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# Neo-Liberal Individualism or Self-Directed Support: Are We All Speaking the Same Language on Modernising Adult Social Care?

Alan Roulstone\* and Hannah Morgan\*\*

\*De Montfort University, Gateway, Leicester

E-mail: AROULSTONE@DMU.AC.UK

\*\*Department of Social Work, Lancaster University, Bowland North, Lancaster

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*This article explores recent developments in the modernisation of adult social care through the lens of changes to English day services. Drawing on wider policy debates, it argues that Disabled Peoples' Movement and governmental ideas on self-directed support, although superficially similar, are growing increasingly apart. It is argued that in the absence of adequate funding and exposure to organisations of disabled people, day service recipients risk moving from a position of enforced collectivism to an enforced individualism characteristic of neo-liberal constructions of economic life.*

## Introduction and scope

This article explores the challenges of effecting self-directed support policies in English day services for disabled people. The article is based on a research project in a large English city completed in late 2006. The challenges identified are not unique to the city context being studied (Gordon *et al.*, 2006) and raise much broader issues of how modernised day services can be established and maintained (DoH, 2005). Arguably, the very language of 'day services' conveys the depth of the paternalist tradition in day centre contexts (Barnes, 1990; Whittaker and McIntosh, 2000) and the need for greater choices and rights for disabled people. However, the article identifies barriers to day service modernisation as well as discursive inconsistencies around some disabled peoples' self-directed options in the context of straitened adult social care budgets. A philosophical question inheres in the future relationship between individualised and collective lives for disabled people. Day centre users have historically not had access to wider disability forums within which to build the self identities and confidence which are often assumed to be the sine qua non of self-directed support. Until 2005, day centre users did not feature strongly in discussions of self-directed support, but have recently been seen as eligible, in principle, for such policy and programme intervention. Can an individual choices discourse contained in the modernisation agenda be applied unproblematically to disabled people who have had no prior exposure to rights-based opportunities?

## Modernisation of adult social care: promoting independence wellbeing, and choice

The apparent convergence of statutory and Disabled Peoples' Movement thinking on individual self determination provides a unique opportunity in furthering the convergence

of governmental and Disabled Peoples' Movement developments towards choices and rights. However, the history of past social care policy can be viewed as unpropitious and as missing opportunities to liberate disabled people from the yoke of paternalism. Notably, the NHS and Community Care Act of 1990, whilst viewed positively by its statutory architects in the Department of Health as ending institutional care and bringing care closer to the individual and community (Griffiths, 1988; House of Lords Select Committee on Health, 2007), was roundly criticised by disability and mental health organisations. Critics pointed to erroneous assumptions of 'imagined communities', cost saving imperatives of community care policy and policy leaving many 'beneficiaries' with few economic and social resources (Bornat *et al.*, 1993; Beresford *et al.*, 2005). The failure to fully fund such a major social care policy was coupled with suspicions that overt policy objectives of providing greater choices masked underlying Treasury-driven cost saving imperatives. That similar dynamics might attach to aspects of recent social care policy has to be taken seriously. What is novel in more recent policy and programme debates is the borrowing by the English government of the language of radical disability politics, which makes criticism of its key precepts seems misplaced and 'unreasonable'. However, critical policy analysis is required to account for the range of dynamics underpinning modernised social care.

The recent convergence of views is significant, with a more generalised governmental championing of self-directed support to a wider range of disabled people. The earliest application of ideas of what are now termed self-directed support, dates back to the 1996 Community Care (Direct Payments Act), and the first disability-led Centre for Integrated Living (now Centres for Inclusive Living) based on a philosophy of 'choices and rights' was established in the mid 1980s (Barnes and Mercer, 2006). Choices and rights summed up the aspirations of the UK Disabled Peoples' Movement that disabled people should have greater control over their lives underpinned by a political struggle that fostered enabling services and a 'sense of pride and collective awareness among the disabled community' (Campbell and Oliver, 1996: ix). Such developments, although important, were not widespread; indeed even some ten years after the Act, less than 5% of the eligible population were receiving direct payments – a key benchmark of self-directed support (Davey *et al.*, 2006). In part because of this poor take up of direct payments, the UK government redoubled its efforts to support a range of self-directed social care policies and a further reduction in traditional services, such as day centres. These ideas have converged since the mid 2000s with earlier ideas from the UK Disabled Peoples' Movement around 'choices and rights', which in concrete terms favoured direct payments, joined-up financial support and the closure of institutional 'care settings' (Barnes and Mercer, 2006). However, concern is beginning to be raised that the Department of Health may be promoting self-directed options to previously overlooked groups of disabled people, whilst failing to underwrite commitments with the additional money required to effect seismic changes in adult social care. In turn, this could lead to a rationing of funding for meaningful self direction. Without such financial commitment, current day centre users could risk being moved from a position of enforced collectivity to one of enforced individualism. The cost of adult social care and risks of unaffordable adult care in an 'ageing society', whilst a legitimate policy concern, has become inextricably linked with notions of choices and self determination:

Indeed we don't simply want to embrace individual choices but in financial terms we have to in balancing the books . . . We are unlikely to raise the revenue needed to fund the needs of an

ageing population using traditional approaches to adult services. (Care Services Improvement Partnership, 2008: 2)

Questions might be raised in policy terms as to why choices and rights remain a funding problem as opposed to social and moral imperatives. Two recent reports published by the Office for Disability Issues (Henwood and Hudson, 2007; Hurstfield *et al.*, 2007) also emphasised the social and economic imperative of promoting independent living:

there are likely to be dynamic, long-term benefits to the exchequer and society in the form of reduced reliance on health and social care services and a reduction in overall dependency on informal support. (Hurstfield *et al.*, 2007: 49)

The ease with which cost savings in health and social care sit alongside reduced reliance on informal care is noteworthy. The transcending of reliance on unpaid informal support suggests more rather than less spending on day services. Similarly a recent policy document makes clear the financial and demographic imperative for ending institutional provision:

Demography means an increasing number of people are living longer, but with more complex conditions such as dementia and chronic illnesses. By 2022, 20% of the English population will be over 65. By 2027, the number of over 85 year-olds will have increased by 60%. (DoH, 2007a: 1)

However, the projected costs of expanded self-directed support are nowhere delineated and policy visions for self direction are based on extrapolating previous self-directed activity where recipients received higher than average support packages (PSSRU, 2006) and were often close to disabled peoples' organisations (Riddell *et al.*, 2005). If the engendering of real choices, personal empowerment and financial savings can be squared through self-directed support, then concerns will have proved to be unfounded. However, the weight of projected cutbacks in adult social care budgets emanating from central government continues to raise real anxiety amongst mainstream service and standards organisations (Commission for Social Care Inspection, 2008; Local Government Association, 2008). As Liz Sayce, chief executive of RADAR recently noted:

When over 70% of local authorities have restricted their eligibility criteria for support to those in 'critical or substantial need' social care budgets are clearly squeezed to breaking point. This stops preventive work – help comes too late – and severely limits support to enable people to participate in social and economic life. It also means the post-code lottery between different local areas is all too likely to continue. (NCIL, 2007: 1)

It is noteworthy that whilst most key policy statements on 'adult social care' emanating from government emphasise cost savings and demographic 'risks', statements from writers close to the disabled peoples' movement emphasise the social or moral imperative for offering greater choices (Barnes and Mercer, 2006). Organisations at the forefront of modernised service delivery and user-led policy have begun to register their significant

concerns on the gap between rhetoric and reality in service provision:

Many of our member groups find themselves increasingly inundated with local disabled people who are struggling to keep their lives together and to stay independent in the face of adult social care service restrictions. It seems for many people that independent living is slipping further away. At the same time, national Government rhetoric consistently advocates empowerment, choice, control and personalisation. (NCIL, 2006: 1)

This is supported by evidence published in the Commission for Social Care Inspection (CSCI) report *The State of Social Care in England 2006–7* (CSCI, 2008) which acknowledged that increasing numbers of disabled people are no longer eligible for statutory funded social care and that access to support resembles a ‘national lottery’.

### Policy background

The arrival of the Green Paper, *Independence, Wellbeing and Choice* (DoH, 2005) has been seen by some to mark a watershed in the UK Government’s approach to future adult social care (Morris, 2008). This Green Paper, alongside the White Paper *Our Health, Our Care, Our Say: A New Direction for Community Services* (DoH, 2006) and the guidance contained in *Fair Access to Care* (DoH, 2003), all emphasise individual choices in preventive approaches to inappropriate care options, maintaining independence and support tailored to individual needs (DoH, 2005). Most recently *Putting People First* (DoH, 2007a) and *Independence, Choice and Risk* (2007b) have added to the message that social care solutions should be personalised, that money should follow individual disabled people and foster the ‘self management of risk’ (DoH, 2007b). In tangible terms, greater choice making will be facilitated by both more supportive professional values and practice, and specifically through the greater use of Individual Budgets and Direct Payments. Similarly, the widespread consultation that fed into the 2005 *White Paper Our Health, Our Care Our Say* (DoH, 2006) also emphasises the importance of choice, joined-up working, the widest use of community resources, preventing health deterioration, wellbeing strategies, more flexible and reflexive service delivery. In day-to-day terms, the modernisation agenda has arrived at a number of key self determination and personalised mechanisms best captured in ‘Person Centred Planning’ (DoH, 2002), direct payments (Glasby and Littlechild, 2002; HM Government, 2003; Woodin, 2006) and individual budgets (Ibsen Consortium, 2007).

The rise of direct payments and individual budgets over time has led some writers to use the term ‘self-directed support’ to sum up disabled peoples’ greater control of their support package. This rapid shift towards self direction has predictably led to diversity of response, with evidence pointing to a lottery of provisions of direct payments and some professional ambivalence towards the implications of greater ‘choice’ (Sapey and Pearson, 2004; Henwood and Hudson, 2007), particularly in relation to those identified as ‘vulnerable adults’ (Glendinning *et al.*, 2008). Evidence suggests that people with learning difficulties often require additional support in direct payment use via brokerage services, whilst some applicants are deemed ineligible, as they do not meet basic eligibility thresholds (Glasby and Littlechild, 2006). Notably, Holman and Collins (1997) made early observations that pre-existing provisions, such as Independent Living Schemes and Trusts, needed to be able to connect fully with new direct payment approaches to empower disabled people.

What the above literature displays is a broad agreement that direct payments and individualised choice are inherently welcome and suited to disabled peoples' lives. It is unclear, however, how broader policy shifts emphasising the central role of user-led organisations (Office for Disability Issues, 2008), which in the guise of Centres for independent or inclusive living have historically been rooted in collective philosophical roots (Driedger, 1989), can connect with the categorical shift towards individual choice making? Writing about mental health day services Bates (2007) emphasises the way in which provision offers 'safe spaces' and an opportunity for both solidarity and sanctuary for service users from often inaccessible and disabling mainstream spaces and locations. This however is a far cry from the Disabled Peoples' Movement's construction of collective struggle.

### **Collective identities**

In relation to collective identity Finkelstein notes:

it is essential that all disabled people join together in our own organisations so that there is a creative interaction between disabled people. (Finkelstein, 1987: 4)

The question of a collective 'disabled identity' as illustrated in Finkelstein's assertion above, although contested (Shakespeare, 2006), might be seen as in philosophical opposition to individual budgets. However, the potential to connect individual control and disabled identity could inhere in the growth of CILs (Centres for Inclusive Living). This was given a boost in the Life Chances report recommendation that a CIL was required in every local authority area:

By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living. (Prime Minister's Strategy Unit, 2005: 77)

However, the Green Paper on adult social care makes no such commitment, although it is flagged up in the Putting People First concordat and the Department of Health is leading on implementation. Moreover, there is growing concern within the disabled people's movement about the approach being taken by government in what it terms the 'disability movement' (Ivory, 2008; Oliver and Barnes, 2008). User-led organisations are increasingly struggling to be awarded service contracts and to remain financially viable in the face of a myriad of local and national organisations 'not led, managed or controlled by disabled people [who] will find it relatively easy to adopt the phrase in order to secure funding' (Barnes and Mercer, 2006 :177).

Advocacy groups such as Values into Action and People First also clearly have a key role in supporting people with learning difficulties through the labyrinth of social care funding. The reality for many disabled people however is that they have little or no contact with activist or advocacy organisations (PMSU, 2005) and for some their sources of collective identity, however dilute, are gleaned through contexts that are rejected by the Disabled Peoples' Movement. The challenge of responding to the majority of disabled peoples' needs and the establishment of new solidarities and identities is easily

under-estimated. To do this we need to reflect on different forms of collectivities and their potential to counter neo-liberal individualisation.

### **Disabled collectivities**

The disabled peoples' movement in the UK (Campbell and Oliver, 1996) and globally (Driedger, 1989) has been founded on what might be dubbed collectivities of identity and a contestation of a range of social barriers to disabled peoples' social participation. There are clearly significant economic facets to this struggle (Shakespeare, 1996), however the disabled peoples' movement is characterised as being concerned with a range of barriers – environmental, economic and cultural – which serve to oppress disabled people. In line with Inglehart's classic formulation, the disabled peoples' movement is concerned with reconceptualising social ideologies (Inglehart, 1990). Inglehart characterised new social movements as post-materialist. This best captures new social movements in their concern with issue-based projects, such as environmentalism, new age religion, sexual politics and of course disability rights. The above diversity of focus and broader redefining role is embodied in Centres for Inclusive Living (CILs). CILs are seen both governmentally and by some disabled people as the focus for delivering future disability services (Prime Minister's Strategy Unit, 2005), for advancing new ways of viewing disability and one could argue new sites of solidarity. Whilst the above provides the ideal conception for many of enabling collective identity, many disabled people remain distant from or unaware of the 'Movement' and constituent organisations. It would be inaccurate however to see such disabled peoples' lives as untouched by collective experience, indeed many have experienced what might be dubbed 'enforced collectivities'. Enforced collectivities are typified in now reduced segregated long-stay, residential and day centre contexts. Critical commentary highlights the negative categorical impulses to segregate disabled people based on assumptions of sub-normality (Barnes, 1990). More generous interpretations point to paternalist impulses to 'protect' vulnerable sub-populations. It is noteworthy and not a little ironic that experiences of enforced collectivities may afford friendships, exposure to new ideas and personal empowerment (Linton, 2007). It is reasonable to assume that collectivised lives can be experienced positively *and* negatively and as potentially empowering and profoundly disempowering. It is also conceivable that aspects of our lives be influenced by collective and individual influences. What then of individualism?

### **On individualism**

It was the French sociologist Emile Durkheim who provided the starting point in our understanding of the rise of 'organic solidarity' in a complex social division of labour. Individualism was perceived as a functional prerequisite of complex, flexible and geographically mobile social systems (Durkheim, 1893). Of note, Durkheim viewed paid work as the currency of individualism, something questioned recently in critiques of work-first agendas at the heart of neo-Durkheimian projects (Malholtra, 2005). Marx of course viewed individualism as the result of competitive capitalism, with its requirement for impersonal social actors who could best embrace the raw cash nexus that characterised industrial capitalism (Marx and Engels, 1848[1992]). Luke's more recent

(1973) appraisal however makes clear that individualism is deeply ambivalent and thus amenable to a range of ideological ends, both reaffirming and also challenging social hierarchies:

Individualism . . . forms the basis for a particular ideological view of a certain society and its social relations. But I have also suggested that this way of constructing the individual has been historically progressive as a crucial weapon in the breaking down of traditional privilege and hierarchies. (Lukes, 1973: 122)

Lukes of course makes clear in his later writings the perception that individualism has been used by neo-liberal governments to support anti-interventionist ideas. More recently, Mike Oliver's classic *Politics of Disablement* (1990) updated Marx in providing a fundamental critique of individualism as a key ideological starting point and one inimical to an a liberatory politics of disablement. It is therefore a challenge to envision the individualisation of adult social care without individualism. Clearly the 'self direction' and 'self management' which have grown out of radical critiques of liberalism and neo-liberalism risk being distorted to equate more fully to 'responsibilisation' and victim blaming discourses (Dean, 2007) . The need for parallel collective contexts with which to comprehend and understand shared experiences and identity alongside enhanced individual control is then very real.

Reflecting on the needs of a globalised economy, Beck *et al.*'s celebration of 'reflexive modernisation' (Beck *et al.*, 1994) is typical of work which envisions the reflexive self as the essential building block of complex and responsive economies. As they note there are implications for individuals and social collectivities as in reflexive modernisation:

A process of self-organization emerges, drawing upon economic, community, and political activities. (Beck *et al.*, 1994: 39).

What is unclear in this and similar formulations are how self organisation and community can cohere. At no point do such arguments acknowledge that self and community ideas might conflict where individualism is promoted as the basis of social and economic efficiency. Komter provides a more critical approach in his appraisal of new 'segmented solidarities' which emerge partly in response to rapid social and institutional change (Komter, 2005). Whilst (rightly) arguing for greater collective strength, the Disabled Peoples' Movement in the UK (Campbell and Oliver, 1996) and US (Charlton, 2000) has not been able to safeguard these ideas for all disabled people in an increasingly individualised and marketised social care context. The ability to articulate needs, or locate and use advocacy in gaining control, seems pivotal in engaging in a reflexively modernised adult care model based on self management. If we fail to build in these supports and safeguards, issues of access, equity and isolation may arise needlessly. We need to be honest in facing up to the reality of many disabled people being far removed from disability organisations and sources of collective solidarity and/or identity. The following aims to provide examples of the lived experience of these current policy contradictions.



### **The need for greater control: service user views of current services**

The following provides highlighted findings of a study of Day Services modernisation in a large English city (population 0.4 million). The fieldwork for this study was completed in the North district of the City in late 2006. In total, over 30 participants were interviewed ranging from the Director of Adult Social Care, frontline managers, informal carers and day service users. Day service users ( $n = 20$ ) were interviewed in day centre contexts. Day service users were purposively sampled using maximum variation principles to include respondents with a range of impairments including physical impairments, learning disabilities and mental health problems. A range of ages, ethnicities, sex and length of time in day services was reflected in the interview sample. The lead researcher had previously completed work on day centre attendees in the south district of the city, and the profile and experiences of this group, once selected, was not untypical of the wider city experience of day centre changes wrought by modernisation.

### **Findings**

Overall, despite the efforts of the city council, current service users had little working knowledge of what the modernisation agenda meant for them in practical terms and most could not envision what a self-directed daily life would feel like. Of the 20 day service users interviewed, only two had any links with disability organisations (both with People First). By definition, most day centre users' social and spatial worlds were largely focused on day centre contexts, although four of those interviewed were also working outside in a paid or voluntary capacity. It was important therefore to briefly explore experiences of current services. The following typifies responses to questions about current choices. There were in reality few choices made available to day centre users adding to the perception of the need to reduce day centre dependency:

If it's a pub lunch, you get to choose where you want to go, you know a few choices. Sometimes you get a choice as to whether to go out and what you want to do... at others they may just say we are going to the shops, and if you want to go. But they decide where... you just tag along like. (Jim, 28, day centre user for 12 years)

However, the following comment from a family carer of a day centre user highlights the inherent challenges of engendering responsive adult services per se and the reality of adult services for some disabled people:

Anna is not a shrinking violet by any means, by and large my observation has been that together we used to be able to speak up for her better when she was younger; they seemed more interested. When you meet professionals in adult services, you seem to be just another 'case' really. So the idea of being in control, as you say, is less nowadays. (Jenny, mother of Anna, 26, day centre user for eight years)

The respondent also later refers to the cash-strapped environment which pervades adult services in the locality; this reflects policy evidence presented earlier (National Centre for Independent Living, 2006; Commission for Social Care Inspection, 2008; Local Government Association, 2008). The gaps in day service provision and the aspiration

to do activities currently not made available was a recurring theme in the study findings. At the same time, many day service users also wanted to hang on to what they had known for some time as it was currently the best option they had. There was evident a pervasive tension between what might be dubbed idealised and pragmatic 'here and now' appraisals of options beyond day centres.

### **Enforced collectivism: lost years or stepping stones to collective empowerment?**

Although often displaying mixed sentiments, there were many comments that supported the value of Day Centres. Many acknowledged that they had been placed together with other disabled people simply because that was the 'done thing'. However, this enforced collectivism turned out serendipitously to be an important collective identity for some centre users:

Day centres in my mind are a place to get together, most people in the city and that are mindin' their own business, by themselves like, that's the way of the world, I mean I've been at work – but since then have enjoyed the thing of being with others, I wouldn't want to lose that – also I met [current partner] through the Day Centre. I understand people with physical disabilities – wouldn't turn my nose up to people with disability as I know what it is like to be disabled-somethin' in common. (Billy, 32, day centre user for four years)

The exact value then of current day centres as expressed by service users depended on the perceived current options, the range of activities on offer and on the age, outlook and impairment of the service user. This offers some clues as to future policy options for self-directed lives into the twenty-first century. As the modernisation agenda aims to afford greater choices and to review the value of day centres, service users were asked to reflect on recent changes in day centres. Interestingly, many service users refer to the reduction in certain forms of day centre activity over time due to cost savings:

We take the Centre bus, they take me for a run out. I used to go for pub lunches and packed lunches, the pub lunches stopped, I don't know why they stopped. We got mixed messages as to why we go out less often and less far, not sure why there are limits. (Colette, 25, day centre user for three years)

It was perhaps predictable that some day centre users who had been placed in day centres without a process of choice, who had witnessed service cutbacks over a number of years, should be somewhat suspicious of proposed mainstreaming of daily lives; as one service user notes:

I'd like to go out more and that, but I would need someone wid' me. One day I might be able to do everythin' myself, but at the moment that scares me. Dunno what I'd do all day, do you? (Dierdre, 53, day centre user for seven years)

This begs a question as to the nature and substance of choice on offer. Of note, none of the research participants had received the more substantial forms of self-directed support such as direct payments during the lifetime of the project and were therefore prey to

the rhetoric of self-directed support without receiving the quantity of financial support required to engage with other disabled people and wider society in a safe and genuinely freely chosen way. Exhortation to seek options outside of day centres often translated into equally 'safe' activities of painting and craft making in contexts identified by centre staff and key workers. Life in the mainstream was beginning to feature more strongly in daily activities, but often took the form of visits to town centres with key workers or where possible individual disabled people spending short periods of time in the 'high street' but a great deal of former centre-based time was beginning to be spent at home. This did not square well with notions of self-directed support and reduced informal care spending being predicted by the DoH (Hurstfield *et al.*, 2007).

### Choices and rights: who's choices, whose rights?

Some comments focused on the principles of choice as outlined in *Independence, Wellbeing, and Choice* (DoH, 2005) and *Our Health, Our Care, Our Say* (Doh, 2006). The majority of day centre users (16/20) concentrated, as might be expected, on the likely impact on service users of feared centre closures:

I'm not sure how closing the Centre is givin' us more choice, we need time to think and get used to the idea of being out by ourselves. Have heard [Centre Name] will close-I dunno where that leaves me and that-need time to think an' try things out an that. Am not ready just yet. (Mark, 24, day centre user five years)

Similarly:

D'ya want my honest view? I don't think they've [council] thought it through really – the only certain thing is they want to save money – we are the price for that really. In my case I might get out sometimes, but I get ill and me mum's going to pick up the tab I suppose – and that's not fair as she is in her 70s. (Clare, 48, day centre user for six years)

A final reflection is provided by a carer of a current day centre user. Whilst not denying the values of choices and rights, the carer notes the reality of moving quickly beyond current day centre provision and the requirement for intensive transition planning:

I worry about too much emphasis on being 'out and about', as I've said she [daughter] is very active work wise and to a lesser extent at the Centre, but she looks different to others and she has been taught by her support worker to be friendly and confident with people, but I worry that by herself that could be misread, put her at risk. How could I hand her to someone I don't know, havenever met. I would never forgive myself if anything happened. (Bridget, mother of Catherine, 33 day centre user for 8 years)

### Conclusions

The advent of a choices agenda around self-directed support is rightly welcomed by the UK Disabled Peoples' Movement and UK Government alike. The notion of greater self

determination will be welcomed by many disabled people where adequately supported. The concerns highlighted in this study suggest that modernisation policy has to account for a diversity of disabled people who may be at very different vantage points in terms of their readiness for self determination. Ironically, in moving away from the enforced collectivities of day services and in the absence of a CIL or user-led organisation in every locality, there is a risk of individual support solutions fostering enforced individualism and isolation. Dependency could shift from day centre to family carer contexts more fully. There is a need to acknowledge the value of collective contexts and identities for disabled people and the urgent need to plan and fully fund transition policy towards greater choice. The recent decision by many local authorities to only fund major self-directed packages to those in 'critical' need (CSCI, 2008) seems at odds with the spirit of the modernisation agenda. Without that financial and organisational support, self direction takes on distinctly neo-liberal characteristics.

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