continue to go unrecognised, which may cause them to struggle to engage. This links to some spending longer within the system, when compared with non-disabled people. Finally, lack of community support links to increased risks of relapse. Over-representation is therefore a public issue of social structures (Mills 1959), which requires structural change. The findings included many examples of innovative practices for eradicating or overcoming disabling barriers, which have been evidenced to work in the cases presented. These lead us to make ten recommendations for practice.

### *Recommendations for Policy and Practice*

1. **Person-centred working:** The user should be at the centre of decision making when designing services. This means genuine involvement, not just tokenistic presence in the room where decisions are made.
2. **Inclusive service design:** Public services can and must be designed with everyone's needs in mind. Chief superintendent Jonathan Betts advises: 'Do what you can to understand your users' experience of your service. Walk their journey and ask yourself if it's meeting their needs. If it's not, do something about it'.
3. People with learning disabilities and/or autism are likely over-represented in the CJS where they suffer additional disadvantages unless their needs are identified and responded to. To enable reasonable adjustments to be made, **screening** for learning disabilities and/or autism should happen upon first contact with the CJS.
4. Many people with learning disabilities and/or autism may not have a formal diagnosis, but they still need support. **Services should be flexible in equating support to needs rather than to a diagnosis.**
5. **Specialist autism services** are needed to meet the unique needs of people with autism and those with co-occurring autism and learning disabilities.
6. People with learning disabilities and/or autism are three distinct groups. Within these groups, individuals are often affected by multiple disadvantages, including childhood trauma, poverty, poor physical and mental health and substance misuse. They may also have specific needs relating to, for example, gender, sexuality and race. They thus require a **multi-agency response.**
7. **Information sharing** is essential across sectors and in transitions (for example, from child to adult services, from hospital to the community). This is best done through a lead practitioner 'holding the story'.
8. We need to support individuals to develop sustainable **key relationships.** These are known agents for change, impacting positively on recovery journeys and include informal social networks, peer support and relationships with professionals.
9. Upon release from prison or discharge from hospital many people with learning disabilities and/or autism require **sustained support with community living,** including practical help (for example, with filling

out housing applications), social care support (for example, help with paying bills, personal hygiene) and continued treatment for any mental health or substance misuse difficulties. Such support should not be time limited to a specific date but based on progress made and ongoing support needs.

10. **Joint training** was recommended in the Bradley (2009) report and the positive feedback at our event further indicates that shared thinking about what works and pooling ideas where challenges exist is welcomed. Delegates requested more events like the one described in this article, which should include:
  - a. **regional** events to allow professionals to build up local networks; and
  - b. ones that **focus on specific groups**, such as women or ethnic minority populations.

### *Final Reflections in the Context of a Global Pandemic*

Despite unprecedented time and resource constraints, public services continue to be obliged to meet the public sector equality duty. Concerns about a fair and just criminal justice and forensic health system, as well as about effective interventions remain applicable at the time of a global pandemic and beyond. However, in the Foreword, Lord Bradley pointed out that some of the practices described in this article have been disrupted or are now, as Lord Bradley put it, considered a 'luxury'. In this context the above ten key recommendations can help to focus the reader's attention on some effective solutions that are worthwhile investing in. This investment will save money. Reoffending costs the UK taxpayer £18.1 billion annually (Ministry of Justice 2019a) and it is therefore of public interest to reduce this cost whatever times we may find ourselves in.<sup>3</sup>

### **Notes**

- 1 WHO uses the term 'intellectual disability', while this article uses 'learning disabilities', as this was the preferred term used by most delegates.
- 2 This means that the author is 'free to use the information received, but neither the identity nor the affiliation of the speaker(s) may be revealed', unless permission is given.
- 3 *Acknowledgements*: We would like to thank Danny, Derek, Ian, Graham and Wayne from the Working for Justice Group for sharing their personal histories and all the hard work they are doing to support peers. Special thanks to Lord Bradley for his support, especially for chairing the event and his thoughtful closing words at the event and Foreword in this article. Thanks to Jenny's colleagues from the Prison Reform Trust, without whose support the event would not have happened. We are equally grateful to Clare Hughes from the National Autistic Society for help with organising the event and feedback on the draft, to Tracy Hammond, Hugh Asher and John Hutchinson for checking the draft with the men who shared their histories and helping them to add more detail. Thanks to Alison Giraud-Saunders, Tracy Hammond, Kerensa Hocken, Salma Ali and Mark Priestley for feedback on draft versions of this article, and finally, thanks to all the participants for their contributions, especially to the table chairs and note-takers. This research was funded by the ESRC (grant ref. ES/L010534/1).

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