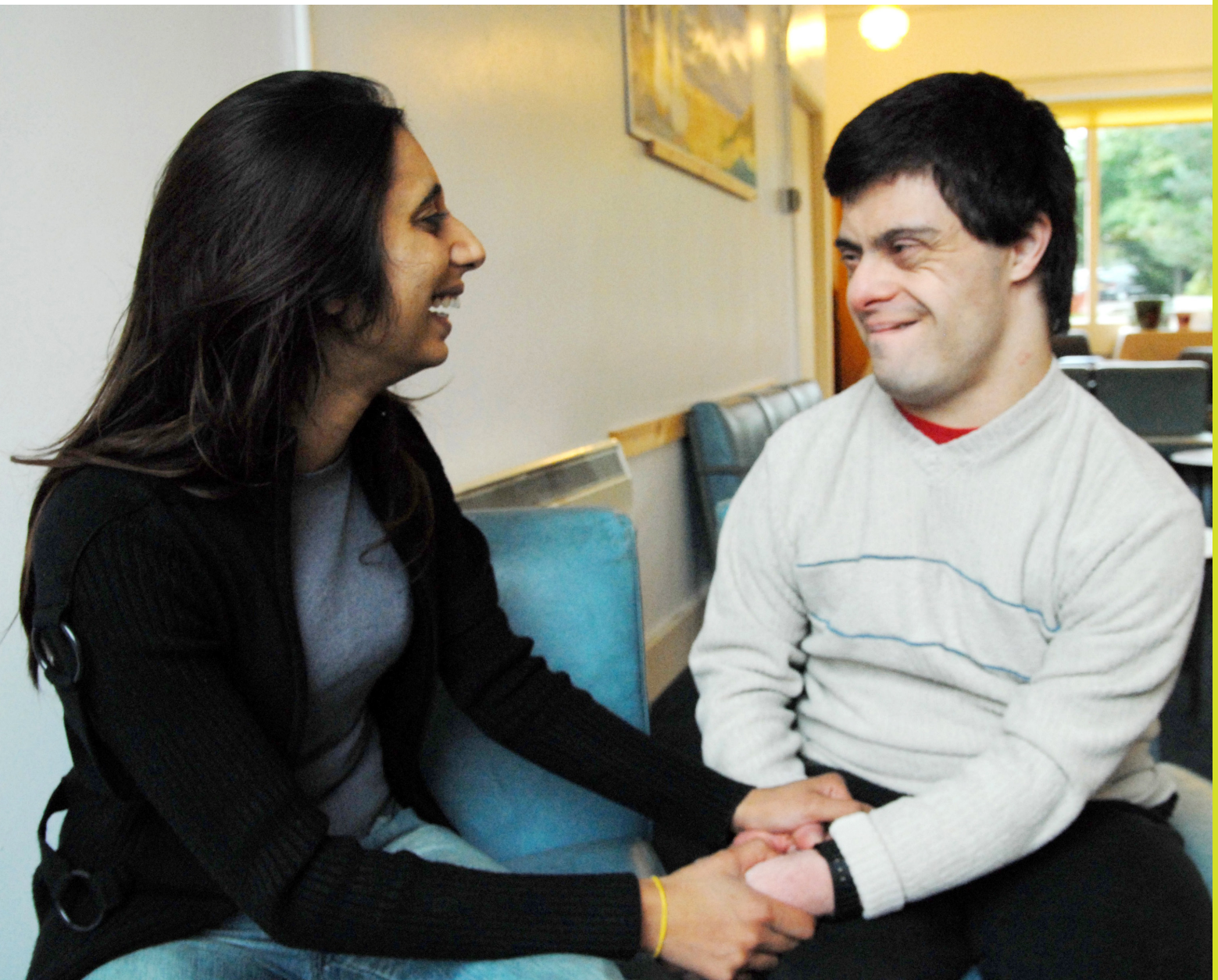
There is an alternative

ASL
The Association for Supported Living



The Association for Supported Living represents organisations that support about 30,000 people with learning disabilities, with combined annual budgets approaching £1 billion. Each operates successful community-based, person centred services, which work because they respond to the needs of the person getting the support.

Foreword

It is appropriate to commence this foreword with a tribute to those many people with learning disabilities who have endured unacceptable standards of care and support during the past two decades, following the closure of our long-stay hospitals in England. For them new futures were reported to lie ahead that would herald optimism in being able to live as integrated citizens within their local communities. Unfortunately some have continued to be denied the enhancement of their personal rights, status and societal position, only to endure further humiliation and (in some cases) actual psychological and physical harm as we have witnessed in Cornwall and Bristol. Hence the journey towards meaningful inclusion within society is far from concluded.

The Association for Supported Living (ASL) has recognised the challenges that lie ahead in providing meaningful living experiences for people with learning disabilities and demonstrates in this report how people can live purposefully within ordinary homes, integrating closely within the context of their local neighbourhoods. Evidence of the successful enhancement of individual rights is provided in this report through the stories of ten people who were previously required to live in institutions because their behaviour was deemed to be challenging. They are all now living successfully in their own homes as tenants, supported appropriately by co-workers of their choice and paid for by their own incomes. The result has been remarkable, providing people with new, enriched life experiences, at a cost that is actually less than that paid for institutional care.

This inspiring report provides optimism for the future and exposes the deficits that continue to imbue existent specialist hospital services that perpetuate an institutional model of care delivery. Such services seek to disempower people with learning disabilities who present as vulnerable members of our community. In their place have emerged vast arrays of supported living housing options that have been proven to influence the actual lives of service users as co-agents of change by offering real choice and self-determination.

These services are co-designed with prospective tenants, customised to meet their exact requirements, irrespective of their level of need. They are therefore person centred, purposefully designed and integrated within the heart of local neighbourhoods. They are sustainable and supported through the provision of discreet systems of local supervision, leadership and quality assurance. Above all, supported living provides people with tangibly better lives that are inspired by creativity, innovation and a belief in the art of the possible.

This report demonstrates that these principles can become a reality, but also confirms that further investment and commitment to improving the quality of life experience for people with learning disabilities is required.

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Introduction

In this report you will read the stories of ten people with learning disabilities, each living happily in ordinary homes around the country. Every story is different, but a common thread runs through them. All tell of people who were at one time contained in institutions because their behaviour was deemed to be challenging, people who have gone on to better lives in community services, which actually cost less than institutional care.

These institutions, which cost the taxpayer huge sums every year, were supposed to be caring and supportive environments, yet life inside them was restricted, impoverished and uncomfortable. Difficult behaviour was often managed using aversive physical restraint. It was an institution like this that was the subject of an edition of Panorama broadcast 31st May 2011. The programme included much disturbing footage of people with learning disabilities in a private hospital, being abused by staff employed to care for them.

There was a swift response: the hospital has closed and former staff are being prosecuted, but history shows that this was not an isolated case. In the past few years there have been similar scandals at Budock Hospital (Cornwall) and Orchard Hill Hospital (Sutton and Merton), with many more before that. Such events cannot be explained away by blaming rogue staff and weak management. Rather, it is about the innate failings of institutional care, a model still in operation across the country, which not only has a detrimental effect on the lives of many hundreds of our most vulnerable fellow-citizens, but also costs the tax-payer a great deal of money. This report presents an alternative, one that offers people a tangibly better life at a considerably lower cost. Added together, the savings generated in the ten cases in this report amount to around £900,000 a year of public money. And what's more, this alternative is already offered by many established, reputable support providers around the country.

For nearly 20 years Government policy, recently reaffirmed, has instructed health and social services that people with learning disabilities whose behaviour challenges need individual, local, long-term support – exactly the kind that ASL recommends. These services are complex and require concerted creative effort. But, as our real-life stories demonstrate, they offer people tangibly better lives. These services are not fanciful notions divorced from the reality of today's constrained economic conditions. They achieve outstanding results, they are cheaper than institutional care, and they are operating now, seven days a week, across the country.

We have analysed these stories from the perspective of years of experience supporting people with learning disabilities, and have identified seven key features of successful community supported living services.

Michael

Michael, who is autistic, lived in a succession of emergency placements before ending up in a special unit at the age of 18, in 2003. His service at the time cost £350,000 a year. Three staff were allocated to him constantly, such was the fear of the threat he posed, and in one year he was restrained 180 times.

Commissioners worked with Michael, his family and a sympathetic support provider to set up a new service. A housing association provided a suitable house and the support provider spent several months working with Michael, his family and the staff in the special unit developing a person centred plan. The plan included the use of non-aversive techniques to cope with challenging behaviour, and money was set aside to ensure that staff would receive appropriate ongoing training in these techniques.

Michael moved into his new house in 2004. Restraint was eradicated within nine months and has never been used since. There have been many qualitative improvements to Michael's lifestyle, and his parents are delighted that he has 'regained his life'. After one year the support provider was able to reduce the cost of the service from £350,000 to £250,000.

Adel

In 2005 Adel, a woman with a learning disability and a bi-polar condition then in her mid-50s, was living in an NHS retained service. She had been there for about 15 years, at a cost to the local authority of more than £200,000 a year. She was regularly restrained because of her challenging behaviour.

Adel was referred to a new support provider, which created a person centred individual transition plan to facilitate a move into a new service. This plan was overseen by the provider, and involved listening to Adel and identifying her needs and wishes. Working closely with the local authority and the Primary Care Trust, the provider set up a community-based service. Challenging incidents and physical interventions were commonplace initially, but the provider believed that environmental factors contributed to Adel's on-going problems. With decent ordinary housing, and a consistent, dedicated team who worked to agreed guidelines, Adel's life became more stable. She now lives in her own home that she part-owns, and has individual support from her hand picked team. The new service initially cost £196,000 per year, but has now fallen to £130,000. Adel is more independent, has reconnected with her family, and is never restrained because her challenging behaviour has subsided.

Person centred

If you are supporting a person with complex needs you have to see beyond the problems and the labels and recognise that you are dealing with someone with aspirations, needs and hopes, just like the rest of us. Yet if that person finds it difficult to communicate through speech, you have to find other ways of 'hearing' what they are saying. People with severe learning disabilities in particular may find it difficult to communicate what is important to them. In those cases, their behaviour becomes the clearest indicator of how they are feeling. Unhappiness, frustration, anxiety and fear can be expressed as aggression or self-harm. This is generally referred to by health and social care professionals as 'challenging behaviour'. All behaviour, even challenging behaviour, is communication. If you listen to it and respond to it appropriately, the chances are that it will reduce.

When working with people with challenging behaviour, you need to establish what the behaviour means, and adapt your approach accordingly. Successful supported living services recognise this, and strive to be person centred. This means concentrating on the person's likes and dislikes, trying to understand what they want to do in their lives, and responding accordingly. The person is supported to be in control, making all the key decisions, including where they want to live and who they want to live with.

Imogen

For much of Imogen's life she was moved around NHS services in the South West of England. The reasons for the moves were directly linked to limited verbal communication, a short concentration span and violent behaviour. And although Imogen, now aged 58, has autism as well as a profound learning disability, the condition was not given the importance it should have had in her support.

In 2005 a new support provider began working with Imogen. From the beginning they set out to devise and develop a person centred plan. Previously she had been placed in group settings in which she was treated as having a certain type of condition requiring a medical intervention to reduce her violent behaviour. The new provider worked with commissioners to develop and manage a supported living service, which allowed Imogen more personal space. Imogen is now living in her own home as a tenant through a private landlord scheme. A hand picked team, trained to understand her particular needs related to autism and communication, supports her. Her service now costs £175,000 per year, down from £220,000, the cost of her final NHS placement.

Nigel

From the age of 16 to 21, Nigel, who is autistic, lived in a hospital where his behaviour was deemed particularly challenging. He was physically restrained two or three times a day, by up to five staff at a time.

A new support provider recognised that one thing that triggered Nigel's behaviour was changes to his support. They worked to ensure continuity and consistency of staffing, also impressing on people working with Nigel the importance of maintaining a planned approach. A daily team debriefing, where people shared what had worked well and what hadn't, helped staff learn how best to support Nigel, as well as track what caused challenging behaviour. Over time the team developed a routine that reduced Nigel's challenges while increasing his independence. Physical restraint, once a twice-daily occurrence, now happens less than once in every ten days, meaning that the support provider has been able to gradually reduce costs, with fewer people on night duty. When the service started, the annual contract price was £363,695. This has fallen to £327,132, a saving of £36,563 (about 10%), and will reduce further in time.

Nigel, meanwhile, has a more active and fulfilling life, with many interests. His family believe that 'life has started again' for him.

Cooperation

In services that prove successful in the long run, planning will start many months in advance of the service commencing. It is crucial that this planning involves fully the potential service recipient, so that they can grow to trust everyone involved and the process itself, along with the support provider, the person's family and friends, commissioners, health professionals, housing providers and others. And this cooperation must not stop once a service has opened, but continue, with support staff working hand in glove with the families and friends of those they support, and with other professionals.

Investment in skill

While supported living services can support people with complex needs in non-institutional and non-restrictive settings, it is difficult, specialist work and requires additional skills above those one would normally expect in support staff. Untrained care workers, never mind how well-intentioned they are, will not be able to perform to the necessary standards. Rather, services like these need staff who combine a fundamental respect for the people they are supporting with skill that can only come from experience and ongoing training. This means maintaining a level of investment. It is not enough to train a team and then leave them to it. In particular, it is important that staff are trained to implement appropriate strategies to respond to challenging behaviours, as agreed with the supported person and their family.

Robert

Robert used to be described as a 'lost cause'. Now 36, he lived in long-stay hospitals and residential care from the age of four. At his last placement restraint was commonplace with the techniques used forceful. He was sometimes locked out of the house during the day, often not appropriately dressed. At times he went hungry and ate grass, twigs and stones, and would take food and drinks from people in cafés. When inspections raised concerns about this service the local authority asked a new support provider to get involved.

The new provider helped Robert to establish a circle of people who knew him and cared about him, who supported him to identify what he wanted. He was clear that he wanted to return to the area he came from and to live in an ordinary house. He was introduced to three people who were looking for someone to live with, and spent time getting to know them before they all decided that they wanted to share a home. A housing association property became available and tenancies were offered to all four.

Initially when Robert moved in he was aggressive, damaged property and took people's food. But with structured, consistent support, the development of routines, and the feeling of security in a homely environment, Robert began to live the life that he wanted. He can now cook for himself and look after his home. He takes part in his local community, has gained weight and uses simple signs to communicate. In addition to having a better quality of life, the cost of Robert's support has reduced to £52,000 a year, down from £150,000 a year in the previous placement.

John

John is an active member of a prestigious golf club where he has made many friends and has achieved a low handicap. He is an excellent cook and has taken up cycling to keep fit. This is in stark contrast to his earlier life. When he was a young man, John, now 51, was moved from home to an NHS assessment and treatment unit because he was aggressive toward his parents. With a diagnosis of moderate learning disability, autism and schizophrenia, he spent two decades in a range of semi-secure placements that never lasted more than 18 months, breaking down after incidents of violence.

Eventually John was referred to a new support provider. By this time he was heavily medicated, was regularly restrained, and had not been out of the building for two years. The new provider did a six-month assessment, and created a support package that gave John the chance to be in control of his life. When John moved into his own house the provider learnt to recognise when he was feeling anxious or angry and the best way to support him at such times. Staff were given specialist training and on the job coaching, and clear guidelines, developed with John, helped him to manage his behaviour. He has never been restrained since, and although he is still prescribed medication this is only given when required. Over time the cost of the support John needs has been reduced from £125,000 to £59,000.

Leadership

Successful supported living services need strong leadership at several levels. Typically, a skilled and trained practitioner, present in the workplace and not desk-bound in a distant office, will manage a successful service. They will be skilled in understanding behaviour and modelling to their staff positive ways to intervene to reduce or prevent challenging behaviour. They will be able to robustly support and supervise their staff, and will in turn need appropriate support themselves from senior managers in their organisation.

Sustained effort

Successful supported living services for people with complex needs require sustained effort. People who challenge are not problems that can be solved with a single intervention, but people who need ongoing support to live meaningful lives. Initial planning and relationship building are crucial to long-term success, so investment in a service must be in place before it opens. There might well be an initial high investment in staff time, training and other resources, but consistency must be maintained thereafter.

We do find that costs reduce over time. As staff become more attuned to the needs of the person they are supporting, and correspondingly more able to offer that person positive opportunities that make life safer and happier, so challenging behaviour decreases. And as challenging behaviour decreases the level of support can be reduced, bringing down costs. Supported living services invariably end up cheaper than institutional services, but they are not a low budget quick fix.

Mandy

Mandy has been known to health and social services since she was six, and was first admitted to a psychiatric hospital at 15. She began self-harming as a teenager and has a history of substance abuse. Now 25, she is diagnosed with schizoaffective psychosis and a borderline personality disorder.

Mandy was sectioned when she was 18, and in hospital her behaviour became more aggressive. She was transferred from the NHS to a private secure hospital, 90 miles from home, where she assaulted eight staff, who pressed charges, and also a police officer who had come to interview her. At its peak her support cost over £8,000 a week.

A new support provider assessed Mandy and also talked to her family, social worker, doctor and secure unit staff, developing a plan for her to move out of hospital. The provider recruited a team that started working with Mandy, and found accommodation that she liked, in an area where she wanted to live. Staff were trained to work with Mandy, and worked closely with other professionals involved in her support. She was at the centre of this planning and support, and given as much control as possible.

Mandy moved into her new flat several years ago, since when she has never assaulted staff and her self-harming has reduced. The cost of her service fell by 80% compared to hospital. She has a cat, is an online advisor and supporter for people who self-harm, an online moderator for an animal protection website, and has started college. She maintains contact with her family and has reconnected with an old friend.

Peter

Peter, a 19 year old man with autism, was living in a residential school where his placement cost £180,000 a year when commissioners chose a new support provider to set up a community service. The new provider gathered information from the school and worked with Peter and his family to develop a person centred plan. Part of the plan consisted of non-aversive interventions to cope with challenging behaviours.

A staff team was recruited and trained, and once the new service opened it was supported by a 24 hour on-call system, with managers available to respond quickly when needed. Nearly a year on and Peter continues to live happily in his own home. His parents are delighted that he has now settled closer to them so they can have regular contact. He has a mobility car, a voluntary job, and is going on holiday and enrolling on a drama course at college. His team leader has good support and supervision from a psychologist, a behavioural nurse and a social worker, and staff have ongoing support and guidance including supervision and appropriate training. Meetings are held regularly and behavioural plans and guidelines are constantly reviewed and reinforced to the staff team. The service costs £130,000 a year.

Local back up

Most people with learning disabilities and complex needs come into contact, at one time or another, with many professionals, including doctors, psychologists, occupational therapists, nurses and social workers. We have already stated that the involvement of all these people in service planning is crucial. What is equally important is that this involvement continues into ongoing, local back up. For too long there has been a tendency for people with complex needs to be passed on to 'expert' services that may well be miles from their homes. The immense disruption of being moved away from family and friends makes an unhappy person even more unhappy, therefore increasing their challenging behaviour. Expert help may be needed, but it must be available locally.

Will

None of this can be achieved without the will of local commissioners, a will that must be expressed in decisions to invest in local community-based services, rather than farm out 'problem' cases to expensive out-of-area placements. Most successful supported living services have their roots in local commissioners' decisions to invest in that service model, acting on sound demographic knowledge of the communities they serve and the needs and wishes of the people with learning disabilities who live within them.

Kelly

When a new support provider was asked to work with Kelly, 23, they found her physically aggressive, destructive to property and harming herself regularly. With a mild learning disability, mental health issues and a history of sexual abuse, Kelly is very vulnerable. She had a succession of emergency placements, moving every few months after incompatibility issues with fellow tenants, and ended up receiving 1:1 staffing 24 hours per day, costing approximately £120,000 a year.

The new provider worked with Kelly in an honest and respectful way, explaining her rights and responsibilities as a tenant and a citizen. Gradually, she took more control over her own life and learned to make choices. She has been involved in devising her own person centred plan and in recruiting and choosing her own staff. She has had regular contact with senior managers and opportunities to talk through problems when they come up. There have been many improvements in Kelly's life, one of the most important being that she has had a relationship with a boyfriend. After one year the cost of her service fell from £120,000 to £42,000 as it has been possible to reduce support. These reductions have been in small steps, negotiated with Kelly and her social worker, so that she feels in control.

Alan

Shared Lives is a type of service where carers are trained and approved to include an adult in their family and community life.

Following a breakdown in Alan's family home and then in a residential placement, his behaviour deteriorated and he began to drink heavily, despite the efforts of a number of expensive out-of-area placements. Alan's care manager approached a local Shared Lives scheme to see if they could arrange a new service for him.

Some health professionals felt that Alan's support needs could not be met in a family home, but potential Shared Lives carers were identified and the matching process commenced. This involved a number of social get-togethers leading to overnight and weekend stays, then a week-long stay, until both Alan and the Shared Lives carers felt the match could work.

Alan has now been supported by his Shared Lives carers for six months. Incidents have reduced and he says he is very happy and wants to stay with his carers for the rest of his life. He has begun accessing community education classes and leisure centres and is also contemplating a work experience placement. The cost to the local authority of Alan's final residential placement was £57,200 a year, compared with the cost of the Shared Lives placement of £14,223 a year.

Conclusion

The ASL believes that the time has come to move away from institutional services in favour of a major development in supported living. Money is being misused and wasted as councils fund out-of-area placements, therefore weakening their capacity to invest in good local provision. But there is an alternative. Our members support hundreds of people who live in their own homes and participate in their local communities, yet have needs similar to other people who are contained in institutions. If the money currently spent on institutional placements was invested in local community-based services, standards would improve, there would be far less risk of abuse, and costs would fall.

Our view is supported by a body of documented best practice, which demonstrates that local community-based support services are more successful than specialist services, as well as being cheaper. This includes The Mansell Report, first published in 1993 and revised in 2007[i], and Prof. Eric Emerson's SCIE report[ii], which illustrates the problems in planning for the needs of this group. Yet despite all the compelling evidence about appropriate support, research published last year using data from the Healthcare Commission found that nearly 1,900 people with learning disabilities continue to live in institutional care[iii].

So, we call on the Government, as a matter of urgency, to compel commissioners to set a timetable for the provision of alternative, community-based supported living services for all of these people. We are not asking the Government to spend new money. Rather, we are proposing that money already in the system should be redirected to supported living, an action that will, in time, generate savings for future investment. We are willing to help. The ASL membership has a wealth of practical experience, and we will work with anyone committed to developing community services like the ones described in this report. Services that, we assert, offer a level of care commensurate with what civilized society expects, and also save the country money.

[i] Department of Health Report: ***Services for people with learning disabilities and challenging behaviour or mental health needs*** (The Mansell Report) by Jim Mansell (1993, revised 2007)

[ii] SCIE Knowledge Review 20: ***Commissioning person centred, cost-effective, local support for people with learning disabilities*** by Eric Emerson and Janet Robertson. (July 2008)

[iii] The Guardian: ***Bristol care home: a failure on every level*** by Jim Mansell (1st June 2011)

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