



Cornwall's Disability History

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Introduction

This report serves as background to the Disability Cornwall, Heritage Lottery Funded project 'Cornwall's Disability History' project that ran in 2013. During this project we video interviewed 20 disabled people living in Cornwall about their lives, to see whether things have changed over time. These video interviews are archived in the Cornwall Record Office, and other video archives in the county.

This written report gives an outline of the development of service provision for disabled people in Cornwall over the past 100 or so years, to support the video interviews. What is interesting from this report is how the fundamental changes we outline here do, or do not, impact on the individual lives of disabled people living in Cornwall in 2014. At the most fundamental level disabled people today live independent lives in the community of their choice, with the people they choose. The further back in time we look the less likely this would have been, with disabled people living in Workhouses in Cornwall, if they had been lucky enough to survive the accident or illness that left them with impairments.

This document will outline the disability provision that exists in Cornwall, and will describe how this has changed over time. So there is more information in this written document than there is included in the interviews we conducted. For example we describe, here, the special school provision, and the full range of voluntary and statutory sector provision that exists in Cornwall.

Between these two pieces of work – the oral, video archives and this written document - we will demonstrate how disability provision has changed in Cornwall, often within individual lifetimes. We will show how, effectively, 'disabled people' and 'disability' were created in the twentieth century by increasingly effective medical provision, together with a newly created statutory sector. This led to a burgeoning disability statutory sector of new buildings, services and professional staff, to meet newly identified needs, including the education, employment and housing of this new minority group.

The mission – in terms of disability and disability provision - for the twentieth century was the creation of this new sector, with the attendant creation of relevant professionals, buildings, skills and expertise. The same time and effort in the very early twenty first century appears to be spent dismantling this sector, and therefore including disabled people in mainstream, rather than segregated, provision.

In parallel with the creation and growth of twentieth century statutory disability provision, the voluntary sector - including groups of disabled people – mobilised itself to provide the services that the statutory sector was not mandated to provide, for and with disabled people. Over time, and as voluntary organisations demonstrated their ability to run effective services, the statutory sector increasingly started commissioning new joint working arrangements with the voluntary sector to meet statutory responsibilities. These arrangements can continue, and broaden, statutory provision in new and exciting ways.

Setting the Scene

I interviewed Doreen (not her real name) as part of my PhD research in 2008. She provided some of the inspiration for this History Project because of the stories she related, including this story about her childhood with her brothers –

Being I was such a plain bent little thing, they (my brothers) obviously used to chuck me up on their shoulder and cart me around with them because they were all much bigger and longer legs and all that I was, [laughs] you know. Carting me round like that, or stick me on the dillies they used to make with a plank of wood and four wheels. [Laughs] Shoved me on that.

A dilly?

Yeah.

What's a dilly?

They used to get a plank of wood, right, and four old wheels off of an old pram or pushchair.

So it's like a go-kart.

And put them on this plank of wood and they'd get like an orange box or something, attached to the top of it and put a cushion in it so you could sit in there and - because they had a disabled brother, Tony, and they used to lift him [laughs] two or three of the brothers used to lift him onto the dilly, sit me on his knees and drag us both around. [Laughs] It was the only way of taking us along with them where they went, blackberry picking and whatever. [Laughs]

In the 1940s and 1950s the world was a very different place in relation to disability and disability provision. For example –

- it was difficult to get hold of wheelchairs and other disability aids,
- most buildings were very inaccessible to people with mobility impairments and people who have difficulty negotiating large granite steps and stairs,
- people with learning difficulties would have been educated in special schools or not at all (it was not until the Education (Handicapped Children) Act 1970, chapter 52, that there was “provision, as respects England and Wales, for discontinuing the classification of handicapped children as unsuitable for education at school, and for purposes connected therewith”)
- Blind and Deaf children were ‘sent away’ to special, impairment-specific schools and colleges, often in Devon, and
- people with medical conditions or illnesses (including Doreen, above) were often sent out of county for long periods of time to e.g. children’s hospitals in London, or other medical provision away from their families and friends.

The stories related by many older disabled people often include dislocation and separation from family, friends and local communities. People therefore built friendships and personal relationships out of county. The ‘local’ area experienced by many Cornish disabled people was often not in Cornwall at all.

For example, Doreen related the following tale when I spoke to her in 2008 –

At the age of nine, the local family doctor heard about and discovered a special hospital that had been set up for children to try and find out what complaints children were suffering from...

Did you spend a long time in that hospital?

From the time I was nine till I was thirteen.

So about four years.

Yeah, you know, going through different tests and examinations and one thing and another.

Did you live there for all that time or did you just go there every now and again?

No, I lived there all that time. Members of my family came up to see me, but, like I said, I did enter the hospital, more or less as a semi-resident for those years. I was entered when I was nine, stayed there till I was thirteen and then came back home.

This Disability History Project grew from a desire to hear the stories of disabled Cornish people, to mark differences with the past, where these exist, as well as to put a marker in the sand against which we could measure the future experiences of disabled people in Cornwall. Disabled people are often not included in oral history archives, and their histories are therefore not often included in mainstream historical archives.

And yet disabled people represent a large, and growing, number of the local population. As medical technology continues to improve and develop there are an increasing number of disabled people in total, including in Cornwall, for a range of reasons, including these –

- More children are surviving a difficult birth than ever before. This can result in an increased number of babies born with impairments;
- Better medical provision means that more people
 - o survive traumatic accident or injury than ever before; and
 - o live longer with medical conditions and chronic illness than ever before – e.g. people live longer now than they ever did before with spinal injuries, with illnesses such as Multiple Sclerosis or Parkinson’s Disease, and with learning difficulties;
- Safer transport systems (including e.g. car seat belts and air bags; motorbike and cycle helmets, safer public transport; etc.) means that more people are now surviving car crashes and accidents than ever before;
- The prevalence of disability rises with age. Around 6 per cent of children are disabled, compared to 16 per cent of working age adults and 45 per cent of adults over State Pension age in Great Britain¹; and
- Increased life expectancy for the whole population means that there is an increasing number of older disabled people than ever before. 69% of people over the age of 85 report themselves as being disabled². Because there are more older people now than ever before there are therefore more disabled people.

So how many disabled people are there in Cornwall?

Numbers of Disabled People in Cornwall

See [APPENDIX I](#) for a fuller discussion of the numbers of disabled people in Cornwall. Here I will outline some key Local Authority data.

¹ <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#g>

² http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

Every ten years the UK government collects Census data from the entire population. However the collection of data asking whether a person has a ‘Long term illness’ did not start until the 1991 Census, with this being extended in 2001 to ‘Do you have a long term illness or disability’. It is therefore not possible to know, reliably, how many disabled people there were in Cornwall before this date.

There are well documented reliability problems for Census data relating to illness and disability. Because these data are self-disclosed there will always be some people – for a range of reasons – who may elect not to declare an underlying health condition or disability.

One of the findings from our own interviews in this Disability History Project is that some disabled people do not self disclose as disabled people unless they have a physical impairment that means they need to use a wheelchair. Several people who we interviewed with congenital impairments stated that they only “became disabled” on a specific date when they became wheelchair users.

For Cornwall the 2011 Census³ data revealed the following –

- In 2011 the total population of Cornwall was 532,273.
- Of the total population, 53,166 people self-reported that their day to day activities were limited ‘a lot’, and 60,549 said their day to day activities were ‘limited a little’ by a long term health problem or disability. The total figure for “limited a little or a lot” is therefore 113,715 people, or 21.36% of the total population.
- This is significantly higher than the national figure of about 17% of the population who self-disclose as having a ‘long term limiting illness or disability’.

In 2013 another piece of research by Disability Cornwall analysed the data from the National Adult Social Care Information Service (NASCIS)⁴. This included data relating to the numbers of Adult Social Care service users in Cornwall. For the time period 2005 – 2011 the data for people aged over 65 looked like this –

	A – Physical Disability Age 65 and over	B – Mental Health 65 and over	C – Learning Disability 65 and over	A + B + C All people aged 65 and over
2005/06	20,975	160	60	21,195
2006/07	20,080	145	60	20,285

³ From Table KS301EW here -

<http://www.google.co.uk/url?sa=t&rct=j&q=census%20disability%20statistics%20table%20ks301ew&source=web&cd=1&ved=0CDIQFjAA&url=http%3A%2F%2Fwww.ons.gov.uk%2Fons%2Frel%2Fcensus%2F2011-census%2Fkey-statistics-for-local-authorities-in-england-and-wales%2Frt-table-ks301ew.xls&ei=GbTmULX6Hqm70QW1i4CwCQ&usq=AFQjCNGsLbMIHZuyTHEZ3hW31cKZoMhOz>

⁴ <https://nascis.hscic.gov.uk/>

2007/08	21,665	165	110	21,940
2008/09	19,420	175	80	19,675
2009/10	11,460	605	205	12,270
2010/2011	10,450	..	185	10,635

This table shows that in 2008/09 there was a slight decrease in the numbers of service users, and in 2009/10 there was a dramatic decrease. At this time Cornwall Social Services – along with the majority of other UK Social Services Departments – implemented the Fair Access to care Services (FACS) criteria. This process grouped people together according to their assessed care needs into four categories – Low, Moderate, Substantial and Critical. Cornwall Social Services made a decision to only provide services for people assessed as having Substantial or Critical care needs, which enabled them to reduce the numbers of people for whom they were providing services.

The picture during the same time period for people aged under 65 is as follows –

	A – Physical Disability Age 18 to 64 Total	B – Mental Health Age 18 to 64 Total	C – Learning Disability Age 18 to 64 Total	A + B + C All Disabled people under 65 Total
2005/06	5070	2245	1405	8,720
2006/07	5005	2205	1320	8,530
2007/08	5515	2095	1425	9,035
2008/09	4845	1900	1705	8,450
2009/10	2010	2350	2160	6,520
2010/11	2030	..	1885	3,915

Again the implementation of the FACS criteria in Cornwall resulted in a drop in the numbers of people accessing services from the Council in 2008/09 and then more dramatically in 2009/10. It is clear that the greatest numbers of social care users are aged over 65, at a ratio of more than 1:2, as shown in the following table –

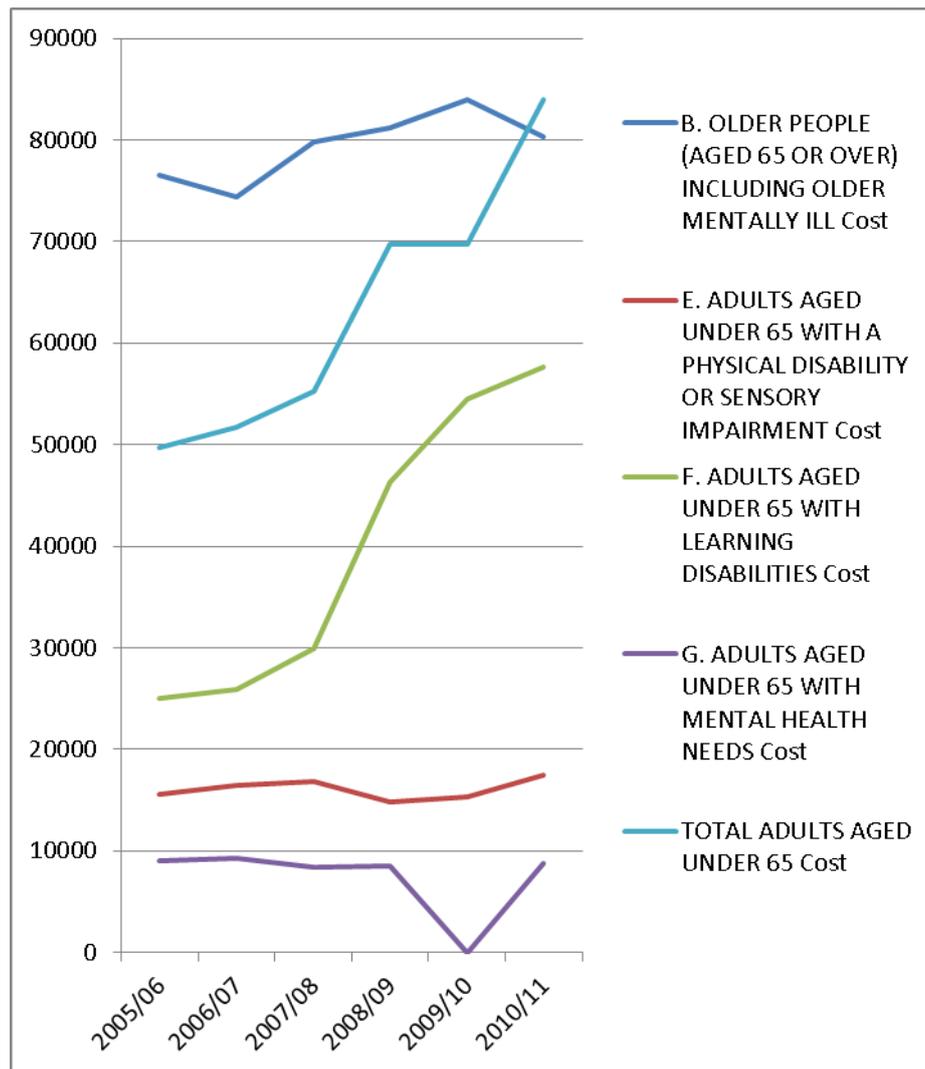
	Service Users aged under 65	Service Users aged over 65	TOTAL numbers of service users
2005/06	8,720	21,195	29,915

2006/07	8,530	20,285	28,815
2007/08	9,035	21,940	30,975
2008/09	8,450	19,675	28,125
2009/10	6,520	12,270	18,790
2010/11	3,915	10,635	14,550

From these data it is clear that the vast majority of disabled people in Cornwall are not in contact with the statutory authorities. Although these figures are relatively reliable, in that they represent the numbers of disabled people accessing services, they are not a reliable indicator of the total numbers of disabled people in the county. They are not very comparable over time, as the FACS criteria in use at any one point in time is not comparable to those used at a different time.

When this History report is being written (2014) there is a great political impetus in relation to service provision for older people. With an aging population there is a lot of debate about how the statutory authorities will cope with the increasing numbers of older service users, including the increasing costs that these older people represent.

However the data analysis that we did of the NASCIS data demonstrates that although the vast majority of Adult Social Care service users are over the age of 65, the costs have been increasing most rapidly over recent years for the younger age group of people - those aged under 65, particularly those with learning difficulties. This is shown by this graph –



It is clear from this graph that the social care costs for all client groups is relatively stable over this five year time period, except for people aged under 65 with learning difficulties, where the costs have more than doubled over the same time-span.

This picture is not unique to Cornwall. Many local authority areas are demonstrating very similar data – that the numbers of service users are increasingly older people, but the money spent on social care provision is increasingly being spent on people aged under 65, specifically people aged under 65 with learning difficulties. If anything Social Care is getting younger.

These data together illustrate several changes in relation to the population in Cornwall, including –

- All people are living longer. This includes disabled and non-disabled people;
- With improving medical provision we are seeing people who previously had relatively short life spans now living almost as long as the rest of the population – e.g. a person returning in 1945 from the 2nd World War with a spinal chord injury might have had a life expectancy of about two years. A person acquiring a similar spinal injury in 2014 can expect to live for ten years less than someone without a spinal injury. This is clearly a dramatic increase in life expectancy;

- Many people with learning difficulties are now living into older age, where previously they may not have done so; and
- Our expectations of older age - in terms of longevity, quality of life, and the statutory and other types of provision that need to be available to the individual – are all increasing.

Adult Social Care is currently in a transition phase as the Local Authority decides what provision is needed, where, when, and for whom. The methods of service delivery are also in transition. This is evident when we look at how provision has changed over time, and the situation right now.

Project Background

‘Disability Provision’ has increased over time. In the nineteenth century, disabled people in general did not have much or any specific provision dedicated to them and their needs on the basis of their impairments. Essentially disabled people did not exist as a coherent minority group at this time.

Disabled people, along with other minority groups, were seen in financial terms, or in terms of their ability to earn money. Those who – for whatever reason – were not able to work and earn money often found themselves in Work Houses, where they were provided with a bed and food at best. Conditions in these places ranged from terrible to horrendous.

The Cornwall Blind Association (CBA) came into existence in 1856 as a response to the high numbers of people with a visual impairment in Cornwall – this pre-dated the national organisation founded in 1868 by Dr. Armitage and known as the British and Foreign Society for Improving Embossed Literature for the Blind⁵, which later became the Royal National Institute for the Blind (RNIB). The reason why the Cornwall Blind Association came into being so early is because Cornwall at the time was the centre of the UK – and world - mining industry. Accidents from mining were fairly common, and often resulted in injuries to the eyes, maybe resulting in blindness.

The census records of the inhabitants of the Work Houses⁶ in Cornwall show that there were often blind people living in workhouses.

In the twentieth century the societal response to disability and disabled people as a distinct minority changed from disabled people as financially unproductive people, to an understanding of disabled people as individuals with specific medical needs. One trigger for this change were the 2 World Wars. Non-disabled soldiers went off to war, and some returned as injured, disabled heroes. Living in the Work House along with poor people seems not to have been an appropriate response to this individual heroism, and so new provision was created for disabled people. This societal response to disability expanded over time to include non-war veterans, including disabled children.

With this identification of disability as a separate issue there was a simultaneous rise in the numbers of medical and other professionals working with and for disabled people. Provision for disabled people changed on an impairment specific basis. As a result specific provision was created for people with physical impairments, people

⁵ http://en.wikipedia.org/wiki/Royal_National_Institute_of_Blind_People

⁶ <http://www.workhouses.org.uk/Bodmin/Bodmin1881.shtml>

with learning difficulties, people with sensory loss, etc. The terminology used to refer to distinct groups of disabled people came into existence and changed and evolved over time as well.

In the twentieth century a range of specific provision for disabled people was created throughout the UK, including in Cornwall, often, but not solely, by the statutory authorities.

Cornwall's Geography

Cornwall is a very long county – it stretches for about eighty miles from one end to the other. Some parts of the county experience extreme rurality, where a house, or small village, might literally be on the edge of a cliff. For people living in these places – disabled and non-disabled people alike – their experience of what it is to be in Cornwall will be very different from people living in the more urban areas, including the Camborne/Pool/Redruth conurbation, which in 2008 was the largest population centre in the county (population c.45,200 in 2008⁷).

Disability provision varies considerably across Cornwall – for example disabled children in the East of the county can be sent relatively quickly/cheaply to special school provision in Devon, including in Plymouth or Exeter, while this is less straightforward for children in the far West. Historically some villages in Cornwall can have poor public transport links, poor access to public services, including telephone and electricity (and today poor access to Broadband connections), and few shops or other facilities.

Added to this geographical complexity is the complexity of the notion of “disabled”. This term can include people with physical, learning, sensory and other impairments. Many people acquire impairments in older age, including sensory loss, reduced mobility, or dementia/Alzheimer’s Disease. For many older people the label ‘disabled’ has such negative connotations that they do not refer to themselves as disabled at all.

A combination of these factors – the geographical differences in Cornwall and the diverse range of people who might be described as disabled – make the overarching aim of this project (namely to document Cornwall’s Disability History) problematic. There is not necessarily a coherent, unifying set of experiences from one individual to another.

For example many Deaf children were sent out of county, as were many Blind children, to special schools. Some children with learning difficulties were segregated in special education while others were accommodated in local mainstream schools. This complexity continues into adult life across a range of Health, Social Care, Education, Employment, Leisure and Social, provision.

Even so there were some clear themes that emerged from the one-to-one interviews we conducted. When discussing negative things about living in Cornwall, for example, many people – particularly wheelchair users and people with mobility impairments - talked about the inaccessible public transport systems. Some people cited the distance from the rest of the UK as a negative factor, while others thought this distance increased the strong, bonding, social capital ties within communities in the county. The clearest theme to emerge from these interviews relates to the

⁷ <http://www.cornwall.gov.uk/media/3638081/Camborne-Pool-and-Redruth.pdf>

negative attitudes of other people in Cornwall, in particular non-disabled people, towards disabled people.

This project has uncovered the specificity of experience – dependent on a range of factors, including the individual her- or him-self; the local situation in which she/he finds her/himself; the people known to the individual; the disability-specific provision that is known to people working with the individual; and more besides.

Here we will examine how disability provision has changed over time.

Disability Provision in Cornwall - The Statutory Sector

The English Poor Laws were a system of poor relief which existed in England and Wales and which developed out of late-medieval and Tudor-era laws being codified in 1587–98. The Poor Law system was in existence until the emergence of the modern welfare state after the Second World War (see below). These Poor Laws were largely based on Christian notions of faith and charity, with the early poor laws not being implemented with any universality across the UK.

The traditional attitude had been one of poverty being inevitable (exemplified by the oft-quoted biblical text "For the poor always ye have with you"), the poor essentially victims of their situation, and their relief a Christian duty. The 1834 Act was guided by a growing view that the poor were largely responsible for their own situation and which they could change if they chose to do so.⁸

In the nineteenth and early twentieth centuries there were several workhouses in Cornwall - including in Bodmin, Truro, Redruth, St Austell and Madron – built to accommodate Cornwall's Poor. Although not 'disability-specific' provision, some disabled people lived in their local workhouse, for example the one in Bodmin –

Bodmin Workhouse⁹

The first work-house built in Bodmin was in 1756

"on some of the Friery lands now belonging to the corporation, at the expence of Sir William Irby..." (Lysons, 1814)

A parliamentary report of 1777 recorded parish workhouses in operation at Bodmin for up to 70 inmates. In 1804 the prison reformer James Neild visited the Bodmin workhouse. He later recorded:

"On visiting the workhouse at Bodmin, in Cornwall, which I found in a very dirty state, I was shown down stairs into a room where a poor lunatic was confined. He lay stretched on a little short and dirty straw, with a few rags on him. His fixed, intent eyes, his shaggy hair, long beard, dirty and livid face gave him the appearance of a monster rather than a man. He took no notice, either on opening the door, or during the time I was in his room, till I came close up to him; he then took his eyes off his book, and looked at me with a more forcible appeal to humanity than I had ever felt. The floor of this room was earth, and literally a puddle of water and dirt more than one inch deep. It was with difficulty I could step into it without treading in his excrement, which laid every where about on the floor; and, from the appearance of what was in

⁸ <http://www.workhouses.org.uk/poorlaws/>

⁹ From the Workhouse: The story of an institution at <http://www.workhouses.org.uk/Bodmin/> accessed 9/7/13

the fire-place, must have been there a fortnight or more. The keeper had most unmercifully beat the poor fellow, and given him two black eyes. I endeavoured to investigate the matter, but the mistress kept such an incessant clack that I could not put in a word edgewise.”

In the twentieth century the workhouse buildings were closed, and have since been converted into residential accommodation, including flats. The isolation hospital is now a private house.

St Lawrence’s Hospital, Bodmin¹⁰

Originally known as ‘Cornwall County Asylum’ St Lawrence’s was founded in 1815 at Westheath Avenue, Bodmin and became known as St Lawrence’s Hospital under the National Health Service.

The County Lunatic Asylum, for the reception of private patients and pauper lunatics, consisted of eight blocks of buildings radiating from a centre, with annexes and detached blocks subsequently erected and residences for the various officers. The first portion, for 100 patients, was built in 1820; in 1842 the “high building” was added, and in 1848 a “new building” was built; A further enlargement was made in 1867 by the erection of the Carew Block; in 1873 an additional building was erected, and in 1884 another. There was a dining and recreation hall, 80 by 34 feet. The Asylum held 760 patients in total. By the end of 1895, there was a desperate shortage of space for patients at the Cornwall Lunatic Asylum and large-scale extensions were being planned, including a 10-bed isolation hospital.¹¹

The first records of any ‘lunatic patients’ in the finished buildings date from 1900¹².

The creation of the Welfare State, following the 2nd World War, included several Acts of Parliament that place legal responsibilities to meet the Health and Social Care needs of disabled people.

The Welfare State

These Acts of Parliament include –

- the National Health Service Act 1946,
- the National Assistance Act 1948, and
- the Chronically Sick and Disabled Person’s Act, 1970.

Other Acts of Parliament add detail to these pieces of legislation, and further Acts relating to education (e.g. the Education (Handicapped Children Act, 1970), Welfare Benefits provision, and other areas of statutory provision have been added to the Statute over time.

All of this legislation combines to make the lives of disabled people very different today from how disabled people lived in previous generations. The move from a rural economy to urban living, increasing population expansion, and the Second World War were all drivers for legislative and social changes in the twentieth century across the UK, including in Cornwall.

¹⁰ From <http://www.whateversleft.co.uk/asylums/st-lawrences-asylum-bodmin> accessed 9/7/13

¹¹ <http://www.whateversleft.co.uk/asylums/st-lawrences-asylum-bodmin>

¹² From <http://www.fosterhall.org/history+of+foster+hall> accessed 9/07/13

With the increasing understanding of disability as a medical ‘problem’, specialist provision was created to cater for the perceived needs of these people in Cornwall. It is impossible to understate the importance of medical provision in the lives of many disabled people. For example a war veteran at the end of the 2nd World War might have a life expectancy of less than ten years, whereas now the life expectancy for people with a spinal chord injury is over forty years¹³.

Other groups of disabled people also have increased life expectancy – for example people with acquired impairments from traumatic injury or accidents, and people with chronic illnesses. Added to this is the fact that we are all living longer and therefore more people are acquiring impairments with older age, including conditions like Alzheimer’s Disease or Dementia.

It is easy to see how and why medical science has come to dominate the Disability Discourse. Medical professionals have been given control over the lives of many disabled people, including those people with acquired impairments. This very ‘top-down’, professional-led Disability World rarely took account of the wishes and desires of disabled people in a structured, formalised way. The provision created for disabled people in Cornwall included –

- hospitals for people with learning difficulties (e.g. Budock Hospital¹⁴);
- a range of medical provision for specific groups of disabled people. This provision has been created over time, and there is enough of this to be the subject of another specific document. For example there is –
 - o Marie Therese House – offering rehabilitation respite and outpatient physiotherapy services - which is part of St Michael’s Hospital in Hayle;
 - o Specialist Multiple Sclerosis Nurses;
 - o Specialist Parkinson’s Disease Nurses;
 - o Specialist Stroke Nurses;
 - o Provision for people with a range of health conditions, including Huntingdon’s Disease, Alzheimer’s Disease, Dementia, etc.
 - o Services and clinics for people with sensory loss;
 - o Etc.
- day services for people with physical impairments¹⁵;
- day services for people with learning difficulties¹⁶;
- residential provision;
- respite care¹⁷; and
- other provision including sheltered employment¹⁸.

¹³ <http://www.lifeexpectancy.org/articles/mccoll.pdf>

¹⁴ http://www.falmouthpacket.co.uk/news/848468.disgraced_hospital_to_close/

¹⁵ <http://www.echocentre.co.uk/>

¹⁶ [http://www.cornwall.gov.uk/health-and-social-care/community-contacts/adult-care-health-and-wellbeing-centres/john-daniel-centre-\(penzance\)/](http://www.cornwall.gov.uk/health-and-social-care/community-contacts/adult-care-health-and-wellbeing-centres/john-daniel-centre-(penzance)/)

¹⁷ <http://www.cornwall.gov.uk/health-and-social-care/community-contacts/adult-care-health-and-wellbeing-centres/chy-koes/>

¹⁸ <http://www.tremorvah.co.uk/>

Today, statutory sector Health and Social Care services are increasingly moving from a provider to a commissioner role. This means that where the twentieth century saw a range of provision created and owned by Cornwall Council or the Cornwall Health Authority (with its variously changing names), this provision might now be commissioned from, and provided by, a range of providers, including the private and voluntary sectors.

There is a range of provision across Cornwall, though there is currently no overarching 'Disability Vision' for the county. Consequently there are gaps in provision across the county by –

- client group – e.g. for example for people with physical impairments, or people with learning difficulties; or
- geography – e.g. there is statutory sector day service provision for people with physical impairments in the East of the county¹⁹, but not in the West.

It is clear that the statutory response to disability has changed over time, from the days of little or no provision, through a blossoming of statutory sector provision in the twentieth century, to a time where other providers are now part of a competitive market place of provision in the county.

Here we will now look at some of the disability provision in Cornwall, starting with the Education sector.

Education

The dominant twentieth century UK disability education narrative has been away from specialist, segregated provision towards inclusion in 'regular' mainstream settings. This is true in Cornwall as it is elsewhere, though there are still several segregated schools in Cornwall. These include –

Nancealverne

Nancealverne School was established in Penzance in 1977 –

We provide specialist education for young people aged from 2 to 19 years who have severe and profound learning difficulties and physical difficulties²⁰

Pencalenick

Pencalenick School was opened as a special school in 1952, after a long history of changing ownership and changing roles, including a period as an army field hospital -

The school offers high quality educational and social support for 110 young people with complex learning difficulties and disabilities²¹

Curnow

Curnow School provides for pupils who have severe learning difficulties. Some have physical and sensory difficulties while others have an autistic spectrum condition²².

¹⁹ <http://www.echocentre.co.uk/>

²⁰ <http://www.nancealverne.org.uk/> - accessed 8/05/2014

²¹ <http://www.pencalenick.net/index.php/parental-information/about/school-history> - accessed 8/05/2014

These three schools are located in the Penzance and Truro areas.

Doubletrees School –

Doubletrees is located in St Blazey, near St Austell, and –

caters for up to 96 pupils from the ages of two to nineteen, designated as having severe and complex learning difficulties. Pupils are grouped for teaching purposes according to their chronological age. From Key Stage 2, pupils in each Key Stage are grouped by ability / need type: AS, more able, less able.²³

The only land border between Cornwall and another county is the border with Devon. There is a range of disability-specific provision in Devon to which disabled people from Cornwall 'were sent', because of a lack of more local facilities. In Devon this segregated provision includes –

- Exeter Royal Academy for Deaf Children
- The WESC Centre – the specialist centre for visual impairment, Exeter (established in 1838, Clutterbuck, J. 2006)
- Dame Hannah School, Ivybridge.

Many mainstream schools and colleges in Cornwall are now accessible to disabled children with a range of impairments.

Employment

The traditional industries in Cornwall are very physical, and often not suitable for many disabled people. These include farming, fishing and mining. The decline of these industries in the twentieth century has made Cornwall an area of high unemployment when compared to other parts of the UK. The work that remains in Cornwall is often seasonal, serving the tourism/holiday industry. This can mean that it is often low paid, and quite physical in nature, including chalet and holiday park maintenance and cleaning.

There have been at least 2 providers of segregated employment for disabled people in Cornwall – Tremorvah Industries and REMPLOY –

Tremorvah²⁴

Tremorvah is a very early example of the statutory and voluntary sectors working together. Cornwall County Council, as it was called at the time, worked with the voluntary sector – specifically the Cornwall Disabled Association – to provide a range of services that they might otherwise not provide.

The business was developed from a rehabilitation centre founded in the early twentieth century by Dr William Rentoul at City Hospital in Truro. Dr Rentoul was working with the Cornwall Disabled Association at the time, and the original project belonged to that organisation.

²² http://www.curnow.cornwall.sch.uk/news_detail.asp?Section=8&Ref=211 - accessed through the school's website, 8/05/2014

²³ http://www.doubletrees-cornwall.co.uk/keyinfo_detail.asp?Section=3&Ref=358

²⁴ <http://www.tremorvah.co.uk/default.aspx?page=1>

In 1985 the "Rentoul Works" moved to its present address on the Threemilestone Industrial Estate where it began operating under the name of Tremorvah Industries. Ownership of the business passed entirely into the hands of Cornwall Council, where it remains.

Tremorvah's stated purpose (according to their website) is to "maximise employment and development opportunities for people with a disability in a supported environment in Cornwall." The website states that "over 70% of Tremorvah's staff have a recognised disability" and fulfil all support services to be found in any business; such as sales, stores control, distribution, catering, customer service, administration and accountancy.

The stated aims include providing a variety of work and training to help people rediscover old skills, acquire new ones and progress within the workshop and into open employment. The centre also acts as a co-ordinator for the Community Development Team, working with more than 70 people in "host organisations" throughout the County. Apparently more than 70% of Tremorvah's earnings come from its own business activities, with the rest provided by the Council.

Remploy Factories

Remploy was set up in the UK under the 1944 Disabled Persons Employment Act by Ernest Bevin, who was then minister of labour²⁵. This was designed to be employment for injured servicemen returning from the 2nd World War.

The first factory in Cornwall opened at Pool, Redruth. The workers there did wood working, including making wooden benches, as well as making a range of military equipment. The factory moved to Longrock Industrial Estate near Penzance, where it continued making army equipment, later branching out to include orthotics equipment, and then car seat covers.

The Remploy factory in Cornwall closed in 2012, as did the majority of the other UK Remploy factories. This was part of a government restructuring of disability employment provision following the Sayce Review²⁶. The Conservative Government of the day stated that it wanted to reduce disability-specific expenditure on segregated provision, and to increase expenditure on helping disabled people to access more mainstream employment provision. The factory closures were part of this systemic shift.

We interviewed five ex-employees of the Cornwall Remploy factory as part of this oral history project, and their stories are included in the "Employment" section.

Disability Provision in Cornwall - *The Voluntary Sector*

In Cornwall there are some key voluntary sector disability-specific organisations and bodies that have a long history of involvement with the county. These organisations include the following –

Residential Accommodation

²⁵ <http://bombasticspastic.blogspot.co.uk/2011/08/remploy-was-set-up-under-1944-disabled.html>

²⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/49779/sayce-report.pdf

There is a range of provision for disabled people in Cornwall within this residential category, including (but not exclusively) –

Leonard Cheshire in Cornwall

The following text is taken from *A brief history of Leonard Cheshire Disability: An extraordinary man and his vision*²⁷–

In May 1948, Group Captain Lord Cheshire of Woodhall, by then a famous war hero, was living alone in an isolated mansion in Hampshire winding up a community project for ex servicemen and women which he had started at the end of the war. Discovering that one of the former members of the community was terminally ill and had nowhere to go, he offered to care for him in his own home.



Before long, other people came to him for help and his home in Hampshire soon became the first Cheshire Home. From this small beginning grew an organization inspired by Leonard Cheshire's vision that disabled people should be able to live with dignity, choice and independence.

Following this experience with his own house Group Captain Leonard Cheshire opened the first Cheshire home for ill and disabled people on Predannack Royal Navy Airfield, on the Lizard, Cornwall, in 1951. He converted what is believed to have been the old Sergeant's Mess on the airfield into accommodation for disabled people.

In around 1954 the residents moved to purpose built premises on land donated by the St Levan family of St Michaels Mount and built with funds raised in Cornwall. Alderman Jack Stephens, Mayor of Penzance, played a large part in the developments and became Chairman of the Management Committee. The new building was officially opened by Lord Denning in May 1956.

Since that time there have been various additions to the home on the Longrock site, which is a traditional 'care home' model of disability provision. The home has permanent and respite residents, with a range of ages and impairments. From this small start the Leonard Cheshire organisation has grown to include services and properties in over 50 countries around the world.

Rosewarne House, Camborne, Scope

Rosewarne House – previously known as Gladys Holman House - in Camborne was a residential home for adults with cerebral palsy. It is owned by Scope, formerly the

²⁷ <http://www.lcdisability.org/?lid=11687> accessed 5/6/2013

Spastics Society, which has a long track record of working in Cornwall with the local authority. This is part of a range of provision in Cornwall owned by Scope, which has included Churchtown farm at Lanlivery near St Austell. Churchtown Farm – an outdoor activity centre for disabled people, finally closed in 2012.

Rosewarne House is an old property, and as such was never fully accessible for many of the people who lived there – a staircase led up to the front door, which opened to reveal a large spiral staircase up to the second floor. Over the years a range of adaptations were made, including the installation of a lift. Eventually, however, a set of accessible bungalows was built in the grounds for the residents, who then moved out of the old country house. In mid-2014 the large property is on the market for sale under the name of Rosewarne House.

There are also a range of residential accommodation for disabled and older people owned by the Local Authority, as well as by other housing providers in Cornwall. With the general trend of having disabled and older people living in community settings along with non-disabled people there is an increasing need for accessible properties in Cornwall.

Other voluntary sector provision in Cornwall

There are several voluntary sector Disability Organisations in Cornwall, with long and dynamic histories. All these organisations take pride in the fact that they are led by, and consult with, disabled people themselves, to design and implement the projects that they manage. This represents a significant shift in the way disability provision is created and managed. We have seen that the further back in time the more ‘top down’ any provision is, led as it is by statute and legislation.

Smaller voluntary sector disability organisations are much more organic in their creation, as groups of disabled people come together, identify a problem or an issue, and then work to fill any gaps in provision. This is known as a ‘bottom up’ model of service creation. Some of these organisations employ numbers of disabled people to deliver their services.

This relatively modern way of designing services is mirrored in other areas across the UK from the late twentieth century onwards. Disabled people have moved from being ‘done to’, to a situation where they are doing things for themselves. The national UK Disability Sector created its own understanding of disability – the Social Model of Disability – which is now written into much legislation as the preferred way of working with disabled people.

Disability Organisations in Cornwall

The disability voluntary sector in Cornwall is similar to the disability voluntary sector in other UK counties. There is a range of large, national, disability-specific organisations, including Scope, Mind, Mencap, Leonard Cheshire Disability Services, the RNIB, RNID, and others. Historically these large organisations may have been contracted by the Local Authority to provide local services.

There is also a list of smaller disability voluntary sector organisations that are specific to Cornwall. Some of these organisations were created by non-disabled people, others by disabled people themselves.

Early Local Disability Organisations

The organisations created by disabled people in Cornwall date back to the 1970s, and include the following –

The Choughs Wheelchair Dance Team²⁸ was formed in 1970 to provide therapy combined with social activity and recreation in which disabled people could take part. The object then as now was to help to improve physical co-ordination and reproduce the art of dance with participants in wheelchairs rather than on their feet. A wide range of dances are used from old time, ballroom, disco, modern pop and anything in between.

In 1971 the Choughs entered their first competition at the Hammersmith Palais and emerged as National Champions, a title they have held every year, except two, until 2014. In 1975 the International Championships were introduced, taking place every other year, again the Choughs retaining the title for every year but two.

Cornwall Leisure And Sports Players (CLASP)

CLASP formally adopted a Constitution and set of rules on the 8th June, 1975²⁹. The group was established under the charitable headings of 'Disability', 'Amateur Sport', and 'Provides advocacy/advice/information'. The list of the Trustees at the start of the group are as follows –

Diana Johnson, James Byers, Jill Byers, Merrion Capper, Daniel Farr, George Evans, Nigel Hocking, Treve James, Carole Moyle, Roger Atkinson, and Dick Forsythe.

The majority of these people describe themselves as disabled people.

Proper Access Now in Cornwall (PANIC)

A group of disabled people formed PANIC in the 1980s, which closed in 2005. Several of the original group's members were also members of CLASP and the Choughs. This is a clear example of disabled people coming together for one set of activities – in this case leisure and sport activities – and then going on to form another group to campaign about another set of issues, in this case disability access.

The charity ceased trading as a result of the legal pressures associated with the legal liability coming from giving access advice to other organisations. The charitable aims for the group were listed as follows³⁰ -

To relieve disabled people in Cornwall ... by providing 'advise' on the issue of disabled access to all areas, facilities and services (particularly those in the public domain) in the area of benefit, and by raising awareness of these issues among the public generally.

ALLDIS (Cornwall) Ltd

Theo Blackmore formed ALLDIS (Cornwall) Ltd in 1995, when he returned to Cornwall. This group started with the ethos that it was disabled people who knew and understood about issues in relation to disability and disabled people in Cornwall. This notion of 'Voice' was crucial to all aspects of the organisation, which worked

²⁸ <http://www.choughswheelchairdance.co.uk/about.html> accessed 30/05/2014

²⁹ <http://opencharities.org/charities/280493> accessed 30/05/2014

³⁰ <http://opencharities.org/charities/1079814> accessed 30/05/2014

hard to bring the voices of disabled people themselves to the projects and consultation exercises with which it was involved.

At the time there was very little provision in Cornwall that was managed and run by disabled people themselves. The initial aim of the organisation was to be a service provider run and controlled by disabled people, and to fill several gaps in information provision in the county, specifically to produce a magazine (discover magazine), and a Disability Information Advice Line (DIAL) telephone service.

The name was adopted at an early meeting. It was suggested by a member who recognised that the name reflected the fact that the group was not impairment specific, but was pan-impairment ('all disabilities'). The name 'Alldis' was also the name of the head-lamp worn by Cornish miners.

The key people involved at the start were Theo Blackmore, Chair; Luke Murray – who became the magazine editor for the first 6 years – and Steve Paget, Vice Chair. Other people became involved over the years, including Anthony Oats, Anthony Dunn and Suzy Murphy from Cornwall People First.

In the early days there was a very close association with Mike Faulds and Stella O'Donnell, who worked for Cornwall Social Services. These two were interested in seeing a formal voice for disabled people in Cornwall, with which they could engage. They brought together a group of disabled people to form the Enable Project (see below) at the same time. They funded Theo Blackmore to go to London to attend an Alliance of Disability Advice and Information Providers (ADAIP) conference in 1996, which led to the creation of the Cornwall Disability Forum (see below).

Cornwall Disability Forum (CDF)

Created in 1996 by ALLDIS, the CDF was seen as a social policy/voice/campaigning body with which the statutory authorities could engage on any matters. The people running the CDF were largely the same as those involved with ALLDIS (Cornwall) Ltd. The audience members – those taking part in the quarterly meetings and bringing the issues for debate – included disability specific voluntary sector organisations, disabled individuals, the statutory sector (including Health and Social Care professionals), carers and other interested individuals including the broader voluntary sector in Cornwall. As well as a discussion forum for local issues of importance, national speakers from the disability field were invited to inform the audience about national disability news.

The Forum was a crucial element in the distribution of the discover magazine, which was usually published to coincide with these meetings. It was difficult to find another organisation like this elsewhere in the country at this time.

2014 – Organisations Active Now in Cornwall

As the twenty-first century gets under way it is becoming clear that a more formal association between the statutory and disability voluntary sectors can create a new, more holistic level of provision for disabled people that meets a broader range of needs than was the case with either sector working alone. Several of the organisations which are currently active in Cornwall in 2014 follow this model of joint working to achieve common goals and ambitions.

See [APPENDIX II](#) for data relating to this sector.

The organisations working in Cornwall include the following (in alphabetical order) –

Activ8³¹

In 1990 as a result of a visit to Churchtown outdoor activity centre at Lanlivery, near St Austell, James Cockle – a young disabled man - started asking why young disabled people from Cornwall could not spend more time together, and more often. David Owens, the manager of Churchtown Farm, worked with James' social worker to create a new organisation for younger disabled people.

David and the social worker found four young people from Cornwall and four from Devon, and Churchtown raised the money for them to go there one weekend a month for two years. They chose the name Active8, and they worked their way through the many activities Churchtown Farm could offer in those days.

After two years the social worker found some more young people, and soon it was 2 groups of eight. Activ8 registered as an independent charity in 1990 and started their own fundraising, with Loraine Kenney as Chair.

In 2004 Active8 left Churchtown by mutual agreement (before Vitalise managed the Farm) and started to run its weekends at Delaware Outdoor Education Centre with Josey Spencer as Manager. In 2007/8 Scope was the support provider, bringing together Andrew Mullen from Scope, Josey Spencer and Liz Olive. In 2010 Activ8 employed Josey to engage with young disabled people over 16 years old. Activ8 also developed projects to help young people with physical disabilities to get their voices heard and influence the services offered to them, and which would support their steps towards independence.

In 2010 the service manager completed a consultation with 40 young people from Cornwall who have a physical, but not a learning, disability, about the routes and barriers to their independence. They felt that this is a group of people which is hardly ever consulted separately and for whom there is hardly any useful information to be found.

Cornwall Blind Association

Cornwall Blind Association was formed in 1856, over a decade before the Royal National Institute for the Blind (RNIB) existed –

In Cornwall at this time there was probably a greater chance of working men going blind than anywhere else in the country – because in the mid-19th century it was the most active mining district in the world.

Clutterbuck, J. (2006)

In his book *150 Years of the Cornwall Blind Association* John Clutterbuck gives a detailed account, including key dates and important people, relating to the formation of the Cornwall Blind Association. From this account it is clear that the early days of the organisation were led by the Quakers, with the involvement of other people as well, notably the Bishop of Truro.

As Clutterbuck writes -

³¹ <http://www.active8online.org/>

The 19th century was a pious age, and nearly all early attempts to help the visually-impaired were aimed above all at improving their spiritual well-being. Many different systems of raised or indented type had been developed, by which a poorly-sighted person could learn to read any of the scriptures that had been 'translated' into that particular type. (pg. 9)

Clutterbuck describes the development of a new raised text for people with a visual impairment, the Moon system –

In 1845, a blind teacher in Brighton named William Moon devised a new kind of raised – or embossed – type, and began publishing 'translations' in a monthly magazine for visually-impaired people a couple of years later. The Moon system used a simplified form of normal lettering that was easy to learn, even for older people and those with limited feeling in their fingertips. William Moon began to promote his new type with missionary zeal, and it quickly became the most widely-used of the various raised-type methods. It's still in use today, as an alternative to Braille for those who have poor manual or mental dexterity. (pg. 10/11)

The Cornwall Blind Association employed blind men to teach other blind people how to use this Moon system. This is very interesting from a historical perspective as this is a very early example of disabled people being explicitly sought for their skills, expertise and understanding in relation to disability issues. This notion became an explicit part of the late twentieth century disability rights movement in the UK, with the slogans including "Nothing about us without us".

Clutterbuck prints (pg. 21) an excerpt about Cornwall from the book, *Light for the Blind* (1873), by William Moon –

In this important county of mining operations an interesting work is being carried on, which was commenced at the same time as the one in London. In mining districts blindness is always more or less prevalent, owing to the accidents arising from the blasting of rocks and other causes.

A blind man, Mr Baker, was the first person employed to teach the miners and others who were blind in the neighbourhood of St Austell. Two teachers are now engaged for the county, who travel from place to place. They remain for three months in places which they visit for the first time, and about one month at each subsequent visit, and instruct them in writing as well as reading. Great success has attended their labours.

Cornwall Disabled Association

The first annual meeting of the Cornwall Disabled Association was held on May 3rd 1934. This means that the organisation must have been created in 1933, and it ceased trading in 2012. The association evolved over the years into an organisation with affiliated clubs and social groups across Cornwall, which also owned an accessible coach and an accessible holiday caravan, located at Par Beach in South East Cornwall.

This organisation provided accessible meeting facilities for disabled people to associate, and form friendships, with other disabled people in Cornwall. One of the strengths of the voluntary sector is that it can move relatively quickly to identify, and then meet, a perceived need. At this time between the wars the situation for disabled

people would have been very different from today – little or no disability provision, including little or no disability equipment; inaccessible buildings and town centres; little transport provision of any kind; poor communications technology; and poor infrastructure support – would all have conspired to make it difficult or impossible for disabled people to meet anyone, let alone each other. Disabled people at this time led solitary lives in their own homes, alone.

This is the kind of service that would not have been provided by pre-Welfare State local, or health, authorities.

Cornwall People First³²

Cornwall People First is a Self Advocacy Group for people with learning difficulties. They aim to speak up, campaign and lobby about things that are important to their members. People with a learning difficulty meet up together “to talk and have fun”.. Cornwall People First is part of a national self advocacy movement.

CPF has over 800 members in Cornwall all of whom “have learning disabilities”. There are regular Self-Advocacy Forums in ten towns, where “adults with Learning Disabilities come and speak up about things that are important to them”. These are facilitated by outreach inclusion workers. Self-advocates have reported to the statutory sector Learning Disability Partnership Board in order to ensure their voices are heard and positive change happens for adults with Learning Disabilities in Cornwall.

We offer Quality Checking of Learning Disability Services. We have checked Hospitals, Residential Homes, Day Services and Supported Living Services.

They also translate documents into easy read accessible information.

Disability Cornwall & The Isles of Scilly

Disability Cornwall and The Isles of Scilly was established in 2007 when ALLDIS (Cornwall) Ltd and the Cornwall Disability Forum merged to become one. There are many reasons why this merger took place, and there had always been discussion about why the originators had tried to keep them separate in the first place.

Disability Cornwall and The Isles of Scilly is now the dominant pan-impairment Disabled People’s User Led Organisation (DPULO) in Cornwall. The over-arching mission/vision statement for the organisation is to create an accessible county for all disabled people³³ –

We provide a range of services to empower, assist and facilitate independent living and when necessary, act as a representative voice for disabled people, their families and carers. We challenge discrimination and inequalities and promote examples of good practice for others to follow.

The organisation operates a number of services, including –

- The Personal Budgets Support Service, including an online Personal Assistant Register

³² <http://www.cornwallpeoplefirst.com/>

³³ <http://www.disabilitycornwall.org.uk/>

- The Disability Information Advice Line (DIAL) service. This service receives about 3,000 contacts per annum, through telephone and drop in advice sessions, as well as a number of outreach services. The main reasons for contact are advice about welfare benefits issues and Social Care provision;
- DISCOVER magazine;
- Carers News – a quarterly publication;
- The East Cornwall Orthotics appointment service, commissioned by the Kernow Clinical Commissioning Group;
- The Parent Partnership Service;
- Fully accessible meeting and conference rooms; and
- Regular consultation events on planning, access and other issues, commissioned by a range of organisations including statutory, private and voluntary sector bodies.

Enable

The Enable project was started in 1996 by Stella O'Donnell and Mike Faulds from the Department of Social Services in Cornwall County Council, working with the national charity Scope. In April 2003 it became a registered charity and, with the help of funding from Cornwall Social Services, commenced trading as Enable in Cornwall Ltd. Enable is a 'not for profit' limited company overseen by a board of directors most of whom are disabled people who have used the services of Enable. There are currently nine directors.

Enable's Aims are³⁴ -

- Working as part of Cornwall Council Adult Care, Health & Wellbeing provision;
- To help adults with disabilities to become more independent by providing an individualised, information, advice, guidance & support service;
- Our qualified and client centred advisers will visit people in their homes working with them to help improve well-being and inclusion; and
- A free, independent service, supporting people to overcome barriers and maximise their abilities.

Enable, like the ECHO Centre, represents a hybrid joint working approach between the statutory and voluntary sectors in Cornwall.

ECHO Centre

The Echo Centre was opened in 1991, after almost 10 years of discussion and fundraising which had started in 1981 with the EU International Year of Disabled People. The Centre brings together the ECHO (East Cornwall Handicap Organisation) Charity with Cornwall Council, and is a purpose-built, multi-functional resource centre which offers a wide range of services and activities to people with physical disabilities living in the East Cornwall area.

³⁴ <http://www.enableincornwall.co.uk/disability.php>

The Centre's Mission statement³⁵ is as follows –

To provide quality services that empower, promote independence and enable individuals to make meaningful choices leading to a fulfilled and valued life within the community.

The partnership between the Council and the Charity means that the Centre is able to fund-raise from a range of sources in ways that the Council cannot. Without the funds raised by the charity many of the activities that are offered would not be available.

It is clear that the evolution of disability provision in Cornwall has changed from the early days of no 'specific' provision at all, through a range of purely statutory sector or voluntary sector provision, to a hybrid of statutory and voluntary sector provision today. Where the statutory sector is governed, guided, and limited, by legislation and national policy guidance, the flexibility of the voluntary sector can facilitate a greater range of provision through statutory sector facilities.

At the ECHO Centre this breadth of provision includes –

- a wheelie boat and a Drascombe Long boat kept at a local lake for access to the water
- purchase of a camera to record activities undertaken
- supporting a trip to the Paralympics in London, 2012
- paying for speakers and tutors to run a wide range of talks and workshops for service users, on subjects such as mono printing, e-safety.
- paying for sessional workers to run regular exercise classes
- supporting volunteer expenses for travel and subsistence, and
- purchase of materials and equipment to provide activities in the centre such as craft materials, sporting equipment, gardening and cooking equipment etc.

Hearing Loss Cornwall³⁶

Founded on 2nd June 1931, by the Right Honourable Viscount Clifden and a committee comprising deaf and hard of hearing people, Hearing Loss Cornwall was then known as the 'County of Cornwall Association for the Deaf and Dumb and Hard of Hearing'.

In 1933 it produced its first report which began:

"In putting forth their first Report and Statement of Accounts, the Committee of the Cornwall Association for the Deaf and Dumb do so with mingled feelings of regret, wonder, and satisfaction. Regret, that the things which are being attempted were not taken in hand a generation or more ago. Wonder, that the needs of the Deaf should for so long have been allowed to be passed over unnoticed and that the age-long inertia and unwillingness to take action are so quickly being overcome. Satisfaction, and a sense of pride that this

³⁵ <http://www.echocentre.co.uk/whoweare.htm#charity>

³⁶ <http://www.hearinglosscornwall.org/about-us/history.html>

Committee are succeeding in their efforts which are being deeply appreciated by the deaf and dumb people themselves.”

In 1981 the Charity Commission officially approved the name ‘Cornwall Association for the Deaf and Hard of Hearing’, and over the years, the shorter working title of The Cornwall Deaf Association was adopted. In 2012 the Association changed its name to Hearing Loss Cornwall.

Mid Cornwall Lifestyles

The vision for the Mid Cornwall Lifestyles Project is³⁷ -

that everyone lives their life to their tune; that disabled people are fully empowered

The Lifestyles Project began as a pilot funded through Scope in 1996 and received a 3-year National Lottery Community Fund award in 1999 which ran until August 2002. They achieved Charitable Status in 2002, since when they have been financially independent, through a mix of income from Cornwall Council Adult Social Care, Health Trusts and various other funders and donations.

The organisation offers a range of services including –

- Individual Support - providing essential support to vulnerable people through contracts with either Adult Social Care or Mental Health Trusts;
- Assisting with Individualised Budgets, Direct Payments and Independent Living Fund;
- Accessible Transport: - two wheelchair-accessible vehicles on offer;
- Project Group/Day Service - individuals pursuing their own particular interests, projects or qualifications in a safe and supportive environment; carting, quad bikes or qualifications;
- Advocacy - individual support, advice or signposting as necessary to gain resolution. Support of other small charitable organisations;
- Training and Qualifications – including Wider Key Skills, Community Volunteering Qualification, and Employability.

The funding route being followed by Mid Cornwall Lifestyles – the creation of a range of services that people can buy on an individual or group basis – is a route that more and more voluntary sector organisations are now following. Funding from the statutory sector is disappearing, and therefore there is greater competition for funding from grant-giving organisations. Many voluntary sector organisations – including disability-specific organisations - are striving to become as self-reliant as possible. Mid Cornwall Lifestyles works in partnership with Cornwall Department of Adult Social Care, Cornwall NHS Partnership Trust, St Austell PHAB and a host of other small groups, charities, colleges, individuals and organisations.

³⁷ <http://www.lifestyles-cornwall.org.uk/>

Pentreath

Pentreath is an award winning mental health organisation working throughout the whole of Cornwall and Isles of Scilly. It was founded in 1990, then achieved registered charity status and became a company limited by guarantee in 1991. They

“inspire and support clients through a journey of both personal and vocational (work) development with the aim of securing future employment, education or training.”³⁸

The organisation has a broader focus than working with individuals, as it also works “to raise awareness and challenge any misunderstandings that society has about mental health.”

Conclusions

It is clear that the picture in relation to Disability in Cornwall has changed in many ways within a relatively short space of time – certainly within the lifetime of many disabled people. Our understanding of Disability is changing as people live longer lives, with better medical provision available to them. Older disabled people – including Doreen who provided the inspiration for this project – can remember a time of little or no disability provision at all, including no disability equipment such as wheelchairs.

Over time – with the creation and growth of the Welfare State, the growth of the voluntary and private sectors, increasingly available and better equipment, and the ‘singling out’ of disabled people as requiring ‘special’ treatment – disabled people have been better catered for in Cornwall. There was a growth in statutory sector provision, including schools, workplaces, day and residential services. This growth in provision was characterised by an increasing specialism in services, with services for specific groups of disabled people, including –

- people with learning difficulties,
- people with physical impairments or sensory loss;
- older or younger disabled people;
- etc.

With this growing disability sector has come a growth in associated professional non-disabled people, to meet the needs of the disabled people with whom they work.

The relationship between disabled and non-disabled people has changed over time. In the past disabled people were seen as passive recipients of care and medical services. Professional people ‘did’ to disabled people, who had little choice in what happened, when or where.

Towards the end of the twentieth century this situation fundamentally changed. Disabled people – after years of campaigning at the national level – effectively changed to become commissioners of individual care packages. Social Care is now increasingly being delivered through Direct Payments or Personal Budgets, and the disabled person is increasingly the employer. Non-disabled care staff answer to the disabled person, who sets the terms and conditions of employment. This represents a paradigmatic shift of power.

³⁸ <http://www.pentreath.co.uk/> - accessed 12/05/2014

However all is not completely rosy for disabled people in Cornwall in 2013/14. For example –

- There are many changes in the welfare benefits system in 2014, including the following –
 - o Incapacity Benefit has been renamed Employer Support Allowance;
 - o Disability Living Allowance has been renamed Personal Independence Payment; and
 - o The Independent Living Fund has closed completely, and is going to be administered by the Local Authority.
- The shift from the statutory sector as a service provider to a service commissioner is causing fundamental changes to disability provision, with many services threatened with closure or significant service reductions
- The move towards Personal Budgets leaves many disabled people feeling uneasy, as their wishes and desires in relation to the size of their budgets, or what they might be able to spend them on, are not met by the reality when the final allocation is decided;
- A disabled person with a Personal Budget living in an area in Cornwall with a relatively high population and a good level of services might be very happy to purchase their care services locally. However a disabled person with a Personal Budget living in a rural isolated location in Cornwall might not have any services locally to purchase. This is a threatening and isolating position to be in, and the individual concerned may feel unable to continue living independently in the community as a result of it; and
- As the national discourse of austerity and service reduction filters through to Cornwall many disabled people feel that they are being hit harder than disabled people in urban areas – for example the costs of living in rural areas are seen as higher than the costs in urban areas; there are fewer services to choose from in rural areas; the additional costs associated with living with impairments are not met by the amount of money awarded to many disabled people.

As the statutory sector grew in size in the twentieth century there was also an expansion of voluntary sector provision. Disabled people often had greater control within this voluntary sector disability provision, including helping to design and create new provision and services. What is surprising from the research for this document is that Cornwall – often regarded as slow to embrace innovation and newness – has a good record of innovation in relation to disability voluntary sector innovative practice. The Cornwall Blind Association sprung into life in the nineteenth century a decade or so before the national Royal National Institute for Blind People, and Group Captain Leonard Cheshire opened his first purpose-built Cheshire Home in Cornwall.

In Cornwall smaller groups controlled and run by disabled people formed themselves at more or less the same time as national organisations such as the Union of the Physically Impaired Against Segregation (UPIAS) came into being in the 1970s. It was UPIAS which created the Fundamental Principles of Disability, which later led to the writing of the Social Model of Disability. For groups of disabled people to form in Cornwall at this time would have been truly ground-breaking and innovative.

Cornwall Leisure and Sports Players (CLASP) was part of a vibrant national disability sports scene. Other groups of disabled people came to Cornwall for sports activity, while CLASP went 'up country' to join in with a broader national disability sports scene (see the full interview with Diana Johnson as part of this video history project for more information).

Cornwall's wheelchair dance group – The Choughs – formed in 1970, bringing disabled people together to enjoy social activity. Proper Access Now in Cornwall (PANIC) formed to campaign to improve mainstream disability access in the 1980s.

All of these early mobilisations of disabled people represent a sea-change in the way that disability and disabled people were viewed. No longer were disabled people content to be 'done to', but more and more they wanted to be in control of their individual, and collective, lives. Increasingly this minority group – along with other societal minority groups – wants self-control, and no more subservience to the dominant societal narrative.

This is now an issue of Human Rights and entitlement, rather than charity. This is the fundamental shift that has happened in Cornwall – as well as elsewhere in the UK – in relation to disability, disability provision and disabled people. This document charts this change.

Here we have outlined Cornwall-specific provision, though by no means all of it. There are also very small, un-funded organisations throughout the county, which may provide services such as a weekly or monthly lunch club, or small scale social activities, including painting or art groups. These organisations are impossible to count in any reliable way, and are reliant on word of mouth for their advertising and membership.

Now (2014) we are in times of increasing financial austerity. The statutory sector is restructuring to reduce expenditure in all areas, including within the disability sector. New partnerships are being created between the statutory and voluntary sectors to meet identified individual needs. Cornwall, for example, achieved 'Pioneer' status in 2013, to model a pilot project that brings together Adult Social Care, the Health Authority, Age UK and Volunteer Cornwall, to create new ways of engaging older people in local community settings, and to reduce the need for acute statutory sector Health and Social Care interventions.

Several of the disability-specific groups described in this document have formal relationships with the statutory Health and Social Care sectors. Services which would previously have been provided solely by the statutory sector may now be provided through the voluntary sector in a partnership arrangement.

Things are changing and will continue to change – though not always for the better. Financial resources have always dictated what can be done, where, and by whom. However it seems that right now a real shift in the levels of provision and services in Cornwall is taking place. This is at the same time as we are all living longer, and there are more disabled people within the population than ever before. The friction between what is required and what is available will continue well into the future.

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APPENDIX I – Numbers of Disabled People in Cornwall

Introduction

It is problematic to talk about the numbers of disabled people in Cornwall. There is no one, consistent way of measuring 'disability' across the various agencies who wish to measure it. Here we collect some of the figures issued by the various agencies which can individually give reliable information on specific disability issues. There is no way of combining these figures to give a reliable 'total' figure in relation to the numbers of disabled people in Cornwall.

Each way of measuring figures relating to long-term illness or disability has its own set of problems in relation to data reliability/validity. In general these problems are associated with the range of eligibility criteria, which are in no way static but in a constant state of change and flux. These are outlined briefly in each circumstance below.

2011 Census data³⁹

The reliability problems of Census data relate to the fact that the data are self-disclosed. Some people may elect to declare an underlying health condition or disability, while others may not.

In the 2011 Census the total population of Cornwall was 532,273. There are 109,731 people in Cornwall aged 65 and over which represents 20.62% of the total population.

Of the total population, 53,166 people self-reported their day to day activities were limited 'a lot', and 60,549 said their day to day activities were 'limited a little' by a long term health problem or disability. The total figure for limited a little or a lot is therefore 113,715 people, or 21.36% of the total population. This is more than double the national figure of 10% of the population.

FACT – Cornwall's population of people with a long-term limiting illness or disability is more than twice the national average.

FACT - There are more people in Cornwall with a limiting long-term condition or disability than there are people aged over 65.

The figures in relation to people aged 16 to 64 are as follows –

People limited a lot for reasons of health or disability = 22,002

People limited a little for reasons of health or disability = 27,627

The total figure for people aged 16 – 64 is therefore 49,629 people with a limiting health condition or disability. This represents c.43.6% of the total figure of people in Cornwall with a long-term limiting health condition or disability.

³⁹ From Table KS301EW here -

<http://www.google.co.uk/url?sa=t&rct=j&q=census%20disability%20statistics%20table%20ks301ew&source=web&cd=1&ved=0CDIQFjAA&url=http%3A%2F%2Fwww.ons.gov.uk%2Fons%2Frel%2Fcensus%2F2011-census%2Fkey-statistics-for-local-authorities-in-england-and-wales%2Frt-table-ks301ew.xls&ei=GbTmULX6Hqm70QW1i4CwCQ&usq=AFQjCNGsLbMIHZuyTHEZ3hW31ckZoMhOzg>

FACT – c.43.64% of the total figure of people in Cornwall with a long-term limiting health condition or disability are aged under 65.

This means that c.56.36% of people with a long-term limiting illness or disability in Cornwall are aged 65 and over (64,086 people in total).

277,462 people aged 16-64 do not report having any limiting long term illness or disability. Therefore 15.17% of 16-64 year olds living in Cornwall report having a long term health condition or disability that affects their day to day activities.

Care

469,081 of the population do not provide unpaid care. However of those who do –

- 39,052 provide 1 to 19 hours of unpaid care per week,
- 8,284 provide 20 to 49 hours of unpaid care per week, and
- 15,856 provide 50 or more hours of unpaid care per week.

This means that 63,192 people provide some level of unpaid care per week, or 11.87% of the total population of Cornwall.

Welfare data⁴⁰

Welfare data relies entirely on an individual's eligibility for specific benefits. The eligibility criteria are currently going through significant changes, so it is likely the figures listed here will change over the coming twelve months, probably following a downward trend, as the financial situation becomes ever more difficult.

The number of people receiving **Disability Living Allowance (DLA)** in September 2012 was 31, 820.

FACT - This figure represents almost 28% of the 2011 Census figure (113,715) of people who have declared themselves as having a long-term limiting illness or disability.

Eligibility for DLA is dependent on an individual's Mobility or Care needs. If an individual is assessed as having low, moderate or high care or mobility needs they can receive different levels of benefit. However there are many disabled people, or people with a long-term limiting health condition, who have no mobility or care needs, and are therefore not included in this figure.

The number of people receiving **Employer Support Allowance** (including Incapacity Benefit and Severe Disability Allowance) in September 2012 was 23,430 people. This benefit is only for people of working age who are deemed as looking for employment.

⁴⁰ *Welfare reform figures at a glance* September 2012, Cornwall Council

FACT – This represents 20.6% of the Census figure (113,715) of people with a long-term limiting illness or disability

The number of people receiving *Carer's Allowance* in September 2012 was 5,560 people.

FACT – This represents only 8.8% of the people from the 2011 Census who reveal they undertake some level of weekly caring responsibilities.

Cornwall Department of Adult Care and Support (DACs) data⁴¹

In 2005/6, 8,720 people under 64 received care from DACs. In 2010/11 this figure had reduced to 3,915 people. This reduction is largely due to the Local Authority changing their eligibility criteria to exclude people with Low or Moderate Care Needs. Even though the eligibility criteria for DACs has become more difficult, there is no evidence to suggest the numbers of people who previously received services from DACs has decreased.

FACT – Only 7.89% of the 2011 Census figures for the total number of people aged under 65 with a long-term limiting illness or disability (49,629) receive services from DACs

Of the total number of people in Cornwall aged 65 or over with a long-term illness or disability (64,086 people in total) 10,635 receive services from DACs. This represents 16.6% of this population.

Of the total number of people in Cornwall aged under 65 with a long-term illness or disability (49,629 people in total) 3,915 receive services from DACs. This represents 7.89% of this population.

At the same time that there has been a halving of the numbers of people aged under 65 receiving care from the Local Authority over the past five years (from 8,720 people to 3,915 people), the budget expenditure has now increased from £49,703,000 in 2005/6 to over £83 million in 2010/11 for this age group. This is the first time the expenditure for people aged under 64 has exceeded expenditure for people aged over 64.

Conclusions

It is clearly difficult to arrive at a single figure in relation to the number of people in Cornwall who have a long-term limiting illness or disability. It seems fair to say that the actual and percentage figures for Cornwall are higher than the national average.

It is also not easy to draw comparisons between the figures used by different agencies as the eligibility criteria may vary.

There will be many people who are not included in any of the data outlined above, and whose needs may therefore remain unaddressed and unmet.

⁴¹ From the National Adult Social Care Information Service database - <https://nascis.ic.nhs.uk/>

APPENDIX II – The local Disability Sector in Cornwall in 2014

In 2013 Disability Cornwall & The Isles of Scilly brought together a consortium of organisations for a range of training, education and to investigate joint working opportunities. This consortium included seven user led organisations, and the membership was as follows –

- Disability Cornwall & the Isles of Scilly
- Cornwall Association for Deaf and Hard of Hearing People
- Cornwall Blind Association
- Cornwall people First
- Parent Carer Council Cornwall
- Pentreath Ltd
- Enable in Cornwall Ltd.
- Mid Cornwall Lifestyles

Between us we work with the following groups of people across the whole of Cornwall, as well as our visitors -

- Any disabled people
- People with hearing loss
- People with visual impairments
- People with Learning disabilities
- Children, young people and families with all disabilities and additional needs
- People with mental health difficulties
- Parent Carers
- Carers

Between us we have –

- a total of 2,274 members
- over 60 associate, organisational members
- a reach of about 14,700 people across Cornwall and the Isles of Scilly
- a combined income of £2,299,341.