



# SERVICES FOR PEOPLE WITH A LEARNING DISABILITY

A review by the Health & Adults  
Services Scrutiny Committee

September 2010

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## Key to abbreviations:

CYPS Devon County Council's directorate of Children & Young People Services  
 ACS Devon County Council's directorate of Adult & Community Services

# Foreword from the Chairman

On behalf of Devon County Council's Health & Adults' Services Scrutiny Committee I am delighted to publish this report. It follows a detailed investigation into support services for people with a learning disability across Devon carried out by this task group previously set up by the committee. I would like to thank all those who participated in the process, for their time and effort and continued commitment to helping to shape this review and recommendations for improvement. I would also particularly like to thank our contributors for the detailed evidence they gave to the task group.



The World Health Organisation defines learning disabilities as a state of arrested or incomplete development of the mind. Somebody with a learning disability is said also to have significant impairment of intellectual and of adaptive and social functioning. This means that the person will have difficulties understanding, learning and remembering anything new and in generalising any learning to new situations. Because of these difficulties with learning, the person may have difficulties with a number of social tasks, e.g. communication, self-care or awareness of health and safety. A final dimension to the definition is that these impairments are present from childhood and not acquired as a result of accident or following the onset of adult illness.

At present approximately 2,000 individuals with a learning disability receive services in Devon and estimates suggest that the total number might be in the region of 10,000 people. The provision of services for people with a learning disability has been the subject of numerous reviews undertaken by the former Healthcare Commission, the Commission for Social Care Inspection, the Mental Health Act Commission, MENCAP and various scrutiny committees in local authorities highlighting a number of very specific concerns relating to e.g. low levels of self-directed care and insufficient arrangements to safeguard vulnerable adults and it was the remit of this task group to examine service commissioning and provision in Devon.

Conducting this piece of work has been very worthwhile and has engaged a large number of people. We have been able to look at the issues involved in depth and it has been wonderful to see such a high level of dedication and enthusiasm from everyone involved. If we continue to work together and develop even stronger partnerships, we will be able to make significant improvements the services for people with a learning disability in Devon.

**County Councillor Eileen Wragg**

Chairman, Services for People with a Learning Disability Task Group

# Introduction

Since 2001, the *Valuing People* White Papers have been published as guidance. The central themes in these government publications were the adequate planning for the needs of people with a learning disability and complex needs to ensure care is accessible, personalised and allows individuals to lead full and independent lives. It is important to enable individuals to exercise as much choice as possible in how they want to live their lives as independently as possible. Implementing *Valuing People* was never a statutory requirement, however, and any funding has to be raised by the implementing authority.

The Health & Adults Services Scrutiny Committee had undertaken some preparatory work in relation to services for people with a learning disability. For example, a task group on mental health services for older people (March 2010) established that people with a learning disability were more likely to develop dementia compared to the general population. Mainstream older people's mental health services do not suit people with a learning disability as such services lack specialist knowledge and assessment tools. Furthermore, there was evidence that conventional services lacked the capacity to provide services for people with a learning disability. However, people with a learning disability and dementia tend to enter mainstream care as this presents a more cost-effective option. The task group recommended:

*To scope the following areas for improvement in the care for people with a learning disability and dementia:*

- a) increase capacity for baseline screening, reactive and proactive monitoring*
- b) improve awareness training for frontline staff*
- c) consider the complex needs of people with a learning disability in residential, nursing and inpatient settings when redeveloping services*

The recent rural access to health task group (March 2010) recognised that many people with autism living in rural areas of Devon lack accessible support services as they mainly relied on public transport which some individuals found difficult to use. Therefore, many people with autism tend to use services only at the point of crisis when they require medication or hospitalisation – an inefficient use of both financial and human resources. People with complex needs are isolated not only by their conditions but also by living in rural areas, with very little physical contact with the outside world and underdeveloped social skills. Third sector organisations spend most of their volunteers' time meeting people in rural areas one-to-one. Often the volunteers are the only people outside patients' families to whom the people speak. The task group recommended

*To recognise and to have regard to the particular isolation of people with complex needs in rural areas.*

# Review Approach

Devon County Council's Health & Adults Services Scrutiny Committee established this task group in July 2009 and the group started its work in February 2010. County Councillors Olwen Foggin, Bernard Hughes, Dennis Smith, Richard Westlake, Eileen Wragg (chairman) as well as West Devon Borough Councillor Philip Sanders served on the group.

The review of services for carers combined an analysis of available data with hearing a wide range of contributors as well as visits. At its first meeting the group agreed to conduct work under the following headings:

- i. transition from the County Council's children & young people services (CYPS) directorate to adult & community services (ACS)
- ii. finance and alignment of CYPS and ACS budgets
- iii. residential care, including closures and supported living
- iv. daytime support, including day centres and employment opportunities

The task group first reviewed plans and proposals from ACS in order to establish how officers envisaged implementing the national objectives set out in *Valuing People* and how they generally supported people with a learning disability. The following statutory bodies participated in the review:

- Devon County Council's Adult & Community Services directorate
- NHS Devon
- Devon Partnership NHS Trust

During the investigation, the task group collected evidence from the following organisations, groups and individuals:

- Aroha House
- Autistic Spectrum Group
- Careers South West (former Connexions)
- Devon & Cornwall Jobcentre Plus
- Devon County Football Association
- Devon County Learning Disability Forum
- Devon Link Up
- Devon People First
- Dove Project
- Ellen Tinkham School
- Guinness Care and Support
- HFT
- Individual parent carers
- Learning Disability Health & Social Care partnership managers and staff
- Learning Disability Parliaments
- Manor Mews Residential Care Home
- Mencap, Exeter and District Society
- Michael Batt Foundation
- Paperchain

- Parent Carer Voice
- Pluss
- South Devon Carers' Consortium
- Stallcombe House
- Westcountry Housing

The task group also considered the following written material:

- Department of Health: *Valuing People: A new strategy for learning disability for the 21<sup>st</sup> century*, March 2001
- HM Government: *Valuing People Now: A new three-year strategy for people with learning disabilities*, January 2009
- HM Government: *Valuing Employment Now: Real jobs for people with learning disabilities*, June 2009
- Devon County Council, NHS Devon: *Accommodation and support joint strategic needs assessment for adults with a learning disability*, January 2010

# Findings

Out of the estimated 10,000 people with a learning disability in Devon, approximately 2,000 receive adult services. Contributors highlighted that people who use services, families, carers and support staff feel their views are not always sought or listened to. Parental involvement also decreases significantly once the individual reaches the age of 18. Contributors emphasised poor communications between commissioners and providers, parent carers and advocates. Numerous examples were raised where correspondence to ACS remained unanswered or, as in one case, where one officer sent two letters on the same day, one stating that an appeal had been upheld and one stating a decision of the panel had been upheld. Better communication should be established in both replying to correspondence and keeping involved parties informed.

**Recommendation 1:** To improve communications with people with a learning disability, parent carers, providers and advocates, to respond to correspondence and to keep all involved parties informed, especially with regard to service access and changes to services.

Parent carers stated that parent involvement needs to improve and that joint training between staff and parent carers would enhance mutual understanding as well as partnership working. Carers have also been campaigning for a coordinated database of needs in order to catalogue conditions and specify how these can translate into tailored service provision as previously piloted in Surrey. Work has commenced in Devon to establish a database based on person-centred plans.

**Recommendation 2:** To expand joint training between staff and parent carers.

**Recommendation 3:** To establish a coordinated database of needs in order to catalogue conditions and their resulting needs which form the basis of accessible and bespoke services.

Learning disabled contributors emphasised that accessibility of buildings, facilities such as shops, leisure activities, transport, toilets and changing rooms needed to improve. Access to housing and other benefits was characterised as particularly difficult due to inaccessible online application processes which some people with a learning disability find difficult to use. The same applied to some written communication from providers and commissioners.

**Recommendation 4:** To ensure that appropriate agencies provide application forms for housing and other benefits as well as all correspondence in formats accessible to people with a learning disability.

There is also scope for improving the provision of information. Welcome packs could be produced including how to comment and complain, which services were not provided by ACS and information on alternative services. Libraries, mobile libraries, schools and GPs could also be utilised better for the display of information.

### **Topical excursion: health care for people with a learning disability**

People with a learning disability and complex needs experience problems in using mainstream health services. Inappropriate judgements are made about the medical needs of people with a learning disability, e.g. women are not offered cervical screening as assumptions are made about their sexual activity. The uptake of dental and eye checks was also low as services lack capacity to deal effectively with people with a learning disability. Patients are required to attend normal clinics and staff have little or no training in understanding the needs of, and care for, people with a learning disability. Carers are not allowed to stay with the patient in adult wards although the patients' mental development might not match their physical age, which often leads to anxieties and challenging behaviour. Some surgeries offer appointments for people with a learning disability at the beginning of the working day as the individuals often do not understand the concept of waiting times.

GPs introduced a registration code for learning disability whereas previously those patients were registered with different conditions such as epilepsy and coronary heart disease. NHS Devon recently started payments to GPs for undertaking health checks with patients with a learning disability through the Directly Enhanced Services scheme and approximately 40% of those patients now have one. Liaison nurses are also in post at the four acute trusts covering the County of Devon who assist patients and their families.

**Recommendation 5:** To recommend to the Health & Adults Services Scrutiny Committee to convene a separate task group to review health care for people with a learning disability.

## Transition from children and young people's to adult services

Approximately 110 young people with a learning disability make this transition each year and challenges include the preparation of young people for adulthood and partnership working between the two directorates. The task group recognises that transition arrangements have improved but remains concerned about a number of issues. People with a learning disability receive a more comprehensive range of services with CYPS than with ACS and one of the problems for ACS is managing expectations. Each individual's transition is twofold and the definition of transition should recognise this fact, i.e. transitions from

- a) CYPS to ACS
- b) current to future placements.

Some schools start person centred reviews from as early as the age of three which provide valuable information about individuals and their aspirations. Other schools collate medium term plans which include details on wider aspects of people's lives such as work experience and transition issues. Some also collate personal profiles for students as well as communication charts which people who do not know the individual well can use. ACS use different plans but contributors emphasised that the partnership working and utilisation of the information was improving.

In addition to this, a transitions protocol for young people with special needs clearly sets out requirements, e.g. initial meetings with individuals, parents and involved agencies and an annual review of care plans. Contributors highlighted, however, an inconsistent involvement of adult social workers in the early stages of transitions. ACS, in some instances, had minimal involvement before students reached their 18th birthday. In one case mentioned to the task group, ACS staff only met an individual one week before the person's 18th birthday. Communication between ACS and CYPS during transition periods could therefore be improved and if support could be coordinated earlier, problems could be addressed more effectively. The history of family involvement should also be respected. ACS should have more involvement during students' final year in full-time education, whatever their age, in order to achieve an effective and smooth transition. There are, however, no dedicated ACS transition workers and balancing staff time and resources with transition and daily responsibilities remains difficult.

**Recommendation 6:** To ensure the involvement of ACS early on in an individual's transition and to improve communications with CYPS from at least Year 9 in order to guarantee a seamless transition.

If the new adult provider is not known to the student, parents and staff until very shortly before the person leaves CYPS, there are few or no opportunities to introduce the new provider and manage a smooth, unrushed transition. People with a learning disability rely heavily on structures and continuity and often find rapid changes distressing. CYPS transition workers cease their engagement when the person reaches 18 but individuals would benefit if the workers accompanied students through the whole of their transition until approximately two years after they had left full-time education.

One education provider recently carried out a citizenship project with the Learning Disability Partnership, in which students were allocated an adult care manager who worked alongside the young person, families, school and future providers and the transition process was significantly improved.

**Recommendation 7:** To better utilise information about individuals collated by support staff such as teachers and career advisors as well as carers.

Information sharing needs to improve so parents can understand the disparities between the two services, e.g. the differences in the entitlement for children and adult respite care or the different language used, especially when referring to brokerage. One parent carer submitted evidence demonstrating that information about the financial changes affecting both carers and people with a learning disability needs to be communicated better during transitions. After a transition period, child benefits and income support associated with children and young people's services cease. Families have to finance changes in taxation, reductions in the independent living allowance, contributions to day activities as well as a reduced employment and support allowance (ESA) compared to the disabled child premium.

**Recommendation 8:** To improve the provision of information for parents about service and financial changes resulting from the shift from CYPS to ACS.

Parent carers emphasised that their offspring had little or no support from ACS in identifying alternative activities after e.g. college was finishing and emphasised that daytime activities as well as readily available support when needed were crucial for the success of independent or supported living (see pp. 11). One parent carer highlighted

that an adult social worker had not been aware of some learning disability services in the local area and the parent carer expressed the view that the social worker had little knowledge about and experience in the specific needs of people with a learning disability, e.g. the support needed to live independently.

## Alignment of CYPS and ACS budgets and ACS finance

The task group received evidence that some transitions seem ad hoc and rushed to individuals, parent carers and teachers. Because there is a definitive and predictable number of people with a learning disability and because individuals' needs rarely change during transitions, services could be budgeted and planned for further in advance. Funding for individuals' future placements could be identified in the financial year prior to a transition which would permit planning for all involved parties and ensure a smooth transition.

**Recommendation 9:** To identify and ring-fence funding for adult placements in the financial year prior to transitions in order to allow planning for all involved parties and ensure a smooth transition.

A number of concerns have been raised with the task group over the reduction of adult support hours for financial reasons. One provider reported that the management was advised to cover funding gaps with volunteer services and ceasing birthday and Christmas presents. Changes in the funding for individual placements could result in changes to the care plans and some care plans were changed to lower needs although participants stressed this does not necessarily reflect reality.

Another contributor described how ACS had been planning to halve the support hours for a number of individuals who had undergone reviews and to introduce telecare although the time between an alarm and staff arriving might have proved impracticable. Reducing the hours for individuals in a unit was unsustainable and unsafe as reducing the hours for one individual might adversely affect on the care of another person who might be less independent. Reduced hours in general meant less support and opportunities and hence a reduced quality of life. One day after the task group had met with the above provider and clients, ACS informed the provider that the level of contracted support would not decrease. When enquiring about the reason behind this decision, the provider was told that they "must have caught him [the decision maker] on a 'good day'". The task group remains concerned about the seemingly arbitrary process of contracting support hours.

**Recommendation 10:** To review the process for determining and contracting levels of support for individuals and to assure the Health & Adults Services Scrutiny Committee that the process is based on evidence.

Any current financial difficulties were potentially being exacerbated by changes to the independent living fund which came into effect on 1 May 2010: The maximum indicative budget identified through the Resource Allocation System (RAS) is currently £521 per week per placement. RAS figures effectively represent a level that is affordable to the authority. Any funding gaps between this sum and the actual cost of placements are being covered by ACS by means of overspends. The Association of Directors of Adult Social Services (ADASS) produced a guide which informs that local authorities cannot

set arbitrary, rigid cost ceilings without regard to individuals' actual needs, hence ACS fund packages above £521 per week where people have high level of needs, but with the aim of getting fees as close to the RAS level as possible. Identifying and securing additional funding from alternative sources is time-consuming and requires creativity from staff. If ACS staff are to be expected to manage a wider range of funding streams, all the organisations involved need to adhere to one process and more staff time is needed to spend sufficient time with individuals, e.g. at annual reviews. Currently, approximately 24% of people who use learning disability services receive no annual review.

It was reported that some individuals have no allocated care manager or named contact within ACS. Different staff deal with cases on different occasions which can result in basic information having to be repeated every time leading to discontinuity of care. Direct contact and the provision of advice and support would be beneficial. One example was highlighted to the task group where a provider had been unaware of the VAT charging regime under direct payments and rectifying the problem became a time-consuming exercise, causing distress and financial difficulties to the people who use the service. Participants suggested that a named contact within ACS could be responsible for overseeing a number of individuals and providers for monitoring and relationship building purposes.

**Recommendation 11:** To establish named contacts, including contact information and direct telephone numbers in ACS for providers and people who use services.

Contributors also expressed their disappointment about funding being allocated to provider away days, meetings and administration and not front-line services. The task group received evidence that the local authority rate did not cover providers' costs in some instances. ACS refrained from commissioning new services if the provider could not offer placements at Devon County Council's rate although other local authorities placed individuals with the same providers who were fully funded. In one example pointed out to the group, a provider funded temporary additional support and physiotherapy after an operation themselves due to unworkable solutions and long response times offered by ACS. Flexible as well as timely solutions should be sought and contributors repeatedly expressed concern that access to services is only available for the articulate. The task group found evidence that people who use services often relied on the goodwill of providers in terms of prices and hours provided. Participants highlighted an example of an individual who lived with parents and who experienced difficulties finding services and a place to live. Such arrangements and circumstances strained the parents and could in extreme cases lead to family breakdown.

One provider described how ACS planned to carry out seven reviews in one afternoon without inviting families, leading the provider to conclude that commissioners were not primarily interested in an individual's care.

Some providers claimed they had little choice but to accept variations of their contracts, such as a 0% annual inflationary increase, as to do otherwise could put a resident's placement – i.e. its future commissioning, and hence the person's future – at risk. Provider organisations would appreciate more openness and transparency in the allocation of resources. For example, ACS had not clarified the level of 2010-11 funding for some organisations which gave evidence to the task group during the early stages of this review which started on 18 February 2010. Medium and long term financial planning was essential, e.g. for the extension of staff contracts in the voluntary sector.

Contributors called for more and improved partnership working with providers and the need for statutory bodies to provide longer-term security for service provision.

**Recommendation 12:** To only alter the terms of contracts in consultation with providers and to improve the process by which funding is allocated in order to provide longer-term security for service provision.

Participants repeatedly emphasised that collaboration with commissioners remains highly desirable as well as a better appreciation from the latter of the cost involved in care. Small providers in particular could struggle with administration and bureaucratic requirements as they often did not employ dedicated office staff.

## Options for living

Options for living for people with a learning disability include residential placements and supported living. In general, contributors pointed out that more accessible services and accommodation were needed, e.g. ground floor flats.

### Supported living

The task group recognises that the average age amongst people with a learning disability is increasing faster than in people without a learning disability. It is therefore important to promote as much independence early on in an individual's life so any achieved surpluses can be reinvested in the care for people with more complex needs. Supported living would provide individuals with more control and lifestyle choices as well as a greater deal of independence.

However, the task group received evidence and recognises that supported living is only suitable with adequate levels of support for individuals. Each individual is supposed to make his or her own choices about where and how they wish to live but some are not able to make choices in life. The task group has received evidence which suggests that in those cases, ACS persistently did not share the views of people closest to individuals e.g. parent carers.

Contributors identified loneliness and maintaining a healthy diet as the two main challenges in supported living and emphasised that housing-related support services are sometimes expected to cover gaps in enabling services to fulfil people's needs. A senior manager in the learning disability service informed parent carers in a letter that "for a young person [...] we start from a presumption that they are able to live in their own tenancy in the community" and members of the task group questioned whether this presumption should readily be applied to individuals with complex needs.

In supported living, individuals are taught skills such as cooking but no services are provided outside the person's home which can lead to isolation as individuals remain at home, largely unoccupied and with particular isolation in rural areas. Securing access to transport was the major challenge in the countryside but more coordination of vehicles could provide a solution and the tight network of parents, carers, teachers, support organisations etc could be utilised if properly planned.

**Recommendation 13:** To better plan services for people with a learning disability in rural areas and to make greater use of the network of parents, carers, teachers, statutory, voluntary and private organisations etc.

Another example included a communal room in a supported living environment not being used by the residents as no support was provided outside their flats and the individuals were not independent enough to use the communal room on their own. A parent carer described a lack of support in a supported living environment and individuals staying up all night and asleep during the day as they do not receive sufficient support to pursue a day-night-rhythm with meaningful activities.

**Recommendation 14:** To facilitate networks of unfunded support for non-eligible support.

Learning disability services are also provided separately from mainstream community services and there is little or no provision for social interaction for adults aged 25 and over. Interaction with able-bodied people rarely happens as people with a learning disability are vulnerable and often meet intolerance. Befriending schemes might alleviate this situation if volunteers receive sufficient training and CRB checks. Enabling services were difficult to get due to long waiting times for assessments.

**Recommendation 15:** To encourage councils for community and voluntary services (CVS) in Devon to raise awareness among their member organisations to consider extending befriending schemes for people with a learning disability.

ACS does not currently inspect or monitor providers and no formal qualifications or other requirements are necessary to set up supported living. Individual providers were pointed out to the task group which did not inspire any confidence in the organisations in relation to the presentation and accuracy of information, claims over existing premises and provided services and hence credibility of the provider and the safety of the people who use the service. Concerns were expressed to the task group that a minority of service providers in Devon might be primarily interested in property speculation. Cases were cited where support for individuals in abusive situations was not provided promptly. Parent carers expressed the view that partner organisations are not working together efficiently in order to resolve situations. Supported living potentially makes alternative funding streams accessible, e.g. housing benefits, reducing expenditure for commissioners and generating more income for providers. Contributors questioned how accountable and transparent providers are in the use of funding made available to them and how they are monitored.

**Recommendation 16:** To formally accredit providers with the commissioners, to establish minimum criteria for safe service provision and to monitor providers regularly, including safeguarding adults and how providers use statutory funding.

**Recommendation 17:** To improve response times to crises and to assess questionable placements carefully before re-offering them to different individuals.

Arrangements to safeguard vulnerable adults need to improve, including the training of staff to recognise safeguarding issues and better joint working between local authorities, primary care trusts and service providers. Staff in contact with people with a learning

disability need better training to develop the specific skills required, which also include ambition and aspiration for what people with complex needs can achieve.

**Recommendation 18:** To improve safeguarding arrangements, including response times to alerts, concerns and crises as well as communication between professionals from different agencies.

**Recommendation 19:** To recommend to the Health & Adults Services Scrutiny Committee to convene a separate task group to review safeguarding arrangements in ACS.

**Recommendation 20:** To improve professional development opportunities in relation to the needs of people with a learning disability, including staff who compile brokerage outcome statements.

One contributor suggested that Supporting People funds should not be ring-fenced for people receiving housing benefits but should be needs-led. Currently, certain individuals, e.g. those who lived with their parents, could not get the funding. Also, more housing needs to be provided for people with a learning disability who desire to live more independently, e.g. move out of family homes, and where they could acquire necessary skills to live more independently.

One housing provider had been approached by neighbouring local authorities regarding future cooperation and development of properties but not by Devon County Council. The movement of tenants also has to be carefully planned and units must not remain unoccupied, causing an organisation financial loss. The Devon County Football Association also pointed out that they had no formal contact with ACS but the organisation is developing disability football clubs across the county.

**Recommendation 21:** To establish working relationships with more organisations with the potential of offering services to people with a learning disability, such as housing and leisure providers.

#### Assessments, reviews and brokerage

A number of concerns have been expressed to the task group about assessments, reviews and brokerage. Assessment forms, for example, were hard to understand and personal interviews should be carried out instead which relate to the mental ability of the individual. Consideration should also be given to how initial assessment questions are formulated in order to obtain accurate responses. For example, instead of formulating the question “can you read?”, the person should be invited to read a short text; otherwise the person’s ability to read could be misinterpreted.

Brokerage outcome statements need to be written very carefully to minimise misunderstandings about people’s actual needs and wishes which require thorough assessment. Services which do not meet needs are more cost and resource intensive the long term. If a person has profound difficulties and is unable to communicate either verbally or by gesture, officers could interpret and make decisions on the person’s behalf which might not fully reflect the person’s needs or preferences. Care managers can use the professional skills of a speech and language therapist or can ask the family or support worker for their assistance. It has been suggested that person-centred plans

should form the basis of assessments and reviews and people who know the individual best should be consulted. Contributors even proposed involving people with a learning disability more so they themselves write their outcome statements, e.g. with the help of pictures if appropriate. This would mean that more flexibility needs to be applied to the required format in which an outcome statement is to be submitted.

All the information needs to be formulated in an understandable and non-misleading manner for all involved parties. Parents usually assist in the compilation of brokerage outcome statements but care and other support staff, including teachers or career advisors, are not routinely involved and would find involvement beneficial. Reviews within the Resource Allocation System (RAS) incorporated short assessment questionnaires which created a score representing the level of care needed. The task group received evidence that reviews did not incorporate the opportunity for feedback by families or support staff.

**Recommendation 22:** To involve all support staff, including teachers and careers advisors, routinely in the compilation of brokerage outcome statements.

**Recommendation 23:** To sign off all final brokerage outcome statements with the person concerned or their families and/or carers.

Processes need to be simplified and service access and/or signposting should be improved in order to enable individuals to get support when needed and prevent their conditions from worsening before support was provided. This requires professional, knowledgeable and trained frontline staff, including e.g. receptionists. After initial telephone assessments, individuals should be provided with information on the process and timescales in order to manage expectations and keep all involved parties informed.

The general perception of brokerage was one of putting vulnerable people to auction. Parents expressed little confidence in brokerage and they found the experience of the process and the lack of control unsettling. One participant suggested to replacing the term brokerage by “best value care” and questioned whether alternative service identification procedures should be developed for people with severe disabilities as a lack of bidders could increase parents’ and individuals’ anxieties.

**Recommendation 24:** To review the commissioning procedure for people with complex and severe needs and to consider offering them placements avoiding brokerage considering the very limited number of suitable providers.

Contributors repeatedly emphasised their impression that brokerage nominates the cheapest provider, who might not necessarily respond to the person’s needs and that assessments and placements were driven by budget considerations. The choice of a place to live for people with a learning disability was compromised by funding restrictions and the current commissioning direction towards supported living in the community. If the local authority was not prepared to increase their funding for a placement, the individual could not exercise choice. In one case, the learning disabled person was able to make choices and his/her preferred option was residential care as the person was of the opinion that s/he was not ready for supported living. Brokerage, however, identified a supported living provider. Choice was also limited due to unsuitable locations of providers and without better developing the provider market. Commercial providers could not compete in this environment and closures further compromised people’s choice. Coordinated joined funding might provide a solution. Participants also expressed the

view that commissioners and providers interpret *Valuing People* differently.

**Recommendation 25:** To further develop the market in order to ensure that services and solutions can be found which meet people's needs.

Some providers find it difficult to compile and submit bids to brokerage within the allocated timescales due to the availability of resources and the outcome statement did not always make it clear which exact information was required for a bid. Providers would also welcome communication if they were not awarded a contract but currently, there are no opportunities for negotiations or feedback.

**Recommendation 26:** To improve communications with providers throughout the brokerage process and to communicate outcomes to all bidding providers.

The commissioning culture does not seem to be flexible with regard to individuals' needs. One provider suggested that instead of commissioning hours of care provision, the emphasis should be laid on meeting needs and desired outcomes which in turn would provide a business incentive for the service provider to meet an individual's wishes with a minimum of resources but challenging the commissioning culture is difficult. A case was highlighted where an existing service provider had identified a new and more beneficial care solution for an individual which would deliver resource savings in staff time and allocated funding but the solution had to be formally brokered and the provider expressed frustration with the lengthy process.

**Recommendation 27:** To consider alternatives to the current commissioning procedures in order to better meet people's needs and desired outcomes and to provide more creative, bespoke and needs-led solutions.

Another case was highlighted to the task group where parents and the learning disabled individual had identified a preferred provider prior to the brokerage process which they had been using for e.g. respite care and would have been able to provide a placement but the brokerage process identified different providers, one of them out-of-county despite the preference for a local provider. The case was awaiting a panel decision less than one term before the student finished full time education.

It was also highlighted to the task group that professional and senior staff spent valuable time with paperwork and CareFirst 6, the case recording system. Administrative staff were employed via a business support unit in adult & community services (ACS) with separate line management who would not cover case recording.

**Recommendation 28:** To explore how professional and senior staff can be relieved of their administrative duties.

In the case of people's dissatisfaction with identified services, panels review cases and determine the way forward. The task group received evidence that panels have no social worker representation and no direct communication with affected individuals. They make decisions on the basis of submitted reports which are collated by assessing and talking with the person and their family as well as others who have been involved in the case. The decisions are part of the operational process and agree placements and the funding of them. Contributors have questioned, however, how panels could determine which arrangements would best meet a person's needs without meeting the individual or

immediate representatives. Members of the task group suggested the direct involvement of social workers and elected members.

**Recommendation 29:** To ensure the representation of the individuals' social workers at review panels as well as at least one elected member as a standing member.

**Recommendation 30:** To give local members the opportunity to represent residents from their divisions at the panel, similar to school transport appeals.

## Daytime support

Daytime support includes meaningful activities at day centres and employment opportunities. The closure of day centres in 2004 left many people with a learning disability across Devon without meaningful daytime activities. For example, day services were closed in Exeter and the subsequent hub centre closed after six months. When this particular facility ceased, a sponsoring charity was not informed about the future of the resources which it had provided. Currently, there is no hub provision in Exeter. Service redesign should not have proceeded before new services had been set up. The only hub in the South Hams, West Devon and Teignbridge areas is in Ivybridge (see below). ACS stated that there are many community hubs provided for people who have an assessed and eligible need. The demand figures for these services were falling, however, and suggest that younger people do not want to access them and many people want to access other community activities or get work.

**Recommendation 31:** To proceed with service withdrawal only after replacement solutions have been successfully established.

**Recommendation 32:** To develop the provider market, particularly in the areas of day activities, housing and transport (reference Rural Access to Health Task Group Report, March 2010, recommendations 1-9).

### **Example of best practice: the Ivybridge Link & Community Hub**

The Dove Project supports adults with learning disabilities and evolved 15 years ago from a residential home which was set up in 1981 following the closure of long-stay hospitals. The Dove Project developed the model of care towards individualised and less institutionalised community based and integrated services. At the start it purchased a property in the centre of Ivybridge as an operational base. The organisation's priority was to provide community based day opportunities and to develop and enable people to move into their own accommodation. It currently supports over 90 people across Devon, 100 in Plymouth and 6 in Cornwall.

The biggest challenges for people with a learning disability are to pursue social activities, to form friendships and relationships and not become socially isolated. The benefits of supported living are limited without sufficient social opportunities and support. The Dove Project recognised this and established a networking group, the Ivybridge Link & Community Hub, in 2006. The group aims to research, plan and organise social activities, offers information and signposting on a wide range of services, including travel,

health, local events and activities as well as parent and carer support. Members meet people with the same interests and explore ideas for events which can be arranged by the Ivybridge Link & Community Hub.

The Dove Project stresses that people with a learning disability can, when initially supported, live more independently with support from friends rather than paid staff. The organisation is looking to establish more hubs at other sites across the county.

**Recommendation 33:** To recognise the Ivybridge Link & Community Hub as an example of best practice and to support the Dove Project as well as other voluntary organisations with similar enabling opportunities to expand their services across Devon.

Participants expressed the view that special needs were not sufficiently recognised in the drive towards community care. For example, day centres were closed for the objective of finding employment opportunities but day centres gave people with a learning disability meaningful occupation as only a minority of them are able to work. Participants stated that commissioners can have an idealistic view of what people with a learning disability can achieve and often solutions such as independent leisure activities or full-time employment are not an option.

### Employment opportunities

Historically, a learning disabled person would access benefits for life and paid employment could provide a viable alternative for some individuals who could benefit from work activities by enhancing their confidence and skills of time-keeping, achieving targets, team working, work ethic, safe and structured working or getting a sense of achievement. However, identifying employers willing to offer disabled people secure and paid jobs was hard. Therefore, opportunities for self-employment are currently being explored. ACS also offers an in-house employment service and also uses one contractor, Pluss.

Pluss, who are owned by four local authorities including Devon County Council, employ 36 people with a learning disability direct and 101 people with a learning disability are supported and placed externally, all of whom are paid and work for 16 hours or more per week. Employment support prevents some social care provision, increases independence and helps in the overall financial climate.

Employment services had improved but Devon County Council could act as a model employer. Barriers should be removed and attitudes should be challenged and changed. "Reasonable adjustments" should also address attitudes and ways of working. Contributors also pointed out that currently there was some confusion about who was responsible for helping people with a learning disability find work within Devon County Council and contracts may be more suitably managed by the Environment, Economy & Culture directorate rather than ACS.

**Recommendation 34:** To explore how best the County Council and NHS trusts can become model employers for people with a learning disability, collect information and issue information and advice to line managers in order to better support people with a learning disability in the workplace. As a target, two work experience placements should be offered in each organisation's department per year.

**Recommendation 35:** To identify and encourage potential employers of people with a learning disability and town managers and to share best practice.

**Recommendation 36:** To provide dedicated support to current and potential employers.

Different challenges were highlighted with the task group in relation to employment, including transition from children and young people's to adult services and preventing individuals from becoming unemployed, complexity for employers, market fragmentation from employers' points of view and hence difficult partnership working as well as difficulties and barriers when individuals moved from one organisation to another.

The task group found evidence that officers with little understanding of the needs of learning disabled people usually decide if a particular occupation is meaningful but all assessments should be carried out from the point of view of the learning disabled person. The skills people with a learning disability offer make them ideal candidates for certain occupations, e.g. shelf filling or beach cleaning, but this might be deemed demeaning by able-bodied people. Disability awareness training for officers would give them a better understanding of disability and capability.

# Conclusion

Throughout this review, the task group has recognised the need for more coordination and better communication between County Council directorates and between ACS and providers, parent carers and advocates and a better planned application of resources. Parent carers repeatedly expressed the view that statutory services could resemble crisis management.

The task group also noted that the recommendations of a snapshot review carried out by the Michael Batt Foundation on service provision and standards in 2007 bear resemblance to this report's recommendations, including:

- providing tenancy agreements to all residents in understandable formats
- all supported living providers fulfilling accreditation criteria
- carrying out CRB checks for all employees
- addressing a lack of understanding of supported living by e.g. setting up a provider network
- introducing peer-to-peer quality checks
- providing mandatory training by a commissioned training provider to include risk assessment and management
- carrying out actions in a multi-disciplinary setting to prevent unilateral decisions
- monitoring contracts and carrying out spot checks
- narrowing the perceived gap between planning and implementing services and communicating to involved parties
- sharing information inter-agency e.g. via a database
- carrying out value for money evaluations out for the most expensive placements
- monitoring the quality and experience of staff

The task group hopes by presenting this report and recommendations to contribute constructively to the improvement of services for people with a learning disability.

**Recommendation 37:** To recommend to the Health & Adults' Services Scrutiny Committee to request a report on the implementation of the recommendations of the learning disability task group in March 2011 and at regular intervals thereafter.

## Summary of Recommendations

<b>1</b>	To improve communications with people with a learning disability, parent carers, providers and advocates, to respond to correspondence and to keep all involved parties informed, especially with regard to service access and changes to services.
<b>2</b>	To expand joint training between staff and parent carers.
<b>3</b>	To establish a coordinated database of needs in order to catalogue conditions and their resulting needs which form the basis of accessible and bespoke services.
<b>4</b>	To ensure that appropriate agencies provide application forms for housing and other benefits as well as all correspondence in accessible formats for people with a learning disability.

<b>5</b>	To recommend to the Health & Adults Services Scrutiny Committee to convene a separate task group to review health care for people with a learning disability.
<b>6</b>	To ensure the involvement of ACS early on in an individual's transition and to improve communications with CYPS from at least Year 9 in order to guarantee a seamless transition.
<b>7</b>	To better utilise information about individuals collated by support staff such as teachers and career advisors as well as carers.
<b>8</b>	To improve the provision of information for parents about service and financial changes resulting from the shift from CYPS to ACS.
<b>9</b>	To identify and ring-fence funding for adult placements in the financial year prior to transitions in order to enable forward planning for all involved parties and ensure a smooth transition.
<b>10</b>	To review the process for determining and contracting levels of support for individuals and to assure the Health & Adults Services Scrutiny Committee that the process is based on evidence.
<b>11</b>	To establish named contacts, including contact information and direct telephone numbers, in ACS for providers and people who use services.
<b>12</b>	To only alter the terms of contracts in consultation with providers and to improve the process by which funding is allocated in order to provide longer-term security for service provision.
<b>13</b>	To better plan services for people with a learning disability in rural areas and to make greater use of the network of parents, carers, teachers, statutory, voluntary and private organisations etc.
<b>14</b>	To facilitate networks of unfunded support for non-eligible support.
<b>15</b>	To encourage councils for community and voluntary services (CVS) in Devon to raise awareness among their member organisations to consider extending befriending schemes for people with a learning disability.
<b>16</b>	To formally accredit providers with the commissioners, to establish minimum criteria for safe service provision and to monitor providers regularly, including safeguarding adults and how providers use statutory funding.
<b>17</b>	To improve response times to crises and to assess questionable placements carefully before re-offering them to different individuals.
<b>18</b>	To improve safeguarding arrangements, including response times to alerts, concerns and crises as well as communication between professionals from different agencies.
<b>19</b>	To recommend to the Health & Adults Services Scrutiny Committee to convene a separate task group to review safeguarding arrangements in ACS.
<b>20</b>	To improve professional development opportunities in relation to the needs of people with a learning disability, including staff who compile brokerage outcome statements.
<b>21</b>	To establish working relationships with more organisations with the potential of offering services to people with a learning disability, such as housing and leisure providers.
<b>22</b>	To involve all support staff, including teachers and careers advisors, routinely in the compilation of brokerage outcome statements.
<b>23</b>	To sign off all final brokerage outcome statements with the person concerned or their families and/or carers.
<b>24</b>	To review the commissioning procedure for people with complex and severe needs and to consider offering them placements avoiding brokerage considering the very limited number of suitable providers.

<b>25</b>	To further develop the market in order to ensure that services and solutions can be found which meet people's needs.
<b>26</b>	To improve communications with providers throughout the brokerage process and to communicate outcomes to all bidding providers.
<b>27</b>	To consider alternatives to the current commissioning procedures in order to better meet people's needs and desired outcomes and to provide more creative, bespoke and needs-led solutions.
<b>28</b>	To explore how professional and senior staff can be relieved of their administrative duties.
<b>29</b>	To ensure the representation of the individuals' social workers at review panels as well as at least one elected member as a standing member.
<b>30</b>	To give local members the opportunity to represent residents from their divisions at the panel, similar to school transport appeals.
<b>31</b>	To proceed with service withdrawal only after replacement solutions have been successfully established.
<b>32</b>	To develop the provider market, particularly in the areas of day centres, hubs, housing and transport (reference Rural Access to Health Task Group Report, March 2010, recommendations 1-9).
<b>33</b>	To recognise the Ivybridge Link & Community Hub as an example of best practice and to support the Dove Project as well as other voluntary organisations with similar enabling opportunities to expand their services across Devon.
<b>34</b>	To explore how best the County Council and NHS trusts can become model employers for people with a learning disability, collect information and issue information and advice to line managers in order to better support people with a learning disability in the workplace. As a target, two work experience placements should be offered in each organisation's department per year.
<b>35</b>	To identify and encourage potential employers of people with a learning disability and town managers and to share best practice.
<b>36</b>	To provide dedicated support to current and potential employers.
<b>37</b>	To recommend to the Health & Adults' Services Scrutiny Committee to request a report on the implementation of the recommendations of the learning disability task group in March 2011 and at regular intervals thereafter.

## Acknowledgements

The members of this task group would like to thank all contributors who gave their time to speak with the group, for their hard work to help to shape the focus of this review, for sharing their expertise and for commenting on draft recommendations.

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