



Reflecting on research since 1987

David Felce provides an overview of what research tells us about the gains made since 1987 and the lessons we need to learn.

I was asked to write about lessons from research over the period since the first edition of *Llais*. Using the search terms 'intellectual disabilities' or 'mental retardation' in the ISI Web of Science, one finds that there have been about 30,000 research articles published on these topics since 1987. This paper is inevitably highly selective. My aim is to trace a connection between the big picture issues that were dominating policy development in 1987 – major change in the pattern of services provided to people with learning disabilities and their families – and the situation that we currently confront.

The All Wales Strategy

Launched in 1983, the All Wales Strategy (AWS) sought to develop comprehensive, local, learning disability services, wider use of generic services and better access to the ordinary resources of the community. Its significance for the UK lay in its comprehensive scope and its apparent strength of commitment, as evidenced by its three underlying principles, the transfer of lead-agency status from health to local authority social services and the promise of additional recurring funding which would total £26m (at 1983 prices)

by 1993. It had a slow start with initial county plans needing to be revised before being passed by the then Welsh Office, particularly for the two supposed 'vanguard' areas which were among the last to be approved. So, moving reform forward was a major concern in 1987.

Of course, the AWS did result in changed service provision; it would have been unthinkable had it not. Table 1 shows headline details of change between 1983 and 1995 taken from Perry et al. (1998): the decline in the hospital

population, increase in independent sector housing provision (accompanied by a change in residential group size from greater than 10 in all sectors in 1983 to 4.3 in local authority settings and 2.8 in independent sector settings in 1995), initial expansion of large day centres followed by a subsequent reduction and greater diversification of options, increase in support going into the family home and increase in the availability of respite care with families or in ordinary housing.



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Grange Hospital*

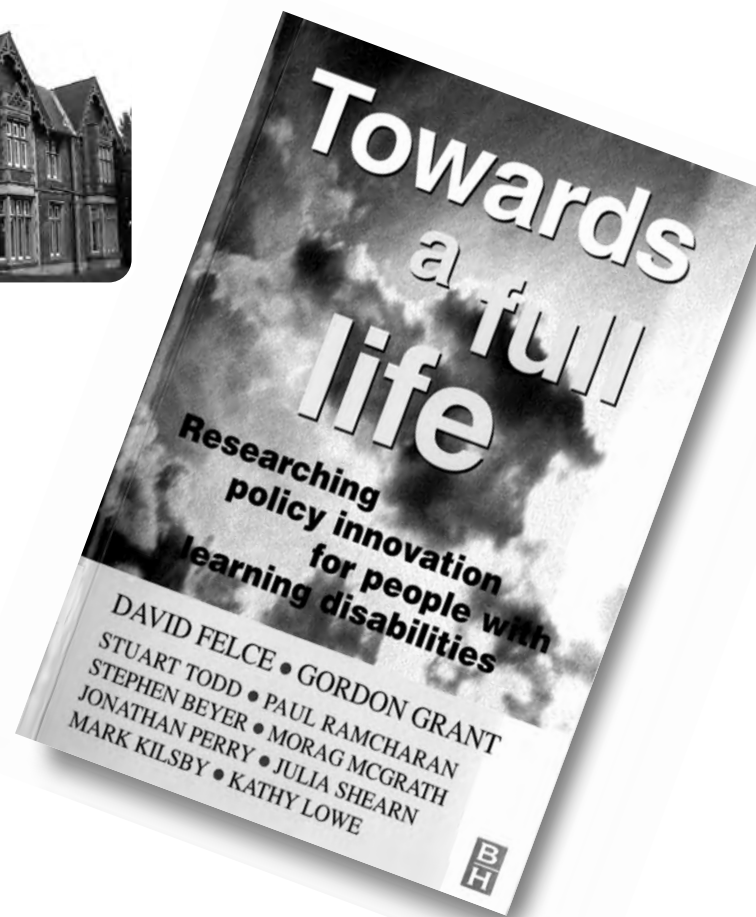




Table 1 Numbers of people receiving certain services in 1983, 1987/88 and 1995

Service provision	1983	1987/88	1995
Residential Care			
Total	3,113	3,049	2,858 ¹
Hospital	2,087	1,735	755
Local authority	676	736	690
Independent sector	130	134	722
Day Care²			
Large centres	2,997	3,192	2,466
Satellite units	Near zero	310	956
Alternative centres	200	315	473
Work experience	-	394	415
College courses	-	320	857
Individual activities	-	42	290
Special business/training	-	-	710
Open employment	-	-	550
Family Support			
Domiciliary support/family aide	41	1,840	1,914
Family-based family respite	32	498	702
Staffed housing family respite	few	Not known	1,153

¹ The apparent reduction is misleading as provision outside of NHS or registered residential care probably increased.

² Sessional attendance means that the figures for day care cannot be added to give total service availability.

But a far more difficult question to address is the extent to which the AWS accelerated the transition to improved service support: had change been more extensive and were the new services providing better outcomes than say in England? In trying to sum up the impact of the AWS (see Chapter 9 in Felce et al., 1998), we concluded that:

1. Deinstitutionalisation was slower in Wales than in England up to the early 1990s, although it accelerated subsequently as Welsh Office policy and additional funding became focused on achieving

hospital closure.

2. Wales achieved a more wholehearted transition from health to local authority commissioning of social care, an issue which England had to revisit post-deinstitutionalisation.

3. Reform was more radical on the whole in Wales than elsewhere in the UK. For example, Wales made a more uniform commitment to a small ordinary housing model in the wake of deinstitutionalisation than did England (again, an issue that has had to be addressed there more recently). Average residential group sizes were

smaller. Costs and staffing per person were greater.

4. The availability of domiciliary support worker input and family-based respite care per head of population was probably a little higher in Wales.

5. As was the early growth of supported employment.

Better outcomes?

The question of whether deinstitutionalisation led to better outcomes generated a lot of research. In line with expectation, the balance of evidence shows that it led to a number of objective quality of life gains. People who moved out of the hospitals to local supported housing experienced significantly improved material standards, personal development, choice, participation in activities of daily living and involvement in activities in the community (see Emerson & Hatton, 1996), albeit often from very low institutional baselines.

However, the research also contained surprises. Some of the expected changes in outcome did not happen. And quality in the new services was extremely variable. The simple prescription of 'an ordinary house in an ordinary street with ordinary staff trained in an ordinary life philosophy' did not guarantee the good life. Moreover, factors thought to be important to outcome such as staffing levels and size of setting, at least between the range of 1-5, turned out not to be that important.

Challenging behaviour was one outcome that proved resistant to change. It did not disappear



because it was often not an artefact of institutionalisation but a reason for admission in the first place. We now know that some of the genetic conditions that are associated with learning disabilities are also associated with challenging behaviour. That does not mean that challenging behaviour cannot be changed but it does mean that understanding has to be more sophisticated. In addition, we also now know that how carers behave in the community may not be that different to how they behaved in the institutions. The environmental factors that maintain challenging behaviour continue to occur and we need to take this on board if we want this to change.

Social networks

Nor did the nature and breadth of people's social networks change as a result of deinstitutionalisation. Even in the community, people with learning disabilities tend to have considerably fewer friends and acquaintances than other people and only the minority have 'inclusive' social networks (i.e., those containing people other than relatives, paid staff or other people with learning disabilities). Social integration may be an important policy principle but we have little evidence about how to achieve it.

Emerson and Hatton's (1996) review of 71 UK research articles comparing aspects of life in hospitals, large community units/hostels and small staffed houses concludes that "On all measures of outcome, the

variation within community-based services was substantial. This suggests that a for a significant minority of people, life 'in the community' would appear to be relatively indistinguishable... from life in hospital" (p.30). Why might this be so? Why did newly provided, architecturally more normal settings, with more staff and contemporary ordinary life policies not outperform the relics from the past? Seeking to explain variation has been an important element of the post-deinstitutionalisation research agenda. Summarising what has been found: (a) the biggest determinant of a range of different objective lifestyle indicators (e.g., choice, community integration, social relationships, activity levels) is the level of independence of the person concerned, as measured by an adaptive behaviour scale – more able or independent people lead fuller lives, (b) higher staffing does not produce better outcome – it may even inhibit

choice and participation in household activity, and, (c) after the characteristics of the people themselves, the most important factor is what staff do (the social milieu they create, the working methods they implement and the extent and nature of the support that they give to compensate for people's lack of independence).

Receiving attention

An early study (Wright et al., 1974) illustrated the barrenness of the institutional social environment. Sixteen children living in an institution were observed for 240 minutes. On average, each received attention from staff for a mere 13 minutes (5.6% of time). For the overwhelming majority of that 13 minutes (94.5%), the attention was classified as 'neutral', neither encouraging nor discouraging. Twenty-two years later, the Emerson and Hatton (1996) review summarised 26 studies that compared the level of attention received by people





living in institutions, large community units/hostels and small staffed houses.

On average, people in houses received attention for 14.8% of the time, a level greater than those found in large community units/hostels (9.3%) or hospitals (4.2%). However, there was substantial variation within types of setting: houses varied between 5% and 31%, larger units between 2% and 17% and hospitals between 3% and 16%. So at their worst, the support being provided in some housing was no more than that found in the old institutions. Studies of staffed housing since the Emerson and Hatton review show a similar picture of variation. Moreover, they also illustrate that, like the attention in the Wright et al. study, only a minority of the attention provided actually constitutes support. Table 2 illustrates the problem. The data relate to 51 staffed houses which have been divided into four groups reflecting their residents' needs for support. What is clear is that individuals in all groups only receive limited assistance to participate in activities - for about one and a half minutes an hour. Moreover, those with higher support needs receive no more assistance than people who are considerably more independent. So we are investing considerable expenditure in staff who are not providing effective support, a conclusion that possibly explains why lifestyle outcomes do not relate to level of staffing.

Table 2 Extent of assistance and relationship to service user needs (Felce & Perry, 2004)

Houses	Group 1 (n=12)	Group 2 (n=13)	Group 3 (n=13)	Group 4 (n=13)
Support needs	Highest	High	Moderate	Low
Attention received (% time)	12%	19%	16%	19%
Assistance received (% time)	2.6%	2.5%	1.7%	2.2%

What should be done?

First, people with high support needs require more and better support. This requires attention to working methods, training and staff supervision. There is no single right way. But as an example, the research on 'Active Support' shows that the level of assistance people receive can be increased up to four-fold without increasing staffing with a corresponding increase in a range of lifestyle outcomes (see Felce et al., 2002). Moreover, those being better supported like it:

"It was boring before; now I do lots of things in the house."

"It gives staff an idea of what they are meant to be doing."

Second, people with low support needs should live with the greatest level of independence possible. Two recent research studies have compared outcomes for similarly able people living in fully-staffed group homes or semi-independent living and found advantages in the latter arrangement (Stancliffe and Keene, 2000; Felce et al. 2008). Moreover, a S Wales provider has even more recently restructured staffing throughout their housing to provide greater independence and introduced assistive technology. Our evaluation found

increased cost effectiveness (Perry et al., in press).

I am aware that I have mainly addressed research on supported accommodation. However, the importance of what staff do is a general issue. Gaining independence is important as the evidence is extremely strong that people who are more independent lead fuller lives. So how do we train staff to teach? This is a forgotten area of importance. Of course, learning will remain slow for many, so we need to support people well, as I have already discussed. We also need to select activities that match people's strengths, adapt demands and provide assistive technology. Rolling these together with skills in teaching defines the key processes within supported employment of job matching, job adaptation and job coaching. My view is that we will not get as far as we would like in extending opportunity for open employment if we ignore these key staff competencies as we have done in the provision of supported housing. Nor will be build comprehensive local provision for people with challenging behaviour and end out-of-area placement without concentrating on staff competence. And so on...



Promises

Back in 1987, the AWS was promising to deliver comprehensive local services. We all know that that has not been achieved; there is a postcode lottery about the level of local service availability and extended living in the family home is the norm for even more adults with learning disabilities than used to be the case. Ironically, strategic planning was a weakness in the unrolling of the All Wales Strategy. Inequalities between areas were created and there was a failure to take account of demographic change. The Action Plan produced by the Learning Disability Implementation Advisory Group in 2008 tried to address the issue of expanding numbers of adults dependent on family care by linking the achievement of greater cost effectiveness within current staffed housing with strategic government investment to expand the availability of out-of-family accommodation. Unfortunately, this was rejected by the Welsh Assembly Government. Nevertheless, the issue is not going to disappear. There is strong evidence of growing longevity among adults with more severe intellectual disabilities, which is something to celebrate. The increase in the number of middle-aged to older adults is set to continue and may even be accelerated with better health care, stimulated by the annual health check, and action on health risks such as obesity and low levels of exercise. Government maintains that health and social care should be evidence-based. We need to

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