

THE CURRENT AND FUTURE NEEDS OF PEOPLE
WITH A LEARNING DISABILITY IN HEREFORDSHIRE

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Lydia Bailey and
Mike Metcalf

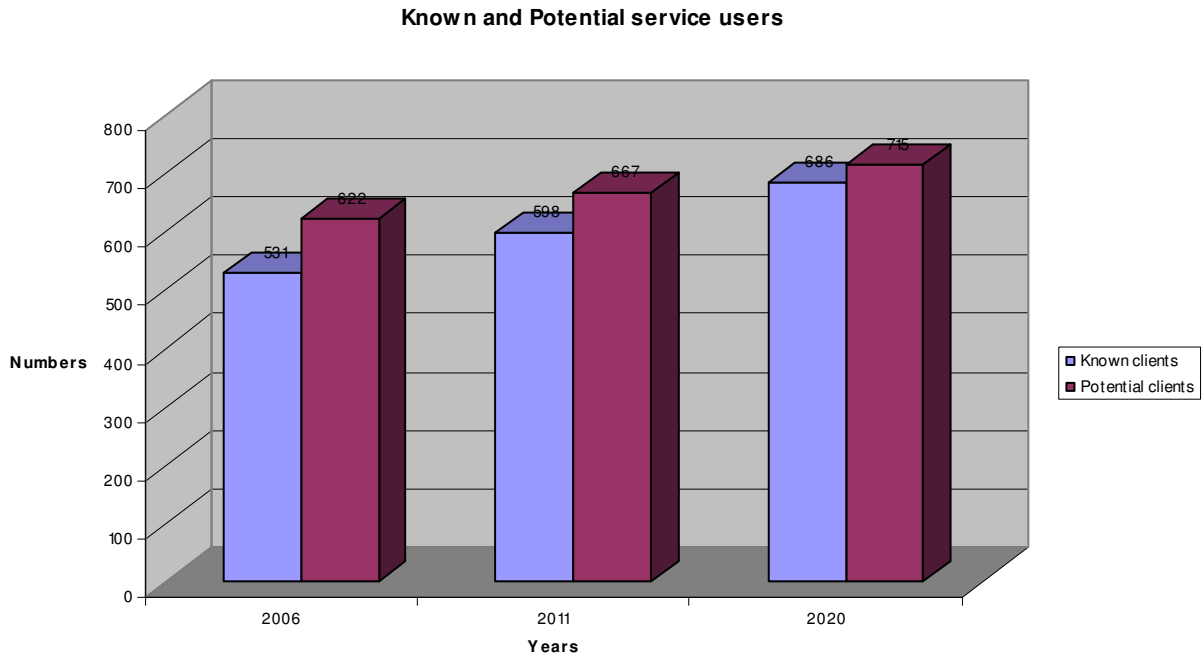
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SUMMARY

Population and trends

- 531 adults are known to Herefordshire Learning Disability Services in April 2006. The majority of these people have a moderate, severe, or profound learning disability, but the service also supports some people with mild learning disabilities.
- 531 is lower than the number that could be anticipated by national prevalence rates for people with moderate to profound learning disabilities, and might imply that some people who would be eligible for services are currently unknown. It is quite possible that these people will be referred for services in the future. The chart below shows the range between known and potential numbers of service users.

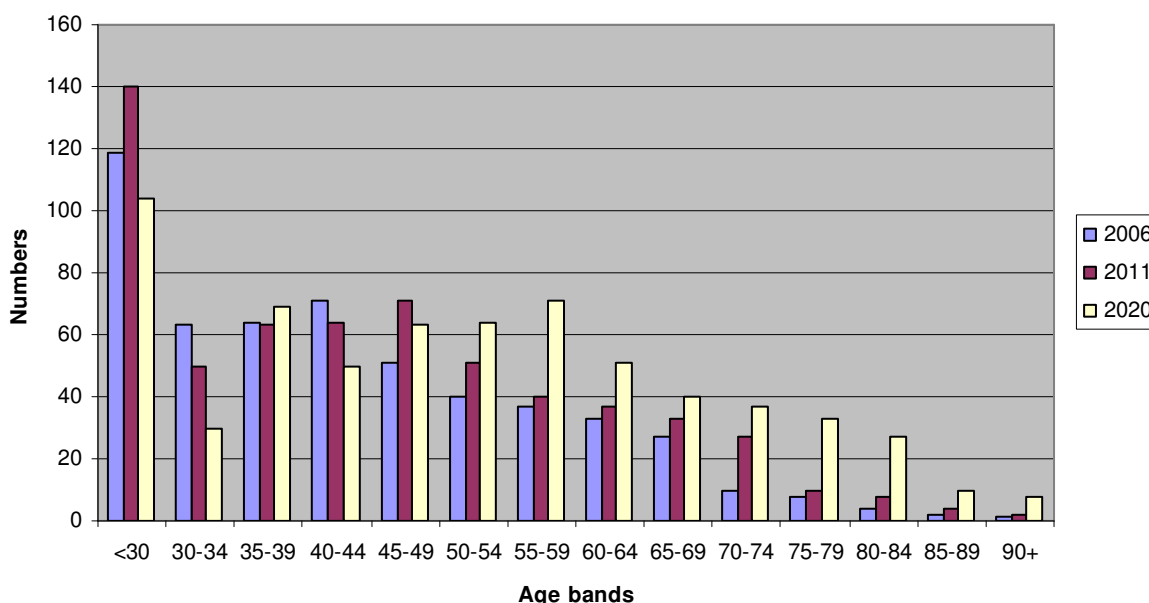


The figures for "potential clients" are based on Emerson and Hatton's estimate of 0.46% of general population related to the proportion of over 20s (see page 9 below). The figure for known clients in 2020 assumes an average of 10 new school leavers per annum. The 2011 forecast figure takes account of the changed age profile for the whole population – ie. a higher proportion over 20 (79.5%). The 2020 projection assumes 81% will be over 20.

- It should also be noted that the ONS-sub population projections for 2020 are based on recent demographic trends and do not take into account housing provision as population forecasts do (only available to 2011 from the Herefordshire Council Research Team).
- As in the rest of the population, people with learning disabilities are living longer, and the effects of this on service demands are already being felt. The age profile of the

client group for the service will change substantially over the next 15 years, and shift towards the older groups, as shown in the chart below.

Age Profiles for 2006, 2011 and 2020



Demands for social and health care

- By the time people with learning disabilities reach their mid 40s, most have moved from the family home into other accommodation and support (ranging from independent living to intensive residential or nursing care). At this age, most family carers are around 70 years old or more. In Herefordshire, there are currently already 33 people living with a family carer over the age of 70 (22% of those in family care).
- The level of demand for care and support services is largely reflected in the dependency levels of the client group. Two major factors influence the changes to the dependency profile of the client group in 2006 and future years:
 - the transfer of children and young people with learning disabilities to adult services (many of whom are now surviving very severe disabling conditions into adulthood)
 - the ageing population of people with learning disabilities, who consequently need more care and support in daily living.

In Herefordshire, clients are assigned into 6 dependency bandings (with 1 being lowest and 6 highest). The changing dependency profile is shown in the table below and takes account of children in special schools who will transfer to adult services in the next 10 years:

	2006	2011	2015	% change
Lower dependency (Bands 1 & 2)	226	245	245	+8%
Higher dependency (Bands 3 – 6)	305	355	388	+27%

- Overall, the number of people in the higher dependency bands will rise by ¼ in the next 10 years (to 2015).
- An important but unknown factor is that people with milder learning disabilities who are not eligible for a service at present may become eligible in the future as their age and dependency increases.
- Another factor is a purely local phenomenon. Herefordshire has a high level of learning disability residential care beds per head of population compared with other authorities (the highest in the West Midlands). The availability of beds has led to an influx of people from outside Herefordshire. At present, out-county people comprise up to 22% of the total population of adults with learning disabilities living here.
- The impact on local services is twofold:
 - Demands for health services from both general teams and the specialist Community Learning Disabilities Team (CLDT)
 - Referrals to the Community Team for adult protection investigations (this currently amounts to between 25-30 per annum)These already impinge on the capacity of the CLDT to meet local needs, and any further expansion of residential facilities will add to these demands.

Herefordshire Learning Disabilities Needs Analysis April 2006

Herefordshire Background Information

- Herefordshire is a Unitary Authority, which has co-terminus boundaries with the Primary Care Trust.
- Current population is 177,800 (mid 2004 estimate).
- Herefordshire has one of the lowest population densities in England and Wales with 0.8 people per hectare. This creates challenges with regard to transport and access to services.
- Herefordshire faces specific challenges in the future as it is predicted that although the general population increase will be in line with England, the number of people over retirement age will increase significantly. This will be accompanied by a large decrease in the number of people aged 0-4 years and 25 – 44 years.
- In 2005 property prices in Herefordshire have increased at a higher rate than that for England (6.2% compared with 4.6% average) with the average house price being £204,180 in the last quarter of the year (£191,327 for England and Wales).*
- Unemployment in Herefordshire remains low at 1.7%. This is compared to 2.6% in the West Midlands and 3.3% in Great Britain*.
- Average earnings are well below the West Midlands average. In November 2005 full time gross weekly earnings were £352.00 for Herefordshire compared with £402.50 for the West Midlands**.
- Although there has been little ethnic diversity in the past, the situation is changing rapidly since the recent expansion of the European Union.
 - 97.5% are White British (compared with 87.5% in England and Wales).
 - 0.2% are Asian or Asian British (compared with 4.4% in England and Wales).
 - 0.1% are Black or Black British (compared with 2.2% in England and Wales).
 - 0.2% are from Chinese or other ethnic backgrounds (compared with 0.9% in England and Wales).
 - The largest single ethnic minority group has been traditional or Romany travellers.
 - For some years there has been a large influx of seasonal workers from Eastern European countries in the summer, to work as fruit pickers.
 - Very recently, many people from both Eastern Europe and Portugal are becoming full time residents, as economic migration brings a fairly rapid change to the ethnic and cultural composition of the county.

*Quarterly Economic Report February 2006 – Herefordshire Partnership

** Quarterly Economic Report November 2005, Herefordshire Partnership

National Prevalence of learning Disability

Definition of Learning Disability

The World Health Organisation defines a learning disability as 'a state of arrested or incomplete development of mind'. Someone with a learning disability is also said to have 'significant impairment of intellectual functioning' and 'significant impairment of adaptive/social functioning.

Although no official statistics exist which show how many people have a learning disability within the UK, there is information available from epidemiological studies and known prevalence rates.

The latest work in this area done by Eric Emerson and Chris Hatton (Institute of Health Research, Lancaster University, 2004) suggests that the true rate of learning disability in the U.K. is 2% of the population (higher in some age groups than others) making a total of 985,000 people in England.

This figure would cover the total range of learning disability across the general population. However some people would not need to access specialist services and would manage well within their local communities with support from generic services.

People with a learning disability are often categorised by the level of learning disability they have. This usually includes 4 divisions:

Degree of Disability	IQ range	Typical levels of need
Mild	Between 50 -70	People with a mild learning disability are usually self-sufficient and live independently, although they sometimes need community and social support. Skills: Hold a conversation. Full independence in self-care. Practical domestic skills. Basic reading/writing
Moderate	Between 35 -50	People with a moderate learning disability can carry out work and self-care tasks with moderate supervision. They typically acquire communication skills in childhood and are able to live and function successfully within the community in a supervised environment such as supported housing. Skills: Limited language. Need help with self-care. Simple practical work (with supervision). Usually fully mobile.
Severe	Between 20 -35	People with a severe learning disability will be able to fulfil basic self-care tasks and have some communication skills. They need to live in highly supported environments such as small residential homes or supported living. Skills: Use of words/gestures for basic needs. Activities need to be supervised. Work only in very structured/sheltered setting.

		Impairments in movement common.
Profound	Less than 20	They may be able to develop basic self-care and communication skills with appropriate support and training. However will always require high levels of care and support (24 hour) Often have additional impairments such as mobility, and associated health needs. Skills: Cannot understand requests. Very limited communication. No or very limited self care skills. Usually incontinent. May have mobility difficulties.

Some individuals are also described as having 'profound and multiple disabilities', indicating they also have physical disabilities with varying degrees of sensory and mobility problems, and may use a wheelchair.

People with a learning disability may also have behavioural problems, which can range from mild to very challenging. This may be linked to specific disabilities, communication difficulties, epilepsy, or mental health problems.

The majority of specialist services funded through a local authority are usually to meet the needs of people with moderate, severe and profound learning disabilities (including people with multiple disabilities), and providing some support and preventative services to a number of vulnerable people with mild learning disability.

Typically there are 3 - 4 people with a moderate to profound learning disability for every 1000 people in the population (0.4%) This means nationally there are approximately 210,000 people in England. This figure would include 65,000 children and young people, 120,000 of working age and 25,000 older people.

Evidence suggests that the number of people with a moderate to profound learning disability will increase by 1% per annum for the next 15 years. This is for four main reasons:

- Increased life expectancy, especially among people with Down's Syndrome.
- Growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood.
- A rise in the number of school age children with autistic spectrum disorder, some of whom also have a learning disability.
- Greater prevalence among some minority ethnic populations of South Asian origin.

Herefordshire Profile

Prevalence of learning disabilities

There are 2 methods to calculate the expected number of people and the results can be compared with the true caseload of the service;

1. National prevalence and levels of disability method:

In Herefordshire, given the current population figures of 177,800 (mid-year estimate for 2004), the number of adults with a moderate to profound learning disability would be approx. 711 people, of which approximately 23% would be under the age of 20. This means that Herefordshire would expect to be supporting approx **547** adults with a moderate to profound learning disability, and providing preventative services to a number of vulnerable people with a mild learning disability.

The number of people currently known to the Adult Learning Disability Services is **531**. This matches the predicted number fairly closely and is the figure that has been used for all analysis purposes within this report.

2. Administrative prevalence:

Emerson and Hatton (2004)* used a more pragmatic measure of “people with learning disabilities who are known to learning disability services”, based on studies of LD registers in 24 authorities. This produced an administrative prevalence rate of 0.46% of the general population, of which 75% are 20 or older, 64% between 20 – 59, and 12% over 60. People with moderate and mild disability levels but receiving support would be included in these numbers.

Current estimates for Herefordshire using this rate gives a total figure of 818 people of whom **614*** are over 20 – ie. an additional 91 over those currently known to the service. There could be discrepancies relating to different eligibility criteria for services in the areas studied for this prevalence rate.

Need for services

It is worth mentioning that, even with a perfect match between national and local figures, there is never a perfect correlation between levels of disability and the need for services. This is because the need for service supports varies considerably even within each level of disability. Factors such as social support networks, capacity of families, previous experience, individual health factors etc. are different for each individual.

Other factors, which have direct relevance are now examined.

Age Distribution

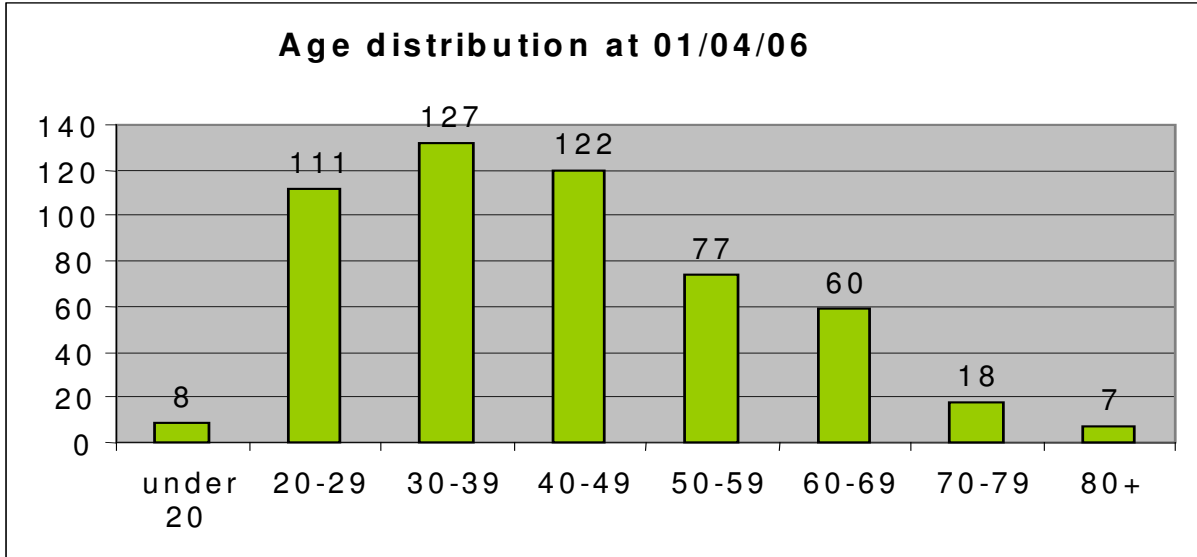
This is analysed in some detail because the balance between younger and older age groups is set to change significantly (see above).

** The figure of 622 quoted in the Summary (page 3) includes a further 8 known clients under 20 years old*

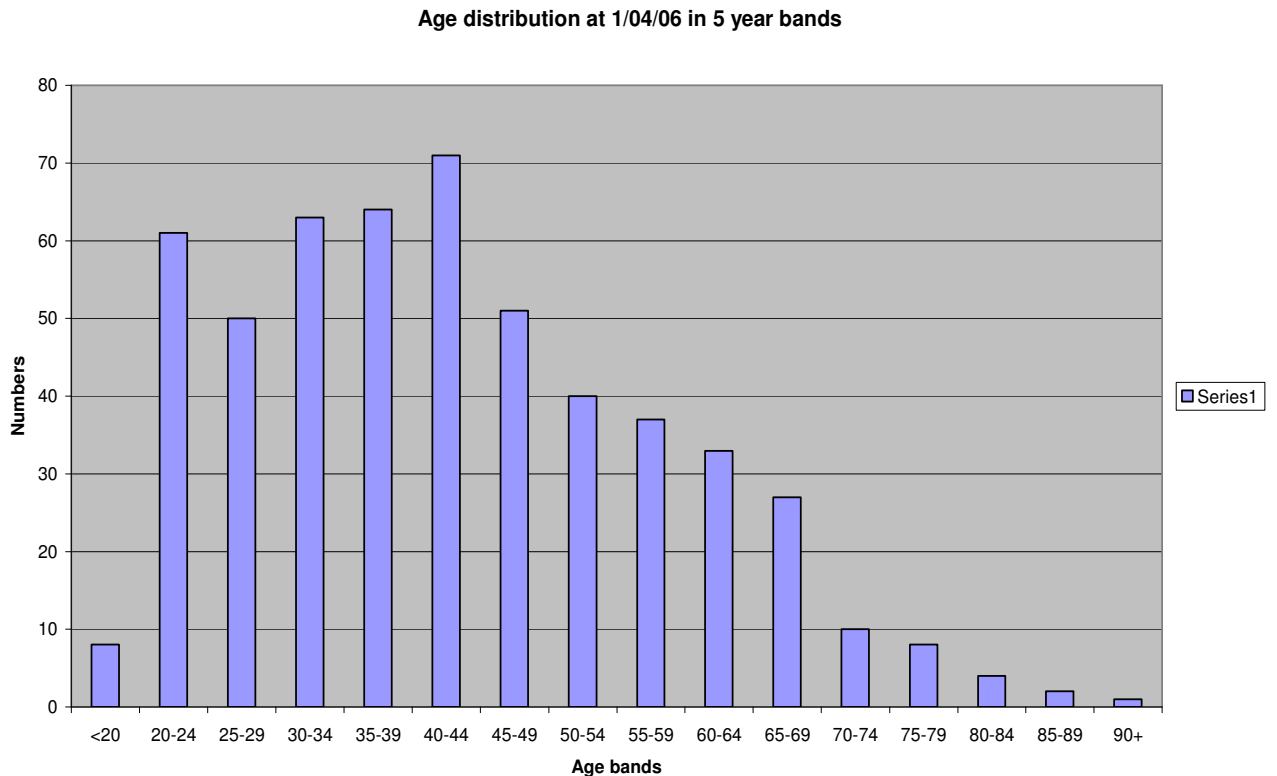
**Estimating the current Need/Demand for Supports for People with Learning Disabilities in England (2004) Eric Emerson and Chris Hatton, Institute for Health Research, Lancaster University.*

Fig. 1

Age distribution of people with a learning disability, known to Herefordshire learning disability services.



And in more detail



Dependency Bandings for all current clients

All people known to the service have been assigned to a dependency category that reflects the demands on the service. **This reflects the "effective demand" for local services in early 2006.** Band 1 represents low dependency and Band 6 represents high.

LD Banding matrix

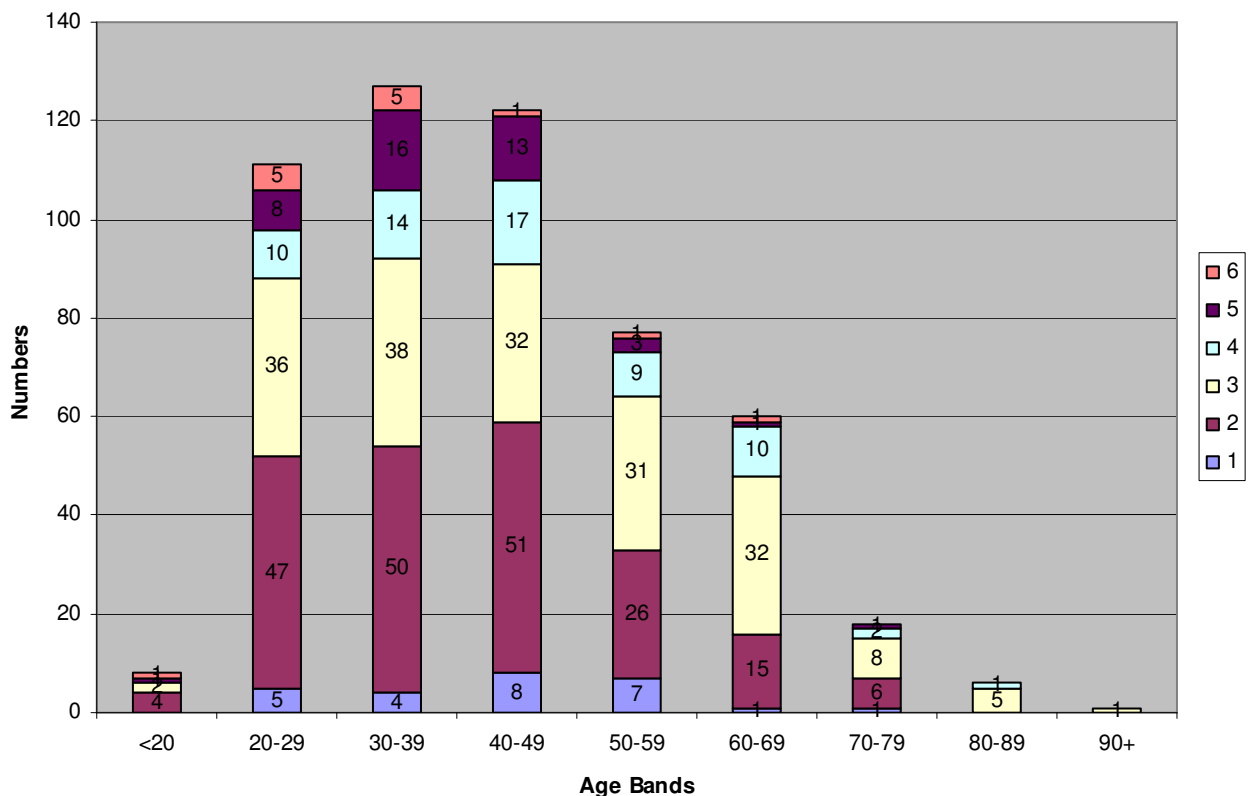
Band	Description	Possible Indicators
BAND 1	Minimal support People with low level need. Need minimal support.	<ul style="list-style-type: none"> With minimal/community support can keep safe, meet own personal care needs, travel independently, and can sustain some involvement in activity (social, occupational) May need some support because of Mental Health problems, adult protection issues etc.
BAND 2	Low-medium support/no care People with low/medium levels of support need, may require 24 hour support (not care) vulnerable	<ul style="list-style-type: none"> Needs supervision or support for set times of the day, in the form of prompts and guidance, There can be gaps in support (either short or medium gaps) Reduced ability to sustain community involvement (social, occupational). Vulnerable and possible mental health problems, adult protection etc.
BAND 3	Medium-high support/low level care People with medium/high support needs (24hour) and low-level, personal care needs.	<ul style="list-style-type: none"> There can be no gaps in support, over the 24 hour period. May need assistance with some personal care, Does not require night time attention (waking night support)
BAND 4	High support/low - medium care People with medium/high level support/care needs, may have additional needs, such as low level challenging behaviour or epilepsy etc	<ul style="list-style-type: none"> Needs 24 hour support and/or personal care May require night- time assistance possibly because of epilepsy. May have behaviour which is difficult to manage, including self injurious but does not pose a serious risk or danger. May have low level physical disability which limits independence.
BAND 5	High Support/High Care People with profound and multiple disabilities or specialist needs because of challenging behaviour or complex health needs.	<ul style="list-style-type: none"> Needs 24 hour support and care May have medical needs which require ongoing management May display difficult behaviour which requires ongoing management and presents some risk to self or others. May have extensive physical disability requiring hands on support.
BAND 6	Specialist support/care People with very specialist needs either because of very challenging behaviour or complex MH or health problems.	<ul style="list-style-type: none"> Needs specialist 24 hour care and support May have very challenging behaviour, which requires management by specially trained staff and poses serious risk to self or others. May have ongoing medical needs which require management

This is the profile for clients in Herefordshire in April 2006:

	Numbers	%
Band 1	27	5%
Band 2	199	37%
Band 3	185	35%
Band 4	63	12%
Band 5	43	8%
Band 6	14	3%
Total	531	100%

The dependency bandings are fairly evenly distributed in the younger age groups, but obviously increase proportionately in the older clients. For example, the proportion in bands 1 and 2 (lower dependencies) is 46% in the under 50s, but drops to 35% in the over 50s. The chart below illustrates this.

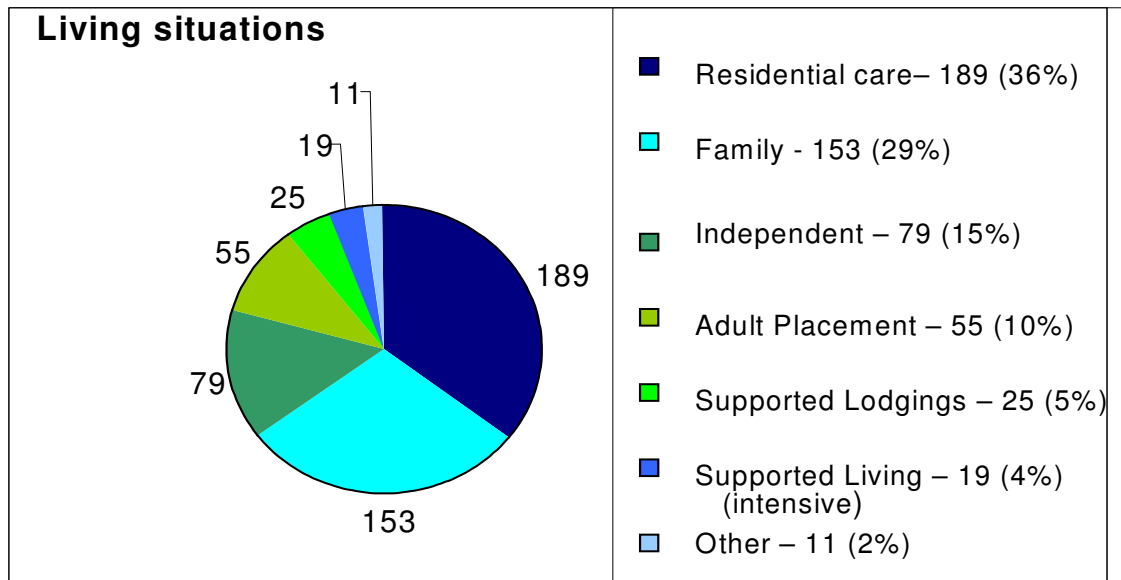
Dependency categories in 10 year age bands



NB. The graph only illustrates the situation at present, and does not reflect the future. In the next section, the changing age profile is illustrated, and this will be reflected in the banding profile too.

Where people live

This is obviously a critical factor for predicting future service demands. The current pattern is as shown in the chart:



It can be seen that the largest number of individuals are living in registered care homes, although this is balanced with a higher than average number of people living in their own home with or without support and supported lodgings. However the most unusual aspect of the breakdown is the very low proportion of people who are living with family carers (153 out of 531 people).

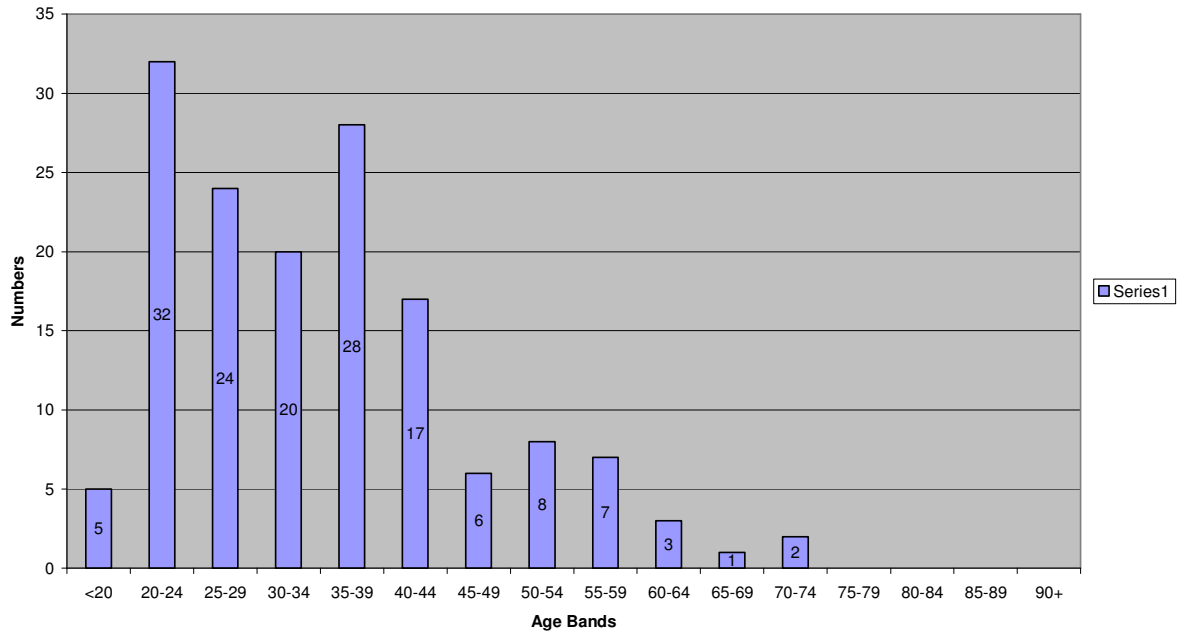
In the majority of authorities 75% of the know population would be living with family carers. In Herefordshire this is 29%. This means that a much higher proportion of people are living in registered care, resulting in Herefordshire having the highest number of care beds as a percentage of the population in the West Midlands.

People living with family carers

This group needs special attention in predicting future service needs.

The following shows the breakdown of ages of the people currently living with unpaid family carers.

Age distribution of people living with family carers (1/04/06)

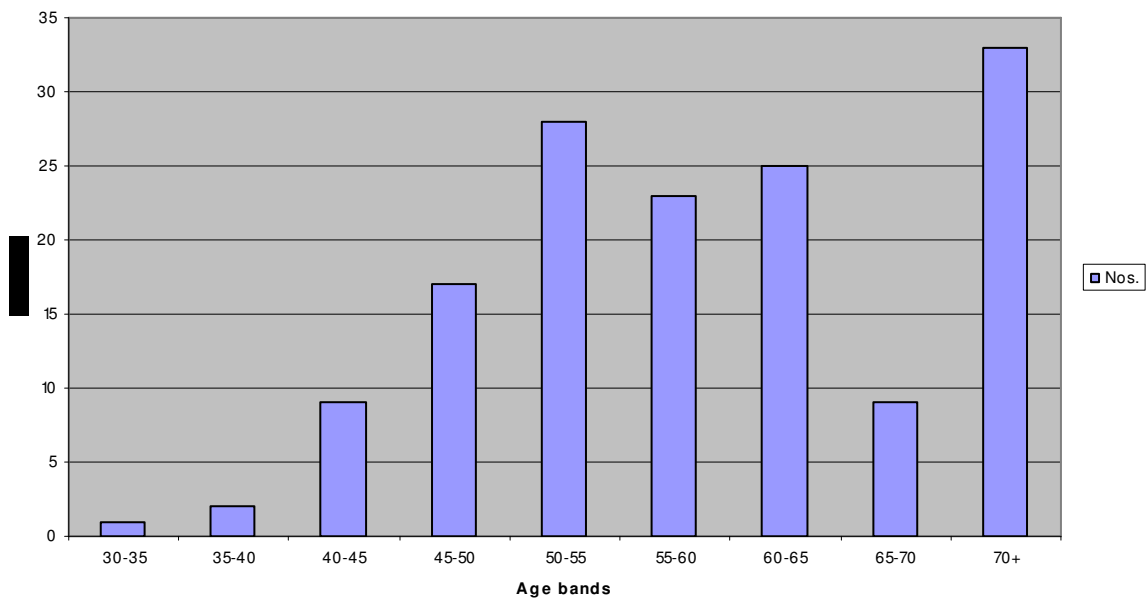


It is clear that the numbers of people remaining in family care drops dramatically after 45 years of age when parents are in their late 60s and 70s. It is this group that is set to increase in relation to the younger group, and this is examined later in the analysis.

Older Carers

It is estimated nationally that about 1/3rd of people with learning disabilities living in the family home will be living with an older carer (aged 70+). (*Valuing People, Department of Health Cm 5086, March 2001*). In Herefordshire, the proportion is lower, and amounts to 22% or 33 people. However, some carers are already in their 80s. The proportion of people living with carers over 65 is 29%. The chart below shows the family carers' age profile*:

Age profile of main family carers April 2006



**NB. The slight difference between the totals in this chart and that on page 13 is because some people left the family home in between the data samples.*

In summary, there are already 33 people living with carers over 70 where a need for service support (alternative residence, or support package for daily living) could arise at any time. By 2011, some of these people will have moved to a different form of accommodation or support, but potentially a further 9 could be added to this cohort. By 2016, a potential extra 25 could be added and by 2020 a further 23.

FACTORS AFFECTING FUTURE SERVICE NEEDS

This section examines the following:

- ⇒ General growth in the adult population, related to ageing and reduced mortality
- ⇒ Transitions – the flow of children into adult services
- ⇒ Specific ethnicity factors
- ⇒ Other local authority clients in Herefordshire.

and calculates the impact to 2011 and 2020.

Changes to the Demographic Profile of the General Adult Population

Emerson and Hatton** estimated the growth in the numbers of people with learning disabilities from general population changes from 2001 – 2021. The general rise is primarily from the huge increase in the numbers of people over 60.

The two main factors here are reduced mortality in adults with learning disabilities and the transition of children to adult services. These factors are examined in more detail.

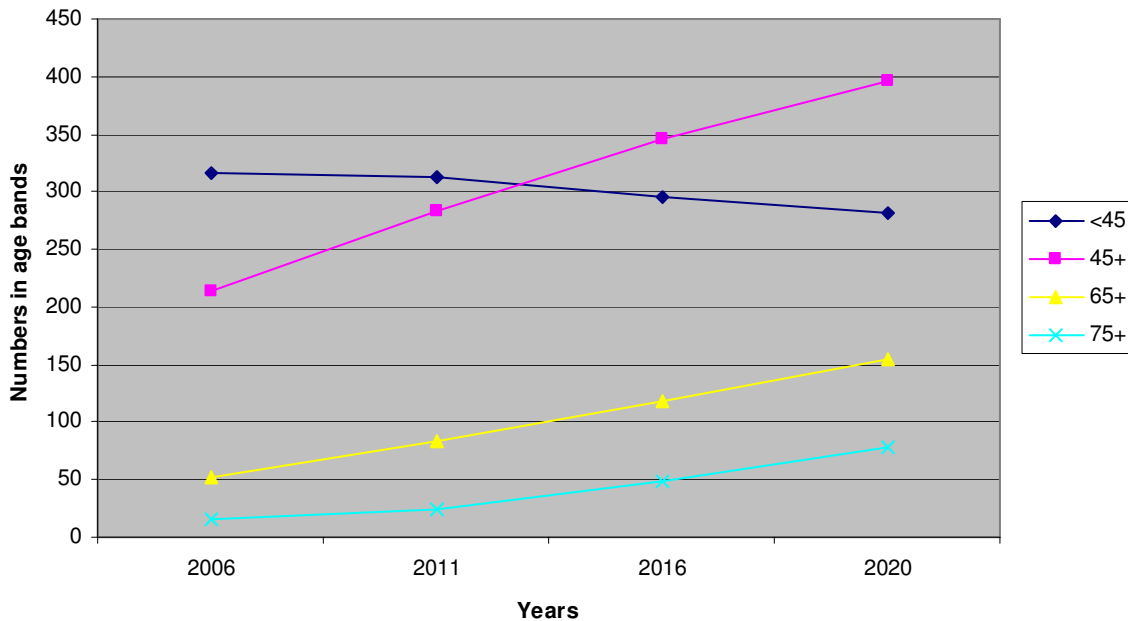
Reduced Mortality

Emerson and Hatton used the Sheffield LD Case Register to predict the changes to age-specific prevalence rates. There was little significant change in mortality in the younger age bands, but in older groups they calculated significant increases.

In Herefordshire, irrespective of mortality rates, as people age and move through the age bands, the profile changes as shown in the chart. Younger age bands from 35 to 44 years start to decrease, whilst those above 45, 65 and 75 increase steeply. This is shown in the table and chart below and refers only to known clients:

	2006	2011	2016	2020
<45	317	313	295	282
45+	213	283	345	396
65+	52	84	119	155
75+	15	24	49	78

Changes in age profiles to 2020



Important note. The figures analysed above are of known service users, they do not “factor in” those who are not known. People with mild learning disabilities may be living independently with success either with or without support from generic services at present. However, in their older years, their dependency may increase and make them eligible for a support from the learning disability service.

In addition, the rates predicted by national prevalence rates and calculated by Emerson and Hatton from LD registers gave higher figures for Herefordshire.

Transitions and increased survival among young adults with severe and complex disabilities

Each year a number of children transfer over from children’s services to adult learning disability services. These can roughly be defined into three different groups

1. Young People who live with family carers and attend one of the two ‘special’ schools in Herefordshire. These are more likely to be people with moderate to profound learning disabilities who will require ongoing support and services from adult learning disability services. As information is already available regarding these young people it is possible to use information to plan future services.
2. Young People who are placed at residential special schools, either because they have very specialised needs or their home situation has broken down. These children are unlikely to be able to return home and will therefore need housing and support. Again it should be possible to plan for their needs as they are already clearly identified.
3. Young People who live with family carers and have attended mainstream education. The majority of these individuals will have a mild learning disability and will access mainstream services. However for some individuals, either because of adult

protection issues or specific needs, they may require support from Adult learning disability services. The difficulty is that it is impossible to identify how many of these young people will require a service, at what stage and at what level. This group therefore remains an unknown quantity.

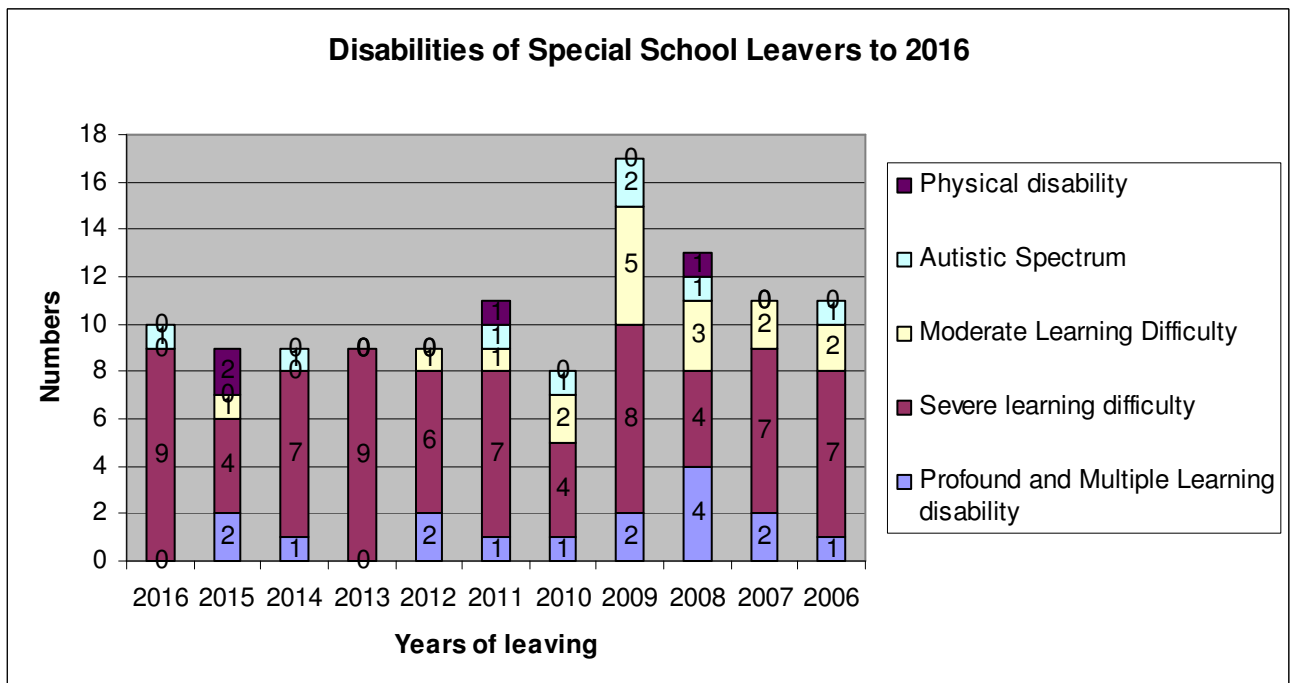
Each year the number of children who will transfer to adult learning disability services will vary. The table below shows the numbers who are currently attending a special school and their profile of dependencies for the next 11 years (using Education coding categories). *NB. These projections cannot reach 2020 because of the lack of reliable school data for the later years.*

Transitions from Special Schools (2006 to 2016) – numbers transferring

Dependency level	Number
Profound and Multiple disability	16
Severe learning disability	72
Moderate learning disability	17
Physical disability (+ moderate learning disability)	4
Autistic spectrum (+ learning disability)	8
Totals	117

As predicted in national studies, the number of young people transferring will have predominantly severe and profound/multiple needs.

The flow of young people to the adult service will be as follows:



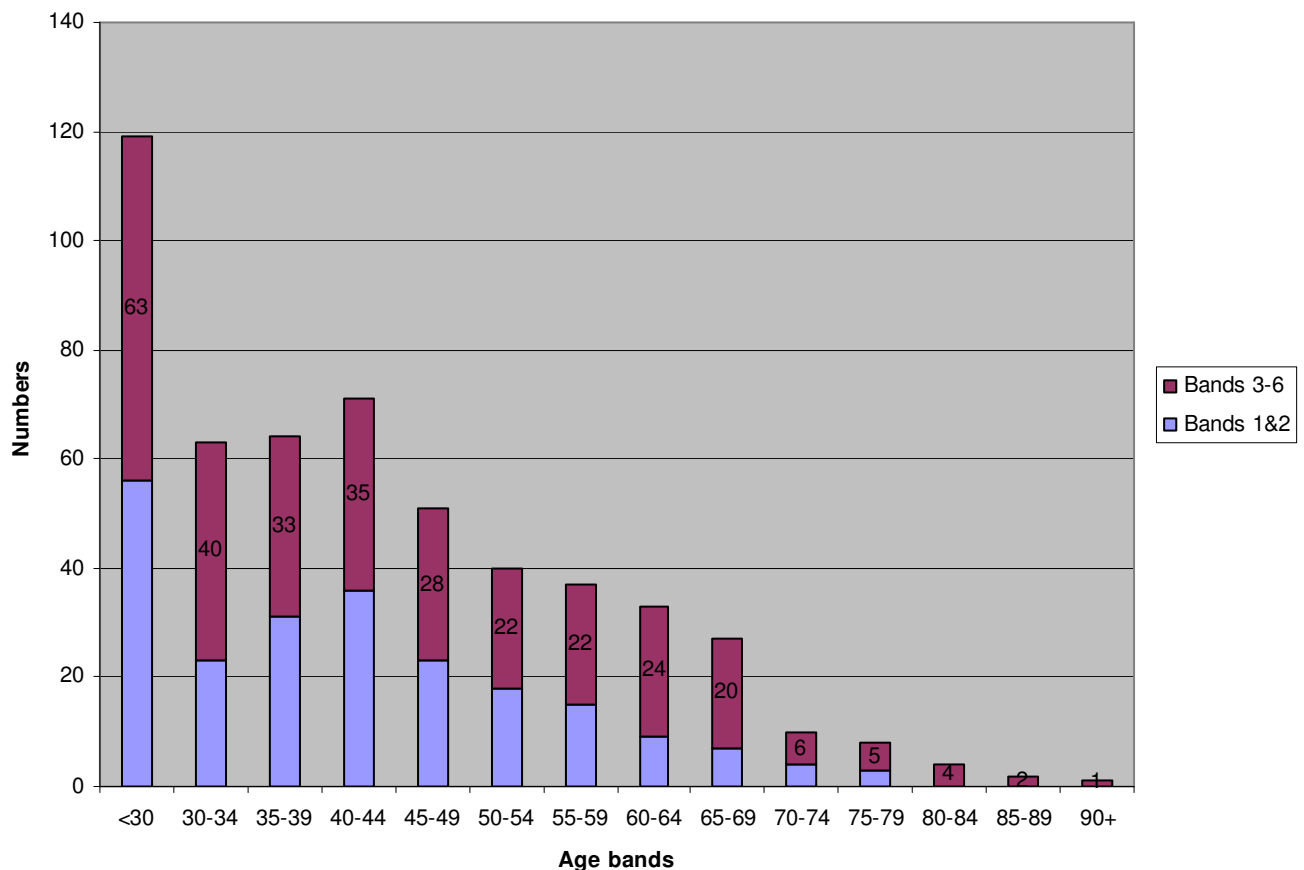
In summary, in the 6 years to 2011 the adult service can expect to support an additional 71 young people of whom the large majority will have severe and profound learning disabilities

(51). In the following 5 years, 2012 – 2016 the service can expect a further 46 young people of whom almost all (41) will have severe and profound needs.

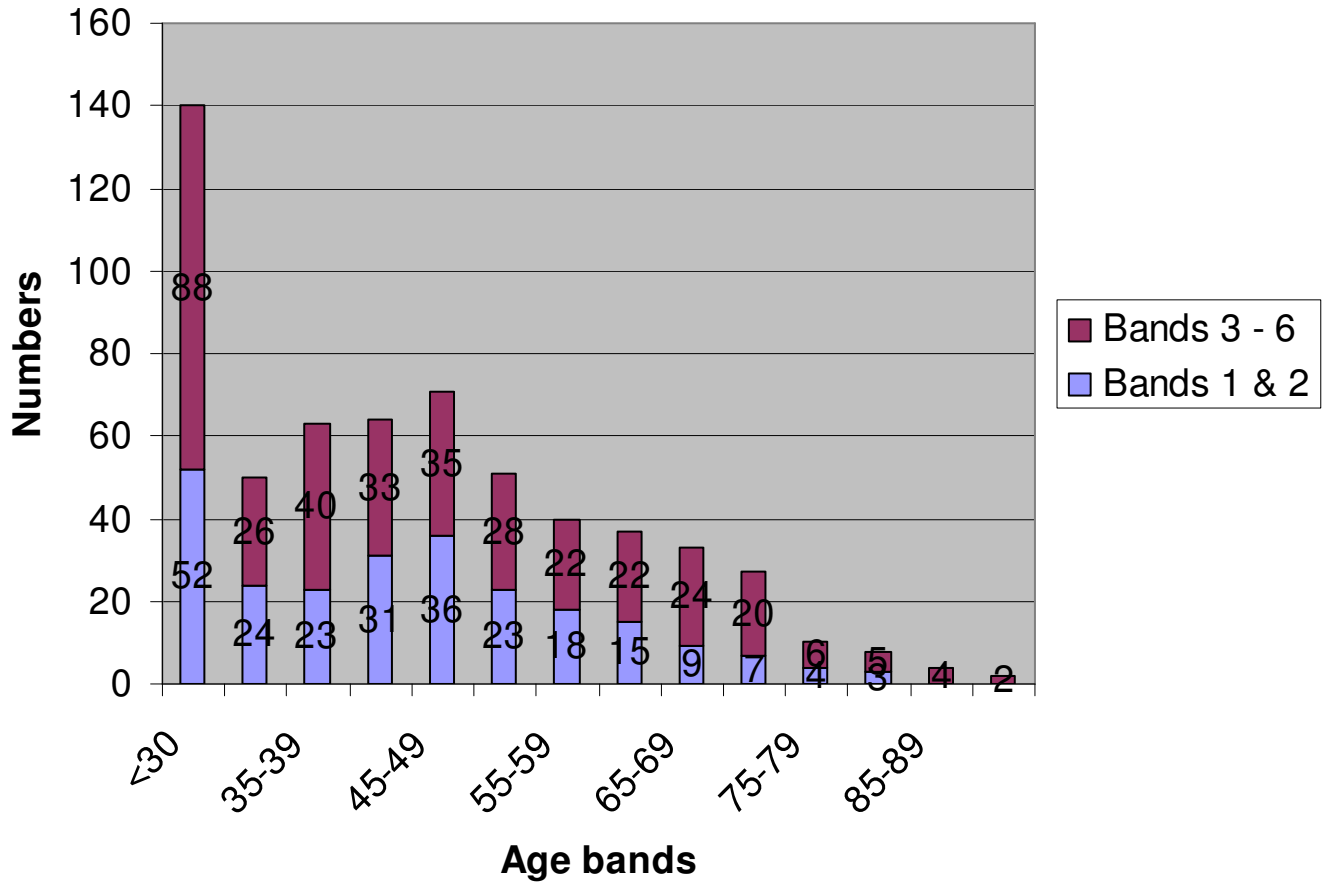
There will be other referrals from children attending mainstream schools who are referred to the service primarily because of complicating social needs, such as adult protection issues. These are small in number and unpredictable (say 1 or 2 per annum) and have not been factored into the figures above.

The effect on the total profile of age and dependency is now illustrated in the charts below. Young people with autistic spectrum disorders will span the dependency ranges (although all in this case have learning disabilities) and have been split between the higher and lower dependency bands.

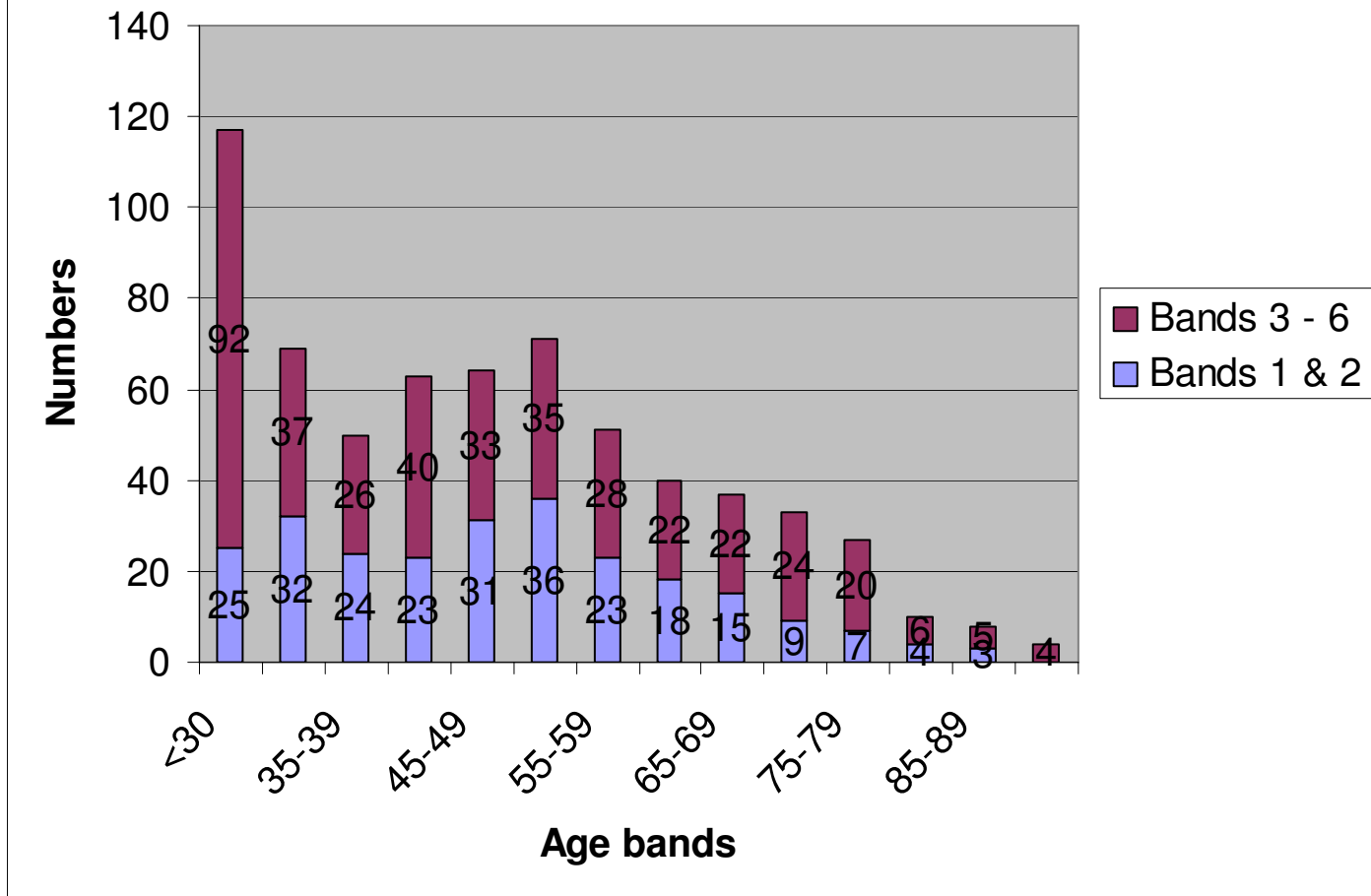
Summary of age and dependency bandings at April 2006



Age and Dependency Profile in 2011 with school leavers added



Age and dependency profile in 2016 with school leavers added



The upwards shift in terms of age and dependency can be tracked in these charts. The conclusions are that:

- the number of people over 65 years old will more than double in the next 10 years
- the number of people in the higher dependency bands in all age groups will rise by over one quarter in the next 10 years.

Ethnicity factors

The prevalence of learning disabilities in South Asian (Bangladeshi and Pakistani) communities is significantly higher. This will have an impact on areas where high proportions of the population come from these ethnic minority communities.

The total population of people of Asian origin in Herefordshire in December 2004 was:

Asian or Asian British (0.2% of county population, or c.350 all ages)	<i>Indian</i>	<i>0.10% (c.100 adults)</i>
	Pakistani	0.03% (c.40 adults)
	Bangladeshi	0.02% (c.25 adults)

From this it is clear that there is unlikely to be any tangible impact on learning disability services unless there is considerable inward migration from these particular communities.

Other new demands on the service

a) Out-county clients

Because of the high level of residential provision in Herefordshire, there is a significant group of people placed by other local authorities and health trusts. It is impossible to be predictive about these people because they are largely unknown to the service, but may number up to 160, from CSCI information. No age and dependency profile is thus available.

Herefordshire is accustomed to demands for health services for these out-county people as they arise, including specialist services from psychiatry, psychology and nursing, plus social work intervention to investigate allegations of adult abuse under the vulnerable adult policies.

These factors, although not quantified here in any detail, already represent a significant operational factor for the community learning disability services, and have done for several years.

b) Other clients not known to services

As indicated above, the service can expect an average of only 2 referrals per year.

c) People with borderline learning disabilities but with high cost needs. These include people who may be referred via the police or courts. Recent experience is an average of 2 – 3 referrals per year. Clearly, the numbers are very small, but the cost of the service response for individuals can place severe strain on the existing budgets. As in other areas of social care, it is extremely hard to forecast this type of demand.

d) Ageing carers

The age profile of family (unpaid) carers is obviously a major factor in predicting the need for service support. The capacity of older carers to continue caring is subject to a vast number of variables and hard to predict. However, the number of existing and future carers over the age of 70 is a challenge to service planning and commissioning.

WHAT DOES THIS MEAN FOR HEREFORDSHIRE?

To sum up, this is how the needs and demands for services will change in future years:

1. The balance between younger and older clients will change.

- The local analysis matches the conclusions of national research by Emerson and Hatton.
- Whilst the proportion of clients aged less than 45 will start to decline, the number of people aged over 45 will rise steeply in the next 15 years. This is particularly significant, because at this age, most people have started to leave the care of the family as their carers approach 70 years.

- The number of clients over 65 will double in the next 10 years.
2. **The balance in dependency levels will change.**
 - The first main reason is the ageing client group, and presents no surprises. At present, the higher dependency bands (3 – 6) increase from 54% of the under 50s to 65% of the over 50s.
 - An important factor here is that people with milder learning disabilities who are not eligible for a service at present may become eligible in the future as their age and dependency increases.
 - Another major reason is the transition of children and young people to adult services. Herefordshire can expect about 10 new young people each year for the next 10 years, and 79% will have severe or profound learning disabilities.
 - Overall, the number of people in the higher dependency bands will rise by ¼ in the next 10 years.
 3. **Ethnicity factors are unknown at present**
 - The specific factors that affect south Asian communities have no bearing on Herefordshire at the moment, given the very low numbers in the county.
 - However, the ethnic mix of the county is rapidly changing as eastern European and Portuguese communities are growing. The possible impact of this is unknown.
 4. **The easy availability of residential care is having an impact**
 - There are already additional demands on the community team for health and adult protection services from non-Herefordshire people in residential homes.
 - If the Herefordshire policy is to assist people in homes to achieve supported living in their own tenancies it is possible that the spaces will be filled by more out county people in order for the homes to remain viable.
 5. **The age profile of informal (family) carers must be factored into service planning and commissioning.**
 - 22% of adults in the family home live with carers over 70 years of age, and some carers are already over 80. 29% live with carers over retirement age.