Advances in Mental Health and Intellectual Disabilities

Number 1
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ISBN 978-1-78973-879-7
www.emeraldinsight.com/loi/amhid
Transforming care in England

When the National Health Service in the UK was set up in 1948, the colonies or institutions which were built originally in the nineteenth century to segregate people with learning disabilities from the rest of society, became “hospitals” in which people were “nursed” and their problems defined in medical terms. We now know how damaging institutional life was for many people. Because of their size, location and regimented routines, institutional services made people dependent, powerless and lacking in choice, privacy or social networks. They were often treated inhumanely, and sometimes with deliberate cruelty or abuse (Sperlinger, 1997). Although since the 1980s many long-stay institutions have closed with a move to new community service provision, many of the attitudes and behaviours and some practices remain as legacies of the past.

Much has advanced in public health, in the management and prevention of infectious diseases, in the delivery of antenatal, prenatal and postnatal care. Premature and low birth weight babies have a significantly higher survival rate, and society now cares for children with multiple disabilities and complex needs. The average life expectancy for an adult with learning disabilities has also risen although we know they die on average 13–20 years earlier than someone without learning disabilities, often from causes that are preventable and avoidable. “Transforming Care” is a three-year NHS England funded programme (2016–2019), in response to the perceived slow pace of change following the exposé of abusive practices at a non-NHS assessment and treatment unit (Winterbourne View) for people with learning disabilities and/or autism. “A hospital is not a home”. At the heart of the Transforming Care Programme is co-production, giving people with learning disabilities (and those with autism) and their families a voice that is listened to, addressing health inequalities through a rights-based approach and building capacity and person-centred support in the community to reduce reliance on inappropriate inpatient provision.

This special issue is a collection of papers, written by clinicians, practitioners, commissioners and others who are working at a national level, alongside experts by experience and family carers, to transform care. It may not be of the same style as previous issues, but it captures the uniqueness of our journal, with its original focus on translating policy into practice and sharing practice-based evidence. NHS England uses the term “learning disabilities” rather than “intellectual disabilities”, so we have allowed for this terminology to be interchangeable in this special issue. Whaley and colleagues remind us that the words we choose to use can either oppress and diminish or empower and humanise. They present a framework for looking at the power of, and around, people with learning disabilities who have mental health issues or display behaviour that can challenge services. Sanderson, in his paper, describes the potential a personalised approach and personal health budgets could have in promoting choice and control over one’s care. He argues they can not only improve health and care outcomes but reduce the total spend across the system.

In October NHS England (2015) published a new national service model (Building the Right Support) and signalled its intention to close the last remaining free-standing learning disability hospital in the country. Turner’s case study in this special issue comes from the North East of the country and illustrates the culture change and local leadership required to make things happen: how every aspect of the jigsaw can come together if we work in partnership, as one team, to create the conditions within which the person can be discharged from a mental health or specialist learning disability hospital, and supported to have and live an ordinary life in the community.
There is understandable anxiety given the current financial austerity and particularly the funding challenges in social care. It is precisely at such times that we need to innovate, hear what people with learning disabilities and their families want, and make the best use of the resources we have in a creative way that achieves meaningful outcomes and healthier lives.

Public Health England’s analysis show 17 per cent of adults with learning disabilities known to primary care services and living in the community, will be receiving antipsychotic medication, and this compares to less than 1 per cent of the population without learning disabilities. This is a shocking statistic and an issue known about for decades. Two papers by Branford and colleagues on Stop Overmedicating People gives us the background and implementation of a national call to action. It is an approach that has galvanised people with learning disabilities, family carers and voluntary organisations as well as healthcare professionals and researchers. Whether this will result in a meaningful reduction in use or better-informed reviews, or improvements in quality of life and patient safety, remains to be evaluated.

The NHS marked its 70th birthday in June 2018, and it was important we celebrated its many successes and the incredible achievements in public health, basic sciences, neuro-imaging and translational research. It was a time to reiterate its universality and commitment to free healthcare at the point of need. It is also right we recognise the experiences of the past, health inequalities, the legacy of institutions and “forgotten lives”. Deb’s review of Professor Nick Bouras’ memoirs (a psychiatrist’s chronicle from deinstitutionalisation to community care) charts the dramatic changes that have occurred in our recent past; the clinical developments, research challenges, successes and frustrations working within systems that may not at times even have a shared vision. Our challenge now is to shift the balance of power from hospital to community, from clinician to patient, from executive boards to front-line staff and from engagement to co-production. But it is not just a health issue. We have a long way to go as a society if we are to truly support people with learning disabilities to have a life rather than a service. Ultimately that is what Transforming Care is all about.


References


Further reading


About the Editor

Dr Jean O’Hara is Chair of the editorial board, Consultant Psychiatrist and National Clinical Director for learning disabilities in NHS England. Dr Jean O’Hara can be contacted at: Jean.O’Hara@kcl.ac.uk
Shifting the balance of power

Jo Whaley, Di Domenico and Jane Alltimes

Abstract

Purpose – This purpose of this paper is to examine the role of engagement and empowerment in “Transforming Care”, for people with a learning disability. The aim is to shift the balance of power so that people are able to live ordinary lives in the community, in the home they choose, close to people they love. It shares ideas to support people to take control over their own lives and to influence the system, so that it works with people, rather than “doing to” people.

Design/methodology/approach – The paper examines barriers and enablers to people having their rights as citizens. So that people have as much choice and control as they are comfortable with to live an ordinary life (bearing in mind any legal restrictions). The paper includes people’s involvement in system/service redesign. It critiques traditional views of looking at language, participation and power. The authors have used the language throughout which people have told us they prefer as a descriptor.

Findings – The authors present a framework for looking at the power of, and around, people with a learning disability who have mental health issues or have displayed behaviour that can challenge services.

Originality/value – This paper offers advice on how to address power imbalances at individual level and at organisational/system level. It looks at the language we use, the information we share and how we work with experts by experience to ensure we can transform care and support and enable people to live ordinary lives as citizens.

Keywords Human rights, Language, Empowerment, Social model, Coproduction, Citizens

Paper type Viewpoint

Introduction

People with a learning disability experience considerable health inequalities, much of which is avoidable. On average, in England, women with a learning disability die 20 years before the general population, and men 13 years (Heslop et al., 2013). Health inequalities are caused by discrimination, poorer employment prospects and poorer health care (Marmot, 2010). There is also a history of mistreatment of people with a learning disability within the National Health Service (NHS) leading to early death (Mencap, 2007; Department of Health (DH), 2012; Heslop et al., 2013). In tragic service failures, such as Winterbourne View (DH, 2012) and Southern Health, people with a learning disability needed to be treated as equal human beings and be at the centre of their own lives. Services needed to listen to people and their families. Service providers and commissioners needed to act on what people told them (Association of Chief Executives of Voluntary Organisations, 2014; Mazars, 2015). People with a learning disability and their families needed to be supported to take power and to be listened to.

Building the right support—choice and control

Building the right support (National Health Service England (NHSE), 2015a) and the “national service model” (National Health Service England (NHSE), 2015b) show what needs to change to enable people with a learning disability to take more control over their own care and support and to ensure that their rights are protected. To have more choice.

Both of these documents were built on the social model of disability. This recognises people’s “impairments” or “differences” but highlights that it is how society is organised which causes “disability” and inequality (Scope, 2017). This is a human rights issue (Morris, 2001). In contrast,
medical model “looks at what is ‘wrong’ with the person. It creates low expectations and leads to people losing independence, choice and control in their own lives” (Scope, 2017). Simply, the social model says that what disables people is their environment; improve the environment and people are not disabled.

A key theme of building the right support and the “national service model” is the idea of person-centred approaches. That is to put the individual at the centre of their own care and support arrangements. This recognises that individuals are the experts in their own lives and have their own ideas about how they want to be supported and how they want to live their lives. This links very strongly to the idea of coproduction. At an individual level this means, people being actively involved in the design of their own support. At organisational/system level coproduction is about people working together as equals, so that people work with health and social care professionals, service providers and commissioners, to shape service design in each area (Local Government Association, 2017a).

Fundamentally, empowerment and coproduction are about a shift in power away from the professional gift model (Duffy, 2009) and towards choice, control and citizenship. However, we know that lots of people who end up in long-stay institutions have no power or control over their lives (Local Government Association, 2017b).

Human rights and disability

The Equality and Human Rights Commission define human rights as the “basic rights and freedoms that belong to every person in the world, from birth to death” (Equality and Human Rights Commission, 2018). In the UK these are protected by law (United Kingdom Human Rights Act, 1998) and apply equally to people who have impairment. They protect people’s rights to be equal citizens. In contrast, the NHS tends to medicalise disabled people, focussing on individual problems, in attempt to “normalise” people (French, 2001). This means that professionals often take a deficit approach to working with disabled people, looking at what people cannot do rather than taking an asset-based approach focussing on skills, resources and knowledge (Mansell and Beadle-Brown, 2004; Foot and Hopkins, 2010) and on people’s aspirations. There is a growing movement towards person-centred approaches to support and away from medicalised, institutional approaches (Salman, 2016). This is both within the NHS (NHSE, 2015b) and in communities (Mansell and Beadle-Brown, 2004).

People with a learning disability

Within, and in parallel to, the mainstream disability rights movement, people with a learning disability have challenged oppression and demanded inclusion (Dybwad and Bersani, 1996, pp. 3-5; Gilbert, 2004). The development of the self-advocacy movement has increased the influence of people with a learning disability on policy (Goodley, 2005). Over recent years policy-makers have involved people with a learning disability (Department of Health, 2001, 2010). However, instead of being treated as experts in their own lives (“experts by experience”), people with a learning disability are often faced with negative assumptions about their capacity to participate (Hoole and Morgan, 2011).

Factors which prevent participation in policymaking include: tokenism, not listening, stigma, self-confidence, organisational culture, and lack of information about involvement (Beresford, 2013). Systemic and impairment effects may be compounded by other marginalising factors such as poverty (Hallet, 1987, p. 3), language, rurality, services being unable to accommodate different behaviour, and exclusion of children and young people (Barber, 2009). The links that people have with others (their “social capital” (Putnam, 2000, p. 9)) is another factor that impacts on the participation of disabled people in civic life. For example, people with a learning disability are more likely to get involved in politics if they live with someone who is politically active (Keeley et al., 2008) and are more likely to voice opinions in focus groups if they are involved in self-advocacy groups (Hoole and Morgan, 2011).

Many practical adjustments can be made to participation activities to make them accessible and meaningful to disabled people (Young and Chesson, 2006; Dunn et al., 2006; Jingree et al., 2006;
Language

The power of words and language is well documented. Its impact is succinctly paraphrased by Orwell (1946), “if thought corrupts language, language can also corrupt thought”. Morris (2001) also notes that “to pay attention to the words we use is not to be ‘politically correct’ but to struggle for a language which describes the denial of our human rights, locates our experience of inequality as a civil rights issue”. However, within health and social care, and especially for people with a learning disability, this is much less researched and much more powerful than we have given credit so far.

The words we use carry great weight and can either oppress or empower and humanise. The user-led organisation, People First, demonstrate a good understanding of the power of language and their name is derived from the idea that individuals are people first, not a label. Using the prefix of “people with” or “someone who has” rather than a label or acronym encourages people to humanise their language. For example, the difference between “she is Downs” and “she has Down’s Syndrome”. Snow (2010) also talks about “people first language” which “puts the person before the disability”, noting that “if people are to be included in all aspects of society” then we should stop using language that “marginalizes and sets them apart”. Snow (2010) highlights that “history tells us that the first way to devalue a person is through language”.

Within many organisations there are many acronyms and shorthand language that marks out the “club”, for example, medical jargon. This may simply make it easier for people to communicate but for those outside the “club” it can be alienating and de-humanising. The use of shorthand such as LD, instead of learning disability or learning difficulty is a good example of a much used term that effectively depersonalises. Surely we cannot depersonalise anyone any further than when initials are used to describe someone? Self-advocates have set a challenge to professionals not to use “LD” as a descriptor (Darlington Learning Impairment Network, 2017). They maintain that the use of depersonalised language like “LD” effectively dehumanises an individual. It contributes to a culture which allows behaviour like that seen at Winterbourne View hospital to happen. Furthermore, there is language used for people with a learning disability that is paternalistic and patronising and not used in “ordinary” life. For example, “cohorts of people with LD living in a setting or a unit, all with a behaviour management plan and a risk assessment”. This is the language of “service land”.

A simple shift in the use of language can result in different outcomes. For example, instead of asking “what’s the matter with you” asking “what’s important to you” opens up the real opportunity to view people as individuals with hopes and aspirations. It enables people to work together to reach an individual solution rather than dealing with a problem that needs to be “placed” somewhere “safe”. In addition, people who need support, have been called “patients”, “clients”, “customers” and “service users”. However, by calling people “service users” we are again drawing people into “service land” and dependency, rather than supporting access to universal services and developing individual social connections—friends and acquaintances. If key components of building the right support (NHSE, 2015a) are coproduction and individual solutions, it may well be that people will not be “service users” but equal partners and experts, commissioning their own support with personal budgets (Sanderson, 2018). A similar argument can also be made in relation to the use of the words support and care. Care can imply a level of passivity, whereas support is more active. The language of personalisation therefore should have a greater focus on how people are supported to live their lives. Self-advocates have also raised the use of the term “vulnerable” as a descriptor. Describing someone as “vulnerable” immediately puts an individual in a negative position. All of us are vulnerable in certain circumstances; however, we are generally not defined by that vulnerability.

Language within the NHS, local authorities and other organisations relies heavily on abbreviation and jargon. It has become embedded within our primarily medical culture. If a key element of
transformation is a shift in the culture within the health and social care environment and the wider community then a core element of that cultural change needs to be the words we use to ensure that they do not oppress or de-humanise.

**Participation and coproduction**

All citizens have a right to take part in society and in decisions affecting their lives (Institute of Development Studies, n.d.). However, participation is often restricted to higher socio-economic status groups (Hallet, 1987, p. 3) and groups already well represented in society (Barber, 2009). Particular groups of citizens, including disabled people, have been excluded from taking part as active citizens and from shaping public services. If people are to contribute to decisions which impact on their lives, policy-makers must share power (Verba, 1995, cited by Bliss and Neumann, 2008) and work to overcome barriers to participation. However, this is not always the case and policy-makers make tokenistic gestures towards participation, without wanting to share power or overcome barriers (Cockburn, 2005; Branfield and Beresford, 2006). Arnstein’s (1969) seminal work about participation describes the tensions between government and citizens whereby governments hold the power, and can choose whether or not to share power. Power-sharing can be seen as a “ladder” (Figure 1) from...
no power-sharing, through information sharing and consultation. It culminates with coproduction (partnership or working as equals (Roberts et al., 2012)) and full delegation of powers. However, portraying participation as a ladder lacks nuance as it is not simply a continuum (Cook, 2012). Not all participation benefits from being higher up the ladder (Titter and McCallum, 2006) and not everyone will want to participate in all types of opportunities to influence. Coproduction therefore is not always easy, sometimes described as “messy”. It takes commitment to make sure people can work together, and learning as you go.

**Shifting power**

It is useful to be aware of different types of power in order to be able to shift the balance of that power. Raven (1965, pp. 371-82) described six types of power: expert; legitimate; reward; coercive; referent and informational. We consider collaborative power to be a seventh and present a new framework for considering power, and ways to shift power, both when working with individuals and to coproduce service/system change (Table I).

Informational power is required for any participation, rather than just being the bottom of the participation ladder as suggested by Arinstein (1969). Information needs to be shared in format/s which are most accessible to the person/people you are working with in line with the Accessible Information Standard (National Health Service England, 2015c) and in language that is personal and humanising.

**Table I**  
Ways to shift power in health and care, to build the right support for people with a learning disability and for family carers, drawing on French and Raven (1959), Page and Czuba (1999), Arinstein (1969), Roberts et al. (2012) and NHS England (2017e)

<table>
<thead>
<tr>
<th>Type of power</th>
<th>Individual level</th>
<th>Organisational/system level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational</td>
<td>Ensure relevant information is available in good time, in the format that person requires (in line with the Accessible Information Standard, NHSE, 2015a)</td>
<td>All participation should be underpinned by accessible, relevant and timely information</td>
</tr>
<tr>
<td>Expert</td>
<td>People are experts in their own lives and should be encouraged to take as much control as they feel happy with</td>
<td>People with lived experience should be involved in all decisions which impact on them</td>
</tr>
<tr>
<td>Referent</td>
<td>Ensure that people have independent advocacy to enable them to express their views and represent their interests</td>
<td>Over time advisory/coproduction groups are likely to grow in effectiveness and be increasingly referred to. This requires investment from the organisation, and a willingness to change practice</td>
</tr>
<tr>
<td>Legitimate</td>
<td>Use person-centred language which emphasises each person’s legitimacy</td>
<td>Employ experts by experience</td>
</tr>
<tr>
<td>Collaborative</td>
<td>Invest in self-advocacy groups</td>
<td>Those with organisational legitimate power (senior managers/clinicians) must be prepared to act on participation “findings”</td>
</tr>
<tr>
<td>Reward</td>
<td>Accept that all behaviour is communication and we should strive to understand this not control it</td>
<td>Ensure the voice of people with a learning disability and of family carers is central to all planning</td>
</tr>
<tr>
<td>Coercive</td>
<td>All people should be treated as equals, not to be bribed or coerced. Challenge unhealthy dynamics. Ensure no-one is punished for being themselves—it’s a violation of human rights</td>
<td>Make dealings with groups transparent</td>
</tr>
</tbody>
</table>

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Accessible information at NHS England

NHS England has been attempting to redress imbalance in informational power at system level by sharing information about work at NHS England in accessible formats. This includes the easy read newsletters (National Health Service England, 2018), accessible videoblogs and a presence on social media. To support informational power at individual level, accessible information is produced about things like personal health budgets and over-medication, to give people information they need to make decisions about their own support.

Expert power is the premise that people with a learning disability and family carers are experts by experience. People’s knowledge of their own lives should shape their own support. Their expertise should also be used to shape system improvements.

The empowerment steering group

An example of expert power in transforming care is the national empowerment steering group. Members are people with lived experience and, supported by the local government association, this group works to promote the principles of empowerment in local systems. It ensures the voices of people with lived experience are informing the work of the transforming care programme, including in how to empower people.

Tapping expert power

Across transforming care we involve people with a learning disability and family carers to steer and advise. For example, we hold events with the NHS England Learning Disability and Autism Forum so that people can help shape projects which impact on them (National Health Service England, 2017c).

Legitimate power comes from the idea that someone has the formal right to have others obey their commands, traditionally senior leaders/clinicians. There needs to be a shift to the person with legitimate power over their lives being that person. At an organisational level, shifts in legitimate power can come employing people as experts by experience.

Employing experts by experience

NHS England employs people with a learning disability, as experts by experience to ensure work remains relevant. People with experience of services for people with a mental health problem or behaviour which is seen as challenging are also employed regionally on care and treatment review panels. This helps the panel understand what someone’s care is like and how it can be improved (National Health Service England, 2017d).

Referent power is based on the perception of someone’s worthiness to respect; people will only follow a leader if they are judged worthy to respect (Grundy, 1996). At individual level, it is only by enabling people to take control of their own lives that they can demonstrate what they are able to achieve. From there, people’s referent power can grow. This can be a leap of faith for staff who have only seen someone over-medicatated in a long-stay institution.
Lucy’s story

After 13 years in hospital Lucy was empowered to live the life she wants, including choosing her own home and staff team. She has learnt to travel independently (Local Government Association, 2016).

At organisational level, groups of experts by experience (such as advisory groups) need referent power, in order to bring about change. Organisational leaders need to see the voice of such groups as worthy to listen to. For this to happen, groups need to be adequately resourced.

Advisory Groups

We have developed the NHS England Learning Disability and Autism Advisory Group, a team of people with a learning disability, autism or both and family carers, who advise on the work of NHS England, based on their experience and that of their networks. The credibility of this group is being increased by publishing their advice on the website—You Said, We Did (National Health Service England, 2017a).

Reward and coercive powers can be seen as different sides of the same coin, where rewards and coercion are used to get what someone wants. Sadly, we hear at individual level, of people living within long-stay institutions and their families being “punished” for behaviour that staff do not feel is right. This can be through over-medication (Branford et al., 2018) or cancellation of visitation rights (Justice Together Project, 2016). These violate people’s human rights and, as such, organisation leaders need to be aware of these possible abuses of power and seek to address power imbalances.

At organisational level, groups can be “rewarded”, for example, through funding. Equally, groups could find doors to influence closed and funding reduced.

Collaborative power—a new dimension

Raven (1965) focussed on individual power rather than the power which comes from people working together. In Arnstein’s (1969) model of participation, power appeared to be a zero-sum game where policy-makers could choose how much of their power to share with citizens. However, power is only zero-sum if the parties have opposing motives. If citizens and policy-makers strive for the same goal, then power becomes additive (Page and Czuba, 1999) and could be considered to be “collaborative power”. This should be the case in the NHS where individuals, families, practitioners and policy-makers all wish to see the system improved and people living the lives they choose. Clashes of power can occur when there are disagreements about how this is done. Further evidence for the need of mindfulness of collaborative power comes from observations that social capital increases the participation of people with a learning disability (Dearden-Phillips and Fountain, 2005; Keeley et al., 2008; Hoole and Morgan, 2011). Supporting people to make links with others can increase their power to improve their own lives and the system.

Stronger together

NHSE asked the Justice Together Project (2016) to bring together families who had (or had had) children and young people in long-stay institutions. We wanted to find out where the issues began, what support had been available, what support was needed and also what recommendations they had. This work has strongly influenced the development of transforming care. It also impacted on the mental wellbeing of the families (Justice Together Project, 2016).
At individual level, people’s collaborative power could be increased through involvement in provider and commissioning forums. Social media also supports people with shared issues to come together. When organisations listen to the people they support, collaborative power is increased and lives are improved.

At organisational level, it is important to invest in voluntary sector organisations, such as self-advocacy groups and family groups to build people’s ability and confidence to speak out (Dearden-Phillips and Fountain, 2005).

At the pinnacle of Arnstein’s ladder was the concept of “devolving” decision making, whereby citizens take responsibility for solving issues. For individuals this can be done with personal health budgets (Sanderson, 2018).

Claire’s story

Claire lives in her own home in Hampshire, next door to her family. She previously lived in residential care. Since having a personal budget and moving closer to home, her quality of life has improved greatly.

She uses a picture-based system to communicate with her family and personal assistants. A personal budget has enabled all aspects of her housing and support to be designed around Claire (Claire Patricia Steeples Trust, 2014).

At organisational/system level, however, participation is at its most powerful when citizens and policy-makers work together to understand the issues and to resolve them together, rather than focussing on an issue chosen by the policy-maker. There is a practical tool you can use to check if coproduction is working well in your area (Local Government Association, 2017a).

Conclusions

Every day our lives are full of interactions which are loaded with power. In our working lives we should be aware of this especially where we interact with disabled people who may not have had the same opportunities to exercise their rights as citizens. There are many easy ways to do this (Table I). In all our interactions we need to pay attention to the power we hold and how we wield it through language and behaviour. We must support people to live their lives in the way that they wish, enabling them to have choice and control over the decisions they make and ensure that involvement, coproduction and empowerment are central to the way we work. It is everyone’s right to have a “gloriously ordinary life” (Nicholl, 2017).

References


Branford et al. (2018), STOMP- this issue of Advances in MH and Intellectual Impairments.


Sanderson, J. (2018), This issue of advances in MH and intellectual impairments.


Further reading


About the authors

Jo Whaley is the Public Engagement Manager for Learning Disability and Autism in NHS England. She manages the Learning Disability and Autism Engagement Team, which ensures people with...
lived experience are part of NHS England decision making. Jo Whaley is the corresponding author and can be contacted at: jo.whaley1@nhs.net

Di Domenico is National Personalisation Lead for the Learning Disability Programme in NHS England, providing expertise and guidance on person-centred approaches for people with a learning disability, autism or both.

Jane Alltimes is Senior Adviser for the Local Government Association (LGA), part of a team supporting local authorities and other transforming care partners to deliver care and support in a person-centred way to improve quality of life.
Ensuring a personalised approach

James Sanderson and Nicola Hawdon

Abstract

Purpose – The purpose of this paper is to outline how personal health budgets and a universal, integrated model of support, can positively transform the way in which individuals with a learning disability experience their health and support needs.

Design/methodology/approach – The review recognises that Integrated Personal Commissioning, as a policy approach, provides the framework to offer personalised care, and enables people to live an independent, happy, healthy and meaningful life.

Findings – Evidence suggests that a personalised and integrated approach to both health and social care not only offers better outcomes on all levels for the individual, but also benefits the system as a whole.

Originality/value – The study reveals that a personalised care leads to people to have choices and control over decisions that affect in better health and wellbeing outcomes for people.

Keywords Wellbeing, Learning disability, Choice and control, Integrated personal commissioning, Personalised care

Paper type Viewpoint

Introduction

The NHS turns 70 this year. It is an institution that has stood the test of time, and whilst healthcare has evolved significantly since 1948, the fundamental principles behind the NHS remain reassuringly constant. However, one of the many challenges currently facing the NHS is the increasing ageing population in the UK. Whilst age itself is not necessarily a factor in pre-determining long-term conditions (LTCs), we do know that more people are living longer, (not necessarily healthier), lives. The increase in life expectancy is due to a number of factors, including: safety enhancements, such as the design of seatbelts and airbags in cars, and other public health initiatives, such as a ban on smoking in public places. Importantly though, the increase in people’s life expectancy is also as a result of the excellent care, support, innovation and development within the NHS itself.

The NHS recognises, however, that there is always room for improvement, and perhaps now is the time for a new and innovative approach to caring for those with a learning disability and/or mental health needs; an approach that looks towards supporting people in new ways. It is becoming clear that the NHS must play a more proactive role, so that those with complex needs are able to live well and manage their health effectively. Not only is this important from a personalisation policy perspective – to ensure that people are getting a personalised level of care – but it is also crucial from a “system” perspective. In 2018, an average of 41 per cent of people who arrive to Accident and Emergency Departments could be accessing different parts of the system to get their needs met. There will be many reasons as to why it is that those people are heading straight to A&E departments, but what is emerging with increased clarity is that we do need to protect the NHS from being used ineffectively so as to safeguard it for our future.

People with LTCs and complex needs make up 30 per cent of the population, account for 50 per cent of all GP appointments, and occupy 70 per cent of hospital beds (Naylor et al., 2012). Our quantitative data shows us that 70 per cent of each health and social care pound is spent on supporting those with LTCs, whilst our qualitative data highlights that people with LTCs, such as
those with on-going mental health support needs or a learning disability, are currently underutilised in managing their own health and wellbeing. All of this, in the context of knowing the positive impact that this more personalised approach can bring:

- Only 39 per cent of people report that their GP is “very good” at involving them in decisions about their treatment, care and support.
- Only 56 per cent of inpatients say that they were “fully involved” in decisions about their care (CQC inpatient survey, 2016).
- Clinicians routinely overestimate treatment benefits by 20 per cent and underestimate harms by 30 per cent (Hoffman, 2015).

In addition, we know that there is a growing demand for empowerment around healthcare across society as a whole, both from individuals, who are rightly demanding increased choice and control, and from system leaders, clinicians and commissioners, who recognise the opportunities that come from capitalising on the positive impact that an individual can have on their care. Supporting people in this way will ensure that people feel in control, live a better life and ultimately, will ensure that they make more informed decisions and reduce their use of elective and urgent care services.

A personalised approach to care and support for those with a learning disability

A universal approach to personalised care and support is one that fundamentally changes the relationship between the person and the “system”. Above all, it represents a cultural shift, requiring a change of position from “what is wrong with you?” to one that asks “what matters to you?” Personalised care is about a more balanced relationship; one in which the person in need of care and support is put at the centre of that support. Services are then designed around the individual, rather than being rigid in their approach.

There is also the broader case to make about providing a more personalised approach to care. As the statistics above demonstrate, the current system and modus operandi is failing some people, and hindering their ability to have choice and control over their care. By remedying this, not only will the wellbeing of those individuals be improved, but we will also reduce emergency visits to A&E and GPs, thus relieving some of the pressures on the NHS. Research suggests that systematic implementation of shared decision making will ensure that people make informed decisions about their care, support or treatment and will, across most pathways, reduce demand for high risk, high cost interventions by up to 20 per cent (Stacey, 2017).

However, personalised care is in no way a new concept. Some of the earliest person-centred care came out of the disabled people’s Independent Living Movement in the 1970s and 1980s, which called for greater choice and control. The “nothing about us, without us” mantra emerged as people called for greater control over their independence (Department of Health, 2001). Many disabled people found themselves living in residential care settings that were not appropriate for them, and their campaigning led to the creation of the Independent Living Fund (ILF) in 1988. The organisation was originally set up to address the changes to the supplementary benefits system, which saw the introduction of income support. Disabled people with high support needs received additional payments under the former scheme (that were not included under the new programme) and consequently, a temporary “fix” was needed. That fix was co-produced with disabled people, and the ILF went on to exist for 27 years, supporting over 46,000 people during its lifetime.

Baroness Jane Campbell, who campaigned at the time for the fund’s creation, made the following comments leading up to the closure of the ILF in 2015:

My enduring first memory of the Independent Living Fund is marching in the sunshine more than three decades ago, to the then Department of Social Security, chanting, ‘Support for Independence Now!’ We were campaigning for an Independent Living Fund – and the ILF delivered that vision for thousands of disabled people who had once been held captive within their homes or institutions. The ILF was one of our treasured liberators.

The success of the ILF model, in part, paved the way and led to the introduction of Direct Payments legislation in 1997, which, for the first time, equipped local authorities with the power to provide their own cash for care model (Direct payments legislation, 1997). The ILF worked jointly
with local authorities and from 1993, joint packages of support had been provided, giving rise to integrated budgets across social care and the benefits system.

The progress of personal budgets for adult social care was initially slow, taking around ten years for the first 10,000 people to benefit. However, the provision of a personal budget has now become a default operating model for social care and support, with many people now benefiting across the country.

The success of schemes like the ILF and personal budgets in social care created a challenge to the conventional community based NHS packages of support. Whilst many people were able to experience full choice and control over their provision of social care when supported by their local authority, as soon as their needs increased or became more complex (particularly their healthcare needs where they reached the level at which they qualified for NHS Continuing Healthcare (CHC)), their package of combined support was then delivered directly to them by the NHS rather than via their local authority. This led to a disparity between the support being offered by local authorities and the support being offered by local healthcare services. However, it was this disparity that led to the trialling by the NHS of personal health budgets (PHB), (between 2009 and 2018), as a way to address this inconsistency and provide a more effective approach for those who were managing often very complex LTCs.

The original PHB controlled trial involved 1,171 people and lasted for three years. The trial tracked individual experience throughout the programme and then mapped those experiences against the experiences of a controlled group receiving services in a traditional way. The trial showed that PHBs were most effective for people with the most complex of needs (Forder et al., 2012). The trial led to the introduction of a “right to request” a personal budget in 2011, and following this, a “right to have” a PHB in 2014, for those people in receipt of NHS CHC funding.

The take-up of PHBs was initially slow and followed a similar pattern to the uptake for personal budgets in Adult Social care, mainly due to the fact that the system had to accommodate a new infrastructure required to support the new approach to the provision of care and support. By March 2015, the scheme had expanded to include people beyond those with CHC funding, and there were just 4,700 people in receipt of a PHB. This figure has since grown to 7,600 in March 2016 and 15,800 in March 2017. As of January 2018 there were 22,895 people in receipt of a PHB, which exceeds the 20,000 target for the end of the 2017/2018 financial year (source data: NHS England data collection).

The Government is clear about its commitment to personalised care, and in 2015, introduced an NHS mandate commitment to support 50–100,000 people through PHBs by 2020/2021 (NHS England, 2014).

So what is a personal health budget and what does it look like in practice?

A PHB is an amount of money set aside to support the identified healthcare and wellbeing needs of an individual. The budget is planned and agreed between the individual (or their representative) and the local clinical commissioning group (CCG). It is not new money, but a different way of spending health funding to meet the needs of an individual in a way that suits them (NHS England website). These budgets are one way to give people with LTCs and disabled people more choice and control over the money spent on meeting their health and wellbeing needs. The money in the budget can be used in a variety of ways, and can include therapies, personal care and equipment. For this process to work successfully and deliver true personalised care via a PHB, support planning is essential. A personalised care and support plan helps people to identify their health and wellbeing goals and together with their local NHS team, it should set out how the budget will be spent in order to enable them to reach their goals and keep healthy and safe.

PHBs are now being offered to people beyond those in receipt of CHC funding, and this includes those with a learning disability, those in need of support for their mental health, children, looked after young people in need of support and for people at the end of their life.

Despite recent incorrect media portrayals of PHBs being a “luxury” that the NHS can ill afford, the work we are doing suggests that PHBs support people with some of the most significant health
and care needs in our society; people who require significant levels of daily support to remain living independently. The vast majority of money spent goes on supporting real needs for people who have high level, complex conditions and they provide the opportunity for precision commissioning, which enables every penny of a care package to be spent on meeting the specific, and sometimes unique, needs of an individual (Haslam, 2017).

We are currently collecting and collating a growing body of evidence that supports the increased use of PHBs in the NHS. Our most recent evidence demonstrates that PHBs help to improve people’s outcomes, particularly around psychological wellbeing and quality of life. This new method of commissioning and funding care and support, also serves to reduce the costs of the care being delivered, and whilst there are challenges around implementing PHBs, the available evidence shows that there is potential reward to both those in receipt of them and the system as a whole.

The latest internal NHS data (Haslam, 2017) shows that:

- PHBs have improved the care-related quality of life, psychological wellbeing and subjective wellbeing outcomes for people.
- The benefits of PHBs depend on them being implemented well. Better results are obtained when the PHB holder has more flexibility on how to use the budget.
- PHBs have, on average, reduced the direct care costs for NHS CHC packages by 17 per cent.
- PHBs have reduced the annual indirect care costs by £4,000 per person per year for NHS CHC packages, and by £3,000 for people with mental health problems.
- Where people have higher levels of need, PHBs are associated with a £3,100 total cost saving per person per year.

It is clear that PHBs can be used as a method to both improve people’s health and care outcomes and to reduce total spending across the system.

In a recent mixed methods study carried out by Midlands and Lancashire Commissioning Support Unit the financial impact of PHBs on spending in Continuing HealthCare were brought to the fore. The project was limited to six weeks and used data that had been gathered on a voluntary basis from 17 CCGs between March and August 2017, across all regions of England. It compared the size of PHBs relative to what the person would have received under conventional services. Data were requested from all IPC demonstrator sites, PHB champion sites, and CCGs involved in the NHS CHC Strategic Improvement Programme. Midlands and Lancashire CSU also collected data from the CCGs they supported in implementing PHBs, as well as information from North of England CSU and from Arden and Greater East Midlands CSU. The response rate was approximately 20 per cent from those organisations who were all asked to supply financial information.

The work by Midlands and Lancashire CSU shows that PHBs result in a cost reduction of around 17 per cent for people in receipt of NHS CHC, based on a comparison of the direct PHB spending relative to the spending on conventional services for the same level of need. This is based on an overall cost reduction of ~23 per cent, combined with an assumed administration cost figure of 8 per cent of PHB spend. It is worth noting that, based on the information available, the 8 per cent administration costs figure is likely to be an overestimate, since the figures returned from CCGs are 1–6 per cent of the initial spend figure, and the 8 per cent assumption has been included to be conservative in the estimates.

However, it is not only the figures that suggest how effective PHBs are and the hugely positive impact they can have on people’s lives. A recent project in Nottinghamshire illustrates how innovative thinking can bring significant cost savings and important health and wellbeing benefits to people.

Sam and Jane are a brother and sister who both have very complex health conditions and were in receipt of a commissioned transport package for their day centre and respite journeys as part of their PHBs. They now use their PHB to lease an adapted vehicle which has resulted in approximately £19,000 of savings in transport costs and, importantly, Sam and Jane now have
more choice and control since they now have flexibility to use the vehicle at any time they need and also have their highly trained support workers with them at all times. This has afforded them the flexibility to attend their medical appointments as well as being able to see their friends and enjoy getting out in their local community.

An example of how a PHB can be implemented for a person with a learning disability and additional health needs

Cookery lessons might seem like an odd thing for the NHS to fund, but consider an individual with a learning disability, diabetes and other complex needs who requires daily personal support, and also needs to eat a specific diet to ensure that their condition remains stable. The individual has perhaps recently been discharged from a long stay in hospital where they have been for a number of years and is now living in supported accommodation in the community, which is much more cost effective and closer to their family and friends. Now consider that this individual is regularly accessing the services of their GP and also A&E due to poor physical and mental health brought on by eating the wrong diet for their condition and lacking social inclusion, other than that gained from a day centre placement. Then consider a different conversation with this individual, which considers how they could be supported to be more proactive in managing their health and identifies that they have a fear of cooking their own food due to a lack of confidence. Does the solution of a college placement in lieu of the day centre where the individual is able to gain life skills, thus improving their health, and meet peers, which enhances their wellbeing, now appear to be so wasteful?

Rolling-out personalised care across the country

PHBs are now just one part of a larger personalised care approach, which is being rolled-out across the NHS.

Importantly, personalised care is now also recognised as being able to play a vital role in addressing the key issues facing the NHS. The NHS’s main priorities are being referred to as its “triple aims” (NHS England, 2014).

They are:
1. improving health and wellbeing;
2. providing better care; and
3. getting greater value for the public pound.

NHS England has run a variety of national programmes to support the shift to personalised care over the last three years. The recently established Personalised Care Group (PCG) has largely been informed by this activity and brings a range of established personalised care programmes together to strengthen the focus on delivery around a single operating model so that many more people experience truly personalised care.

The NHS’s Next Steps on the Five Year Forward View sets out a number of important objectives for the PCG:

- “A programme to promote healthy communities and support disabled people and those with LTCs to manage their own health, care and wellbeing. Through an extension of the Integrated Personal Commissioning (IPC) model, to reach over 300,000 people by the end of 2018/2019, including in the best Integrated Care Systems (ICS) and STP geographies; and then, if successful, scale it substantially thereafter. We will work with the voluntary sector and primary care to design a common approach to self-care and social prescribing, including how to make it systematic and equitable”.

- Ensuring that “disabled people and people with complex health needs benefit from a personal budget, with expansion to over 20,000 people in 2017/2018 and 40,000+ in 2018/2019”, on the way to delivering our mandate objective of 50,000–100,000 people having a personal budget by 2020/2021.
Supporting and working with local areas across the country to deliver these commitments will be the primary focus of the PCG. The Group will work closely through IPC sites, New Care Model Vanguards, ICT, Sustainability and Transformation Partnerships and CCGs across England to help achieve these ambitions.

As the Next Steps document indicates, IPC is the mechanism around which a coherent, whole population personalised care programme will be built, reaching beyond its initial focus on people with complex needs and evolving into a standard operating model for a wide range of personalisation and self-care interventions.

The IPC model of working enables people to join up care and support planning across both the health and care sectors. Crucially, it brings the different funding streams together, so that people’s experience is seamless, regardless of whether funding is from the NHS, the local authority or potentially, in the future, other funding avenues. It also provides a best practice approach for implementing PHBs and other personalised care programmes, and is the backbone to offering people a more personalised care approach to their healthcare service.

Figure 1 highlights the operating model for personalised care.

Whilst appearing initially complex, IPC is actually a relatively simple new model of care. It is characterised by five “key shifts” in people’s experience of care, made possible by a number of changes in how services are delivered:

- proactive co-ordination of care;
- community capacity and peer support;
- personalised care and support planning;
- shared decision making;
- supported self care.

Figure 1 | Personalised care operating model

<table>
<thead>
<tr>
<th>WHOLE POPULATION</th>
<th>ACCESS ROUTES: people with a change in their health status</th>
<th>ACCESS ROUTES: people with long term conditions and people with complex needs</th>
<th>30% OF POPULATION (Cohorts identified on basis of local priorities and need and using Right Care data packs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEADERSHIP, CO-PRODUCTION AND CHANGE ENABLER</td>
<td>GP assessment/ diagnostic triage (reactive - person presenting with change in health status)</td>
<td>GP list (proactive - by population risk stratification)</td>
<td>Voluntary Community and Social Enterprise Orgs (VCSE)</td>
</tr>
<tr>
<td>WORKFORCE ENABLER</td>
<td>Specialist or acute health services</td>
<td>Social care (children’s and adults)</td>
<td>Hospital discharge and intermediate care</td>
</tr>
<tr>
<td></td>
<td>Community capacity planning</td>
<td>Self-referral</td>
<td>Community and informal supports that build people’s knowledge, skills, confidence (All tiers)</td>
</tr>
<tr>
<td></td>
<td>Workforce capacity planning</td>
<td>Personalised care contract and accountable payment system</td>
<td>Universal offer when people’s health status changes</td>
</tr>
<tr>
<td></td>
<td>Workforce development plan</td>
<td>Optimal medical pathway</td>
<td>Proactive coordination of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community centred approaches</td>
<td>Personalised care and support planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Making the most of people’s knowledge, skills, confidence (All tiers)</td>
<td>Targeted and specialist offer for people with long term conditions and complex needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Personal budget</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Access support around self care, including health coaching, self-management education and peer support (Targeted and Specialist)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A personal budget combines resources from across the system to empower people to achieve their health wellbeing and learning outcomes (Initially Specialist)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Review</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>A key aspect of the personalised care and support planning cycle. Check what is working and not working and adjust the plan (and budget where applicable)</td>
</tr>
</tbody>
</table>

IPC key shifts (colour coded)
choice and control; and
personalised commissioning and payment.

We have already started to see the positive results that IPC can bring to people and communities from the recent “accelerated personal care site” pilot in Stockton-On-Tees. The pilot focused on frail, older people (65+ years), and the initial findings indicated that the impact of this programme resulted in a significant reduction in unplanned hospital admissions for that group, as well as a 35 per cent reduction in delayed transfers of care from hospital, and a 41 per cent reduction in A&E attendances in the final quarter. The pilot project included three cohorts with a total of 505 people, two community based teams and one hospital team.

The vision with IPC is that in the future, people should expect the same focus on their independence, the same regard for their wishes and the same opportunities to make choices and take control, whether they have a long-term physical or mental health condition, a complex need, or are making a decision about particular care or treatment, such as maternity services or end of life care. It lays the foundations for and provides the enabler to offering personalised care across the board.

Making personalised care an everyday reality for people also requires the systematic implementation of a number of evidence-based interventions which the PCG are currently working to collate. This will involve changes to frontline practice and to commissioning, as well as stronger partnership and co-production. Whilst the ways and means will vary, a number of specific programmes, outlined below, will need to be universally adopted to realise the full potential of personalised care:

- enabling choice and embedding shared decision making, so that people are informed and supported as equal partners in decisions about their care and treatment;
- systematic referral to sources of non-clinical support through social prescribing and community connecting roles, aligned with wider approaches to community capacity building and stronger partnerships with the voluntary sector;
- personalised care and support planning as a proactive process, bringing together people’s physical and mental health and wellbeing needs into a single conversation focussed on what is important to them and coordinating better access to personalised care and treatment, alongside psychosocial and community based support;
- supported self-care tailored to people’s level of knowledge, skills and confidence, including health coaching, self-management education and systematic access to peer support options, measured through tools such as the patient activation measure; and
- integrated personal commissioning, including PHBs and integrated personal budgets, enabling people who could benefit to take direct control of resources available for their health and care, providing an essential counterbalance to a “one-size-fits-all” commissioning approach, with a greater choice of care and support options.

Figure 2 illustrates how these personalised care programmes and interventions come together into a whole population approach.

It is an NHS England priority to develop community services as an alternative to inpatient facilities for people with a learning disability and/or autism who display challenging behaviour, including those with a mental health condition (NHS England, 2014). In addition, when building the right support and the national service model (NHS England, 2015) it was clear that: “people should have choice and control over how their health and care needs are met – with information about care and support in formats people can understand, the expansion of personal budgets, PHBs and integrated personal budgets, and strong independent advocacy”.

NHS England has recently published a national plan, and PHBs and IPC play an important part of it (NHS England, 2017a, b). The key elements are that:

- The national cross-organisational learning disability programme is working to ensure that people live in homes not hospitals. It is also focussed on improving people’s quality of life and the care they receive.
- PHBs offer a real opportunity to enable people with a learning disability to live in their own homes or with their families, rather than in institutions.
- People with a learning disability who are eligible for NHS CHC have a right to have a PHB. Anyone else whose support is funded by the NHS, including those with jointly funded packages, could also benefit.
- In line with this, national Transforming Care Partnerships have already begun to offer PHBs and integrated personal budgets to people with a learning disability who have complex health needs or behaviour that challenges.

Recent studies and case studies demonstrate the positive impact that PHBs can have for people with a learning disability. The “Winterbourne View programme” states that: “PHBs are aimed mainly at people with significant health needs, providing a potential win-win opportunity for the NHS to address health inequalities and improve health outcomes for those who are not well served by conventional (often high cost) services”. The report is focussed on people with a learning disability who have complex health needs, and suggests, “PHBs should be considered for all people identified in relation to the Winterbourne View programme”.

Jason’s story

Jason lived in a long stay in-patient unit for 22 years. When he first moved out, some of the staff transferred to a support agency to provide his care. This did not work very well because the system was institutional and inflexible. Jason’s sister asked about a PHB, since hearing about the positive impact a PHB had had on a person in the national pilot. Over the next few months, things changed considerably for Jason. His sister became his appointee, and with help from an independent support agency she was able to recruit a whole team of staff, and give the team leader more autonomy in developing a care plan that allowed both flexibility and creativity. Jason is now fully involved in his own care planning. He has moved from his original rented home with all its restrictions to a self-contained bungalow on a farm where he is surrounded by animals (a similar environment to that in which he grew up), his sister has purchased a car on his behalf and the staff can take him out regularly.

Since moving to his new home there have been no incidents of self-harm, and there has been a significant reduction in the frequency and duration of Jason’s seizures. His sister and staff believe that this is largely due to the more flexible structure to his care, and enabling Jason to use up his surplus energy by going for walks. Jason’s challenging behaviour has ceased and there is no longer a need for 2:1 or 3:1 staffing. He is now part of the local community and is a frequent visitor.
to the local pub and attends social events in the village, supported by one of his team of local workers. Jason continues to have his problems, but his sister reports that his life now has meaning and not just containment and survival (Turner, 2014).

For people with a learning disability, this work is fundamentally about how the system can adapt to deliver better support people to live “a gloriously ordinary life” (Nicoll, 2017) in a place that they choose to be with people they love and who love them. Indeed, Winterbourne View: A time for change (2014), highlighted that to achieve this, the system needs to “make it easier to do the right thing” and “harder to do the wrong thing” (Bubb, 2014). A personalised approach across system boundaries is key to making this happen.

Conclusion

How we provide health and social care services is at a critical juncture; not only is the demand for these services increasing but people want more choice and control over managing their own experience of them. This is especially relevant for people with a learning disability.

The evidence demonstrates that a personalised approach results in better health and wellbeing outcomes for people, which means that they are less likely to have a medical emergency resulting in an unplanned visit to A&E or their GP.

Personalised care means that people have choice and control over decisions that affect their own health and wellbeing within a system that harnesses the expertise, capacity and potential of people, families and communities in delivering better outcomes and reducing health inequalities.

References


Haslam, M. (2017), Evidence Summary for Personal Health Budgets, NHS.


Further reading


Corresponding author

Nicola Hawdon can be contacted at: Nicola.Hawdon@nhs.net

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North Cumbria and North East Transforming Care, transforming lives case study

Ursula Turner

Abstract

Purpose – The purpose of this paper is to describe how, as part of a national initiative led by NHS England and key partners, it is transforming lives by helping people with a learning disability, autism or both to live more independent and better quality lives in their own home rather than spending many years in hospital unnecessarily.

Design/methodology/approach – The methodology applied was to capture the real experience of a person with a learning disability, autism or both who successfully moved from long-term hospital care to home. This was achieved through developing a narrative story by capturing their experiences in their own words and the words of the individual’s support team who made this life changing event possible.

Findings – This story shows how with the right planning and support, people with a learning disability can live in their own homes, gain their independence and be supported to take risks.

Originality/value – This is an original case study that has not been published previously and has been written for the sole purpose of this journal.

Keywords Autism, Learning disabilities, Transforming care, Building the Right Support, Care and Treatment Reviews, Promoting independence

Paper type Case study

Remaining in hospital for longer than is clinically appropriate can limit life chances and opportunities.

Children, young people and adults with a learning disability and/or autism have the right to the same opportunities as anyone else to live satisfying and valued lives, and to be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships, and get the support they need to live healthy, safe and rewarding lives. (Building the Right Support 2015)

The national publication, Building the Right Support (BRS) (NHS England, 2015) in October 2015 put into context the need to continue to reduce the over reliance on inpatient treatment for children, young people and adults with a learning disability and or autism who could, given the right support, be at home and closer to their families and loved ones. This means building on previous experience and implementing a quantum shift in how care and treatment is provided to children, young people and adults with a learning disability, autism or both. Nationally, we need a change in culture, a shift in power to individuals and a significant change in the way in which episodes of care are provided.

Implementation of BRS means transformational change is now happening across England, where strong local leadership is building a new generation of community-based services. In total, 48 Transforming Care Partnerships (TCPs) have been set up across the country to work with people with a learning disability, autism or both and their families and carers to agree and deliver local plans that give people the opportunity to lead better quality independent lives with support in their own home or a home-like setting matched to their preferences and needs.

This case study sets out the policy drivers for change and shares one story of how the Transforming Care Programme is transforming lives in North Cumbria and the North East by...
helping people like Tom with a learning disability, autism or both to live more independent and better quality lives in their own home rather than spending many years in hospital.

Tom who has a learning disability, grew up in a loving and supportive family. When his mental health got worse he had to spend a year in hospital in an Assessment and Treatment Unit (ATU).

Fast forward to a part of Northern England today. Tom sits on his sofa next to his support worker, drinking tea and talking about their plans for the evening. Just an ordinary conversation with a young adult who is planning to see his friend from one of the other bungalows on the six-home site where they live, and looking forward to the takeaway they will be getting. There is discussion about whether they will have a Chinese or a curry; chicken tikka masala, seems to be their preference.

This ordinary domestic scene would have been unthinkable for Tom a few years ago. He has now been living in his own home for three years, thanks to careful planning around his individual needs, which were underpinned by the transformational changes that are taking place. The walls of his two bedroom bungalow are lined with DVDs and pictures of his family. He is much happier now and says: “I prefer it here [to hospital]. I can go out when I like.”

Where Tom lives, they have been making changes for the better to improve things for people like Tom in North Cumbria and the North East of England. The TCP brings together Clinical Commissioning Groups (CCGs) and local authorities with NHS England’s specialised commissioners (who commission some specialised services at national level). In North Cumbria and the North East, partners across health, social care and the voluntary sector are collaborating to significantly strengthen support in the community for individuals and their families. Key inputs also come from not-for-profit organisations like Inclusion North and Skills for People, as well as from the North East and Cumbria Learning Disability Network and Health Education England.

North Cumbria and the North East’s vision is that by developing their community infrastructure, better supporting their workforce, avoiding crisis and through earlier intervention and prevention they will be able to support people in the community, so avoiding the need for hospital admission. The aim is to ensure that everyone has a chance to live as a valuable member of their community; close to the important people in their lives and supported by those who understand and care for them.

The chair of the TCP’s Transformation Board, which brings all the local partners and voices together says that, to her, the focus is on supporting people to have better lives. She also states: “In North Cumbria and the North East our priority is to listen to what people want from life. To ensure they have the right accommodation and the right support. It’s about developing services and infrastructure that will support people to be safe and optimise their health and wellbeing now and well into the future”.

The lead person who runs the TCP’s Resettlement Hub, which was set up to help make strategic decisions across the whole area, says: “We wanted to change the culture. We still have a long way to go but are making big strides and things are getting better. The opportunity is here for us all to do things differently. People are now automatically looking at how they can support a person in the community, rather than in hospital”.

For Tom, this meant he was supported to move from hospital to one of the six bungalows in one of Northern England’s specially commissioned core and cluster housing sites. Each person has their own private bungalow, with a second bedroom for a support worker to sleep over in. Bungalow number one has extra staff on hand if any of the residents needs extra support, and communal space for the six residents to socialise, including parties for events such as Christmas and Halloween.

For anyone to be happy and able to live a good life they need a home appropriate for them. Tom says he always wanted to live with other people who he could socialise with, so with his input, which was critical, his parents and staff from the hospital and CCG worked together and his current home, with its mixture of private and communal space, was identified as the right place for him.
Using the national guidance, Building the Right Home, (NHS England, 2016a), the TCP is working with people across North Cumbria and the North East to find and adapt the right home for each person with a learning disability, autism or both. This might be an existing residential unit, an existing home that is identified and bought for them, or a newly built home.

Meanwhile, in the kitchen, the support worker encourages Tom to make cups of tea for his guests. As he fills the kettle, he jokes about his approach to housework: “They’re a soft touch; they do my cleaning for me”.

“We do the housework together”, the support worker smiles.

Tom clearly values his supportive team of staff, who he has built good relationships with. “I love my staff”, he says. He explains how he helped to choose some of his staff members, and got to know them in advance. As part of their training they all had a day getting to know him and his family who were also moving nearby.

The TCP is taking a holistic approach to transform the local workforce by making sure that people have the right skills, knowledge and values to give people the right support at the right time.

All Tom’s staff may have received training in positive behavioural support (PBS), which is a person-centred approach to people who display or are at risk of displaying behaviours which challenge. PBS has been developing within a variety of settings in the UK over the past three decades and there is now a strong practice base for its use including the national publication, Positive Behavioural Support Competence Framework (PBS Coalition UK, 2015). A recent study included over 250 single case design studies and confirmed that behavioural interventions deliver positive outcomes for individuals whose behaviour challenges (Heyvaert et al., 2012). There is limited randomised control trial evidence which attests to the efficacy of PBS. PBS is recommended as a preventative approach within a range of professional practice documents. Through the TCP workforce plan, a range of accredited learning programmes for staff and families are available across the region in line with the PBS strategy, as it can improve people’s quality of life and reduces the need for someone to use behaviour that challenges which makes it less likely they will need a hospital admission.

The multi-agency workforce steering group leader of the North East and Cumbria Learning Disability Network says: “We have adopted an organisational change approach to this rather than simply ‘training’ families and staff. A key part is promoting cultural change in how people with behaviour that challenges are perceived, and how least-restrictive approaches can provide effective support to the individual so they can learn how to cope well in their daily lives”.

To achieve this requires everyone to work together in the interests of the individual person, for example, commissioning, education, health and social provider services, people and families. To this end, we have developed a community of practice to learn and support each other, and have worked collaboratively to raise awareness about PBS and to develop a range of accredited learning programmes for staff and families. Workforce development managers (specialists in PBS and teaching others) have worked across the region to enable people to learn about PBS and to be supported in practice to use these skills and develop the appropriate values and attitudes to bring about organisational change.

Tom still needs extra support sometimes when his mental health gets worse, “I have my days”, he says. PBS means his staff have a good understanding of what Tom needs and strategies to use when this happens. “Having someone to talk to makes me feel better”, he says.

He also speaks to his psychologist every Friday afternoon and has regular visits from his learning disability support nurse, who help to make sure he is getting the support he requires.

Every six months his care is formally reviewed to see whether anything needs to be changed so that he continually has the support he needs to help him to live well at home.

All across North Cumbria and the North East adults now have their care reviewed regularly using Care and Treatment Reviews (CTRs) NHS England (2017) which bring together people involved in the person’s care with an independent panel. CTRs are shown to be supporting people and reducing admission to hospital. Children and young people up to age 25 are supported to
have a Care, Education and Treatment Review (CETRs) which takes into account the education they also need.

Dynamic support registers, which monitor factors that might cause someone to go to hospital, are used alongside CTRs to identify people who might need extra support, and monitor whether their needs have changed.

From April 2017 to November 2017 the TCP held 271 inpatient CTRs (for people in hospital). During the same period, there were 88 community CTRs, CETRs and local area emergency protocols for people living at home, which are held when a problem is detected and there is too much of a risk to wait to set up a full CTR in case the individual deteriorates further. Due to this action, 84 per cent of these people did not require admission to hospital because they received the support they needed at home.

Types of additional support given to other people across North Cumbria and the North East include extra visits from the community team, sessions with other professionals or support in their home which allows the staff team or family to have a break. The community team have stayed with people overnight at home or while they are in general hospital, and arranged for people to have their medication reviewed.

Tom recently had a medication review of his own, when some of the medication he was taking was stopped, as he says: “it didn’t do us any good”.

His medication was reviewed in line with the campaign Stopping the Over Medication of People (STOMP) with a learning disability, autism or both. It is estimated that every day about 35,000 people with a learning disability, autism or both are prescribed psychotropic medicines when they do not have a diagnosed mental health condition.

The medication review was held at a clinic in the local area that has been specially set up to carry out STOMP reviews. This meant Tom could have more time than at an ordinary medication review, and his parents and three support workers were encouraged to and did attend. The lead pharmacist from Northumberland, Tyne and Wear NHS Foundation Trust and lead pharmacist for the STOMP programme at NHS England carried out the medicines review in collaboration with his psychiatrist and support team. He says: “Having everybody there and everyone say what they wanted was superb”. This approach is so important for people like Tom as you can potentially give him a better quality of life, which can lead to better access to activities in the community.

The TCP is committed to delivering the STOMP aims, which are to make sure people get the right medicine if they need it, have regular reviews and are involved in decisions about their medication.

Following this review, Tom is now no longer taking the medication. He feels much better again, and is more able to do the things he likes to do.

Tom is sociable and being around other people is really important to him, he likes to socialise with his friend from one of the other bungalows, and some of his old friends come and visit. However, he says he is still lonely sometimes and is interested in getting to know more people and would like to be in a relationship. Staff from the TCP’s strategic partner, Inclusion North, have recently suggested some local groups that he may want to get involved with.

Tom has ambitions to get out and about and be more independent. He has been with friends to the pub at the end of the road, and sometimes goes nightclubbing in the city centre. He would like to spend the weekend in London on his own, and talks about going to Scarborough first to build up to it.

Tom’s staff are supporting him to visit more places, and as a result he recently went to a nearby town with one of his support workers. When he goes to visit his parents each weekend, he sometimes goes there on his own by bus.

Tom’s next aim is to find a job, preferably gardening. “I think it’s better for you to have a job. You’re not sitting round here all day; it helps your mental health”.

Meanwhile, the North Cumbria and the North East TCP is looking to provide services differently for people in secure services, as they make up the majority of people with a learning disability,
autism or both who are in hospital in the area. The TCPs have set up the new Secure Outreach Transitions Team (SOTT) which helps people who have been in secure services to live in their own homes, and work with community-based staff to have the skill and confidence to give them the support they need. The SOTT team is supporting people as they are discharged from hospital and preventing re-admissions.

The TCP’s next priority is enhanced community services which allow people to access out of hours services and cover seven days a week—giving them extra support to stay at home. These services are already in place in some areas, such as Sunderland, North Durham and Darlington and are being rolled out across the rest of the patch.

This means that if someone, like Tom, has a crisis, their staff can call on someone for advice and support, even if it is out of normal working hours.

Early intervention and prevention are also key. In Cumbria, they are piloting a project which supports families to develop the necessary skills to both support their own children and to teach other families. Working collaboratively with families, professionals and third sector organisations, they aim to develop capacity for people to gain the skills and support they need thus reducing the requirement for more intensive support and services often when things reach a crisis. Outcomes of this pilot project will help inform future strategy for Cumbria as well as the North East.

This is a key priority for the TCP. The Transformation Board’s chair says: “We need to make sure families, children and young people get the right care and support from an early age. We need to get it right for them, as they are our future generation”.

People with a learning disability, autism or both, their families and carers are being fully involved in Transforming Care. The TCP’s confirm and challenge group works hard to make sure everyone is given a chance to have their say. While the TCP recognises they do not always get it right and co-production is not truly always achieved, it continues to be at the heart of the TCP throughout the changes in North Cumbria and the North East.

Part of this is the Tomorrow’s Leaders course, run by Inclusion North, where people with a learning disability, autism or both can learn to be an effective leader. One of the course’s recent graduates says: “I took part in Tomorrow’s Leaders just after I started at [self-advocacy group] Sunderland People First. I gained a lot out of it. My project was about dementia because my nana was going through it at that point and I’m now a Dementia Friends champion. Just before Christmas I got my gold badge because I’ve delivered training to over 100 people, so that they can be Dementia Friends too. Tomorrow’s Leaders gave me confidence and knowledge. I’m now mentoring other people to go through the programme themselves. It was interesting to do the course again as a mentor, so I’ve done it in both roles”.

As an expert by experience, she is also making her voice heard as a member of the TCP board.

While there is still a long way to go, the progress made in North Cumbria and the North East is helping transform care for people with a learning disability, autism or both. Between April 2017 and December 2017, 14 people who had been in hospital for over five years moved to their own home.

At the Resettlement Hub, the lead manager reflects: “My advice for others is to really get to know and understand the people we are here to support. You need to listen to people, involve and listen to their families and support staff so that we get to know people’s individual stories. Data is really powerful, and needs to be backed up by this wider information. Now we know our population it’s much easier to understand and develop the support they need. Transforming Care has given us that push to make things happen”.

The TCP is committed to sustaining these cultural and structural changes beyond the life of the Transforming Care programme. The chair of the programme board says: “In North Cumbria and the North East we are refreshing our commitment. We are making sure we maintain a focus on people and thinking about what is needed long term, to ensure we have good quality services. It’s an ongoing commitment to keep listening to people and keeping people safe”.

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In order to make a real difference, not only to Tom but for many people like him, having a national strategy along with resources has resulted in a range of partners and local organisations publically committing to establishing stronger support and improved services closer to home in the community. The key learning and success of the Transforming Care Programme has been due to everything being centred on the needs of the individual, their friends and families to ensure they are fully involved in decisions about their future. A focus on changing attitudes is also important. The focus needs to be more on ability rather than disability. Approaches, such as PBS can play a part in encouraging and enabling individuals to function at their best level as part of their care and support. Experience shows that prevention and early intervention is important to keep people well for longer.

Partnership working is vital and, in North Cumbria and North East, all partners have collectively needed to think differently about how services are organised so they better meet the needs of people living in the community and therefore provide services closer to home. Collaboration amongst partners has been critical to upskill, recruit and retain the right workforce as this is a particular area of challenge because of staff shortages. They have also had to address existing culture including resistance to delivering care and support in a different way.

It is clear that all this collective effort is worthwhile to support Tom and people like him to live more happily and independently. Meanwhile, Tom is keen to have the last word. He is looking forward to seeing his mum: “I see my mum once a fortnight, she comes here. We stay in when she comes here, as I want to save a bit of money up”.

Tom’s story shows how with the right planning and support, people with a learning disability can live in their own homes, gain their independence and be supported to take risks. Tom’s clear about the best thing about living there. “I have my freedom,” he says.

References


Further reading


Corresponding author
Ursula Turner can be contacted at: ursula.turner1@nhs.net

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Abstract

Purpose – The programme – Stopping the over-medication of people with an intellectual disability, Autism or Both (STOMP) is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However, despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View not only raised concerns about the overuse of antipsychotic drugs but of antidepressants and multiple psychotropic drug use. The purpose of this paper is twofold: Part 1 is to present the history and background to the use of psychotropic drugs in intellectual disabilities, autism or both; and Part 2 presents the progress with the STOMP programme.

Design/methodology/approach – The review tracks the various concerns, guidelines and attempts to tackle the issue of over medication of people with intellectual disability autism or both.

Findings – The review identifies that despite the many studies and guidelines associated with the prescribing of psychotropic drugs for people with an intellectual disability, autism or both the practice is common. Programmes that minimise the use of psychotropic drugs involve a full use of the multidisciplinary team and an availability of alternative methods of managing challenging behaviours.

Originality/value – STOMP is part of an English national agenda – Transforming care. The English Government and leading organisations across the health and care system are committed to transforming care for people with intellectual disabilities, autism or both who have a mental illness or whose behaviour challenges services. This review identifies many studies, programmes and guidelines associated with psychotropic drug use for people with an intellectual disability, autism or both.

Keywords Autism, Intellectual disability, Learning disability, Polypharmacy, Call to action methodology, Psychotropic drugs

Paper type Literature review

Introduction and background

The programme – Stopping the Over-medication of people with an intellectual disability, Autism or Both (STOMP) is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View (an assessment unit for people with an intellectual disability, autism or both who demonstrated challenging behaviours) not only raised concerns about the overuse of antipsychotic drugs but of antidepressants (South Gloucestershire Safeguarding Adults Board, 2012). This paper – Part 1 presents the history of psychotropic drug use for people with an intellectual disability, autism or both and the background to STOMP. Part 2 (Branford et al., 2018) STOMP – the story so far presents the approach adopted to reduce over medication (the “Call to Action”) and the progress so far at the half way stage.
Historical concern about the use of psychotropic drugs for people with an intellectual disability autism or both

People with an intellectual disability. Psychotropic drugs are widely prescribed for people with an intellectual disability. Since the 1970s concern has been expressed that the prescribing of psychotropic drugs is excessive, inappropriate and potentially harmful. The concern is fuelled by:

1. studies that show high prescribing rates for such drugs;
2. studies that demonstrate a significant reduction in such prescribing following close scrutiny by either physicians, pharmacists or drug review committees; and
3. failure of studies to clearly associate the prescribing of psychotropic drugs with their indication – either mental illness or challenging behaviours.

Surveys of prescribing for people with an intellectual disability

Surveys of the prescribing of psychotropic drugs for people with an intellectual disability who lived in institutional care became common following an initial study by Lipman of 109 institutions in the USA. That study demonstrated that 51 per cent of residents were prescribed at least one psychotropic drug. Aman and Singh (1988) reviewed 35 such USA based surveys and concluded that typically 30–50 per cent received a psychotropic drug of which antipsychotic drug prescribing was the main component. In addition 25–45 per cent received an antiepileptic drug.

There were far fewer studies in the UK. However, the most comprehensive were those undertaken by Fischbacher (1987) of 509 residents of an institution for people with an intellectual disability in North and West Lothian (Scotland) and Branford (1994) of 486 residents in Leicester. Psychotropic drug use is shown in Table I.

There are few early studies of the prescribing for people with an intellectual disability who were cared for in the community. A variety of different methods were used to identify such people which led to great variance in the results. The results were also dependent on whether smaller institutional style facilities in the community were categorised as “living in the community”. The results from two UK studies (Branford, 1994) and by far the largest survey involving the population of 35,000 people with an intellectual disability living in New York who received services are shown in Table II.

In addition to surveys of whole populations attempts have also been made to understand the drug use for specific syndromes or behaviours. Deb et al. (2015) reviewed 100 people with an intellectual disability who attended at clinic with aggressive behaviours. They showed 90 per cent to be on psychotropic drugs. They showed that not only the use of psychotropic drugs is common among adults with ID who attend psychiatric clinics for aggressive behaviour, the use of polypharmacy of psychotropic medications in general and high dose of antipsychotics in particular are equally prevalent. There was no significant association with demographic variables such as physical health conditions or psychiatric diagnosis.

<table>
<thead>
<tr>
<th>Table I</th>
<th>Psychotropic drug use in an institution for 509 people with an intellectual disability who lived in North and West Lothian in 1984, and 486 who lived in an institution in Leicester</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting</td>
<td>Percentage receiving psychotropic drugs Clarke et al.</td>
</tr>
<tr>
<td>Institution</td>
<td>40.2</td>
</tr>
<tr>
<td>Community based care settings</td>
<td>19.3</td>
</tr>
<tr>
<td>Living with family</td>
<td>10.1</td>
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</tbody>
</table>
Drug review programmes

Although there are many surveys of the use of psychotropic drugs by people with an intellectual disability there are fewer studies comparing the prescribing patterns before and after an active drug review programme. Of the older USA studies one showing the greatest change was a seven year programme using rigidly mandated guidelines. It demonstrated a reduction and maintenance of antipsychotic drug use from 41 per cent of an institutional population to 12 per cent (Findholt and Emmett, 1990). The study used a drug review committee with the specific remit to manage the use of psychotropic drugs. The committee involved a team of psychologists, pharmacists, nurses and physicians.

Other drug review programmes have been reported in the UK (Branford, 1996a, b; Ahmed et al., 2000). A 2014 Dutch (De Kuijper et al., 2012) study investigated the effects of controlled discontinuation of antipsychotics prescribed for behaviour that challenge. Of 98 participants, 43 achieved complete discontinuation; at follow-up 7 had resumed use of antipsychotics. There were no significant differences in improvement of behavioural ratings between two discontinuation schedules. Higher baseline problem behaviour rating predicted higher odds of incomplete discontinuation.

Guidelines for the prescribing of psychotropic drugs for people with a learning disability

Concern about the overuse of psychotropic drugs prescribed for people with an intellectual disability has resulted in many guidelines. In 1995, a guideline for the use of psychotropic medication was developed in the USA following an international consensus conference on psychopharmacology. Its summary document proposed “The 10 dos — 4 don’ts principle” still remains very relevant to the current time (Reiss and Aman, 1998).

The ten dos included: treat any behaviour medication as a psychotropic medication; use within a coordinated care plan; base treatment on a diagnosis or specific hypothesis; obtain written consent; track efficacy by defining index behaviours; monitor side effects using rating instruments; monitor for tardive dyskinesia (NB. this could now be amended/add to by monitor for metabolic syndrome); review systematically and regularly; strive for lowest optimal effective dose; monitor use by peer or quality review.

The four don’ts included: don’t use psychotropic medications excessively, for convenience, or as a substitute for meaningful activity; avoid frequent medication and dose changes; avoid intraclass polypharmacy; minimise the use of long-term pm. orders (“pro re nata” or “as needed”); long-acting sedative/hypnotics, long-term hypnotics or anxiolytics, high antipsychotic doses and long-term anticholinergics.

In 2000, the American Journal on Mental Retardation published an expert consensus guideline for the treatment of psychiatric and behavioural problems in ID. It stated that a prescription for a psychotropic medication should be based on a psychiatric diagnosis or a specific behavioural—pharmacological hypothesis that results from a diagnostic and functional assessment. The medication should be given a trial of several weeks, use the same or lower

<table>
<thead>
<tr>
<th>Psychotropic drug category</th>
<th>Percentage of patients receiving</th>
<th>Percentage of patients receiving</th>
</tr>
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<tbody>
<tr>
<td>Antipsychotics</td>
<td>32</td>
<td>44</td>
</tr>
<tr>
<td>Anxiolytics</td>
<td>4.2</td>
<td>5</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>2.6</td>
<td>6</td>
</tr>
<tr>
<td>Hypnotics</td>
<td>11.1</td>
<td>5</td>
</tr>
<tr>
<td>Anticonvulsants (antiepileptics)</td>
<td>36</td>
<td>44</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>15.4</td>
<td>13</td>
</tr>
<tr>
<td>Lithium</td>
<td>1.6</td>
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Table II: Surveys of psychotropic drug use across different settings

<table>
<thead>
<tr>
<th>Psychotropic drug category</th>
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maintenance maximum doses as in general population and periodically consider gradual dose reduction. However the expert consensus group also advocated both start low and go slow – use lower initial doses and increase more slowly than in the general population and reduce doses at the same rate or slower both of these have been disputed.

In 2006, Deb et al. developed a quick reference guide “Using medication to manage behaviour problems among adults with learning disabilities”. This used both expert surveys and critical evaluation of available literature to achieve a consensus. Their guide, in addition to issues raised above, identified a wide range of other issues associated with the prescribing of psychotropics.

Deb then followed this up in 2009 with the collaboration: “International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities”. The key statements were that “The medication should be prescribed at the lowest possible dose and for the minimum duration, non-medication based management strategies and the withdrawal of medication should always be considered at regular intervals; if the improvement of the behaviours that challenge is unsatisfactory, an attempt should be made to revisit and re-evaluate the psychiatric formulation and the management plan”.

However, despite the numerous guidelines serious concerns were again raised about the overuse of antipsychotics and antidepressants by the report into the events at Winterbourne View, a private treatment and assessment facility near Bristol UK.

People with autism

There are similar views and controversies about the use of psychotropic drugs for people (predominantly children) with autism. A US study of 2,853 children with Autistic Spectrum Disorder (Coury et al., 2012) showed:

- 763 (27 per cent) were taking psychotropics; 15 per cent were prescribed one, 7.4 per cent received two and 4.5 per cent received three or more.
- Among children aged 3 to 5 years, 11 per cent were taking psychotropics; among 6-to 11-year-old children, 46 per cent; and 66 per cent of adolescents aged 12 to 17 years.
- A parent report of comorbid diagnosis of attention-deficit/hyperactivity disorder, bipolar disorder, obsessive-compulsive disorder, depression, or anxiety was associated with a high rate of use, with 80 per cent receiving psychotropics.
- Only 15 per cent of children with no comorbid psychiatric disorder were taking psychotropics.
- Psychotropic drug use was also related to sleep and gastrointestinal problems.
- The prescription of psychotropics was highly related to comorbid psychiatric disorder. Other factors associated with use include medical comorbidities, race, ethnicity and older age.

Another study of 33,565 children with Autism Spectrum Disorder (Spencer et al.), 64 per cent had a filled prescription for at least 1 psychotropic, 35 per cent had evidence of psychotropic polypharmacy (≥2 classes) and 15 per cent used psychotropics from ≥3 classes concurrently. Among children with psychotropic polypharmacy, the median length of polypharmacy was 346 days. Older children, those who had a psychiatrist visit, and those with evidence of co-occurring conditions (seizures, attention-deficit disorders, anxiety, bipolar disorder, or depression) had higher odds of psychotropic use and/or polypharmacy.

The Winterbourne scandal and psychotropic drugs

The exposure of mistreatment of people with intellectual disability autism or both at Winterbourne View near Bristol shocked the UK. Although the Panorama programme primarily focussed on the abuse of residents the subsequent enquiry raised concerns about the use of psychotropic drugs and in particular antipsychotic drugs and antidepressants.
Quotation from the serious case review by Margaret Flynn:

7.31 We have heard deep concerns about over-use of antipsychotic and antidepressant medicines. Health professionals caring for people with learning disabilities should assess and keep under review the medicines requirements for each individual patient to determine the best course of action for that patient, taking into account the views of the person wherever possible and their family and/or carer(s). Services should have systems and policies in place to ensure that this is done safely and in a timely manner and should carry out regular audits of medication prescribing and management, involving pharmacists, doctors and nurses.

Studies of the use of psychotropic drugs post Winterbourne View

Following the publication in 2012 of Transforming Care: a national response to Winterbourne View Hospital the Chief Pharmaceutical Officer for England commissioned three pieces of work:

- investigate the prescribing for people with an intellectual disability, autism or both via the general practice (GP) clinical practice research datalink (CPRD);
- commission the Care Quality Commission (CQC) to examine Second Opinion Authorised Doctor (SOAD) data in relation to medicines agreed for those detained using the Mental Health Act; and
- commission a collaborative improvement programme.

Also in addition to the above, a question about the use of antipsychotic drugs was included in an intellectual disabilities hospital Census and a research programme was undertaken by the Department of Psychiatry, University College of London.

The clinical practice research datalink (CPRD) study

The CPRD study examined the prescribing of drugs acting on the central nervous system to people with intellectual disabilities or autism by general practitioners (GPs) in England. The numbers of relevant patients identified (17,887 people with an intellectual disability and an additional 11,136 with autism) suggested that the database covers about 7.8 per cent of the English population. The study focussed on the use of drugs in four of the sections of chapter 4 of the British National Formulary. Following the concerns of the Winterbourne enquiry antipsychotics and antidepressants were included. However, following representations from carer organisations and the literature that a wider range of drugs is used for behaviour management in this group of people, the study included hypnotics, anxiolytics, the rest of the section covering drugs used in psychoses and related disorders and antiepileptic drugs. The findings can be summarised as follows:

- rates of prescribing of antipsychotics and antidepressants were very high;
- prescribing rates rose almost continuously with age;
- there was a 40 per cent overlap of the prescribing of antipsychotics and antidepressants; and
- prescribing rates were substantially higher than the rates of psychosis or affective disorders.

Simultaneous prescribing of drugs from more than one of the five BNF (sub)-sections was common. Two in five adults (39.9 per cent) and 17.6 per cent of all children and young people with an intellectual disability who were receiving any of the drugs were receiving drugs from two or more groups. Corresponding proportions for people with autism but not intellectual disability were 30.3 per cent for adults and 13.6 per cent for children and young people.

Second opinion authorised doctor (SOAD) data (CQC, 2016)

The CQC coordinates the provision of Second Opinion Appointed Doctors (SOADs), who visit people detained under the Mental Health Act. They consider clinical records and opinion from others, and decide whether medication to be prescribed for mental disorder is appropriate.
As part of this process, the CQC receives information about the type and dose of medication prescribed, together with the patient’s diagnosis. The key findings were:

- A total of 86 per cent of patients were prescribed at least one antipsychotic drug to be given on a regular basis. In total, 18 per cent were prescribed more than one antipsychotic drug to be given concurrently on a regular basis.
- A total of 24 per cent of patients were prescribed more than one different psychotropic drug to be given on a regular basis. When medication prescribed to be given “as required” is included, 57 per cent were prescribed more than one psychotropic drug; with 40 per cent prescribed five or more drugs.
- For more than a half of the prescriptions, the patient did not have a diagnosis of a disorder for which that drug was a recognised indication.

A collaborative improvement programme

NHS improvement invited expressions of interest from areas of England to get a deep understanding of current practices and test new ways of working. Their report categorised six key issues:

- the need to understand the pressures and reasons for prescribing;
- the importance of sharing up-to-date and comprehensive information;
- the significance of understanding the current medication processes;
- the value of integrated pathways of care;
- the importance of involving of people with ID, their families and carers; and
- the development of teams, skills and culture.

2013 intellectual disabilities hospital Census

The publication of a census from the Health and Social Care Information Centre has further raised concerns about the use of psychotropics. Survey responses were received from 104 provider organisations on behalf of 3,250 people with an intellectual disability, autism or both who met the inclusion criteria for the 2013 intellectual disabilities census. Over two-thirds (68.3 per cent or 2,220) had been given an antipsychotic leading up to census day.

Independent research undertaken by department of psychiatry university college London

Sheehan et al. studied the data from 571 general practices contributing data to The Health Improvement Network clinical database. This involved 33,016 adults (58 per cent male) with an intellectual disability who contributed 211,793 person years’ data.

Their primary conclusions were similar to the CPRD study that:

- the proportion of people with intellectual disability who have been treated with psychotropic drugs far exceeds the proportion with recorded mental illness;
- antipsychotics are often prescribed to people without recorded severe mental illness but who have a record of challenging behaviour;
- the findings suggest that changes are needed in the prescribing of psychotropics for people with intellectual disability;
- more evidence is needed of the efficacy and safety of psychotropic drugs in this group, particularly when they are used for challenging behaviour; and
- the rate of new antipsychotic prescribing was significantly higher in people with challenging behaviour, autism and dementia and in those of older age, after control for other socio-demographic factors and comorbidity.
National institute for health and care excellence (NICE) guidance

In addition to the research undertaken on the prescribing of psychotropic drugs the National Institute for Health and Care Excellence was commissioned to undertake a number of reviews of various aspects of practice in relation to intellectual disability.

Prior to the Transforming Care programme NICE had issued guidance: Autism – The management and support of children and young people on the autism spectrum (CG170). Key guidance relating to psychotropic drug prescribing from NICE guidance CG170 Autism – The management and support of children and young people on the autism spectrum was as follows:

1. Consider antipsychotic medication for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour.

2. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist who should:
   - identify the target behaviour;
   - decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact;
   - review the effectiveness and any side effects of the medication after 3–4 weeks; and
   - stop treatment if there is no indication of a clinically important response at 6 weeks.

Key guidance relating to psychotropic drug prescribing from NICE guidance NG11 “Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges” was as follows:

1. Consider antipsychotic medication to manage behaviour that challenges only if:
   - psychological or other interventions alone do not produce change within an agreed time or;
   - treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or; and
   - the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

2. Only offer antipsychotic medication in combination with psychological or other interventions.

In 2015, NICE issued “Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges” NG11. Key guidance relating to psychotropic drug prescribing from NICE guidance NG54 “Mental health problems in people with intellectual disabilities: prevention, assessment and management” was as follows:

1. For pharmacological interventions for mental health problems in people with intellectual disabilities, refer to the NICE guidelines on specific mental health problems and take into account the principles for delivering pharmacological interventions.

2. For people with intellectual disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms:
   - consider reducing or discontinuing long-term prescriptions of antipsychotic drugs;
   - review the person’s condition after reducing or discontinuing a prescription;
   - consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems; and
   - annually document the reasons for continuing the prescription if it is not reduced or discontinued.

In both CG170 and NG11 of the psychotropic drugs only antipsychotic drugs were considered to have any level of evidence sufficient to make a recommendation.
In addition to considering the role of psychotropic drugs for the management of challenging behaviours and for autism in NICE guideline (NG54) Mental health problems in people with learning disabilities: prevention, assessment and management it addressed the issue of mental health problems. The interpretation of challenging behaviours displayed by people with intellectual disabilities autism or both as manifestations of mental illnesses lies at the heart of views about whether the use of psychotropic drugs is appropriate or not. It is a widely held belief that people with an intellectual disability have significantly higher rates of mental illnesses and such illnesses often prove refractory to treatment with psychotropic drugs. However, so many of the studies to support such a stance had categorised challenging behaviours as mental illnesses. Despite such methodological problems NG54 made two key recommendations.

The “call to action” and the birth of STOMP

In July 2015, NHS England called together various stakeholders to discuss the findings from the various studies reported above and agree a way forward. It was clear that producing yet more guidance would not change the approach to prescribing psychotropic drugs for people with an intellectual disability, autism or both. For five years prior to this a similar concern about the overuse of antipsychotic drugs in dementia had been addressed using a novel approach of a “Call to Action”. The “Call to Action” resulted in an increase in reviews of antipsychotic prescribing and a reduction in the inappropriate prescribing of this form of medication by 51.8 per cent Health and Social Care Information Centre (HSCIC) (2012) in people with dementia.

NHS England agreed to adopt a similar “Call to Action” methodology for the ID population called “Stopping over medication of people with an intellectual disability, autism or both (STOMP)”. The progress with STOMP is reported in a companion paper in this journal (Branford et al., 2018).

References


Further reading


NICE guideline Autism (2012), “The management and support of children and young people on the autism spectrum (CG170)”.


Corresponding author

David Branford can be contacted at: david.branford@nhs.net; davebranford@gmail.com

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Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2 – the story so far

David Branford, David Gerrard, Nigget Saleem, Carl Shaw and Anne Webster

Abstract

Purpose – The STOMP programme – stopping the over-medication of people with an intellectual disability, autism or both is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However, despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View not only raised concerns about the overuse of antipsychotic drugs but of antidepressants. Part 1 presented the historical background to the use of psychotropic drugs for people with an intellectual disability, autism or both. The purpose of this paper (Part 2) is to present the approach adopted to reduce over-medication (the “Call to Action”) and the progress so far at the half way stage.

Design/methodology/approach – The “Call to Action” methodology is described in a Manchester University report – mobilising and organising for large-scale change in healthcare “The Right Prescription: A Call to Action on the use of antipsychotic drugs for people with dementia”. Their research suggested that a social mobilising and organising approach to change operates could provide a mechanism for bringing about change where other approaches had failed.

Findings – The adoption of the “Call to Action” methodology has resulted in widespread acknowledgement across intellectual disability practice that overuse of psychotropic medication and poor review was resulting in over-medication. Many individual local programmes are underway (some are described in this paper) however to what extent the overall use of psychotropic drugs has changed is yet to be evaluated.

Originality/value – STOMP is part of an English national agenda – transforming care. The government and leading organisations across the health and care system are committed to transforming care for people with intellectual disabilities autism or both who have a mental illness or whose behaviour challenges services. This paper describes a new approach to stopping the over-medication of people with an intellectual disability, autism or both.

Keywords Learning disability, Intellectual disability, Autism, Polypharmacy, Call to action methodology, Psychotropic drugs

Paper type General review

Introduction

The programme – stopping the over-medication of people with an intellectual disability, autism or both (STOMP) is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View (an assessment unit for people with an intellectual disability, autism or both who demonstrated challenging behaviours) not only raised concerns about the overuse of antipsychotic drugs but of antidepressants (South Gloucestershire Safeguarding Adults Board, 2012). The purpose of this paper is to present the approach adopted to reduce over-medication (the “Call to Action”) and the progress so far at the half way stage.
The “Call to Action” and the birth of STOMP

In July 2015 NHS England, the government body responsible for commissioning NHS care called together various stakeholders to discuss the findings from a number of studies of psychotropic drug use in populations of people with an intellectual disability, autism or both in England and agree a way forward. It was clear that producing yet more guidance would not change the approach to prescribing psychotropic drugs. For the three years prior to this a similar concern about the overuse of antipsychotic drugs in dementia had been addressed using a novel approach of a “Call to Action”. The “Call to Action” resulted in an increase in reviews of antipsychotic prescribing and a reduction in the inappropriate prescribing of this form of medication by 51.8 per cent (HSCIC, 2012) in people with dementia.

In 2013 Manchester University (UK) published a report: Mobilising and organising for large-scale change in healthcare “The Right Prescription”: A Call to Action on the use of antipsychotic drugs for people with dementia. It was felt that the issue of over-medication of people with an intellectual disability, autism or both met the criteria and was an appropriate methodology to use.

Antipsychotic drugs in dementia – the right prescription

The Dementia Action Alliance is an alliance for organisations across England to connect, share best practice and take action on dementia. Members include leading charities, hospitals, social care providers, Government bodies, pharmaceuticals, royal colleges, and wellbeing organisations. The Dementia Action Alliance’s (2011) first call to action was launched in on the use of antipsychotic drugs for people with dementia. The aim of the call to action was to see all people living with dementia, who were receiving antipsychotic drugs, receive a clinical review from their doctor to ensure that their care complied with current best practice and guidelines and that alternatives to medication were considered. To reduce the use of antipsychotics, people with dementia, their carers, GPs, leaders in care homes and pharmacists, were asked to commit or pledge to outlining how they can play their part in ensuring reviews take place.

A call to action pledges, workstreams and developing the message

In England a very large number of people and organisations are involved with the care of people with an intellectual disability, autism or both. There are the people themselves; direct carers (both paid and unpaid), professionals such as psychiatrists and nurses, organisations that fund and oversee the provision of care, organisations that provide support and advice to professionals, carers, families and others, organisations that advocate on behalf of the people, statutory organisations that oversee standards of care and many others.

In addition to the many organisations is the complexity of the prescribing of medicines. In England most prescribing is undertaken by general practitioners (GPs). However most initiation of prescribing is undertaken by specialists who refer the person back to the GP when the situation or illness is stabilised. Alternatively the specialist works by recommendation and the treatment is prescribed solely by the GP on the recommendation of a specialist. It is not uncommon for a person with an intellectual disability, autism or both to receive advice about their care from more than one specialist but for the overall prescribing to be undertaken by GPs. To bring about a review or change to the prescription requires a degree of collaboration and commitment from a number of medical and other healthcare professionals.

Programme workstreams

Pledges

Pledge no. 1 professional organisations. Pledges or commitments are a key aspect of the “Call to Action” methodology. For any programme of review and possible reduction of psychotropic drugs to be successful it requires the commitment of a number of key professionals. In England those directly involved in the prescription itself are the General Practitioners, Psychiatrists, and
Pharmacists, those who can provide ways of managing the problems for which the drugs are prescribed in alternative ways include the nurses and psychologists.

On 1 June 2016 together with the Minister for Care for the UK Government, Alistair Burt the STOMP intellectual disabilities, autism or both pledge was signed at a summit in London by:

- Royal Colleges of Nursing, Psychiatrists and GPs.
- Royal Pharmaceutical Society.
- British Psychological Society.
- The Minister Alistair Burt.

The Challenging Behaviour Foundation (CBF) also supported the pledge.

The signing of the pledge accompanied the launch of a guidance document for GPs developed by NHS England in collaboration with the above organisations (NHS England 2016a, b, c). The guidance is aimed at GPs but is equally applicable to other professional groups (www.england.nhs.uk/wp-content/uploads/2016/06/stopping-over-medication.pdf).

In addition the Royal College of Psychiatrists (2016) issued guidance for psychiatrists called “Psychotropic Drug Prescribing for People with Intellectual Disabilities, mental health problems and/or behaviours that challenge”.

Since then many other professional representative organisations have also signed the pledge. The STOMP project team regularly attend the Intellectual Disability Senate (an England wide multidisciplinary forum ) to ensure that the pledge signees continue to develop their commitment and actions to showcase their support for the guiding STOMP principles. As a minimum each organisation should have a clear list of commitments that their entire workforce should utilise in their day to day practice. One such example is found on the Royal College of Psychiatrists website where the ten commitments are clearly displayed (www.rcpsych.ac.uk/pdf/STOMP_Faculty_Psychiatry_Intellectual_Disability_(002).pdf).

Pledge no 2. social care organisations. In addition to healthcare professional many others are involved with the care of people with an intellectual disability autism or both. Much of the day to day care is provided by social care organisations and families. Without their involvement any attempt to reduce psychotropic drug use is less likely to succeed. The success of the pledge work with royal colleges has been further developed to include social care providers that offer services and support to people with an intellectual disability, autism or both.

The Voluntary Organisations Disability Group (VODG) a national charity that represents leading not-for-profit organisations, NHS England and sector stakeholders took the lead and developed the STOMP pledge for social care. The resources (www.vodg.org.uk/campaigns/stompcampaign/) offered include a self-assessment template, access to the STOMP logo, advice on preparing to visit the doctor and other audit tools.

The STOMP pledge for social care

The pledge offers a framework to support social care providers to identify practical steps they will take to support people to reduce the amount of inappropriate psychotropic drugs they take. This document also provides links to useful resources.

The VODG social care pledge:

We pledge to act in the best interests of the people we support at all times by:

- Actively promoting alternatives to medication such as active support, intensive interaction or positive behaviour support.

Ensuring the people we support, and their circle of support, are involved in decisions about their care, including their medication.
Ensuring all staff have an understanding of psychotropic medication, including its main uses and side effects.

Encouraging staff to speak up if they have a concern that a person we support may be over-medicated.

Maintaining accurate records about the health, wellbeing and behaviour of the people we support.

Supporting people to have regular reviews of their medication.

Monitoring the use of psychotropic medication.

Working with people with intellectual disability, autism or both, their families, health professionals, commissioners and others to stop over-medication. This includes working closely with prescribers.

We will set out the actions we will take and report annually on the progress we have made.

In addition to the VODG material the Care Management Group (CMG) produced guidance for social care providers (http://cmg.co.uk/wp-content/uploads/2017/06/STOMP-Guide-Final-version.pdf) and launched it at a high profile meeting near the Houses of Parliament.

Healthcare provider pledge

The pledge initiative has now been extended to challenge healthcare providers (both NHS and the independent sector in England) to develop their own pledge principles together with a toolkit of actions and a range of measures to enable a clear auditable trail of STOMP activity. It is envisaged that all healthcare provider organisations will be able to sign the pledge and commit to a range of actions that demonstrate their support for the STOMP principles. This should be publicly available on each organisations website allowing people who use their services, together with their circle of support, to hold individual organisations to account for their actions.

Empowerment

Disempowerment is a theme that was commonly expressed by all the parties associated with reducing the over-medication of people with an intellectual disability autism or both.

Many of those directly involved with the prescription (GP, community pharmacist, practice nurses, etc.) felt that changing the medication was outside their skill base and the task for specialists. However many specialist services are designed to cope with crisis and do not have neither the capacity nor the role to oversee medication reduction programmes that may extend over many months.

Many of those directly involved with the person with an intellectual disability, autism or both such as the family carers, professional carers, non-medical professionals, advocates etc. felt that the medication was someone else’s responsibility and not something they could influence. A focus on the many medications the person was receiving was often absent (Anderson et al., 2014).

The empowerment workstream involved the following:

- Developing an information pathway for family carers on STOMP: the CBF, a charity for people with severe learning disabilities whose behaviour challenges was commissioned to develop a set of online and hard copy resources for families. These resources will give families helpful advice at each step of the journey, from the possible introduction of psychotropic medication to withdrawal from medication. The resources are based on a consultation that CBF that was carried out with over 100 families to find out about their experiences of medication and what would be helpful to them. The resource is published on the CBF website (http://medication.challengingbehaviour.org.uk/).

- Using a Musical performance piece to get the STOMP messages across.

A musical performance piece was developed by Inclusive pop group Mixit, following research with many families and people with an intellectual disability. The piece is based on someone’s real
life experience of over-medication of their daughter, and gets across all of the STOMP core messages in a fun but powerful way.

This piece was commissioned by NHS England to be used around the country with professionals, providers, families and people with an intellectual disability. This has proven to be a powerful reminder for all regarding the need to prioritise this work as the people performing genuinely understand what the campaign means. Mixit have performed at many of the royal colleges annual conferences including most recently at the royal college of psychiatry annual conference.

Communications and developing the messages

One of the most important aspects of the Dementia Alliance “Call to Action” was to agree a simple message that highlighted a clear, definable, “intolerable” condition and a specific “ask” (goal(s)). The following is the key STOMP message used throughout the campaign.

The core message of the STOMP campaign:

Stop Over Medicating People with an intellectual disability, autism, or both.

Public Health England (2015) estimates that every day 30,000 to 35,000 adults with an intellectual disability are prescribed an antipsychotic, antidepressant or both, when they don’t have a mental health condition. Unnecessary use of these drugs, puts people at risk of significant weight gain, organ failure and even premature death.

In addition to the core messages communication from NHS England with regards to STOMP has been varied including much use of social media such as tweets and blogs on Facebook. There have been “TweetChats” that have engaged professional audiences in discussions on STOMP and use of infographics based on the core messages. There has been provision of STOMP overview leaflets, flyers, GP prescribing booklet, videos and delivery of conferences at national and regional events. The team have a “we support STOMP email signature” which STOMP supporters are also encouraged to use.

Education and alternatives workstream

Education

The STOMP project team have worked with a number of organisations to raise awareness of the campaign and to ensure quality training materials are available to skill various workforces and interested parties. A major piece of work is currently being finalised with NHS Education to develop a STOMP module as part of the Transforming Care Massive Open Online Course (https://openeducation.blackboard.com/mooc-catalogue/courseDetails/view?course_id=1257_1). This is an online module that explains the STOMP principles and highlights appropriate and inappropriate use of medication in relation to any current evidence and guidance. It also highlights the need to consider non-medication ways to manage behaviour that is thought to be challenging rather than prescribing medication.

The team have also linked to the Centre for Postgraduate Pharmacy Education (2017) and have helped to develop a general awareness pack that was distributed to more than 65,000 registered pharmacists and technicians in April. In addition they have also helped to create two workshops linked to holding STOMP style medication reviews aimed at pharmacists who work in GP surgeries (www.cppe.ac.uk/programmes/l/learndislc-d-01).

Alternatives to psychotropic drugs

Any programme that solely encourages the removal of psychotropic drugs without contingency plans to deal with the problem behaviour is likely to be unsuccessful. Alternatives to medication include concepts such as positive behaviour support (PBS). For a better understanding of the principles of PBS a short educational video has been produced by the British Institute of Learning Disability (www.bild.org.uk/). The module is due for launch in early 2018 and can be accessed via the NHS Education website.
The STOMP project team have also linked to other interested parties who have been commissioned to create additional awareness raising and educational information sources. Included in this work have been:

- the CBF who have produced an educational set of leaflets aimed at appropriate and inappropriate medication use for families of people with a learning disability, autism or both; and
- the British Psychological Society who have produced a leaflet promoting the STOMP principles and the use of non-medication methods of managing behaviours that are thought to be challenging.

Drivers/levers workstream

It was accepted from the start of the STOMP programme that the “Call to Action” methodology may not be enough to bring about change. To encourage the review of the prescribing of antipsychotic drugs in dementia a number of additional drivers/levers were put in place to incentivise healthcare providers. These included building the reviews into contractual requirements, financial incentives such as quality payments and the expectation of reviews in place as part of inspections standards. The aim of the STOMP drivers/levers workstream was to encourage the uptake of similar incentives.

The following are examples of some of the levers/drivers/resources in place:

- the Care Quality Commission, the England organisation responsible for the registration and quality of care providers has developed standards and recommendations for their inspectors;
- prescQIPP an organisation responsible for providing support information about prescribing for GPs and pharmacists working in GP practices is producing evidence-based resources and tools for primary care commissioners, and provide a platform to share good practice across the NHS;
- care transformed is an NHS England database which holds STOMP case studies and good practice which is available for all NHS clinicians to access; and
- a STOMP audit was sent out to all Clinical Commissioning Groups (CCGs) that manage the care locally in the North of England.

Embedding STOMP in other parts of the England intellectual disabilities programme (Transforming Care Programme)

Care and Treatment Reviews (CTRs)

CTRs focus on people who are either in a specialist inpatient service or who may be admitted to one. The idea is that by bringing in an extra level of review the admission may be ended or avoided. The reviews have been incorporated to include a “Key Line of Enquiry” on STOMP. The review process in addition to challenging the need for the person to be in such a restrictive environment will challenge the overuse of psychotropic medication. It also will look at whether prescribing practice is evidence based, e.g. following the appropriate NICE guidelines.

The annual health check

Every person in England under the care of a GP has access to an annual health check. However the existing template made little reference to the need to review the medication. The Annual Health Check template and guidance was reviewed in 2017 to incorporate questions based on STOMP.

The Learning Disabilities Mortality Review (LeDer)

The LeDer programme in relation to ensuring the reviews of deaths consider whether over-medication was a contributory factor.
Transforming Care Partnerships (TCPs)

The local arms of England Intellectual disability programme (Transforming Care Programme) are the TCP. There is an expectation that TCPs will all have a plan that includes STOMP. TCPs are the partnerships that have been put in place to “transform care” for people with an intellectual disability, autism or both, and they include health, social care and people with lived experience of receiving care and support.

Children and young people

Although children and young people receive their medication predominantly via the GP and through pharmacies the infrastructures are completely different. From an early age people with intellectual disabilities, autism or both are likely to receive care from paediatricians and community paediatricians. If presenting with behavioural or mental health problems they will have input from child and adolescent mental health services. They will most likely be attending schools and receive support through a different set of agencies and support services.

Parent and carer organisations raised concerns that much initiation of psychotropic drugs for people with an intellectual disability, autism or both occurs in childhood and that their use was widespread in children’s special schools and facilities it became clear that there was a need for a children’s and young people’s STOMP.

Data outcomes

At the end of the three-year “call to action” programme it is likely that the issue of over-medication will have a much higher profile that at the beginning of the programme. However will this have resulted in a fall in the use of the various psychotropic drugs? A programme of GP data evaluation will soon commence to look at the trends in prescribing over a large number of GP practices and the extent of the impact of STOMP.

Co-production

Co-production is about developing equal partnerships between people who use services, carers and professionals. There are different definitions of co-production but a consensus that working co-productively leads to improved outcomes for people who use services and carers, as well as a positive impact on the workforce (www.thinklocalactpersonal.org.uk/Browse/Co-production/Equalities/learningdisabilities/). Co-production recognises that people who use social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.

Co-production is a key principle of the STOMP programme:

My name is Carl Shaw and I am a person with a mild learning disability. I've worked for NHS England for around two and a half years as a learning disability expert advisor.

I feel that NHS England has really adopted a co-productive role because I co-lead on this piece of work and I am encouraged to make decisions, I represent people with a learning disability.

In October 2015 I started my role as a learning disability expert advisor at NHS England. Through my role and my involvement in the STOMP initiative, I have presented to lots of different audiences including families, adults and children with intellectual disabilities and Autism. I've also spoken to Social care providers, GP's, learning disability nurses, psychiatrists and many other audiences as everyone in every sector has a role.

I have heard families and people who have had experiences where they gain weight, have being unable to do the activities they enjoy and some families have talked about their loved ones dying prematurely.

The STOMP programme at NHS England is due to end in March 2019 which isn’t very long so I see that it is very important that there are resources in place so work can continue after the end of the programme.
Some of the resources that I and my team are working on are having a pathway resource where people can identify where they are on their journey for example if you’ve just being prescribed Psychotropic medication or you’ve being taking them for years, you can choose where you are and there will be different things to help you which is a piece of work being done between the Challenging Behaviour Foundation and NHS England. We have other resources for GPs and Social care providers which give guidance on what they can do.

One other thing I have learnt about is that through my involvement in this piece of work is that my team have had to do their role in a very easy to understand and co-productive way. So I say to all organisations that people with Learning Disabilities, Autism or both can be involved in big pieces of work because that has being my positive experience.

Individual programmes and case studies

North East England: a description of the programme and a case example

Summary. The North East England programme involved a GP pilot and the establishment of a STOMP review clinic in Sunderland.

GP Pilot – January–March 2017. In the North East of England a pilot was developed to understand the complexity of the STOMP work in relation to primary care. Six GP surgeries agreed to take part and to allow a specialist intellectual disability pharmacist and Commissioning GP lead to visits practices to interrogate records to identify people needing a STOMP review of medication.

The pilot clearly identified the need to run specific searches to analyse how many people need a STOMP review followed by a detailed interrogation of each record to exclude the following people:

- open to secondary care teams (30 per cent);
- taking anti-epileptic drugs (AEDs) for epilepsy (10 per cent);
- taking an antidepressant for anxiety or depression (these are licensed indications that can be managed by GPs) (30 per cent); and
- miscoded patients who don’t have an intellectual disability which has been incorrectly coded on the GP record.

The pilot showcased a process for holding a STOMP review.

Sunderland STOMP clinic. A community intellectual disability team in Sunderland has developed a STOMP clinic as collaboration between a prescribing pharmacist and the Positive Behavioural Support (PBS) Team. People with an intellectual disability, autism or both receive full PBS support including staff training sessions in collecting behavioural data, a full functional assessment of behaviours and development of a behavioural support plan. The PBS nurse then refers to the pharmacist who works with the person taking medication, their staff and family members to deprescribe the psychotropic medicine. The process is fully supported by the PBS team and behavioural data is collected to guide evidence based, future prescribing decisions. The views of staff, family and the person is regularly sort to guide decision making ensuring a fully person centred approach is taken. No targets or timescales are set when the work is initiated. To date several people have come off their medication altogether and others are undergoing a reduction programme. Only one person out of 12 has needed medication to be restarted which clearly demonstrates the impact of PBS in supporting a deprescribing regime. Further details are described at http://fabnhsstuff.net/2017/01/25/stopping-overmedicating-people-learning-disability/ and www.nice.org.uk/sharedlearning/adhering-to-the-nice-guidance-for-initiating-and-reviewing-antipsychotic-medications-in-people-with-a-learning-disability-for-the-prevention-and-intervention-of-challenging-behaviours

Case example from the Sunderland STOMP Clinic – Daniel’s Story:

Daniel is a 35 year old gentleman who has been taking the antipsychotic drug risperidone to manage his behaviour for at least 10 years. No attempt had been made to reduce this medication. Staff felt
Daniel was challenging and were often scared to engage due to his grabbing behaviour. Following a full functional assessment of his behaviour Daniel was referred to the STOMP clinic to challenge his ongoing need for risperidone.

This was the first major attempt at deprescribing utilising the skills of the PBS team. With limited technical evidence to guide the process it felt, at times, uncomfortable having to reply on “common sense” and a degree of “logical rationale”. The strength of teamwork, joint decision making with carers and family together with significant amounts of evidenced based behavioural analysis gave the team strength to analyse the situation and support the care staff to consider things in a different way. This resulted in Daniel coming off risperidone, a process that took more than 8 months. He is now more lively and wanting to go on more outings and tackle new activities. Staff are aware to offer active support to meet his needs and his grabbing behaviours are now understood as communication of his needs rather than a challenge.

Clearly, team spirit and a belief in each other’s abilities was key to enabling ongoing medication reduction. Wining the hearts and minds of the care staff allowed behavioural analysis to demonstrate what was actually happening.

### Bury CCG STOMP: a description of the programme and a case example

The Bury CCG STOMP programme involved collaborative working between Bury CCG, the GP Federation and the local NHS Trust. The programme of work involved the following:

- The CCG Medicines Optimisation team worked with the towns 30 GP practices. The team looked at the lists held by GPs of which patients have an intellectual disability and were prescribed psychotropic medicines (primarily antipsychotic drugs). They looked at why people were taking them, how much they were taking and what health checks and blood tests each person had done.

- Pharmacists, consultants and GPs worked together with people and their families and carers to develop a personal action plan to help them reduce the amount of medicines being taken. Each person was given support to manage their symptoms and a check up on how things were going once a month. Anyone needing extra support was referred to the community intellectual disability team.

- They found out that of the 195 people who were prescribed an antipsychotic, 65 per cent had been given this medication for challenging behaviour. (Table I)

#### A case story from Bury CCG STOMP programme:

A person with Intellectual disability under the care of the Consultant was prescribed benperidol 250micrograms three times daily for hypersexuality since 2015 as well as chlorpromazine 100 mg every morning and 200 mg at night since 1994.

Benperidol is a potent D2 antagonist whilst chlorpromazine is a weak D2 antagonist. Combination use of a weak D2 antagonist and a potent one simply makes the weak one a sedative. Chlorpromazine is simply acting as a sedative as the D2 receptor would fully be occupied by the benperidol. The chlorpromazine was reduced over a 6 month period. The patient continues to be prescribed just one antipsychotic now: benperidol.

The learning points from the Bury programme are:

- consultants may require support around capacity issues;
- joint working between GP practices, consultants and the intellectual disabilities community team is a must;

<table>
<thead>
<tr>
<th>Table 1</th>
<th>No of people prescribed antipsychotic drugs for challenging behaviour in Bury CCG</th>
</tr>
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<tbody>
<tr>
<td>Prescribed antipsychotics for challenging behaviour</td>
<td>No.</td>
</tr>
<tr>
<td>No. of patients where consultant review is required to ascertain if reduction possible</td>
<td>52</td>
</tr>
<tr>
<td>No. of patients where agreement of action plan required (between GP, service user and carer)</td>
<td>1</td>
</tr>
<tr>
<td>No. of patients who are currently on a reduction plan</td>
<td>35</td>
</tr>
<tr>
<td>No. of patients where antipsychotic medication has been successfully reduced and withdrawn</td>
<td>21</td>
</tr>
<tr>
<td>No. of patients where dose of antipsychotic medication has been reduced (although not possible to withdraw completely)</td>
<td>17</td>
</tr>
</tbody>
</table>
the intellectual disability team nurses are a great resource to provide behavioural support;
involving patients, carers and family members is crucial to decision making; and
monthly follow up calls are necessary to make any changes to reduction plans.

**Cornwall: a description of the programme and a case example**

Cornwall TCP decided to review everyone with an intellectual disability who taking antipsychotic medicine, according to their level of risk from it.

In addition the team developed the “The Purple Book” scheme is for people with an intellectual disability, autism or both. The person, their family or carer use the book to monitor the medicines they are taking and their general health. This allows them to take ownership of and have more control over the medicines they are taking.

The team looked at everyone recorded on their GP register as having an intellectual disability. They prioritised people who were taking a long acting (depot) formulations and have successfully withdrawn the medicine of everyone who was at risk.

They are now reviewing everyone taking two antipsychotics, and prioritising people who do not have a suitable diagnosis. The team plans to review each person and reduce or stop their medicine if needed.

The Purple Book is designed to reassure everyone on antipsychotics that they are safe, while the local team works their way through the risk matrix. If the Purple Book highlights concerns, that person can be given a review quickly.

Each person will be given a “STOMP Stamp”:
- “Green” if they stop taking medicines or are taking the correct ones for their diagnosis.
- “Amber” if the medicine is not perfectly suitable for the indication but coming off it is not in their best interest at the moment (this is decided by everyone working together and using evidence).
- “Red” where other social factors may stop someone reducing their medicines. They might need a suitable placement or support team, for instance. People given a red STOMP stamp are monitored by a new electronic tool called “Connect” and referred back to the team once these issues have been solved.

**Case story from the Cornwall STOMP programme:**

In the 1990s, Brian was given an injectable antipsychotic known as a depot without a clear reason. He was considered high risk as he had a history of violence, used heroin and had spent time in prison.

When the intellectual disabilities consultant suggested reducing his medication, Brian was reluctant at first but was persuaded to try it. Over 12 months his support team helped him to manage whilst he took less and less medicine, which he has now successfully stopped. Brian is very positive. He likes to go for walks, his self-confidence has gone up and his life is changing. He is cooking for himself and is keen to find work.

**Conclusions**

The adoption of the “Call to Action” methodology has resulted in widespread acknowledgement across intellectual disability, autism or both practice of overuse of psychotropic medication and poor review. In addition to the programmes described many individual local programmes are underway, however to what extent the overall use of psychotropic drugs has changed is yet to be evaluated.

**References**


Further reading


Fab NHS stuff. Available at: http://fabnhsstuff.net/2017/01/25/stopping-overmedicating-people-learning-disability/


Corresponding author

David Branford can be contacted at: david.branford@nhs.net; davebranford@gmail.com

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When my daughter was in school she could not wait for the Harry Potter instalments to come out and she would start reading the book on the moment the book was out and would read non-stop until the whole tome was finished by the late evening. Despite a lot of encouragements from her, I have never moved beyond the first page of the first book. However, when I started reading Professor Nick Bouras’ book, I felt the same urge like my daughter to finish the whole book in one go (and I am a slow reader!). Such is the attraction of this book for someone like me who has travelled some of the same paths with him. I know Professor Bouras as an excellent Clinician, Scientist, Leader, Academic, Educator, Mentor, Trainer, Policy Maker, Medical Manager, International Networker (all these qualities that made him the Renaissance man in the field!), but did not know that he is such a master storyteller!

There is a hierarchy in science and at the top is perhaps the “rocket science” and at the bottom, “medicine”. Within “medicine”, “psychiatry” perhaps comes at the bottom and within “psychiatry” the “intellectual disability (ID)”. Professor Bouras’ endeavour to collect data meticulously and analyse them using scientific methods as described in his book, no doubt, helped to make ID psychiatry respectable nationally and internationally. His book is the proof of the disaster that can happen if you go with the flow and do not ask questions and gather the right evidence! In that sense, Professor Bouras was ahead of his time, perhaps because of his exposure to community-based mental health services very early on through the Mental Health Advice Centre about which he writes passionately in his book!

In his book, Professor Bouras through his personal journey also takes us through the journey of the NHS in the UK in the last four decades as well as services for people with ID. Many of us will remember the profound changes that Griffith’s report brought into the NHS that advised the Government to run the NHS like a supermarket only to realise that unlike the supermarket the consumers of health service do not have to pay for the service. In order to rectify this mistake, a pseudo market was created by developing the commissioner-provider split. That was the beginning of the manager culture in the NHS and ring-fenced budget within small units, a small amount of resources guarded dearly by the managers of those units. Professor Bouras talks in his book about the tension that these changes brought for implementing community care and how medical establishment in the hospital was perhaps understandably reluctant to give any of their meagre share of resources to community care. At a personal level, I felt the same as a psychiatry registrar when I went to ask for some syringes and bottles from an inpatient unit as I was going to do a home visit and needed to take some blood samples from a patient. The ward manager told me that I could not use their equipment for patients who were not in their unit. This in a way exemplifies the wider problem of loss of flexibility within the NHS as a whole!

Professor Bouras’ book reminds us of many forgotten stories such the extra-contractual referrals, many of which were necessary because of expensive out of area placements in private settings (£8.8m just from one London area in 2017 quotes the book) that created a false economy in the NHS (the latest figures show in the UK, there are 2,500 psychiatric inpatient beds in the NHS and 2,800 beds in private sectors most of which are in locked units). This book also resurrects for me some of the anecdotes we used to hear through the grapevine as psychiatry SHOs such as Professor Elaine Murphy’s sedan doing home visits in the not so affluent parts of London. His book also reminds us how in the old days our clinical psychologist
colleagues were involved more in doing psychological tests than providing meaningful interventions. At a personal level, I remember that as a psychiatry SHO we used to often demand from our clinical psychologist colleagues Minnesota Multiphasic Personality Inventory test without realising how time consuming and how useless this was for our clinical work.

Many of the conflicts mentioned in the book that started decades ago are still rife today. I have already mentioned provider vs commissioner and community vs institutional care conflict. Professor Bouras’ book also discusses other tensions such as health care vs social care (whether psychiatry of ID, particularly problem/challenging behaviour is a mental health issue or an ID issue and who should fund the service), physical health vs mental health care (often both services denying that the health of people of ID is their responsibility, therefore, the funding should come from elsewhere!). Similarly, the issues of the role of the Community Learning/ID Team members, for example, community nurses spending more time in sorting out housing budget rather than helping to monitor mental health, medication, etc., for people with ID in the community (Unwin et al., 2017), and generic mental health vs ID service (specially ID psychiatry) (who has the expertise to treat psychiatric illness, particularly problem behaviour in ID and whose resource should be used), are as prominent now as they were four decades ago as Professor Bouras’ chronicle eloquently discovers.

As a passionate researcher in the field, Professor Bouras talks in his book about his frustration regarding the lack of research funding in the field. For example, funders of mental health research and the ID research both saying simultaneously that research in mental health in ID is not their responsibility (another example of many of the tensions mentioned in his book).

However, it is not all doom and gloom in the book, indeed there are many examples of successes even at the face of adversities, the jewel in the crown being, perhaps the establishment of Estia centre (a concept which was ahead of its time in the UK at the time of its establishment). This is an excellent example of how one can combine clinical service with research, education and training, which should be the case in an ideal world.

Similarly, the book shows how international collaboration can raise the profile of ID psychiatry, which was evident from Professor Bouras’ leadership in many international organisations such as the World Psychiatry Association Section on Psychiatry of Intellectual Disability, the European Association of Mental Health in Intellectual Disability, which produced under his leadership the first ever evidence-based international guide on the assessment and diagnosis of psychiatric disorders in ID (Deb et al., 2001), which is still considered as one of the classics in the field and was later followed by the American National Association for the Dually Diagnosed publication, “Diagnostic Manual-Intellectual Disability” (Fletcher et al., 2007). Professor Bouras’ another classic contribution to the field is the textbook in psychiatry of ID that he edited with his colleagues which because of its huge success has been produced in its third edition recently (Hemmings and Bouras, 2016). The chronicle describes how Professor Bouras’ efforts to organise many high quality national and international conferences have brought fruits by raising the profile of the specialty both nationally and internationally. I personally remember the first among many high quality international conferences Professor Bouras organised in the UK in Canterbury in which I took part, which he mentions proudly in his book.

Professor Bouras’ chronicle provides a list of “Who’s Who” among psychiatry, more specifically ID psychiatry not only in the UK but worldwide. This shows his great skill as a networker and friend maker not only within the UK but worldwide, which made him the best person to run the Maudsley International to which he is now the Director. Indeed his book shows that while in trying to achieve your goal you will come across some people who are not so helpful but there will be many more who will be accommodative and enthusiastic about the cause, who have the right attitude of “can do, will do” and who could become your lifelong friends. The book shows how throughout his journey over four decades through all the policy and service changes (from “social role valorisation” in Scandinavia through ENCOR in Nebraska USA to “Valuing People” in the UK), Professor Bouras remained determined to provide person-centred, multi-professional service for people with ID in the right settings to fulfil the
well-used prophecy that the measure of how civilised a society is by how well they look after their disadvantaged in the society. Despite his international renown, Professor Bouras was firmly rooted to the ground and committed to the NHS in the UK from de-institutionalisation to community care. This is a lesson for the future generation.

History does not only remind us of the good and the bad of the past but also warns us about the potential problems ahead! Therefore, this book is not only an essential reading for our generation of psychiatrists but also for the others who will be making history in future. This book should be a source of inspiration not only for doctors and psychiatrists but many who want to overcome barriers and achieve their goals at the face of many adversities with their hard work, determination, tenacity and the right skills.

Shoumitro Deb

Shoumitro Deb is based at the Faculty of Medicine, Imperial College London, London, UK.

References


