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EXTRACT FROM

Redland Children and Young People's Partnership

Improving the social inclusion of disabled children and young people and their parents - Commissioning strategy

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Redland Children and Young People's Partnership

Improving the social inclusion of disabled children and young people and their parents - Commissioning strategy

1 Introduction

This strategy has been prepared by Redland Children and Young People's Partnership. It covers the years 2010-2020 and tells disabled children and young people, and their families and local partner agencies how the identified needs of disabled children and young people and their parents could be met within available resources provided by health, the local authority and the voluntary sector across the next 3, 5 and 10 years.

The objectives for this strategy are to:

- Bring together existing needs identified by key strategic bodies into a coherent, single document
- Identify the cohort of disabled children and young people in terms of existing need being met, partially met and not met at all
- Establish links with other existing and developing strategies and services (Vulnerable families, Autism strategy, Corporate Parenting Strategy, etc)

This information is presented in numbered sections following this introduction:

2. National requirements and research
3. Needs assessment: Statistical analysis
4. Needs assessment: File audits
5. Needs assessment: Consultation
6. Current services and the people known to them
7. Gap analysis and the design of future provision
8. Monitoring arrangements
9. Appendices

This strategy focuses on children and young people known to the Partnership aged 0-19 years, and up to 25 years for those in further or higher education. A particular focus is given to children aged 6-14 years with complex behavioural needs; children in this age range have a substantially higher level of need than their peer group, and these individuals will require substantial resources in the future.

2 National requirements and research

Services for children and young adults with disabilities, including those going through the transition process from children's services to adult services have been highlighted as an area of concern in a range of recent Welsh and English policy documents and associated guidance, including *We Are On the Way* (2008), a Welsh Assembly Government policy statement about transforming the lives of disabled children and young people and their families.

Despite the consensus on the importance of good transition planning, research shows that young people are not getting the help they need[1]. The National Service Framework for Children, Young People and Maternity Services[2] recognises that young people with disabilities and their families experience particular difficulties in the transition from full time education into the adult world. Young people's lives change rapidly during this period. Leaving compulsory schooling is accompanied by decisions about future education and employment and there are also changes in family life and social networks[3]. The choices for individuals are often a range of segregated services, rather than help to achieve the same things as other young people[4].

At age 16, young people with disabilities have aspiration levels similar to their non-disabled peers, yet these diverge significantly in early adulthood[5]. A report for the Joseph Rowntree Foundation highlighted that few young people with a disability are employed, many use day centres, college is often the expected route of progression from school regardless of desire, and little emphasis is placed on leisure, friendship and emotional support.[6] In addition, young disabled people often find that the only option for leaving their parents' home is not a move into a home of their own, but instead into a 'housing scheme' or group home[7]. The decision about where to live is more often determined by what vacancies are available, than by a young person's choice about where and who they want to live with.

Disabled children are not a homogenous population. The Report on Disabled Children and Health (June 2009) [8] indicates some of the groups that may require health support at some point in their lives as:

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[1] Beresford, B (2004) 'On the road to nowhere? Young disabled people in transition', Child: Care, Health and Development, 30, 6, 581-587

[2] Department of Health, Department for Education and Skills (2004) The National Service Framework for Children, Young People and Maternity Services

[3] Everitt, G. (2007) Transition? How to find your way through. An overview of recent transitions research for parents and practitioners. Dimensions (UK) Ltd. p9

[4] DH (2007) Valuing People Now. From Progress to Transformation, London, DH Publications

[5] Burchardt T (2005) The education and employment of disabled young people: Frustrated ambition. York: Joseph Rowntree Foundation, Policy Press

[6] Morris, J. (1999) Hurtling into a Void: Transition to adulthood for young disabled people with complex health and support needs, Joseph Rowntree Foundation.

[7] Everitt, G. (2007) Transition? How to find your way through. An overview of recent transitions research for parents and practitioners, Dimensions (UK) Ltd.p61

[8] Every Disabled Child Matters, the Children's Trust Tadsworth, Disabled children & health – campaign briefing from the Every Disabled Child Matters campaign (June 2009)

- Children with a long-term condition (e.g. cerebral palsy)
- Children with complex health needs (e.g. uncontrolled epilepsy, osteopenia or gastro-oesophagel reflux)
- Children with multiple impairments/ profound and multiple learning disabilities (e.g., severe learning disability with physical disabilities and additional complex health needs)
- Children with a learning disability (e.g. Down’s syndrome)
- Children with a physical disability (e.g. muscular dystrophy)
- Children dependent on technology (e.g. children on ventilators or with tracheostomies or gastrostomies)
- Children with a life threatening or life-limiting condition (e.g. cancer or Batten Disease)
- Children with a rare condition (e.g. Rett syndrome)
- Children with an acquired brain injury which can cause physical, cognitive and behavioural difficulties
- Children with an autistic spectrum disorder
- Children with sensory impairments

The above is not an exhaustive list, and these are not discrete groups – children may fall into more than one group (and this list does not include child and adolescent mental health needs). However, it does serve to illustrate the wide and varied needs of disabled children and young people. Consequently, every disabled child will need his or her own package of services to ensure that they achieve the Every Child Matters outcomes and the Welsh Assembly Government’s 7 Core Aims which are based on the United Nations Convention on the Rights of the Child. These are that all children in Wales:

- Have a flying start in life; have a comprehensive range of education and learning opportunities;
- Enjoy the best possible health and are free from abuse, victimization and exploitation;
- Have access to play, leisure and cultural activities;
- Are listened to, treated with respect and have their race and cultural identity recognized;
- Have a safe home and a community which supports physical and emotional well-being; and
- Are not disadvantaged by poverty.

Disabled children have the right under disability discrimination legislation to access all services that other children use. In addition, many disabled children will need input from a range of specialist services, such as equipment services, therapists and specialist teachers, if they are to achieve their full potential.

It is essential that service providers are flexible and child-centred in their approach to providing services for disabled children and their families. A mixture of accessible mainstream services, specialist services and family support services should be available to every family, with the precise mix determined by each individual child’s needs.

The full review of policy and best practice is given as Appendix 2; a summary of key issues is given below.

2.1 Key Issues for Children and Young People with Disabilities and their Families

According to research, disabled young people are nine times more likely to be excluded from school than other children, more likely to live in poverty, and more likely to be not in education, employment or training (NEET) beyond the age of 16. Families of disabled children report high levels of dissatisfaction with social care, health and education services, and 8 in 10 families with severely disabled children surveyed by Mencap described themselves as ‘at breaking point’ [9].

The Parliamentary hearings on services for disabled children (October 2006) highlighted five pervasive themes that affect children and young people with disability and their families. These are:

- Poverty
- Social exclusion, including Housing
- Inequality
- The lack of data
- The voice of children and parents

Additional key areas to consider when commissioning services for disabled children and young people and their families are:

- Health care
- Case management

Each of the above themes are summarised in the sections below.

2.1.1 Poverty

There is a strong relationship between low income, social exclusion and disability among families who have a disabled child. Families with disabled children remain disproportionately likely to be in poverty[10]. They are more than twice as likely as other families to be unable to afford more than five or more everyday items.

2.1.2 Social exclusion

Disabled children and their families want to live ordinary lives as part of their communities. A survey of the social care needs of children with complex health

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[9] Every Disabled Child Matters, Making disabled children matter locally – a guide for supporters on campaigning to make disabled children and their families a priority for local government and health agencies (Updated April 2009)

[10] Kemp, P. et al (2004) Routes out of poverty, York: Joseph Rowntree Foundation

care needs and their families[11] found that in relation to' what matters most' these children and young people have the same 'ordinary' wishes and needs as other children. What matters most to them is being able to live at home, go to school, spend time with friends and participate in leisure and community activities with family and peers.

2.1.3 Housing

Disabled children and young people spend more time at home than non-disabled children, which means that their home environment is even more important. However, evidence suggests that it can also be the most restrictive environment in which disabled children spend time. For example, living in unsuitable housing can restrict children's leisure and play experiences, primarily because it restricts their ability to move about the house independently and/or safely.

In addition, unsuitable housing impinges on disabled children and young people's ability to develop self-care skills, such as cooking, and also meant they needed (unnecessarily) their parents to help them with bathing and using the toilet. The impact on parents/carers of living and caring for a disabled child or young person in unsuitable housing can be both physical and psychological.

By contrast suitable housing promotes independence and life skills which disabled children value.

2.1.4 Inequality

Inequality in service delivery in services for disabled children in Britain is present both within and between geographical areas. Only those parents who are able to fight sustained battles with agencies can access services; and even those families able to fight have highly unequal service outcomes dependent on their location.

The Audit Commission[12] found a 'national shortage of inclusive and specialist (play) provision and 'gaps in play and leisure provision within a locality, for children of particular age group or with certain needs'. The Government's review of children's play[13] stated that 'disabled children and young people have significantly worse access to good play opportunities.'

2.1.5 The lack of data

There are fundamental gaps in the data on disabled children that should be available to public services. In relation to disabled children there is very little reporting of robust analysis of local needs by Children and Young People's Partnerships.

Without this data, it is obvious that planning and commissioning of services cannot take place on any informed basis. A lack of comprehensive national data sets is a major barrier to accurate cost benefit analyses.

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[11] Social Care Institute for Excellence, Knowledge Review 18 'Necessary stuff': the social care needs of children with complex health care needs and their families (January 2008)
[12] Audit Commission (2003) Services for Disabled Children.
[13] DCMS, (2003) Getting Serious About Play: A Review of Children's Play

2.1.6 The voice of children and parents

The importance of involving children, not just parents, in service developments is well recognized. A survey conducted in 2003 with children and young people in Wales on behalf of the Welsh Assembly Government identified the following overriding messages:

- Attitudes and behaviour of staff – disabled children and young people placed significant importance on being listened to, talked to and treated with understanding and respect by staff.
- Provision of information – many disabled children and young people receive information ‘second hand’ via parents or carers not directly from professionals.
- Participation – disabled children and young people’s involvement in making decisions about their own care is not consistent across services. However, disabled children and young people want to participate in decisions about their individual care and services they use.

2.1.7 Health care

All disabled children in Wales should enjoy the best possible health (ibid). Their families can face physical, emotional and financial pressures, however, it has been shown that early intervention and the provision of appropriate support can reduce the impact of these pressures. Disabled children should have access to appropriate health care services and therapies, including:

- Early diagnosis
- Early signposts to support and services
- Early intervention

Access should be provided to skilled professionals that can respond to assessed needs for both mental health and learning disability.

2.1.8 Case management

The provision of targeted and individualised services to disabled children and their families, given the wide and varied needs of this group, is dependent on effective case management by the professionals involved. Parents and carers should be offered an assessment, and for those that meet eligibility criteria, outcomes should be set in the care plan for both children and young people and parents and carers. Services should be commissioned on the basis of outcomes, with reviews held at appropriate intervals. Supervision of cases should be consistent and thorough, and case files need to be accurate and kept up to date.

In terms of transition, the biggest single obstacle to progress is the lack of recognition that transition is a process, not an event. For example, a move from child to adolescent mental health services to adult mental health services may be managed separately from their move from secondary school to college, or from living at home to living independently. Therefore, transition planning needs to be person-centred, with the young person’s preferences, goals and aspirations taking centre stage.

3 Needs assessment: Statistical analysis

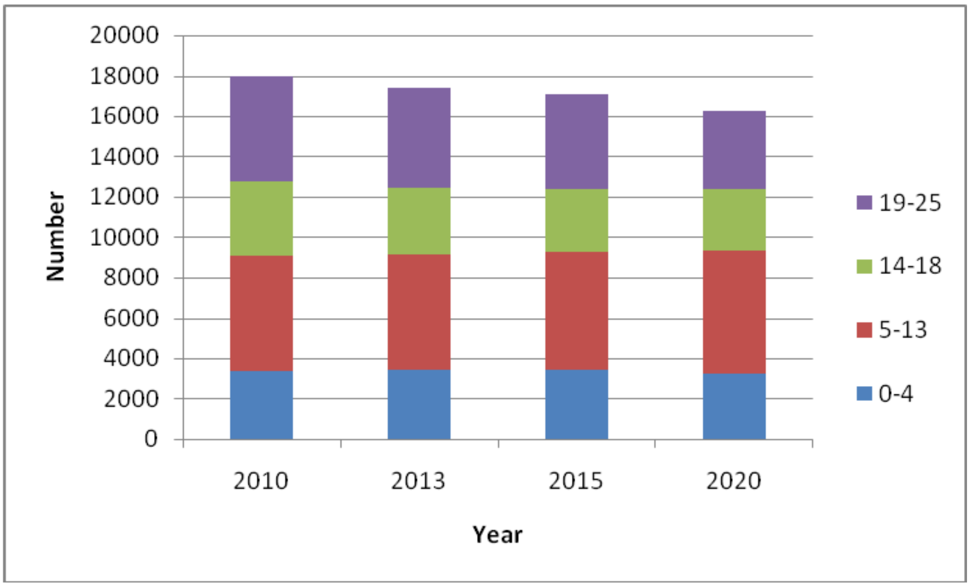
3.1 Demographic analysis

Population estimates for Redland are available for years 2001-2008[14]; numbers for year 2008 are given as Appendix 3a. Population projections were published by the Welsh Assembly Government in July 2008. Figures for each age 0-25, for the years 2009-2031 are provided in Appendix 3b. For all children in Redland, population trends can be summarised as follows:

- The population of 0-19 year olds has been decreasing since around 1999, and it is projected that this population will continue to decrease until 2017 when it will reach its lowest level. The population will then increase slightly until 2021, before declining gradually from here on.
- There has been an increase in the number of 0-4 year olds in recent years which will gradually lead to an increase in primary school age children and then secondary school age children. This is because birth numbers in Redland have increased since 2002, and are projected to continue increasing, albeit slightly until 2011.
- The effects of the recent increase in the number of births will be carried through over the projection period, leading to increases in the numbers of children in each age group.
- Trends for each age group are similar within most local authorities in Wales, although turning points occur at different years.

This strategy is concerned with the next 3, 5 and 10 years. The following charts show the projected demographic trend in Redland over this period of time, followed by percentage change over the same period:

Projected numbers of children and young people in Redland by year and age band



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[14] 2008 Mid-year Estimates of Population, Welsh Assembly Government, August 2009

Percentage change in projected population by age band

Year	2010	2013	2015	2020
Age band				
0-4	0	1.93	1.60	-3.42
5-13	0	-0.24	1.93	5.49
14-18	0	-10.15	-14.99	-16.07
19-25	0	-4.25	-9.41	-24.54

Population estimates are a more accurate indicator of the current population than projections. For Redland, there is generally a good fit between 2008 estimates and projections, with an average variation of 1.53% for each age between 0 and 25. However, it should be noted that for age 0, the variation is most significant; estimates are 13% higher than projections, and this should be taken into consideration when reviewing projected numbers of service users.

3.2 Infant mortality, low birth weight and disability

For low birth weight, the proportion of babies born in Britain with a low birth weight is similar to a decade ago (2007). At 8.8% of all live births, the proportion of babies born with a low birth weight in Redland is one of the highest in Wales and higher than the average in Britain[15].

The rate of infant deaths in Wales, at 4.5 per 1000 live births, is somewhat lower than that in most other regions in the UK[16]. Within Wales, Redland has the lowest rate of all local authorities at 3.5[17].

Infants with a low birth weight and early gestation are more likely to have multiple and complex disabilities[18] . The combination of a relatively high low birth weight rate together with a low infant mortality rate would appear to indicate that Redland may experience a higher proportion of children with complex and multiple disabilities, than that indicated by prevalence rates from research.

3.3 Ethnicity

The most recent available ethnicity data comes from the 2001 census. Numbers are presented by age band as Appendix 4. 98% of 0-24 year olds were White British.

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[15] Data for the 10 years to 2007 combined, Key population and vital statistics, ONS, April 2009

[16] Average across 2005-2007, Key population and vital statistics, ONS, April 2009

[17] Data for the 10 years to 2007 combined, Key population and vital statistics, ONS, April 2009

[18] Children With Disability - An Overview, Orlagh Barnes, NHS Norfolk, 2 April 2008

Ethnicity	% of total population aged 0-24 2001 Census
White - British	98.00
White - Other	0.62
Chinese or other ethnic group - Chinese	0.26
Mixed - White and Asian	0.20
Asian or Asian British - Indian	0.20
Asian or Asian British - Pakistani	0.16
White - Irish	0.13
Mixed - Other	0.11
Mixed - White and Black Caribbean	0.10
Asian or Asian British - Bangladeshi	0.07
Mixed - White and Black African	0.05
Asian or Asian British - Other	0.05
Black or Black British - Other	0.03
Black or Black British - Black African	0.02
Chinese or other ethnic group - Other ethnic group	0.02
Black or Black British - Black Caribbean	0.00

Children particularly from Black African and Pakistani ethnic groups are more likely to have a severe disability than other ethnic groups[19], therefore it would be expected that at least 2% of those on the children with disabilities register would be from non-White British ethnic groups.

3.4 Severe disability

National Statistics[20] provide prevalence rates for children with a severe disability in the UK. For Wales, the rate is 10 per 10,000. The following table shows projected numbers across 3, 5 and 10 years.

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[19] The Health of Children and Young People: Disability, Nazma Nessa, National Statistics, March 2004

[20] The Health of Children and Young People: Disability, Nazma Nessa, National Statistics, March 2004

Projected numbers with a severe disability by age band, in Redland

Age	2010	2013	2015	2020
0-4	3	3	3	3
5-13	6	6	6	6
14-18	4	3	3	3
19-25	5	5	5	4
Total	18	17	17	16

The definition covers all types of severe disability. Distribution of most predominant severe disabling conditions for 0- to 16-year-olds in 1990 and 2000 were found to be as follows:

Predominant condition	Percentage 1990	Percentage 2000
Asthma	5%	2%
Autism, Behavioural Disorders	4%	25%
Cancers/Tumours	2%	3%
Cerebral Palsy	12%	8%
Deafness	6%	3%
Down's Syndrome	6%	3%
Epilepsy	4%	3%
Global Development Delay	0%	4%
Mental Handicap	18%	15%
Central Nervous System Disorders	5%	2%

Conditions which have shown a consistent increase in prevalence over the ten year period are cancer, global developmental delay, and most strikingly autism and behavioural disorders, where other conditions are shown to have decreased. The two most predominant conditions likely to occur are ‘autism, behavioural disorders’ and ‘mental handicap’.

Whilst projected numbers of the most severe types of disability (above) are too small to apply an estimate of predominant conditions, it would be expected that a large proportion of the severely disabled children in Redland will have ASD, behavioural disorders, or a learning disability and therefore these areas should be a priority for future investment in services.

Since the above study, more recent research has been published around learning disability and ASD, providing rates for both severe and less severe occurrences, and this is explored respectively for these wider groups in the following sections.

3.5 Learning disability

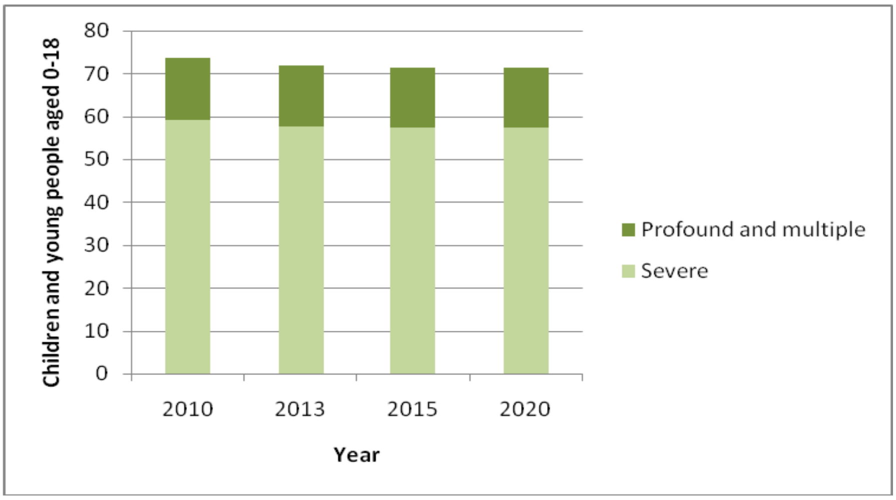
A Centre for Disability Research report[21] found prevalence of children in England aged 4-15 with learning difficulties, per 1,000 children, as follows:

Learning difficulty category*	Rate per 1,000 children aged 4-15
Severe	4.63
Profound and multiple	1.14

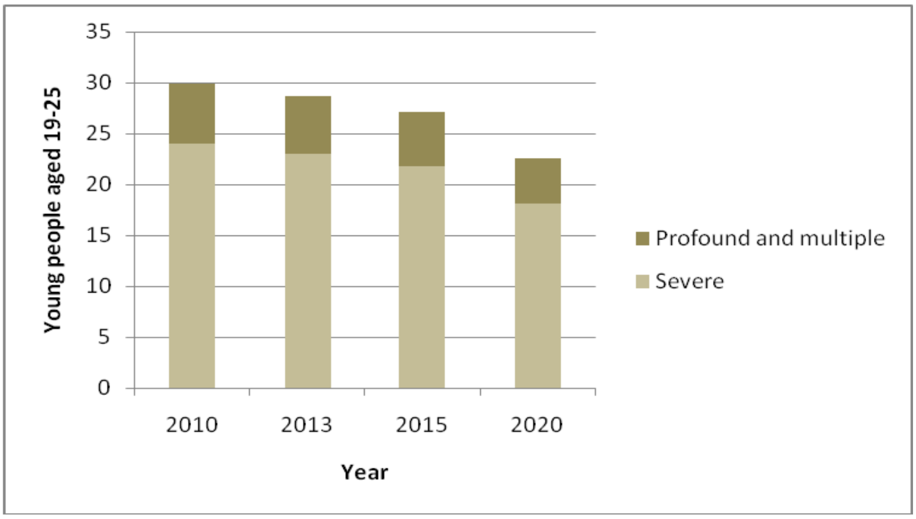
*The categories refer to general learning difficulties (i.e. what would be termed learning disabilities in non-educational settings).

These rates, not adjusted for mortality, have been applied to the projected population figures for Redland as follows:

Numbers aged 0-18 predicted to have a learning disability, by severity



Numbers aged 19-25 predicted to have a learning disability, by severity



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[21] Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England, Eric Emerson & Chris Hatton, CeDR Research Report 2008:6, November 2008

Whilst the figures for the 0-18 population stay fairly constant, numbers for those aged 19-25 can be seen to be falling in line with the drop in the general population. From this it can be inferred that there will be a reduction in the numbers of people with a learning disability coming through to adults' services over the next ten years.

3.6 Autistic Spectrum Disorder

1.0% of the adult population has ASD. The rate is higher in men (1.8%) than women (0.2%), which fits with the profile found in childhood population studies. Autistic Spectrum Disorder (ASD) has been assessed among children and young people, and two recent, large-scale surveys estimated the prevalence of childhood ASD to be around 1%, and higher in boys than girls. The number of reported cases of ASD increased steeply throughout the 1990s. It is likely that this was due to changes in public awareness of the condition, different diagnostic definitions and practices, availability of services and referrals, and earlier age at diagnosis[22].

Of those with ASD, numbers found with a learning disability (IQ less than 70) have been estimated at 55%[23]. The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.'

The tables below show estimated and projected numbers by gender for children with ASD in Redland, and of those, children with an associated learning disability (LD).

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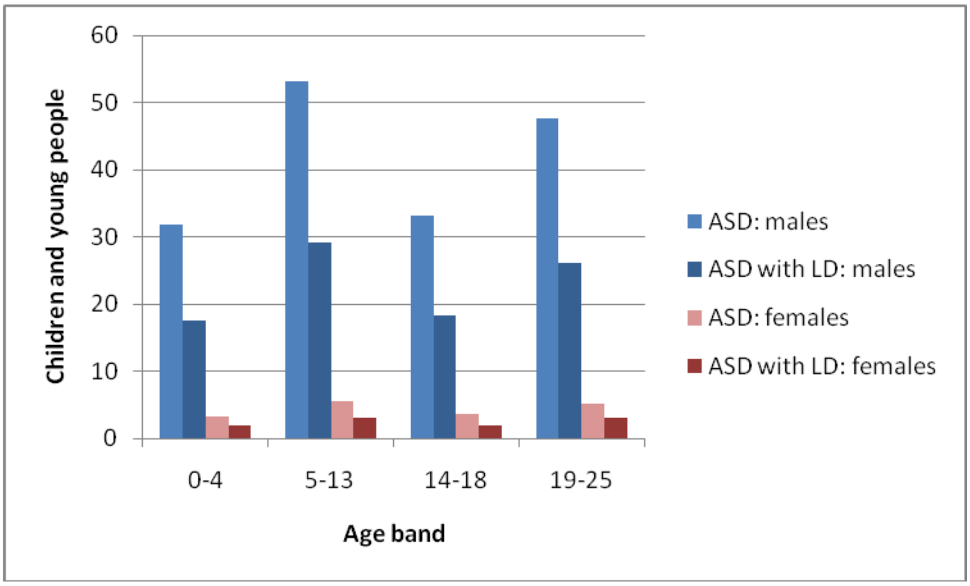
[22] Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007, NHS Information Centre

[23] Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), Baird, G. et al, The Lancet, 368 (9531), pp. 210-215, 2006.

Projected numbers with ASD, and ASD with a learning disability, by gender, 2010



Projected numbers for ASD with a learning disability, by age band

Age band / Year	2010	2013	2015	2020
0-4	19	19	19	18
5-13	32	33	33	34
14-18	20	18	17	17
Total 0-18	**72**	**70**	**70**	**70**
19-25	29	28	26	21

Early assessment and intervention is central to maximising opportunities for recognising children's difficulties and needs and for improving their emotional, educational, social and cognitive development and their health. Early action may also help to tackle some of the many social and physical barriers faced by children with ASD and enable their full participation in society[24].

In terms of investment priorities in Redland, these should include the provision of early interventions for this group of children.

3.7 Mental health problems in disabled children

Children with a significant learning disability are three to four times more likely to experience mental health problems than children without a disability. These children are generally at increased risk of developing mental health problems, particularly at times of stress and change, including periods of transition, in education, employment or relationships. At these times emotional difficulties, such as anxiety and depression and behavioural difficulties are particularly

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[24] The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales, Welsh Assembly Government, April 2008

common[25]. The independent inquiry[26] into meeting the needs of people aged 13-25 with learning disabilities, identified that young people with learning disabilities are disproportionately vulnerable to many of the known risk factors for mental illness, including poverty, abuse, bullying, low self-esteem and physical ill-health.

Children suffering physical illness, especially chronic conditions such as diabetes and cystic fibrosis, and very severe conditions such as leukaemia – even after successful treatment – are at higher risk of mental health problems and disorders. Children with sensory deficits such as sight and hearing loss are at special risk as are particularly, children who suffer brain injury. The risk of mental disorder in children with a physical illness has been assessed as being two to three times the average population prevalence if the physical illness is combined with disability[27].

Therefore, provision of CAMHS should be a key component of services available to disabled children.

3.8 Early intervention

Behaviour problems are common in young children with developmental disabilities. If untreated these problems are likely to persist and become more challenging and severe in adulthood. Behaviour problems interfere with cognitive, social and emotional development, create additional family stress, often lead to exclusion from community services, and result in additional financial costs to the community. Intervention research provides some support for the effectiveness of parent management training and interventions based upon applied behaviour analysis, in the preschool years[28].

Therefore, provision of early interventions should form a key aspect of investment plans.

3.9 Children with Disability Register

The Children with Disabilities (CWD) Register is a statutory requirement, comprising a list of all children with any type/severity of disability in Redland known to the Children with Disabilities Team (CWDT), regardless of whether their families are receiving a service from CWDT. These numbers should broadly fit with those estimated in the above sections.

Statistics were provided by CWDT to indicate the number of children and young people on the Register.

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[25] Emerson E (2002). *Self-reported strengths and difficulties of children and adolescents with and without developmental disabilities*. Lancaster University.

[26] The Foundation for People with Learning Disabilities (2002). *Count Us In*. The Mental Health Foundation.

[27] NHS Health Advisory Service (1995). *Together We Stand: The commissioning role and management of child and adolescent mental health services.* HMSO

[28] Early Intervention for Behaviour Problems in Young Children with Developmental Disabilities, Clare Roberts et al, International Journal of Disability, Development and Education, Volume 50, Issue 3 September 2003, pp 275-292

Registrations on CWD Register by Age Group and Gender, 5 August 2009

Age Group	Female	Male	Totals
0-4	9	16	25
5-11	25	50	75
12-15	20	49	69
16+	6	33	39
Totals	**60**	**148**	**208**

Children on the Register are categorised by type of disability, by gender, and this is show in the tables below.

Females on CWD Register by age, 5 August 2009

Registration Category	0-4	5-11	12-15	16+	Total
Autistic Spectrum Disorder	1	1	1	0	3
Learning & Physical Disabilities	1	2	2	1	6
Learning Disabilities		9	11	3	23
Physical Disabilities	5	11	6	2	24
Sensory Disability – Hearing	1	1	0	0	2
Sensory Disability - Visual	1	1	1	0	3
Totals	**9**	**25**	**21**	**6**	**61**

Males on CWD Register by Age, 5 August 2009

Registration Category	0-4	5-11	12-15	16+	Total
Autistic Spectrum Disorder	4	7	9	1	21
Learning & Physical Disabilities		10	6	3	19
Learning Disabilities	3	17	25	20	65
Physical Disabilities	9	18	10	6	43
Sensory Disability – Hearing	0	0	1	3	4
Sensory Disability - Visual	0	0	0	0	0
Totals	**16**	**52**	**51**	**33**	**152**

It is not possible to compare numbers here against the proportions estimated for particular conditions; categories are different across the two sets of data, and the register includes all those regardless of the severity of their condition. However, it is possible to compare numbers overall with a learning disability – prevalence rates from research suggest that there should be 70-80 with LD aged 0-18; the register lists 113.

The Autistic Spectrum Disorder (ASD) Strategy Action Plan – Baseline Survey puts the number of people known to the local authority, as at 31 December 2008, at 92. Prevalence rates from research suggest that about 70 aged will have ASD with LD. For ASD the register lists a total of 24; If the register categorises those with ASD with LD as LD, then there is a good fit between estimated and actual numbers.

Children on the Register are categorised by age and ethnic group.

CWD Register by age group and ethnicity, 5 August 2009

	0-4	5-11	12-15	16+	Totals
Not Recorded	0	2	9	10	21
Asian or Asian British – Other Asian	0	0	1	0	1
Black or Black British-African	0	1	0	0	1
Black or Black British – Other Black	0	1	0	0	1
White – British	25	70	59	29	183
White – Other Cultural Background	0	1	0	0	1
Totals	25	75	69	39	208

This table shows that ethnicity has been recorded for 187 children. Of these, 4 are non-White British, i.e. 2.14%. This figure is commensurate with census data and therefore it can be deduced that ethnic minorities are probably not under reported.

4 Needs assessment: File audits

A case file audit was carried out during July 2009 in order to help construct an in-depth profile of children, young people and families receiving services. In particular the case file audit set out to examine:

- The key characteristics of children, young people with disabilities and their families receiving services? For example, disability types; severity of disability; family characteristics.
- To what extent are the needs of children and young people receiving services met by existing provision, including the identification of gaps in existing provision.
- To what extent is the Partnership able to meet local demand for provision; for example, are there any areas of unmet need?

In all twenty case file audits were carried out across the age ranges 0-4; 5-13 and 14-18 in the Children with Disabilities Team, and ages 19-25 in Adults Services. Detailed findings from the case file audit are provided as Appendix 5. Findings can be summarised as follows:

4.1 Key characteristics

- 8/20 families were either lone parent families or the parents were not living together. In 17/20 families the disabled child or young person had siblings, indicating that most parents would have the additional responsibility of looking after other children as well as the disabled child. In conclusion, many parents were having to bring up their disabled child plus their other children on their own.
- For 17/20 families there were issues affecting parenting capacity, illustrating the numbers of problems and resultant degree of stress families were experiencing.
- Regarding mental health of parents/carers, of the 11 files where information about this was recorded, 7 had a history of mental health problems. For 4 out of 20 families there were issues with substance misuse, and 5 of the 20 domestic violence issues. These findings indicate that for many families there may have been issues around parenting capacity, over and above the pressures of bringing up a disabled child.
- Of the 15 families where there was any information about parents' employment status, there were 5 families where both parents were unemployed and a further 4 families where one parent was unemployed. These findings indicate that a high proportion of parents were unemployed and therefore at risk of poverty.
- In terms of housing, the file audit found that homes both owned and rented were adapted appropriately to meet the needs of the parents/carers, with the exception of 1 household where the family was very large and there was overcrowding. Our findings appear to suggest that the current provision and level of support is satisfactory.

4.2 Assessments and services provided

- It was difficult to gather clear information about referrals, services provided and outcomes of intervention from the case files. It was not possible to ascertain waiting times for services.
- More than half of cases reviewed appeared to be need rather than service led; this was commendable given that many cases had numerous and complex needs.
- Little evidence was seen of outcomes being set and monitored for children and young people. For example, case notes stated ' continue with medical appointments' or often blank spaces were left in the 'Outcomes' column on a form.
- At times little emphasis placed on leisure, friendship and emotional support for the child/young person and a stronger emphasis on behaviour management.
- Some files revealed a gap between identification of a need for service, and provision of services to meet those needs. This was particularly the case for children's clinical psychology services, CAMHS, sensory impairment services and therapies including speech and language therapy.

- Child protection issues appear dealt with thoroughly but following initial activity, reviews re planning health, emotional, educational outcomes for LAC remained limited.
- Many siblings, while none officially classified as young carers, were often supported via receipt of the Barnardos Young Carers service. This is an example of good practice.
- 5/20 families were in receipt of direct payments.

4.3 The voice of children and young people and their parents

- Little evidence of service user involvement in children's case files was found; this was particularly of concern for older children in transition. However in all case files for the 19-25 year olds there was some evidence of the young person's voice being evident in relation to expressions of enjoyment of leisure activities and school/college placements.
- Views and wishes of parents were not always recorded, in relation to choices, assessment, care planning and service delivery.

4.4 Case file recording

Observations made regarding case file recording practice are included as Appendix 6.

5 Needs assessment: Consultations

A wide ranging consultation exercise was conducted during September to November 2009. Details of findings from the consultations are provided as Appendix 7. Overall there was a shared sense between agencies and parents/carers of current issues faced by Redland around service provision, in terms of funding constraints, with economies of scale being difficult to achieve given the small size of the borough.

Findings can be summarised into the key areas as follows:

Prevention of poverty

- Consultations with parents/carers revealed a gap in terms of information available, both in terms of benefits and entitlements, but also in terms of services available and eligibility criteria for those services.
- For parents and carers who want to work, staff and parents said that there was no breakfast club available.
- For working parents, staff noted that a lot of juggling needs to be done to meet gaps in childcare regarding timings, school holidays, age of child etc.

Social inclusion

- Parents/carers reported feeling exhausted and stressed from looking after their disabled child and their other children, but felt that agencies recognised these issues.

- Parents noted that over the last ten years, the amount of social work support available had decreased significantly.
- Parents/carers felt strongly that there was a lack of respite care.
- Limited play opportunities although the service valued highly.
- Often children with disabilities are not taught independence early enough.
- Some families in receipt of direct payments, which enabled more choice and flexibility.
- Parents/carers and staff reported greater parental expectations for disabled children in recent years.
- Staff predicted that in future parents may wish their children to be provided with independent living arrangements.
- The FIS is rarely contacted by parents of children with disabilities regarding childcare services.
- Council small with limited funds, and so expectations for additional services or changes to services were correspondingly low.

Suitable housing

- Findings from the consultation would appear to suggest that current provision and level of support is satisfactory.

Equality

- Larnis is a multi-agency voluntary organisation which offers a service to families of pre-school age children with special needs by providing supported playgroup places. For disabled children, two funded sessions per week are provided, whereas non-disabled children are provided with five sessions. For disabled four year olds there is a gap in provision.
- The CAMHS service excludes those with a learning disability.
- The outreach team at Highfields School had begun a programme of training for teachers in mainstream schools to raise awareness of ASD and support them in teaching those children effectively and inclusively.
- More employment opportunities after college/school needed, to match those available for non-disabled young people. College should be providing the skills to gain employment - the same as it does for the non-disabled.

Sufficient data

- Consultations revealed that staff want to see clear and co-ordinated actions designed to improve the life chances of disabled children and young people.
- Sharing information between agencies was at times problematic.

The voice of children and parents

- Many parents and carers felt involved in the planning of services for their child.
- Staff were not clear if there were systematic processes in place for families' involvement in the strategic commissioning and purchasing of services.

- More work to be done to obtain young people's views on what opportunities and services they want.
- Play providers noted that there were currently no people with disabilities on the Junior or Youth Forums.

Quality health care/therapies

- Some parents/carers had been disappointed with the delivery of diagnosis of a learning disability.
- Many parents of children and young people with ASD expressed a great deal of disappointment that they had not received early intervention with regard to assistance with communicating with their child.
- There is currently a gap in services for challenging behaviour.
- Shortages of speech and language therapy and portage services; for the latter there is a 20 month wait for provision.
- Shortages of sexual health/puberty information and support for young people.
- Children's Community Nursing Team feedback: parents and carers had greatly valued the service and were grateful for the respite offered.
- Signposting to services was cited by staff as not always clear, and that problems existed with referral routes and care pathways.
- It was thought that services for children with a learning disability were not currently cost effective as the service is fragmented and not focussed.

Good case management

- Both parents/carers and staff spoke positively about the new arrangements for transition.
- Senior staff wanted to see outcome-based care plans in place for all children.
- Staff concerns that some families have unrealistic expectations in terms of services available for their child/young person on transfer to further services.
- Parents/carers expressed concern that there were insufficient social work staff.
- Staff in health and education would like to see a multi-agency approach in place with wrap-around care for children with disabilities, across health and social care.
- Others would like to see a key worker in place to plan and co-ordinate services and take forward key issues, including for transition.
- Having staff based together in one location would provide further benefits including efficiencies in terms of time and resources.