



Learning Disability  
Implementation  
Advisory Group

# **POLICY AND PRACTICE FOR ADULTS WITH A LEARNING DISABILITY**

## **PROPOSED ACTION PLAN**

**Consultation Document**  
prepared by the  
**Learning Disability Implementation Advisory Group**

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## INTRODUCTION

The purpose of this *Action Plan* is to identify the key priorities that need to be addressed across Wales to deliver appropriate and responsive advice, treatment and support to adults with learning disabilities, in order to fulfil the Welsh Assembly Government's vision for all people with a learning disability, as full, equal and equally valued citizens of Wales. The recently issued *Statement on Policy and Practice for Adults with a Learning Disability* sets out policy principles and a practice framework directed towards helping individuals to:

- live healthy, productive and independent lives
- be individuals and decide everyday issues and life-defining matters for themselves joining in all decision-making which affects their lives
- live their lives within their communities, maintaining the social and family ties and connections which are important to them, and
- have the support of the communities of which they are a part and access to general and specialist services that are responsive to their individual needs, circumstances and preferences.

This *Action Plan* sets out a range of recommended actions for the next five years, at which point progress will be reviewed and further recommendations considered.

The *Statement on Policy and Practice for Adults with a Learning Disability* updates and consolidates what has been a consistent individually-oriented, values led approach to the local delivery of needed support to people with learning disabilities in Wales for over 20 years. Considerable investment to improve and extend service support has occurred during that time. Great progress has been made. However, not all people are provided the support that they need as close to home as possible and there is undue variability in what services achieve and the opportunities for fulfilment which people with learning disabilities have.

➤ **This *Action Plan* sets out priority actions to improve local implementation of policy and the quality of local provision.**

The 10 year strategies for health and social services, *Designed for Life* and *Fulfilled Lives, Supportive Communities*, recognise that there are increased expectations for the quality, consistency and immediacy of services from service users, the general public, commissioning and regulatory bodies and from the Government itself. They also recognise that rising standards can bring new pressures. Increased life expectancy, for example, has raised support needs among various sections of the community. Clearly, neither raised expectations nor increased life-expectancy are anything other than to be welcomed. However, they set challenges which have to be addressed strategically by closer matching of resources to need and greater implementation of evidence-based, cost-effective<sup>1</sup> practice. With this in mind, the 10 year strategies set out a configuration of services reflecting four tiers of need and intervention, with the associated aims to provide world class performance, more services in or closer to people's homes, earlier intervention so as to prevent escalation to higher tiers of need and a person-centred orientation which ensures that service users are integral to service design and delivery.

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<sup>1</sup> The term 'cost-effective' is used here and subsequently in its true technical sense to refer to the outcomes or benefits of services in relation to their costs. Greater cost-effectiveness can mean increased outcome or benefit at no greater cost or no worse outcome or benefit at reduced cost.

- **In considering how to improve local implementation of policy and the quality of service provision, this *Action Plan* sets out priority actions to develop learning disability services in line with the thrust of the two 10 year strategies.**

Increased expectations about the quality of service support and longer life expectancy have been two major achievements shared by adults with learning disabilities in recent decades. Reformed housing support, coupled with greater attention to community inclusion, maintenance of social relationships, better health and a wider range of opportunities for continued learning and constructive and gainful occupation, has broadened horizons for people with learning disabilities. Increased life expectancy has contributed to a 26% reported increase in people aged 16 years and over on local authority learning disability registers in Wales between 1990 and 2005. There are increasing numbers of adults with complex needs requiring support. Meeting higher expectations for more people makes greater demands on the capacity and availability of local services. It is important that services are as cost-effective as possible and have competencies which closely match the needs of their users.

- **This *Action Plan* sets out priorities for development which will give the best quality return from the current and future resources available.**

Notwithstanding the investment and progress made in Wales, more needs to be done. The *Statement on Policy and Practice for Adults with a Learning Disability* highlights the inequality in the distribution of services across local authorities for reasons other than variation in demand. It stresses the importance of extending service availability to reduce geographic disparities. This, together with the need to respond to the demographic changes highlighted above, has implications for further strategic investment.

- **This *Action Plan* sets out priorities for new investment and the scale of new resources required to achieve new developmental milestones.**

## **INVESTING IN CONTINUOUS IMPROVEMENT**

Welsh policy is committed to the provision of community-based supports which become better and more comprehensive over time. In common with the 10-year strategies mentioned above, the *Statement on Policy and Practice for Adults with a Learning Disability* recognises that work is required to develop clear quality standards and a set of measurable outcome indicators for ongoing performance monitoring. Workforce development is another important area. Moreover, the achievement of sustained improvement in any service area requires support for innovation, joint working, good practice dissemination and co-ordination of effort. This is particularly the case if, as is the case here, the service area spans health, social services, other local government functions and the independent sector.

### Performance Monitoring and Management

The two 10 year strategies involve a strong emphasis on performance monitoring and management to ensure that service deliver the outcomes, which are wanted and expected, and that standards continuously improve. The national performance measurement framework, programmes for inspection and regulation, and the Wales Programme for Improvement will provide public assurance and will promote improvement. As part of the *Fulfilled Lives, Supportive Communities* developments, the Welsh Assembly Government will work with the WLGA, ADSS, the voluntary sector and others to develop a core of universal standards for social services. These will include

training and performance of staff and use of research evidence. Joint strategic outcomes for health and social services will also be developed as part of this work.

Citizens have the right to know how well social services are doing. Service users and carers have a right to know that their views are heard and acted on. The Welsh Assembly Government's regulation and inspection functions are already increasing the use of self-assessment and placing the experience of the service user at the centre of their work. Outcome measurement in relation to adult services needs to improve. Gaining feedback on the quality of services from service users is also fundamental. The current Learning Disability Implementation Advisory Group is producing guidance which will help authorities to assess the range and quality of their accommodation and day services and their provision for people with challenging behaviour.

In addition, the Welsh Assembly Government will start two new lines of work early in the period covered by this *Action Plan*:

- it will work with service users and carers to formulate a Health and Social Care Charter for service users with learning disabilities and their carers, setting out expected outcomes and ways by which people with learning disabilities and their families can contribute to service monitoring
- it will establish a working group to develop an outcome-oriented minimum data set and the monitoring mechanisms necessary to provide effective local management information for continuous self-assessment.

### Workforce Planning

Services are only as good as the people who work in them. More personalised and responsive health and social services require people with the right personal qualities as well as formal training and skills. A well-motivated and high quality workforce in the right numbers and with the right balance of skills is vital.

Workforce planning is becoming critical given changing demography. For example, whilst there has been some promotion of social care as a career, much of this has focussed on qualified social workers. As well as developing registration processes and the qualification requirements for the health and social care workforces, initiatives to improve the status of elements of both workforces are required. Harmonisation of conditions with other parts of the health or social care workforce, appropriate training and targeted recruitment and retention actions are specifically necessary for people working with people with a learning disability.

While workforce planning in relation to staff working in specialist learning disabilities is vital, it is important also to broaden the learning disability friendly skills of generic staff in mainstream services. How to relate to people with learning disabilities and serve them as well as other users of generic services should be explicit elements in the qualifying and post-qualifying training of other workers. This will inevitably require the involvement of people with learning disabilities.

As a priority, the Welsh Assembly Government will, therefore, invite

- the Care Council to prepare a National Workforce Action Plan for the social care workforce supporting people with learning disabilities which will set out the roles, standards, longer term skills and development needs of the care sector across adults' and children's services, and

- all public service providers to review the arrangements made for the development of disability awareness within their workforces.

### More Sophisticated Commissioning

Good commissioning by health and social services must be based on sound needs analysis and be sensitive to local needs. The total number of people with learning disabilities to be served is relatively small when compared to some other areas of provision. Small scale is further accentuated when more specific needs are identified. Commissioning must, therefore, exploit opportunities for collaboration between local authorities and health and other public services, involve genuine partnership with service users, carers and independent sector providers, and get the right balance between mainstream and specialist services. Commissioners need to take an active role individually and collectively in shaping the mixed market of private, public and voluntary care. This means working within developed partnerships with private and voluntary service providers, recognising that commissioners and providers need each other.

The development of more active regional commissioning could provide a means to address matters that are difficult for individual organisations. Use of such arrangements may facilitate proper planning for future service provision and even have an impact on the costs of provision.

Commissioning at a local or regional level is recognised as a basic area of activity that should be utilised to the full. Improving the information upon which to base commissioning is important. Better analysis of need, determining appropriate support and developing wider partnership working are all necessary components for future commissioning activity. In relation to this, the Learning Disabilities and Autism Research network has been funded through CRC Cymru to develop an aggregate National Learning Disabilities Database. Together with the continuing development and co-ordination of the electronic systems supporting the implementation of the unified assessment process across authorities, this should result in a common minimum dataset which will be available to inform collaborative strategic planning and commissioning across agencies and authorities.

The Health Act (Wales) 2006 provides the opportunity to utilise arrangements for lead commissioning, integrated service provision and pooled budgets. These have not yet been implemented across Wales to any significant effect.

It is also important for commissioning strategies to begin to take account of workforce planning strategies. For example, career paths for practitioners that allow excellent practitioners access to promotion without moving away from practice and into management are essential for promoting improved quality. Achieving this is currently very difficult given the commissioning of comparatively small volumes in any one geographical area at any one time and the cost pressures under which services operate. Different commissioning strategies could enable a more strategic approach to provision and workforce development and improve cost-effective outcomes.

### Maximising Developmental Learning

Service users and carers have a right to expect similar high quality services to be available wherever they live. An important dimension of this *Action Plan* is to seek continuous improvement in policy implementation and to eradicate unwarranted variability in the nature and quality of learning disability services across Wales.

Commissioners and provider bodies in different parts of Wales face similar challenges. However, there are no formal arrangements for those involved in planning and managing

learning disability services in different authorities to meet, share knowledge, discuss problems and responses, and learn from each other. The Welsh Assembly Government would like to see the formation of a Learning Disabilities Learning Network with representation from all local authorities, health partners, key provider bodies and service user communities, which would meet regularly and bring forward recommendations on priority issues faced by all authorities. Issues which might be addressed by such a Network are indicated in this *Action Plan*, although it is recognised that the Network partners will increasingly want to set their own agenda.

#### External Advisory Group

The Learning Disability Implementation Advisory Group was established in 2002 to advise on the implementation of the initiatives which the Welsh Assembly Government Cabinet agreed to take forward in response to the Learning Disability Advisory Group report, *Fulfilling the Promises*. It has fulfilled that function and helped the Welsh Assembly Government formulate its new *Statement on Policy and Practice for Adults with a Learning Disability* and this *Action Plan*, which accompanies the *Statement*. The Welsh Assembly Government will, therefore, appoint a new Learning Disability Policy and Practice Advisory Group with a new remit, based on advising the government on meeting the goals set out in this *Action Plan*.

#### Implementation Task Force

In view of the major commitment being made to the development of learning disability services in the next five years, the Welsh Assembly Government will appoint a small central Task Force to work with local authorities and their commissioning and provider partners and help them to respond to this *Action Plan*. Such a Task Force would provide momentum and co-ordination nationally. It will also work with the Learning Disabilities Learning Network to facilitate cross agency and cross border collaboration and learning.

#### Research

Evidence on the cost-effectiveness of different models of care, service arrangements and methods of treatment is vital to the delivery of world class services. The Welsh Assembly Government have funded the Learning Disability and Autism Research Network as part of its development of CRC Cymru. The government expects the Learning Disability and Autism Research Network to work closely with the Advisory Group, Task Force and Learning Network to address the research needs identified by commissioners, service providers and user groups.

### **IMPLEMENTATION PRIORITIES**

The *Statement on Policy and Practice for Adults with a Learning Disability* set out policy and practice in six areas. This section reviews key actions required to ensure that objectives in these six areas are met.

#### Putting People First: Person-centred Planning, Accessible Information and Advocacy

- The core aim is for adults with learning disabilities to be independent and to take informed decisions about their lives, throughout their lives, with support when wanted from other people who know them and represent their best interests.

##### i) Person-centred planning

People with a learning disability must be at the centre of any assessment and planning processes established. The guidance *Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care* should be fully implemented.

In addition, proper account should be taken in respect of the complementary guidance *Person Centred Assessments within the Statutory Assessment Processes*.

As part of the *Fulfilled Lives, Supportive Communities* review of the Unified Assessment Process, the Welsh Assembly Government is committed to build on the experience of implementing unified assessment to date. It will work to create a streamlined common assessment system that properly reflects the principles of person-centred care, is proportionate, works effectively and leads to good outcomes. The Welsh Assembly Government recognises that those involved with learning disabilities policy and practice development over many years have a long track record in promoting first individual and now person-centred planning. The Welsh Assembly Government will, therefore, involve key individuals and organisations from the learning disabilities field as partners in the review of the Unified Assessment Process.

All people with a learning disability should have a named care co-ordinator or care manager and their individual plan should be reviewed at least once a year. This should apply equally to people in specialist (i.e. NHS provided) residential services and to people who may be currently placed out-of-area<sup>2</sup>.

Planning should be comprehensive in its scope. The aim is to promote the quality of life of people with a learning disability and, therefore, aspects important to people's current and future lifestyles should be reviewed, including their health, home and neighbourhood, family and friendship networks, social lives, community activities, constructive occupation (household management, work, leisure), personal development, emotional wellbeing, financial security, safety and social status.

Diversity should be respected in a multi-cultural society. Authorities need to show sensitivity to the diversity of beliefs and practices which impact on family functioning and daily living. It is important that individual and carer perspectives are established with each person and family in turn and that cultural stereotyping is avoided.

Each plan should specify a review date and plans should be presented in such a way that outcomes can be evaluated.

#### Target

- By 2009, all adults with a learning disability will have:
  - a) a named care co-ordinator or care manager,
  - b) a person-centred plan, and
  - c) a review of the person-centred plan at least annually, which would determine the extent to which agreed outcomes are achieved.
- ii) Transition planning

Transition planning requires effective joint working arrangements. Transition planning may be required at different points in a person's life. Authorities must ensure that planning commences at an early stage prior to transition and that individuals and their carers are properly prepared.

It has been a long standing requirement that education, adult social services, Careers Wales and health partners should collaborate to develop transition plans for teenagers with learning disabilities as they approach adulthood. It is particularly important that

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<sup>2</sup> The fact that people were not receiving an external scrutiny of their care is a key theme of the Cornwall and subsequent investigations.

knowledge about individuals is effectively transferred between agencies and that all agencies commit personnel to the planning process over a sufficient timescale so as to ensure that continuing education, employment or occupational support is planned well ahead of time, is in line with individual aspirations and circumstances and is agreed by the people concerned.

Transition planning arrangements are also the concern of the National Service Framework for Children, Young People and Maternity Service in Wales. Key action 5.33 recommends that a key transition worker is appointed to all disabled young people at age 14 years who will co-ordinate the planning and delivery of services throughout and beyond transition up to the age of 25 years. The Welsh Assembly Government will allocate resources to prioritize the implementation of this recommendation.

Target:

- By 2010, all teenagers with a learning disability will have a person-centred transition plan completed no later than six months before they are due to leave school.

iii) Accessible information

Authorities should consider what information is available to people with learning disabilities and their families, through specialist and mainstream services, and with regard to the Disability Discrimination Act. Accurate, accessible and culturally appropriate information should be available and this should be produced in a range of formats and languages. Authorities face a common challenge in making information accessible and available in a variety of languages. They might ask the Learning Disabilities Learning Network to identify good practice in relation to accessible information and multi-culturalism for recommended implementation across all authorities.

iv) Advocacy

The Welsh Assembly Government is committed to fostering the availability of advocacy for people with learning disabilities, as it is for other vulnerable people. Making users central to service design and the drive to higher standards is central to the 10 year strategies for health and social services, *Designed for Life and Fulfilled Lives, Supportive Communities*. It is important that access to advocacy should be extended to people in specialist (i.e. NHS provided) residential services and to people who may be currently placed out-of-area<sup>3</sup>.

Advocacy should be of a high standard. The *Quality Standards and Code of Practice* produced by Action for Advocacy and the guidance, *Good Practice in Advocacy and Advocacy Standards*, produced by the British Institute of Learning Disabilities specify a range of criteria which should be met. Small-scale advocacy providers should consider the advantages of merging to create larger organisations which can provide a service across several authorities and can concentrate leadership and management experience and infrastructure.

The Welsh Assembly Government is aware that sustained core funding for organisations which deliver advocacy in all its forms is difficult to obtain from charitable or other independent sources and that arguments concerning protection of independence to criticise mean that funding from local authorities or health boards, while welcome in the absence of alternative support, is not ideal. It is also aware that needs for advocacy and access to it vary across different sections of the community. The Welsh Assembly Government will, therefore, consider the case for developing an Advocacy Strategy for

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<sup>3</sup> See footnote 2.

Wales. The Welsh Assembly Government will consider the possible extension and future use of the learning disability Advocacy Grant within this commitment to review advocacy needs generally.

### Community Living

- The core aim is for adults with learning disabilities to lead fulfilling, constructive and enjoyable lives at home and within the communities of which they are a part.

Local authority social services and housing departments, health partners and housing providers should develop joint strategic plans for the provision of independent and supported accommodation which reflect the demography of the locality and the needs and preferences of people with learning disabilities and their families.

The Welsh Assembly Government will establish a working group to review Welsh Office Circular 1/91 on Support and Accommodation for People with a Learning Disability with a view to issuing updated, contemporary guidance. In addition, the 'Meaningful Lives' subgroup of the Learning Disability Implementation Advisory Group are preparing guidance on best practice.

Deciding where and with whom to live are important decisions in everyone's lives. Individuals should be consulted about their housing, tenancy and support arrangements. This will include considering their feelings about other people who may be sharing their accommodation.

Friendships that people have formed should be considered when planning transitions. The development of friendships and leisure and lifelong learning opportunities should be positively pursued. Existing ties can be positively nurtured and family involvement and the employment of local staff can assist with this. Statements to encourage these aspects of life should be written into service contracts.

Unless service users choose differently, the assumption should be that providing accommodation locally within individuals' existing communities is to be preferred. Due consideration should be given to the desirability and safety of the neighbourhood and the accessibility of community activities and facilities, shops and public transport. New models of supported accommodation are broadening the provision options available. For example, there is growing experience of arranging semi-independent living, where individuals live with reduced staff support, using assistive technology and telecare, and harnessing naturally available community support for defined functions. Extending such developments is consistent with the tiered approach of the new 10 year strategies. Authorities might ask the Learning Disabilities Learning Network to review such service arrangements which maximise independence, self-determination, constructive occupation and social and community inclusion.

Research has shown that using an 'Active Support' approach<sup>4</sup> within supported accommodation results in adults with severe or profound learning disabilities being much more constructively involved in household and community activity. Such involvement is important to growing independence. Commissioning and provider bodies should work together to ensure that staff have the skills to provide Active Support and that services have the systems to monitor and maintain the quality of the support provided.

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<sup>4</sup> Jones *et al.* (1999) Opportunity and the promotion of activity among adults with severe mental retardation living in community residences: the impact of training staff in Active Support. *Journal of Intellectual Disability Research*, **43**, 164-178. Jones *et al.* (2001) Evaluation of the dissemination of Active Support training in staffed community residences. *American Journal on Mental Retardation*, **106**, 344-358.

As a matter of good practice, service providers should seek to engage people with learning disabilities in the recruitment and training of staff.

Authorities should also work with support providers to explore opportunities to develop personal and local networks which meet an individual's support needs rather than relying exclusively on formal paid support. Fostering 'Circles of Support'<sup>5</sup> is one way of mobilising personal networks to help individuals accomplish their personal goals in life.

The presence of additional or complex health needs, sometimes requiring specific treatments, should not be a reason for excluding an individual from mainstream accommodation, employment or occupation, education or leisure activities.

Additional or different support should be made available to allow the individual to remain in their home when their needs change. Moving people out of their home to receive treatment (e.g. for behavioural, psychiatric or medical reasons), should ideally be no more common than it is for the general population. Where out-of-home treatment is required, the expectation is that the individual will return to their home after a period of acute treatment. In the exceptional circumstance that this proves to be difficult or impossible to achieve, temporary residential provision and support may be appropriate. However, the aim should be for the individual to return home (or to a new chosen home in their community) at the earliest opportunity.

Where individuals have been placed, through no choice of their own, a long way from the communities in which they have their main ties, authorities should commit themselves to developing the needed local services which would give individuals the opportunity to move back to their home communities. Greater effort needs to be given to creating jointly commissioned models of residential care for people with more complex needs. The current polarisation which categorises individuals as either a health or social care responsibility is unhelpful and creates a perverse dynamic for shifting responsibility and costs of care between agencies. Further guidance in relation to a particular group of people with complex needs will be forthcoming from the Welsh Assembly Government commissioned Secure Services Review, which is due to report in 2008.

Authorities should take all possible action available to them, including the use of planning controls, to build positive community attitudes and to ensure a fully accessible built environment, with appropriately developed and implemented non-discriminatory policies. Authorities and service providers should also take every possible opportunity to present a positive image of people with a learning disability to the public, and avoid the negative stereotyped imagery so often associated with disability. Local authority social services should act as corporate champions across local government to achieve these ends for the most vulnerable and at-risk groups in their area.

The Welsh Assembly Government recognises that independent sector providers may develop healthcare facilities within Wales which are not necessarily sought locally but are a response to the lack of availability of provision for people with particular needs in other areas. A number of concerns have been highlighted in relation to this, not least that the development of large, congregate facilities is a return to the provision that the deinstitutionalisation policy was directed towards eliminating. The Welsh Assembly Government will, therefore, undertake a review of the Private and Voluntary Health Care (Wales) Regulations 2002 to address issues of size and congregation, National Minimum Standards in relation to learning disabilities and mental health services, and recent Healthcare Commission and Health Inspectorate Wales recommendations.

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<sup>5</sup> See Circles Network at [http://www.circlesnetwork.org.uk/circles\\_of\\_support.htm](http://www.circlesnetwork.org.uk/circles_of_support.htm) .

### Targets:

- By 2010, local authorities, along with relevant partners, will produce a joint commissioning strategy for the provision of independent and supported accommodation, which will ensure that:
  - a) the support provided meets identified needs, including arrangements for people with complex needs,
  - b) the accommodation will be provided locally or in a place of the individuals choosing, except for the rare occasion where a person might require highly specialised regional arrangements,
  - c) services are cost effective, and
  - d) potential to expand the availability of supported accommodation by reinvestment of cost-effectiveness savings are identified.

### Employment and Day Services

- The core aim is for adults with learning disabilities to lead lives in which personal development, work, other forms of constructive contribution to society and leisure have a balance typical of other citizens of the same age.

The Department of Education, Lifelong Learning and Skills, together with Careers Wales, should ensure that vocational training closely reflects the available jobs market and results in individuals gaining a qualification recognised by employers. There should be realistic entry criteria so that those accepted on courses have a reasonable expectation of reaching the required standards.

Assessment of whether vocational training would be a productive route for individuals to follow should be part of their transition plan or later unified assessment. Advice and counselling should be provided to all people to inform the decision-making process.

Where people do not reach training/educational entry criteria and are, therefore, uncertain to gain a recognised qualification, they may be better served by place and train approaches to gaining paid employment, i.e. supported employment. Those who gain qualifications may still need this form of support to enter employment. Authorities should assess the nature and level of support which an individual may need to gain and sustain employment. Determining the nature and level of this support should be part of their transition plan or later unified assessment.

Effective links should be developed between local employers, supported employment services, social care day services and mainstream employment services in order to ensure a co-ordinated approach.

Authorities should use their strategic planning processes to ensure that a range of employment and daytime occupation options is available in local communities which is collectively sufficient to meet need, including to people with complex or challenging needs. Options may include: competitive employment, supported employment, social firms, community enterprises, local community bases, programmes of individual community-based activity and leisure pursuits, involvement in civic works, voluntary activity and retirement schemes. Under the public sector equality duty, public bodies and those independent sector organisations in contractual arrangements with public bodies are required to remove barriers to the employment of people with disabilities within their agencies. When developing and implementing their Disability Discrimination Act Equality Action Plans, public bodies should aim to be exemplar employers.

The replacement of traditional large day centres should be made a priority within these strategic plans. Much has been done already but progress needs to be sustained so that all adults with learning disabilities are offered non-segregated opportunities for constructive occupation. Importantly, a holistic view should be taken so that local strategies to achieve day service reform go hand in hand with those to maximise employment and other forms of constructive occupation.

Authorities should be aware of the opportunities to develop employment stemming from European Union funding streams. Beyond this, the Welsh Assembly Government recognises that countries which have had a co-ordinated, national strategy for the employment of adults with learning disabilities have achieved significant increases in employment rates. The Welsh Assembly Government, therefore, proposes to develop an All-Wales Supported Employment Strategy.

Moreover, the Welsh Assembly Government undertakes to discuss with the UK government the implications for Wales of the Department of Work and Pensions plan to reform the operation of the Workstep programme so as to ensure that the new arrangements neither disadvantage the share of resources received nor the extent to which the resources can be used to support the employment of people with learning disabilities. This will be undertaken as part of the development of an All-Wales Supported Employment Strategy.

Currently, it is estimated that 12-17% of adults with learning disabilities have part- or full-time paid employment at or above the minimum wage. The ambition should be to increase the proportion to 18% by 2011 and 25% by 2014.

Voluntary placement opportunities should be provided as something positive in their own right, not just as a simpler alternative to supporting a person in paid work. People should be linked to a mainstream volunteering scheme wherever possible.

Day activities should reflect people's interests and ambitions, and link in with other leisure, social and educational activities in their lives. Co-ordination and forward planning should be achieved through transition planning or the unified assessment process.

#### Targets:

- By 2010, local authorities, along with relevant partners, will produce a commissioning strategy for the provision of employment and day occupation options, which will set local targets and identify how:
  - a) the number of adults with a learning disability in paid work will increase,
  - b) the range of constructive day occupation options can be extended, including for people with profound and multiple disabilities or with challenging behaviour, and
  - c) how reliance on traditional large day centres will reduce.

#### Health and Complex Health Needs

- The core aim is that adults with learning disabilities have the good health necessary for a fulfilling life and a normal life expectancy.

People with a learning disability should normally have their health needs met at home or in their local community. This undertaking should include those with complex physical and/or mental health needs.

In 2006, the Welsh Assembly Government introduced the entitlement to an annual health check for all adults with a learning disability on local authority registers as a LHB

directed enhanced service. It remains committed to this. Local Health Boards (LHBs) should ensure that all adults with a learning disability on local authority learning disability registers who want one should have an annual health check.

The Welsh Assembly Government proposes that the National Public Health Service for Wales will monitor the roll-out, take-up and quality of health checks. It will also ensure that suitable adaptation to computer software is made and issued to allow general practices to integrate the recording of the health check within their electronic medical recording. It will also ensure that an electronic educational package is made available to general practices to support the conduct of health checks.

It is important that public health initiatives concerned with the promotion of health and healthy lifestyles are as accessible to people with learning disabilities as anyone else and are taken up in equal numbers. This includes all health screening programmes. Public health and specialist learning disability services should work together to develop a common strategy to ensure that people with a learning disability have access to timely and up-to-date information in an accessible format so they can make informed choices about health and lifestyle issues such as diet, alcohol and cigarette consumption, level of activity or exercise, sexual practice, oral health and dental care, and substance misuse. In addition, there should be effective supports tailored to their needs to help them change health related behaviours. Obesity and lack of exercise are particular risks and, therefore, support to increase the level of moderate to vigorous exercise undertaken and to eat a healthier diet are priorities. Moreover, it is important that the goal to eliminate health inequalities is backed by national Health Gain Targets. The Welsh Assembly Government proposes to include Health Gain Targets for people with learning disabilities within its targets framework.

All people with a learning disability should be registered with a general dental practitioner who should be able to access specialist support from the community dental services and specialist hospital provision (including emergency dental treatment where needed).

Community learning disability teams should provide specialist assessment and treatment skills and, through collaboration with generic services, enable access to the full range of appropriate and effective health interventions. Community learning disability teams should provide a link between the home and mainstream health services. Teams should normally include a mix of staff skills and include all relevant clinical disciplines.

Generic mental health services and specialist learning disability services should work together in close collaboration to ensure that a full range of high quality services for individuals with mental health problems is available. Services should establish joint working protocols.

Community learning disability teams should maintain contact with their clients when they are admitted to acute hospital or mental health units, providing advice and support to the mainstream services as appropriate and participating closely in plans for discharge and follow-up.

Authorities should consider additional training for all professional staff in primary and secondary health services to raise awareness and understanding of the needs of people with learning disabilities. In particular, secondary care providers should recognise and train staff in the specific clinical risk that can result from communication difficulties and the lack of recognition of disease (see National Patient Safety Agency ([http://www.npsa.nhs.uk/admin/publications/docs/learningdisabilities\\_issues.pdf](http://www.npsa.nhs.uk/admin/publications/docs/learningdisabilities_issues.pdf))).

Community learning disability teams and other relevant professionals should provide carers with training, advice and support when specific clinical procedures need to be delivered within the community to enable an individual to continue to live in their own home. This needs to be supported by the development of protocols clarifying standards, responsibilities and accountability, particularly in the administration of intrusive clinical procedures. It is important that local variation and inconsistency in approach are eliminated in favour of the implementation of recognised good practice, such as that contained within NICE Clinical Guidelines 32 on Nutrition Support in Adults.

Learning disability services should review and, where necessary, strengthen their recruitment and retention strategies to ensure that specialist multi-disciplinary skills are available within the community.

Commissioning local authorities and LHBs should develop arrangements which create a seamless service, such as joint management and pooled budget arrangements, and assess whether they bring about improved outcomes for service users and their families.

#### Targets:

- By 2011, there should have been a year-on-year increase in the proportion of adults with a learning disability offered and taking up the opportunity of an annual health check, rising to 90% by the final year.
- By 2009, the Department for Public Health in the Welsh Assembly Government should review information derived from the research on the implementation of health checks and other available data to establish health gain targets to improve the proportion of adults with a learning disability who (a) meet healthy diet, weight and exercise recommendations, and, (b) have access to the usual health screening programmes for their age and gender.

#### Behaviours which Challenge

- The core aim is that adults with learning disabilities and challenging behaviour are able to lead lives which are as fulfilling as other people despite the challenges posed by their behaviour.

Individuals typically have needs which are the responsibility of different agencies and have to be met through a co-ordinated response by a mix of statutory, private and voluntary bodies. This requires joint planning, commissioning and delivery of services. Local multi-agency strategies and action plans should make an explicit acknowledgement of the shared responsibilities between agencies for the provision of services to manage challenging behaviours. Authorities should take account of the recommendations in the Revised Edition of the Mansell Report which has been issued in England to provide guidance in this area.

Early identification and assessment, and the development of proactive and reactive strategies for managing challenging behavioural problems, should be essential components of all services providing support to people with learning disabilities. It is important that evidence-based care and treatment should be available at all ages.

Early intensive behavioural intervention with children may avoid the development of entrenched patterns of behaviour or behaviours with more serious consequences in adulthood.

Specialist expertise in the assessment and management of challenging behaviour should be available either from specialist resource teams or from individual professionals

in local community learning disability teams. In either case, teams need to be adequately and comprehensively staffed in order to provide a timely, responsive and proactive service with a broad range of therapeutic interventions.

Specialist psychiatric services should be available to assess the presence of mental illness, the impact of concurrent morbidity and treatment options. These services will be responsible for inpatient assessment where it is indicated under the Mental Health Act.

Training and support to regular carers and service providers should be provided by community learning disability teams and/or specialist services. Authorities should consider collaboration to provide a national programme for the training of carers in understanding challenging behaviour and evidence-based approaches, such as positive behaviour support.

For individuals who have offended and are likely to be subject to the requirements of the courts and/or the Mental Health Act, there should be effective co-ordination and links between the judicial, probation, health and social services.

Access to specialist support for complex behavioural or mental health needs should be available as close to the individual's home area as possible. A positive emphasis on how to maximise each person's quality of life, including maintaining their important social relationships and community ties, should reduce the use of services that require people to travel a great distance within Wales or outside of the country to receive such support.

The Learning Disability Implementation Advisory Group has produced a self-assessment tool for authorities to use to explore the adequacy and quality of support to people with challenging behaviour in or from their area. This should help authorities to identify areas for improvement prior to formulating the comprehensive joint commissioning strategies called for on page 10.

Multi-agency strategic plans for the provision of comprehensive local services in the future are required both to prevent new placements being made, which unnecessarily separate individuals from their home communities, and to facilitate the repatriation of those already placed, who wish to return to their local areas. Consideration of this should be part of the joint commissioning strategies called for on page 10.

It is possible that some highly specialist services for a small number of people cannot be provided in every locality. These should be kept to the minimum number possible. Adequate provision should be made within Wales, so that out-of-Wales placements become a thing of the past. Moreover, provision should be made regionally in a way which takes account of the population distribution, geography and ease of travel within Wales, so that the likelihood of individuals being able to maintain their important family and social relationships and community ties is as great as possible.

Authorities should identify the resources which support current placements and determine the extent to which such resource support can be maintained if and when more local service provision is made. The transfer of funding which supports individuals is recommended when they move, wherever possible.

*Fulfilled Lives, Supportive Communities* recognises that joint working is often difficult for organisations. Restrictive finance and performance systems, and a lack of joint training, leadership and managerial capacity can hinder partnerships. Confusion is currently caused by the Continuing Health Care guidance. The key principle is that the term 'continuing health care' should be applied to an element of care, treatment or support which an individual needs and not become a means of categorising the individual. The Welsh Assembly Government does not want to see the extension of the role of the NHS

as a housing or support provider, nor of the NHS as a commissioner of housing or support provision. This would run counter to the tiered approach set out in the 10 year strategies and would undermine the commitment to comprehensive community-based support set out above. The Welsh Assembly Government will, therefore, appoint an expert group to review the working of the Continuing Health Care guidance and the Health Act Flexibilities (which allow pooled budgets and the delegation of functions between local government and the NHS) in this area, in order to advise authorities on how to develop the comprehensive pattern of local services which policy advocates.

#### Target:

- By 2012, with the exception of a small number of people who may require highly specialised regional provision within Wales, all adults with a learning disability with challenging behaviours will be accommodated, as other people, either locally or in a place of their choosing.

#### Families and Other Carers

- The core aim is that carers receive support which enables them to achieve the life balance that they want between their role as carers and their pursuit of other fulfilling aspects of their lives.

In 2007, the Welsh Assembly Government published the *Carer's Strategy for Wales Action Plan*. This will be the main vehicle for taking strategic objectives in relation to carers forward. Objectives to be achieved and the key actions which the Welsh Assembly Government will undertake are set out there rather than here. The following paragraphs emphasise points of importance.

Particular attention needs to be paid to developing procedures to inform, encourage and provide for carers to have an assessment of their own. Young carers are particularly important in this respect.

Full information about all relevant matters should be provided in co-ordinated, accessible and relevant formats and languages (as in, for example, Carers' Information Packs). It is important to be proactive, encouraging and helpful in providing information to carers and others in a timely way and not to wait until it is requested. The health and social care workforce should not presume that carers are necessarily in possession of all of the information that they need.

The role of families should be recognised, encouraged and formally built into all stages of the decision-making process for individuals, according to Unified Assessment and other guidance. The whole process should be regarded as a partnership, and one which respects the cultural affiliations of families.

Families, alongside other stakeholders, should be formally incorporated into all stages of strategic planning, and the end results should reflect their needs and perspectives.

The provision of timely and appropriate short breaks or domiciliary support is among the top priority needs for carers. Short breaks or domiciliary support are not just about giving the carer a needed break for recuperative purposes, but can include the provision of replacement care while the carer goes about essential business.

Domiciliary and other forms of support should be given to families in ways which help them lead as normal a life as possible and meet the positive goals which they want to achieve, as identified in consultation with them.

However, activities arranged for people with learning disabilities primarily as breaks for carers should be rethought in consultation with the people concerned as opportunities to promote their quality of life.

Service agencies can make a number of practical contributions to developments which are needed across society as a whole. They can develop family-friendly employment policies and be a model for how to support carers to remain in or regain employment. They can also demonstrate understanding of the extra demands on family carers by making sure to offer arrangements which are convenient to them (e.g. for attendance at meetings, or at appointments with professionals).

## **MOVING TOWARDS MORE COST-EFFECTIVE SERVICES**

The Welsh Assembly Government and the Welsh Office before it has provided considerable funding to develop services for people with learning disabilities in Wales. Most recently, it provided a 3 year programme of increasing funding to support the implementation of the *Section 7 Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability*. This is evidence of the government's commitment to develop the pattern of comprehensive local services which its policy sets out.

Increasing expectations and increases in the number of adults with severe learning disabilities requiring support mean that there is pressure to do more. The Welsh Assembly Government is willing to consider new investment to meet new developmental milestones. However, this needs to be matched by local authorities, their health partners and provider bodies making sure that provision is as cost-effective as possible<sup>6</sup>.

There are a number of areas where the continuing refinement of how to provide support to people with learning disabilities in line with policy might indicate that cost-effectiveness gains can be made.

### Reducing the Reliance on Staff within Supported Accommodation

The Welsh Assembly Government wants to help adults with learning disabilities live as independently as possible, exercise self-determination and be fully included in the lives of their communities. As staff presence can inhibit independence at home and in the community and the degree to which individuals exercise choice, a more expensive service with more staff should not necessarily be viewed as better<sup>7</sup>.

Results from UK research (and elsewhere) suggest that there are no robust associations between resource input and quality of life outcomes within supported community accommodation<sup>8</sup>. This should not be understood as suggesting that resources are irrelevant. Clearly, a sufficient level of resources is necessary to deliver any service. Rather, the lack of association between resources and outcomes may reflect two types

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<sup>6</sup> Any discussion of reinvestment of cost savings makes the assumption that authorities would choose to take this course. It is hoped that they would choose to do so given the evidence of growing unmet need.

<sup>7</sup> Research which has sought to identify how the design of supported accommodation influences quality of life outcomes has rarely found staff-to-resident ratios to be a significant factor. The fact that improved outcome in a minority of studies has been linked to both greater and less intensive staffing reinforces the conclusion that staff presence needs to be closely matched to the support needs of service users, and not seen as desirable in its own right. (See Felce D, Perry J. (in press) Living with support in the community: Factors associated with outcome. In S.L. Odom, R.H. Horner, M. Snell & J. Blacher (Eds) *Handbook on Developmental Disabilities*. New York: Guilford Press.

<sup>8</sup> Felce D, Emerson E. (2005) Community living: costs, outcomes and economies of scale. Findings from UK research. In R. Stancliffe and C. Lakin (Eds) *Costs and Outcomes of Community Services for People with Intellectual Disabilities*. Baltimore: Paul H Brookes Publishing Co.

of failing. First, resources may not be entirely allocated on the basis of need (there is research<sup>9</sup> and anecdotal evidence to support this). As a result, some services may be over-resourced, the addition of 'excess' resources failing to result in further benefits or, indeed, reducing benefits by reducing the opportunities and demands for independent action. Second, there may be inefficiencies in the use of the available resources. This view is supported by evidence that changes in staff training, organization and management practices can, without additional resources, result in significant improvements in outcome<sup>10</sup>.

A rather standard model of fully-staffed group home was provided to achieve the resettlement of adults from traditional hospitals. Provision is now changing again with new models of supported living. There is growing experience of arranging semi-independent living. Recent research<sup>11</sup> has shown that semi-independent living for people with relatively low support needs is not only less expensive than fully staffed settings but also provides better outcomes in terms of independence in the community and self-determination. Experience is also growing in the application of assistive technology and many provider bodies are making a concerted attempt to train staff in Active Support and other effective approaches.

One current project exploring the potential for restructuring staffing to provide more flexible individually tailored input together with the use of assistive technology and Active Support has estimated an overall saving of staff costs of 10-20%. As staff costs constitute about 60-80% of residential care costs, an average 15% saving on staff costs would constitute a 10% saving overall. This project is being independently evaluated by the Welsh Centre for Learning Disabilities.

Local authority returns published in Social Statistics Wales suggests that the combined provision of lodgings, supported living and residential care totals 3,426 places. A 10% saving in average costs could be reinvested to provide an additional 340 places. This would go some way to reducing the recent growth in the number of adults with learning disabilities who continue to be supported in their family homes.

#### Resettling People in Out-of-area Placements

People are placed outside of their originating areas for a variety of reasons, including to have access to chosen services, accompany their families when they move, and receive services with a particular expertise not available locally. The Welsh Assembly Government is committed to supporting individuals to make choices and arrangements that fit their own wishes or family circumstances. It is aware that some out-of-area placements may occur for positive reasons. It is not seeking to change arrangements where this is the case. However, it believes that people are unlikely to be best served when out-of-area placements arise from inadequate local service availability.

Some people placed out of area but within Wales may be being served locally to their home, albeit in a neighbouring authority. Such constructive collaboration between authorities is consistent with the flexibility of response which the Welsh Assembly Government wants to encourage. However, other people, and particularly those placed

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<sup>9</sup> Felce et al. (2003) Rational resourcing and productivity: Relationships among staff input, resident characteristics and group home quality. *American Journal on Mental Retardation*, **108**, 161-72.

<sup>10</sup> Jones et al. (1999) Opportunity and the promotion of activity among adults with severe mental retardation living in community residences: the impact of training staff in Active Support. *Journal of Intellectual Disability Research*, **43**, 164-178. Jones et al. (2001) Evaluation of the dissemination of Active Support training in staffed community residences. *American Journal on Mental Retardation*, **106**, 344-358.

<sup>11</sup> Felce et al. (2008) Outcomes and costs of community living: Semi-independent living and fully staffed group homes. *American Journal on Mental Retardation*, **113**, 87-101.

outside of Wales, may be being served at a distance which inhibits continued family contact and community integration and may even fracture relationships.

It is thought that out-of-area placements tend to be high cost. However, there is limited information about comparative costs of in-area and out-of-area placement.

Notwithstanding this, there is likely to be a cost-effectiveness gain from re-providing for people locally not only through potential cost reduction but also through enhancing the quality of people's lives. This needs to be demonstrated.

According to the audit accompanying local authority funding applications in response to the *Section 7 Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability*, local authorities placed 354 people out of county but remaining in Wales and 176 people outside of Wales. Gross annual costs to local authority social services departments of these placements were returned by 18 authorities, providing for about 85% of both totals. Average annual costs per place to social services were approximately £44k and £59k respectively. However, total costs where placements were funded by more than one agency were not returned.

Research on people with learning disabilities and challenging behaviour in the 7 local authorities served by the Bro Morgannwg NHS Trust Learning Disability Directorate<sup>12</sup> found that 184 people (out of 1,424 with challenging behaviour) lived in an area different from their funding source: 107 funded locally but placed outside the Directorate territory, 27 living within the territory but funded from outside (14 by authorities in Wales and 13 by authorities outside of Wales) and 50 living within the territory but within an authority area other than the funding one. Discounting the 13 people placed within Wales from outside and extrapolating to the whole of Wales gives 398 people with challenging behaviour placed out of funding area (about 75% of the combined figures in the paragraph above). Information on funding arrangements and placement costs was available for 113 people (11 within the territory and 102 outside). Only 30% were sole funded by local authority social services departments. Social services contributed to the costs of 69%, at an average annual cost per place of £49.5k. With costs falling to other agencies included (e.g., the NHS, Health Commission Wales, education), the average annual cost per place was £97.9k.

The above average is higher than typical average placement costs. Resettlement of people currently placed outside of Wales at a cost per placement 25% below existing costs would generate savings of £4.3m. Reinvestment of these savings would meet the revenue costs of an additional 80-85 places in supported accommodation. For such reinvestment to occur, funding provided through Health Commission Wales would need to be transferred to local agencies when individuals are resettled. This requires a change in existing operational arrangements.

### Expansion of Supported Employment

Supported employment is more successful than traditional job readiness training in helping people with more severe learning disabilities to gain paid employment. Research has shown that the return to the national exchequer can be significant under certain conditions<sup>13</sup>. Critical in these is achieving a high proportion of full-time working. This maximises savings on social care day services and provision of welfare benefits, while

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<sup>12</sup> Lowe et al. (2004) *Mapping the service needs of children and adults with learning disabilities and challenging behaviour: Summary report*. Special Projects Team, Bro Morgannwg NHS Trust Learning Disabilities Directorate.

<sup>13</sup> Beyer et al. (1996) *The costs and benefits of supported employment agencies*. London: The Stationery Office.

establishing the possibility that some people may contribute tax revenues. In practice, however, past UK welfare benefit arrangements have resulted in a high level of part-time working in line with the therapeutic earnings disregard; potential savings and revenues have rarely been realised. Therefore, like alternative daytime occupation, supported employment has continued to be cost-ineffective and have ongoing revenue costs.

Recent changes in UK welfare benefit arrangements have created new opportunities for greater cost-effectiveness. While some of the past problems which have inhibited full-time working remain, there are non-means-tested disability allowances and tax credits which, together with the addition of paid employment, can result in people having incomes higher than those which they had before when they relied on means-tested benefits. One of the keys is to ensure that the advice people receive about benefits and employment possibilities are integrated, so that a judgement can be made about their joint contribution to income. People need good advice about maximising their income from all sources, rather than about maximising their receipt of welfare benefits.

This *Action Plan* asks authorities to develop new joint commissioning strategies for employment and day opportunities which include new targets for achieving the employment of adults with learning disabilities. Complementary to this, the Welsh Assembly Government is proposing to develop an All-Wales Supported Employment Strategy geared towards helping people with learning disabilities to work full time as opposed to being reliant on social care support.

#### **NEW INVESTMENT PRIORITIES: EXPANDING THE AVAILABILITY OF SUPPORTED ACCOMMODATION IN LINE WITH DEMOGRAPHIC CHANGE**

The last 15 years has seen the numbers of adults<sup>14</sup> with learning disabilities on local authority registers increase by over 2,100 (from 8,324 to 10,450). While the proportion living in family homes has reduced slightly in that time, the numbers of adults dependent on extended family home care has increased. 575 more people with learning disabilities over the age of 16 years live in family or foster homes in 2005 than in 1990 (from 4,545 to 5,120). It is likely that as many as 1,700 adults living in family homes in 2005 were living with carers aged 70 years or over.

The Welsh Assembly Government considers that expanding the availability of supported accommodation is the highest priority for new investment. Delay in addressing the growing dependency on extended family home care would:

- a) seriously diminish the credibility of an outcomes-oriented policy directed towards achieving social inclusion, independence and normal patterns of life within the community for people with learning disabilities,
- b) seriously diminish the credibility of the Carers' Strategy,
- c) increase the risk that mutually dependent vulnerable adults and failing carers cease to be able to maintain decent standards of living, and
- d) precipitate a later crisis.

A variety of targets for the required expansion of supported accommodation in Wales are possible. The Learning Disability Advisory Group report, *Fulfilling the Promises*, suggested that 1,500 more places should be provided<sup>15</sup>. A more modest preliminary

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<sup>14</sup> Adults in this instance = people aged 16 years and over. Source: Social services Statistics Wales.

<sup>15</sup> Guidance issued by the Valuing People Support Team suggests that the scale of needed expansion of supported accommodation in an area can be estimated by multiplying the total population of the area by 0.0005. Applying this factor to the population of Wales yields a similar estimate of 1,460 places.

target would be to reverse the expanding dependency on extended family care - 575 more places are required to reduce the 2005 figure of 5,120 adults living in family/foster homes to the 1990 level of 4,545.

Even this lower target has considerable implications for increasing the level of revenue funding available. Using a unit cost estimate of £50k per year, the additional annual revenue required to meet this expansion targets would be £28.8m.

If the cost-effectiveness improvements concerning supported accommodation and out-of-area placements discussed above are made during the next five years, and if authorities make a commitment to reinvestment, the Welsh Assembly Government undertakes to provide additional recurring funding rising to £7.5m by the fifth year to achieve this target expansion nationally.

It is logical that greater numbers of adults requiring support also has implications for the availability of support for employment or other daytime occupation. This *Action Plan* has already indicated the Welsh Assembly Government's undertaking to develop an All-Wales Supported Employment Strategy and to facilitate the move away from activity programmes based in traditional large day centres where people are still congregated in far greater numbers than is acceptable. As there are difficulties in being precise about the extent of current provision against demand, the Welsh Assembly Government is also asking local authorities and their partners to set out joint commissioning strategies for the provision of comprehensive employment and day occupation options (see page 11). At this point, it will be possible to determine a better estimate of needed expansion in service availability and the form that support should take.

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