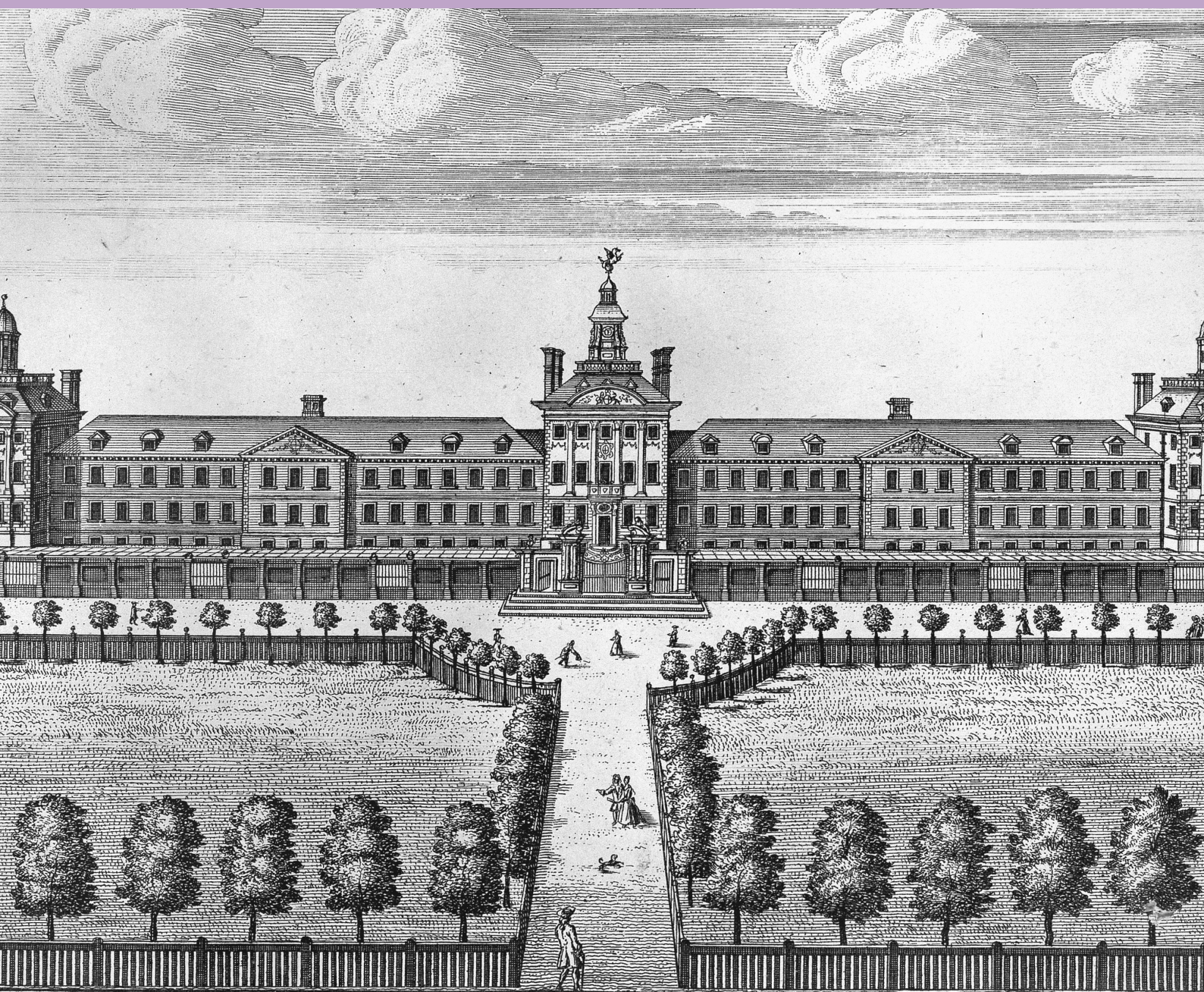


Back to Bedlam

WHAT KIND OF FUTURE FACES PEOPLE WITH A LEARNING DISABILITY?

by **Robin Jackson**



New Bedlam in Moor-fields.

Back to Bedlam

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LEARNING DISABILITY?

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SUMMARY



- The claim is made that successive governments in the UK have ignored people with a learning disability because this population is perceived to be too small and insignificant to warrant government interest and action.
- It is argued that the attitude of successive governments towards people with a learning disability has been not only unnecessarily cruel but also too frequently characterised by administrative maladroitness and political ineptitude.
- It will be demonstrated that the rights of people with a learning disability in the UK have been either ignored or violated by successive governments.
- The last government's assertion that the UK is a world leader in disability rights and equality is challenged.
- The future of social care and the reasons for the growing number of care home closures are examined and some of the implications of local authority cuts in social care provision are highlighted.
- Reasons for the declining influence of the major disability charities and the consequences for people with a learning disability are examined.
- Ways in which successive governments have succeeded in muzzling the voice of the larger national charities and 'independent' advocacy programmes are identified.
- Some of the negative consequences of state control in the field of research are described.
- The impact of technology on the provision of services for people with a learning disability is examined.
- The effect of escalating levels of prejudice and discrimination involving people with a learning disability is discussed.
- The question is posed as to whether we are witnessing the return of institutionalization of people with a learning disability.
- Attention is drawn to the detrimental effect of successive governments' practice of outsourcing social care provision for people with a disability.

PROLOGUE

Over a period of fifty years I have been professionally and personally involved in the field of learning disability – as a school principal, academic/researcher, advocate, consultant – and last but not least – a parent. My purpose in writing this paper is prompted by a fear that learning disability is no longer registering on the national radar as the number of people with a learning disability is seen by government as too small to merit attention. The recent and highly critical UN report on the situation facing people with a disability in the UK underlines that lack of governmental interest and concern.

The record of the major disability charities in the UK representing people with a disability and their families is woeful but predictable given the extent to which they are financially dependent on state support and it has been left to grassroots organisations (e.g. Disabled People against Cuts) to speak up for those with a disability.

If one focuses on the question of social care provision for people with a learning disability, it is clear the situation is fast deteriorating. The abandonment in the past two decades of this sector to the private (for profit) sector has proved catastrophic. It is known that the major providers in this sector are experiencing acute financial difficulties and that many smaller providers are being forced to abandon the sector. The likelihood of a further significant contraction is inevitable.

The regulatory body - the Care Quality Commission - has demonstrated that it is not fit for purpose: in particular its consistent failure to follow up on those care homes which have failed to meet satisfactory levels of performance. Many of the problems facing social care anticipated by Dame Denise Platt, formerly Chair for Social Care Inspection, eight years ago have been realised.

The fact that a large number of social care providers have been paying staff below the national minimum wage has diminished the chances of recruiting well-qualified and highly motivated staff and increased the probability of not only high staff turnover and poor quality service but also a rise in the maltreatment and abuse of residents.

The implications of Brexit, too, cannot be ignored given the significant proportion of staff in social care settings who are currently drawn from Eastern Europe. If this source is cut off, from where will staff be recruited? A further probable consequence of what is likely to be a hard Brexit is that the UK will have even fewer financial resources on which to draw to assist the beleaguered social care sector.

If some of the large for-profit organisations currently providing social care ‘go bust’ or decide that the social care sector no longer offers them a worthwhile investment, what then? Where will those people with a learning disability formerly resident in homes run by these organisations go given that local authorities have largely abandoned this sector?

Some local authorities – like Rochdale – are reviewing the policy of offering tenancies to people with a learning disability in supported housing in the community. Such local authorities argue that they are being forced to make savings: one such saving

being achieved by transferring residents to facilities catering for larger numbers. Some commentators have represented this trend as a return to institutionalisation.

The claim that we may be returning to a period of institutionalisation cannot be lightly dismissed. The last two decades have witnessed the closure of day centres, adult training centres, sheltered employment schemes (e.g. Remploy) and the growth of chronically understaffed care settings where opportunities for residents to participate in community activities are limited.

Another factor that cannot be ignored is the growing impact of artificial intelligence and robotics which will eliminate a wide range of unskilled, semi-skilled and skilled forms of employment so that competition for those jobs remaining will be intensified. In such a situation job opportunities for people with a learning disability are likely to be negligible to non-existent.

One reason that we are currently in such a dire situation is because over the past three decades we have viewed educational, health and social care provision for people with a learning disability through too narrow a prism – one constrained by a limited perception of the meaning of inclusion and community.

My fear is that the current pursuit of the policy of austerity when combined with the likely negative consequences of Brexit will set in train an irreversible process that will adversely affect all people with a learning disability and their families. If something is going to be done to reverse this process then it needs to be done very soon as time is fast running out.

1. LOW PROFILE

It has been argued that people with a learning disability – those with significant limitations in both functioning and adaptive behaviour – have become an invisible population in the UK. The Chief Executive of the National Development Team for Inclusion in the UK recently observed that people with a learning disability have achieved little or no profile for the last 20 years (Greig, 2015). He highlighted a conversation that he had had with a senior government official who informed him that any attempt to seek radical improvements in provision for people with a learning disability would fail because the numbers were too insignificant to warrant government action. But what is an insignificant number? It is estimated that there are at least 1.2 million people with a learning disability in England (Emerson et al, 2012). When one adds to that total those directly involved in the support of people with a learning disability, including family members and care staff, that figure is significantly increased.

In a recent survey conducted by Mencap it was found that parents who had children with a learning disability believed that mainstream schools were failing to help their children reach their full potential. According to this survey 1,000 parents found mainstream schools were failing children with a learning disability – with 81 per cent of parents saying they were not confident their child's school was helping them do their best. Nearly two-thirds of parents (65 per cent) were convinced their children were receiving a poorer education than those without special needs. A similar number (64 per cent) indicated that their child had been taken out of class or activities because of their disability. Jan Tregelles, Mencap's chief executive, concluded: "parents feel the education service is woefully ill-prepared to properly support children and young people with a learning disability to reach their full potential" (Garner, 2014).

The low profile of learning disability in professional discourse is strongly evidenced in a recent report published by The Commission on Residential Care (Burstow, 2014). Notwithstanding its broad remit, the report's principal focus was on older adults and people with a physical disability. Of the nine commissioners there was not one who had a professional background in learning disability. Four of the commissioners held senior positions in for-profit organisations, whilst two were from not-for profit organisations. In the list of just under one hundred references at the end of the report, there was only one which specifically addressed issues relating to people with a learning disability. The main recommendation of this report was that the term 'residential care' should be abandoned and replaced by 'housing with care'. The effect of this semantic mutation appears to place greater emphasis on 'housing' than 'care', yet it is the 'care' which is paramount not the

location in which the care is offered - a fact established in research undertaken by Tizard half a century ago (Tizard, 1960)!

According to the Confidential Inquiry into Premature Deaths of People with Learning Disabilities it was found that people with a learning disability have poorer health than the general population, much of which is avoidable (Heslop et al, 2013). These health inequalities often start early in life and result, to a significant extent, from barriers they face in accessing timely, appropriate and effective health care. The impact of such health inequalities is serious. As well as having a poorer quality of life, it was also found that people with a learning disability died on average 13 years younger than men in the general population and women 20 years younger. Data has also shown that people with a learning disability are three times as likely as people in the general population to have death classified as potentially avoidable through the provision of good quality care.

Flood has highlighted the fact that people with a learning disability not only have complex needs but they may have more than one disability; may exhibit challenging behaviour; may have multiple morbidities; consume multiple medications; and may not use words to communicate (Flood, 2016). For people with a learning disability medicines can only be helpful when used appropriately and kept under review and monitored. Equal outcomes for people with a learning disability are important but the evidence of what intervention works is sparse. Society has a responsibility to target services to this vulnerable population because of the high risk of medication safety incidents. Flood has argued that the type of model of care used in each community should be determined locally and based on the professional resources and health and social care needs of the population with a learning disability.

It is revealing that after winning the general election in 2015 David Cameron downgraded the importance of the role of the minister for disabled people. The ministerial post had previously been a junior ministerial role until October 2013 with the appointment of Mike Penning who became a minister of state. At the time Penning observed that making this a senior ministerial post showed the government's commitment to disabled people (Pring, 2015). Kate Green, Labour's shadow minister for disabled people commented that what disabled people needed and deserved was a minister who understood the issues, commanded respect of colleagues and would stand up for their rights. She concluded that downgrading the role in government called into question the importance David Cameron gave to the interests of disabled people. A spokesperson for Number 10 stated that the status of the office of minister for disabled people remained unchanged and that ministerial ranks were based on the experience of the office holder and did not have any bearing on the importance of the office itself.

The downgrading of the importance of the role of Minister for Disabled People can scarcely be regarded as surprising given the very abbreviated tenure of this post during the coalition government (2010-2015) and Conservative government (2015 – to date). The average length of time of the person holding that post has been one year scarcely time enough to master the brief with the result that the post holder is heavily reliant on the civil service which by disposition is disinclined to be enthusiastic about changes – particularly new ideas that might lead to radical departures from current practice.

Half of those appointed to this role in the two administrations had had no previous ministerial experience and of those that had, it was in quite unrelated fields – Armed Forces, Immigration and the Northern Ireland Office. It would also appear that relevant knowledge, qualifications and experience in the field of disability have no bearing on who is appointed. This situation places the civil service at a great advantage particularly if an enthusiastic minister is contemplating a departure from established practice for

they will have through their long acquired knowledge and experience all the reasons why a minister's ideas would inevitably encounter problems - real or imaginary. Ministerial colleagues, too, are unlikely to be supportive of a Minister for Disabled People given that they are likely to share the general perception that this is a minor and unimportant office. Or to put it more crudely there are few votes to be gained by devoting time and effort to this subject.

Penny Mordaunt Minister of State for Disabled People, Health and Work 15 Jul 2016

Previous ministerial experience: Minister of State for the Armed Forces

Justin Tomlinson Parliamentary Under Secretary for Disabled People 2015-16

No previous ministerial experience

In May 2015 the role of *Minister of State for Disabled People* was replaced by the role of *Parliamentary Under Secretary of State for Disabled People*

Mark Harper Minister of State for Disabled People 2014-15

Previous ministerial experience: Minister for Immigration

Mike Penning Minister of State for Disabled People 2013-14

Previous ministerial experience: Minister of State for Northern Ireland Office

Esther McVey Parliamentary Under Secretary for Disabled People 2012-13

No previous ministerial experience

Maria Miller Parliamentary Under Secretary for Disabled People 2010-12

No previous ministerial experience

Jonathan Shaw Parliamentary Under Secretary DWP (Minister for Disabled People) 2008-10

Previous ministerial experience: Minister for SE of England

Anne McGuire Parliamentary Under Secretary DWP (Minister for Disabled People) 2005-8

Previous ministerial experience: Department for Constitutional Affairs

2. GOVERNMENT ATTITUDES

Looking in detail at all the changes to the benefits system in the last five years, Ryan has concluded that the government's attitude towards disabled people has been pointlessly cruel (Ryan, 2015). The actions of successive governments have been characterised by administrative maladroitness and financial incompetence. Eight government policies have been identified by Ryan that have had a particularly negative impact on people with a disability.

1. **Work Capability Assessment (WCA)** The assessment procedure used to determine if a disabled or chronically ill person is eligible for this allowance has been shown to be seriously flawed and poorly administered. For example, people with degenerative conditions – conditions which by definition are only going to get worse – were being judged by the WCA as likely to 'recover' enough for applicants to look for work.
2. **Personal Independence Payments (PIP)** At the same time that there were serious problems in the administration of the Employment Support Allowance, the government decided to scrap a key disability benefit – Disability Living Allowance (DLA) and to replace it with Personal Independence Payments (PIP). Just over three million disabled people in 2012 were receiving DLA to help pay for their additional care or mobility needs. The abandonment of the DLA and the introduction of the PIP were prompted by the (false) belief that vast numbers of disabled people were making unnecessary and fraudulent claims.
3. **Bedroom Tax** The intention of the bedroom tax was to cut the housing benefit of social tenants who were deemed to be 'under-occupying' their home. However, almost two thirds of the tenants affected by this policy came from households that contained someone who had a disability. Indeed the government's own impact assessment had anticipated that a policy of penalizing people for needing extra space would result in hurting the disabled and chronically ill. Research examining the impact of the bedroom tax demonstrated the negative impact of this national welfare policy on life chances (Moffat et al, 2015). The authors of this study made the case for revoking the bedroom tax due to its impact on health and wellbeing. They concluded that if it was not withdrawn then the longer term impact of the bedroom tax would to increase poverty, worsen health and widen health inequalities.
4. **Council Tax** Whilst the introduction of the bedroom tax attracted widespread publicity, it came at the same time as another hit on the ability of the vulnerable to pay the rent. From April 2013 funding for council tax benefit was cut by £500 million which left cash-strapped local authorities with the decision how to spend the remainder. The result was that 2.3 million families who had been previously exempt from council tax now had to pay at least a portion of their council tax which had the effect of affecting most the poorest, the disabled and carers.
5. **Independent Living Fund (ILF)** The ILF was a standalone fund that helped 18,000 of some of the most severely disabled people to live in their own homes. Access to the fund made the difference between living independently as an adult or having to go

into residential care. In defence of their decision to close the ILF the government argued that a person formerly supported by the fund would simply be transferred to local authority care provision. However the money transferred to the local council was not ring-fenced which meant that local councils, which were in the process of contracting social care, were under no obligation to spend it on current recipients.

6. **Social Care** The Association of Directors of Adult Social Services has drawn attention to the fact that over the past four years social care has had over £3.5 billion taken from its funding by the government (ADASS, 2014). One third of people who benefit from social care are working-age disabled people. The result has been that councils have been forced to reduce the number of disabled people deemed to be eligible for social care. Research undertaken by the charities Scope, Mencap, The National Autistic Society, Sense and Leonard Cheshire Disability has revealed the scale of the crisis facing over 100,000 disabled people (Scope, 2016). In many cases it was found that basic needs were not being met:
 - 40% said social care services did not meet basic needs like washing, dressing or getting out of the house
 - 47% said the services they received did not enable them to take part in community life, like seeing friends or volunteering
 - 62% said they had spent their own money to help them eat, dress, wash or get out of the house.
7. **Access to Work** Only after legal action threatened by campaigners did the Department for Work and Pensions agree to publish the secret guidance it had given to Job Centre staff that indicated who was eligible for support (Pring, 2014). The limits which had been placed on the amount of help available resulted from the creation by government of a climate of suspicion. The Department of Work and Pensions was warned by the Work and Pensions Select Committee that the process by which people can challenge decisions needed to be made much more transparent.
8. **Benefit Sanctions** In 2014 the number of benefit sanctions against disabled and chronically ill people had risen by 580%. Measures were introduced by the coalition government to increase the amount of money they were able to take from sanctioned disabled and chronically ill people. The application for hardship payments to help keep people alive during the sanction period appeared to be designed in such a way that it was too difficult for vulnerable people to understand. Thus the people potentially most in need of the hardship system were the least likely to be able to access it. Not only were Job Centre managers routinely encouraging staff to sanction claimants' benefits but Job Centres competed with one another in achieving the targets set. The Public Services Commercial (PSC) union revealed that Job Centre staff who failed to achieve targets set were placed on Performance Improvement Plans which could result in them losing out on annual pay awards. Thus there was a strong incentive for Job Centre staff to deny claimants access to hardship payments.

Early in 2012 the UN Committee on the Rights of Persons with Disabilities began receiving information about the alleged adverse impact on persons with disabilities of the implementation of these reforms of legislation and policies. The information indicated that the implementation of the welfare reforms had introduced significant cuts to social benefits that were affecting several of the rights of persons with disabilities enshrined in the Convention.

In April 2013 the UN Committee received a formal request from a number of grassroots organisations representing persons with disabilities (e.g. Disabled People against Cuts) – not the major charities – claiming that serious and systematic violations of the provisions of the Convention were occurring against persons with disabilities. They requested that the UN Committee initiate an investigation into the matters raised in their request. According to its rules of procedure the Committee requested the UK government to submit a response. Responses were received from the UK government on 20 August 2013 and 28 March 2014. In April 2014 the UN Committee assessed all the information before it and determined that there was sufficient and reliable information to indicate that there were grave and systematic violations of the rights set forth in the UN Convention. The UN Committee decided to establish an inquiry and appointed two of its members as rapporteurs. This decision was communicated to the UK government on 29 May 2014.

It is worth noting that when the UN Committee made known its intention to undertake an inquiry it met with a hostile response from the government and the right-wing press. According to Jack Doyle in a MailOnline article, Tory MPs branded the investigation ‘politically motivated’ and observed that Britain’s record on help for disabled people was among the best in the world (Doyle, 2014). The investigation was presented as the latest in a series of interventions into British domestic policy by the UN. This provoked fury among ministers. Conservative MP Michael Ellis commented:

“This politically motivated loony left decision brings the UN organisation into disrepute. At a time when there are grave international crises around the world and when in dozens of countries around the world there are no benefits available, this absurd decision is made to attack our country which rightly does more than almost any other to protect the rights of disadvantaged people from all walks of life.”

(op.cit)

A fellow Conservative Philip Davies observed:

“These people at the UN are idiots, frankly. There’s no other way to describe them. This country has led the way in the support and rights that we give to disabled people – such as through the Disability Discrimination Act which was passed by a Conservative government in 1995. If the UN drew up a list of countries in the world showing how much they gave to disabled people they would find the UK was the highest in the world. They are exposing the UN for the completely useless organisation that it is.”

(op.cit)

The visit to the UK took place from 12 to 23 October 2015. The UN Committee’s rapporteurs had the opportunity to interview more than 200 individuals, among them government officers, members of the House of Lords and the House of Commons, members of the devolved legislatures, representatives of the independent monitoring mechanisms, representatives of trade unions, representatives of organizations of persons with disabilities and other civil society organizations, researchers, academics and lawyers.

The UN Committee expressed its regret that local authorities and councils did not cooperate with it during the visit, despite several invitations addressed to them to

participate. The UN Committee would also have appreciated it if the first meeting agreed with the central government had been held on the first day of its visit. Instead that meeting was postponed to the last day!

On the 6 October 2016 the UN Convention on the Rights of Persons with Disabilities published its report which was entitled 'Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention' (United Nations, 2016). As a result of an examination of research and a number of independent studies, a number of issues were identified by the Committee:

- ◆ financial loss for persons with disabilities, lower income for households claiming benefits under the welfare system and persons with disabilities being the biggest single group affected by the reforms
- ◆ significantly greater impact in the poorest areas
- ◆ more persons with disabilities living in poverty
- ◆ no account being taken of those people no longer eligible for entitlements and services
- ◆ more inequality and growing restrictions on social care services owing to the decreasing budget allocations earmarked for social care
- ◆ reduction in services available for home care and on services for older people
- ◆ risk of social isolation and more reliance on informal and family care
- ◆ loss of eligibility for or reduction in entitlement under the assessment for the Personal Independence Payment
- ◆ the negative impacts of the reduction on housing benefits
- ◆ the closure of the Independent Living Fund
- ◆ the transition from the Disability Living Allowance into Personal Independence Payment
- ◆ the changes in the Employment and Support Allowance
- ◆ impact on public transport services available for persons with disabilities
- ◆ negative stereotyping of persons with disabilities.

The UN Committee submitted the following recommendations to the UK government:

1. It should conduct a cumulative impact assessment of the measures adopted since 2010 on the rights to independent living and to be included in the community and social protection and employment of persons with disabilities.
2. It should ensure that any intended measure of welfare reform is rights-based, upholds the human rights model of disability and does not disproportionately and/or adversely affect the rights of persons with disabilities to independent living and an adequate standard of living and employment.
3. It should ensure that any intended legislation and/or policy measure respects the core elements of the rights analysed in their report:
 - persons with disabilities retain their autonomy, choice and control over their place of residence and with whom they live
 - they receive appropriate and individualized support and have access to community-based services on an equal basis with others

- they have access to social security schemes that ensure income protection that are compatible with an adequate standard of living and ensure their full inclusion and participation in society
- they have access to and are supported in gaining employment in the open labour market on an equal basis with others.

4. It should ensure that public budgets take into account the rights of persons with disabilities and that sufficient budget allocation is made available to cover extra costs associated with living with a disability and that appropriate mitigation measures, with appropriate budget allocations, are in place for persons with disabilities affected by austerity measures.
5. It should introduce those adjustments necessary to make all information, communications, administrative and legal procedures in relation to social security entitlements, independent living schemes and employment/unemployment-related support services fully accessible to all persons with disabilities.
6. It should ensure access to justice, by providing appropriate legal advice and support, including through reasonable and procedural accommodation for persons with disabilities seeking redress and reparation for any alleged violation of their rights.
7. It should actively consult and engage with persons with disabilities through their representative organizations and give due consideration to their views in the design, implementation, monitoring and evaluation of any legislation, policy or programme related to the rights addressed in the report.
8. It should take appropriate measures to combat any negative and discriminatory stereotypes or prejudice against persons with disabilities in public and the media and should adopt measures to address complaints of harassment and hate crime by persons with disabilities, promptly investigate those allegations, hold the perpetrators accountable and provide fair and appropriate compensation to victims.
9. It should ensure that, in the implementation of legislation, policies and programmes, special attention is paid to persons with disabilities living with a low income or in poverty and persons with disabilities at higher risk of exclusion, such as persons with learning disabilities, psychosocial or multiple disabilities and women, children and older persons with disabilities.
10. It should set up a mechanism and a system of human rights-based indicators to permanently monitor the impact of the different policies and programmes relating to the access and enjoyment by persons with disabilities of the right to social protection and an adequate standard of living, the right to live independently and be included in the community and the right to work, in close consultation with persons with disabilities and their representative organizations.

3. THE GOVERNMENT'S RESPONSE TO UN REPORT

Gwen Owen, Political Correspondent for the Mail on Sunday, indicated that the government had been braced for criticism of its welfare policy and the conclusion of the UN report that disabled people in Britain were unfairly bearing the brunt of austerity cuts (Owen, 2016). She further noted that Ministers were planning to counter the Report's criticisms by arguing that the findings were out-of-date and by questioning the credibility of the authors, one of whom had called for state funding for disabled people to visit prostitutes. What this particular criticism overlooks is the fact that sexual services for disabled people have been and continue to be offered in the Netherlands and Denmark (Withnall, 2017). And to this writer's knowledge such a practice has been in operation in a number of English local authorities for the past thirty years.

One senior Whitehall source is reported to have said that they intended to 'push back hard' against the UN report by pointing out that the UK spends more on disability welfare than the average among developed countries. According to Work and Pensions Secretary, Damian Green, the report was "patronising and offensive" and presented an outdated view of disability in the UK. He went on to claim that Britain was "a world leader in disability rights and equality" (Butler, 2016).

However disability activists and charities welcomed the report, saying it accurately highlighted the real economic and social pressures faced by disabled people after years of harsh spending cuts to social security and social care (op. cit). The Shadow Work and Pensions Secretary, Debbie Abrahams, said the UN report was "crystal clear" in its identification of UK government failures and confirmed that the government was failing sick and disabled people. Further, the UN committee had made quite clear that its report examined the cumulative impact of legislation, policies and measures adopted from 2010 to October 2016 so that the government's claim that it was outdated did not stand up to scrutiny. Linda Burnip, founder of Disabled People against Cuts (DPAC), a grassroots campaign group that helped to trigger the UN inquiry in 2013, indicated that the findings would come as no surprise to anyone who had followed the progressive and remorseless stripping away of disabled people's rights over the last six years.

The less than enthusiastic response by the UK government to this inquiry, which was reflected in the delaying of any contact until the final day of the team's visit, can be seen as both diplomatically insensitive and politically inept. Further, the unwillingness of any local authority in the UK to meet with the inquiry team is likely to have resulted from pressure applied by the UK government. Had local authorities been allowed contact, they

would almost certainly have confirmed the concerns expressed by those organizations that had approached the UN Committee.

The Equality and Human Rights Commission (EHRC) raised concerns about the government's response to the report and found it guilty of "grave or systematic" violations of the UN disability convention. It reported that the government's social security reforms had had a "particularly disproportionate, cumulative impact" on disabled people's right to independent living and an adequate standard of living (Pring, 2016).

The report called on the UK government and the Scottish and Welsh devolved governments, to incorporate the UN Convention on the Rights of Persons with Disabilities – and the other six "core" human rights conventions the UK has ratified – into domestic law. The report also expressed its concern at the worrying lack of progress with society's most vulnerable and marginalised in danger of being left behind.

A coalition of 60 national disability charities condemned the government's cuts to benefits as a 'step backwards' for disabled people and their families (Cowburn, 2016). The Disability Benefits Consortium said the cuts, which will see people lose up to £1500 a year, will leave disabled people feeling betrayed by the government and will have a damaging effect on their health, finances and ability to find work. Rob Holland, co-chair of the Disability Benefits Consortium (DBC) indicated that cuts to employment and support allowance and universal credit mark a step backwards for disabled people and their families many of whom live in poverty and struggle to make ends meet.

A survey of 500 people in the affected group by the DBC found that 28% of people had been unable to afford to eat while in receipt of the benefit. Around 38% of the respondents said that they had been unable to heat their homes and 52% struggled to stay healthy. Only one per cent of those asked said that the cut would motivate them to get a job sooner despite claims from Conservative ministers suggesting that cutting ESA entitlement for new claimants would prove an incentive for them to return to work.

Holland noted that the government was pushing ahead with the cut in spite of widespread opposition from all 60 members of the Disability Benefits Consortium, disabled people, the general public, the Equality and Human Rights Commission and MPs and Peers from across all parties warning that the cuts would push disabled people closer to poverty and further from the work place. Holland concluded that many disabled people would feel betrayed by a government that had promised not to cut disability benefits but had now pushed the cut through without showing any real understanding of the damaging effects it would have on people's health, finances and ability to find work. The Disability Benefits Commission did not accept the Government's reasoning that cutting disabled people's benefits would 'incentivise' them to look for work as the barriers were much more complex than that.

So how does UK expenditure on benefits and services for disabled people compare with spending in other countries? Does it measure up to Damian Green's claim that the UK is a world leader in disability rights and equality? To answer that question, it is necessary to find a framework where spending in countries with different policies and institutions can be fairly assessed. There are two such frameworks, one from the Organisation for Economic Co-operation and Development (OECD) and one from Eurostat. Although they measure different things – the OECD provides data on expenditure on 'Incapacity-related benefits' and Eurostat on 'social protection benefits in the disability function', both adopt similar approaches to fundamental issues of classification and definition. If one wants to compare the UK with other countries on a like-for-like basis, these are probably the best sources (L'Art Social, 2013).

Both Eurostat and the OECD are explicit about the conventions they use in order to ensure comprehensive coverage of all the relevant types of expenditure so there is no excuse for the confused comparisons made by Lord Freud, when welfare reform minister in June 2013:

'I will set a little bit of context by saying that even in these hard economic times this Government continues to spend around £50 billion a year on disabled people and services to enable those who face the greatest barriers to participate fully in society. That figure compares well internationally. We spend almost double the OECD average as a percentage of GDP – 2.4% against the OECD average of 1.3%. Only two out of the 34 OECD countries spend more.'

(Hansard, 2013)

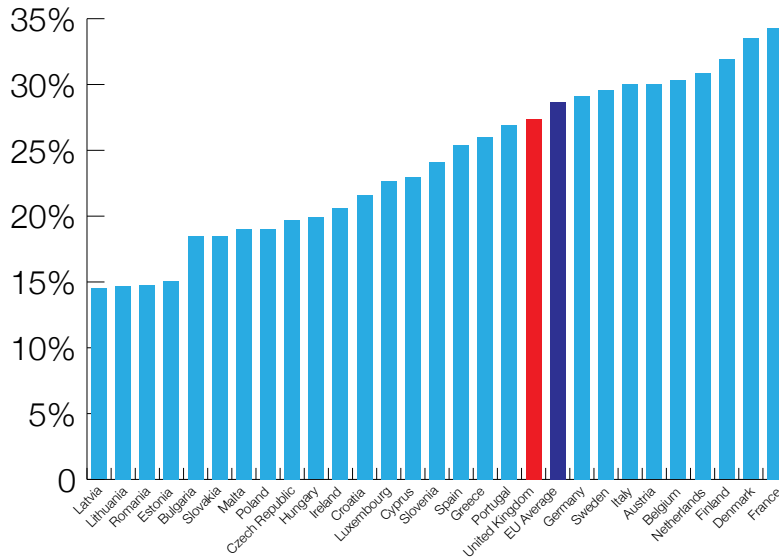
A cursory glance at the OECD social expenditure database shows that:

- ◆ the OECD average expenditure on 'incapacity-related benefits' in 2009 was 2.6% of GDP, not 1.3%.
- ◆ 2.4% of GDP in 2009 was not £50 billion but £34bn, and even if one applies the 2.4% figure to UK GDP in 2013/14, this only gets us to £38 billion.
- ◆ ten, not two, OECD countries spend more than the UK. So we have a number of serious factual inaccuracies in two sentences. The only figure which is plausible is 'about £50 billion' for overall spending, which is reasonably close to what you get if you apply the correct 2009 percentage (3%) to the forecast GDP for 2013-14. But this figure is patently inconsistent with the other figures Lord Freud cites.

It is important that expenditure on disability should be looked at in the round. Cherry-picking individual components falls into the category of what has been described by Gaffney as 'applied data torture' (Gaffney, 2013). It also brings out what is really distinctive about the UK system. Compared to other European countries, UK spending on helping disabled people with the additional costs they face (counting both cash 'care allowances' and benefits in kind) looks respectable, lower than Sweden but similar to Denmark and Norway and higher than France or the Netherlands. But the UK spends very little on the benefits which cover basic living costs for sick and disabled people, Incapacity Benefit and ESA, and this is even more marked when one takes into account the fact that these benefits are also to some extent substituting for sick pay. Under the coalition's plans the UK would have been spending less on both types of benefit, which may help explain why Lord Freud felt the need to grossly exaggerate the UK's spending relative to other OECD countries.

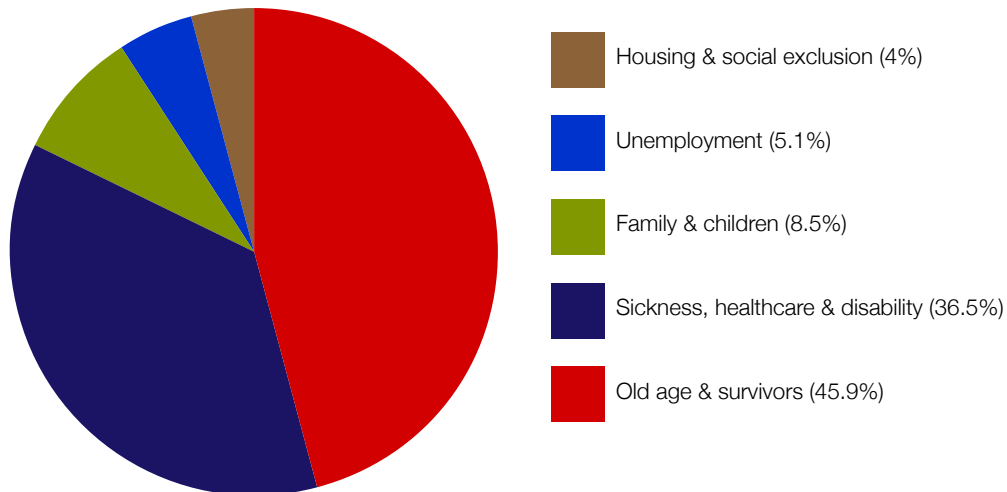
According to a recent news release from Eurostat the UK is the only rich EU country to cut welfare spending as a proportion of GDP between 2011 and 2014 (Eurostat, 2016). The allocation to sickness/health care and disability benefits accounted for 36.5% of total social benefits on average in the EU in 2014. In the UK it was 37.2%; however this percentage was exceeded by nine countries: Iceland (51.5%); Norway (46.2%); Croatia (45.8%); Germany (42.8%); Netherlands (42.3%); Estonia (41.2%); Ireland (40.6%); Czech Republic (38.0%); Sweden (37.9%). Thus close inspection of the relevant data provides no support for Damian Green's claim that Britain is "a world leader in disability rights and equality" (Butler, 2016).

It is instructive to examine the diagrams below which are taken from a Eurostat news release for the 21 December 2016. The source dataset is available as a pdf at: <http://ec.europa.eu/eurostat/documents/2995521/7777866/3-21122016-BP-EN.pdf/d353fafe-b6e6-48be-8384-948ae60e2951>



SOCIAL PROTECTION EXPENDITURE IN THE EU MEMBER STATES, 2014 (% GDP)

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SOCIAL PROTECTION EXPENDITURE BY MAIN FUNCTIONS IN THE EU, 2014 (% OF TOTAL BENEFITS)

Social Protection Expenditure 2014										
	Expenditure					Benefits by function, in % of total social benefits				
	in % of GDP				PPS per capita 2014 EU = 100	Old age & survivors	Sickness/ healthcare & disability	Family & children	Unemployment	Housing & social exclusion
	2011	2012	2013	2014						
EU	28.3	28.7	28.9	28.7	100	45.9	36.5	8.5	5.1	4.0
Belgium	29.7	29.6	30.1	30.3	123	40.3	37.2	7.5	11.6	3.3
Bulgaria	16.5	16.6	17.6	18.5	32	49.5	35.4	10.6	2.9	1.7
Czech Republic	20.1	20.4	20.2	19.7	62	47.2	38.0	8.7	3.0	3.1
Denmark	32.3	32.2	33.0	33.5	140	44.3	32.9	11.2	5.2	6.5
Germany	28.6	28.7	29.0	29.1	131	39.2	42.8	11.3	3.9	2.8
Estonia	15.6	15.0	14.9	15.1	41	44.3	41.2	10.9	2.8	0.9
Ireland	23.5	23.2	22.3	20.6	87	29.8	40.6	13.1	13.8	2.7
Greece	27.7	28.2	26.7	26.0	66	65.0	26.1	4.4	4.3	0.2
Spain	25.3	25.5	25.8	25.4	77	49.1	33.4	5.3	10.8	1.4
France	32.7	33.5	33.9	34.3	131	45.4	35.0	7.8	6.2	5.5
Croatia	20.4	21.1	22.0	21.6	44	43.7	45.8	7.2	2.3	1.1
Italy	28.5	29.3	29.8	30.0	98	58.6	29.4	5.4	5.8	0.8
Cyprus	21.5	22.3	24.2	23.0	66	55.5	23.3	6.3	8.6	6.4
Latvia	15.4	14.4	14.6	14.5	33	52.0	33.3	9.1	4.0	1.6
Lithuania	16.9	16.3	15.3	14.7	40	47.7	39.0	7.8	2.4	3.1
Luxembourg	21.9	22.8	23.2	22.7	188*	37.7	36.7	15.6	6.5	3.6
Hungary	21.7	21.4	20.8	19.9	50	52.1	32.1	11.9	1.9	2.1
Malta	18.8	19.0	18.8	19.0	56	51.7	36.6	6.6	2.9	2.2
Netherlands	30.2	31.0	31.2	30.9	137	42.5	42.3	3.1	5.6	6.4
Austria	29.0	29.3	29.8	30.0	134	50.7	32.3	9.5	5.6	2.0
Poland	18.7	18.9	19.4	19.0	49	60.4	29.6	7.6	1.3	1.0
Portugal	25.8	26.4	27.6	26.9	71	57.5	31.2	4.6	5.8	0.9
Romania	16.4	15.4	14.9	14.8	29	55.1	34.3	8.3	1.0	1.3
Slovenia	24.5	24.9	24.9	24.1	68	49.0	37.0	7.9	3.0	3.1
Slovakia	17.8	18.0	18.3	18.5	52	45.6	39.9	9.3	2.9	2.3
Finland	28.9	30.1	31.1	31.9	123	41.7	34.9	10.4	8.2	4.8
Sweden	28.2	29.3	30.0	29.6	123	43.4	37.9	10.6	3.8	4.2
United Kingdom	29.1	29.2	28.4	27.4	100	43.1	37.2	10.4	1.7	7.7
Iceland	23.9	23.7	23.4	23.9	99	28.1	51.5	11.5	3.1	5.8
Norway	24.8	24.5	25.0	26.0	152	35.9	46.2	12.4	2.3	3.2
Switzerland	25.4	26.3	27.0	27.1	142	48.1	39.0	6.0	3.6	3.3

* See country note

4. THE FUTURE OF SOCIAL CARE

A survey conducted by the Association of Directors of Adult Social Services in 150 English local authorities, which received a near 100% response rate, suggested that the current system was under severe stress. A third of directors believed people who would qualify for care support were already unable to access it as a result of spending cuts and tightened eligibility criteria. As well as cuts, future savings were likely to come from reducing service users' personal care budgets. Relatively few directors saw increasing charges to service users as a major source of savings.

Social care chiefs have warned that more older people and citizens with disabilities will be denied state funded care support as local authority finances continue to take a battering from funding cuts. The scale and severity of the financial squeeze was laid bare in a survey which showed that by April 2013 councils in England will have stripped out £2.7 billion from adult care services since 2010 – equivalent to 20% of their care budgets even as demand for services continue to rise.

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Councillor Zoe Patrick, Chair of the Local Government Association Community Wellbeing Board has stated:

“The stark reality is that if such vast sums of money continue to be taken out of the system it could be in very real danger of collapse.”

(Butler, 2013)

As a recent report by the think tank ResPublica has pointed out, concerns over funding for social care, and the sector's viability, are not new (Crawford and Read, 2015). In July 2010, the government created an independent commission to review future funding of care and support. The commission's overall conclusion was clear: “the current social care system is inadequately funded (Commission on Funding of Care and Support, 2011). People are not receiving the care and support that they need and the quality of services is likely to suffer as a result”. The commissioners added that the system of funding care and support was not fit for purpose and had desperately needed reform for many years. The report made a number of specific suggestions including:

- ◆ a cap on the amount any individual should contribute to his or her care
- ◆ a rise in the means-tested threshold at which individuals became eligible for state help with care costs.

The government broadly accepted the report's recommendations, with the cap and the change in threshold forming part of planned changes under phase two of the Care Act

2014. The intention was for both changes to come into force in April 2015. Yet in July 2015, the government announced a delay until 2020.

The authors of the report argue that the funding crisis demands urgent action as continuing to do nothing is simply not an option when:

- ◆ the residential care home sector is facing a £1.1 billion funding gap within five years
- ◆ residential care is required to pay the National Living Wage, necessitating care homes finding an extra £382 million by 2020/21
- ◆ chronic underfunding makes closure of care homes a real possibility
- ◆ closure of homes would lead to a loss of up to 37,000 beds
- ◆ the NHS would need to find £3 billion to care for older people no longer homed within residential care.

The report concluded that there was a need for fundamental reform across the system. A piecemeal approach was no longer an option when faced with an imminent and explosive crisis.

In January 2017 the prime minister received the sternest of warnings from the chairs of three influential Commons Select Committees – Conservative MP Sarah Woolaston of the Health Committee; Labour’s Meg Hillier of the Public Accounts Committee and Clive Betts, another Labour MP of the Communities and Local Government Committee (Ruddick, 2017). They all called for a new political consensus to address the problems confronting social care.

It has been claimed that up to half of Britain’s care homes will close and the NHS will be overwhelmed unless steps are taken to prevent the devastating collapse facing social care, an alliance of charities, local councils and carers has warned (Campbell, 2015). In a joint letter, 15 social care and older people’s groups warn that social care in England, already suffering from cuts imposed under the coalition, will be close to collapse unless money is found to rebuild support for the 883,000 older and disabled people who depend on personal care services in their homes. It was recognised that social care in England has been in retreat for a long time. The fact that the industry was now losing its appeal, both as a business and as a form of employment marked a dangerous phase in its decline according to Caroline Abrahams, Age UK’s charity director.

It has been revealed that since 2010 a hundred or more care home businesses had collapsed than had been previously thought. According to the Insolvency Service, 380 have been declared insolvent since 2010. The number of failures each year has risen sharply since 2010, when 32 businesses failed. In 2015, 74 were declared insolvent, while another 34 failed in the first six months of 2016, the most recent figures available. The squeeze was being particularly felt by the smaller family operators, who ran one or two care homes but accounted for about 55% of the industry.

One reason that care homes are struggling is because of a fall in the amount that councils pay towards fees for residents at the same time as costs are rising driven by the introduction of the government’s National Living Wage. This means that from April 2016 workers aged 25 or over must be paid at least £7.20 an hour. This will lead to an increase in payroll costs of about 5% for most businesses last year. This rise would have been problematic anyway, but local authorities are also reducing how much they pay towards social care after seeing their budgets cut by up to 50% as a result of government austerity measures.

Large companies are also in trouble. Four Seasons, the biggest care home operator in the UK with more than 400 properties, is the most at risk. It recorded a pre-tax loss of £28 million in the three months to the end of September 2016 for which financial accounts are available. The company is also sitting on more than £500 million of debt, a legacy left by the previous owners. This debt means it pays about £30 million in interest to its lenders every three months. As well as care home operators collapsing, other companies may simply pull out of the industry. BUPA, one of the largest operators behind Four Seasons, was reported to be looking to sell 200 homes, although it indicated it remained committed to the industry.

The Independent and Corporate Watch examined Britain's 10 largest care home providers, as ranked by Laing & Buisson, of which eight are for-profit companies (seven private and one provident). The corporate structures and debts of many of them leave them at the mercy of the market. The debts of Four Seasons, Care UK and NHP are rated as risky (junk bonds) (Lakhani and Whittell, 2012).

An alliance of charities, local councils and carers has warned that up to half of Britain's care homes will close and the NHS will be overwhelmed unless the government acts (Campbell, 2015). In a joint letter, 15 social care and older people's groups have urged the government to plug a funding gap that the claim will hit £2.9 billion by 2020. They warn that social care in England, already suffering from cuts imposed under the coalition, will be close to collapse unless money is found to rebuild support for the 883,000 older and disabled people who depend on personal care services in their houses. According to Caroline Abrahams, Age UK's charity director, the fact that the care industry is losing its appeal, both as a business and as a form of employment, marks a dangerous phase in its decline.

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According to research undertaken for a BBC Panorama programme by Opus Restructuring and Company Watch:

".....sixty-nine home care companies have closed in the last three months and one in four of the UK's home care companies is at risk of insolvency."

Responding to accusations that the autumn 2016 statement by the Chancellor of the Exchequer ignored social care, Sajid Javid, the Communities and Local Government Secretary, announced that councils could increase council tax by an extra 3% to fund social care. He also announced that there would be a £240 million 'adult social care support grant' to help councils with the care of older residents.

However Robbie Barr, chairman of Four Seasons, was cautious about the impact of this proposal. Figures collected by Four Seasons showed that although more than 90% of councils increased council tax last year, less than half of these passed it on to care homes through an increase in their fees. Even if the package of measures worth £900 million were introduced by Javid, this would not cover further increases in wage costs this year. The National Living Wage is scheduled to rise by 4.2% in April 2017 to £7.50, which is larger than the proposed 3% increase in council tax.

The Local Government Association estimates there will be a £2.6 billion funding gap in providing adult social care in England by 2020. A report by the Health Foundation, the King's Fund Centre and the Nuffield Trust calculates the gap would be £1.0 billion in 2017 alone (King's Fund Centre, 2016).

Richard Humphries, assistant director of policy at The King's Fund has pointed out that:

“Cuts to social care funding are leaving older and disabled people reliant on an increasingly threadbare local authority safety net. For many, the care they get is based not on what they need but on what they can afford and where they live. More people are left stranded in hospital. This government has committed to creating a country which works for everyone, and they now need to match this with action by using the Autumn Statement to address the critical state of social care.”

Anita Charlesworth, director of research and economics at the Health Foundation, has observed:

“On too many occasions over the last few years the approach to funding for the NHS and care system has been to rob Peter to pay Paul. Social care cut to protect the NHS, budgets to train new doctors and nurses reduced to fund care now, capital budgets raided to meet day-to-day costs. It is absolutely clear that this is not sustainable and has undermined the drive to improve efficiency. While the pressures on the health service are very real, the case to prioritise social care funding in the Autumn Statement is compelling.”

This squeeze is not just leading to the closure of care homes but compromises to the quality of care and an increase in costs for private residents. The Care Quality Commission has recently warned that adult social care is “approaching a tipping point” (Care Quality Commission, 2016). This conclusion was based on its inspections, tip offs and external data. Its damaging findings included that half of the 1,850 social services rated as needing improvement had not changed when re-inspected and that 153 were downgraded to inadequate. Furthermore, it said the total number of nursing homes had dropped for the first time in five years and 81% of local authorities had reduced their real-terms spending on social care.

A survey conducted by Unison in association with Community Care highlighted the importance of residential care providers prioritising support for staff even in the face of budget cuts (Carter, 2016). The research, which examined findings from 50 homes which fell short of ‘good’ ratings and 50 homes which were rated ‘good’, revealed:

- ◆ 62% of homes that fell short of a ‘good’ rating did not have enough staff on duty compared to only 2% of homes rated ‘good’
- ◆ 48% of homes that fell short of a ‘good’ rating were not offering staff regular one-to-one supervision and annual appraisals, compared to just 10% of ‘good’ services
- ◆ 52% of homes that fell short of a ‘good’ rating were not providing staff with regular training opportunities, whereas all ‘good’ homes had ensured staff were appropriately trained.

Andrea Sutcliffe, the CQC’s chief inspector of social care, has made clear that training, supervision and support for staff are essential components of a quality service. The regulations make clear what the obligations of employers are in this regard.

The biggest problem for many home care companies is the recruitment and retention of carers. The Centre for Workforce Intelligence estimates at least two million more carers

will be needed by 2025 in England alone, in both in-home care and care homes, to cope with growing demand (BBC, 2017).

The savagery of local authority cuts and their effect on social care provision has recently led one council, Surrey County Council, to rebel (Toynbee, 2017). After cuts of £170 million since 2010, the Council argued that cutting any more would do serious harm to vulnerable people. And leaders of Isle of Wight council resigned because, in their opinion, the cuts would have made their position ‘untenable’ and ‘intolerable’.

According to the Health Service Journal, Freedom of Information (FOI) requests from the campaign group Disability United found that 37 clinical commissioning groups (CCGs) in England are in the process of introducing rules about ongoing care that could force up to 13,000 people with disabilities and long-term health needs into care homes (Brown, 2017). The CCGs will be telling people with disabilities and long-term health needs that if they have not got the cash for homecare then they will have to be moved to a care home.

The FOI requests also found CCGs were setting limits on how much they were prepared to pay for supporting people in their homes compared to an ‘alternative option’, which is usually a care home. The campaigning group Disabled People against the Cuts has indicated that cutting funds for maintaining people at home can only mean a return to institutionalisation.

The CCGs appreciate that what they are considering is at the very least highly contentious. Two CCGs acknowledged in their documents that this policy might contravene an individual’s right to respect for his or her private and family life under the Human Rights Act but felt they could justify their actions on the grounds of cost. But it should be noted here that the Prime Minister, Theresa May, has indicated that she would like to see the UK pull out of European Court of Human Rights and scrap the Human Rights Act.

It is estimated that disabled people represent a third of all social care users: this equates to around 400,000 working-age disabled people in England alone. An impression has been conveyed by the government that family members should take greater responsibility for looking after elderly relatives (Ryan, 2017). While Theresa May pledged to ensure that people would receive the care they needed in old age – she forgot about those with disabilities who rely on services for most of their lives. It would appear that while older people are seen by politicians as reliable voters to be courted, disabled people are viewed as insignificant and do not merit a mention (op. cit.).

In most discussions on social care, disabled people tend to be described by the abstract and vague term ‘vulnerable’. When politicians talk of disabled people as being vulnerable, it perpetuates the mistaken belief that vulnerability is an inevitable consequence of disability rather than the direct result of government choices. In other words it is not being unable to walk that makes a quadriplegic vulnerable: it is slashing their social care budget so there is no personal assistant to help them get dressed.

According to the charity Leonard Cheshire Disability there are more than a million disabled people living without social care. After six years of cuts to local authority budgets, almost half the disabled people who say they need support are not receiving any at all, while those already in the system have seen their care packages significantly reduced.

Mencap recently issued a Freedom of Information request to 151 local authorities in England that provided day services and conducted a survey of 280 people with a learning disability and their families and 194 professionals who work with people with a learning disability (Mencap, 2012). The data revealed that in the past three years, 32% of local

authorities had closed day services, with one in five of these not offering any form of alternative service. Fifty-seven percent of people with a learning disability who were known to social services did not receive any day service provision whatsoever, compared to 48% in 2009/10. In addition, 60% of local authorities had increased charges for going to day services and for vital services like transport to a service, on average by 70%.

What appears to be happening in the social care system is emblematic of a wider assault on disabled people's right to live independently (Ryan, 2017). Nearly £28 billion has been pulled from social security for disabled people since 2013 and the Independent Living Fund which helped 18,000 severely disabled people live in their own homes, has been axed. Benefit cuts have resulted in wheelchairs and adapted cars being taken away from disabled people.

The fact that politicians can engage in a conversation about social care without referring to disability is a reminder of how, for certain people, the most basic rights and needs can be simultaneously characterised as expendable and simply forgotten. Ryan argues that this mindset is a product of a culture that still does not equate disability with a normal adult existence and a government that is content to perpetuate that myth (op. cit.). The fact that we are now living in an era of 'scrounger' rhetoric and austerity policies exacerbates the situation. While older people are largely seen as a group that should be protected, disabled people are widely perceived as a costly burden on the state.

5. THE CQC: A FAILED ENTERPRISE

It can be argued that many of the problems now experienced in social care stem from developments that took place over a decade ago. In April 2004 the Labour Government set up the Commission for Social Care Inspection (CSCI) with the aim of modernizing the system of regulating care services. In November 2004 the CSCI published its first performance ratings of all councils with social services responsibilities. The rapid privatisation of the care sector coincided with the decision by the CSCI to transfer greater responsibility for the assessment of care standards to care providers. Thus, within a short time of the CSCI having been established, self-regulation was accorded a high priority. In November 2004 the CSCI published a consultation document *Inspecting for Better Lives - Modernizing the Regulation of Social Care* in which it proposed that self-assessment be introduced for care providers (Commission for Social Care Inspection, 2004).

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The Commission indicated that it expected care providers to be honest about the strengths of their service and explain what they were doing to improve it. It went on to state that it would take a tough line on misleading self-assessments and view them as a sign that the service was not being well managed. In a follow up document, published in July 2005 entitled *Inspecting for Better Lives - Delivering Change*, it was acknowledged that there were some who believed that the adoption of a self-assessment system could be open to abuse (Commission for Social Care Inspection, 2005). Notwithstanding these reservations the CSCI made clear its determination to introduce what it described as 'provider self-assessment' which it viewed as an essential part of its new ideas.

Given the scale of the problem facing the CSCI, in terms of seeking to raise care standards, it was all the more surprising that it proposed to cut its own workforce by 25%. These changes, which were a direct result of the Government's policy of devolving powers in the public sector and its commitment to reducing public sector expenditure appear to be built upon the naive assumption that if care providers take part-ownership of the regulatory process that they will do so in a responsible manner.

Unison, the principal trade union representing social care staff in the UK, campaigned to highlight the effects of these changes on the safety and quality of care provision. Union members were reporting that the new regulatory system, with its reduced staffing, was failing because of a lack of time:

- ◆ to target its resources on those providers giving a poor service
- ◆ to follow up on concerns and complaints or detect problems in the early stages
- ◆ to impose and follow up on enforcement measures

- ◆ to spend time in the field talking to service users.

Unison pointed out that inspectors were ‘too thin on the ground’ and that the situation would be further exacerbated by planned redundancies (Samuel, 2009a).

However, in 2009, only five years later, responsibility for regulating and inspecting adult social care and healthcare was passed to the Care Quality Commission which represented a merger of the CSCI, Healthcare Commission and the Mental Health Act Commission. In its final report in 2009 the CSCI noted that services for those with complex needs were being adversely affected by poor strategic commissioning, lack of person-centred care and ‘marginalisation’ of human rights (Commission for Social Care Inspection, 2009; Latchem, 2009). It also drew attention to the fact that some service users had little if any choice about their services and councils relied on inappropriate out-of-area residential care (Ahmed, 2009).

The outgoing chair of the Commission for Social Care Inspection, Dame Denise Platt, went out of her way to warn about the ability of the CQC to act as an effective social regulator. She stated that it would struggle to balance its health and social care responsibilities because the focus of public attention would be on health care which meant that failings in adult social care were unlikely to attract much attention. She highlighted the fact that the CQC lacked people with social care expertise at senior level, as many CSCI managers had not transferred to the CQC. She also questioned the ability of the CQC to shape social care policy in the way that the CSCI had done through the publication of its annual State of Social Care reports. She further observed that the focus on social care policy was likely to be diluted in a body which had been set up to look at both health and social care (Samuel, 2009b).

Dame Denise could not conceal her exasperation that the decision to abandon the CSCI appeared to have been made out of ignorance: ‘there was really a big misunderstanding in central government about the nature of our role. People think social care is the mirror image of health. It isn’t’ (Davies, 2005). She pointed out that their values might be similar but the underpinning policy assumptions were different, not least because users have to pay for social care. ‘Many of the things the Chancellor wanted to achieve around burdensome regulation can be achieved by changing the regulations, not necessarily by changing the institutions’ (op. cit.). Not only had the Government succeeded in creating one of Europe’s biggest regulators but also there was an increased fear that the move heralded the long anticipated ‘takeover’ of social care by the health service. When asked if the Chancellor had been badly advised, Dame Platt pointedly and crisply replied:

‘...the level of ignorance in the Department of Health about how social care as a sector operates should not be underestimated’

(op. cit.)

For its part the former Labour Government made clear that the Care Quality Commission would continue to focus on reducing its operating budget. Early indications suggested that this meant a reduction of 40% on the budgets of the three predecessor organizations. Closely linked to the budget reduction was the decision to continue the deregulated inspection methodology practised in the CSCI which was termed ‘proportionate risk-based inspection’. When translated this meant fewer inspections. The previous statutory requirement to inspect care homes twice a year had been abandoned. Now the minimum requirement was for care homes and homecare providers to be

inspected once every three years and inspections were to be replaced by 'Annual Service Reviews' which were paper exercises based on provider 'self-assessment' and any other intelligence received.

But even prior to the demise of the Commission for Social Care Inspection, it was already clear that many social care premises were failing. An examination was made of the inspection reports of 24 of the premises run by one of the market leaders (Jackson, 2010). It was found that one quarter of the premises had to meet at least six or more statutory requirements. There were three areas that occasioned the Commission particular concern:

1. **Overuse of agency staff** The inspectors drew attention to the need for the company to review recruitment procedures to ensure that more was done to employ permanent staff teams thus reducing the use of agency staff. A further matter noted was a failure to obtain satisfactory clearance for agency staff and to produce evidence that they were appropriately qualified.
2. **Staffing levels** A recurrent issue noted by the inspectors was a failure by the company to employ a sufficient number of staff to meet the needs of residents, particularly those requiring 1:1 attention. It was pointed out that if demands for 1:1 staffing were not met then this could lead to restricted choice for other residents thus increasing the risk of neglect and abuse. Insufficient staffing also meant that opportunities for social, educational and recreational experiences for residents were limited.
3. **Failure to implement Commission requirements** The company failed to implement the statutory requirements repeatedly identified by the Commission. In one case the registered manager had been required to ensure that suitably qualified, competent and experienced persons were working in the home at all times and in such numbers that were appropriate for the health and welfare residents. This requirement had been made on no fewer than three previous occasions.

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It might be reasonably expected that a responsible service provider would pay attention to requirements or recommendations made by the CSCI and seek to implement the changes needed as expeditiously as possible. The apparent failure of the company to appoint sufficient permanent and appropriately qualified staff to meet the needs of residents would seem to imply an unwillingness to invest adequately in staffing. The evidence from these inspection reports could be interpreted to suggest that running costs were being deliberately kept down through the use of agency staff and by maintaining low staffing levels.

According to Philpot, the CQC was an unhappy creation (Philpot, 2011). The merger of the Commission for Social Care Inspection, the Health Commission and the Mental Health Act Commission led to a budget that was a third less than the total budget of its predecessors and with a third less staff. The new body had to reconcile three different management systems and three very different managerial cultures. To complicate matters further dentists and GPs were brought under its oversight. In 2012 The Department of Health published a Performance and Capability Review of the CQC which noted that since its establishment, it had faced:

- ◆ operational and strategic difficulties
- ◆ delays in registering providers
- ◆ shortcomings in compliance activity
- ◆ a negative public profile (Department of Health, 2014).

All of these had seriously challenged public confidence in its role. The Review further acknowledged that the Department of Health and CQC had seriously underestimated the scale of the task, as Dame Platt had warned.

Whilst the CQC was charged with the responsibility of encouraging the improvement of health and social care services, it was noted that there was a lack of clarity as to how the CQC fulfilled this role given its emphasis on compliance against essential standards rather than seeking ways to improve the quality of services above essential standards, as the previous organizations had sought to do.

In 2014 the Care Quality Commission published a review which focused on services that provided care for people with a learning disability and challenging behaviours. CQC inspectors carried out 150 unannounced inspections that looked at two national standards: (1) care and welfare; and (2) safeguarding (protecting people's health and wellbeing and enabling them to live free from harm) (Care Quality Commission, 2014). The inspections took place at 71 NHS Trusts, 47 private services and 32 care homes. Five of the 150 inspections were pilots and were not included in the overall analysis.

Of 145 inspections:

- ◆ 35 met both standards
- ◆ 41 met both standards with minor concerns
- ◆ 69 failed to meet one or both standards

It was noted that many of the failings were a direct result of care that was not centred on the individual or tailored to their needs. Almost 50% of hospitals and care homes that were inspected did not meet national standards.

The King's Fund Centre has warned against expecting the CQC to guarantee high quality in the social care sector. It argued that the CQC could only ever be the third line of defence against poor care (King's Fund Centre, 2014). The first line of defence must be frontline staff who deliver the care and who when properly empowered and supported can improve quality and address problems. The second line of defence was the leaders in the relevant professions and the managing boards of organisations. And the third line of defence was the national bodies, of which the CQC was one. In the opinion of the King's Fund Centre the expectation that the CQC could guarantee high quality care at all times was not only unrealistic but it ran the risk of distracting attention away from the fact that the quality of care offered was a local responsibility.

The prediction by Dame Denise that the CQC would prove an ineffective social care regulator had been clearly demonstrated not least by the growing number of cases of abuse and maltreatment in a variety of health and care settings and by the scathing judgements on the operation of the CQC made by a succession of Parliamentary Select Committees.

In 2011, the Commons Health Committee reported that:

- ◆ the CQC was established without sufficiently clear and realistic definition of its priorities and objectives
- ◆ the timescales and resource implications of the functions of the CQC were not properly analyzed
- ◆ the registration process itself was not properly tested and proven before it was rolled out
- ◆ the CQC failed to draw the implications of these failures adequately to the attention of ministers, Parliament and the public (Commons Select Committee, 2011).

In 2015 Meg Hillier, Chair of the Public Accounts Committee, indicated that six years after having been set up the Care Quality Commission was still not fully effective. Attention was drawn to the fact that there was too often a long gap between inspections and reports being published - and sometimes an alarming lack of attention to detail when reports were being prepared (Commons Select Committee, 2015).

6. THE DECLINING IMPACT OF PRESSURE GROUPS

Charities

It is significant that none of the major disability charities in the UK were involved in extending an invitation to the UN Committee on the Rights of Persons with Disabilities. But then, as will be pointed out later, given that the large UK charities are financially dependent upon public funds, they may have been reluctant to be seen to question government policies. Thus it has been left to grassroots organizations like Disabled People against Cuts (DPAC) to offer a challenge to the UK Government's current austerity programme (Jackson, 2015).

Debbie Jolly, co-founder of DPAC, pointed out that challenges to the UK Government's current austerity programme, which led to severe cuts in services for people with disabilities, was not being led by the well-paid directors of UK charities but was coming from the grassroots, in which individuals with disabilities employed social media, Freedom Of Information requests, as well as the support of sympathetic media, lawyers, and MPs (Connolly, 2015). In that process individuals with a learning disability were still at a disadvantage and might be excluded, because some measure of sophistication is required to exploit the social media and other communicative mechanisms.

What cannot be in dispute is that fundamental changes in the structure and operation of the charities representing people with a learning disability and their families in the UK are urgently needed. If it is the case that the current profile of people with a learning disability is barely discernible, as has been claimed, then the major charities have to shoulder part of the blame for that situation. There is a compelling case for these charities to be re-grounded and to act more assertively, imaginatively and independently. But is it too late?

William Shawcross, the chairman of the Charity Commission, has warned that charities are risking their reputations if they are not seen to be getting a grip on boardroom excesses (Hope, 2013). Jan Tregelles, the current Chief Executive of Mencap, recently wrote an article in which she sought to explain the reality of being a charity boss and why such bosses deserve their controversially high pay checks (Tregelles, 2013). She acknowledged that many of her colleagues, donors and beneficiaries believed her salary was very high. In her article Tregelles nevertheless failed to justify her salary of £169,000 which was considerably in excess of that of the Prime Minister.

At a time when many charities are experiencing shortfalls, trustees should consider whether very high salaries are appropriate and fair to both donors and the taxpayers who fund charities. Disproportionately high salaries run the risk of bringing organizations and the wider charitable world into disrepute. It is a matter of particular concern that

charities are not subject to the same level of scrutiny and accountability as government departments or quangos. The number of people in the UK saying that they trusted charities fell from 50% to 32% over the last year (Grierson, 2017). Lloyds Bank Foundation has reported that charities with incomes between £100,000 and £500,000 lost nearly half their income from local government between 2008 and 2013 (Ginns, 2016). In contrast, large charities, which enjoy incomes between £10 million and £100 million, lost just 2% of their local government income over the same period.

Despite rising costs, many of the UK's best known charities are still based in London. Given that 68% of people believe London-based charity offices are wasteful, is it time for a rethink of resources (Cahalane, 2015)? London-based charities tend to argue that a London based location is important; however with improvements in transport links, meetings could be held in London at various low cost venues or through using teleconferencing. As policy work only forms a small part of a charity's work, a location with access to Westminster is unnecessary as a small satellite office would be sufficient. And this is a strategy adopted by an increasing number of charities.

A number of general criticisms of disability charities have been identified by Wood (2014):

- ◆ they are not run by disabled people
- ◆ impairment specific charities contribute to the segregation of disabled people
- ◆ they reinforce negative stereotypes of disabled people, particularly through advertising and marketing
- ◆ they benefit as much, if not more, than the people they claim to be helping, and that as part of this process charities receive a positive image, while disabled people are once again portrayed as needy
- ◆ charity is linked closely to the medical model focussing on the impairment rather than the person and implying that it is the impaired person that is 'faulty' rather than society
- ◆ they plug gaps in state provision with many social services activities being farmed out to charity organisations

Some of the most strident criticism of the role of today's charities has come from Iqbal Wahhab in his book *Charity Sucks* (Wahhab, 2016). He argues that organized charities in the UK have failed and will continue to fail because they are complacent and wedded to an outdated model of *noblesse oblige*. The Charity Commission is represented as a toothless regulator nestling in a cosy world of failure. Wahhab believes that the adoption of a business model is the means to restore trust. In his opinion the difference between social enterprise and charity is straightforward: social enterprises make loans, see business opportunities, enable people to work and encourage profits. Thus when one hands over one's money, one is making an investment and one is in a better position to measure outcomes (Lott, 2017).

It is conceded that some of the disability charities have been forced to change but this has been largely due to changes in the economic climate. In 2012 Mencap anticipated making 30 staff redundant as it was facing a reduction in income due to a drop in public sector work and the inability of fundraising to plug the gap. Mark Goldring, former Mencap chief executive, indicated that redundancies were necessary in an environment in which government was funding less of the work that the charity delivered. Mencap had a heavy reliance on public sector contracts for revenue. For the year ending 31st March

2011, Charity Commission records show that of a total income of £193.6 million, £179.2 million came from charitable activities and just £12.5 million from fundraising.

The disability charity Scope has had to cut staff numbers by 260 and make redundancies costing more than £900,000 in the year to March 2016 according to its most recent annual accounts (Scope, 2017a). Total staff numbers have been reduced from 3555 to 3295 – a 7% reduction – leading to redundancy costs of £905,256. The charity announced in its fifth annual report an operating deficit and its fifth year of reduced overall income. In his introduction to the annual report, Andrew Macdonald, wrote that Scope had been financially “up against it” and had had to take tough decisions. He observed that it was a difficult environment in which to run a charity with the purse strings on public expenditure continuing to tighten and new needs in society being exposed. At the same time public trust in charities was falling with frequent criticism of the charities in the media. Macdonald concluded that the role of charities in society was facing fundamental challenges which merited a proper public debate.

The role of the country’s largest disability charities in providing back-to-work services under the government’s new Work and Health Programme has been recently called into question (Pring, 2016). They have been accused of “selling out” disabled people. From May 2016 charities and other organisations will no longer be allowed to spend government grants on lobbying ministers. A new clause is to be inserted into all new and renewed grant agreements from 1 May 2016 forbidding the use of such funds for lobbying. The Cabinet Office said the new clause would mean funds are spent on improving people’s lives and good causes, not on “activity intended to influence – or attempt to influence – parliament, government or political parties”.

This means that the charities will be unable to campaign effectively on welfare reform because of the size of contracts on offer. For their part the “big seven” disability charities - Mencap, Scope, Mind, Disability Rights UK, Leonard Cheshire, RNIB, Action on Hearing Loss - have insisted that any contracts they win from the government will have no impact on their campaigning work. They claim that it will not preclude them from speaking up about social security reform, including cuts to disability benefits and back-to-work policies for disabled people. Confidence in such an assertion is weakened by the disclosure that the Charity Commission has written to Mind’s trustees following a complaint about the charity’s close links with the government. There is a fear that the independence of the charity has been compromised through collaborating with the government which goes beyond constructive joint working. It is also difficult to see how organisations taking money from government to provide services of any kind will be in a position to campaign effectively against the policies of welfare reform.

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But DPAC have dismissed the suggestion that the charities would speak out strongly against the Department of Work and Pensions if they won multi-million pound contracts under the new programme. Linda Burnip, DPAC co-founder, has commented that the contracts are rumoured to be worth between £2 million and £30 million and that once part of propping up the system, any independence would be lost.

A survey of 150 members of parliament from across the major political parties has shown that 62% of Conservative MP respondents believe charities are currently too political, while 30% think that charities should be banned from actively campaigning in parliament, compared to just 1% of Labour MP respondents. The survey also showed that in general, Conservative MPs were more likely to hold critical views of charities compared to Labour and SNP MPs (Radojev, 2015).

Charity bodies have strongly criticised the government's attempts to silence them, arguing that charities have a vital role to play in campaigning for the most vulnerable and disadvantaged. They argue that, as the organisations working on the front lines, charities are often best placed to know what policy changes are needed, and to draw government's attention to failures and areas for improvement. Charities have also argued that the new rules on how to spend government grants is tantamount to making them take a vow of silence.

Sir Stuart Etherington, chief executive of the National Council for Voluntary Organisations, has expressed the view that such an insane policy proposed by the government is unworkable. Lord Harries, former Bishop of Oxford and chair of the Commission on Civil Society and Democratic Engagement has argued that the charities are on the 'front line' and often best placed to identify where government policy is failing. In such circumstances, he asks, surely charities are morally bound to tell the government where policies are not working and where improvement could be made.

For their part ministers have asserted that the new clause would promote value for money and lead to better services. Yet the Cabinet Office has been unable to provide any evidence to support either claim other than stating that the clause "closes a loophole". It has also been unable to indicate how often this apparent loophole has been exploited and could not cite a single example of abuse (Butler, 2016b).

A study of 120 contract tenders has found that the smaller charities are being shut out of competition for government and council contracts by complicated bureaucratic and inappropriate processes (Brindle, 2016). The future of many smaller charities with priceless local knowledge and connections is being put at risk by their inability to comply with the myriad requirements and paperwork that typifies official tendering. In one case, an invitation to tender for a contract worth less than £350,000 a year was found to require answers totalling 27,000 words to 44 questions! One charity bidding for a mental health contract was found to have been marked down for not having a hard-hat policy – the process being used to decide the contract was the same as for procurement of building work.

Paul Streets, chief executive of Lloyds Bank Foundation, which undertook the study expressed the view that common sense has failed in the commissioning of services (Streets, 2016). He expressed alarm at the scale of the commissioning crisis which was engulfing small charities and threatening their survival. The report published by the Foundation, entitled *Commissioning in Crisis*, indicated that many of society's most intractable problems can only be solved through the reach of grassroots organisations and their application of bottom-up solutions. The survival of such groups is imperilled by their growing failure to win or retain service contracts. Without dedicated bid-writing teams or business development departments they cannot compete with national charities,

housing associations and for-profit service providers in increasingly onerous tendering processes.

The report found that although most of the tenders it analysed had an annual value of between £100,000 and £600,000 with many falling below £150,000, the Foundation expressed the view that the processes “often appeared more suited to multimillion pound contracts for no discernible rhyme or reason”. Further, some tenders stipulated minimum turnover sizes for contractors that prevented smaller charities from even bidding. In other cases, charities were informed they would have to work in partnership with another organisation not of their choice.

In Streets’ opinion change is needed now and at every level. Commissioners and government need to change the systems that govern processes, with corresponding work in the voluntary and community sector to increase smaller charities’ capacity to meet commissioners’ needs. The report calls upon councils and government to adopt a more collaborative approach to commissioning, to take a proportionate view of necessary process and to place more emphasis on the social and long-term value of contracts. It also calls upon ministers to challenge poor commissioning practice. Finally, there needs to be greater transparency in process and a measurable target should be introduced to oblige commissioners to work with small and medium-sized charities.

Research to be published in mid-May 2017 by New Philanthropy Capital (NPC) draws attention to the increasingly dysfunctional relationship between charities and the state with many charities that are most dependent on public service contracts struggling (Butler, 2017). The charities claim that years of austerity have led councils and the NHS to seek contracts at the lowest possible price with the result that the quality of services has been driven down leaving many providers in a financially unsustainable position. Particular concerns have been expressed by charities that they are being required to subsidise the cost of contracts with donor funds as a condition of being awarded a contract. It is pointed out that this leaves trustees with an ethical dilemma as to whether to continue out of a sense of duty to beneficiaries. The research by the NPC reveals that over half of the charities it surveyed had turned down contracts because the operational risks of trying to deliver a quality service on the cheap were too high. Other charities had handed contracts back because they felt they could not deliver value to beneficiaries with the available funding.

Neil Cleeveley, chief executive of the National Association for Voluntary Community Action (NAVCA), has highlighted a further trend which he regards as unhealthy (Cleeveley, 2016). The government is increasingly using insider conversations rather than open consultations when dealing with the use of the voluntary sector. He makes the point that democracy is damaged when people, companies and organisations are able to influence politicians in private. If the government is really concerned about lobbying then openness and transparency would do more to improve the climate than any set of bureaucratic standards. Cleeveley concludes:

“Charities play a vital role in bringing together politicians and the people directly affected by their decisions. This is how decision making is improved. Rather than fearing charities’ criticism, government should be looking at what they can learn from smaller charities.”

Advocacy

What then of the role and effectiveness of advocacy programmes? A problem with many advocacy schemes is that they are usually dependent on statutory sector funding from health authorities and/or social work departments. Although this financial support is welcome and serves to provide stability and security to local advocacy projects, there are inherent dangers in relying too heavily on such funding. A particular concern in the UK is the trend for advocacy schemes to be funded through contracts rather than grants. The Scottish Executive some time ago made the point that the tendering process is not a creative way to achieve the effective provision of advocacy (Scottish Executive, 2001).

- ◆ It requires the commissioners to specify in considerable detail what is to be provided. However, a better picture of what people need most from advocacy emerges more clearly over time.
- ◆ It sets up the purchaser-supplier dynamic, where the advocacy scheme is expected to see itself as delivering a service on behalf the commissioners, not in response to the people who need advocacy. This compromises an agency's independence.
- ◆ It encourages advocacy schemes to be dependent on the funding provided by the commissioners, so that the advocacy only happens if this funding continues to be provided. By definition, advocacy means a continuing commitment to people over time and not abandoning that commitment in difficult times.
- ◆ It tends to encourage the allocation of funds to the larger, national advocacy agencies which can present bids, demonstrate a track record and negotiate contracts. This makes it harder for advocacy to become genuinely rooted in the community.

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The tendency for statutory service funders in the UK to impose service agreements is undesirable for the following reasons:

- ◆ they present a direct challenge to the integrity of advocacy schemes
- ◆ they can lead to subtle or blatant pressures on advocacy schemes to disclose confidential information
- ◆ they can accentuate the bureaucratisation of the service provided
- ◆ they permit the funder to retain control and place a check on the process of client empowerment.

There must be some doubt as to the future of community-based advocacy schemes for people with a learning disability and for the following reasons. First, there are too few volunteers in our communities to make advocacy a viable option. Second, the statutory services have succeeded over the years in introducing measures to nullify the impact of advocacy schemes. This has been done by:

- ◆ funders imposing tight contractual arrangements which limit the operational independence of an advocacy scheme
- ◆ a process of assimilation whereby advocacy schemes are absorbed into the statutory system
- ◆ granting to advocacy token and not substantive recognition.

Third, the abrasive manner in which some self-advocacy organisations have pursued a narrow radical agenda has alienated support for advocacy. Fourth, the pressure on advocacy services to become increasingly professionalized and bureaucratic in character is likely to discourage volunteer advocate recruitment. Fifth, as other priorities are identified, advocacy will slip down the political agenda of national governments and organisations. This means that less money will be directed to already financially over-stretched advocacy schemes reducing further their capacity to offer a worthwhile service (Jackson, 2005).

Lobbies

There is strong evidence to suggest that the best organised and most effective lobby groups are those representing intellectually able individuals who may have a physical or sensory disability. Perhaps the most significant intervention in this regard is the 1981 Education Act which for the first time emphasised the inclusion of pupils with special educational needs into mainstream educational settings. This emphasis resulted in large measure from the intervention of Physically Handicapped and Able-Bodied (PHAB), a lobby group representing people with a physical disability. Not only did this lobby influence the general direction of legislation, but it also helped draft some amendments to the Bill, which were subsequently incorporated into the Act. This disclosure was made by Neill Evans, a civil servant at the Department of Education and Science, who was responsible for steering the Bill through its various parliamentary stages (Rozenberg, 1981).

There is a certain irony in the fact that when giving the 2005 annual lecture to the General Teaching Council for Scotland, Mary Warnock stated: “no serious suggestions for reform can be made without proper research and a proper reliance on evidence”. It is ironic because the Committee of Enquiry that she chaired sponsored no major research (Special Educational Needs, 1978)! In that respect it differed significantly from all previous committees commissioned to examine important aspects of British educational systems: Plowden Report on primary education (Central Advisory Council for Education, 1967), Newsom Report on secondary education (Central Advisory Council for Education, 1963) and the Robbins Report on higher education (Committee on Higher Education, 1963).

The low estimation of the value of research revealed in the contents of the Warnock Report may have been influenced by the attitude to research of the person responsible for setting up the Committee of Inquiry – Margaret Thatcher. On frequent occasions she had communicated her lack of enthusiasm for research which she saw as both costly

and time-consuming. It was Mrs Thatcher's antipathy to academic research and her refusal to provide the funds required to support university research that contributed to the unprecedented refusal by the Senate of Oxford University to confer an honorary doctorate upon her in 1985.

Shortly after the Warnock Report was published and in my capacity as a M.Ed. course leader at what is now the University of Winchester, I invited Mary Warnock to address a student seminar on the subject of the Report. What made a clear and lasting impression upon me and all the students in attendance, most of whom were heads or deputy heads of special schools for pupils with learning disabilities, was the admission by Mary Warnock that perhaps too much attention had been paid to the needs of pupils with physical and sensory disabilities and too little attention to the needs of pupils with learning disabilities.

Nearly three decades after the publication of her report Mary Warnock acknowledged in a pamphlet written for the Philosophy of Education Society of Great Britain that the implementation of her ideas in the Report had left a "disastrous legacy". She concluded that: "governments must come to recognise that even if inclusion is an ideal for society in general, it may not always be an ideal for school" (Warnock, 2005). The logic of including pupils with a learning disability in mainstream schools is being increasingly questioned given the rapid growth of specialist academies and free schools for pupils with different abilities (e.g. mathematical, scientific, technological, musical, sporting, etc).

The key point to make here is that the ability of charities, advocacy schemes and lobbies to speak up for people with a learning disability has been progressively and consciously weakened by central government over the past few decades which means that governments can proceed with policies disadvantageous to this population with little effective challenge.

7. EMPLOYMENT AND PEOPLE WITH A LEARNING DISABILITY

One clear illustration of the way in which charities have failed the populations they purport to serve can be found in the employment field. In 2012 the government proposed the closure of 36 of Remploy's 54 factories leading to compulsory redundancies for 1,752 people of which 1,518 were disabled. Established in 1945, the state-owned company Remploy was the UK's leading specialist employer of disabled people with some 3,000 people on its payroll. Mencap, Scope and RADAR strongly supported the closure of the factories arguing that they were an outdated and segregated form of provision.

Mark Goldring, then Chief Executive of Mencap, put the view of the charity:

"While Remploy factories have been of real benefit in the past, we believe that employment in the mainstream market place is key to the inclusion of people with a learning disability in all parts of society and to actively changing public attitudes towards people with a learning disability. Value for money is crucial and it is sensible to reinvest funding released from less effective employment programmes into Access to Work, which is widely supported by disabled people"

(Mencap, 2012).

Liz Sayce, chief executive of the Royal Association for Disability Rights (now Disability Rights UK) went so far as to describe Remploy factories as 'ghettoes' (Brindle, 2011). However Tracy Lazard from Inclusion London argued that at a time of recession, when non-disabled people could not find jobs and when benefit cuts were pushing genuinely disabled claimants off benefits and into poverty, it was irresponsible to remove meaningful employment from thousands of disabled people (Lazard, 2012).

In a survey conducted by the GMB trades union in March 2014 with 489 former Remploy employees, it was found that:

- ◆ 52.8% (258) were unemployed
- ◆ 23.1% (113) had retired
- ◆ 24.0% (118) were employed

To have opposed the closure of the Remploy factories, Mencap would have had to abandon its unqualified and unquestioning commitment to an inclusionist agenda and this would have constituted an embarrassing ideological volte-face.

According to the report *Ahead of the Arc* by the All-Party Parliamentary Group on Disability (APPGD), there has been a failure by public and private employers to provide

appropriate support to disabled people in the workplace and to offer fair access to start-up funds, business advice and business networks which amounted to “institutional disability” (Enable, 2016). The Group argued that it was time to consider abandoning a voluntary-only approach towards requiring employers to measure and to increase disability employment (Connolly et al, 2016).

The report recommended that employers which have been found to have discriminated against disabled people should face lesser penalties if they have “substantive” equality policies in place. And it went on to argue that the government needed “a tighter legal framework” to ensure that disabled employees were no longer “managed out of the workplace” by their employers, something that was happening to an estimated 35,000 to 48,000 disabled people every year.

The government was urged to take a new, innovative and multi-dimensional approach combining incentives, persuasion, funding and legislation in six broad areas:

- ◆ self-employment
- ◆ the availability of government business loans and grants to disabled people
- ◆ securing support from mainstream and specialist business networks
- ◆ taking advantage of the large sums of government money spent on public procurement
- ◆ spreading best practice
- ◆ offering employers incentives such as tax breaks, but also imposing new regulations.

Further the government must ensure that public sector contracts were only awarded to organisations with a good track record on employing disabled people. It pointed out that the £242 billion the government spent on buying goods and services every year was largely a missed opportunity to use that influence and help redress disability-related employment disadvantage. This could mean that inclusive recruitment and retention policies were standard clauses in public sector contracts with targets monitored by the organisations commissioning those contracts.

The APPGD report also recommended that organisations should as a routine procedure collect, record and analyse the disability status of their users, employees or applicants. It also called upon the government to provide a new right to return to work for newly-disabled workers within a year of acquiring a major disability or long-term health condition.

However within a short time of the report being published, there were signs that the Minister for Disabled People, Penny Mordaunt, was distancing herself from the report and in the process dismissing the months of work invested in the report by disabled people, user-led organisations, academics, charities, MPs and peers.

One explanation for the Minister distancing herself from the report was that there was not the political will to follow through on any of the recommendations. This response was entirely predictable given the government’s consistent record of ignoring the recommendations of reports (e.g., UN Convention of the Rights of Persons with a Disability; European Human Rights Commission).

The role of the country’s largest disability charities in providing back-to-work services under the government’s new Work and Health Programme has been called into question (Pring, 2016a). They have been accused of “selling out” disabled people. From May 2016 charities and other organisations will no longer be allowed to spend government grants on lobbying ministers. A new clause is to be inserted into all new and renewed grant

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In 2011 the Department of Work and Pensions published a report entitled *Getting In, Staying In and Getting On*. Five core principles were set out in the report:

1. Employment matters. Work is positive for health, for income, for social status and for relationships. Employment is a core plank of independent living and for many people work is a key part of their identity.
2. Public money should be used to deliver the best outcomes – for as many people as possible, on the most equitable basis possible.
3. There should be a clear recognition of the role of the individual, the employer and the State in achieving equality for disabled people.
4. Disabled people should have choice and control over the support we need to work. Resources and power should be allocated to individuals who, where they wish, have the right to control that resource to achieve agreed outcomes.

5. There is a clear role for specialist disability employment expertise – as a resource not a world apart from mainstream support – available to those who demonstrably have the greatest support needs and/or labour market disadvantage, and also to those who support or employ them (Department of Work and Pensions, 2011).

The Report acknowledged that change was difficult and that some recommendations in the report would pose real challenges to individuals and organisations. It was claimed that the model of employment support needs to change so that it:

- ◆ met disabled people’s aspirations
- ◆ was based on evidence
- ◆ was fit for the future, and
- ◆ served far more people than it does today.

It was therefore necessary to think about what would best meet the aspirations of young disabled people and people who will become disabled in the years to come. If that is not done the next generation of disabled people would still be out of work for lack of good cost effective support and they, their families and the British economy would be the losers.

It is instructive to see how this approach has played out in Scotland. Recognising the role of supported employment in tackling inequality, the Scottish Parliament’s Equal Opportunities Commission published a report *Removing Barriers and Creating Opportunities* in 2006 in which it recommended good quality supported employment be funded in Scotland. In February 2010 the Scottish Government and Convention of Scottish Local Authorities published *The Supported Employment Framework for Scotland*. Supported employment was defined as ‘an end to end’ service for people with disabilities or long-term health conditions. It was argued that it should sit within the local employability pipeline so services and individuals could be linked to local resources but supported employment clients needed to be offered consistent, ongoing support from one employment support worker, who holds the thread of their employment journey into and within work.

Unease was expressed in the Scottish Parliament by Sarah Boyack MSP at the rapid introduction of supported employment programmes (*Learning Disability Alliance Scotland*, 2017). Five areas of concern were identified:

1. Supported employment for adults with a learning disability has never had a clearly recognised source of funding. Many DWP programmes are targeted at people with disabilities who are closer to the labour market than people with a learning disability who need longer term interventions. Moving funding from social work to economic development may have a certain superficial logic but economic development departments have a much wider responsibility for the local economy and have little or no experience or expertise in working with people with a learning disability.
2. There is some evidence here of ‘policy rush’ where a policy has been adopted and pursued without consideration for possible modifications or alternatives. It is made clear that the programme is designed to support people after they get a job not to train them first. The problem here is that the people who lose out are those with little experience and skill who need help. It was pointed out that it was not necessary to take this restricted approach for funding could have been divided between training and supported employment.

3. The payment-by-results policies which are integral feature of the programme put pressure on organisations to get more people into work. 30% of the funding is linked to the numbers that obtain jobs. The pressure will be on achieving success by helping those closest to the job market to the detriment of those needing more intensive support.
4. Tendering for social care services means that organisations who want to win have to put in a competitive bid. 'Give back' is the term that has been used to describe how this system works. An organisation calculates what they could do for the total money and then decides how to 'give back' which reduces their service by 5-10%. The lowest bid has the best chance of winning. Those organisations bidding reason that it is better to have a reduced service than none even if it means that the service is reduced in scope. The result is that the market decides the nature of the support offered to the most vulnerable rather than properly planned services with agreed standards.
5. The Scottish Government's new policy of Self Directed Support is meant to mean choice for those that use services. However a single tendered contract means that people can only get the service the Council has chosen. Thus those wanting some form of initial training are left with no choice. The question arises as to how many other services for people with a learning disability rely on are suffering from a gradual restriction on council funding, competitive tendering and 'Give Back'.

In Edinburgh one high profile casualty of the adoption of the Supported Employment Framework was The Engine Shed a supportive business that had been operating since 1989 providing a three year work-based training for up to 30 young adults with a learning disability. In 2008 Jim Mather, Minister for Enterprise, Energy and Tourism, acknowledged that The Engine Shed's high reputation in Edinburgh for the quality of its products and the added value of its training programmes gave trainees not only enhanced employment opportunities but also a good quality of life (Mather, 2008). He saw the mix of business and social purpose as a winning combination through generating income and creating employment opportunities. This was a clear example of the role that the third sector could play.

Dharmendra Kanani, Director of the Big Lottery Fund Scotland, commended The Engine Shed for its ambition to demonstrate that 'disability' should be positively regarded by taking an approach that matched need with opportunity and providing hope, confidence and sustainable livelihoods for those participating in the programmes. In Kanani's view The Engine Shed represented a shining example of a social enterprise that possessed the power to transform communities and deliver social change.

It should be noted that the closure of The Engine Shed in 2014 which occasioned a wide public outcry in Edinburgh had been preceded by the shutting down of two other supported businesses in the city – BlindCraft in 2011 and Remploy in 2013.

What those advocating the Supported Employment Framework appear not to have recognised or have consciously overlooked is that businesses like The Engine Shed provide an inclusive environment within which trainees are able to interact with members of the public and for their part members of the public can appreciate the level of practical and social skills exercised by the trainees. I can confirm the positive features of such training programmes having had the line management responsibility for a farm training centre for adults with a learning disability for five years.

There would appear to be a number of serious weaknesses in the Supported Employment Framework. Firstly, the most obvious is that it excludes those individuals

with a learning disability who would find integrating into a mainstream work setting too daunting. What provision is made for this population given the closure of day and adult training centres? Secondly, there must be a temptation on the part of those administering a regime, which appears to be heavily reliant on tick-boxing, to outsource this role to an external agency. However, there are serious ethical and practical problems when outside agencies like Atos, Capita, G4S and Serco become involved (see Section 11). Thirdly, proponents of this Framework also appear to have overlooked the impact of technology on those industries in which placements are likely to be sought. As discussed later, the speed of technological change cannot be ignored (see Section 8). With increased competition in the workplace for those jobs remaining, it is difficult to see either managements or workforces being enthusiastic about accepting people with a learning disability. In such circumstances the probability of negative feelings directed at such placements cannot be ignored. Fourthly, the impact of Brexit cannot be entirely overlooked for if we witness a significant contraction in commerce and industry, competition for jobs will intensify. In such a situation it is difficult to see how the Supported Employment Framework could continue.

8. PROBLEMS IN UNDERTAKING INDEPENDENT RESEARCH

In the 1940s and 1950s the state of services for people with a learning disability and the level of understanding of their needs and capabilities, were both extremely limited in the UK. The legal framework for services was still as set out in the 1913 and the later 1927 Mental Deficiency Acts. Hospitals were overcrowded and were administratively separate from the rest of the hospital network. Educational psychologists were few in number and were not attached to the adult mental handicap institutions. While the introduction of the NHS in 1948 brought these hospitals within the new service, there was only limited public and political awareness of the parlous state of these hospitals, which were massively underfunded and with overwhelming staffing problems.

According to Gunzburg learning disability was not seen as a worthwhile or even respectable field of work: those doctors, psychologists and teachers possessed of vision and ideas and whose contributions would have been invaluable in advancing practice failed to see any attraction in a service they perceived as static, sterile and stultifying (Gunzburg, 1960). Nevertheless against this background, from the early 1950s a number of psychologists in England carried out groundbreaking research into the extent to which people with a learning disability could learn; two of the most influential being Jack Tizard and Neil O'Connor (Tizard and O'Connor, 1950).

Following a year as a lecturer in the Psychology Department at the University of St Andrews, Tizard was appointed in 1948 to the Medical Research Council's Social Psychiatry Research Unit (or, as it was later called, the Unit for Research on Occupational Adaptation) which was based at the Maudsley Hospital and headed by Sir Aubrey Lewis. Here for the next 16 years he was mainly concerned with pioneering research in the neglected field of learning disability. According to his own account, he and O'Connor were 'detailed' by Lewis to engage in work on learning disability about which Tizard freely admitted he knew absolutely nothing.

The appointment of Tizard and O'Connor to the Maudsley Hospital marked a milestone in the history of learning disability research, not only for the United Kingdom but for the whole world (Hall, 2008). The Maudsley at that time contained a large number of patients who appeared to be uncared for and staff who were apathetic and uncaring. However their pioneering work gradually brought about fundamental changes in attitude and practice. Although the impact of their research was strongly resisted in certain quarters, their persistence in conducting research and publishing their findings was finally recognised by the government and administrators. Tizard recognised that one can only effect change by providing sound information on which to base that desired change

(Lewin, 1976). An interesting fact about the pioneers in the field of learning disability in England at this time, with the exception of Alan and Ann Clarke at Manor Hospital, was that none were British. Tizard was from New Zealand, O'Connor from Australia, Gunzburg, Koenig, and Mittler from Austria and Kushlick from South Africa (Gunzburg, 1974; Koenig, 1960; Mittler, 2010). This meant that they were not part of what was widely recognised to be a professionally conservative and social exclusive British medical establishment, a not insignificant number of whom were sympathetically disposed to the kind of solutions proposed by the eugenicists in dealing with the problems posed by people with a learning disability. It might be added that there was during and after the war considerable hostility directed at émigrés, particularly Jewish émigrés, by members of the medical establishment (Jackson, 2013; Weindling, 2009).

Tizard and O'Connor had two undoubted advantages; first, they were not part of the British class system and did not possess its outlook and values; and second, they were present in Britain at a time when serious attempts were being made by the newly elected Socialist government to address social divisions and injustice. Thus the kind of reforms in policy that Tizard and O'Connor were seeking, as far as provision for people with a learning disability were concerned, were much more likely to be met with a sympathetic and supportive political response. It is also worth noting the fact that in these early pioneering years the research was not being conducted on university campuses but in hospital settings. Thus there is a sense in which this work was firmly grounded in the real world and not some academic cloister.

Through their research Tizard and O'Connor were able to establish that the average IQ of those certified 'feeble-minded' was 70 and that many did not have a learning disability. They also showed that young adults with IQs in the 30-40 range were capable of learning, retaining and applying knowledge to different situations. Their work challenged almost all aspects of the then current practice and produced considerable turmoil. They strenuously fought against institutionalisation and segregation and showed how people with a learning disability could be helped to learn normal work habits. While their work was of high scientific value and concerned with the psychology of learning processes, their deep conviction was to 'improve the lot' of people with a learning disability.

It was Tizard's conviction that people with a learning disability should have access to services available to the rest of the population, and not in the first instance specialist services. This was an early expression of what he saw as being the need for social inclusion. Particularly important was his work at Brooklands where he demonstrated that when children with a learning disability were removed from a large hospital and put into a residential nursery school they showed considerable improvement in their language and general behaviour (Tizard and Grad, 1961; Tizard, 1964). In the Brooklands experiment, which challenged the traditional method of residential care, he showed that it was feasible to approach social issues in a truly scientific manner. He established that the evaluation of a complex problem, which in other hands might have led to woolly value judgements, could be treated with as much rigour as a more laboratory-based problem.

Nowhere in his book *Community Services for the Mentally Handicapped* does Tizard seek to formulate any set of principles or attempt to discuss the theoretical implications of his findings. Indeed Tizard was later to acknowledge that his approach to research was sometimes construed by some of his academic colleagues as excessively pragmatic and a-theoretical. Tizard dismissed this criticism noting that the backwardness of the social sciences resulted from too great a dependence on surmise and interpretation and too little on data collection and analysis.

Although the notion of normalisation was part of the conceptual currency in circulation in Europe in the early 1960s, Tizard appears to have avoided theoretical, ambitious and ambiguous formulations which would not translate meaningfully to practice (Jackson, 1995). One person who would certainly have been aware of Tizard's sceptical attitude to the value of theory at this time was a young American psychologist working at the Medical Research Council Unit from 1962 to 1963, Dr Wolf Wolfensberger, who later was to acknowledge the importance of the time spent in Britain in helping to shape his own philosophy (Wolfensberger, 1988). The work of Tizard and O'Connor deserved and commanded international respect and in 1968, they were both awarded the Kennedy International Scientific Award and in 1973 Tizard was the recipient of the Research Award of the American Association on Mental Deficiency.

One cannot fail to be impressed in Tizard's writing by his open-minded, realistic and optimistic outlook, his over-riding commitment to the role of research, his obvious distaste for technical jargon and the formulation of grandiose theories, his keen awareness of the dangers of professional imperialism and his absolute determination to improve the quality of life for all people with a learning disability (Jackson, 1995). Zigler and his colleagues at Yale University had also pointed out that the failure to base normalisation theory on a sound empirical base frequently led to a barren and bitter polemical debate (Zigler and Hall, 1986; Zigler et al, 1986).

The importance of establishing a sound empirical base is illustrated by a study which sought to analyse the quality and costs of different types of residential facilities for adults with a learning disability. The project was commissioned and funded by the Department of Health (Emerson et al, 1999). The main part of the project investigated the characteristics and needs of, supports provided to, and outcomes experienced by, 500 people with a learning disability. The participants were being supported in one of three types of residential provision: village communities operated by independent sector organisations – none of which had been developed as a direct result of the retraction and closure of NHS mental handicap hospitals; residential campuses operated by NHS Trusts which were developed as a direct result of closure of NHS hospitals; community-based dispersed housing schemes. These services were identified through a process of consultation with various organisations the purpose of which was to identify services considered by key informants to be examples of 'good practice'.

In their final report two very important qualifications were made by the project team which the Department of Health either overlooked or deliberately ignored. The team stressed that the project did not provide an accurate picture of current practice within the three approaches examined so that the results were likely to be skewed within all the models towards the better end of the continuum of current provision of the participating organisations. There is therefore a limit to the extent to which one can generalise with any confidence to a wider universe of village communities, residential campuses and dispersed housing schemes. Notwithstanding this important qualification the Department of Health chose to highlight the performance of the dispersed housing schemes and later to totally disregard the fact that across the 20 indicators of 'quality' examined by the project team the village communities did as well as the dispersed housing schemes. Clearly this was an inconvenient finding as it challenged the government's stated policy of supporting the development of dispersed housing schemes.

The danger today is that the parameters of research are too often set by the funder (i.e., the government), particularly the time-frame within which the research has to be undertaken (Humes, 2013). Government departments sponsoring research are unlikely to be too concerned about the finer points of research methodology as their principal

aim is often to placate their political masters and demonstrate that something is being done. If the results of research are politically embarrassing, they can always be shelved, notwithstanding the fact that public money has been used to fund the research. The politicisation of the research process makes inevitable the production of compromised and flawed research. The situation is further aggravated where researchers let the evident ideological inclinations of the funders influence the way in research is framed and conducted and the findings are subsequently presented and disseminated.

But this is not a new problem as Professor John Nisbet, a former editor of the *British Journal of Educational Psychology*, has persuasively argued ‘he who pays the piper determines the tune’ (Nisbet, 1995). For example, in 1975 the Centre for Educational Sociology at the University of Edinburgh proposed undertaking a large-scale quantitative study involving school leavers (McPherson, 1984). The study was to be collaborative not only in the sense that it involved schools and local authorities but also in the sense of making the resulting data sets available to others and so broadening the constituency of informed opinion about what was happening in Scottish education. But for some within the Scottish Education Department, the sponsoring body, this raised issues of who had ownership of the research. The position of the Scottish Education Department was that if government was funding it, then the government should decide how the data was disseminated. The reason that this story hit the headlines was that there was an implicit threat by the government that it might withdraw support from what was generally recognised as a highly prestigious and internationally renowned research facility.

But even when the results of government sponsored research is criticised, it is not unknown for the government to threaten sanctions (Pickard, 1994). For example, the Scottish Office Education Department threatened to withdraw an annual grant to the principal academic journal on Scottish education - *Scottish Educational Review* - because of unhappiness at the tone of two articles which criticised the findings of research sponsored by the government. Whilst the withdrawal of its annual grant could have led to the closure of the journal, the editorial board held firm and indicated that it had no intention of responding to what it saw as interference in editorial independence. (I confess to being one of the authors of one of the critical articles!)

A curious development in recent years has been the establishment of ‘observatories’ sponsored by government departments to monitor developments in different areas. For example, the Improving Health and Lives Learning Disabilities Observatory which was set up in 2010 ‘to keep a watch’ on the health of people with a learning disability and the health care they receive. The Observatory is part of Public Health England which, in turn, is an executive agency sponsored by the Department of Health.

More recently a Scottish Learning Disabilities Observatory has been established which is funded by the Scottish Government to generate evidence and build understanding of the causes of poor health and health inequalities experienced by people with a learning disability and people with autism. It is claimed that this Observatory will “generate and translate information into knowledge that is designed to inform actions, practice and policy to benefit people with learning disabilities and people with autism”.

The use of the term ‘observatory’ is curious given that it usually refers to an institution or building specially designed and equipped for observing meteorological and astronomical phenomena or to any building or structure providing an extensive view of its surroundings. The term ‘observatory’ is also interesting as it seems to suggest not only detachment but remoteness from what is being observed.

In recent years there has certainly been no shortage of discussion in academic circles of the meaning of quality of life as it relates to people with a learning disability and ways

in which it can be realised. It has been the subject of numerous seminars, conferences, journal articles and books (Schalock and Verdugo, 2002; Brown and Brown 2009; Johnson and Walmsley, 2010; Kober, 2012). Yet there is very little evidence of field research that has sought to examine ways in which the lives of people with a learning disability can be enhanced. Indeed, as the preceding sections of this paper have shown, whilst there has been widespread academic interest in discussing this topic, the quality of life of people with a learning disability continues to deteriorate. In other words, there appears to be a profound disconnect between academic interest and the realities of the present world.

Those who have a professional interest in learning disability research have an obligation to assume a higher profile at a time when the quality of life of people with a learning disability and their families is under threat (Jackson, 2011). This can be done in a number of ways through:

- ◆ the establishment of demonstration projects, either independently or in association with the voluntary and statutory sector, to explore innovative and practical approaches to enhancing the quality of services offered to people with a learning disability
- ◆ looking at ways of improving the quality of training programmes for care staff by moving away from current approaches that emphasise narrow instrumental competences to strategies that develop essential expressive and relational aspects of care practice
- ◆ offering a more considered and rigorous critique of current professional practice and assuming a leadership role at a time when leadership in this field is lacking.

Perhaps it is time to drop the routine and ritualistic plea for further research that frequently concludes many research papers and government reports, for it is often not more research that is required but appropriate and timely action on the findings of existing research. This could lead to scarce financial resources being more profitably directed to improving services for people with a learning disability. At a more fundamental level, the question arises as to the *raison d'être* of learning disability research itself, given the increasing politicisation of the research process to which reference has been made. Further the application of the purchaser-provider model to the research process also prompts concerns as to the credibility and ethical propriety of often one-sided contractual arrangements.

The question arises as to why some parts of the research community with a professional interest in the field of learning disability appear to have voiced so little concern about adverse trends that are clearly discernible. The argument that such intervention might compromise the academic detachment of the research community by leading it into the political arena is not persuasive. It overlooks the fact that through its uncritical acceptance and promotion of some aspects of the inclusion agenda, parts of the research community long ago forfeited any claim to be acting with scholarly objectivity.

9. THE IMPACT OF TECHNOLOGY

Over the coming years the kind of care provision for people with a learning disability is going to undergo profound change. And that is because we are on the brink of a period of fundamental and irreversible change in the way that the expertise of the professions is made available in society; the main driver of this change being technology. It has been observed that information technology is a general-purpose technology and its impact will occur across the board (Ford, 2016). Virtually every industry in existence is likely to become less labour-intensive as new technology is assimilated into business models – and that transition could happen quite rapidly. All of this suggests that we are headed toward a transition that will put enormous stress on both economies and societies throughout the world. Beyond the potentially devastating impact of long-term unemployment and underemployment on individual lives and on the fabric of society, there will be a significant economic price.

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According to Ford it is not just technology that will shape our future, rather it will intertwine with other major societal and environmental challenges such as an aging population, climate change and resource depletion. It has been argued that if we do not recognize and adapt to the implications of advancing technology, we may face the prospect of a ‘perfect storm’ where the impacts from soaring inequality, technological unemployment and climate change unfold roughly in parallel, and in the process amplify and reinforce one another. The most frightening disclosure by Ford is the inevitability that machines will eventually be invented that are capable not only of thinking but of out-thinking humans. A point will then be reached when it is perfectly possible that governments may be created and run by robots with no human involvement. Some of course may see that as an improvement!

Any discussion about creating a fairer society in which the needs of those with a learning disability are met has to be set against the impact of the kind of technological developments described by Ford. It is important to re-emphasise here that he is not just describing what may happen in a distant future but what is happening now. As we move into these uncharted waters, we have to face the fact that we do not possess the maps to help us navigate a safe course.

Pleading for greater investment by the government in health, social and education services at this time is not the answer. It has been argued that we will need to think far more radically. This could involve a lesser role for the state in the provision of services through the processes of decentralisation, debureaucratisation and deprofessionalisation. For example, a case could be made for shortening the length of medical and nurse training in the light of current and future technological advances. By significantly

shortening the length of training for doctors and cutting their currently high salaries, considerable savings could be achieved. In local surgeries most GPs could be replaced with nurse practitioners and paramedical staff responsible for operating diagnostic equipment. Some of the significant savings achieved could be directed to improving front-line day and residential services for people with disabilities and the elderly which are seriously underfunded. If social justice is to be achieved then some rebalancing of resources has to be undertaken.

Because the political and social landscape is and will continue to undergo accelerating change, it will be necessary to come up with radical ideas for the creation of new structures and ways to redistribute scarce resources. If we wait then events will overtake us and we will end up with the mass unemployment to which Ford makes reference. Given the speed of technological advances that time may not be so far away so we need to act now.

Let us look at the implications for the social care sector. Current problems in recruiting social care staff, when combined with the economically precarious position of many social care providers in the UK, are already leading to the exploration of new ways of providing social care. One leading company in the UK, which is deploying assistive technology in the care sector, has claimed that it could prove a cost effective alternative to traditional residential care. It is asserted that such technology enables personalised care, choice, dignity and control and provides the user with an enriched experience.

In one example where assistive technology is in operation, the physical environment of the resident is described. Rooms are equipped with sensors that monitor a range of factors:

- ◆ telecare sensors to manage possible fire, flood or gas leaks
- ◆ personal pendants to enable residents to request assistance
- ◆ sensors to alert staff if a resident has fallen
- ◆ epilepsy sensors to reduce/remove the need for night-time checks
- ◆ environmental sensors to control curtains, heating and lighting
- ◆ sensors to access automatic doors.

The company responsible for introducing this technology has indicated that once an assistive technology/telecare support package is in place, it is reviewed regularly to ensure it is meeting the users' evolving needs. It is pointed out that software is currently in the process of being developed which will enable data from this technology to be gathered to create detailed reports which measure the benefits for the individual. This facility is represented by the company as being a cutting-edge development, harnessing as it does, available and emerging technologies to promote the independence and dignity of the residents. It is further claimed that this results in the delivery of the best possible outcomes and makes sustainable care possible.

It is argued that this radically new model of 'housing with care' gives individuals choice and control which is not possible in other care environments. Further, it is a financially sustainable model which will deliver cost savings as a result of individual residents becoming more independent. Thus through the use of technology it is possible to offer the least restrictive models of supervision and to support the independence, privacy and dignity of residents. At the same time the residents and their community are protected from any breakdown in support and well-being. Such a regime, it is contended, provides a significantly improved user experience as it enables freedom, manages risk and enriches lives.

What is revealing is that this form of provision is represented as ‘personalised care’, yet what we are witnessing is a process of depersonalisation. It is difficult to see how the process of depersonalisation can be reconciled with the importance of according to each resident dignity, respect and sense of personal worth. It is also difficult to see how meaningful relationships can be established where the carer by virtue of the character of her/his professional task operates at a psychological and physical distance from those receiving care.

The promotional literature relating to assistive technology is replete with the buzzwords of the ‘progressive’ care professional - least restrictive settings, personalised care and quality of life. When a company claims that this kind of assistive technology model is economically sustainable, it actually means that it can employ fewer staff; none of whom needs to be highly qualified. After all, why engage expensive care practitioners to perform essentially custodial roles?

Whilst it can be argued that the unrestricted use of surveillance cameras would constitute an intrusion into personal privacy, a recent survey undertaken by one of the largest trade unions in the UK found that three in five residential workers were relaxed about cameras being installed in care settings (Dinsdale, 2015). The union’s national officer further acknowledged there was a degree of inevitability about introducing CCTV into care settings. But why is it inevitable?

That inevitability perhaps becomes apparent when one places this issue in a broader context. The British Security Industry Authority (BSIA) has estimated that there are up to 5.9 million CCTV cameras in the UK, including 750,000 in sensitive locations such as schools, hospitals and care settings. The survey’s maximum estimate works out at one for every 11 people, which makes the UK one of the most surveilled societies in the world (Barrett, 2013). The omnipresent CCTV camera is not only part of our everyday experience but is viewed by the majority of UK citizens as a public good! Why should there be a problem in installing CCTV in care settings?

It may well be the case that some care workers see CCTV as a valuable form of professional protection. The current climate of aversion to risk in situations where practitioners are responsible for vulnerable clients may disincline them from being alone with them or acting with them in a natural manner. For example, there may be a reluctance to give physical comfort to a distressed youngster for fear that their action might be construed as inappropriate, possibly leading to allegations of sexual misconduct. However, if there is 24 hour CCTV surveillance, care workers might feel more at ease and more inclined to express a natural and appropriate human response.

Whilst such an argument has a certain superficial plausibility, it has to be remembered that the rationale for introducing CCTV into care settings is to reduce staff numbers with the result that it is difficult for individual practitioners to form one-to-one relationships with clients. It would also be naive to assume that those observing a videotape of an interaction between a practitioner and a client would necessarily draw the same conclusions. In other words, the availability of such tapes does not bring objectivity, merely the subjective judgments of those observing the tapes, who for a variety of reasons may wish to see only what they want to see. In September 2015 a company specialising in surveillance technology introduced a system that will enable relatives to check up on residents via their smart phones, while at the same time filing footage which experts can monitor for possible cases of abuse or malpractice (Cooper, 2015).

A further question that arises concerning the instalment of CCTV is whether a resident is given a choice and if so, whether s/he is made fully aware of the terms and conditions which determine its use. It is generally recognised that data protection legislation in

the UK governing how long images can be kept and accessed is outdated and has failed to keep up with technological changes. Without detailed legislative regulation, the risk of CCTV being misused and abused is high. Further, at the present time any codes of practice are not binding so that those installing CCTV need only have 'regard' to a code, as breaching such a code does not automatically lead to a company facing legal sanction.

There is no unanimity among parents and relatives of care residents with respect to the merits or otherwise of deploying CCTV. Some see the installation of CCTV as a way of minimizing the risk that their son or daughter, father or mother, is subjected to abuse or maltreatment by staff or other residents. There is a naive presumption here that an offending member of staff would not erase incriminating material or switch off the CCTV prior to entering a resident's room. A further issue is whether a CCTV or any recording device should be in operation when a resident is receiving a visitor, whether a relative or professional person (e.g., doctor; nurse). Clearly any conversations between a visitor and resident should be private and not be accessible to any other person.

Whilst the introduction of the kind of assistive technology so far described is significant, what cannot be ignored is the potential of robotics. A recent report published by the Institute for Public Policy Research has estimated that robots will replace 1 in 3 UK jobs over the next 20 years (Institute for Public Policy Research, 2017). More than 10 million jobs in the UK – a third of the total – are thought to be at risk from automation within the next two decades.

And it has been acknowledged in the UK that humanoid robots, with cultural awareness and good bedside manner, could help solve the crisis over social care (Richardson, 2017). An international team is currently working on a £2 million project to develop versatile robots to help look after people in care homes and sheltered accommodation. The intention of the research team is to create a world where robots co-exist with humans in harmony, for a smarter, healthier, safer and happier life. The robots will communicate through speech and with gestures, be able to move independently and pick up signs that a person is unwell or in pain. The robots would offer support with everyday tasks like taking tablets, as well as offering companionship. It is hoped to develop culturally sensitive robots within the next three years. Assistive intelligent robots could relieve pressures in hospitals and care homes as well as improving care delivery at home and promoting independent living. Such robots are already in use in hospitals in Japan to perform such tasks as lifting patients and serving food. In the third and final year of the project, the robots will be tested at Advinia Healthcare care homes in the UK.

It has been estimated that 250,000 public sector workers could lose their jobs to robots over the next 15 years according to a new report published by Reform, a right-of-centre think-tank (Hitchcock et al, 2017). The report argues that websites and artificial intelligence "chat bots" could replace up to 90% of Whitehall's administrators, as well as tens of thousands in the NHS and GP surgeries by 2030 and in the process save as much as £4 billion a year. Nurses and doctors could fall victim to the march of machines, which the report says can outperform humans at some diagnoses and routine surgical procedures and are more efficient at collecting information.

A recent publication by BlackRock – a leading UK investment house – makes clear its excitement at the potential of robotics to revolutionize care provision and practice by undertaking tasks (whether around the home or in residential care) that would otherwise be carried out, at greater cost, by humans. It notes that as the sophistication of robotics rises, and costs fall, over time, this potential is already beginning to take shape (Cullen, 2016). As well as removing the need for humans in certain aspects of care, technology

also has the potential to help individuals in care maintain or improve day-to-day human interaction in a number of ways (although clearly these ideas are built on assumptions about technological development over the coming years):

- ◆ using data analytics to inform the bringing together of like-minded people – both remotely and physically
- ◆ utilising the rise of autonomous vehicles to maintain geographical mobility for longer, reducing the tendency for people to become stuck in their own homes
- ◆ using innovations such as virtual reality and hologram technology to facilitate genuine, albeit virtual, human interaction not only with family and friends, but other individuals / organizations as well.

However BlackRock does acknowledge that ‘robo-care’ has been criticized as likely to increase social isolation and that social isolation and loneliness have been linked to cognitive decline, potentially increasing the care burden

A particular problem in any discussion of the role of technology is the tendency to equate technology with progress, when the contrary may well be the case. Objections to the use of technology stem from a fear that it may lead imperceptibly to the reinstitutionalisation of vulnerable people. Thus, before witnessing a further expansion in such provision research should be conducted – not sponsored by companies promoting and selling assistive technology – in order to assess its impact on the quality of life of people in care.

The remorseless growth of the ‘for profit’ sector also raises the question of accountability and the extent to which this sector is beholden to shareholders eager for a profitable return on their investment rather than considerations of the quality of life of those receiving care or concerns relating to the professional freedom and discretion of practitioners. There appears to be a growing and profound disconnect between what is being delivered in care services and what is professionally appropriate.

In this situation what should be the responsibility of the professional associations representing care staff? And how do those responsible for training equip students with the professional skills to operate in a system that is, in many respects, antithetical to most enlightened philosophies of care practice? What does the growth of these morally, culturally and socially aseptic settings have on those who live and those who work in them? What does their existence tell us about the prevailing value systems of the countries in which they flourish?

Perhaps the most critical question of all is how to recruit to the profession enthusiastic and resourceful people who are prepared not only to challenge the remorseless technologisation of the care sector but also are willing to advocate for a system which forthrightly respects individuality, inclusivity and human dignity.

10. GROWING PREJUDICE

Home Office figures show the number of disability hate crimes recorded by police increased by more than 40% in 2015/16 (Corcoran and Smith, 2016). There were 3,629 disability hate crimes recorded by police in England and Wales in 2015-16 compared with 2515 in 2014-15 and only 1,748 in 2011-12 meaning they had more than doubled in just four years. The Home Office said it was possible that some of the increase could be due to an increase in actual disability hate crime but that improved reporting and recording was likely to be a factor across all the strands of hate crime including race, religion and sexual orientation.

Mencap and Ipsos MORI conducted a survey of over 2000 people to determine public attitudes to people with a learning disability (Mencap, 2016). According to Jan Tregelles, chief executive of Mencap, it is the first time in over 30 years that a robust picture has emerged of how society views people with a learning disability. Whilst the survey shows that on the whole there is support from the public for people with a learning disability, there is still widespread confusion about what it means and a real nervousness about coming into contact with someone with a learning disability. A small group continue to hold profoundly negative attitudes; 27% of people surveyed think that learning disability is a form of mental illness and another 27% of people think learning disability does not last a lifetime.

Almost two thirds (63%) of parents of a child with a learning disability stated they had missed social engagements in the past 12 months due to the fear of how other people would react to them. 70% felt unwelcome in public and 21% had been asked to leave public spaces because of behaviour resulting from their child's learning disability. Other findings included 41% of parents saying they felt other parents were somewhat or very unhappy for their child to spend time with their children and 50% thought public attitudes towards children with a learning disability were negative.

Tregelles argues that there is no reason why in 2016 anyone should say they would not want to share a swimming pool or sit next to someone with a learning disability in a cinema, show or concert. The report highlights the inequalities faced by people with a learning disability making them one of the most marginalised groups in society:

- ◆ every year 1,200 people with a learning disability die avoidably in hospitals
- ◆ only 6% of people with a learning disability known to social services are in paid employment
- ◆ children with special educational needs (SEN) are twice as likely as other children to be bullied regularly
- ◆ almost one in three 18-35 year olds with a learning disability spend less than one hour a day outside their homes.
- ◆ 56% of disabled people say that they have experienced hostility, aggression or violence from a stranger because of their condition.

A recent survey by the disability charity, Scope, found over half of disabled people had experienced bullying or harassment at work because of their impairments. According to a survey of 501 disabled people, some 53% said that they had been bullied and 58% felt at risk of losing their jobs (Scope, 2017b). One in five of the survey's respondents hid their disability from their employer and one in eight said that they had been overlooked for promotion.

A government sponsored confidential inquiry into premature deaths of people with a learning disability examined the circumstances of all deaths involving people with a learning disability in the South West of England over a two-year period – about 250 in total (Heslop et al, 2013). These were compared with a sample of deaths involving non-disabled people. It was found that 42% of deaths of people with a learning disability were 'premature' and 37% might have been avoided with better or quicker treatment. While early deaths among non-disabled people were often associated with factors such as smoking and drinking – for those with a learning disability the most common factors were delays or problems with diagnosis, referral and treatment as much as a wide failure to make allowance for special needs.

About a third of those with special needs who died had had trouble communicating pain and a similar proportion had not had an annual health check in the previous year. The most common age for men with a learning disability to die was just 65 – 13 years before other men. For women with a learning disability the median age at death was 63 – two decades earlier than other women in the same area. Similar proportions in the two groups presented promptly for health care but significantly more people with a learning disability experienced difficulties in the diagnosis and treatment of their illness than did the comparator group.

All aspects of care provision, planning, coordination and documentation were significantly less good for people with a learning disability than their comparators. It found many instances of inappropriate Do Not Attempt (cardiopulmonary resuscitation) orders based on assumptions about the quality of life the person would have if they survived. There were a number of cases where the decision not to resuscitate a person appeared to have been made prematurely in a non-emergency situation before a full assessment of the person or before gaining the views of those who knew them best. Beverley Dawkins, Mencap national policy manager, commenting on the findings of this research indicated that it revealed the scale of discrimination faced by disabled patients and supports Mencap's belief that the lives of people with a learning disability are valued less than other patients in the NHS (Bingham, 2013).

One further area in which people with a learning disability are at particular and increasing risk is through participation in virtual communities (Molka-Danielsen and Balandin, 2015). Some of the major dangers here include the risk of cyber-bullying, fraud and invasion of privacy. People with a learning disability are also at a greater risk of experiencing sexual, verbal or emotional abuse than other users unless specific efforts are made to ensure that when faced with difficult situations they know what to do (op. cit.). Further, with the growing sophistication of virtual communities, people with a learning disability are likely to be increasingly excluded from a form of community that has become progressively more important in people's lives.

The policy of placing people with a learning disability in the open community is predicated on the assumption that the communities in which people with a learning disability are located are going to be welcoming and supportive. But as the research undertaken by Lemos&Crane in association with the Foundation for People with a Learning Disability has found that people with a learning disability living 'independently

in the community’ frequently experience a disturbing range of crime, abuse and harassment: incidents often characterised by cruelty (Gravell, 2012).

A survey by Turning Point, a leading health and social care provider, found that more than half of those surveyed believed that people with a learning disability were the most discriminated against group in society (Williams, 2010). Growing public concern at the vulnerability of disabled people, in particular their greater risk of experiencing violence or hostility than the wider population, led the Equality and Human Rights Commission to examine the issue. The findings of the Commission were subsequently published in the report Promoting the Safety and Security of Disabled People (Equality and Human Rights Commission, 2009).

Adam Penwarden, Turning Point’s director of learning disability services, has indicated that:

“As a sector, we need to work together to challenge preconceptions and show what a positive contribution to society people with a learning disability can make. This includes working, living independently and playing an active role within the local community.”

(Samuel, 2010)

A further difficulty is the common and wholly incorrect assumption that learning disability constitutes a mental health problem (Jackson, 2015; Birrell, 2017). That degree of ignorance was made evident at the highest level when Theresa May encountered Cathy Moran in Abingdon market during the election campaign (Mason, 2017). In response to Ms Moran’s declaration that she could not live on her remaining benefits after her Disability Living Allowance had been replaced with the Personal Independence Payment, the Prime Minister replied that she had a lot of plans, particularly for people – like Cathy – with mental health problems.

This chance market place meeting provides an unambiguous illustration of the disturbing lack of knowledge not only of the meaning of learning disability but of the distinction between learning disabilities and mental health problems. The concern here is that prejudice against people with a learning disability is made much more likely when even at the highest level in government there is a profound misperception of the meaning of learning disability.

11. A RETURN TO INSTITUTIONS?

Since 2001, learning disability policy has sought to increase the choice and control people have over where they live (Greig, 2016). This policy called on care managers to have an increased focus on home ownership and assured tenancies as a model for housing and support. This led to a move away from the default model of residential care to a more rights-based approach known as 'supported living' where people had housing rights through a landlord and a separate contract for their support. This provided people with greater control over their lives and enabled them to change support provided without the need to move house.

However in 2015 the government announced that housing benefit in the social housing sector would be capped at the same level as the Local Housing Allowance rates, which were currently 30% of the local market average. It has been estimated by the National Housing Federation that if these proposals went ahead 40% of current supported housing schemes would close and 80% of planned schemes would not be completed leaving many people with a learning disability homeless.

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It is acknowledged that whilst savings have to be made it is not fair to apply a cap to tenants in supported and sheltered housing where rents are higher as a result of the extra facilities they need. The government introduced the Bedroom Tax without thinking through the impact on disabled people; changes that were likely to have devastating consequences for older people, disabled people and those with mental health needs who relied on supported housing. One consequence of this change is that local housing authorities are often left with no option but to close many care and support services.

Recently some commissioners have started to move back to a residential care model on supposed cost grounds. The National Development Team for Inclusion (NDTi) has been told of five local authorities where this has been given as an informal directive to social workers. More explicit is the current Rochdale council consultation which seeks a £1.4 million saving by 'transforming' supported living provision and replacing it with a range of residential care and other services.

According to Greig, Rochdale's proposal illustrates much of what has gone wrong with social care commissioning. Firstly, it does not understand the meaning of 'cost-effectiveness'. Claims that residential care provides greater 'value for money' (VFM) are not backed up by evidence. A review of VFM and cost effectiveness in housing and care by the NDFi found no robust evidence that residential care or large group settings are more cost-effective than other, rights-based housing and support models. Secondly, it represents short-termist commissioning. A more person-to-staff ratio means people receive less individual attention and support. This leads to more large-group activities, doing things that others want or need, rather than having personalised support that develops life skills and independence.

Thirdly, it does not understand learning disability best practice. It describes approaches which were dropped 30 years ago as if they were new (the core and cluster model). It

confuses supported living with small group homes (which are often residential care) and does not even suggest providing independent advocacy while people's rights are being removed. Fourthly, it misunderstands the meaning of personalisation. It is stated that the Council will use "personal budgets to determine the most appropriate care and support". But it should be for the people themselves to determine how their personal budgets are to be used – not the council; that being the whole point of personal budgets.

More fundamentally according to Greig, such a proposal challenges the rights-based approach for people with a learning disability that started with the 2001 Valuing People policy (Department of Health, 2001). In supported living, people have housing and other rights through their tenancies. In residential care – people have no right to stay in a house, for care managers and providers can require them to move for service management or budgetary reasons. People have no right to control who they live with, who supports them, who enters their house and whether friends can stay over. They will never achieve paid work as the benefits system makes work financially punitive for anyone in residential care.

Rochdale Council has argued that by remodelling its supported living offer and moving some people who currently have their own tenancies into alternative settings, including residential care units, it can save £1.4 billion (McNicoll, 2016). A pre-consultation paper issued by the Council stated that care teams had already considered "possible future living options" including care homes for all 263 people potentially affected. A reduction in the number of supported living tenancies formed the basis of savings claims. The Council stated their supported living arrangements normally involved two to four people sharing one home – with staff on site round-the-clock to support them. According to the Council this model of care did not provide value for money as the same staffing numbers could support a greater number of people in larger premises! In addition, not everyone's needs are the same in a supported living home but the staffing level needs should be based on the person with the highest need. The Council rejected any suggestion the proposals amounted to 'institutionalisation' and stated service users would only be moving if their new options were assessed as meeting their needs and after detailed conversations with them and their families. Learning Disability England, a membership organization for people with a learning disability described the plans as "shocking" and "a proposal to return to institutionalised services".

If the public sector is no longer able to make provision for people with a learning disability there is a strong probability that these services will be outsourced (Bowers, 2013). What confidence can we have that the firms to which these services are outsourced will provide a high quality service?

Research suggests the market for public service outsourcing has an annual turnover of £72 billion: about 24% of the expenditure on public services in the UK. In 2013 the National Audit Office reported that £4 billion of taxpayers' funds was paid out in 2012 to the four largest outsourcing contractors – Atos, Capita, G4S and Serco (National Audit Office, 2013).

The NAO argued that these companies should be forced to open their books on taxpayer-funded contracts and be subject to fines and bans from future contracts in the event that they are found to have fallen short. The NAO report identified a number of serious concerns:

- ◆ the quasi-monopolies that have sprung up in some parts of the public sector
- ◆ the lack of transparency over profits, performance and tax paid
- ◆ the inhibiting of whistleblowers
- ◆ the length of contracts that taxpayers are being tied to; and
- ◆ the number of contracts that are not subject to proper competition.

Margaret Hodge, Chair of the Public Accounts Committee, who commissioned the NAO to carry out the study, commented:

“It is the government’s policy to outsource delivery of public services, but what it cannot do is outsource responsibility. Departments have a duty to ensure that the taxpayer is not being ripped off and that people, not profit, remain at the heart of our public services”

(Commons Select Committee, 2013).

All four firms have seen their respective share prices outperform the wider stock market as investors have grown increasingly confident the UK and other austerity-constrained governments will continue to prove increasingly lucrative. The concern of the NAO is that the government is, to a certain degree, dependent on its major providers. There is a sense that some may be too big to fail and difficult to live without.

The record of these four firms is not encouraging. Atos is perhaps best known for its Work Capability Assessments and deciding whether benefits claimants were fit to work. There were many allegations of distress and deaths caused by its assessments. Around 40% of decisions made by Atos were overturned on appeal.

Capita received £1.1 billion from the UK public sector in 2012. Its contracts cover local and central government services across education, transport, health and legal services. In 2011 Capita was criticised for its work for the UK Border Agency as the company incorrectly informed people living legally in the UK that they had to leave the country. In April 2014, the government had to step in because Capita was failing to deal with a backlog of medical assessments for payment to sick and disabled people.

G4S is the world’s largest security company, with more than 650,000 employees and operations in 125 countries. The company received £700 million for UK public sector contracts in 2012. G4S runs, prisons, immigration detention centres, police services, schools, hospitals and public surveillance schemes. G4S is under criminal investigation by the Serious Fraud Office for defrauding the taxpayer. A Survation survey showed that 77% of the public thought that G4S should not be allowed to bid to run public services, whilst 59% thought that G4S should never be allowed to run public services again (Survation, 2014).

It is instructive to read the assessment of G4S by Corporate Watch (2012):

“Chief among G4S’ qualities is its perceived knowledge of how to run services. This will provoke hollow laughter from anybody who has suffered from the company’s cost-cutting, often brutal, approach to service provision, but it’s not in doubt that the company has governments convinced. Still, £2.2 billion remains a huge amount of goodwill. If the company loses half of its goodwill, for example, its equity would be reduced to £400 million. Much more and the accountants would start getting itchy.

G4S is also carrying a significant level of debt. Its accounts show it owes around £900 million in loans to banks, and almost £1.2 billion due through loan notes issued since 2007 to unknown investors. £830 million of these notes are private, £350 million are publicly traded (known as Eurobonds). G4S has recently added to this debt by issuing a £489 million Eurobond in March 2012.”

Is it the judgment of board members of G4S that it is far too big for the government to let it fail?

Serco has more than 100,000 employees working in over 30 countries, with 60% of its business UK based. It is the UK's largest supplier of public services. In 2012 it received £1.8 billion from public sector contracts. Serco has government contracts in defence work, transport, IT and business outsourcing, central and local government functions, health, education and welfare to work. Serco is currently under investigation by the Serious Fraud Office for defrauding the taxpayer. The company overcharged the government for tagging criminals who were later found to be dead or abroad. Polling showed that 79% of the public think that Serco should not be allowed to bid to run public services at the moment, whilst 63% thought that Serco should never be allowed to run public services again. Despite this – the government is still allowing Serco to bid for contracts. These organizations are so large that few countries could afford – politically or financially – let them fail. Also given the extent to which former civil servants and MPs serve on their boards, they are insulated from attack.

White has argued that the political ideology among our main political parties when it comes to outsourcing is strikingly homogeneous which may explain why our politicians rarely have an answer when things go wrong (White, 2016). This prompts the obvious question, why do we outsource? For the politician the answer is obvious – it saves money. But does it? Governments take pains to insulate the process of outsourcing from media criticism. The right-wing thinktanks which are strongly supportive of outsourcing do not go out of their way to disclose the fact that they receive large sums from outsourcing companies. Indeed the issue of transparency is the major weakness in the evolution of outsourcing over the years. A survey by the British Medical Journal discovered around a third of doctors in charge of the new clinical commissioning groups had interests in private medical companies (Iacobucci, 2013).

But there is also a political dimension. In February 2014 the Daily Mirror revealed that private healthcare firms with links to the Conservative Party had been awarded NHS contracts worth nearly £1.5 billion (Lyons, 2014). If one undertook a trawl of the register of members' interests one would find scores of MPs with various connections to private health firms – many have received political donations – while others have held directorships or been majority shareholders and others have been paid for consultancy work. Just as there is a huge question over the lack of transparency in political interests, so there is considerable concern over the 'revolving door' whereby civil servants leave their jobs and join firms they were, until recently, responsible for commissioning.

The truth is that Britain has been hijacked by a group of companies that do not offer the value they say they do. They operate in a broken market, squeezing out or sitting on smaller providers who could bring more expertise to the arenas in which they operate. They are given an easy ride because government offers no effective oversight, and consistently draws up contracts with generous terms.

The fact is that general public barely knows this industry exists. Yet it is an industry that has been responsible for such poor quality services that lives have been lost and still it remains one of the things on which the political class pins its hope for the delivery of public services. Without true transparency, accountability and a market that allows a proper diversity of providers to flourish, the same horrifying stories will be generated, time and again. Until then, the shadow state continues to thrive.

It is relevant to note that in April 2015 Remploy was outsourced to a joint venture between the US international outsourcing giant Maximus and Remploy's employees, who have a 30% stake in the business. Of Remploy's current staff of 750, less than a third is now disabled (Salman, 2017). Shortly after this re-organisation Remploy (as part of the Maximus Empire) applied for and successfully won a contract from the Care Quality

Commission to recruit and manage staff to inspect care homes in the CQC's North, South and London regions (Gallagher, 2016).

This Experts by Experience programme was designed to recruit people who had experience of using health and care services in order to support the commission's inspections of those services. The 'Remploy experts' were to be responsible for carrying out around 10,000 annual inspections across London, the South and the North of England – three of the four contract regions previously managed by two charities, Choice Support and Age UK. However by the beginning of 2016 when the scheme was scheduled to commence hundreds of staff were on the brink of quitting or had quit because Remploy was making them re-apply for their former jobs with the CQC on half the pay!

Maximus was the organisation which had previously come under fire as a provider of the Department of Work and Pensions' controversial 'fit for work' tests. A damning report by the National Audit Office published in January 2016 found that Maximus had performed worse than its much-criticised predecessor, Atos, in key areas. This organisation has a lengthy record of discrimination, incompetence and fraud in the USA. In 2007, they were fined £20 million over allegations they cheated Medicaid, the US equivalent of the NHS, by making tens of thousands of false claims. While paying the penalty, they did not accept liability. In 2010 they paid out £1.3 million in a lawsuit brought by the State of Connecticut for the "abject failure" of their computer system, which was supposed to run a police database. The state's attorney-general Richard Blumenthal said: "Maximus minimised quality – squandering millions of taxpayer dollars and short-changing law enforcement agencies" (Brown, 2014).

The second biggest market for Maximus is Australia. Until 17 years ago the Australian government through the Commonwealth Employment Service (CES) had been responsible for welfare payments. However the CES was effectively privatised with private sector organisations (and sometimes charities such as the Salvation Army) taking on this function. But then credible claims became widespread of agencies engaging in significant fraud and other forms of criminality – one of those firms was Maximus. It was found that claimants had had their benefits stopped for no reason, signatures on paperwork had been faked and the most marginalized claimants had been abandoned completely as there was no profit in helping them. These strategies were the same as those employed by Maximus in the USA.

Outsourcing of health and human services function to private for-profit firms raises significant concerns. According to non-profit research group In the Public Interest, a comprehensive resource centre on privatization and responsible contracting, many children and adults rely on government-provided health and human services. The ability of these programmes to deliver services efficiently and appropriately often is a matter of life and death. Numerous state and local governmental entities are discovering that turning over these programmes to private contractors – like Maximus – not only fails to achieve projected cost savings but also decreases access to these important services, hurting many vulnerable families. In many cases, the service quality declines dramatically and many sick or at-risk people are left with substandard care.

In the present political and economic climate there seems to be a certain inevitability that these large companies will seek to exploit the growing residential care market. To be financially attractive to them such settings will need to be of a sufficient scale to confer clear monetary benefits. There is very unlikely to be any political opposition to such a development given the growing reliance of successive governments on outsourced provision.

Criticism that the creation of large residential settings constitutes a return to institutionalisation will no doubt be countered by claims that such provision is urgently required and that steps will be taken to ensure that satisfactory standards will be maintained in such settings. Given the track record of the companies likely to be involved, one can be confident that high standards will not be maintained and that the regulatory body charged with the responsibility for enforcing such standards will be no more successful with these new forms of provision than it currently is in maintaining acceptable standards in provision and practice.

But another form of institutionalisation is already occurring. What has been overlooked for too long is the growing number of people with a learning disability who are increasingly to be found in penal institutions (Talbot, 2008). According to the Prison Reform Trust, recent research has shown that:

- ◆ 7% of prisoners have an IQ of less than 70 and a further 25% have an IQ of less than 80 (Mottram, 2007)
- ◆ 23% of prisoners under 18 years have an IQ of less than 70 (Harrington and Bailey, 2005)
- ◆ 20% of the prison population has some form of 'hidden disability' that will affect and undermine their performance in both education and work settings (Rack, 2005)
- ◆ between 20 and 25% of men in prison have a specific learning disability.

A disturbing discovery in research cited by the Prison Reform Trust was that less than a third of prisoners with a learning disability or verbal comprehension difficulties received support from a designated appropriate adult during police interviews, in contravention to national guidelines. The court system also came out badly under scrutiny with a high proportion of people with a learning disability indicating that they did not fully understand what was going on and had had no access to clear information. Because of that there was a high risk of miscarriages of justice.

The Criminal Justice Joint Inspection Report for 2015 noted that prison and probation staff were failing to identify people with a learning disability which meant that opportunities to help those offenders were being missed. Nick Hardwick, Chief Inspector of Prisons, said on behalf of both inspectorates:

“In prisons we were alarmed that there were extremely poor systems for identifying prisoners with learning disabilities in one prison we were even told that they could not identify a single prisoner who had a learning disability. ... We are also concerned that little thought was given to the need to adapt the regimes to meet the needs of prisoners with learning disabilities who may find understanding and following prison routines very difficult.”

Criminal Justice Joint Inspection Report, 2015

What we are witnessing, more generally, is the phenomenon of 'warehousing' where people with care needs are located under one roof to reduce the costs of providing them with the supports they require (Brown, 2017). The word 'warehousing' captures the repulsion most people feel about being forced into institutional care, losing privacy and autonomy. The tendency to see people with a learning disability as objects rather than complete people leads to the view that they are less than human so that whenever

attempts at reducing the cost of supporting people with disabilities arises, the policy solution frequently advanced is ‘warehousing’. Once the validity of the economic argument lying behind the ‘warehousing’ model is conceded then logically there is nothing to prevent the creation of larger and larger ‘warehouses’. If this model is adopted, it is unlikely to take the form of the sturdily constructed and imposing Victorian edifices, many of which are still standing in different parts of the UK either as spectacular ruins or as converted private (often luxury) accommodation.

A real fear here is that the responsibility for the construction, maintenance and running of future ‘institutions’ will be outsourced to one or more of the limited number of multi-national organizations. Opposition to this trend is likely to be muted given the increasingly straitened economic, social and political circumstances that are likely to affect most people in the UK following upon Brexit and the profound changes in the labour market brought about by technological advances.

12. THE CASE FOR INTENTIONAL SUPPORTIVE COMMUNITIES

There is a strong case for broadening and not restricting the range of day and residential options for people with a learning disability. I would like to make the case here for the intentional supportive community. The focus of such a community is to provide an environment within which adults with and without a learning disability can live and work together in a climate of mutual respect. It is not being argued here that the policy of placing adults with a learning disability in ‘homes in the community’ should be discontinued. What is being argued is that a range of options should be made available, including intentional supportive communities, so that a person with a learning disability is offered genuine choice – a right to which s/he is morally and legally entitled. For that to happen, the current invisibility of this population in the eyes of government, to which Greig makes reference, has to stop (Greig, 2015).

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There are six qualities that can usually be found in intentional supportive communities: mutuality, rhythmicity; well-being; tranquillity; ecological sensitivity; and economic sustainability (Jackson, 2013).

1. Mutuality

The relationship between the carer and the person with a learning disability in such settings is characterized by mutuality, defined here as the respectful give-and-take between and among persons. Mutuality is not merely a technique or attitude; it is a practice that embodies the value of interaction and understanding—not isolation and alienation. This life-sharing aspect of living in an intentional supportive community is one of its defining features, as this ensures that the principles of dignity, value, and mutual respect can be meaningfully translated into practice. The daily process of learning across difference and inequality is vital, for it transforms the basic attitudes of care-givers toward difference. Furthermore, the negotiation of power sharing across inequality makes a reality of the rhetoric of empowerment, because such an approach requires the power to come from, and be given up by, someone else, namely the care-giver. What we are talking about here is the establishment of an affective relationship that is unconditional. It is mutual friendship that provides the cohesive force that binds together the different elements of a community; it is the mortar without which any communal edifice would collapse.

2. Rhythmicity

Rhythmicity is a potent force not only in linking people together but also in creating a sense of internal togetherness. Life comprises a wide range of natural rhythms, from the regularity of the heartbeat to the change from day to night. Rhythmicity is an essential ingredient in human communication and development. In attempting to communicate effectively with an individual, the carer has to fall into step with that individual so that they dance to the same tune. The individual and the care-giver then search for ways to establish and maintain that joint rhythm in a mutually inclusive way. An awareness of this engagement can help carers pace their interactions and further their capacity to interact and to speak with, rather than to, the individual. It is important for carers to learn to listen, to look, and to explore in a new way the pulse of groups with which they are working. Only by living one's work in a community can one become sensitized and respond appropriately to these rhythms.

3. Well-being

Attention to the well-being of the individual is an integral facet of life in intentional communities. Well-being, which may have everything or nothing to do with religious belief and observance, may be an integral and essential aspect of everyday life. It can be defined as a sense of good health about oneself as a human being and as a unique individual. It occurs when people are fulfilling their potential as individuals and as human beings are aware of their own dignity and value, enjoy themselves and have a sense of direction, can sense this quality in others and consequently respect and relate positively to them, and are at ease with the world around them. A sense of well-being does not result from the acquisition and application of a series of techniques and skills; it results from sharing together and learning together. It comes by addressing questions that relate to the value and meaning of life.

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4. Tranquillity

A further feature of many intentional communities is the tranquillity of the environment in which many are set. This contrasts with the location of many 'homes in the community' in busy, noisy and atmospherically polluted centres of towns and cities. There are few visitors who do not quickly become aware of this distinct and rare quality. But what do we mean by tranquillity? Too often, tranquillity is simply equated with silence or an absence of noise, but tranquillity is a quality that has to be created. It can be defined as a state of inner emotional and intellectual peace. While many people may recognize its importance, few understand its benefits. Tranquillity can help individuals overcome feelings of anger, nervousness, and fear that are often part of daily life. It brings enhanced levels of emotional and mental calm that enable the individual to feel mentally stable and grounded. By keeping the mind clear and stable, tranquillity can help improve judgment and, by so doing, make the future appear bright and positive. This in turn helps

to maintain a person's good physical health by keeping the body strong and resistant to illness. Thus there is a sense in which tranquillity has a healing or curative quality.

5. Ecological sensitivity

Particular importance is attached to ecological sensitivity by most intentional supportive communities. A wide range of activities are involved in the enhancement of the quality of the natural environment - soil, plants, water and air. This is done through: (a) the use of natural fertilisers and the banning of chemical herbicides and pesticides; (b) the employment of organic and/or biodynamic practices in agriculture and horticulture; (c) the construction of installations which harness solar, wind and geothermal energy so as to reduce the importation of external power supplies; (d) the recycling of materials and the minimisation of waste creation; and (e) the construction of buildings from natural materials which are in harmony with their surroundings (Heitzman, 2016).

6. Economic sustainability

It has been estimated that the cost for adults with disabilities in intentional supportive communities is between one-half and one-sixth the cost of state-funded or other private options (Larson et al, 2010). This is achieved by a variety of means: the absence of incremental salary structures; the opportunity for collective budgeting; the sale of community-made products; the emphasis on self-sufficiency (e.g., providing their own fruit, vegetables, dairy products, bread, etc); the minimisation of waste; the use of economic power sources; keeping the construction and maintenance of buildings and equipment 'in house'; and, the rental of community facilities to external groups.

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The meaning of 'institution'

Some critics of the intentional supportive community model nevertheless claim that it is a form of institutionalisation (Collins, 2000). But that argument does not withstand close inspection. Goffman identified what he saw as the essential characteristics of 'a total institution' (Goffman, 1961). They are:

- ◆ the progressive loss by individual residents of their sense of identity
- ◆ the imposition of constraints on basic liberties of residents (i.e. freedom of movement, speech and action)
- ◆ the development of professional hierarchies which lose sight of, and work against the realization of an institution's therapeutic and rehabilitative aims
- ◆ the increasingly routinised and closely regulated nature of institutional life
- ◆ staff seeking to create and maintain a social distance between themselves and residents.

But the intentional supportive community is the antithesis of the ‘total institution’ when one looks at its main features:

- ◆ staff’ who live alongside residents
- ◆ a generally low ‘staff’ turnover
- ◆ an absence of shift work
- ◆ no managerial hierarchies
- ◆ engagement in meaningful work
- ◆ location in a congenial and safe environment
- ◆ handy access to the local neighbourhood for residents
- ◆ convenient access by members of the public to the community (e.g. community shop)
- ◆ availability of a range of creative, social and recreational activities, and
- ◆ the perception of the intentional community as a local asset by the surrounding neighbourhood.

But a note of caution should be sounded. Intentional supportive communities can only survive if their work:

- ◆ is grounded in everyday reality and is not anchored to some mythical past
- ◆ is operationally transparent to funders and users
- ◆ is outwardly orientated and not insular in its philosophy and practice
- ◆ possesses a clearly articulated philosophical purpose
- ◆ has policies and practices which are conceptually clear and not opaque.

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It is relevant here to examine the findings of one of the few research studies that have explored the quality of life of residents in an intentional supportive community – Botton Village in North Yorkshire (Randell and Cumella, 2009). The results confirm the strongly positive findings obtained by Emerson et al. in their study (Emerson et al, 1999). The authors advance a number of suggestions to explain the high degree of satisfaction felt by residents in this Camphill community.

1. The absence of the overt subordination of residents to staff. The founding philosophy of the Camphill Movement emphasises the spiritual and essential equality of its disabled and non-disabled members and this was reflected in the communal sharing of the village’s income and participation in joint decision making. For both members and co-workers, work and remuneration operated on the principle that each contributed according to their abilities and each was rewarded according to their needs.
2. The facilitation of friendship with other people with a learning disability. The reported high rate of social interactions with each other when added to the perceived personal safety of life in the village contributed to the creation of a climate of trust and friendship for people with a learning disability. It also made it easier for residents to sustain friendships than would be the case with some dispersed housing schemes.
3. High levels of meaningful employment. All respondents (apart from one who had retired) were able to work full time in a range of unskilled and skilled work which was essential to the daily life and economy of the village: they were also able to exercise a measure of choice where they worked. Those residents interviewed regarded their work as a means of sustaining the daily life and economy of the village, and reported that they were formally engaged in making communal and personal decisions.

4. A sense of community. The combination of shared involvement in economically sustaining the village, participating in its decision-making processes, taking part in village rituals and religious practice, all within a close network of friendships enabled its members to re-affirm their sense of community identity and belonging. The authors observe that this pattern of organisation and functioning contrasts strikingly with that found elsewhere in most residential care and supported living services for people with a learning disability.

The authors concede that the kind of intentional community offered by Botton Village would not appeal to all, no more than all people would wish to live in their own one-person flat or in the suburbs of large cities. This is an inconvenient fact for those who have a clear and simple vision of what constitutes a 'normal life'; however as the authors concede human diversity has always been an impediment to social engineering!

Two prominent figures in the reform of public policy and services for people with a learning disability have been profoundly influenced in their thinking and writing by the Camphill intentional community model (Lakin, 2001). Burton Blatt, after having written the book *Christmas in Purgatory*, which exposed the degrading conditions of people with disabilities living in state institutions in the USA, made a visit in the late 1970s to Camphill Village Copake (Blatt and Kaplan, 2004). Before his premature death in 1985 he expressed his wish to retire to Copake as he saw it as a model form of residential provision. Rud Turnbull, former President of the American Association on Mental Retardation, who has been described by his peers as a person who has changed the course of history in the field of learning disability, highlighted and commended the inclusive character of life in Camphill communities as portrayed in the photographic essay *Village Life: the Camphill communities* (Pietzner, 1986).



LOCH ARTHUR CAMPHILL VILLAGE SHOP, DUMFRIES, SCOTLAND



THE CAFÉ, CAMPHILL VILLAGE COPAKE, NEW YORK STATE

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CAMPBILL VALLERSUND, NORWAY



THE WEAVERY, CAMP HILL DINGLE, IRELAND



CAMP HILL COMMUNITY, HERMANUS, SOUTH AFRICA



CAMP HILL COMMUNITY, SVETLANA, RUSSIA



PEACEFUL BAMBOO FAMILY, HUE, VIETNAM



CAMPBILL DORFGEMEINSCHAFT HAUSENHOF, GERMANY

As a result of continuous dialogue with Camphill leaders and friends during the latter part of his long career, Wolf Wolfensberger modified the principle of normalization with which his name has come to be closely identified. Initially this principle advocated making available to all people with disabilities patterns of life and conditions of everyday living which were as close as possible to the regular circumstances and ways of life in society. Wolfensberger subsequently revised this principle because he saw it being interpreted too inflexibly and narrowly thus failing to take account of what Camphill communities have traditionally seen as being pre-eminent importance – the quality of a person's whole experience of living.

There is a certain irony in the fact that critics of Camphill claim that the kind of services it provides runs counter to the normalization principle (Collins, 2000). What these critics fail to appreciate is that normalization should be viewed as a philosophy and not a technology. It is a system of values and beliefs which should help guide, not dictate

thought and action. As Wolfensberger was later to argue this necessitates a sensitive, sensible and pragmatic approach not an inflexible and dogmatic one.

John O'Brien, author of *The Five Accomplishments* and a colleague of Wolfensberger, has recently expressed his respect for Camphill and other intentional communities that take a disciplined approach which allows those who freely join to discover and practice ways of living together that develop people and benefit the wider community and the environment (O'Brien, 1992). He argued that the study and application of Rudolph Steiner's esoteric teachings about economics, education, art, architecture, medicine, as well as teachings specific to the care of people with a learning disability, have helped shape and sustain Camphill's struggle with questions of how people with significant apparent differences can thrive in each other's company. Unfolding Steiner's teachings to meet the demands of a changing world according to O'Brien give the movement a coherent, positive stance which is at some distance from common cultural assumptions. According to O'Brien it is just this different angle of expression of a common value on expanding freedom to live a meaningful life that makes Camphill communities different (O'Brien, 2017).

The essential point here is that as a matter of urgency steps need to be taken now to develop a range of alternative forms of residential provision for people with a learning disability. There are two principal reasons why the focus in this report has been on Camphill communities; firstly, because they are ones with which I am personally familiar (Jackson, 2006; 2011); and secondly, they have been strongly and unequivocally commended by some of the key thinkers and opinion-shapers in the field of learning disability; for example, Burton Blatt, Wolf Wolfensberger, Rud Turnbull and John O'Brien.

The cartoon accompanying Collins' article represents a 'village community' as a prison surrounded by high walls and barbed wire. This has a certain historic poignancy which will not be lost on those working in Camphill settings, given that Camphill owes its origin to the flight from Central Europe of a small group of men and women whose religious and social beliefs would almost certainly have brought them into conflict with the authorities at that time and their subsequent confinement to, and probable death in, concentration camps.

One of the gifts of Dr Karl Koenig, who led this small group, was recognising and responding to the perceived needs of his time. Over sixty years ago, Camphill was one of the first communities in the UK to accept and work with children with a learning disability. If he was alive today, it is likely that he would feel a sense of profound unease at the way in which certain groups promote the idea that there is only one solution when discussing appropriate provision for people with a learning disability. Koenig knew to his cost that a civilised society is only civilised to the extent that it has the capacity to tolerate diversity. Ideology elevated to the status of unchallengeable truth leads to tyranny.

EPILOGUE

In writing this report I am conscious of the fact that I am at the same time reflecting on ‘the state of health’ of democracy in the UK. What emerges is a country in which successive governments have exhibited scant concern for those in our society who, for whatever reason, find difficulty in fending for themselves. Amongst this growing population are people with a learning disability and their families.

Successive governments have succeeded in rendering mute and ineffectual those bodies which purportedly seek to represent the interests of people with a learning disability. Increasingly, too, the provision of a wide range of services catering for people with a learning disability is being outsourced by government to monolithic, profit-seeking and democratically unaccountable organizations possessing an abysmal record for the quality of the services they provide.

While there are examples of innovative and inspirational day and residential services and pockets of excellent professional practice, they exist within a rapidly contracting sector. A climate has also emerged in which the level of tolerance and support for people who exhibit differences – whether intellectual, racial, ethnic, religious or sexual orientation – is declining.

One of the most dispiriting features of recent years has been the way in which the key concepts of ‘community care’ and ‘inclusion’ have been misinterpreted and misrepresented by politicians, administrators, academics and social commentators. The services that have subsequently developed are the antithesis of what such pioneers in the field of learning disability as Jack Tizard, Wolf Wolfensberger and John O’Brien advocated.

In the years following the Second World War we had a government that not only sought to provide education, health and social services to meet the needs of the whole population but actively encouraged research to find ways of best delivering these services. That radical impetus has long gone only to be replaced by a succession of governments that appear to be more concerned with protecting the interests of the favoured few and in the process creating an increasingly polarised society.

If there is not a reversal to current trends then we will return to the situation that existed in the UK seventy years ago when people with a learning disability were a neglected and unfavoured population. In choosing the title for this report – Back to Bedlam – I am not indulging in hyperbole.

RECOMMENDATIONS

1. The government should promote and ensure the full realization of all human rights and fundamental freedoms for all persons with disabilities which are set out in the UN Convention on the Rights of Persons with Disabilities.
2. The government should accord an equivalence of regard to a Ministry of Disability as to any other government department.
3. Charities representing people with a learning disability should be more assertive and challenge government policy when and where it is seen to be disadvantageous to people with a learning disability and their families.
4. Charities should avoid any arrangements with government agencies that have the potential of threatening their operational independence and functioning.
5. Advocacy services representing people with a learning disability should be financially resourced from central government and be given the freedom to operate free of external interference.
6. Social care should be treated separately from the National Health Service in order to safeguard its professional integrity and ensure access to adequate financial resources.
7. A new regulatory body for social services should be established to replace the ineffective and discredited Care Quality Commission.
8. The practice of successive governments outsourcing social care provision to large companies should cease.
9. The government should encourage local authorities, charities and private providers to explore and develop a new range of day and residential services for people with a learning disability.
10. The government should closely monitor the introduction of technological developments within the social and health services which have the potential to threaten the wellbeing of people with a learning disability.

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About the Author

Robin Jackson is currently a Visiting Research Fellow at the University of Hertfordshire. He has a PhD in Education from the University of Exeter. The subject of his doctorate was an assessment of the post school adjustment of leavers from day special schools for pupils with an intellectual disability in Edinburgh and Midlothian. On completing his doctorate he spent 10 years at Aberdeen College of Education where he lectured in the Sociology of Education. He then moved to King Alfred's College (now the University of Winchester) where he was responsible for setting up the first Master's Degree in Special Education in the UK.

After 10 years in Winchester he returned to Scotland and took up a post as Principal of a residential special school and farm training centre in Aberdeen. This experience convinced him of the critically important role residential special schools play in the range of provision for pupils with special needs. He rejects the frequent portrayal of such schools as institutionalized forms of provision which are out of touch with best professional practice. One of the most rewarding aspects of his role was the opportunity to work in close partnership with the parents. A lack of appreciation by some professionals of the experience and expertise of parents with children with special needs prompted the publication of *Bound to Care* (1996) which he edited: this anthology chronicles the often heart-breaking experiences of parents trying to seek an appropriate care setting for their child.

After five years as special school head, the author went on to set up an advocacy service funded by Aberdeenshire Social Work Department and Grampian Health Board. Most clients of this service were adults with an intellectual disability and/or their families. The author found this role one of the most professionally satisfying he had experienced. After four years he reluctantly left because of an increasing erosion of the operational independence of the service. Resulting from his experience as an advocate, he co-edited the book *Advocacy and Learning Disability* (Jessica Kingsley, 2002).

Moving on from the advocacy service, the author obtained the post of Development and Training Co-ordinator for Camphill Scotland - a body representing the 10 Camphill communities in Scotland. He had two principal tasks: (1) making co-workers in the Camphill communities aware of the importance of obtaining an appropriate care qualification and (2) helping to convince the Scottish Social Services Council (SSSC) that the in-house B.A. in Curative Education (later B.A. in Social Pedagogy) run by Camphill School in association with the University of Aberdeen was an appropriate care qualification. A particular feature of Camphill practice that impressed the author is that it is largely based on a social pedagogic model: a transdisciplinary professional activity in which aspects of care, education, therapeutic and medical activities, the use of crafts and creative arts are all brought

together to form a holistic approach in supporting children with special needs. It is an approach that the Department for Education has recently shown some interest in promoting.

Another role at Camphill performed by the author was making known to as wide a professional and public audience as possible the essential nature of Camphill's philosophy and practice, as it has been generally poorly understood and frequently misrepresented. This prompted the publication of two books: *Holistic Special Education: principles and practice* (Floris Books, 2006) and *Discovering Camphill: new perspectives, research and developments* (Floris Books, 2011).

The author has a particular interest in exploring the meaning of community inclusion as it relates to people with an intellectual disability. He guest reviewed a special issue on this topic for the *Journal of Intellectual Disability Research* (2011) and guest edited a special issue on the same subject for the *International Journal of Developmental Disabilities*. A more extensive exploration of this theme was explored in a book co-edited with Maria Lyons entitled *Community Care and Inclusion for People with an Intellectual Disability* (Floris Books, 2016). In 2015 the Centre for Welfare Reform published a report written by the author entitled *Who Cares? The impact of ideology, regulation and marketisation on the quality of life of people with an intellectual disability*.

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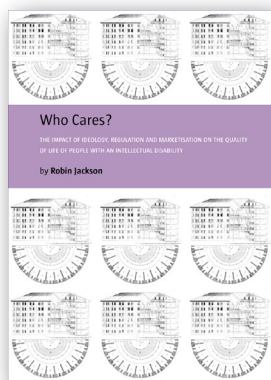
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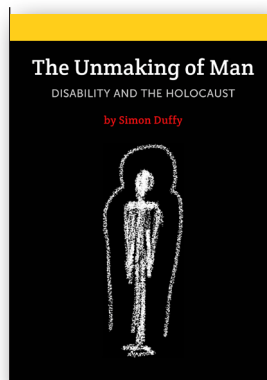
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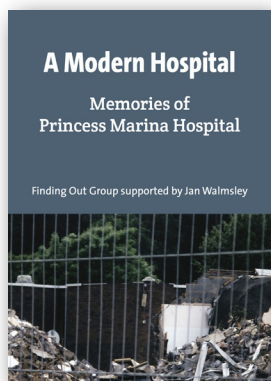


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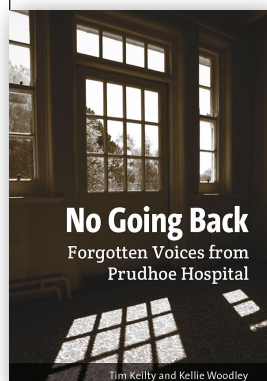
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