Invited review

Challenges of residential and community care: 'the times they are a-changin'

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Abstract

This paper seeks to examine a number of issues which relate to the provision of appropriate and high-quality residential and community care for people with an intellectual disability. A number of key themes emerging from this Special Issue of the *Journal of Intellectual Disability Research* are identified and explored: (1) normalisation; (2) inclusion; (3) choice; and (4) regulation. It is concluded that the research community has an obligation to assume a higher profile at a time when the quality of life of people with an intellectual disability and their families is under threat. This can be done in a number of ways through: (1) the establishment of demonstration projects, either independently or in association with the voluntary and statutory sector,

to explore innovative and practical approaches of enhancing the quality of services offered to people with an intellectual disability; (2) looking at ways of improving the quality of training programmes for care staff by moving away from current approaches that emphasise narrow instrumental competencies to strategies that develop essential expressive and relational aspects of care practice; and (3) offering a more considered and rigorous critique of current professional practice and assuming a leadership role at a time when leadership in this field is lacking.

Keywords choice, inclusion, intellectual disability, marketisation, normalisation, regulation

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Introduction

'The times they are a-changin!', this title of one of Bob Dylan's best-known songs is singularly apposite at this point in time. As I write this paper, one of the largest private companies providing health care for the elderly and people with intellectual disability (ID) in the UK is on the point of financial collapse and at the same time an undercover investigation undertaken by the BBC Panorama programme has revealed appalling incidents of abuse in a home run by one of the other leading companies providing

residential care for people with ID. To compound matters it later emerged that the national regulatory body – the Care Quality Commission – had ceased inspecting all privately run units for people with ID for a period of 4 months (October 2010 to January 2011), notwithstanding the fact that a year earlier it had published a report highlighting poor practice in specialist health services for people with ID! These two damaging developments are perhaps not quite so surprising when one notes the 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 health and social care sector (Samuel 2010).

My reason for making reference to these two developments in the UK is to underline the point that the current economic recession in Europe and North America – the full impact of which has yet to be felt – is going to present a real challenge as far as providing high-quality care for children, young people and adults with ID. The great merit of this Special Issue of the *Journal of Intellectual Disability Research* is that it provides an opportunity to examine a number of important issues which relate to the provision of appropriate and high-quality residential and community care for people with ID. No attempt has been made to comment upon the content of all the papers in this Special Issue; instead, a number of key themes have been identified and explored: (1) normalisation; (2) inclusion; (3) choice; and (4) regulation.

Normalisation

A brief examination of the relevant literature shows that confusion still exists over the meaning of the principle of normalisation as defined by Wolfensberger (1980). Wolfensberger's advocacy of the term 'social role valorisation' in preference to 'normalisation' revealed the degree of his disenchantment with the continuing misunderstanding and misapplication of the principle. He saw the goal of 'social role valorisation' as the enhancement of the social role of individuals or groups at risk of social devaluation. He believed that such a goal could only be achieved through an improvement in people's social image and social competence. Central to Wolfens-

berger's argument was the belief that significant advances in the quality of life of people with an ID can only result from a shift in the value orientations of professional workers and the general public. In short, there had to be an ideological readjustment. The essential point here is that the principle of normalisation represents an ideology: a system of shared values, attitudes and beliefs which should help guide not dictate thought and action. This necessitates a sensitive and pragmatic approach not an inflexible and dogmatic one.

However, the particular problem with ideologies is that they can create ideologues who become wedded to what they perceive as the fundamental purity of a given ideology. But as Zigler & Balla (1977) have consistently argued normalisation is an ideology lacking the practical means for its implementation. They have repeatedly pointed out that the social policy of moving people with an ID from large institutions to small residential community settings, which started in the early 1960s, evolved almost completely without an empirical base. They warned then that: 'the almost total lack of data on what constitutes the most adequate care setting for retarded individuals is potentially disastrous for those involved in the creation of social policy'. A decade later the same authors were to repeat this point (Zigler *et al.* 1986). Empirical examination, they argued, should replace polemics about the relative virtue of community-based facilities versus large-scale institutions. Zigler & Hall (1986) succinctly sum up the position:

> Unfortunately, many of the forces at work . . . depict the issues surrounding normalization as win-lose, either-or choices, driving out the moderate middle ground position. Those who polarize the situation by promoting either normalization or institutionalization to the complete exclusion of the others do the situation and its complexity a grave disservice. (Zigler & Hall 1986, p. 1)

What concerns Rapley & Baldwin (1995) is the way in which the 'theories' of normalisation, social role valorisation and inclusion are promoted. Paradoxically, instead of being genuinely enabling, empowering and liberalising, ideology is being deployed to support policies which place a low tolerance on diversity, however that may be expressed, and which offer only rhetorical and not real oppor-

tunities for genuine choice. As Jackson (1996a) has indicated, promoting the normalisation principle in the crusading terms of the ideologue is counterproductive for it can: (1) foster professional intolerance, division and disaffection (Hansen 1976); (2) lead to the application of powerful pressures on professional staff to conform (Boucherat 1987); (3) devalue the worth and work of those who, for valid reasons, find grounds for criticism (Mesibov 1990); (4) promote the growth of a propaganda industry which places a low value on objectivity and truth (Jackson 1989); (5) prompt the use of strategies and techniques which indoctrinate rather than teach (Renshaw 1986); (6) encourage a poorly trained workforce to believe that the application of a simple formula will resolve the complex problem of delivering an effective and humane service (Tadd 1992); and (7) result in the creation of an inflexible service that is unresponsive and insensitive to the client's needs (Rhoades & Browning 1977).

Inclusive exclusion

One of the most thought-provoking papers in this Special Issue is the one by Bertoli *et al.* (2011), in which the experience of a cohort of individuals with Down syndrome, aged between 30 and 35, is examined. The cohort was drawn from possibly one of the first groups to have been raised in a fully integrated school system, where they attended mainstream schools and participated in a wide range of community and social activities (e.g. gym clubs, playgrounds, concerts). However, after secondary school, it was found that this cohort faced a sudden abandonment as there were few support services for adult people with Down syndrome and their families in Rome. Much of their free time involved little activity – a fact that the paper's authors acknowledge could adversely affect mental functioning as well as their overall sense of well-being. Participation of individuals with Down syndrome in employment, including sheltered work, was limited. Even allowing for the number of people employed in educational activities (e.g. day centres), it was evident that two-thirds of adults with Down syndrome had 'full days of empty time'.

The authors indicated that the lack of employment opportunities was likely to contribute to a loss of acquired skills. What was needed was a policy of work inclusion for all, on a daily basis. While the authors noted that some people with Down syndrome could enter the open market, the majority of the adults urgently required opportunities for daily employment in day centres or sheltered workshops. It was believed that such inclusion would contribute to improved social interaction, increased autonomy, better health checks and relief for families whose quality of life would be considerably enhanced.

The authors observed that the media tended to focus on people with Down syndrome who were coping remarkably well. While in one respect this could be seen as encouraging, it also contributed to the marginalisation of the majority of people living with Down syndrome who faced enormous challenges. What was needed was a change in public opinion and popular culture to make *all* citizens visible, including those with Down syndrome. Support services had to be adapted to the changing needs of people with Down syndrome which required staff to be properly trained (Jokinen & Brown 2011). The concluding observation of the authors is worth highlighting. They make the point that it is increasingly evident that an inclusive school system alone does not in itself guarantee a satisfactory quality of life for people with Down syndrome in adulthood. What is needed is a comprehensive policy of inclusion and support which should extend over the entire lifetime of people with Down syndrome.

However, some caution needs to be exercised before accepting the implicit assumption in Bertoli *et al.*'s (2011) paper that the inclusion policy within the Italian state school system is working. Research undertaken by Reversi *et al.* (2007) has indicated that students with special needs continue to show a higher sense of loneliness compared to their peers without special needs. Given that a sense of loneliness arises from a feeling that one has few or no friends, it raises questions as to the actual degree of acceptance and inclusion experienced by children with special needs. Sidoli (2008) has also drawn attention to the critical importance of professional development to enable special education and class teachers to implement the inclusive policy in Italian schools. She notes that class teachers do not always find it easy to work with the special education teacher as the assumption is

made that it is the function of the special education teacher to work on her own with the child with a disability whether in or outside the classroom. Ianes (2006) has acknowledged that too much is still asked of the special education teacher whose work, if performed in isolation, is often ineffective as many of them lack a specific training and are managed inadequately by school and local authorities. Additional Italian research indicates that only a small group of disabled pupils experience full inclusion according to their parents (51% in vocational training, 46% in kindergarten, 30% in primary school, 25% in secondary junior and 44% in secondary high school) (D'Alonzo & Ianes 2007). Research evidence therefore suggests we should be somewhat cautious before accepting the view that the Italian school system presents a model of inclusive practice.

The question arises as to why the Italian government introduced the policy of inclusion. Was there an expectation that it would contribute to the creation of a more inclusive society or was it simply because it offered a cheaper option? There is no compelling evidence that in the 40 years since the introduction of this policy in 1971, the message of inclusion has gone beyond the schoolroom. The findings from Bertoli *et al.*'s (2011) research reveal no evidence of the existence of an inclusive society willing to accept people with Down syndrome.

Lindsay (2007) in a recent review of the literature has concluded that the available evidence 'does not provide a clear endorsement for the positive effects of inclusion' in education. The assumption that mainstreaming is best for all children (those with an ID and those without) has been accompanied in Lindsay's view by the loss of the ability to study the cause and nature of negative attitudes to disability with a view to combating discrimination at source. Instead, there has been an assumption that inclusion of young people with an ID in mainstream schools will cure society of prejudiced and discriminatory attitudes. The Italian inclusive model would not appear to offer any proof for that assumption.

Cummins & Lau (2003) have drawn attention to the attitude of teachers to the inclusion of pupils with special needs in their classroom. They observe that few teachers have a choice on the matter and may resent the children's inclusion for a variety of

reasons. These may include feelings of personal and professional inadequacy to manage a mixed ability class, concerns about time distribution between class members, or even philosophical opposition to inclusive education. And as Jordan & Stanovich (2001) have shown, teacher attitudes to children with special needs can impact on the children' self-respect.

Recent research by the Foundation for People with Learning Disabilities, which sought the opinions of students with special needs included in mainstream settings, highlighted a number of concerns – the most important of which was a plea by students to be allocated designated safe places in their schools and colleges where they could escape the social rejection, intimidation, and bullying experienced when not attending classes (Foundation for People with Learning Disabilities 2008). MacIntyre (2008) has also drawn attention to the predicament of young people with ID who are being marginalised socially and excluded in mainstream schools and colleges. These two studies demonstrate that it is important to avoid conveying a unidimensional representation of the inclusion process and move beyond ideological and bureaucratic inspired definitions of social inclusion to one that is meaningful and relevant to students with special needs.

It is worth noting that the Department of Education in England has recently published a consultative document (Green Paper) on special educational needs, which recommends the abandonment of the long held presumption of a mainstream placement for children with special educational needs (Department of Education 2011). The intention of the Department is:

. . . to give parents a real choice of school, either a mainstream or special school. We will remove the bias towards inclusion and propose to strengthen parental choice by improving the range and diversity of schools from which parents can choose, making sure they are aware of the options available to them and by changing statutory guidance for local authorities. Parents of children with statements of special educational needs will be able to express a preference for any state-funded school – including special schools . . . (Department of Education 2011, p. 2)

Exclusive inclusion

In their paper Brown *et al.* (2011) argue that while the application of the policy of inclusion may have brought some positive changes in the development and performance of persons with ID, they acknowledge that there is an increasing number of children within service systems who have multiple diagnoses and severe physical, medical and/or behavioural needs that are not being met. Many of these children are rejected by both mainstream and day special schools because they are regarded as unmanageable and within the family setting they present challenging behaviour. For some of these children the most appropriate placement is a residential special school. However, the common experience of many parents in this situation is that the funding authority refuses placement in such a school on the grounds that it runs counter to the local authority's policy of inclusion.

The argument that such a placement is socially and educationally undesirable merits closer examination. What it ignores is the fact that there are families which are forced to withdraw into a state of self-imposed isolation, through fear that their child with an ID will be bullied and tormented by other children or verbally abused by neighbours. Such parents recognise this kind of isolation for what it is – enforced 'imprisonment' for both their child and themselves. There is a sense in which this form of 'imprisonment' is harsher than that experienced by inmates of penal institutions. At least, most prisoners have visitors, opportunities for parole and an expectation of eventual release. Living with a child with complex needs can seem to some parents like an indefinite sentence with no possibility of remission (Jackson 1996b).

It is not unusual for parents of such children to find that as their child grows up, visits by friends, relatives and neighbours decline. This stigma by association leads many parents to be excluded from the outside world. Partly by choice and partly by circumstance, they are obliged to live a segregated life. A family has to be extraordinarily resilient and resourceful to withstand the pressure generated by this exclusion. While some families find that the presence of a child with complex needs can act as a positive and integrative force, many do not, with the result that one finds high incidences of marital dis-

harmony and conflict, psychological breakdown of a parent (usually the mother) and acute difficulties in the management of the other children. Such families are asked to cope with degrees of stress about which most people can have little understanding, but they are families nevertheless that almost invariably have a love for their child. Indeed, this love, coupled with their inability to cope and the frustration that flows from that inability, engenders feelings of guilt that are difficult to assuage (Jackson 1996b).

The argument commonly advanced by funding authorities is that these problems should be tackled in the home, but such a strategy can come at a heavy economic cost. Where there is a family breakdown or problems with siblings through truancy, delinquency or disruptive behaviour, there may be a need for costly intervention by a social worker, educational welfare officer, probation officer or educational psychologist. At a time when there is increasing attention paid to finding ways to support the family as a unit, funding authorities choose to ignore an option that provides just that support. Adherence to the policy of inclusion should not require a funding authority to insist that parents of a child with complex needs and/or challenging behaviour should retain their child at home whatever the human cost.

Physical presence, whether in school or neighbourhood, is only meaningful if it involves social interaction and acceptance (Wolfensberger 1972). Dogmatic insistence on inclusion can lead to social isolation, rejection and exclusion – the very opposite of what the policy of inclusion seeks to achieve. Those supporting the inclusion agenda too readily dismiss residential special school provision on the grounds that it is ethically unacceptable and an anachronistic irrelevance (Abbott *et al.* 2001; Morris 2002). However, this stance ignores the fact that some parts of the residential school sector are highly innovative and forward-looking (Smith 2005; Jackson 2006, 2011a,b; Garfat 2011) and are able to offer parents a choice to which they are entitled (Department of Education 2011).

Choice

One of the key issues discussed by a number of contributors to this Special Issue relates to the

matter of client's choice. In their paper Stancliffe *et al.* (2011) make the point that it should not be presumed that independent choice is always the most desirable outcome. The argument is advanced that while having no choice is almost always undesirable, the degree of support provided when a person makes a choice should be guided by individual needs and preferences. Thus, a well-supported choice leading to selection of a wise alternative may be preferable to a more independent but ill-informed choice that results in problems. The question then arises as to who decides that a choice is a wise one and who judges that a choice is 'ill-informed'. Such a rationale could easily be advanced by a social worker seeking to implement a particular policy directive (e.g. placement in a single tenancy), which is at odds with the reasoned and reasonable wishes of a person with an ID. Any other choice could be construed by the social worker as unwise or ill-informed.

Cocks & Boaden (2011) argue that at least one person with a clear vision or strong idea is needed to shape the picture of a desirable living arrangement and lifestyle for the person. Such leadership may come from professionals or family members advocating on behalf of the person with a disability. It may also come from the person with a disability. What is not clear here is whether Cocks & Boaden are arguing that in most instances the choice of living arrangement should rest with others. It is difficult to reconcile this approach with the personalisation agenda where primacy is accorded to the individual in key decision making. However, as Chou (2011) notes in her study, the choice as to 'where to live' and 'who to live with' was rarely made by the residents as the residents' life was still governed by the staff's expectations.

In their paper Shaw *et al.* (2011) contend that people with ID should have the opportunity to choose where and with whom they live and not be obliged to live in a particular living arrangement. They should have access to a range of in-home, residential and other community support services, including personal assistance to supported living and inclusion in the community to prevent isolation or segregation from the community. By acknowledging the existence of a range of residential options, Shaw *et al.* (2011) present a challenge to the notion that the only alternative to independent

living arrangements is 'congregate care' – the undifferentiated residential option usually cited.

It is also worth noting that participants in the study undertaken by Shaw *et al.* (2011) preferred models of housing that provided the opportunity for people with ID to live in larger groups than the traditional three to four people that are catered for in dispersed community housing. They also expressed a strong preference for residences to be in close proximity to other residences that housed their peers. Shaw *et al.* (2011) refer to evidence which suggests that small living arrangements in the community may be associated with disadvantages for residents. They also point to research that shows that social activities with non-disabled peers or friends were very infrequent and even non-existent for many people, in spite of living in the community. The assumption that any form of inclusion has a positive influence on the quality of life of people with ID is challenged as misleading, because successful inclusion is hard to achieve and that unsuccessful integration can be more stressful than beneficial (Cummins & Lau 2003; Fisher *et al.* 2008).

However, problems with community inclusion have not stopped the drive to provide single tenancies for people with ID in the UK even when a range of housing options are available. Despite having their own tenancy in the community, many tenants find themselves more socially isolated than they had been when they lived with their family or lived in an institutional setting, because they have little regular contact with anyone other than their paid carer. The opportunity for choosing friends and developing preferred social relationships is very limited.

The case for providing single tenancies cannot be judged without reference to the social and geographical context within which the tenancies are set. Whether or not people with ID can cope with the demands of living independently in a single tenancy will depend in large measure on local community acceptance and freedom from victimisation. In a recent survey by Turning Point, a leading health and social care provider in the UK, it was found that more than half of those surveyed believed that people with ID were the most discriminated against group in society (Williams 2010a,b). Growing public concern at the vulnerabil-

ity of people with a disability, 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 & Mickel 2009; Walker 2009; Williams 2010a,b). The findings were subsequently published in the report *Promoting the Safety and Security of Disabled People* (Equality and Human Rights Commission 2009). The Commission recommended, among other things, investment in and evaluation of innovative approaches to independent advocacy to ensure that the most marginalised people with a disability 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 & Jackson 2002). The Commission also recommended that policies relating to care and support should be reformed and that the role of social housing associations in creating and minimising the risks of people with a disability be examined. However, what the Commission could not do was challenge the normalisation agenda upon which programmes of community inclusion, including single tenancy provision, are based. As Zigler & Hall (1986) have observed, judicial bodies – and presumably that includes quasi-judicial bodies like the Equality and Human Rights Commission – are not going to weaken in any way their commitment to the principle of normalisation which includes the right of people with an ID to be integrated into mainstream society.

In the paper by Martinez-Leal *et al.* (2011), attention is drawn to the research of Kozma *et al.* (2009), who found that the prevalence of health risk factors such as inactivity and obesity among people with ID was high and that less restrictive living arrangements increased the probability of smoking, poor diet and obesity. This finding would tend to suggest that people with ID living in single tenancies where contact with carers was intermittent were particularly at risk. Martinez-Leal *et al.* (2011) conclude that people with ID are in need of tailored primary health programmes that guarantee their access to quality health, health promotion and preventative health actions such as vaccination pro-

grammes, systematic health checks, specific screenings and nutritional controls.

The paper by Dijker *et al.* (2011) is of interest as it presents a challenge to the view that establishing homes in the community can be construed as a practical expression of the policy of community inclusion in action. In this study it was found that the individuals with and without ID that were interviewed did not seem to hold the same assumptions and expectations about what it meant to engage in neighbouring. In particular, while the former might attach great importance to a warm and safe environment with only a few friends or volunteers nearby, the latter distinguished between friends and neighbours and expected most neighbours to be competent in balancing benevolence and distance. The question thus arises whether, under these circumstances, one can expect people with ID to engage in normal neighbouring at all, and to what extent they benefit from being forced to do so. Dijker *et al.* (2011) acknowledge the fact that many residents in homes in the community are not there because they have chosen to be there – for they have not been offered a choice. So paradoxically, this exemplar of good community inclusion practice is often based on the denial of an individual's right to choose.

Wolfensberger (2003), who has been closely identified with the normalisation principle, has acknowledged that the community living revolution that started in the late 1960s opened up innumerable opportunities for people with disabilities and conveyed many of the good things of life to many of them. However, in his opinion, one of its greatest shortcomings has been that a large proportion of adults with disabilities who have been impaired since childhood do not have much opportunity for genuine community participation: they have few or no real friends, or they associate almost entirely with other people who are societally devalued themselves, and/or with paid caretakers.

Wolfensberger (2003) has indicated that the advent of the ideologies of radical individualism coupled with radical self-determination and the derivative constructs of 'choice', self-advocacy and empowerment has resulted in many people with an ID being turned loose without any, or without sufficient, supports, guidance, tutelage or outright controls. He makes the further point that in the

Western world it has been believed until very recently that rights were linked to corresponding obligations. Now, he argues, people claim rights without seeing themselves as having any corresponding obligations. In fact, the common mentality now appears to be 'the rights are mine, the obligations are yours'. Wolfensberger singles out for particular criticism the kind of assertiveness training promoted by People First and other collective advocacy groups. While he accepts that elements of it are certainly adaptive, one should never teach assertiveness outside the contents of a broader preparation for life and without regard to the characteristics of the person at issue. Particular concern is expressed at the radicalisation of the advocacy movement – its increasingly confrontational stance and the strident tone which threatens to antagonise and alienate those whose support is vital if appropriate services are to be developed (Jackson 2005).

Regulation

While Barron *et al.* (2011) touch on some of the regulatory problems in the social care sector in the UK, the picture that is presented is a partial one. The key issue not addressed is how you regulate a sector dominated by 'for-profit' companies when the regulatory authority itself is inefficiently managed, chronically undermanned and has poorly motivated staff (Samuel 2010). The opening up of the social care sector to market forces occurred despite the acknowledgement by the first regulatory body – the Commission for Social Care Inspection (CSCI) – that care services run by the 'for-profit' sector in England were consistently outperformed by those run by the 'not-for-profit' sector. With the passage of time, it has become generally acknowledged that 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 by the recruitment of poorly paid, inadequately trained and under-motivated staff. The implication of this is that 'not-for-profit' organisations will be squeezed out, leaving commercial companies to dominate the market.

It is important to put the issue of regulation of social care in an historical context. Over the course of the last two decades, there has been a succession of major crises in social care in the UK which has produced a series of enquiries and reports indicating profound concern about the working of the social care sector (Wagner 1988; Utting 1991; Skinner 1992; Waterhouse 2000). In April 2004 the Labour Government set up the CSCI with the aim of modernising the system of regulating care services. In November 2004 the CSCI published its first performance ratings of all councils with social services responsibilities. However, in 2009, only 5 years later, responsibility for regulating and inspecting adult social care and health care was passed to the Care Quality Commission, which represented a merger of the CSCI, Healthcare Commission and the Mental Health Act Commission.

In its final report in 2009 the Commission noted that services for those with complex needs were being impeded by poor strategic commissioning, lack of person-centred care and the 'marginalisation' of human rights. 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). For its part the Government indicated that the Care Quality Commission would continue to focus on reducing its operating budget. Closely linked to the budget reduction was the decision to continue the deregulated inspection methodology practised in the Commission which was termed 'proportionate risk-based inspection'. When translated this means fewer inspections. The previous statutory requirement to inspect care homes twice a year was abandoned. Now the minimum requirement was for care homes and home care providers to be inspected once every 3 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 (Unison 2007).

Unison, the principal trade union representing social care staff in the UK, has 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 lack of time: (1) to target its resources on those providers giving a poor service; (2) to follow up on concerns and complaints or detect problems in the early stages; (3) to impose and follow up on enforce-

ment measures; and (4) 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.

This problem is best illustrated with an example. The author examined the performance of one of the market leaders in providing residential care for adults with an ID in the UK. The accuracy of the company's claim to being a market leader was assessed by examining the inspection reports on 24 of its premises which had been published by the Commission and were accessible on the Commission's website. It was found that one quarter of these premises had to meet at least six or more statutory requirements. In other words, a quarter of the premises were in serious breach of their legal obligations. Three areas occasioned the regulatory body particular concern:

1 *Overuse of agency staff.* The inspectors drew attention to the need for the company to review recruitment procedures to ensure that more was done to employ permanent staff teams, thus reducing the use of agency staff. A further concern noted was a failure to obtain satisfactory clearance for agency staff and to produce evidence that they were appropriately qualified.

2 *Staffing levels.* A recurrent concern 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.

3 *Failure to implement Commission requirements.* The company repeatedly failed to implement the statutory requirements identified by the Commission inspectors. 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 regulatory body and seek to implement the changes needed as expeditiously as possible. The failure of the company to appoint sufficient permanent and appropriately qualified staff to meet the needs of residents pointed to an unwillingness to invest adequately in staffing. The evidence from the inspection reports strongly suggests that the running costs were being deliberately kept down through the use of agency staff and by maintaining low staffing levels.

No apology is offered for devoting so much space to concerns about regulation for without regular and not token inspection of health and social care services, the quality of provision will inevitably decline. A further factor of critical importance is the need to create a workforce that has been appropriately trained for the demanding and responsible role of carer. As has been shown, 'for-profit' care companies tend to recruit the least qualified as they are the least costly.

The shadow hanging over the health and social care sector for people with an ID is the possibility of its collapse. If an investor in a 'for-profit' care company can no longer see any financial benefit in what was once a highly profitable investment, he or she can exercise the option of withdrawing their investment and placing it elsewhere. If there were to be a general collapse in the care sector, we could be presented with a situation where local and/or central government could be forced to step in and nationalise the social care service!

Final observations

Those who have a professional interest in ID research have an obligation to assume a higher profile at a time when the quality of life of people with an ID and their families is under threat. It can do this in a number of ways through: (1) the establishment of demonstration projects, either independently or in association with the voluntary and statutory sector, to explore innovative and practical approaches to enhancing the quality of the services offered to people with an ID; (2) looking at ways of improving the quality of training programmes for care staff by moving away from current approaches that emphasise narrow instru-

mental competencies to strategies that develop essential expressive and relational aspects of care practice; and (3) offering a more considered and rigorous critique of current professional practice and assuming a leadership role at a time when leadership in this field is lacking.

Perhaps it is time to drop the routine and ritualistic plea for further research that frequently concludes most research papers, for it is often not more research that is required but appropriate and timely action on the findings of existing research. This could lead to scarce financial resources being more profitably directed to improving services for people with an ID rather than funding further and possibly unnecessary research. At a more fundamental level, the question arises as to the raison d'être of ID research itself, given the increasing politicisation of the research process whereby the research agenda is to a significant degree dictated by external bodies (Jackson 1993). The application of the purchaser–provider model to the research process also prompts concerns as to the credibility and ethical propriety of often one-sided contractual arrangements.

The deepening economic recession facing Europe and North America is likely to lead not only to a major contraction in services but also to a significant deterioration in the quality of life of people with ID. This situation might not have been quite so serious, had there been some kind of challenge to the normalisation and inclusion agenda and the remorseless and destructive progress of the marketisation process. The question arises as to why the research community with a professional interest in the field of ID appears to have voiced so little concern about trends that were clearly discernible. The argument that such intervention might compromise the academic detachment of the research community by leading it into the political arena is not persuasive. It overlooks the fact that through its uncritical acceptance and promotion of the normalisation and inclusion agenda, some parts of the research community long ago forfeited any claim to be acting with scholarly objectivity. However, on the basis of some of the evidence advanced in this Special Issue of the *Journal of Intellectual Disability Research*, there may be signs of movement in the right direction. Perhaps, at last, 'the times they are a-changin'!

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