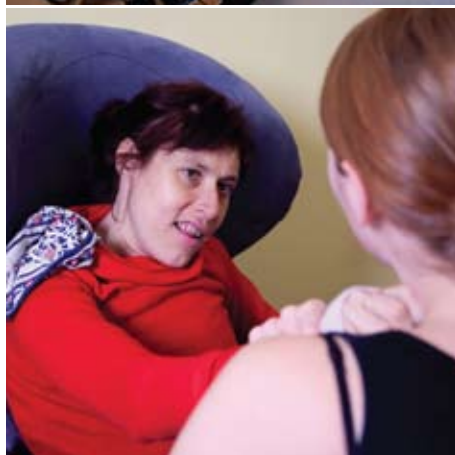
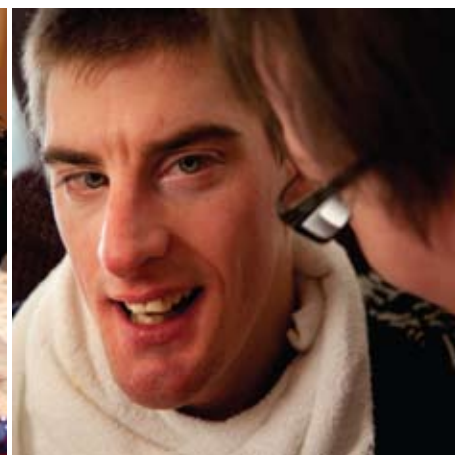
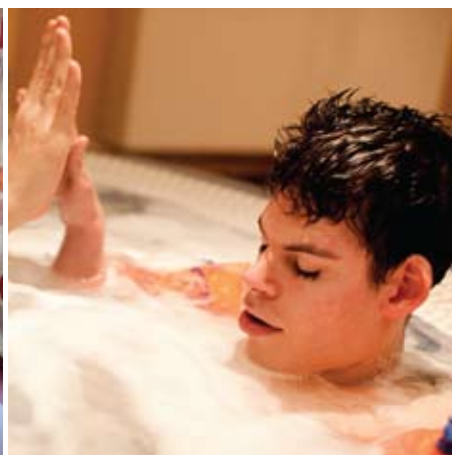


Raising our sights: services for adults with profound intellectual and multiple disabilities

A report by Professor Jim Mansell



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Foreword



Following the publication of *Valuing People Now* in 2009 I was asked to undertake a review of services for adults with profound intellectual and multiple disabilities and to make recommendations. *Valuing People Now* examined progress in implementing the 2001 White Paper *Valuing People*: it concluded that, while good progress had been made on many fronts, commissioners and policy makers were not sufficiently addressing the needs of people with learning disabilities who had more complex needs, including people with profound intellectual and multiple disabilities. The strategy was strengthened to ensure that it did address these needs, and this report is part of the process of implementation.

I have sought examples of good practice which could be used to illustrate both what is possible and what policy obstacles have to be overcome. I found that, where families were supported to make the most of the opportunities presented by the Government's 'personalisation' agenda, they were in general getting what they and their disabled family member needed and wanted. These families are pioneers. They have often had to struggle to get what they need. I identified a number of specific obstacles to which national and local government need to attend to enable more families to take up the new opportunities available. However, the major obstacles to wider implementation of policy for adults with profound intellectual and multiple disabilities are prejudice, discrimination and low expectations. I have called my report *Raising our sights* because I believe that we can achieve considerably more for this group of people than we have in the past.

To illustrate the issues addressed in the report, an accompanying film has been produced by the Central Office of Information. I hope that this will help readers of the report, who may not themselves know people with profound intellectual and multiple disabilities, to understand what needs to be done and why. I am particularly grateful to the families involved for being prepared to share their experiences.

In carrying out this review, I was fortunate to have the help of the Profound and Multiple Learning Disabilities Network and particularly of Ms Beverley Dawkins of Mencap, whose advice and assistance was invaluable. All the families, care staff, service managers and other respondents I met gave unstintingly of their time and expertise to help me understand the issues. To all of these people I express my warmest thanks.

This report completes my review and I look forward to the Government's response in due course.

A handwritten signature in black ink, appearing to read 'Jim Mansell', written in a cursive style.

Professor Jim Mansell
Tizard Centre, University of Kent
March 2010

1. Introduction

Definition



Adults with profound intellectual and multiple disabilities:

- have a profound learning disability and
- have more than one disability and
- have great difficulty communicating and
- need high levels of support with most aspects of daily life and may have additional sensory or physical disabilities, complex health needs or mental health difficulties and may have behaviours that challenge

1. People with profound intellectual and multiple disabilities¹ are among the most disabled individuals in our community. They have a profound intellectual disability, which means that their intelligence quotient is estimated to be under 20 and therefore that they have severely limited understanding². In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury.
2. This means that people with profound intellectual and multiple disabilities need high levels of support from others with most aspects of daily living: help to eat, to wash, to dress, to use the toilet, to move about and to participate in any aspect of everyday life³.
3. Despite such serious impairments, people with profound intellectual and multiple disabilities can form relationships, make choices and enjoy activities. The people who love and care for them can often understand their personality, their mood and their preferences.

Numbers

4. Recent research⁴ estimates that there are just over 16,000 adults with profound intellectual and multiple disabilities in England now. That this is a relatively small, easily identifiable group with undeniable needs for support should make improving services easier.
5. The number of adults with profound intellectual and multiple disabilities is estimated to increase by on average 1.8% each year to 2026, when the total number would be just over 22,000 people. In an 'average' area in England with a population of 250,000 the researchers suggest this would mean that the number of adults with profound intellectual and multiple disabilities will rise from 78 in 2009 to 105 in 2026, and that the number of young people with profound intellectual and multiple disabilities becoming adults in any given year will rise from 3 in 2009 to 5 in 2026. These rates will be higher in communities that have a younger demographic

¹ This phrase is the term used internationally. It refers to the same people often identified in the UK as having 'profound and multiple learning disabilities'.

² World Health Organisation. (1992) *ICD-10 Classification of Mental and Behavioural Disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation.

³ PMLD Network. *Profound and Multiple Learning Disabilities*. London: Mencap.

⁴ Emerson, E. (2009) *Estimating future numbers of adults with profound multiple learning disabilities in England*. Lancaster: Centre for Disability Research.

profile or contain a greater proportion of citizens from Pakistani and Bangladeshi communities (where the incidence of learning disability is higher). The projected rates will not be influenced by level of socio-economic deprivation.

The challenge facing families

6. Families caring for a son or daughter with profound intellectual and multiple disabilities face an exceptionally heavy responsibility. Research by Mencap⁵ showed that, on average, 60% of parents of children and adults with profound intellectual and multiple disabilities spent more than ten hours per day on essential physical care. A third of these parents said their caring role was continuous and meant they were caring for their son or daughter 24 hours a day. Fifty-seven per cent of parents were spending more than eight hours per day on therapeutic and educational activities. Parents were woken up, on average, three times a night by the need to care for their son or daughter.
7. Nearly half the families interviewed received no support from outside the family to help with care tasks and less than a quarter received more than two hours support a week to help them cope at home with care tasks. Seventy per cent of families responding to a Mencap survey said they had reached or nearly reached breaking point because of the lack of short-break services⁶.
8. Not only do these families have to devote time and effort to supporting their disabled family member (usually in the context of maintaining the rest of family life and employment and career): they also have to navigate around the complexities of the service system. The severity and complexity of the needs of people with profound intellectual and multiple disabilities are such that different health specialities and disciplines will be involved alongside social care services, education, housing and social security. These different agencies and different professions all have to be found, approached, educated in the needs of the individual person and their family, negotiated with and coordinated. In the Mencap study⁵, 37% of families were in contact with eight or more professionals and 80% thought that professionals were poorly or very poorly coordinated.
9. Getting services that can meet the needs of people with profound intellectual and multiple disabilities may also be very difficult. General health services, for example, have been found

⁵ Mencap. (2001) *No ordinary life : the support needs of families caring for children and adults with profound and multiple learning disabilities*. London: Royal Society for Mentally Handicapped Children and Adults.

⁶ Mencap. (2006) *Breaking point – families still need a break: a report on the continuing problem of caring without a break for children and adults with severe and profound learning disabilities*. London: Mencap.

to fail to make sufficient reasonable adjustments for people with learning disabilities⁷. A survey of professionals and families by the PMLD Network⁸ in 2006⁹ found that only 6% of respondents thought that there was effective planning for transition from child to adult services; only 8% thought that people got as much therapy in adult services as they did when they were in children's services; and only 3% thought there was enough provision of services for adults with profound intellectual and multiple disabilities. Mencap's 2006 survey found that:

“Access to services is becoming an increasing problem. Families report cuts in services, difficulties in getting an assessment and the tightening of eligibility criteria for essential services, despite their needs staying the same or, in many cases, worsening.”¹⁰

Prejudice, discrimination and low expectations

10. Faced with such undeniable need, why is it that people with profound intellectual and multiple disabilities have such difficulty getting help? The evidence from families themselves is that prejudice, discrimination and low expectations underlie their plight.
11. It appears to be the common experience of families that they are given extremely negative, not to say bleak, prognoses for their child.

“When she was 10 months old (1992) we were told by the wise and the wonderful at Great Ormond Street that she would die very soon. If she didn't die very soon she would die a little bit later. If she didn't die then she would probably be a vegetable for the rest of her 'short' life”¹¹

Families may be told that their child will never recognise them, will be incapable of responding and will have no quality of life.

“To be told that your child is a cabbage and that you will lose all your friends if you don't place them in institutional care is inhuman. To be told without empathy for your situation reinforces the damage – and it still happens. Fortunately, we have learned to ignore experts.”¹²

12. Although families of adults with profound intellectual and multiple disabilities reporting these kind of statements are referring to a period some years ago, it is not clear that families of young children always have better experiences now.

⁷ Michael, J. (2008) Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. London: Independent Inquiry into Access to Healthcare for People with Learning Disabilities.

⁸ <http://www.pmldnetwork.org>

⁹ PMLD Network (2006) Unpublished survey

¹⁰ Mencap (2006) op cit p15

¹¹ Myerson, T. (2009). Life and death decisions with a disabled child. *The Independent*, 10 November 2009.

¹² Mencap (2001) op cit p22.

13. Families may also experience discrimination in the provision of health and social care services. Services may be denied because the person is deemed 'too disabled' to be coped with by staff – even though families are expected to cope. For example, families report not being able to access short breaks or day activities because of the degree of their family member's disability.

“We had been on a waiting list for overnight residential breaks for two and a half years and I heard that the centre Matthew was waiting to go to was under threat of closure. I felt in a black hole with no light at the end of the tunnel. I felt I couldn't go on any more.”¹³

14. When they do, there are problems of poor quality care because the needs of their family members are not recognised and dealt with adequately. In health care, the Michael Inquiry concluded:

“People with learning disabilities appear to receive less effective care than they are entitled to receive, especially as they move from children's to adult services and discrimination is evident in access to and outcomes from services. Many of these problems concern basic shortcomings in the way that treatment is delivered that would be simple to remedy. However, there is also evidence of a significant level of avoidable suffering due to untreated ill health, and a high likelihood that avoidable deaths are occurring. All these areas require urgent attention.”¹⁴

15. Some families report discrimination through the unthinking application of standard rules or procedures:

“They said she couldn't have incontinence sheets until next term as we'd had our allocation already.”¹⁵

Some families report that services are extremely risk-averse, to the extent that they injure the person's quality of life rather than manage the risks involved. A common experience appears to be that families are told that they cannot have the services they need because their needs are too great – that the amount of money involved is 'better spent' meeting the needs of a larger number of people with less severe needs.

16. As well as prejudice and discrimination, expectations of what it is possible to achieve are very low. The best illustration of this is in respect of the use of technology to enable adults with profound intellectual and multiple disabilities to control events around them.

¹³ Mencap (2006) op cit p14.

¹⁴ Michael (2008) op cit p21.

¹⁵ Mencap (2001) op cit p29.

Although such technology is beginning to be used in schools and some Further Education colleges, it appears to be almost unheard of in adult social care services. The investment made in childhood in helping the person to learn to use devices to express a choice is thereby wasted.

17. Thus, people with profound intellectual and multiple disabilities and their families face being written off, as not worth bothering with, as too difficult to support well and as people for whom the poor standards of the past are all that can be achieved. As Ron Turnbull said, after his wife was convicted of the manslaughter of their two profoundly disabled sons

“At the end of the day people thought my sons were worthless, utterly worthless, and we were too. I thought they were very special.”¹⁶

18. In fact, the underlying prejudice that people with profound intellectual and multiple disabilities are not fully human is wrong. The daily experience of their families and others who care for them, together with a large body of research¹⁷, demonstrates this. The protection of the law, including the Human Rights Act and the Disability Discrimination Act, extends to them too. And personalised services offer the prospect of a clear break with the low expectations of the past.

¹⁶ Mencap (2001) op cit p5.

¹⁷ See for example Hogg, J. and Sebba, J. (1986) *Profound Retardation and Multiple Impairment: Volume 1 Development and Learning: Volume 2 Education and Therapy*. London: Croom Helm

2. Raising our sights

Introduction

“She is listening and turning her head. She will smile at people and she recognises people’s voices and stuff like that. You just know she loves it and she loves getting out and about.”

(Mother interviewed during fieldwork for this report)

“This is probably the best we’ve had it and I think that it is definitely the way forward”

(Mother interviewed during fieldwork for this report)

19. Although people with profound intellectual and multiple disabilities are very disabled and do experience a much higher mortality rate than the rest of the population, it is evident that many live well into adult life, do recognise people around them, do respond to circumstances and do enjoy activities and relationships. Irrespective of the difficulties, and just like any other parents, most families love their disabled child and want the best for them. They want to protect them from harm, and to provide love and security for them. New models of providing services in a person-centred way should make us raise our sights. Examples of good practice show that, in general, the ‘personalisation agenda’^{18/19} – the framework of person-centred planning and highly individualised services, increasingly funded through individual budgets, is providing what people need and want.
20. A second reason for revising our expectations is the coming revolution in information technology. Research already shows great possibilities for using technology to increase choice and control by the disabled person. Because of their profound intellectual disability, most people in this group are not likely to be able to control complex devices like communication aids with multiple choices or ordinary electric wheelchairs with complex controls. Many people, however, are likely to be able to learn to use equipment expressing at least one important message, or to use intelligent wheelchairs to move around their home.

Elements of good services

Good services are individualised and person-centred

21. All the examples of good practice involved designing and delivering arrangements tailored to the individual person’s needs and preferences. Where people were living with their parents, the plan of each day depended on what was best for the person and their family and was adjusted to reflect, for example, the individual’s health and alertness. Where activities included going to a day centre or college, the activity was chosen because of its value and interest for the person concerned. Where people lived in their own home, this was designed for them. Where people shared accommodation with other people then this was because families had chosen this, the individuals got on with each other and the number of residents was small enough to maintain an individual focus.

¹⁸ Prime Minister’s Strategy Unit. (2005) *Improving the life chances of disabled people. A joint report with the Department of Work and Pensions, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister*. London: Cabinet Office.

¹⁹ Department of Health (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*. London: Department of Health.

“When you work with an individual it has to be for that individual... what you would do for him is different to somebody else... [His needs are] individual to him, we do not want to know about anybody else, we just learn about him and it just makes it so much easier.”²⁰

22. This contrasts with the service models of the past, where adults with profound intellectual and multiple disabilities would be congregated together in larger groups in day centres or nursing homes. Where these were inadequately staffed they risked neglecting the physical care of individuals and of leaving people socially isolated and ignored. Where higher staff levels were provided they risked not being able to coordinate and organise staff sufficiently well to maintain an individual focus of care.
23. Some families had achieved personalised arrangements before individual budgets were possible, through lobbying to shape services in the way they needed. Others were using individual budgets to achieve the same result. In both cases, good services also overcome organisational barriers (for example between health and social care) to deliver the services the individual needed in a coordinated way.

Good services treat the family as expert

24. In all the examples of good practice families had taken a leading role, often battling against the perceived indifference of public services to get what they needed for their disabled family member. Usually they had recruited other people to help them – friends, other families supporting adults with profound intellectual and multiple disabilities, professionals from service providing agencies or commissioners of services, and advisers from voluntary organisations. These were not always constructed as ‘circles of support’²¹ but they were clearly important sources of ideas, energy and commitment.
25. In most cases families had used self-directed services involving individual budgets to control and direct the main services they needed. Some families were playing a large part in recruiting and managing staff, others were leaving most of this to service providers.

“We did not know anything about employing personal assistants... they did all the adverts and we did the interviews at the Centre of Independent Living and they sorted out the contracts... showed us this manual about what we had to do... the bedrock fundamentals, everything.”²²

²⁰ Personal assistant interviewed during fieldwork for this report.

²¹ <http://www.circlesnetwork.org.uk>

²² Mother interviewed during fieldwork for this report

“it just gave us another problem, so we decided, no, we’ll take on the service directly... they are incredibly successful with families who need to keep control but don’t want to spend the time or the energy, or don’t know enough about managing staff or the rules and regulations around social care, so we are a bit unusual in that respect.”²³

“it’s a social enterprise... [the arrangement] is built on trust and we had a kind of courtship where they came and they kind of sussed us out and they looked at our material and we sussed out whether what they were saying was what they were actually going to do.”²⁴



26. In contrast to the experience reported in the previous chapter, these families were also being treated as experts by other services they used. For example, in using hospital and other health services they described how professionals listened to their advice about how best to serve their disabled family member, making adjustments to appointment times and approaches to assessment and treatment as required.

Simon and Alex share a 3 bedroom bungalow in an ordinary residential street. The bungalow was the property of Alex’s family and when it became available it was decided that it would become Alex’s new home. Alex’s father approached SENSE to ask them to find someone else to be a tenant in the property and so Simon (who has less severe disabilities) joined him. They had not known each other particularly well before living together as they went to different schools. The families knew of each other but had not had much previous contact.

Simon and Alex have one bedroom each and the third is used as an office/sleep over room for night staff. The bungalow has a small kitchen and this includes some adapted equipment, such as a drinks level indicator and a talking microwave. It has a garden which is paved with raised flower beds (good for both young men as they both have visual disabilities) and a garage. Additional hand rails were put on the steps in the garden.

Both families receive funding for the package of care as a direct payment. This pays for 1:1 staff support but includes only one sleeping member of staff at night. In addition Simon and Alex receive housing benefit, incapacity benefit and upper rate Disability Living Allowance which are used for rent and living costs. They are both tenants and both pay monthly rent. Alex and Simon also attend a SENSE Resource Centre for 5 days per week which they attend with their support staff. The Learning and Skills Council fund 3 days per week and social services fund the other 2 days per week.

Alex and Simon appear in the film accompanying this report.

²³ Mother interviewed during fieldwork for this report

²⁴ Mother interviewed during fieldwork for this report

“We had the opportunity to share our fears about him going into hospital... I will be so angry if it is the transition process that kills him... They were very understanding about that. I had a letter summarising the discussion and also inviting us [to visit]... So basically we are working out as much as we can what would happen and trying to build some of the relationships that he needs.”²⁵

“She had a body brace mould made without anaesthetic... took us two hours, and they all had to sing to her, but we did it. See that's good practice. Because she couldn't have anaesthetic any more, kidneys can't manage it, but I needed her posture to be in a good shape, so if they listen, really listen and believe in us, and listen to her team as well.”²⁶

27. Recognition of the expertise and commitment of the family means that these services are not only person-centred, but they are also family-centred.



Mitchell lives in his family home, which has been adapted so that Mitchell can get around and also has his own bedroom and en-suite bathroom, with ceiling-mounted hoist, special bed and other equipment to help manage his PEG feeding, tracheostomy and long-term ventilation. Dissatisfied with support at home from a hospital-based team, his family opted for a personal health budget funded by the local Primary Care Trust so that they could organise the support they wanted. Using a local not-for-profit organisation for backup and support, the family recruit, train and manage Mitchell's team of personal assistants.

This individual budget pays for 175 personal assistant hours a week, 161 of which are funded by health and 14 by social services. Mitchell is shortly to be assessed for continuing health care funding. During the day Mitchell goes to school, and there are plans to go to a Further Education college when he leaves school next year.

Mitchell's appears in the film accompanying this report.

Good services focus on quality of staff relationships with the disabled person

28. It is evident from the description given earlier of how families support people with profound intellectual and multiple disabilities that sufficient personal assistance is essential, both to provide safe care and support and also to enable the person to have as good a quality of life as possible. As one professional explained:

²⁵ Mother interviewed during fieldwork for this report

²⁶ Mother interviewed during fieldwork for this report

“DSM-IV states that ‘optimal development may occur in a highly structured environment with constant aid and supervision and an individualised relationship with a caregiver. Motor development and self-care and communication may improve if appropriate training is provided’... I use this quote to support bids to commissioners for 1:1 funding”²⁷

29. In describing the staff who provided support to their disabled family member, there was remarkable consistency in family views about what was important. The key attribute was that staff should have a warm, respectful and caring relationship with the person. This was viewed as much more important than the particular background or training that staff had.

“Often – not always but sometimes – the best people have been people who have come with the right values and attitudes and with no experience whatsoever... That’s why it is so important that the person understands and has that ability to build a relationship, to see the person as a person. You can teach all the rest.”²⁸

30. Families did, however, put a lot of effort into ensuring that staff learned how to support the disabled person in the best way, using written policies and procedures, modelling by more experienced staff, supervised practice and attendance at training courses.

“We wrote it putting him first, then through some of the personal care getting to the more technical stuff as you went along. And then... towards the end of each unit we personalised it to him... we have a shadowing system [and they] are signed off to say they’re competent in all those different areas.”²⁹

31. Communication is fundamental to these skills. Staff need to be able to recognise and respond to the full range of communication, including eye-movements, facial expression and body language.

“It is not acceptable for people to just say ‘he can’t communicate’. They need to learn how to see the many ways in which people are communicating and start valuing and acting on it.”³⁰

32. In addition, research suggests that there is scope for better support from personal assistants given more access to training:

“I see too many people being wheeled round shopping centres for hours at a stretch, by poorly paid and insufficiently trained staff.”³¹

²⁷ Professional interviewed during fieldwork for this report. DSM-IV is the American Psychiatric Association. (2000) *Diagnostic and statistical manual of mental disorders: Fourth Edition Text Revision (DSM-IV-TR)*. Washington, DC: American Psychiatric Association.

²⁸ Mother interviewed during fieldwork for this report

²⁹ Mother interviewed during fieldwork for this report

³⁰ Professional interviewed during fieldwork for this report

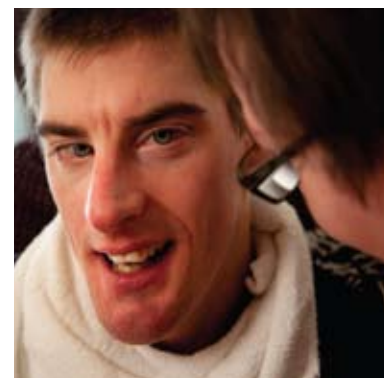
³¹ Professional interviewed during fieldwork for this report

James lives on his own in a semi-detached bungalow in an ordinary residential close in a suburban area. He bought the house through a shared ownership scheme with Advance Housing and uses income support to pay the mortgage. The bungalow and garden are adapted for James' wheelchair, and there is space for the equipment he needs (eg a ceiling hoist from his en-suite bathroom through to his bedroom, a special bed, lots of storage space for supplies). There is also a bedroom for a personal assistant to sleep overnight, as James needs 24/7 support. James also has a Motability car in which he can be driven in his wheelchair.

James has an individual budget, funded 50/50 by the local authority and the health service. He also receives Independent Living Fund monies and other benefits. This pays for 1:1 support in the morning, afternoon and evening and at weekends. Support is provided by a local service agency and James' parents play a central role in selecting, training and working with staff to ensure James gets the support he needs. During the day he attends a nearby day centre provided by social services.

James appears in the film accompanying this report.

There is great potential here to provide a better quality of life for the person with profound intellectual and multiple disabilities, if staff are helped to build on the foundation of a good relationship with the person they support by using person-centred approaches, such as intensive interaction and person-centred active support. Intensive interaction is a method of developing reciprocal interaction³² and person-centred active support is a method of enabling people to participate in activities and relationships irrespective of the degree of disability³³. These approaches are not yet widely understood or implemented.



Good services sustain the package of care

33. Families described the importance of reliability and continuity in the provision of basic supplies like incontinence pads, rubber gloves and medicines. They were clear that if these were to fail, they undermined the quality of life of their disabled family member.

“it is a part of his life and it is important, it is what sustains him, but that is not his life, that is what we do so that he can have a life.”³⁴

34. Having achieved the package of services they wanted, some families were confident that they would continue to be supported. A key source of this confidence was sometimes a good relationship with a social worker or a commissioner:

³² Nind, M. and Hewett, D. (2001) *A Practical Guide to Intensive Interaction*. Kidderminster: British Institute of Learning Disabilities.

³³ Mansell, J., Beadle-Brown, J., Ashman, B. and Ockendon, J. (2005) *Person-centred active support: a multi-media training resource for staff to enable participation, inclusion and choice for people with learning disabilities*. Brighton: Pavilion.

³⁴ Mother interviewed during fieldwork for this report.

“one of the things that have come out of this experience is that we actually have a direct relationship with the Commissioner so it’s the Commissioner who we talk to in the PCT”³⁵

35. Others were anxious that they had to repeatedly justify the package in the face of pressures to make financial savings or that restrictions might be imposed on how they could use their individual budget.

“I went to a workshop and this lady was discussing [our need for a car big enough to sit with the disabled person] and she said why don’t you use your budget. So we did... but I really got my knuckles rapped for that and they said I really shouldn’t have done it... I wouldn’t do it again because I would be fearful they would take it away.”³⁶

Good services are cost-effective

36. There appears to be no research on the cost-effectiveness of services specifically for adults with profound intellectual and multiple disabilities. The families using services identified in this report as providing good practice reported that they were similar in cost to the alternatives they had considered or had experience of. The cost of care packages ranged from £62,952 to £179,000 a year. It is self-evident that services for adults with profound intellectual and multiple disabilities will be more expensive than those for people with less severe disabilities: the major element of costs is personal assistance and these people will need personal assistance almost all of the time if they are to have a good quality of life.
37. The cost-effectiveness of good services for adults with profound intellectual and multiple disabilities is therefore much more likely to be reflected in:
- higher quality of life
 - lower costs on families (including non-monetary costs)
 - lower needs in other areas (eg health)
 - or in the future, than in lower costs of the package of care.

On this basis all the families, and the commissioners they were working with, thought that the arrangements they had were cost-effective.

³⁵ Mother interviewed during fieldwork for this report.

³⁶ Mother interviewed during fieldwork for this report.

Victoria and Lisa share a bungalow in a residential estate in north London. The house is rented from a housing association and is a ground-floor property adapted for wheelchair use. The house and support staff arrangements were planned many years ago – long before direct payments or individual budgets – and Victoria and Lisa have lived there for nearly 20 years. The bungalow has bedrooms for Victoria and Lisa and for a member of staff to sleep-in at night and is suitably adapted.

Centre 404 provide staff support 24/7, with 1:1 or sometimes 2:1 support. Victoria does not use day services, but has support from her personal assistants to do different things during the day and in the evenings. The service is jointly funded by social services and health. Victoria and Lisa also receive Independent Living Fund monies and other benefits.

Victoria and Lisa appear in the film accompanying this report.

Extending good practice

38. Government plans to continue to extend self-directed services will provide the opportunity for more families to experience the benefits. As this happens, a number of risks or potential problems can be identified. These apply broadly to the process of personalisation but they will have an impact on adults with profound intellectual and multiple disabilities.

Ensuring effective implementation

39. Previous attempts to introduce more individualised services through the introduction of care management have had limited success as funding pressures and the culture of control have constrained choice and flexibility³⁷. There is a risk that the aspirations of personalisation will be compromised as it is implemented. For example, there is a risk that local authorities will in practice only offer self-directed support where they can make a saving in expenditure, ignoring increases in cost-effectiveness due to higher quality, lower costs on families or lower needs in other areas (eg health) or in the future. There is also a risk that what is intended to be a liberating experience of being 'in control' is overlaid with anxiety and paperwork in order to comply with rules and procedures. Personalisation is not so well understood or embedded in services that it will survive on its own. Continued leadership from government will be required to ensure that personalisation is not compromised.



³⁷ Mansell, J. and Beadle-Brown, J. (2004) Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17, 1-9.

Noaf lives at home with her parents and younger brother. She has two older sisters who visit often. She enjoys being part of busy family life and likes it best when everyone is home and around her. She loves music, being with people and likes to be taken out and about by her family and her support workers.

Noaf's support is funded by the Primary Care Trust who have assessed her as needing 100% continuing health care. The funding for her support is paid directly to the family and provides Noaf with 1:1 staff support for 10.5 hours a day for 7 days a week, 3 nights a week of waking night staff and 20 nights of respite care a year with a further 40 hours of respite to be used flexibly.

Noaf's mother had to work hard to get this package in place after Noaf left school but now she has as a very reliable team, some of whom have been in place for 5 years. Noaf's team are able to meet all of her communication and complex health needs, as well as enabling Noaf to go out and about and visit places like shopping centres and museums. The package has enabled Noaf to have good support whilst still enjoying family life. It has also enabled her mother to feel so confident about her support, that this year she was able to travel abroad to visit her relatives, confident that all would be well with Noaf.

40. Recommendation 1. The government should continue to provide leadership to ensure that personalisation is extended to more people, including more adults with profound intellectual and multiple disabilities, in a way which secures the benefits of improved quality of life and increased cost-effectiveness.

Supporting families

41. Not every family supporting someone with profound intellectual and multiple disabilities will want or be able to take on the task of arguing for, leading and providing self-directed services. Generally, families did not look first to statutory agencies for help or advice nor did they think that families in future would be best served by doing so. They identified user-led organisations like centres for independent living or self-help groups of other families with experience of using self-directed services as likely to be the most useful sources of support. Stimulating the creation of these kind of resources may therefore be an important part of extending good practice.

42. Recommendation 2. Commissioners of health and social care services should identify mechanisms for supporting and enabling families to get advice and help in securing and running self-directed services from user-led organisations or self-help groups of other families.

Advocacy

43. A related point is that not everyone will have a family able to engage in shaping self-directed services and as parents age, they may want to play a less prominent role if they can be sure that their son's or daughter's quality of life will be protected. For these people in particular, it will be important to ensure access to independent advocacy. Since the publication of *Valuing People*, there has been a focus on developing the body of self-advocates with a learning disability operating at local and national levels. People with profound intellectual and multiple disabilities have largely been excluded from this. There needs to be a focus on ensuring these groups are meaningfully representing people with profound intellectual and multiple disabilities. There seem to be few advocacy schemes which can support people with profound intellectual and multiple disabilities and yet this group of people are probably most in need of independent advocacy. There needs to be investment in advocates trained in non-instructed advocacy techniques (ie based on a wide range of communication methods and consideration of the person's 'best interests').

44. Recommendation 3. Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of adults with profound intellectual and multiple disabilities. They should include funding for continued advocacy in the package of self-directed services for adults with profound intellectual and multiple disabilities.

Predicting need for support

45. Despite very substantial attention over many years, it is clear that transition from children's to adult services is still typically a very difficult and poor experience for people with learning disabilities who have complex needs and their families. Preparation is not started early enough and needed services are not developed, so that at the point of transfer there is a marked reduction in the amount of service (eg speech and language therapy, short break provision) and provision of second-best solutions (eg nursing home placement).

46. Recommendation 4. The government should continue to lead the development of more effective transition arrangements for people with learning disabilities, including those with profound intellectual and multiple disabilities, so that there is proper planning and timely provision of appropriate services as people move into adulthood.

47. Lack of preparation for people known to have been disabled since birth is coupled with poorly developed registers, so that few authorities seem to have information about the number of adults with profound intellectual and multiple disabilities and their needs and circumstances available for planning purposes (for example, in the Joint Strategic Needs Assessment³⁸). It will of course be important that this information includes people from minority ethnic communities and other groups likely to be socially excluded. In order to realise the benefits of personalisation, it will be essential that local authorities, health bodies, service providers, professionals and families can plan ahead on the basis of accurate information.

48. Recommendation 5. Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in future to enable effective planning of services.

Recruiting and training personal assistants

49. It is not clear whether sufficient staff with the right motivation, values, attitudes and skills will be available as self-directed services become more widespread. Changes to further education funding mean that local authorities will in future have wider responsibilities for developing and training the social care workforce in their area. They will need to project demand for personal assistants and to reflect the needs of adults with profound intellectual and multiple disabilities in their work.

50. Providing personal assistance to adults with profound intellectual and multiple disabilities is not an unskilled job. It will be important that new arrangements for training, including funding but also the introduction of new kinds of qualification and the delivery of induction and in-service training reflect the needs of adults with profound intellectual and multiple disabilities more fully than has been the case in the past. A critical requirement is that training should involve families and people with profound intellectual and multiple disabilities in the delivery of training. The content of training should strongly reflect person-centred approaches to communication and support, and should be based on individualised approaches that meet the needs of adults with profound intellectual and multiple disabilities and their families.

51. Recommendation 6. In fulfilling their responsibilities for developing and training the social care workforce, local authorities should ensure that sufficient numbers of personal assistants are available, trained in person-centred approaches to communication and support that meet the needs of adults with profound intellectual

³⁸ Department of Health (2007) Joint Strategic Needs Assessment. London: Department of Health.

and multiple disabilities, through training that involves families and adults with profound intellectual and multiple disabilities in its delivery.

Using assistive technology

52. Research suggests that people with profound intellectual and multiple disabilities can learn to use microswitches to indicate a preference or control an event^{39/40}. Such microswitches may need to be adapted so that they are operated in different ways, depending on the physical impairments of the disabled person. In order for the person to learn the connection between their movement and the effect, it is important that the effect is consistent. If, for example, a person learns to press a switch which says "Come and talk to me" but the people around them often ignore their request, then they are unlikely to learn the connection between using the switch and contact from others; if they have learned it in the past, they will stop using the switch if it becomes ineffective.
53. Similarly, electric wheelchairs have been adapted to follow a track and their controls replaced by motion sensors or other microswitches tailored to the disabled person's skills. This provides a means by which people with profound intellectual and multiple disabilities can move around their environment^{41/42}. The intelligence built-in to the wheelchair makes it safe to use in spite of the person's disability.
54. Such technological aids offer the prospect of enabling people to communicate with others and to control aspects of their environment such as where they are. For people often dismissed as unable to communicate the possible impact on the attitudes of others is at least as important as the direct effect on the person's quality of life.
55. These technological developments, are beginning to make an impact in schools and colleges and so some people with profound intellectual and multiple disabilities will have had experience of them. They appear, however, to be almost unknown in services for adults with profound intellectual and multiple disabilities.

"No, she's never had it and it is something we have always wanted"⁴³

³⁹ Lancioni, G.E., O'Reilly, M.F. and Basili, G. 2001 An overview of technological resources used in rehabilitation research with people with severe/profound and multiple disabilities. *Disability and Rehabilitation*, 23(12): 501-508.

⁴⁰ Lancioni, GE, O'Reilly, MF, Singh, NN, Sigafoos, J., Oliva, D., Antonucci, M., Tota, A, Basili, G. (2008) Microswitch-based programs for persons with multiple disabilities: An overview of some recent developments *Perceptual and Motor Skills*, 106 (2): 355-370.

⁴¹ Nilsson, L. and Eklund, M. (2006) Driving to learn: Powered wheelchair training for those with cognitive disabilities. *International Journal of Therapy and Rehabilitation*, 13(11), 517-527.

⁴² Odor, P. and Watson, M. (1994) *Learning through Smart Wheelchairs: A formative evaluation of the effective use of the CALL Centre's Smart Wheelchairs as part of children's emerging mobility, communication, education, and personal development*. Edinburgh: CALL Centre, University of Edinburgh.

⁴³ Mother interviewed during fieldwork for this report.

3. Specific obstacles to improvement



Introduction

56. In the previous chapter a number of risks and challenges to the continued development of person-centred services were identified. These apply broadly to the process of personalisation. In the course of reviewing good practice, a number of more specific obstacles to improvement have become apparent. These obstacles particularly affect people with profound intellectual and multiple disabilities. This section addresses each of these in turn.

Housing

57. There are three main ways in which housing is provided for people with learning disabilities, and each includes disincentives to make provision of suitably adapted housing for adults with profound intellectual and multiple disabilities.

58. The first route to housing for adults with profound intellectual and multiple disabilities is through rented housing provided by Housing Associations or Registered Social Landlords using public capital subsidy. The public capital subsidy is paid through the Homes and Communities Agency (HCA). The HCA apply value for money considerations which can crudely be interpreted as 'less grant means better value for money'. Adults with profound intellectual and multiple disabilities need accommodation which costs a great deal more than a flat/house for a non-disabled tenant (extra space, equipment, insulation, communal facilities in addition to private ones etc). Funding this additional cost is the major barrier. The HCA are reluctant to fund because they get fewer housing units for their capital investment. Local Authorities or Primary Care Trusts have very little money available to offer as capital subsidy, and as Registered Social Landlord rent levels are restricted by statute, it is not possible to borrow more money as a rent high enough to service debt cannot be charged. The management costs of housing must also be met from rental income. These too are much higher for adults with profound intellectual and multiple disabilities (maintenance costs are higher, accessibility and communication requirements demand a much higher staff ratio).

59. So not only are capital costs much higher, rental income available to service a mortgage is much lower. A solution would be for the HCA to recognise the need for 'reasonable adjustment' to the capital grant rate and unit cost so that a programme of new housing for adults with profound intellectual and multiple disabilities could be introduced.

60. Shared ownership is the second route and has become a realistic option for people with learning disabilities. This can be made to work with either HCA grant subsidy or with investment from the family or another source. The shared owner is eligible for Income Support on a mortgage and housing benefit on the rental element (usually paid to a housing association). The barrier for adults with profound intellectual and multiple disabilities is again cost. As with rented housing the cost of the house will be more than for a non-disabled resident. Although the individual can get a mortgage of, for example, £200,000 the barrier is that the value of the house will not be sufficient security for the lender. For example, if the house were bought for £200,000, with £100,000 spent on adaptations and special design requirements it will have cost £300,000 in total. However it may only still be worth £250,000, so a lender will not lend enough to cover the cost.
61. The solution is for capital grant to meet the elements of extra cost which do not increase property value. Once again the HCA could offer this solution by making these costs eligible for capital grant. The extra costs which do add to the value of property can be borrowed.
62. The disadvantage of HCA capital grant subsidy is the time it takes to plan and deliver homes and the limited amount of funding available. This is why the third route to housing through rental from organisations which are not Registered Social Landlords should not be overlooked. Charities or voluntary organisations, for example, which cannot attract capital subsidy from the HCA are able to charge higher rents because their rent levels are not controlled by statute in the same way as Registered Social Landlord's rents are. They are therefore able to borrow more money through private financing and recover the costs through higher rents. This allows these agencies to be more flexible in their approach to providing and financing more specialist accommodation for people with profound intellectual and multiple disabilities.
63. The major obstacle currently to making this route work to its full potential is the effect the 'Turnbull judgement' has had on agencies which are not Registered Social Landlords, such as charitable organisations charging higher rents under the 'exempt accommodation' rules where the housing provider does not itself provide the care support required. The Turnbull judgement has meant that those housing providers who follow

Government policy guidelines on individualised services and therefore allow their tenants to commission their own support services independently, are now faced with challenges by housing benefit departments over the higher rent levels they charge. This has created an uncertainty that discourages investment in this provision.

64. Resolving this problem is in the Delivery Plan for *Valuing People Now*⁴⁴. Clearly, to ensure that the investment is retained for public benefit and not distributed as profit, housing benefit payments for excluded and exempt accommodation would need to be restricted to Registered Social Landlords and registered charities. The Department of Work and Pensions should fully compensate local authorities who fund these schemes through the targeted use of higher housing benefit. The present subsidy regime does not always recognise this.
65. In the case of accommodation for adults with profound intellectual and multiple disabilities an additional problem is that even if the higher costs of housing can be borrowed, a private lender will not lend if the extra costs do not add value (ie they need security for their lending). So once again part of the solution appears to be capital grant subsidy. The rules about the HCA target rent regime would need amending to allow Registered Social Landlords to receive smaller amounts of public subsidy but still charge higher than target rents in these circumstances.
66. These obstacles to the implementation of *Valuing People Now* also apply to other people with complex needs, such as individual whose behaviour presents a challenge. They cannot be overcome within the health and social care system. They require interdepartmental action by government to coordinate housing with health and social care policy.
67. Recommendation 7. The government should revise arrangements for capital subsidy from the Homes and Communities Agency to remove the disincentive to provide adequate housing for adults with profound intellectual and multiple disabilities.
68. Recommendation 8. The government should resolve the apparent contradiction between social care policy and housing policy created by the Turnbull judgement to facilitate the provision of adequate housing for adults with profound intellectual and multiple disabilities.

⁴⁴ Department of Health. (2009) *Valuing People Now: The Delivery Plan*. 'Making it happen for everyone'. London: Department of Health.

Access to community facilities

69. Making the built environment accessible for people using wheelchairs will benefit many adults with profound intellectual and multiple disabilities. However there are two areas in which specific obstacles need to be overcome.
70. The *Changing Places Consortium* campaigns on behalf of those people who cannot use standard accessible toilets. This includes people with profound and multiple learning disabilities and their carers, as well as many other disabled people. The campaign is for Changing Places toilets with enough space and the right equipment, including a height adjustable changing bench and a hoist. Over 100 Changing Places toilets have been provided in the UK by public and private sector organisations but this level of provision still falls far short of what is needed. A first step would be for the government to amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet.
71. Recommendation 9. The government should amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet.
72. The second specific area is the provision of swimming pools. Swimming or hydrotherapy is important to many people with major physical disabilities both for physiotherapy and for enjoyment. For such facilities to be accessible for adults with profound intellectual and multiple disabilities, they need level access, automatic doors, sufficient changing and toilet facilities, hoists and pool ramps and the ability to increase water temperature in a pool and air temperature in pool and changing areas to be comfortable. Examples of this kind of good practice exist (for example, provided by Liverpool City Council) but issues of access for adults with profound intellectual and multiple disabilities do not appear to be widely understood or considered. The Local Government Association should be invited to identify and disseminate good practice as part of helping its members respond to their responsibilities for 'place-shaping'⁴⁵.
73. Recommendation 10. The government should invite the Local Government Association to identify and disseminate good practice in the provision of access for adults with profound intellectual and multiple disabilities to public swimming pools, as part of helping its members respond to their responsibilities for 'place-shaping'.

⁴⁵ Lyons, M. (2007) *Place-shaping: a shared ambition for the future of local government*. London: The Stationery Office.

Health

74. People with profound intellectual and multiple disabilities have substantial, sustained, complicated health care needs. All the problems identified recently in the health care of people with learning disabilities^{46/47/48} apply to adults with profound intellectual and multiple disabilities. In addition, people with profound intellectual and multiple disabilities face several specific problems where services for adults are often not sufficiently well-developed to recognise and intervene effectively:

(i) Postural care: failure to protect body shape, damaging movement, breathing and eating

(ii) Dysphagia: problems swallowing, damaging nutrition, breathing and resistance to infection

(iii) Epilepsy: poorly controlled seizures, preventing activity and engagement

These problems can lead to discomfort, pain and premature death. A fourth area identified by families and professionals is the detection of pain and distress, the provision of effective pain relief and treatment for the underlying cause.

75. The *Michael Report* and the Local Government, Parliamentary and Health Service Ombudsmen made specific recommendations to address the problems identified in recent inquiries, which were accepted by government and are now the subject of action by the National Health Service.

76. Recommendation 11. NHS bodies should pay particular attention to meeting the needs of adults with profound intellectual and multiple disabilities in implementing the government's response to the *Michael Report* and the report of the Local Government, Parliamentary and Health Service Ombudsmen.

77. Recommendation 12. NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities in each area which focus on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress.

78. Recommendation 13. The Board of each NHS Trust should consider a report specifically focused on the adequacy of health services for adults with profound intellectual and multiple disabilities and approve an action plan to ensure adequate treatment.

⁴⁶ Mencap (2007) *Death by indifference: following up the Treat me right! report*. London: Mencap.

⁴⁷ Michael (2008) *op cit*.

⁴⁸ Local Government Ombudsman and Parliamentary and Health Service Ombudsman. (2009) *Six lives: the provision of public services to people with learning disabilities. Part one: overview and summary investigation reports. Parts two to seven: individual cases*. London: The Stationery Office.

Wheelchairs

79. At present, wheelchair services are often a major source of difficulty for adults with profound intellectual and multiple disabilities. Individuals often have to wait months or years for wheelchairs; the chairs provided are often not suitable for the postural care or use of the individual; their repair is often difficult to arrange. These are problems experienced by other wheelchair users too. The gap between the performance of the NHS wheelchair service and the potential contribution that good wheelchairs make to the quality of life of disabled people has been recognised by government for some time⁴⁹ and proposals for reform are still being developed⁵⁰. Alternative service delivery arrangements which provide more useful wheelchairs more quickly, apparently at no greater overall cost, have already been developed in children's services⁵¹.
80. Reform of the wheelchair service remains a pressing priority to which the government should attend urgently. In doing so, it is particularly important to adults with profound intellectual and multiple disabilities that powered wheelchairs be provided where carers need them or where they would sustain or enhance the quality of life of the disabled person (such as through the provision of a 'smart' wheelchair). At present some wheelchair services operate a blanket policy of not providing powered wheelchairs in these circumstances.
81. Recommendation 14. The Department of Health should reform the wheelchair service to address the problems identified in 2006.
82. Recommendation 15. Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person.
83. Recommendation 16. People with profound intellectual and multiple disabilities who have used powered wheelchairs (eg 'smart' wheelchairs) at home or at school during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life
84. Recommendation 17. Other people with profound intellectual and multiple disabilities should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where this sustains or enhances their quality of life.

⁴⁹ Care Services Improvement Partnership (2006) *Out and about: Wheelchairs as part of a whole-systems approach to independence*. London: Department of Health.

⁵⁰ Ivan Lewis MP, HC Deb, 22 October 2009, c1659W.

⁵¹ Whizz-Kidz and Accenture (2009) *Defining a high-quality service – what does 'good' look like for a wheelchair service?* London: Whizz-Kidz.

Communication aids and assistive technology

85. The great potential represented by research on use of microswitches is beginning to be reflected in practice in schools and further education. For adults, the obstacles to their wider use are that knowledge about the possibilities is scarce in adult services, that no-one is responsible for their provision and maintenance, and that staff may not be aware of the importance of responding consistently to them to sustain the person's motivation to use them. As with wheelchairs, some people find that the equipment they used at school is not transferred to, or otherwise available from, adult services.
86. These are largely unrecognised needs and therefore no agency sees itself as responsible for meeting them. This is not, therefore, a problem of coordination which can be resolved through the mechanism of individual budgets. It requires decision by government.
87. Recommendation 18. The government should decide whether funding the provision and repair of communication aids for adults with profound intellectual and multiple disabilities is the responsibility of the National Health Service or of Local Authority social care services.
88. In order to increase knowledge and expertise about what is possible, government should review and disseminate the available evidence, stimulate innovation and support the development of an infrastructure to advise and help families and service providers. Just providing equipment will not be enough. All of this work will need to focus both on the technology available and on the involvement of staff – both professional staff like Speech and Language Therapists and personal assistants – to ensure that the technology is used well in practice.
89. Recommendation 19. The Department of Health should commission the Social Care Institute of Excellence and/or the National Institute for Health and Clinical Excellence to review and disseminate the available research and practice on the use of communication aids and assistive technology for adults with profound intellectual and multiple disabilities.
90. Recommendation 20. The Department of Health should fund research and demonstration projects in each region (perhaps through the Health Technology Assessment programme of the

National Institute of Health Research) to identify opportunities for increasing the quality of life of adults with profound intellectual and multiple disabilities through the use of communication aids and assistive technology.

91. Recommendation 21. The Department of Health should commission organisations, such as Communication Matters⁵² and HFT⁵³, which have expertise in this area, to advise families and agencies about new opportunities presented by these communication and control aids; to offer opportunities for people to try out different equipment; and to train staff.

Further education

92. Since people with learning disabilities have difficulty learning, further education is potentially a very important opportunity for people to continue to grow and develop. Only 14% of people with profound intellectual and multiple disabilities were in further education in 2003/4⁵⁴. Since then, there has been a marked reduction in further education provision for people with learning disabilities^{55/56}. People with profound intellectual and multiple disabilities may have been particularly affected by a shift in priorities towards award-bearing courses and by a view that some provision is just day care rather than education.

93. The goal should be that everyone with profound intellectual and multiple disabilities has access to further education which helps them grow and develop in independence. New arrangements for funding further education are being implemented by the government. In order to ensure fair access to further education for people with profound intellectual and multiple disabilities, the government should restate its policy and ask the relevant bodies to monitor their progress.

94. Recommendation 22. The government should state as policy the goal that everyone with profound intellectual and multiple disabilities should have access to further education, in order to help funding bodies develop appropriate objectives and plans.

95. Recommendation 23. The government should ask the Young People's Learning Agency and the Skills Funding Agency to monitor the volume and quality of provision they fund for people with learning disabilities, distinguishing people with profound intellectual and multiple disabilities within that population.

⁵² <http://www.communicationmatters.org.uk>

⁵³ <http://www.hft.org.uk>

⁵⁴ Emerson, E. and Hatton, C. (2008) *People with learning disabilities in England*. Lancaster: Centre for Disability Research.

⁵⁵ Learning and Skill Council (2007) *Impact on Adults with Learning Difficulties and/or Disabilities: Issues from the 2006/07 Planning Round*. London: Learning and Skill Council.

⁵⁶ Learning and Skill Council (2010) *Impact of Changes in Provision on People with Learning Difficulties and/or Disabilities Post-19: Final Report*. London: Learning and Skill Council.

96. Some of the best practice in further education provision for adults with profound intellectual and multiple disabilities exists in specialist colleges. These have the disadvantage that people living far away have to board and thereby risk weakening their family and community links. The example of Orchard Hill College in London, a non-residential specialist college with units spread through local communities, offers a better model for future development.
97. Recommendation 24. The Young People's Learning Agency and the Skills Funding Agency should create incentives for specialist colleges to partner with local non-specialist further education colleges to increase the quality and amount of local provision for adults with profound intellectual and multiple disabilities.

Employment and day activity

98. A major aim of current policy is to increase the number of people with learning disabilities, including people with complex needs, in employment⁵⁷. Employment is seen as critical because it addresses so many issues relevant to personal development – money versus poverty, social contact instead of isolation, goals instead of purposelessness. Examples of adults with profound intellectual and multiple disabilities in any kind of employment are rare⁵⁸. Many families and professionals are sceptical of the possibilities of employment for adults with profound intellectual and multiple disabilities. *Valuing People Now* recognises this

“it has to be recognised that for some people with highly complex needs, such as those with profound and multiple learning disabilities or who are medically dependent, paid employment poses particular challenges, although it remains an aspiration.”⁵⁹

99. Employment is therefore likely to be only one of a range of activities and opportunities that adults with profound intellectual and multiple disabilities experience. Its value to them will be the benefits they experience from the activity and the attitudes of and interactions with those around them. The goal is that people should have the opportunity to take part in meaningful activities outside the home, including work, education and leisure.
100. Many adults with profound intellectual and multiple disabilities like to take part in everyday activities in the community and there is evidence of the imaginative use of personal assistants and

⁵⁷ Department of Health. (2009) *Valuing Employment Now: real jobs for people with learning disabilities*. London: Department of Health.

⁵⁸ Commission for Social Care Inspection, Mental Health Act Commission and Healthcare Commission. (2009) *Commissioning services and support for people with learning disabilities and complex needs: National report of joint review*. London: Commission for Social Care Inspection, Mental Health Act Commission, Healthcare Commission.

⁵⁹ Department of Health. (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities. 'Making it happen for everyone'*. London: Department of Health, paragraph 1.5.

individual budgets to enable this^{60/61}. The implementation of the 'personalisation agenda' and initiatives like *Sport for All* and *Valuing Employment Now* will increase the range of these opportunities. It is important that in developing opportunities as part of their 'place-shaping' role⁶², local authorities ensure that people with profound intellectual and multiple disabilities are included.

101. Recommendation 25. Local authorities should ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities.

102. However these opportunities are likely to be sessional, and the nature of profound intellectual and multiple disabilities are such that often people will need to rest between them, or will not be well enough to participate. For people living in supported accommodation it may be appropriate to use their home as the base from which to operate but for people living with their families this may not be appropriate or possible. As day centres are replaced with community-based activities, families supporting adults with profound intellectual and multiple disabilities are often extremely anxious about the adequacy of alternatives.

103. It is therefore important that, as traditional day centres are replaced with a wider variety of alternatives, provision is made for a local base from which people can access different activities. Models of such centres are already available (eg in South Lanarkshire⁶³).

104. Recommendation 26. Local authorities should ensure that they continue to provide somewhere which can be used as a base from which adults with profound intellectual and multiple disabilities can go to different activities during the day. This does not have to be restricted to people with profound intellectual and multiple disabilities – a place used by a wider range of people might be more interesting and provide more opportunities for social interaction.

Short breaks

105. The provision of short breaks for families supporting adults with profound intellectual and multiple disabilities at home is an essential service. A wide range of different approaches to short breaks is needed, not all of which need involve accommodation.

⁶⁰ Swift, P. and Mattingly, M. (2009) *A life in the community: an action research project promoting citizenship for people with high support needs*. London: Foundation for People with Learning Disabilities.

⁶¹ Wightman, C. (2009) *Connecting People: the steps to making it happen*. London: Foundation for People with Learning Disabilities.

⁶² Lyons, M. (2007) op cit.

⁶³ www.southlanarkshire.gov.uk

The local authority and NHS in each area should ensure that they have the staff with sufficient skills, expertise, equipment and facilities to meet the needs of adults with profound intellectual and multiple disabilities. Given evidence that short breaks are still not being given sufficient priority, despite extra funding⁶⁴, Learning Disability Partnership Boards should specifically assess and report on the adequacy of short break provision for adults with profound intellectual and multiple disabilities in their annual reports. The Care Quality Commission should address the adequacy of short break provision in its annual review of commissioning of local health and social care services.

106. Recommendation 27. Commissioners of health and social care services in every area should commission a range of short break services that provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with profound intellectual and multiple disabilities. No family supporting an adult with profound intellectual and multiple disabilities at home should be denied regular short breaks.

Training

107. The importance of training was identified in the previous chapter. A specific problem now is that families are sometimes excluded from the training opportunities provided by statutory or non-statutory agencies for their own staff, being required to pay for their own training. Individual budgets may not include sufficient provision for training. This is likely to be a short-sighted approach on the part of public authorities, since supporting families to care for their disabled relative at home is much less costly to health and social care budgets than providing such care directly.

108. Recommendation 28. Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with profound intellectual and multiple disabilities. Individual budgets should include provision for training of personal assistants.

Clinical procedures

109. Some agencies unilaterally determine policies which prevent their own staff undertaking clinical procedures (for example, learning to administer rectal diazepam in the treatment of epilepsy), or prevent others from being trained to undertake them. By failing to coordinate with other agencies to ensure a consistent approach, and by failing to attend to the needs of the people

⁶⁴ Princess Royal Trust for Carers and Crossroads Care (2009) *No breaks for carers: A report on Primary Care Trusts and the Carers Strategy*. London: Princess Royal Trust for Carers and Crossroads Care.

they serve, these agencies effectively deny services to people who need and want to use them. In some cases, family members are obliged to visit services to carry out these procedures.

“The team was part of social services, they could only do things that were social. They couldn’t give any medication, they couldn’t give a tube feed or suction or oxygen and all along I was saying could we not have someone from health [as well]... it was just like I was banging my head against a brick wall”⁶⁵

110. The problems include a lack of agreed guidelines, policies and procedures, the fear of litigation, the extent of insurance cover for clinical tasks and a lack of clarity about training and support for short break carers and staff. The solution to these problems is that within each area, health and social care commissioners and service providers, working with families supporting adults with profound intellectual and multiple disabilities under the auspices of the Learning Disability Partnership Board, should define comprehensive guidance to ensure that people receive the support they need, when and where they need it, in order to maintain their health and quality of life.
111. Substantial progress has already been made to deal with this issue in children’s services. The House of Commons Select Committee on Health Services for Children in the Community concluded in 1997 that it was unacceptable for health professionals to refuse to train non-parent carers for fear of litigation and that it should be made clear that the training of parents and non-parent carers by health care professionals is an important part of the work of the NHS⁶⁶. Policy Guidelines were subsequently developed for joint work between agencies and professions^{67/68/69}, and endorsed by the government⁷⁰. A national training programme under the auspices of the National Children’s Bureau followed.
112. What is required in adult services is a similar initiative, led by the Department of Health and involving all the relevant parties, and implemented within each area by health and social care commissioners and service providers, working with families supporting adults with profound intellectual and multiple disabilities under the auspices of the Learning Disability Partnership Board.

⁶⁵ Mother interviewed during fieldwork for this report.

⁶⁶ House of Commons Select Committee on Health (1997) *Health Services for Children and Young People in the Community*. Third Report, 1996-97. London: Her Majesty’s Stationery Office.

⁶⁷ Shared Care Network. November (1998) *Towards a healthy future: multi-agency working in the management of invasive and lifesaving procedures for children in family-based services*. Abingdon: Marston Book Services.

⁶⁸ Rhodes A (1999) *Promoting partnerships: supporting disabled children who need invasive clinical procedures*. Ilford. Barnardo’s.

⁶⁹ Council for Disabled Children, Shared Care Network and National Children’s Bureau (2004) *The Dignity of Risk*. London: National Children’s Bureau, Council for Disabled Children and Shared Care Network.

⁷⁰ Department of Health, Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services*. London: Department of Health.

113. Recommendation 29. The Department of Health should lead an initiative to adapt policies and procedures used in children's services for use in services for adults, involving representative bodies of the relevant professions and agencies.

114. Recommendation 30. Local policies should be based on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps.

115. Recommendation 31. Local policies should focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people's own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.

Funding

116. There is sufficient anecdotal evidence to suggest that the option of classifying all the support needed by a person as 'NHS continuing health care', and therefore to be funded by the National Health Service, is creating three obstacles to providing acceptable services in some areas:

- Where all the funding comes from the National Health Service, the local authority may fail to provide comprehensive, local authority-led assessments under section 47(1) of the NHS and Community Care Act (1990), as they have a duty to do⁷¹.
- Primary Care Trusts, with less experience of personalisation, may attempt to contract for nursing home places for adults with profound intellectual and multiple disabilities, instead of developing personalised services.
- Where all funding is defined as continuing health care there is a loss to the individual – and the local health and social care system – of Disabled Living Allowance and Independent Living Fund resources.

⁷¹ Behan D (2006) Follow up to Cornwall Partnership NHS Trust investigation report. Dear colleague letter reference 7308. London: Department of Health.

117. These problems reflect the difficulty that when resources are separated in different agencies, perverse incentives are created to seek savings by transferring costs elsewhere, and significant resources are spent in assessing and reassessing eligibility. They would be somewhat mitigated if the proposed *Right to control* was implemented and included continuing health care funding (which is not currently proposed)⁷².
118. Proposing a resolution to this fundamental problem is beyond the remit of this report. However, in the meantime, it is essential that local authorities and health bodies should work closely together.
119. Recommendation 32. For adults with profound intellectual and multiple disabilities, both health and social care services should always work in close partnership both in planning and commissioning services and in providing them. Local authorities should continue to play an active part as the lead agency for learning disability services in all service development and should continue to lead individual assessment and planning, even where continuing health care funding is provided.
120. Recommendation 33. However funded, services for adults with profound intellectual and multiple disabilities should be developed in line with the government's personalisation agenda. They should be designed around the individual and person-centred, they should treat the family as expert, they should focus on the quality of staff relationships with the disabled person as the key to service quality and they should sustain the package of care.

⁷² Office for Disability Issues (2009) *Making choice and control a reality for disabled people: government response to the consultation on the Right to Control*. London: Office for Disability Issues.

4. Resources, timetable and monitoring

121. In a population of 52 million people in England⁷³, there are approximately 16,000 adults with profound intellectual and multiple disabilities, needing very high levels of support throughout their lives. It is a commonplace observation that the mark of a civilised society is how it treats its least fortunate members. The quality of life of people with profound intellectual and multiple disabilities is part of that measure.
122. No amount of investment is going to radically change the need for support for this group of people. Greater efficiency elsewhere in health and social care may free up resources which can be spent on them but they are not going to be the source of savings. Their services are relatively expensive because their needs are high. Greater cost-effectiveness will come from getting the most out of those resources in terms of the quality of life experienced by them and their families, and through the reduction of harm and ill-health to them and their carers.
123. Most of the work required to tackle the obstacles identified in the previous chapter does not require large amounts of extra resources. It requires reasonable adjustment to policies, procedures, rules and priorities to ensure that adults with profound intellectual and multiple disabilities get the support they need. In general, adults with profound intellectual and multiple disabilities require such substantial amounts of support from staff that person-centred services are not likely to be significantly more expensive than the old congregate models of care.
124. Where extra resources are required (as for example in the application of technology to empower and enable people) these will be difficult to find during the current world economic crisis. Hard times should, however, dictate the pace at which we can achieve our objectives, not the nature of the objectives themselves. In the words of the United Nations Convention⁷⁴ our obligation is to work towards “achieving progressively the full realization” of the rights of this group of disabled people.
125. Government has taken steps in recent years to move away from a centrally-directed performance management framework for the National Health Service and local authorities, in favour of more local priority-setting and decision-making^{75/76}. In this context the role of Learning Disability Partnership Boards and of voluntary organisations like the PMLD Network will be very important in continuing to scrutinise services and give a voice to people with profound intellectual and multiple disabilities and their families.

⁷³ Office of National Statistics (2009) *Mid-2008 Population Estimates: England; estimated resident population*.

⁷⁴ United Nations. (2006) *Convention on the rights of persons with disabilities*. New York: United Nations, Article 4 paragraph 2.

⁷⁵ Department of Health (2008) *High Quality Care For All: NHS Next Stage Review Final Report*. Cm 7432. London: Her Majesty's Stationery Office.

⁷⁶ Department for Communities and Local Government (2006) *Strong and prosperous communities*. Cm 6939. London: Her Majesty's Stationery Office.

126. Organisations and services are, however, likely to continue to be sensitive to the views of government and of regulatory bodies such as the Audit Commission, the Care Quality Commission and the Health and Safety Executive. It is important that these bodies take account of the likely effect of demands they make on statutory and non-statutory agencies on the quality of life of adults with profound intellectual and multiple disabilities.

Conclusion

127. Adults with profound intellectual and multiple disabilities are a relatively small, easily identified group of people with undeniable needs for care and support. Despite these needs, they and their families have often not been provided with services to adequately meet them.
128. The 'personalisation agenda' expressed in government policy does appear to provide a better quality of life for adults with profound intellectual and multiple disabilities and their families. Continued progress in widening access to these kinds of services will enable more people to benefit.
129. There are a number of obstacles to wider implementation to which government and other agencies should attend.
130. Shortage of resources may influence the speed with which the recommendations of this report can be implemented but should not change the direction of policy and practice.
131. Learning Disability Partnership Boards and voluntary bodies will have an even more important role in future in scrutinising services and giving voice to people with profound intellectual and multiple disabilities and their families. Government and regulatory bodies should take account of the likely effect of their work on the quality of life of adults with profound intellectual and multiple disabilities.

Appendices

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