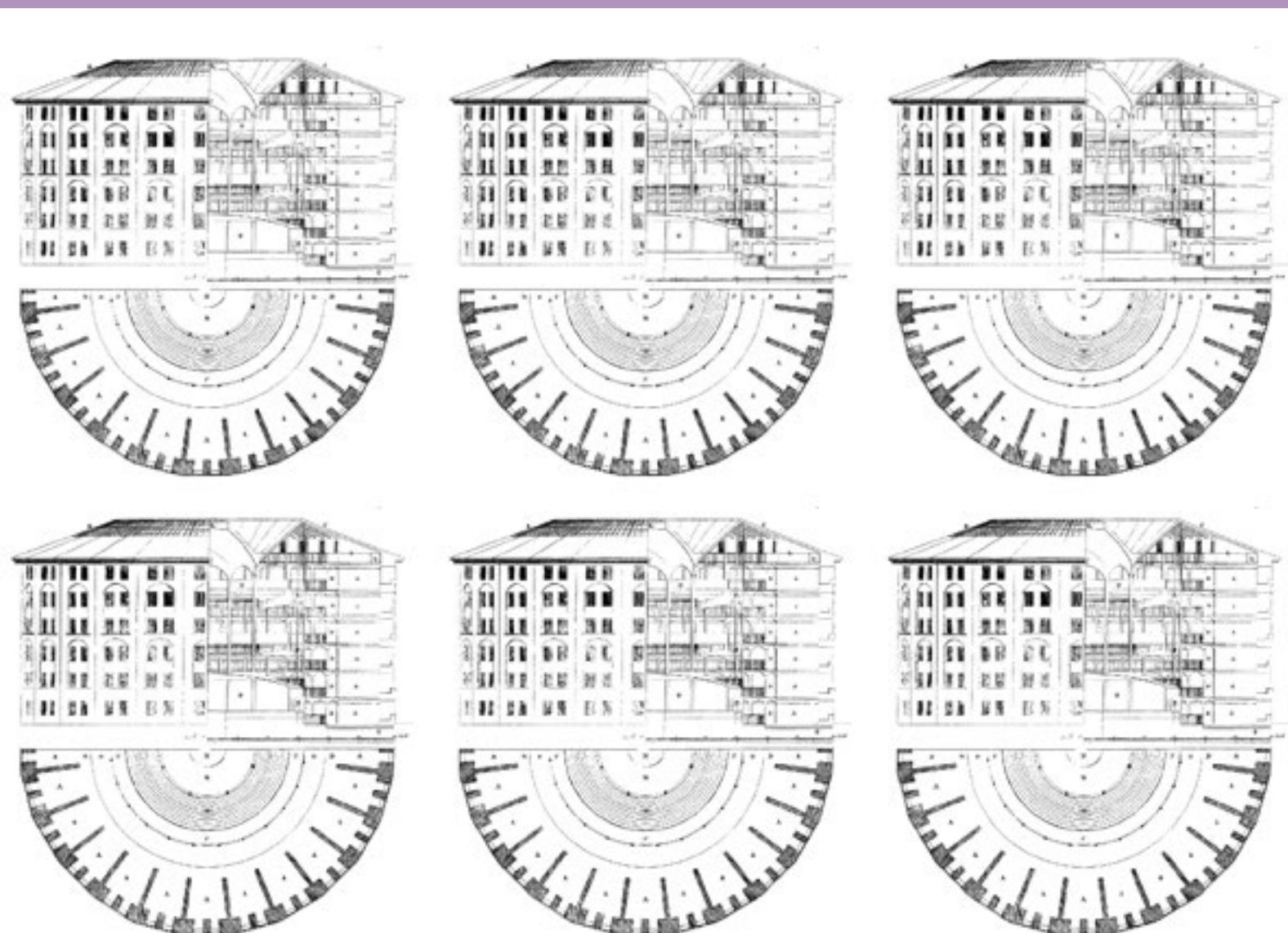# Who Cares?

THE IMPACT OF IDEOLOGY, REGULATION AND MARKETISATION ON THE QUALITY OF LIFE OF PEOPLE WITH AN INTELLECTUAL DISABILITY

by **Robin Jackson**

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FOREWORD

It is one of the joys of my work at The Centre for Welfare Reform that I get to read, and publish, papers and reports from unexpected sources. Robin Jackson's report was one such gift: it is a clear, well argued and evidenced critique of the whole social care system - particularly as it affects people with learning disabilities.

However, in this case my pleasure was tinged with some pain. The report's power comes from its unflinching objectivity, and that means few of us will come away unscathed. In particular, many of its criticisms seem to apply to my work, or to the work of my colleagues. However, as the Bible says, "The ear that hears the rebukes of life will abide among the wise" (Proverbs 15:31) so I think, however painful it is, all of us involved in disability policy and practice should listen carefully to his argument.

I think it is true that we are drifting towards micro-institutionalisation; and for many of the reasons that Robin Jackson outlines:

- If we focus only on rights, without regard to responsibilities and relationships then we miss the essence of what helps people have good lives - love.
- When we cannot rely on love then we must use the organising power of the state to 'give people their rights' - and so we need regulation.
- When we cannot rely on love then we must buy care and support - and so we commodify care and use 'the market.'
- But as the market must deliver profit to its investors so we must economise on care and use technology to drive down costs.
- And as Government is also under pressure not to spend too much money, especially on people without political power, the market itself becomes financially vulnerable to 'austerity.'

If you think this is all too alarmist then remember that in the UK, between 2009 and 2014, social care has been cut by 30%, with 500,000 people losing social care - and this has happened without any significant public outcry (ADASS 2014).

Robin Jackson's analysis also tallies well with the findings of other Fellows of The Centre for Welfare Reform. For example Bob Rhodes has argued persuasively that the health and social care system has forgotten the value of friendship, family and community (Rhodes 2010). One extreme example is the devastating impact of CQC regulations on the Camphill Community, which is now being dismantled in the name of professionalisation (Rhodes and Davis 2014).

Karl Nunkoosing and Mark Haydon-Laurelut recently offered a powerful analysis of empowerment; they show that it is all too easy to mistakenly believe that empowerment is something that you can do to people rather than being something that happens within relationships (Nunkoosing and Haydon-Laurelut 2013).

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We can see the impact of flawed and paternalistic approach to social change across social care today. Even seemingly attractive ideas like personalisation and inclusion can be corrupted and turned into disastrous policies, like the current 'Work Programme.' It is quite possible for Government, or any of us, to use all sorts of positive and optimistic rhetoric about our intended destination, but if we are not prepared to really walk alongside people, and to change both ourselves and our society together, we will end up with the kind of mad micro-management which typifies modern social policy - not so much the Nanny State, but increasingly the Wicked Step-Mother State.

However painful it might be, I whole heartedly commend this paper to anyone interested in social care and social policy in the UK today.

Simon Duffy

Director, The Centre for Welfare Reform

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SUMMARY

This report explores the recent history of services for people with intellectual disabilities (or learning disabilities) in the UK. Unthinkingly, we are slipping into the same institutional practices that were common at the beginning of the twentieth century, although now in a more modern guise. The reasons for this backward drift in policy and practice are various, but include:

1. Ideas like inclusion or normalisation have been interpreted in an overly simplistic manner by some academics and thought-leaders. Too often one experience of disability tends to dominate all other experiences.

2. Some strategies of political activism that aim to defend the rights of disabled people effectively exclude many people with intellectual disabilities or their primary allies. Such exclusive strategies don't work for people with intellectual disabilities.

3. Charities, who society expects to protect the interests of people with intellectual disabilities, are now largely service providers and are increasingly passive in the face of pressure from central or local government.

4. Regulation, despite its many and repeated failings, is seen as the primary method for ensuring the safety of people. This has led to an increasingly bureaucratic and destructive mentality that corrodes human relationships.

5. The increasing marketisation of social care has merely eroded the quality of support, and reduced salaries, skills and securities.

6. Technological solutions - cameras and alarms - rather than people are increasingly seen as the only feasible solution to the growing funding crisis in social care.

7. The dependence of the sector on private-sector care homes, often dependent on highly leveraged debt, makes it likely that many private services will collapse as the economy continues to falter and as social care continues to be cut.

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The risks today are similar to those of the Victorian period. Social and economic problems - which have nothing to do with disabled people - are leading to heartless policies that will undermine human dignity and community relationships.

It is time for those who are committed to the rights and interests of people with intellectual disabilities to change their thinking and to find new strategies to bring about positive social change.

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1. Introduction

In a recent paper the Chief Executive of the National Development Team for Inclusion made the sobering point that people with an intellectual disability in the UK have achieved little or no profile for most of the last twenty years (Greig, 2015).

The author highlighted a meeting he had had with a senior government official where he was personally informed that any attempt to seek radical improvements for people with an intellectual disability in the UK would fail as the numbers were too small to warrant government action! This off-the-record judgement may well have been shaped by a perception of this particular population as having limited political leverage when set against constituencies with a higher profile (e.g. people with a physical disability).

A further factor is the low status of the particular government department responsible for disability affairs in the UK which can be gauged from the fact that over the past seven years there have been no fewer than six Ministers for Disability. As it usually takes a Minister about a year to master their brief, the direction and implementation of policy in this area is left to the civil servants which is usually a recipe for no change - an outcome which would be wholly satisfactory to any Sir Humphrey Appleby in the Ministry.

Whilst it is clear that the various government departments involved with education, health, social care and employment seek to promote a policy of inclusion where people with an intellectual disability are concerned, it is an unsophisticated policy which takes little account of the profound differences within that population. In exploring the concept of inclusion and the meaning of intellectual disability it is important to take a cross-cultural and historical perspective.

There are a number of common assumptions that merit examination with respect to the meaning of intellectual disability; firstly, that in 'simple' rural societies people were more tolerant and sympathetic to those with an intellectual disability; secondly, that the intellectual and social skills required to cope in such a society were significantly less demanding than those needed to survive in a modern industrial society; and, thirdly, that less stigma attached to those with an intellectual disability living in such a society.

Anthropological and historical research provides proof to contest these assumptions. Edgerton (1968) was able to demonstrate in his anthropological research conducted with African tribes that there is no such thing as a 'simple' society, for even in the least elegant cultures survival is a far more complex and difficult process than is commonly supposed; that tribes were capable of identifying and labelling those that they deemed to be 'learning disabled'; and that these people were more rather than less stigmatized because of their disability than would be the case in our modern society. A child with an intellectual disability born to a family in pre-industrial England was viewed, just as in African tribal society, as a social inconvenience but, more critically, as an economic liability. Historical accounts that describe the composition of the growing pauper population in the 16th century England suggest that a significant proportion were people with an intellectual disability, many of whom were residents in the poorhouses, the forerunners of the mental institutions (Midwinter, 1969).

The fact that people with an intellectual disability in African societies rarely married also posed an acute problem for their families, as the family could not achieve either

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wealth or security if its children did not marry. Another reason why intellectual disability was usually a serious social problem in many 'primitive' societies was because there was a corporate responsibility for any wrongdoing. Not only was the family held responsible for any misdemeanour by a member with an intellectual disability, but the whole family was implicated. Therefore clan members were assigned to supervise those with an intellectual disability in order to keep them out of trouble. In extreme cases, they were confined to the house. These two 'primitive' responses, supervision and confinement to the house, bear a striking similarity to those subsequently adopted in more 'advanced' societies - sheltered provision and institutionalisation.

Unlike many 'primitive' societies, Victorian Britain felt no sense of societal responsibility for those with an intellectual disability. On the contrary, they were seen as a parasitic and predatory population responsible for most of the social ills that ravaged the cities - poverty, crime, alcoholism, drug addiction, vagrancy and prostitution. In addition, they were seen as a threat to social order and the genetic purity of the race. The lack of compassion shown towards people with an intellectual disability is perhaps understandable when set against the dominant philosophical, religious, scientific and popular views of the time. The impact of Darwin's theory of evolution, when translated into Social Darwinism by Spenser, encouraged the belief that people with an intellectual disability were the biologically 'unfit'. Acceptance of the Malthusian doctrine that there was an optimal population for every society led many to believe that the apparently higher reproductive capacity of those with an intellectual disability constituted a threat to the nation's stability and welfare. The Benthamite principle of self-help popularised by Samuel Smiles ('Heaven helps those who help themselves'), laid the onus on the individual to make good. Thus people with an intellectual disability, who were perceived as constitutionally incapable of helping themselves, gained little sympathy. Finally, the influence of conflicting religious beliefs encouraged either a fatalistic or condemnatory attitude towards the plight of people with an intellectual disability.

A Victorian observing the squalor of the cities, the unchecked escalation in crime, the extent of poverty among the urban population, the growing frequency of massive epidemics of cholera, typhoid and smallpox, and the increasing social disorder and unrest, might be forgiven for feeling uneasy and for trying to find a cause for the existing social malaise. Predictably the underlying cause - the demographic explosion - was ignored. As often happens when a society is confronted by uncertainty, tension and conflict, the 'scapegoat principle' is invoked. The kind of proposals advanced by British scientists and social reformers to counter the 'menace' of the people with an intellectual disability - segregation, castration, sterilisation and euthanasia - bear a depressing similarity in intent and character to the measures taken against another minority group - the Jews in Nazi Germany. The close identification of the eugenics movement with these proposals for a final solution may help to explain why any suggestion today to establish or support separate residential provision for people with an intellectual disability generates such a strongly negative and emotive response (Jackson, 2011a).

There is a certain irony here as Wolfensberger, a refugee from Nazi Germany, who was one of the fiercest and most outspoken critics of the institutionalisation of people with an intellectual disability came to modify his principle of normalisation as a result of a continuous dialogue he had in the latter part of his career with friends from Camphill communities in the USA. These communities are residential settings for people with an intellectual disability and can be found in over 27 different countries. The first Camphill community was created in Scotland by Dr Karl Koenig, like Wolfensberger a refugee from Nazi oppression (Jackson, 2013).

Initially the principle of normalisation advocated making available to all people with an intellectual disability 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 the quality of a person's whole experience of living. He believed that his new principle of social role valorisation should be viewed as a philosophy and not a technology: it was 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, dogmatic and ideological one.

Burton Blatt, another prominent figure in the worldwide reform of public policy and services for people with an intellectual disability, was profoundly influenced by Camphill in his thinking and writing (Lakin, 2001). After having written Christmas in Purgatory, a photographic essay exposing the degrading conditions of people with an intellectual disability living in state institutions in the USA, he made a visit in the late 1970s to Camphill Village Copake (Blatt and Kaplan, 1966). Before his premature death in 1985, he had 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 professional peers as a person who has changed the course of history in the field of intellectual 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). The question then arises as to what it is that Wolfensberger, Blatt and Turnbull saw in this kind of community setting that appears not to be seen by contemporary critics?

One concept which has not been subjected to close critical scrutiny is 'community' in the context of 'care in the community'. The fact that the traditionally accepted notion of the community has been dismissed by most sociologists as being largely mythical in character is significant given that the policy of community care is predicated upon the existence, beyond the walls of the institution' of 'communities' in which:

1. there exists among residents a clear sense of, and loyalty to, their 'community';
2. residents know one another;
3. residents feel a sense of obligation to one another;
4. there are networks for mutual support; and
5. a wide range of beliefs and values are shared by all residents.

But in discussing community it is important to note that the immediate social environment for most urban families is best considered not as the local geographical area in which they live, but rather a network of social relationships they maintain, regardless of whether these are confined to the local area or run beyond its boundaries (Bell and Newby, 1971).

Two aspects of this concept of community are relevant here. Firstly, the nature and extent of the network varies from locality to locality. Secondly, the range and spread of the network will vary from individual to individual. One of the discernible changes that is occurring for many, but not all, social groups is that social networks are becoming less locality bound and less close knit given that an increasing amount of social interaction takes place through high speed communication (e.g. e-mail, Facebook, Twitter). What is significant about this form of social interaction is that it disadvantages people with intellectual disabilities not simply because of the cost of expensive equipment and the

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recurrent need to update it but because of the skills needed to operate increasingly technically sophisticated equipment (e.g. iPhones, iPads, etc). In the face of these changes, community recedes in its meaning to the individual and also declines as a significant means for the organization of social life. As Cohen (2004) has observed 'community' is one of those words like 'culture', which are bandied around in ordinary everyday speech, readily intelligible to speaker and listener but which, when imported into the discourse of social science, causes immense difficulty.

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2. Ideology

The first part of this paper seeks to examine the ideological position taken by the following three groups with respect to the community inclusion of people with an intellectual disability:

1. a small but readily identifiable group of academics (e.g. in Disability Studies Departments);

2. collective advocacy schemes purportedly representing people with intellectual disabilities (e.g. People First); and

3. major disability charities (e.g. Mencap). These three groups have been identified because of their profound influence on shaping the professional and public perceptions of the concept of inclusion.

Kavale has pointed out that supportive arguments for full inclusion have been primarily based on ideologies with anecdotal case studies and testimonials, but not on quantitative research evidence (Kavale, 2000). He believes a solution that simply calls for full inclusion without accompanying empirical support is neither logical nor rational, resulting in a degenerative research programme with too many ad hoc explanations. The problem of ideologists who single-mindedly promote a narrow form of inclusion, which accepts no exceptions, is their failure to recognize the fact that they are seeking the realization of an unattainable utopian ideal. It is an aspiration that most empirical research from across the world has demonstrated to be unrealizable. The pursuit comes at a heavy cost for a significant number of children and adults with intellectual disabilities, who find that the kind of total inclusion advocated by the ideologists fails to meet their special needs. Paradoxically, such ideologists appear to be unwittingly promoting the creation of a dystopian environment characterized by intolerance, conflict, and inhumanity.

Further, propagation of the principle of inclusion within a crusade is both dangerous and counterproductive, for it can foster professional intolerance, division and disaffection (Hansen, 1976), lead to the application of powerful and insidious pressures on professional staff to conform (Boucherat, 1987), devalue the worth of those who, for valid professional reasons, find ground for criticism (Mesibov, 1990), promote the growth of a propaganda industry which places a low value on objectivity and truth (Jackson, 1989), prompt the use of strategies and techniques which indoctrinate rather than teach (Renshaw, 1986), encourage poorly trained professional staff to believe that the application of a simple formula will resolve the complex problem of delivering effective and humane services (Tadd, 1992), and result in the creation of an inflexible service that is unresponsive and insensitive to the needs of people with intellectual disabilities (Rhoades and Browning, 1977).

The crucial point that advocates of the inclusion principle miss but which earlier writers took pains to stress is that inclusion is a philosophy and not a technology (Tizard, 1964; Nirje, 1969). It is a system of values and beliefs which should help guide, not dictate, thought and action. Thus empirical examination should replace polemics: not to do so

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is to engage in a massive programme of social engineering (Zigler, Balla and Kossan, 1986). Zigler and Hall (1986) have argued that we should avoid adopting an all-or-nothing attitude in any debate about providing appropriate services for people with intellectual disabilities. They noted that there are many forces at work that depict issues as being either-or choices, driving out the middle ground position. In their judgment anyone who polarizes the situation by promoting one solution to the total exclusion of all others does that situation and its complexity a disservice. What is urgently required now is an approach that is open, evidenced, and respectful. It is a system of values and beliefs which should help guide, not dictate, thought and action. This necessitates a sensitive and pragmatic approach, not an inflexible and dogmatic one.

The resolution of issues relating to appropriate placements cannot be satisfactorily determined where an inflexible insistence on one particular form of provision takes precedence over all other options. The personalisation agenda presupposes that most people with an intellectual disability can exercise an informed choice. It is not for professional workers involved in the placement process to dictate choice because of their own particular preference or what they perceive to be official policy.

2.1 Disability studies

Lester, a Senior Fellow with the Libertarian Alliance, notes that Disability Studies has become a growth area in academia which possesses a number of illiberal aspects (Lester, 2011; 2012). It presents itself as relatively new and progressive and employs such fashionable buzzwords as 'oppression', 'bourgeois', 'empowerment', 'rights', 'equal opportunities', 'discrimination', 'prejudice', 'citizenship' and 'social justice' – words that, in Lester's view, are not obviously related to disabilities in any serious way. As far as one commentator is concerned, the field of disability studies does not seek to generate powerful insights or useful empirical evidence, and is over-reliant on simplistic and ideological accounts (Shakespeare, 2005). What has happened is that over the years, stimulating insights from the 1970s, such as normalization and social role valorization, have become ossified into a disability dogma that is difficult to develop or dislodge. Rather than refining this dated analysis or responding to changes in the external world, the radical disability community in the UK has opted to follow the same outworn path. This contrasts with other parts of the world, such as in the Nordic countries, the US and Australia, where there is a broader alliance between disabled and non-disabled people, and a more dynamic research agenda. In the UK, a separatist and anti-intellectual disability culture has developed which, sometimes, in Shakespeare's opinion appears almost Maoist in its intensity (Shakespeare, 2005).

According to Lester, the main argument that emerges from disability studies literature is that 'disability' is socially constructed, often for sinister (bourgeois) class reasons, rather than objective ones (Lester, 2012). He concedes, though, that there is a grain of truth in this 'social construction' claim. A further argument is that the disabled are an oppressed group but, unlike women and members of non-white races, that oppression has not yet

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been generally recognized even among 'progressives'. However, as Lester points out, genuine oppression would surely take the form of proactive impositions as exemplified by persecution, enslavement, and expropriation. What disabilities studies regard as 'oppression' is, in fact, merely failing to provide the full benefits of opportunities that are completely equal to those given to the non-disabled. Lester has drawn attention to the fact that there is not much obvious published opposition to this output to be found on the shelves of bookshops under the heading 'disability studies'. Anyone questioning the kind of arguments advanced is often represented as heartless and possibly risks ostracism and professional difficulties. At the extreme, anyone opposing is sometimes even hysterically accused of advocating Nazi eugenics programmes and/or a form of attempted "genocide" of the disabled (Rickell, 2003).

At the heart of disability politics, there has been an emphasis on individualism that opposes collective welfare provision in favour of direct payments to enable individuals to make their own choices. Yet, this liberal rights-based approach has its limitations. Many disabled people, particularly those with an intellectual disability, are unable to take advantage of the freedom to choose and compete. Not all disabled people want to employ their own staff, or will find it easy to do so (Jackson, 2011b). In such situations, an ethic of interdependence and mutual support may be more appropriate for many people with intellectual difficulties or mental health problems (Jackson and Irvine, 2013). A key problem with the stance taken by some disability studies academics is that they often fail to acknowledge the distinction between those who are intellectually able but possess a physical or sensory impairment and those who have an intellectual disability. Intellectual disability, which can result from a genetic cause, complications during birth or acquired brain injury, imposes limitations on a person's ability to function in different areas of daily life (e.g., communication, self-care, and coping in social situations and learning activities), which may require lifelong support. The notion that one can eliminate intellectual disability by simply changing the environment of a person has been proven to be unrealistic (Jackson, 2011b).

Shakespeare has highlighted the fact that, in the UK, the social model of disability has been largely developed and promoted by a group of men and women from academia who themselves have a mobility impairment – not an intellectual disability (Shakespeare, 2005). Thus, extending their analysis to other groups, such as people with intellectual disabilities or mental health problems, is not a straightforward approach. Lobbies representing people with a physical or sensory disability have no mandate, moral or actual, to speak on behalf of all people with a disability.

Perhaps one of the most significant interventions in this regard in the UK was the 1981 Education Act, which for the first time emphasized 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 phases (Rozenberg, 1981).

It is difficult to reconcile the policy of including children and young people with intellectual disabilities in mainstream schools which is advocated by those committed to the ideology of inclusion, at a time when specialist schools and academies are being established at a bewildering pace for pupils with different abilities (e.g., mathematical,

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scientific, technological, musical, sporting, and so on) and different faiths. If the determining principle behind this rapid expansion is to meet the particular needs of different groups of pupils, then there is a strong logical case for making provisions for the particular needs of pupils with intellectual disabilities. One problem here is that many of the specialist training courses to equip teachers with the skills to teach pupils with intellectual disabilities were closed two decades ago as a result of the policy of inclusion; consequently, teachers in mainstream primary and secondary schools perennially complain of being ill-equipped to teach such pupils (National Union of Teachers, 2011) .

The need for schools to perform well in the various league tables, which are now regularly published, has introduced a strong competitive ethic into schools – one that confers a low value on those unable to compete and thus help a school realize its academic goals. More serious still, because academies are funded by the state with no control or support by the local education authority, head teachers have the power not to include children with intellectual disabilities because their presence is perceived as adversely affecting the school's academic performance. The question then arises as to what happens to the children with intellectual disabilities? What the academic community has yet to come to terms with is the fact that the kind of developments outlined above makes the policy of inclusion not only undesirable but unrealizable.

Even when research is undertaken to assess the efficacy of different forms of provision, the findings and conclusions can be coloured by ideological considerations.

For example, the Hester Adrian Research Centre at the University of Manchester conducted research to examine the quality and costs of three different types of residential provision for people with intellectual disabilities, namely:

1. Camphill village communities,
2. residential campuses operated by NHS Trusts, and
3. community-based dispersed housing schemes (Emerson et al, 1999).

Across the 20 indicators of 'quality' examined in the project, the research found that the 'segregated' village communities performed marginally better than the dispersed housing schemes. Notwithstanding the positive findings relating to village communities, these were downplayed in the report submitted to the Department of Health, and in subsequent public presentations of the project's findings (Jackson 2000). One may speculate on the reasons for this.

The Department of Health is unlikely to have welcomed the findings of a study, which ran counter to the existing government policy favouring community care and inclusion. The concern here is the way in which research in the UK has become a market-place commodity. One of the biggest dangers in such an arrangement is the strong temptation for the researcher either to give the sponsoring department what he thinks is wanted or to avoid giving what he thinks is not wanted. The nature of this exchange is potentially a corrupting one: one which subverts a researcher's independence and integrity (Jackson, 1993). As it is the government that largely dictates the research agenda, contentious issues like the success or otherwise of the implementation of the policy of inclusion can be ignored.

In a recent study comparing gradings awarded by the Scottish Care Inspectorate to different types of registered service in Scotland, Baron (2012) found that the 12 Camphill communities in Scotland received the highest gradings on all four of the Inspectorate's quality criteria.

Descriptor	Grade
Unstatisfactory	1
Weak	2
Adequate	3
Good	4
Very Good	5
Excellent	6

TABLE 1. Care Inspectorate Grading System

Camphill Scotland Research Report No. 1: The Comparative Standing of the Camphill Communities in Scotland in the Quality Gradings of the Care Inspectorate. The Camphill Scotland Research Group, July 2012

Type of Organisation	Number
Charities	106
Other Intentional Communities	1
Local Authorities	73
For-profit Service Provider	69
Other/Unknown	1

Table 2. Organisational Characteristics of the Random Sample

Camphill Scotland Research Report No. 1: The Comparative Standing of the Camphill Communities in Scotland in the Quality Gradings of the Care Inspectorate. The Camphill Scotland Research Group, July 2012

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Organisation	Care	Environment	Staffing	Management
Camphill	5.12	4.95	5.08	4.96
Charities	4.75	4.58	4.53	4.42
Local Authority	4.66	4.37	4.25	4.26
For-profit	4.33	3.98	4.34	4.21

Table 3. Mean Grade Rankings by Organisational Type and Care Inspectorate Criteria

Camphill Scotland Research Report No. 1: The Comparative Standing of the Camphill Communities in Scotland in the Quality Gradings of the Care Inspectorate. The Camphill Scotland Research Group, July 2012

Closer analysis of the data revealed that:

1. Camphill as an entity performed better on all four Care Inspectorate Quality Criteria than the Scottish Care sector as a whole across the relevant type of service registration categories;

2. such differences were part of a wider pattern in which charities outperformed for-profit service providers on all criteria and local authorities in terms of staffing;

3. Camphill outperformed local authorities and for-profit providers on all four criteria and

4. Camphill as a whole could claim to be outstanding in Scotland in its own right in terms of the environment provided, the quality of staffing and the quality of management and leadership.

What would represent a significant advance is where the state does not exercise a near monopolistic control in determining the research agenda in the fields of education, health and social care: a level of control which can lead to the politicisation of the research process. The public and voluntary sectors along with the universities should be encouraged to identify areas that merit examination and have the potential for improving the quality of life of people with an intellectual disability.

2.2 Disability advocacy

Advocacy has been defined by Wolfensberger as speaking, acting and writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by:

❖ being on their side and no-one else's
❖ being primarily concerned with their fundamental needs
❖ remaining loyal and accountable to them in a way which is emphatic and vigorous and which is, or is likely to be, costly to the advocate or advocacy group.

In Wolfensberger's opinion, the adoption by the People First Movement of 'the pernicious new ideology of radical individualism and self determination' risks antagonizing and alienating those whose support is vital if appropriate services are to be developed (Wolfensberger, 2003). In the UK particular frustration has been expressed at the way in which research on inclusion has been hampered by certain collective advocacy groups dogmatically committed to the principle of 'Nothing about us, without us'. Researchers have urged this lobby to give them the freedom to discuss issues relating to inclusion and not seek to determine the scope and direction of that research (Walmsley and Johnson, 2003).

The aggressive manner in which these activist groups have pursued their interests was shown when they gave oral evidence to the Joint Parliamentary Committee on the Draft Mental Incapacity Bill on the 23rd October 2003. Representatives of People First, Changing Perspectives and Values into Action, all organizations promoting collective advocacy for people with an intellectual disability, vigorously challenged the right of parents and relatives to have any say in the key decision-making affecting their children's

future. The overwhelming impression of parents and relatives, portrayed by these organizations, was an entirely negative one. They were characterized as self-centred, over-protective and controlling. For their part the parents questioned the authority of these organizations to speak on behalf of all children and adults with an intellectual disability and they challenged the assumption that there were any people who were better equipped to represent their children than themselves. The evidence of the last decade would appear to suggest that government departments have tended to listen more attentively to the views of these advocacy collectives than parents and relatives in the mistaken belief that they present the authentic voice of people with an intellectual disability.

The most outspoken of the collective advocacy groups in the UK has been the Direct Action Network (DAN) (Jackson, 2005a). Whilst members of DAN claim that they belong to an organization dedicated to nonviolence, they fail to recognise that violence is not simply the commission of a physical act. The words chosen for use in its pamphlets could well incite a violent response. If this should happen those responsible for writing such material are as morally culpable as those who commit a violent act. There is frequent reference in its pamphlets to 'sisters and brothers', 'freeing our people' and 'the struggle for freedom': all obviously intended to portray the Direct Action Network following in the footsteps of members of the 1960s civil rights movement.

DAN has included among its targets the major disability charities, professionals, parents, special schools and residential care settings of any kind. What is disturbing is the depth and intensity of the antipathy and venom directed towards these targets.

Members of DAN should take note of Dr Martin Luther King's own words:

> *"Hatred paralyses life; love releases it. Hatred confuses life; love harmonizes it. Hatred darkens life; love illuminates it."*

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A particular target of DAN has been the academic community. Simone Aspis, a member of People First and a DAN activist has contended that the intellectual disability research field is riddled with the vested interests of non-disabled academics that have no desire to support people with an intellectual disability (Aspis, 2003). The reality, according to Aspis, is that everything is done under the pretence of 'partnership', as there is no possibility for people with an intellectual disability to manage the research themselves. In short, anything that people with an intellectual disability want to say and do has to be sanctioned by the non-disabled researchers. Aspis has stated that nothing is likely to change because influential non-disabled academics are content to continue working in this unethical manner which upholds the power imbalance between non-disabled academics and people with an intellectual disability.

Walmsley and Johnson (2003), two academic researchers, have argued that members of this collective advocacy lobby - including Ms Aspis - should give academics space to consider, reflect and come up with ideas relating to inclusive research without members of this lobby claiming the right to be ever present. Walmsley and Johnson (2003) accepted that this might well fly in the face of the current orthodoxy in inclusive research which proclaims 'Nothing about us without us'.

Walmsley and Johnson have clearly sought to be diplomatic in their dealings with this collective advocacy lobby. They could have pointed to the evident exploitation of the semantic confusion surrounding the terms 'learning difficulty' and intellectual disability. Whilst it is generally accepted that a learning difficulty does not affect general intelligence, an intellectual disability is linked to an overall cognitive impairment. Whilst it is known that a number of the lobbyists had specific learning difficulties, none had an

intellectual disability yet they claimed they had a mandate to speak on behalf of all people with an intellectual disability. The danger of collective advocacy being taken over by individuals wishing to pursue their own agendas has been recognised by Wolfensberger (2003).

What the Direct Action Network has failed to recognise is that fundamental change is unlikely to be brought about by its abrasive and abusive approach. Nowhere in any of the literature published by DAN is there an acknowledgement that most parents and professionals act for the best, and not the worst of motives. The kind of indiscriminate denigration engaged in by the Direct Action Network ill-serves the inclusionist cause that it so blindly and uncritically supports. Members of the Direct Action Network could well take on board Wolfensberger's advice that: "some people need to be taught to be less assertive, to talk less or less loudly and to better control what comes out of their mouths; others need to be taught consideration, courtesy, and other competencies, hand-in-hand with assertiveness" (Wolfensberger, 2003).

What is of critical importance is the need for a well-developed network of advocacy services representing the interests of people with an intellectual disability: one which is genuinely independent and not administratively or financially tied to any of the statutory services. Unfortunately at a time when the voice of people with an intellectual disability most needs to be heard, cutbacks in local authority budgets are leading to the closure of advocacy projects as they may be perceived to be of only peripheral value by those responsible for introducing the cuts.

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2.3 Disability charities

One example of the influence of disability rights thinking has been the transformation in, or radicalization of, some charities (Shakespeare, 2005). Twenty years ago, such a slogan as 'Rights not charity' was commonplace during disability demonstrations. A clear dividing line was drawn between organizations 'of' and 'for' the disabled people – the former were seen as democratic and took a civil rights approach to disabled people, were staffed and controlled by disabled people themselves, and were consequently eligible to join the British Council of Disabled People (BCODP). In comparison, organizations 'for' the disabled people were seen as patronizing and unaccountable, advocated for segregated living and education, and were run by non-disabled professionals and those representing 'the great and the good'.

The largest charity representing people with an intellectual disability in the UK is Mencap. Its stated aim is to create the opportunity for all people with an intellectual disability to be equal citizens in all respects. However, people with an intellectual disability are clearly viewed by Mencap as a homogeneous population. This viewpoint has been challenged by Marrin, who points out that there are some children and adults within this population who are so seriously impaired that they cannot undertake the responsibilities that go with their rights (Marrin, 1998). In Marrin's view, Mencap's position may be well intentioned, but it is profoundly misguided because it ignores reality. At worst, it constitutes a form of tokenistic window dressing designed to convey the impression that Mencap is in tune with current thinking and is acting in a politically correct manner.

Klatt (2000) has defined political correctness as: 'a canon of orthodoxies and prohibitions and as a set of claims that society today does not readily allow to be questioned'. He observed that psychology was replete with such dogmas that were based on ideology rather than empirical research. Put another way, political correctness occurs where any policy (e.g., inclusion) comes to be seen by those directly affected by it, as an imposed, unchallenged and unchallengeable orthodoxy.

In 1985, a group of parents broke away from Mencap, because they felt that their concerns for their children with an intellectual disability were being overlooked by the charity. These were mainly parents of children with more severe intellectual disabilities. Many of these children had been or were in hospital settings and would, in their parents' opinions, experience great difficulties in living in the community as dictated by government policy – one that Mencap itself strongly supported. Over the years, relations between this new body, called the National Society for Mentally Handicapped People in Residential Care (Rescare), and Mencap became increasingly strained, because the latter saw the former as a charity promoting an outdated and discredited form of provision that resulted in the unnecessary institutionalization of people with an intellectual disability. For its part, Rescare saw Mencap as too closely identified with different government initiatives that disadvantaged the families it represented. There was also the feeling that Mencap had lost touch with its grassroots supporters.

As Mencap has grown in size, so has its income. According to the published accounts for the year ending 31 March 2011, its income was £193 million with an annual salary bill of £137 million. No fewer than 151 employees in Mencap were recorded as working on campaigning and lobbying; almost double the number for 2008 (88 employees). Some outside observers, including members of the House of Commons Public Administration Select Committee, believe that some of the larger charities spend too much on campaigning (Mills, 2011). According to Mencap's accounts, six employees earned £100,000 or more, with the CEO earning between £170,000 and £180,000.

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General Charities	Salary or Salary Range of Highest Paid Employee	Charity Income Year End
Consumers Association	£300k - £310k	£76m (June '11)
Marie Stopes International	£260k - £270K	£345m (Dec '11)
Save the Children	£261,309	£63m (Dec '11)
Cancer Research UK	£210K - £220k	£493m (Dec '11)
British Red Cross Society	£180k- £190k	£214m (Mar '12)
Age UK	£180k- £190k	£168m (Dec '11)
Shaw Trust	£180k- £190k	£86m (Mar '12)
National Trust	£170k- £180k	£436m (Feb '12)
Royal Mencap Society	£170k- £180k	£194m (Mar '11)

TABLE 4. Top Incomes by Charity Sector

Source: Charity Trends website 2012

The magnitude of the salaries paid to CEOs of some charities should occasion concern given that charities are legally non-profit-making bodies and the fact that a significant proportion of the population they serve is acutely financially disadvantaged. However, as Pizzuro has pointed out, non-profit organizations can easily turn into profit making conglomerates if there is inadequate oversight and monitoring (Pizzuro, 2012). He cited the case of the Young Adult Institute in New York City, which was established to run a variety of programmes for the developmentally disabled in the city and state. The New York Times revealed that the chief executive officers had awarded themselves salaries commensurate with the highest paid Wall Street executives!

Last year the chief executive of Mencap felt compelled to write an article for *The Guardian* in defence of her salary given the increasing unease at the salaries being paid to charity bosses (Tregelles, 2013). She pointed out that the board of trustees for Mencap felt that her salary was pitched at the right level for someone who had such a complex and high risk job. However she did concede that for many of her colleagues, donors and beneficiaries her salary was seen as 'a huge amount of money'.

If it is the case as Greig (2015) has asserted that people with an intellectual disability have failed to achieve any kind of discernible profile over the past two decades then the question arises as to what Mencap has been doing over this period to raise that profile.

One of the reasons for the establishment of Rescare was a feeling that Mencap too closely identified itself with government policies to the neglect of the best interests of the population it claimed to represent. An illustration of that tendency which was widely and unfavourably commented upon concerned the closure of Remploy factories in the UK. 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 (Disabled People Against Cuts, 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 and
- 24.0% (118) were employed.

To have opposed the closure of the Remploy factories, Mencap would have had to abandon its unqualified commitment to an inclusionist agenda and this would have constituted an embarrassing ideological volte-face. But it is possible to commit to a policy of inclusion and at the same offer special employment opportunities to adults with an intellectual disability in the open community, one has only to the look across the Atlantic at the successful operation of The Center for Discovery in New York State (www.thecenterfordiscovery.org/) and the Melwood Horticultural Centre in Maryland (www.melwood.org/). The Center for Discovery was founded in 1948 and is a not-for-profit and nationally known provider of health, educational and residential services for approximately 500 children and adults, ages 5-78, with severe disabilities and medical frailties, including a growing number of individuals with autism spectrum disorders. The Center offers individuals and families from New York State a wide range of innovative clinical, social, creative arts and recreational experiences designed to enrich their lives through personal accomplishment. Melwood which is also a not-for-profit agency is now in its 50th year and offers services for more than 1,900 people with disabilities. Its community services include supported employment, day services, supported living and recreation to maximize their independence and inclusion within the community.

Mencap's unqualified support for the policy of placing people with an intellectual disability in the open community comes at a cost. This policy is predicated on the assumption that the communities in which people with an intellectual disability are placed are going to be welcoming and supportive. But as the report researched by Lemos&Crane in association with the Foundation for People with a Learning Disability found, people with an intellectual disability living independently in the community frequently experienced a disturbing range of crime, abuse and harassment: incidents frequently characterised by cruelty (Gravell, 2012).

In a recent survey by Turning Point, a leading health and social care provider, it was found that more than half of those surveyed believed that people with an intellectual disability were the most discriminated against group in society (Williams, 2010a). 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 recently to examine the issue (Sale and Mickel, 2009; Walker, 2009; Williams, 2010b). The findings were subsequently published in the report Promoting the Safety and Security of Disabled People (EHRC, 2009). The Commission recommended, among other things, investment in and evaluation of innovative approaches to independent advocacy to ensure that the most marginalized disabled people have a voice and the confidence to challenge negative behaviours and to seek protection and redress. This recommendation ignores the fact that almost all advocacy programmes in the UK are funded by health and social services and, therefore by definition, are not independent (Gray and Jackson, 2002; Jackson, 2005b).

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Mencap and other national disability charities face challenges that are endangering the quality of social care provision for people with intellectual disabilities; such challenges include the following:

- commercialization of social care;
- expansion of the 'for profit' private sector at the expense of the 'not for profit' voluntary sector;
- uncertainties caused by frequent changes in regulatory structures;
- shift to self-regulation of care services;
- neutering of the power and influence of advocacy services; and
- inadequacies in the professional training of personnel working with people with an intellectual disability in health, education, and social care services (Jackson, 2010).

The fact that UK charities are financially dependent upon public funds may well deter them from departing too far from stated government policies (e.g., inclusion). The criticism directed at Mencap could equally be applied to other large disability organizations in the UK, including SCOPE (formerly The Spastics Society) and Disability Rights UK.

The integration of relatively small disability groups into larger organizational entities reflects a significant trend in recent years. One consequence of this process is the progressive loss of identity and voice both for those groups coming together and the individuals within them. This may explain the recent phenomenon of grassroots action. Jolly, co-founder of Disabled People Against Cuts (DPAC), pointed out that challenges to the UK Government's current austerity programme, which has led to severe cuts in services for people with disabilities, is not being led by the well-paid directors of UK charities but is coming from the grassroots, in which individuals with disabilities employ social media, Freedom Of Information requests, as well as the support of sympathetic media, lawyers, and MPs (Connolly, 2012). In that process individuals with an intellectual disability are still at a disadvantage and may be excluded, because some measure of sophistication is required to exploit the social media and other communicative mechanisms.

If it is the case, as the Chief Executive of the National Development Team for Inclusion has claimed, that the government attaches little importance to the concerns of people with an intellectual disability and their families because of their numerical insignificance, then charities representing people with an intellectual disability need to act. There is a strong case for disability charities to look at the manner of their working and the extent to which they are currently fit for purpose.

As a starting point it could be argued that the major disability charities should:

- acknowledge and act on the fact that people with an intellectual disability do not constitute a homogeneous population
- recognize the lack of wisdom and justice in pursuing a narrow inclusionist agenda that lacks empirical support
- engage in a process of demetropolitisation, as currently the major disability charities are too London-centric and are perceived in some quarters as being too distant both physically and psychologically from the populations they serve

- reduce their high running costs resulting from a central London location which is unnecessary by virtue of easy access to high speed information exchange and face-to-face contact (e.g. Skype)
- engage in a process of staff reduction and structural simplification as most of the major disability charities appear to be over-staffed and overly bureaucratic
- stand up to government and challenge more vigorously any proposed policy where it is evident that the best interests of people with an intellectual disability may be placed at risk
- make the case for strengthening the role and status of the Ministry of Disability
- stress to the Ministry that people with an intellectual disability and their families do constitute a numerically significant population and have problems which differ from those of other disability groups
- encourage innovation in provision and practice in the fields of education, social care, health, recreation and employment
- financially support research and demonstration projects and disseminate the findings to relevant audiences
- adopt a higher research profile either through engaging directly in research or sponsoring research in priority areas defined by its membership with funding being made available through cost savings resulting from geographical re-location, revised salary structures and staff downsizing
- monitor closely the impact in the social and health care sectors of the process of marketisation and technological innovation on people with intellectual disability
- apply pressure on government to improve the quality of professional training in those sectors (education, social care and health) which have a direct bearing on the wellbeing of people with an intellectual disability
- make the case to government for the creation of genuinely independent advocacy services which are centrally and not locally funded
- actively promote and support the non-profit sector where it provides educational and social care services for people with an intellectual disability.

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What cannot be in dispute is that fundamental changes in the structure and operation of the charities representing people with an intellectual disability and their families are urgently needed. If it is the case that the current profile of people with an intellectual disability is barely discernible, as has been authoritatively claimed, then the major charities have to shoulder part of the blame for that situation. There is a compelling case for the major charities to act more assertively.

3. Regulation

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 (CSCI, 2004).

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 (CSCI, 2005a). 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; and
- 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 had 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 (CSCI, 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 be 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 Platt 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, p.1). 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' (Davies, 2005, p.2). 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' (Davies, 2005, p.2).

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.

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The CQC was an unhappy creation according to 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, 2012)

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 an intellectual 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). 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, (CQC, 2014).

The King's Fund Centre (2014) has warned against expecting the CQC to guarantee high quality in the social care sector. It has argued that the CQC can only ever be the third line of defence against poor care. 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 is the leaders in the relevant professions and the managing boards of organizations. And the third line of defence is the national bodies, of which the CQC is one. In the opinion of the King's Fund Centre the expectation that the CQC can guarantee high quality care at all times is not only unrealistic but it runs the risk of distracting our attention away from the fact that the quality of care offered is a local responsibility.

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The prediction by Dame Platt that the CQC would prove an ineffective social care regulator has 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 highly scathing judgements on the operation of the CQC made by a succession of Parliamentary Select Committees. A strong case can be argued for the reversal of the current policy of merging the health and social services so that social care can retain its own distinct professional identity and voice.

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4. Marketisation

The reforms implemented following the 'commercialisation' of care resulting from the National Health Service and Community Care Act (1990) brought about far-reaching changes to the provision and financing of health and social care in the United Kingdom. Market forces received an enormous boost, 'for-profit' organizations became increasingly active, notions of 'best value' became increasingly relevant within funding formulae, and users of services were more likely to be involved in decision making (Knapp and Kavanagh, 1995). Market ideals as a key principle of public service provision continued to be an acceptable feature of the neo-liberal agenda pursued by New Labour. Initially, there was the establishment of a 'quasi-market' within the public services where the 'not-for-profit' sector occupied a much more level playing field with the 'for-profit' sector.

The marketisation of the social care sector continues despite the acknowledgement, in one of the first comprehensive reports on social care, that care services run by the 'for-profit' sector in England are consistently out-performed by those run by the 'not-for-profit' sector (Commission for Social Care Inspection, 2005b). However, with the passage of time, competition is likely to favour those 'for-profit' companies that are able to maintain their competitive edge by keeping costs low. Pollock (2005) has argued that this is likely to be achieved through the recruitment of poorly paid, inadequately trained and under-motivated staff; the implication being that 'not-for-profit' organizations will be squeezed out, leaving commercial companies to dominate the market. Bakan (2004) has convincingly demonstrated how for-profit companies operating in deregulated systems invariably act in an aggressive, exploitative and self- interested manner. Are there any grounds for believing that care corporations will act differently?

Bakan (2004) has provided ample evidence to support the notion that a 'care corporation' is a contradiction in terms. He has pointed out that the legally-defined mandate of a corporation is to pursue its own self-interest. If a corporation is caught breaking the law, it can pay the large fines and continue doing what it did before. The fines and the penalties paid by corporations can be trivial when compared with its profits, especially if the corporation is large. In the opinion of Milton Friedman - Nobel Laureate in Economics - corporate executives have but one 'social responsibility' and that is that they must make as much money as possible for their shareholders. This is a moral imperative. Those executives who place social and environmental goals over profits - in other words who try to act morally - are, in Friedman's judgment, immoral. Friedman contended that there is only one instance when corporate social responsibility can be tolerated and that is when it is insincere. In other words, the executive who treats social or environmental values as a means of maximizing shareholder's wealth is committing no wrong (Friedman, 1979).

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Pollock (2005) has drawn attention to the situation in the National Health Service, also faced with increasing privatisation. In the past, doctors were free to speak out – in fact they were under a moral obligation to do so – if they felt it was in the interests of their patients. In a business culture, however, loyalty is said to be due above all to the shareholders. Stone (2000) has argued that there is a fundamental clash between care and business ethics. Once care is contracted out to a 'for- profit' managed care organization, the ethical situation becomes problematic. Every rationing decision has an impact. While the 'for profit' sector continues to expand, there is increasing evidence that the 'not for profit' sector is struggling to compete. One of the largest providers of care for adults with intellectual disability in Scotland - Quarriers - threatened to make all its 2000 staff redundant if they failed to agree to cuts in their sick pay, night shift allowances and payments for holidays (Unison, 2009).

The voluntary sector in the UK, which is largely comprised of organizations with charitable status, has been forced to face a number of critical challenges:

- there has been a downturn in individual and corporate giving to charities
- falling asset values for the funds held by charities is affecting investment income
- a freeze on local tax, coupled with greater autonomy given to local government in its spending, means that those sectors, like social care which are seen as low priorities, are suffering.

A further consequence of the marketisation of social care has been the growing marginalisation of professional workers (e.g. social workers, educational psychologists, clinical psychologists, GPs, etc.) in decision-making processes related to assessment and placement. Decisions are increasingly being taken by local authority commissioners for services (Care Service Improvement Partnership, 2008). Thus a process of deprofessionalisation is occurring in which the role of those with relevant knowledge, expertise and experience and who are well placed to make informed decisions concerning the individual needs of clients are being sidelined. These changes appear to be driven by cost and not quality of life considerations.

It is instructive to look at the performance of one of the self-proclaimed market leaders in social care in England which is listed on the London Stock Exchange (Jackson, 2010). The accuracy of the company's claim to being a market leader was assessed by examining the inspection reports on 24 of their premises which made provision for people with an intellectual disability and which were published by the Commission for Social Care Inspection and which were accessible on-line. It was found that one quarter of the premises run by this company had to meet at least six or more statutory requirements. In other words, a quarter of the premises were deemed to be in breach of their legal obligations.

There were three areas that occasioned the Commission particular concern:

- **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.

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◆ **Staffing levels**: A recurrent issue noted by 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.

◆ **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 of residents. This requirement had been made on no fewer than three previous occasions.

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 strongly 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.

This general position has not improved since that study was undertaken. The Future Care Workforce report of 2014 has drawn attention to the following facts:

◆ care workers and home carers, who account for 700,000 of the total workforce, are paid an average of £7.90 an hour, but 40% are paid below £7.00 an hour
◆ 30% are on zero-hour contracts
◆ there is a 19% staff turnover across the sector
◆ 37.2% have no relevant qualifications
◆ 82% of the care sector workforce is made up women (International Longevity Centre, 2014)

In an effort to meet their workforce needs, many employers have turned to migrant workers, often from Eastern Europe which has led to concerns that some care workers lack the ability to speak good English.

There is a strong argument for restricting the extent to which some parts of the private sector are involved in the provision of services for people with an intellectual disability given their proven poor record. At the same time the voluntary sector should be enabled to play a greater role in the provision of day and residential services. Equally important, opportunities should be afforded this sector to engage in pioneering innovatory practice.

5. Technology

One strategy being deployed by an increasing number of care companies to tackle the issue of staff costs is the introduction of CCTV to monitor residents and staff. It is argued in defence of this practice that it protects both the resident and staff member; acting as a safeguard, preventing abuse and encouraging good practice. However, by adopting such technology it could be argued that one is re-introducing some of the salient characteristics of the total institution identified by Goffman (1961):

- individuals progressively losing their identity
- constraints being placed on basic liberties (e.g., freedom of movement and action)
- life within a setting becoming routinised and closely regulated
- staff maintaining a social distance between themselves and residents.

If as a result of the introduction of CCTV the size of a staff team in a care home is significantly reduced then this will limit the ability of the staff to accompany residents should they wish to leave the care home in order to go shopping, attend a recreational or social event or visit friends. In other words, the financial advantage gained by a 'care business' in installing CCTV may be at the expense of curtailing the freedom of movement and action by residents. This limitation of access to the outside world can then lead to the creation of a quasi-custodial regime in which members of care staff increasingly find their role changing from that of carer to custodian.

The notion of the custodian is not farfetched. In the late 18th century Jeremy Bentham, English philosopher and social theorist, conceived of the construction of the Panopticon - a particular type of institutional building. The concept of the design was to allow a single person to observe the inmates of an institution without the inmates being able to tell whether or not they were being observed. Bentham saw the basic plan as being applicable to hospitals, schools and asylums as well as prisons. The Panopticon was intended to be cheaper than the prisons of his time as it required few staff.

Whilst Bentham regarded the Panopticon as a rational and enlightened solution to a societal problem, Foucault (1975) saw the Panopticon as creating a consciousness of permanent visibility which acted as a form of power. Contemporary social critics have argued that such technology has allowed for the deployment of panoptic structures throughout society (Elden, 2002). Surveillance by CCTV cameras in public spaces in the UK is an example of a technology that brings the gaze of some unknown and external body into people's daily lives. Whilst Foucault accepted that the Panopticon was a form of architecture, it was above all else a form of government. It was a way for mind to exercise power over mind (1994).

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It is not entirely coincidental that technology is increasingly been utilised in residences housing the elderly and people with an intellectual disability - both vulnerable populations with little political influence. In a custodial regime it could be argued that it is difficult to see the relevance and value of employing highly qualified care staff. Thus it is not beyond the bounds of possibility that the future staffing of residential care homes is outsourced to one of the large security companies in the UK which currently exercise a near monopolistic hold in the prison sector. These companies flourish notwithstanding their very poor operational record - a fact repeatedly highlighted by a succession of Parliamentary Select Committees (Wallace 2014).

This scenario may be thought unduly alarmist but it is anticipated that the cuts in the social care budget following the next UK General Election in May 2015 are going to be of unprecedented severity. In such circumstances the reduction in social care budgets will lead not only to staff cuts but also to an urgent exploration of ways to exploit the labour-saving potential of technology. It is difficult to see how the quality of life of people with an intellectual disability is enhanced by these developments.

Whilst it is easy to overstate the risks involved in the introduction of technology, it is nevertheless a development that operates at a subliminal level with the result that one may only become aware of its widespread and harmful consequences much later when remedial action or countervailing strategies are difficult to implement.

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6. Financial vulnerability

There is one further broader concern about the marketisation of the care sector that needs to be highlighted. It has been estimated that of the 4,872 firms operating 20,000 care homes across the UK, 1,449 of them - one quarter - have been rated as 'financially vulnerable' (Burns-Callandar 2013). The relatively low profit margins generated within 'the care industry' means that care companies are only able to survive through the acquisition of financially vulnerable competitors. As a result, ownership of care homes is falling into fewer and fewer hands. However if investing in this financially troubled sector becomes unattractive, investors are likely to withdraw their funds.

The 'nuclear scenario' would occur if monopoly providers found themselves financially overstretched and as a result subsequently collapsed. Will local or central government be forced to step in to re-nationalize the social care service? This scenario may seem far-fetched until one recalls Dame Denise Platt's strongly voiced concerns about the ability, capacity and willingness of the newly created social care regulator - the Care Quality Commission - to monitor effectively developments in the social care field. It should also be noted that it was, in part, a failure on the part of the Government established financial regulator - the Financial Services Authority - to see the danger signals in the financial market and to take appropriate and timely remedial action to prevent or in some way mitigate the effects of the market crash.

It is not being claimed in this paper that the overwhelming majority of people with an intellectual disability in the UK are at risk but one does need to take into account the following factors:

- the rapid marketisation of the social care sector
- the inadequately led and resourced regulatory and inspectoral regimes
- the reliance on a poorly paid and inadequately trained workforce
- the marginalisation of professional workers involved in the decision-making processes
- the lack of government interest in conducting nation-wide research to gauge the health of this sector, and
- the depersonalizing effect resulting from the introduction of technology.

It is not immediately apparent how one can raise the profile of people with an intellectual disability at a time of increasing austerity when people are inclined to focus on their own personal circumstances. However, it is important that the relevant regulatory bodies monitor on a regular basis the state of health of the social care sector as the risk of a financial meltdown is real and the consequences for people with an intellectual disability and their families of such a meltdown would be dire.

7. Epilogue

If current predictions for the state of the British economy over the next two decades are correct then people with an intellectual disability and their families are going to be at particular risk. The purpose of this paper has been to:

1. Encourage the abandonment of the often sterile academic debate about the meaning of inclusion;

2. Protect those parts of the social and health care sector that provide high quality services; and

3. Urge a reformed disability charities sector to defend more effectively the interests of the populations they represent.

A particular cause for unease at this time is the widespread adoption of the twin utilitarian philosophies of mercantilism which promotes the perception of education, health and social care services as simply economic processes, and managerialism which contends that improvements in the quality of services can only be achieved by professional managers or commissioners who are unremittingly committed to a mercantile ethic. The impact of these two philosophies has been to depersonalise the individual, to devalue the role of the professional and to create a widening gap between managers and those managed. This re-statement of Victorian values in the second decade of the 21st century is cruelly ironic, for it was the application of precisely these same economic values which eventually led to the dehumanising and brutal treatment of individuals with an intellectual disability at the end of the 19th century.

What is a matter of concern is the flawed ideology of inclusion which:

1. takes no account of the differences between people with an intellectual disability and people with other forms of disability; and

2. makes no allowance for important differences within the population of people with an intellectual disability.

There is a risk that the macro-institutionalisation of the 19th century, a notorious episode in our social history, is in the process of being replaced by an equally shaming process of extensive micro-institutionalisation where people with an intellectual disability are placed in under-resourced, inadequately staffed and socially and physically isolated residences in the community. At the same time we have witnessed the nationwide closure of day and residential special schools, adult day centres and sheltered employment centres for individuals with an intellectual disability. This is the legacy of successive governments' policies which have failed to take account of the needs of this population: a population which appears to be perceived as too small to matter.

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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.

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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 written on a wide range of issues relating to people with an intellectual disability in: American Journal of Mental Retardation; British Journal of Special Education; Educational Review; International Journal of Developmental Disabilities; International Journal of Disability and Human Development; Journal of Austrian Studies; Journal of Intellectual Disability Research; Journal of Intellectual Disabilities; Journal of Moravian History: Scottish Medical Journal.

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The author has a particular interest in exploring the meaning of community inclusion as it relates to people with an intellectual disability. He recently guest reviewed a special issue on this topic for the Journal of Intellectual Disability Research (2011) and is currently guest editing a special issue of the International Journal of Developmental Disabilities on the same subject. A more extensive exploration of the theme of community living, inclusion and intellectual disability is to appear in a book to be published in 2016 which he is co-editing.

The author has identified a set of professional goals to which he is strongly committed:

1. An elevation of the political profile of people with an intellectual disability.

2. The abandonment of narrow definitions of inclusion and community care.

3. The promotion of the principle of diversity in provision and practice in the fields of education, health and social care for people with an intellectual disability.

4. The assumption by the third sector of a greater and more innovatory role in the provision of services for people with an intellectual disability.

5. Fundamental reforms in the structure of charities representing people with an intellectual disability and their families.

6. Greater professional and public recognition of the importance of the role of families in the support of people with an intellectual disability.

7. The adoption by professional bodies in the fields of education, health and social care of training programmes based on a social pedagogic model.

8. A reversal of the current policy trend of merging social care and health sectors in order that the social care sector can retain its own distinct identity and voice.

9. Moving to a situation where the state does not exercise near monopolistic control over determining the research agenda in the fields of education, health and social care.

10. The creation of advocacy services for people with an intellectual disability which are genuinely independent and not administratively or financially tied to statutory services.

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Relevant Publications

REGULATION

This report analyses the devastating impact of bureaucratic regulation on the lives of people with learning disabilities living in intentional communities.
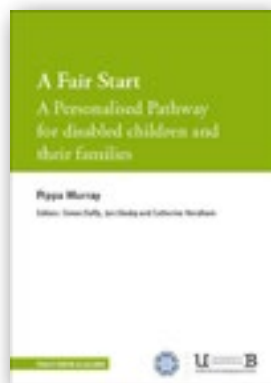
http://bit.ly/cfwr-regulation

THE RELATIONAL BASIS OF EMPOWERMENT

Empowerment is not personal but social; it depends on our relationships with others and their attitude towards us and our communities.
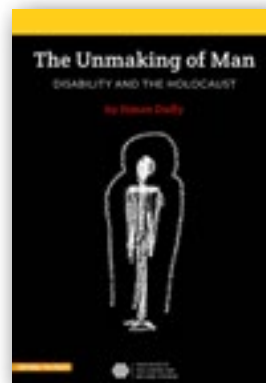
http://bit.ly/rbempower

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A FAIR START

Families with children with disabilities describe the kind of system that could really work for them. They do not just want budgets - but meaningful partnerships with professionals. The real wealth model is also explained.

http://bit.ly/a-fair-start

THE UNMAKING OF MAN

Exploring what we can learn from the Holocasut, eugenics and the development of institutional models shows the vulnerability of human dignity in the face of social and economic forces.

http://bit.ly/unmaking