

## The Public Sector Equality Duty

The Equality Duty requires public bodies to have **due regard** to the need to:

- Eliminate unlawful discrimination harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it
- Foster good relations between people who share a protected characteristic and people who do not share it

### Protected Characteristics:

- Age
- Disability
- Gender Reassignment
- Pregnancy and Maternity
- Marriage and Civil Partnership (elimination of discrimination only)
- Race
- Religion or Belief
- Sex
- Sexual Orientation

**Due Regard** means consciously thinking about the three aims of the Duty as part of the process of decision-making. For example:

- How they act as employers
- How they develop, evaluate and review policy
- How they design, deliver and evaluate services
- How they commission and procure from others

**Advancing equality of opportunity** involves considering the need to:

- Remove or minimise disadvantages suffered by people because of their protected characteristics
- Meet the needs of people with protected characteristics
- Encourage people with protected characteristics to participate in public life or in other activities where their participation is low

**Fostering good relations** involves tackling prejudice and promoting understanding between people who share a protected characteristic and others.

**Complying with the Equality Duty may involve treating some people better** than others, as far as this is allowed in discrimination law. This could mean making use of an exception or positive action provisions in order to provide a service in a way that is appropriate for people who share a protected characteristic.

### Officers should:

**Keep an adequate record showing** that the equality duties and relevant questions have been actively considered.

**Be rigorous in both inquiring and** reporting to members the outcome of the assessment and the legal duties.

**Final approval of a proposal, can only happen after the completion of an equality impact assessment. It is unlawful to adopt a proposal contingent on an equality impact assessment**



<b>Title of the Assessment:</b>	<b>Children with Disabilities – Payments to Voluntary Organisations &amp; Other Provisions</b>	<b>Date of Assessment:</b>	05/02/16 & ongoing
<b>Responsible Officer Email:</b>	<b>Name:</b> Ken Harvey <b>Title:</b> Head of Children with Disabilities <b>Email:</b> Ken.Harvey @centralbedfordshire.gov.uk	<b>Extension Number:</b>	76599

**Stage 1 - Setting out the nature of the proposal and potential outcomes.**

<b>Stage 1 – Aims and Objectives</b>	
<b>1.1</b>	<b>What are the objectives of the proposal under consideration?</b>
<b>Budget Proposal Children With Disabilities (CWD) - £158,000</b>	
The proposal can be broken down as follows;	
<ul style="list-style-type: none"> <li>• <b>Removal of top up payment to Adult Social Care Occupational Therapy Services - £40k</b> – this payment helps ensure that disabled children are assessed more quickly and essential equipment is provided</li> <li>• <b>Removal of top up payment to Disabled Facilities Grant – £50k</b> this payment helps to ensure that additional provision is provided to ensure that disabled children are safe in their own home</li> <li>• A reduction of £68,000 to Voluntary organisations which includes the following reductions to Service Level Agreements             <ul style="list-style-type: none"> <li>○ Autism Beds – reduction from £35k to £17.5k</li> <li>○ Bedford and District Cerebral Palsy – reduction from £35k to £17.5k</li> <li>○ Family United Network – reduction from £30k to £15K</li> <li>○ Special Needs Out of School Club – reduction from £30k to £15K</li> </ul> </li> </ul>	
These organisations help support the provision of short break opportunities for children with disabilities.	
Short breaks are opportunities for children and young people with disabilities to spend time away from their primary carers, and provide opportunities for their parents and carers to have a break from caring responsibilities. In Central Bedfordshire, Short Breaks can include day, evening, overnight, weekend or holiday activities that take place within the home of the child or young person, in the home of an approved carer, a residential or a community setting. Short breaks come in many different forms and can be anything from a couple of hours to days – the length and type of break will depend on the needs of the child and their family.	
The Council’s is proposing to <b>target services on children with the highest needs:</b>	
<ul style="list-style-type: none"> <li>• Children receiving a service from social care Children with special educational needs Specialist</li> </ul>	
Services would need to be withdrawn from:	
<ul style="list-style-type: none"> <li>• Siblings of children with disabilities</li> <li>• Other children – i.e. children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and the Children Act 1989.</li> </ul>	

Families will be supported to consider accessing short break opportunities in different ways, for example via universal services such as leisure activities.

Following feedback from the voluntary organisations, it was agreed that the same level of funding would be made available for the period April – Sept 2016, in line with the period April – September 2015 and then it was proposed that 50% of 15/16 level of funding would be available from Sept 16 to end of March 17. In order to ensure that appropriate consultation takes place before a final decision is made in relation to future levels of funding, the voluntary organisations have recently been advised that funding will continue at 2015/16 levels for the remainder of the financial year 2016/17 and transitional funding will be provided at the beginning of 2016/17.

The review of all Children with Disabilities short break provision will take place from June 2016 – January 2017 reporting in March 2016. There will be full co-production with disabled children and their families on the review scope, review process and plans for future development and delivery of the services.

A transitional plan for the Voluntary Organisations will be in place to ensure stability for disabled children and their families and the organisations whilst the full review decisions are implemented.

The proposal only relates to the funding which comes to the above organisations from the Children with Disabilities Service and does not apply to any additional funding provided by other areas of the Council.

Voluntary organisations 1-4 above have been asked to come back with proposals for 2016/17 and an indication of the potential impact of the proposed reductions.

### 1.2 Why is this being done?

The Council is required to ensure that resources are targeted to areas of most need, and that all services deliver value for money. The drive for efficiencies and different ways of working is informed by national drivers that will see Councils' financial settlement reduce by approximately 15% over the next four years. There is a need to make efficiencies and identify areas where potential savings could be made. There is also a need to ensure that services are appropriate for the population of children living in Central Bedfordshire.

### 1.3 What will be the impact on staff or customers?

#### Current Access to Short Breaks:

For children to be eligible for a service from the specialist Children with Disabilities Team they must:

Be aged under 18 years old and live within Central Bedfordshire

Have a permanent and substantial diagnosed disability from one or more of the following categories:

- Severe or profound learning disabilities / autism
- Severe or profound physical disabilities
- Severe visual disability
- Severe or profound hearing loss
- Significant or profound sensory disabilities
- Multiple disabilities which together severely impact on quality of life
- Complex long term health needs
- Severe or profound social and communication difficulties related to disability

Children with the following disabilities would not be eligible for services from the Children with Disabilities Team unless they also have a diagnosed disability as outlined above:

- Emotional and behavioural disorders
- Mental Health Difficulties
- Medical conditions that are not permanent
- If the presenting problem is not related to the child with a disability (e.g. Another family member)

Families meeting Blue and Red Levels of the eligibility threshold will be eligible for the Local Offer

The children in Yellow and Green Levels can access main stream services through the Family and Youth Information Service.

Central Bedfordshire's Local Offer indicates that there are currently two levels of support, depending on the needs of the child which meet the threshold for accessing services. This is a flexible system and families can move between levels as their needs change.

**BLUE LEVEL These children with have a severe diagnosed disability in the categories outlined. Their disabilities are likely to have a moderate impact on family life and the children's quality of life would be improved with access to universal services, signposting and up to 156 hours per annum of Short Breaks activities. These children will either have a severe diagnosed disability and be in special schools or have a severe diagnosed disability and be receiving a minimum of 20 hours per week 1:1 help in mainstream schools.**

All eligible children and young people are offered flexible support so that they can take part in local activities. Children can access the Local Offer of **up to** 156 hours of support which can include

- Up to 156 hours of direct payments – allocated cash, to a maximum of £1519.44, for the family to provide a personal assistant to support their child **or**
- Up to 156 hours of an alternative short break such as
 

* Youth groups	* Playscheme or holiday activities
* 1:1 support at home	* 1:1 community support

**RED LEVEL Children in this category will have severe diagnosed disabilities in the categories detailed which are having a severe impact on family life and the children's quality of life is severely affected. These children are unlikely to be able to access universal services and will need specialist provision in education, health and social care.**

This level of support is available to fewer families facing extra challenges and includes:

- Families with a child with a life limiting condition;
- Families with a child with a disability whose severe behaviour difficulties challenge carers/siblings/other family members;
- Families with a child with complex health needs which require a carer with specialised training;
- Families with additional caring responsibilities.

Options can include:

- Overnight stays in a residential setting;
- A comprehensive package of direct payments or Short Breaks

Central Bedfordshire Council Equality Impact Assessment

	Meets Threshold for Services		Does Not Meet Threshold for Services	
Disability Category	<b>Profound Impairment RED LEVEL</b>	<b>Severe Impairment BLUE LEVEL</b>	<b>Moderate Impairment GREEN LEVEL</b>	<b>Mild Impairment YELLOW LEVEL</b>
Learning	Has a Statement of Educational Needs. Attends a Special School for children with severe learning difficulties	Has a Statement of Educational Needs. Attends a Special School for children with severe learning disabilities or has a severe learning disability and attends a mainstream school receiving a minimum of 20 hours 1:1 support a week	Has a Statement of Educational Needs Attends a mainstream school with limited support.	Does not have a Statement of Educational Needs
Mobility	Unable to walk. Totally dependent on others for mobility. Wheelchair user.	Unable to walk without aids or assistance. Able to manoeuvre self some of the time. May be able to stand or transfer with support.	Able to walk, but occasionally requires aids or assistance.	Able to walk/move independently, but with some limitation of function. May have poor co-ordination of movement.
Gross & Fine Motor Skills	Unable to use hands for any purposeful movement.	Mostly unable to use hands to complete tasks effectively. Able to use switch systems	Considerable difficulties with control of hands. Requires some assistance to complete tasks.	Some difficulties with control of hand movement for precise work.
Health	Unable to take part in normal social and educational activities.	Frequent or daily interruption of normal tasks. Significant interference with development and / or learning.	Intermittent but regular limitations on ability to perform everyday tasks. The child's development or learning may be affected.	Known health condition, which is under control and only occasionally interfering with everyday activities in a minor way.
Vision	Mobility restricted without special provision. Requires education by non-sighted method. Eligible for registration as blind.	Unable to read large print without assistance or aids. Severe visual field defect with impaired visual acuity. Eligible for registration as blind or partially sighted.	Able to read print with simple aids or assistance. Defect of at least half visual field. May be eligible for registration as partially sighted.	Severe or profound problem with one eye. Defect of less than half visual field. Able to function independently.
Hearing	Hearing loss over 95 dB.	Hearing loss between 71 - 95 dB.	Hearing loss between 41 - 79 dB	Severe or profound hearing loss in one ear. Hearing loss between 20 - 40 dB.

Communication	Unable to communicate needs by any method. Unable to use communication aids.	Limited or no verbal communication. Able to communicate basic needs without the use of language.	Delayed or disordered communication, including language disorders. Speech supplemented by another method of communication.	Mild delay of language development.
Personal Care	Total assistance required for bathing, dressing, toileting and eating.	Assistance required for bathing, dressing, toileting or eating.	Some supervision or assistance required for bathing, dressing, toileting or eating.	Occasional difficulties meeting own self-care needs.
Consciousness	Comatose. Intractable seizures, in frequent succession.	Regular seizures on a daily basis. Impacts on the child's learning or development.	Seizures day or night on a regular basis, usually once per week.	Occasional daytime seizure (up to one per month)
Behaviour & Social Integration	The challenging behaviours are impacting on all aspects of the child's functioning. The behaviours pose a significant risk to the safety of the child or others.	The challenging behaviours are impacting on some aspects of the child's functioning. Specialist provision is required for the child to function socially or within the family group.	The frequency or severity of the behaviours requires some specialist advice or provision.	Behaviours are occasionally difficult to manage. Special provision not required when managing the behaviour.
Safety and Supervision	Needs constant supervision both day and night. No ability to perceive danger to self or others.	Needs constant supervising during the day. Would place themselves or others at serious risk without supervision.	Requires supervision to perform daily tasks. Requires supervision significantly greater than that expected for children of the same age. Limited perception of danger to self or others.	On occasion, requires more supervision than other children of the same age.

It is more difficult to establish eligibility of under fives using the above classifications, The classification below is the eligibility criteria backbone for the under fives in Central Bedfordshire. The children receiving services from the Children with Disabilities Team in Central Bedfordshire would be expected to have a diagnosed disability.

	Meets Threshold for Services		Does Not Meet Threshold for Services	
Age	<b>Profound Impairment</b> <b>RED LEVEL</b>	<b>Severe Impairment</b> <b>BLUE LEVEL</b>	<b>Moderate Impairment</b> <b>GREEN LEVEL</b>	<b>Mild Impairment</b> <b>YELLOW LEVEL</b>
Under 5 years	Significant failure to meet developmental milestones.	Functioning moderately behind the level expected for age.	Functioning moderately behind the level expected for age.	Functioning slightly behind the level expected for age.
Over 5 years	Child is completely dependent on others to perform tasks.	Child is unable to perform tasks without aids or assistance most of the time.	Child requires some assistance to perform some tasks.	Some limitation evidenced, but able to function independently.

Information must demonstrate that the referred child needs more help or supervision than other children of the same age.

**Proposed Future Access to Short Breaks:**

In recent years it has been possible for the Council to apply the above thresholds more flexibly, so that some families in the green and yellow categories have also, on occasions, been able to access the more specialist services available under the Local Offer.

A revised Threshold Criteria is proposed as follows:

	Meets Threshold for Specialist Services		Need met through Universal Provision & Early Help	
Disability Category	<b>Diagnosed Profound Impairment</b>	<b>Diagnosed Severe Impairment</b>	<b>Diagnosed Moderate Impairment</b>	<b>Diagnosed Mild Impairment</b>
Learning	Has a Statement of Educational Needs. Attends a Special School for children with severe learning difficulties	Has a Statement of Educational Needs. Attends a Special School for children with severe learning disabilities or has a severe learning disability and attends a mainstream school receiving a minimum of 20 hours 1:1 support a week	Has a Statement of Educational Needs Attends a mainstream school with limited support.	Does not have a Statement of Educational Needs

Central Bedfordshire Council Equality Impact Assessment

<b>Mobility</b>	Unable to walk. Totally dependent on others for mobility. Wheelchair user.	Unable to walk without aids or assistance. Able to manoeuvre self some of the time. May be able to stand or transfer with support.	Able to walk, but occasionally requires aids or assistance.	Able to walk/move independently, but with some limitation of function. May have poor co-ordination of movement.
<b>Gross &amp; Fine Motor Skills</b>	Unable to use hands for any purposeful movement.	Mostly unable to use hands to complete tasks effectively. Able to use switch systems	Considerable difficulties with control of hands. Requires some assistance to complete tasks.	Some difficulties with control of hand movement for precise work.
<b>Health</b>	Unable to take part in normal social and educational activities.	Frequent or daily interruption of normal tasks. Significant interference with development and / or learning.	Intermittent but regular limitations on ability to perform everyday tasks. The child's development or learning may be affected.	Known health condition, which is under control and only occasionally interfering with every day activities in a minor way.
<b>Vision</b>	Mobility restricted without special provision. Requires education by non-sighted method. Eligible for registration as blind.	Unable to read large print without assistance or aids. Severe visual field defect with impaired visual acuity. Eligible for registration as blind or partially sighted.	Able to read print with simple aids or assistance. Defect of at least half visual field. May be eligible for registration as partially sighted.	Severe or profound problem with one eye. Defect of less than half visual field. Able to function independently.
<b>Hearing</b>	Hearing loss over 95 dB.	Hearing loss between 71 - 95 dB.	Hearing loss between 41 - 79 dB	Severe or profound hearing loss in one ear. between 20 - 40 dB.
<b>Communication</b>	Unable to communicate needs by any method. Unable to use communication aids.	Limited or no verbal communication. Able to communicate basic needs without the use of language.	Delayed or disordered communication, including language disorders. Speech supplemented by another method of communication.	Mild delay of language development.
<b>Personal Care</b>	Total assistance required for bathing, dressing, toileting and eating.	Assistance required for bathing, dressing, toileting or eating.	Some supervision or assistance required for bathing, dressing, toileting or eating.	Occasional difficulties meeting own self-care needs.
<b>Consciousness</b>	Comatose. Intractable seizures, in frequent	Regular seizures on a daily basis with significant	Seizures day or night on a regular basis, usually	Occasional daytime seizure (up to one per

succession. learning or development.		impact on the child's	once per week.	month)
<b>Behaviour &amp; Social Integration</b> of the child's functioning. The behaviours pose a significant risk to the safety of the child or others.	The challenging behaviours are impacting on all aspects	The challenging behaviours are impacting on key aspects of the child's functioning. Specialist provision is required for the child to function socially or within the family group.	The frequency or severity of the behaviours requires some specialist advice or provision.	Behaviours are occasionally difficult to manage. Special provision not required when managing the behaviour.
<b>Safety and Supervision</b> and night. No ability to perceive danger to self or others. supervision. age. Limited perception of danger to self or others.	Needs constant supervision both day	Needs constant supervising during the day. Would place themselves or others at serious risk without children of the same	Requires supervision to perform daily tasks. Requires supervision significantly greater than that expected for	On occasion, requires more supervision than other children of the same age.

This revision to the criteria will result in children assessed as mild / moderate / no impairment being signposted towards universal services, possibly with the provision of specialist support.

The Council for Disabled Children, the Audit Commission and CSCI, have previously expressed concern about the complexity of eligibility criteria and the confusion this can sometimes cause. In 2009 the lawfulness of eligibility criteria was clarified by the Islington Judgement. Any changes to eligibility criteria therefore need to be considered in the light of this judgement.

Further detail relating to the Islington Judgement is set out in section 2.2.10 of the EIA.

**1.4 How does this proposal contribute or relate to other Council initiatives?**

**Central Bedfordshire Five Year Plan 2015 - 2020**  
***Priority - Protecting the Vulnerable; improving wellbeing***

We will protect the vulnerable, be they children or adults, ensuring that they are not exploited, abused, or suffering as a result of neglect or lack of support. We will also work to improve the health and wellbeing of our residents.

**Children's Services Transformation Programme:**

The proposals included in this assessment support Children's Services Transformation Programme – to identify new ways of working with partners and children and families that will improve outcomes for the most vulnerable in Central Bedfordshire. This proposal will also contribute to the understanding of need in different localities which will support new delivery models in the future.

**1.5 In which ways does the proposal support Central Bedfordshire's legal duty to:**

- Eliminate unlawful discrimination harassment and victimisation and other conduct prohibited by the Act
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it
- Foster good relations between people who share a protected characteristic and people who do not share it

Disability is a protected characteristic under the Equality Act. Life chances for disabled children and young people are often disproportionately poor. The provision of quality Short Break opportunities can support families to live an 'ordinary life' whilst offering learning and leisure opportunities for disabled children and young people.

Under the requirements of equality legislation, all service providers must ensure that services are as accessible as possible for all sections of the community. The aim of the legislation is to help ensure that disabled people have equal access to services, with the intention that by increasing access to mainstream services, they are enabled to participate on more equal terms with wider society.

**1.6 Is it possible that this proposal could damage relations amongst groups of people with different protected characteristics or contribute to inequality by treating some members of the community less favourably such as people of different ages, men or women, people from black and minority ethnic communities, disabled people, carers, people with different religions or beliefs, new and expectant mothers, lesbian, gay, bisexual and transgender communities?**

Consideration will need to be given to the extent to which the proposal might have an adverse impact on disabled children and their families who do not meet the thresholds for diagnosed profound or severe impairment and who will be directed towards universal services.

Research indicates that disabled people can sometimes still experience barriers to accessing universal services. This can happen for example if staff members haven't received appropriate disability awareness training and don't provide a welcoming atmosphere that responds to differing needs and which challenges negative attitudes which can sometimes be displayed by members of the public.

**Stage 2 - Consideration of national and local research, data and consultation findings in order to understand the potential impacts of the proposal.****Stage 2 - Consideration of Relevant Data and Consultation**

**In completing this section it will be helpful to consider:**

- **Publicity** – Do people know that the service exists?
- **Access** – Who is using the service? / Who should be using the service? Why aren't they?
- **Appropriateness** – Does the service meet people's needs and improve outcomes?
- **Service support needs** – Is further training and development required for employees?
- **Partnership working** – Are partners aware of and implementing equality requirements?
- **Contracts & monitoring** – Is equality built into the contract and are outcomes monitored?

**2.1. Examples of relevant evidence sources are listed below. Please tick which evidence sources are being used in this assessment and provide a summary for each protected characteristic in sections 2.2 and 2.3.**

<b>Internal desktop research</b>		
<input type="checkbox"/>	Place survey / Customer satisfaction data	<input checked="" type="checkbox"/> Demographic Profiles – Census & ONS
<input checked="" type="checkbox"/>	Local Needs Analysis	<input checked="" type="checkbox"/> Service Monitoring / Performance Information
<input checked="" type="checkbox"/>	Other local research	
<b>Third party guidance and examples</b>		
<input checked="" type="checkbox"/>	National / Regional Research	Analysis of service outcomes for different groups
<input type="checkbox"/>	Best Practice / Guidance	<input checked="" type="checkbox"/> Benchmarking with other organisations
<input type="checkbox"/>	Inspection Reports	
<b>Public consultation related activities</b>		
<input checked="" type="checkbox"/>	Consultation with Service Users	<input checked="" type="checkbox"/> Consultation with Community / Voluntary Sector
<input type="checkbox"/>	Consultation with Staff	Customer Feedback / Complaints
<input type="checkbox"/>	Data about the physical environment e.g. housing market, employment, education and training provision, transport, spatial planning and public spaces	
<b>Consulting Members, stakeholders and specialists</b>		
<input type="checkbox"/>	Elected Members	<input checked="" type="checkbox"/> Expert views of stakeholders representing diverse groups
<input checked="" type="checkbox"/>	Specialist staff / service expertise	

*Please bear in mind that whilst sections of the community will have common interests and concerns, views and issues vary within groups. E.g. women have differing needs and concerns depending on age, ethnic origin, disability etc*

**Lack of local knowledge or data is not a justification for assuming there is not a negative impact on some groups of people. Further research may be required.**

**2.2. Summary of Existing Data and Consultation Findings: - Service Delivery Considering the impact on Customers/Residents**

**2.2.1- Age:** e.g. Under 16 yrs / 16-19 yrs / 20-29 yrs / 30-44 yrs / 45-59 yrs / 60-64 yrs / 65-74 yrs / 75+

**2.2.2 - Disability:** e.g. Physical impairment / Sensory impairment / Mental health condition / Learning disability or difficulty / Long-standing illness or health condition / Severe disfigurement

**2.2.2.1) Research:**

**1.1) Still missing out? Ending poverty and social exclusion: messages to government from families with disabled children – Barnados 2002**

At present, a disproportionate number of families with disabled children are living in poverty, for the following reasons:

- Work – parents with disabled children are often unable to work because they cannot secure childcare suitable for their child's needs.

- Extra costs – on average it costs three times as much to raise a child with severe impairment than a non-disabled child.
- Benefits – many parents are confused about entitlements and find procedures overly complicated. As a result, uptake is limited and the poorest families are not accessing the benefits they need.
- Lone parents – there is a higher rate of lone parents among families with a disabled child, which places greater pressure upon the caring parent.
- Minority ethnic families are more likely to have low incomes and unsuitable housing. In many cases they are less able to access services.

Families with disabled children also face many other difficulties.

- Unsuitable housing is a key issue for all the families interviewed. Some cannot use wheelchairs indoors because of narrow doorways; others have to carry their children upstairs. Families have to wait years for adaptations.
- Transport – many families have unmet needs, as most public transport is inaccessible and cabs are expensive.
- Access to services – families are uncertain about the services available, many of which can only be obtained following persistent pressure.
- Accessing community life – there are barriers preventing disabled children from accessing play schemes and other community facilities.

### **1.2) Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities** - Social Policy Research Unit, University of York 2009

- Disabled children and young people appear to have very limited opportunities to access positive activities in their local areas.
- Disabled children, young people and their families want more and different things to do so that they can choose where and how they spend their free time.
- Participating in positive activities is associated with positive outcomes in terms of children's health, experiences of enjoyment and achievement and community participation.
- At the same time, disabled children and young people report that bullying or fear or bullying spoils their experiences of, or stops them accessing, inclusive activities or using local leisure and recreation facilities.
- Achieving inclusion for disabled children requires planning, resources and the active involvement of skilled staff.
- There is scope for children's centres, extended schools and youth services to become more inclusive. Examining service delivery alongside best practice examples would be of benefit.
- There is variability in how services have interpreted what inclusion means and this has led to different modes of service delivery, some of which are not genuinely inclusive.
- Disabled children and young people value provision which is designed to facilitate disabled children's participation in activities and interaction between disabled and non-disabled children. However, they also value provision for disabled children or young people only.
- Supporting the participation of disabled children and young people in positive activities requires much more than making a service inclusive.
- The provision of information about positive activities needs to be improved and some families will need active support to identify and join positive activities provided.

- Opportunities to access positive activities need to be provided in inclusive settings and in 'disability only' groups. The most appropriate setting will differ according to children and young people's own preferences, the nature of the child's impairment, and the type of activity.

### **1.3) The impact of the Aiming High for Disabled Children short breaks programme on the prevention of disabled children and young people entering the Looked After System - Together for Disabled Children 2011**

It should be noted that the local authorities who took part did so voluntarily and that there was no randomisation of selection, therefore these findings may not be representative of the entire population of local authorities. Three strands were explored:

Strand 1 – Was there a reduction on numbers of children who entered the Looked After System?

Strand 2 – Was there a reduction in numbers of disabled children placed out of the area?

Strand 3 – Was there a reduction in the need for emergency, high cost placement?

#### **Key Findings:**

- Short break services appear to have prevented disabled children entering the Looked After System and thus potentially saved money for the LA.
- All participating local areas state that they are focussing on early identification and support as a means of preventing children and young people from requiring emergency and long term Looked After placements.
- All local areas have developed a wide range of holiday provision recognising it as the peak time for increased requests for children to be at risk of becoming 'Looked After' or for emergency placements.
- Short breaks have reduced the need for costly out of borough placements. In staying closer to home, children are potentially enabled to have improved engagement in their own communities and reduced transition issues.
- Targeted support via the Common Assessment Framework has had the added value of improving multi-disciplinary working relationships. Local authorities involved in this study see short breaks as part of their preventative strategy.

#### **1.4) Contact A Family:**

- 92% say that finding childcare for disabled children is more difficult compared to non-disabled children (Counting the Costs, 2014).
- 40% say they are unable to access the full free childcare offer of 15 hours per week (Levelling the Playing Field, 2015).
- The majority of disabled children participate in a limited number and range of leisure activities (Fair play for disabled children: Bevan foundation report, 2010).
- 99.1% of disabled children live at home and are supported by their families.
- 52% of families with a disabled child are at risk of experiencing poverty.
- The income of families with disabled children averages £15,270, 23.5% below the UK average income of £19,968, and 21.8% have incomes that are less than half the UK mean.
- Only 16% of mothers with disabled children work, compared to 61% of other mothers.
- It costs up to three times as much to raise a disabled child, as it does to raise a child without disabilities.
- 56% of parents with disabled children and children with special educational needs reported

there was a lack of sufficient childcare in their area.

- Only one in 13 disabled children receive a regular support service of any sort from their local authority.

### **1.5) Prevalence of childhood disability – Blackburn Spencer and Read 2010**

7.3% (CI 6.9, 7.7) of UK children were reported by as disabled according to the DDA definition.

Patterns of disability differed between sexes with boys having a higher rate overall and more likely than girls to experience difficulties with physical coordination; memory, concentration and learning; communication.

Disabled children lived in different personal situations from their non-disabled counterparts, and were more likely to live with low-income, deprivation, debt and poor housing. This was particularly the case for disabled children from black/minority ethnic/mixed parentage groups and lone-parent households. Childhood disability was associated with lone parenthood and parental disability and these associations persisted when social disadvantage was controlled for.

These analyses suggest that UK disabled children experience higher levels of poverty and personal and social disadvantage than other children.

### **Outcome following preterm birth AT Gibson 2007**

Since the 1980s there have been changes in the population of disabled children. Increasing numbers of those with multiple and complex impairments are living longer and being cared for at home. This is due in part to improved survival rates for low birth weight and extremely premature babies.

### **Technology dependent children in the community – Glendinning, Kirk, Guiffrida and Lawton 2001**

When children have higher support needs or complex impairments, some parents may have to take responsibility for administering medication, tube feeding, assisted ventilation, and resuscitation procedures as well as other treatments and interventions.

### **Palliative care statistics for children and young adults – Cochrane, Liyanage and Nantambi 2007**

It is estimated that around 18,000 children and young people in England have multiple and complex impairments which result in their needing some form of palliative care.

### **1.9) Autism Levy Mandell and Schultz 2009 and Developing ADHD Taylor 2009**

Recent years have seen a marked increase in numbers of children identified as having autistic spectrum disorders and attention deficit hyperactivity disorder.

### **0) Feeling down improving the mental health of people with learning disabilities Burke 2014**

When disabled children have multiple impairments it is not uncommon for some of their needs and difficulties to go unrecognised because the diagnosis of one condition may over shadow another.

### **1.11) Exploring disability, family formation and break up Clarke and Mckay 2008**

Research points to a clustering of childhood and adult disability within households.

### **Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK Blackburn Spencer and Read 2010**

Almost half of disabled children (compared with a fifth of non disabled children) live with a parent who is also disabled. In addition a quarter of disabled children live with one or more siblings who are also disabled.

### **State of the Nation - SENDirect 2016 Why**

#### **do families need Short Breaks?**

Short Breaks are a fantastic opportunity for parents to take a break from their caring duties, but they also help disabled children to become more independent and involved in their local community.

- 76% of parent carers said they have experienced stress or depression (*Short Breaks in 2015: An Uncertain Future, EDCM*).
- 66% of parent carers find accessing services and products that meet their child's needs stressful (*Baseline Survey, SENDirect, 2015*).
- Short Breaks have a direct positive impact on the lives of disabled children and young people who use them, making them more confident and independent (*EDCM, 2015*).

### **The Barriers Facing Families**

- **It can be difficult for families to find out about their rights / entitlements:** Short Break statements are not always easily accessible to families. In some cases, the Short Breaks statement is incomplete, which means parent carers that live in these Local Authorities only have access to a limited amount of information about their eligibility and the application processes. We would suggest that best practice would be to include these in the local offer, as surprisingly only **91** Local Authorities have done so (*Emily Tyrell, 2015*).
- **It's time consuming and stressful to find out what's out there: 66%** of respondents to the survey said it is stressful to find information on services and products that meet their child's needs (*SENDirect, 2015*). Contact a Family's research found that many parents were unaware of their Local Offer except those who are actively engaged in their local Parent Carer Forum (*EDCM, 2015*). Even if Local Authorities are not obliged to carry out formal assessments of needs to give access to a service, they must do so if they intend to refuse the children from the same service.
- **It can be difficult to negotiate the process of assessment: 53%** of parent carers who responded to Contact a Family's research, and self-identify as having a disabled child, say that they have never accessed any form of Short Breaks service (*EDCM, 2015*). Not only does this suggest that a large number of eligible children are missing out, but also the lack of available information means that parent carers are missing out on the support that they need the most.

### **Understanding the needs of disabled children with complex needs or life-limiting conditions WHAT CAN WE LEARN FROM NATIONAL DATA? Council for Disabled Children and the True Colours Trust 2017**

- There are **rising numbers of disabled children with complex needs and/or life-limiting conditions**, who, with their families, are likely to need support from health, education and social care continuously or at times throughout their life

- More than 10 years ago, the National Service Framework (Standard 8: Disabled Children and Young People and those with Complex Health Needs) noted In the past ten years, the prevalence of severe disability and complex needs has risen. This is due to a number of factors, including increased survival of preterm babies and increased survival of children after severe trauma or illness. There are up to 6,000 children living at home who are dependent on assistive technology. Children and young people with life-limiting conditions, such as cystic fibrosis, have better life expectancy.
- Three years later, Aiming High for Disabled Children: Better Support for Families (DfES, 2007) estimated that around 100,000 disabled children had complex care needs
- Better Care, Better Lives (DH, 2008), informed by the Independent Review of Children's Palliative Care Services, noted the challenge faced by service providers and commissioners due to: 'the change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances and increased survival rates of low-birthweight babies

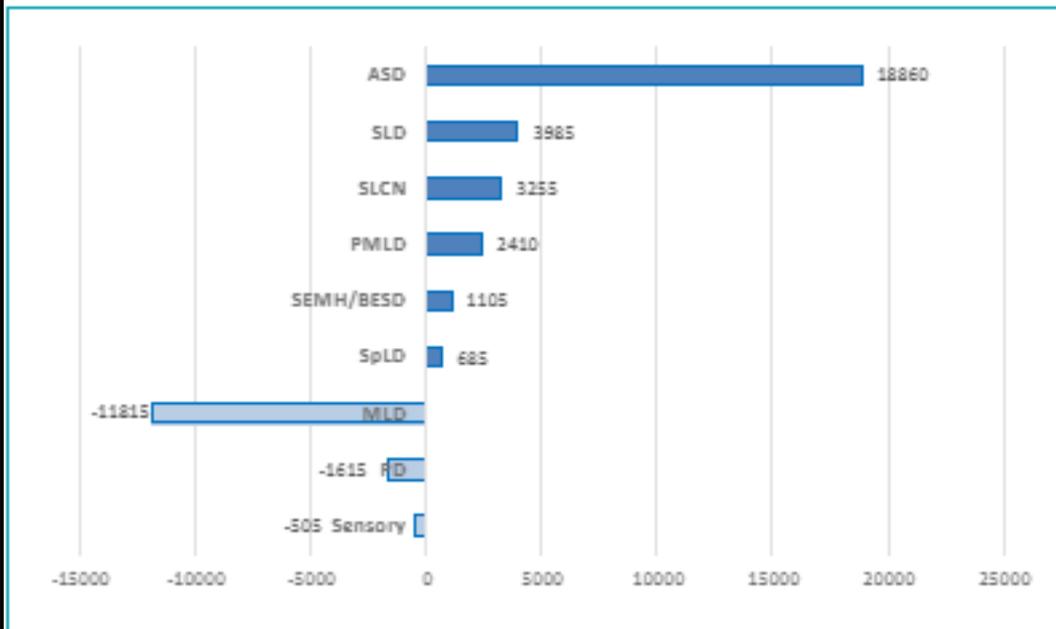
School Census data shine some light on these trends. The School Census collects detailed data on the great majority of school children in England

- a narrow estimate of the number of school children (broadly, aged 5-16 years) with complex needs is 73,000, made up of:
  - 10,900 children with profound and multiple learning difficulties
  - 32,300 children with severe learning difficulties
  - 27,500 children with autistic spectrum disorders in special schools
  - 2,300 children with multi-sensory impairments.
- The equivalent figure in 2004 was 49,300.
- This suggests that **the number of school children with complex needs in schools in England may have risen by nearly 50 per cent in just over a decade.**

The actual number is higher, as

- 13,500 children with statements/EHC plans placed in independent schools, which provide some of the most specialist placements
- 23,100 more young people aged 16-25 years with statements or EHC plans who are not included in School Census data, including over 1,000 aged 20-25 years.
- Nearly 118,000 children and young people with statements or EHC plans are placed in specialist schools and colleges. Special schools now cater for many more children with complex needs than in 2004 (Chart 1). The number of children with complex needs in mainstream schools has also risen over the same period.
- These **trends are not evident in the social care data**, partly because so **few disabled children are assessed as children in need** (0.4 per cent of all 0-17 year olds) or looked after under the Children Act 1989 (with only 2,250 children nationally whose main reason for being looked after is disability). It is clear from the data analysed **that thresholds for support from social services for disabled children and their families are high and vary widely from area to area.**

**Chart 1: Change in the primary needs of children in special schools between 2004 and 2016 (increases on right, decreases on left)**



**'SEN type' – Codes and descriptions used in School Census reporting<sup>66</sup>**

SpLD	Specific learning difficulty (e.g. Dyslexia, dyspraxia)
MLD	Moderate learning difficulty
SLD	Severe learning difficulty
PMLD	Profound & multiple learning difficulty
SEMH	Social, emotional and mental health
SLCN	Speech, language and communication needs
HI	Hearing impairment
VI	Visual impairment
MSI	Multi-sensory impairment
PD	Physical disability
ASD	Autistic spectrum disorder (includes Aspergers syndrome).

Major efforts are being made to improve health data on children, with the introduction of a standard approach to recording childhood disabling conditions and the support needs of children, young people and families, as part of the mandated Children and Young People's Health Services data set (CYPHS).

Two key trends were highlighted repeatedly, both contributing to rising numbers of disabled children with complex needs or life-limiting conditions:

- **improved survival rates** of preterm babies and babies with congenital conditions
- **increased life expectancy** for children with complex disabilities, including children with severe cerebral palsy, cystic fibrosis and Duchenne muscular dystrophy.

These perceptions are consistent with academic evidence, but hard to discern from national data. This contributes to a widespread lack of awareness and policy attention, locally and nationally, on the rising numbers of disabled children with complex needs and life-limiting conditions.

This matters, because **many local authorities and clinical commissioning groups (CCGs) have an incomplete and out-of-date picture of disabled children and young people in their area**, undermining the potential for forward planning and intelligent commissioning of specialist provision. Poor data has been highlighted as a challenge for local areas in inspection reports.

#### **1.15) These are our children - A review by Dame Christine Lenehan Director, Council for Disabled Children Commissioned by the Department of Health 2017**

An independent review which examined the care of disabled children and young people with challenging behaviour and complex needs which involve mental health problems and learning disabilities and/or autism. The review was commissioned by the Department of Health and carried out by the Director of the Council for Disabled Children. The review drew evidence from civil servants, clinicians, managers, parents and young people. The findings cover following areas: children's rights; articulating vision of care; what a good model of care should look like; the leadership and professional responsibility required to implement the model; supporting parents and families; developing coherent strategy within the system; commissioning; and the workforce. The review found that despite a number of Government initiatives, **there is not a clear vision for the treatment of children with complex needs involving challenging behaviour and a mix of mental health problems, learning disabilities and autism.**

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion." *Challenging Behaviour: A Unified Approach, 2016*

The evidence shows us that our group of children tend to be in poorer families and live in challenging circumstances. Even for more affluent and settled families the cuts in local authority support services are biting hard. **The loss of local authority early intervention and short breaks services affects our group of children disproportionately.**

**The continuing philosophical debates about causation and treatment of challenging behaviour is one of the main reasons that children fall between gaps and fail to get access to appropriate services.** The system has a number of built-in barriers which restrict access to supportive interventions. Added to this, our children are complex in their needs and their presentation and they **do not always fit individual labels** of autism/ learning disability/ neuro developmental disability/challenging behaviour /mental health. It is more likely that they have a combination which does not fit neatly into any one team's existing definitions for service. Furthermore, mental health problems frequently don't manifest themselves until adolescence adding to the difficulties in getting clear diagnosis.

For example, in one local area even where they have a great positive behaviour support service for children:- *"The team did not have capacity to support those with less severe levels of challenging behaviour (no early intervention team) and there was nothing for young people with autism but no learning disability. One family of a 13 year old boy with autism were told by Social Services to call the police and although they were reluctant they had to call the police 47 times in 4 years. The GP prescribed liquid diazepam to the child and the family were told there was*

*nothing more they could do and the family were told it was bad parenting. There was no family support, behaviour support, autism or CYPMH specialist support.”*

*In another area, “families explained that children where provision was good in schools were doing OK overall but these tended to be the children “in the middle” – those with more severe learning disabilities (and at risk of later ATU admission) were not able to access good support (except for those who happened to have a paediatrician who took it upon herself to be a key- worker above and beyond what she was required to do) and those with milder learning disabilities (and so at potential risk of encountering the criminal justice system later were similarly lacking support.”*

NICE (The National Institute for Health and Care Excellence) has issued guidelines on *Autism Spectrum Disorder in under 19s: support and management, Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, and Mental health problems in people with learning disabilities*. These **guidelines are all evidence based, all useful but can be a struggle to adapt for children whose needs spread across the boundaries of individual guidelines.**

### **2.2.2.2) Local Data:**

#### **2.1 Central Bedfordshire Joint Strategic Needs Assessment**

##### **Estimates for the number of disabled children and young people in Central Bedfordshire 2011/12**

- Disability Living Allowance (DLA) Higher Care rate, Department for Works and Pensions (DWP), Feb 2011 (0.8%) – **607**
- Together for Disabled Children - Aiming High (1.2%) - **907**
- Disability Living Allowance - entitled cases DWP Feb 2011 (2.6%) - **1,970**
- Family Resource and General Household Survey, Office for National Statistics (ONS) & School Census - Spring 2011 (7.0%) - **5,292**
- Lancaster University (10.0%) - **7,560**
- Ages 0-24, 2010 mid year estimate ONS - June 2011 - **75,600**

It is estimated that only one in 13 disabled children receive a regular support service of any sort from their local authority. Only 8% of families get services from their local social services. (Contact a Family: Statistics)

The Central Bedfordshire Council Children with Disabilities Social Care Team work with up to 250 disabled children and their families at any one time.

The Children with Disabilities Register has 1100 children included on it.

Current data available to us indicates that Central Bedfordshire Children's Services are working to the Aiming High figure of 1.2%

**School Census January 2011 – Primary Learning Difficulty/ Disability (LDD) Levels of need**

	Nos. per category	Percentage per category	Nos. per 100,000 rounded up
Behaviour, Emotional and Social Difficulty (BESD)	699	25.5%	27960
Moderate Learning Difficulties (MLD)	428	15.6%	17120
Autistic Spectrum Disorder (ASD)	388	14.1%	15520
Speech, Language & Communication Needs (SLCN)	348	12.7%	13920
Specific Learning Difficulties (SPLD)	313	11.4%	12520
Severe Learning Difficulties (SLD)	189	6.9%	7560
Other (OTH) which may include children without a clear diagnosis	118	4.3%	4720
Physical Disability (PD)	113	4.1%	4520
Hearing Impairment (HI)	79	2.9%	3160
Visual Impairment (VI)	37	1.3%	1480
Profound and Multiple Learning Difficulty (PMLD)	26	0.9%	1040
Multi Sensory Impairment (MSI)	8	0.3%	320
<b>Total</b>	<b>2,746</b>	<b>100.0%</b>	<b>109840</b>
Total number of all children and young people on school census	39,214		

**Source:** Central Bedfordshire Council

Short break provision in Central Bedfordshire includes:

- Holiday activities.
- Out of school social activities during the week and at weekends.
- Sibling Group activities.
- Overnight Short Breaks.
- Support to access the community.
- Assisted leisure activities.
- Direct Payments.
- Day Care.
- Specialist Childminders (up to age 11).

**2.2. Service Usage Second Quarter (July, August September) 2015**

**Autism Bedfordshire Summer Playscheme**

<b>Children 56</b>	<b>Hours total: 1210</b>
CWD children – 22 <b>39%</b>	CWD Children 445 <b>37%</b>
SEND Children -12 <b>21%</b>	SEND Children 292 <b>24%</b>
Non CWD - 15 <b>27%</b>	Non CWD 308 <b>25%</b>
Unknown on mosaic – 7 <b>13%</b>	unknown 165 <b>14%</b>

**LOAF**

<b>Children 50</b>	<b>Hours total: 477</b>
CWD children – 5 <b>10%</b>	CWD Children : 60 hrs <b>13%</b>
SEND Children - 11 <b>22%</b>	SEND Children : 105 hrs <b>22%</b>
Non CWD - 15 (3 unknown) <b>30%</b>	Non CWD : 126 hrs <b>26%</b>
Sibs - 19 <b>38%</b>	Sibs: 186 hrs <b>39%</b>

**Autism Bedfordshire Wanted Fun**

<b>Children 38</b>	<b>Hours total: 343</b>
CWD children – 4 <b>11%</b>	CWD Children : 39 hrs <b>11%</b>
SEND Children - 13 <b>34%</b>	SEND Children : 131 hrs <b>38%</b>
Non CWD - 21 (8 unknown) <b>55%</b>	Non CWD : 173 hrs <b>50%</b>

**SNOOSC Summer Holiday Club 2015**

<b>Children : 22</b>	CWD 15 <b>68%</b>	<b>Hours Total</b> 758	CWD 446 hrs <b>59%</b>
Non CWD	2 <b>9%</b>		Non CWD 84 hrs <b>11%</b>
18+	5 <b>22%</b>		18+ 228 hrs <b>30%</b>

**SNOOSC After School Club 3<sup>rd</sup> Q 2015**

<b>Children : 22</b>	CWD 15 <b>68%</b>	<b>Hours Total</b> 344	CWD 188 hrs <b>54%</b>
Non CWD	4 <b>18%</b>		Non CWD 96 hrs <b>28%</b>
18+	3 <b>2%</b>		18+ 60 hrs <b>17%</b>

**SNOOSC Saturday Club 3<sup>rd</sup> Q 2015**

<b>Children : 15</b>	CWD 10 <b>66%</b>	<b>Hours Total</b> 355	CWD 216 hrs <b>61%</b>
Non CWD	2 <b>13%</b>		Non CWD 49 hrs <b>14%</b>
18+	3 <b>20%</b>		18+ 90 hrs <b>25%</b>

**FUN Summer Holiday Club 2015**

<b>Children : 60</b>	CWD 22 <b>37%</b>	<b>Hours Total</b> 995	CWD 446 hrs <b>45%</b>
Non CWD	21 <b>35%</b>		Non CWD 84 hrs <b>8%</b>
Sibs	15 <b>25%</b>		Sibs 240 hrs <b>24%</b>
18+	2 <b>3%</b>		18+ 50 hrs <b>5%</b>

**Half Term Holiday Club: Children 31**

CWD Children	11 <b>35%</b>	Hours Total	195
Non CWD children	11 <b>35%</b>	CWD hours	60 <b>31%</b>
Sibs	8 <b>26%</b>	Non CWD hours	90 <b>46%</b>
18+	1 <b>3%</b>	Sibs	45 <b>23%</b>

**Special Events**

Children	42	CWD hours	60 <b>45%</b>	
18+	1 <b>2%</b>	non CWD hrs	40.5 <b>30%</b>	over 18 2hrs1%
CWD	17 <b>40%</b>	Sib Hours	32 <b>24%</b>	
Sibs	12 <b>29%</b>	<b>TOTAL</b>	<b>134.5</b>	
non CWD	12 <b>29%</b>			

**2.2.2.3 Local Consultation:****3.1 JSNA**

**The 2011 consultation informed the authority that all partners including parents and children would like to see further improvements:**

They wanted us to:

- Provide information from people who understand the issues for disabled children and their families.
- Increase the number of activities in Biggleswade and Leighton Buzzard.
- Increase activities and opportunities for teenagers which include those designed to develop life skills and independence.
- Increase support for the siblings of disabled children.
- Support families in managing children with challenging behaviour.
- Offer more flexibility in support services, especially at weekends and school holidays.
- Provide suitable transport arrangements for children to access short breaks.

**3.2 SEND Parent/Carer Survey Feb - April 2014:**

Central Bedfordshire Council's Support and Aspiration Board worked in partnership with SNAP (Central Bedfordshire's Parent/Carer Forum) to develop the survey. During its development it was agreed that 2 surveys should be circulated:

**Survey 1- focussed on families with children with more complex special educational needs and disabilities (SEND)**

78% of Parent/carers felt the support they are receiving meets their child's needs: 71% of parents/carers said it was difficult to find out about what was available to them.

The key elements of a successful service were identified as:

- Staff attitude
- Staff training/knowledge
- Close to home
- Information on how to access

The main changes listed as potentially making the biggest difference

- More local clubs and activities
- More information/awareness
- Flexibility

Suggestions for improvement included

- being sensitive to parents emotions and pressures
- More opportunities for children with profound and multiple learning disabilities/medical conditions
- Awareness of leisure facilities/youth centres/activities available and plugging of the gaps (weekends/evenings/school holidays)
- Support to access these, including trained staff
- Consideration of additional funding to local organisations to extend what they can offer, e.g BDCPS

**Survey 2 - for families with children with SEND in mainstream schools, both with and without statements of SEN.**

85% of parents/carers who responded were satisfied or quite satisfied with the support provided  
 36% of parent/carers have children participating in after school activities

Suggestions for improvements included:

- Emotional support/social support for children
- Localised opportunities for families.

**2.2.3 Carers:** *A person of any age who provides unpaid support to family or friends who could not manage without this help due to illness, disability, mental ill-health or a substance misuse problem*

**2.2.3.1) Research:**

**1.1 ) Contact A Family:**

- One in five say that isolation has led to the break up of their family life (Forgotten Families, 2011).
- 72% of parents / carers experience mental ill health such as anxiety, depression or breakdown due to isolation (Forgotten Families, 2011).
- More than three quarters of families say that the opportunity to spend time with their spouse or partner away from the role of caring is poor or unsatisfactory (What Makes My Family Stronger, 2009).
- 53% of parents say that caring for a disabled child has caused major difficulties or the breakdown of their relationship (No Time for Us, 2003).

**2.2.4 Gender Reassignment:** *People who are proposing to undergo, are undergoing or have undergone a process (or part of a process) to reassign their sex by changing physiological or other attributes of sex*

**2.2.5 Pregnancy and Maternity:** *e.g. pregnant women / women who have given birth & women who are breastfeeding (26 week time limit then protected by sex discrimination provisions)*

**2.2.6 Race:** *e.g. Asian or Asian British / Black or Black British / Chinese / Gypsies and Travellers / Mixed Heritage / White British / White Irish / White Other*

**2.2.6.1) Research:**

- African Caribbean pupils and pupils from mixed white and Caribbean backgrounds are more likely to be identified as having special educational needs (SEN) and are over-represented among the behavioural, emotional and social difficulties categories.
- Pakistani and Bangladeshi pupils are under-represented in identification of Speech and Language difficulties
- Travellers of Irish heritage and Gypsy or Roma pupils are over-represented among many categories of SEN

**2.2.7 Religion or Belief:** *e.g. Buddhist / Christian / Hindu / Jewish / Muslim / Sikh / No religion / Other*

**2.2.8 Sex:** *e.g. Women / Girls / Men / Boys*

**2.2.8.1) Research:**

- Boys are more likely to be identified as having special educational needs: 70% identified SEN are boys.
- Boys are more likely than girls to attend special schools,
- Boys are nine times as likely as girls to be identified with autistic spectrum disorder;

**2.2.9 Sexual Orientation:** *e.g. Lesbians / Gay men / Bisexuals / Heterosexuals*

**2.2.10 Other:** *e.g. Human Rights, Poverty / Social Class / Deprivation, Looked After Children, Offenders, Cohesion, Marriage and Civil Partnership*

**2.2.10.1) United Nations Convention on the Rights of the Child:**

**Article 3**

- The child's best interests must be a top priority whenever anything is done that affects children.

**Article 23**

- Every disabled child has the right to a full life and to active participation in the community.

**Article 31**

- Every child has the right to rest, play and leisure.

**2.2.10.2) UN Convention on the Rights of Persons with Disabilities:**

**Office for Disability Issue – HM Government UK Initial Report On the UN Convention on the Rights of Persons with Disabilities 2011**

Disability legislation in the UK is characterised by an 'asymmetrical' approach introduced by the Disability Discrimination Act and carried forward into the Equality Act 2010. The asymmetrical approach to disability discrimination law in the UK is a fundamental acknowledgement that disabled people are a particularly vulnerable group in society and need additional support in the form of legislation to enable them to live and work on an equal basis as non-disabled people. It means that disabled people can be treated more favourably than non-disabled people, but one disabled person cannot be treated more favourably than another disabled person."

Paragraph 54 of [The First Report on the UN Convention \(link to Office for Disability Issues\)](#), November 2011.

### **Article 7 – Children with disabilities**

The UK is continuing work to implement the UN Convention on the Rights of the Child (UNCRC) to make that Convention a reality. Through the HRA, the rights of all children to privacy, freedom of assembly, freedom of expression, freedom of thought, conscience and religion set out in the ECHR are incorporated in UK domestic law.

71. In the UK, a number of programmes are helping to deliver those rights. In England, following the publication of the 3rd and 4th Periodic reports to the UNCRC10, standards were included within the National Service Framework for children with specific needs – including disabled children. The Government provides grants to support low-income families with severely disabled children. It is providing £800 million to fund short breaks for parents with disabled children in the next four years.

### **Article 19 – Living independently and being included in the community**

### **Article 23 – Respect for home and the family**

#### **Support for parents, families and carers of young disabled people**

The UK recognises that the parents, families and carers of young disabled people can face challenging circumstances and may need co-ordinated and extra support to help ensure their well-being and that of the young person. This support is provided in a variety of ways.

Across the UK, the Government is providing £20 million for additional respite care for carers of severely disabled children. Up to £30 million funding has been made available in 2010/11 to support local projects developing children's palliative care services.

In England and Wales the 'Early Support' programme is designed to improve the quality and coordination of services for young disabled children and their families, whilst keeping parents at the centre of any decisions about their child. In England, the 'Recognised, valued and supported: Next steps for the carers strategy' launched in November 2010 sets out a framework for supporting the carers of both adults and ill and disabled children. £6 million of new funding has been made available to train GPs to identify and support carers. An additional £400 million will provide breaks for all carers, including the carers of ill and disabled children. Local authorities will also be provided with £800 million over the next four years to fund short breaks for families with disabled children.

In England, the '[Safeguarding Disabled Children – Practice Guidance](#)' explains how Local Safeguarding Children Boards, agencies and professionals at the local level are expected to draw up and agree detailed ways of working together to safeguard disabled children.

### **Article 28 – Adequate standard of living and social protection**

The UK Government is committed to supporting disabled people, to improving the quality of life of

those facing disadvantage, and to tackling poverty by addressing its causes.

### **Disabled children**

317. The Government is committed to tackling poverty and has enacted the Child Poverty Act 2010, which puts in legislation a commitment to eradicate child poverty by 2020. Children living in families with a disabled adult and children living in families with a disabled child are included among the groups disproportionately more likely to be in poverty and affected by socio-economic disadvantage

### **Article 30 – Participation in cultural life, recreation, leisure and sport**

The latest data available shows that disabled people in the UK remain less likely to participate in cultural, leisure and sporting activities than non-disabled people.

### **2.2.10.3) Disability Discrimination Act / Equality Act**

#### **Definition of Disability:**

A person has a disability if they have a physical or mental impairment, which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. However, special rules apply to people with some conditions such as progressive conditions and some people are automatically deemed disabled for the purposes of the Act.

The definition covers physical or mental impairments. This includes sensory impairments, such as those affecting sight or hearing. The term 'mental impairment' is intended to cover a wide range of impairments relating to mental functioning, including what are often known as learning disabilities.

There is no need for a person to establish a medically diagnosed cause for their impairment. What it is important to consider is the effect of the impairment, not the cause.

A substantial adverse effect is something which is more than a minor or trivial effect. The requirement that an effect must be substantial reflects the general understanding of disability as a limitation going beyond the normal differences in ability which might exist among people.

Account should also be taken of where a person avoids doing things which, for example, cause pain, fatigue or substantial social embarrassment; or because of a loss of energy and motivation. An impairment may not directly prevent someone from carrying out one or more normal day-to-day activities, but it may still have a substantial adverse long-term effect on how he or she carries out those activities. For example, where an impairment causes pain or fatigue in performing normal day-to-day activities, the person may have the capacity to do something but suffer pain in doing so; or the impairment might make the activity more than usually fatiguing so that the person might not be able to repeat the task over a sustained period of time.

Day to day activities include - but are not limited to - activities such as walking, driving, using public transport, cooking, eating, lifting and carrying everyday objects, typing, writing (and taking exams), going to the toilet, talking, listening to conversations or music, reading, taking part in normal social interaction or forming social relationships, nourishing and caring for one's self.

Anyone who has HIV, cancer or multiple sclerosis is automatically treated as disabled under the Act. In some circumstances, people who have a sight impairment are automatically treated as disabled under Regulations made under the Act.

Progressive conditions are conditions which are likely to change and develop over time. Where a person has a progressive condition they will be covered by the Act from the moment the condition leads to an impairment which has some effect on ability to carry out normal day-to-day activities, even though not a substantial effect, if that impairment might well have a substantial adverse effect on such ability in the future. This applies provided that the effect meets the long-term requirement of the definition.

Public authorities have duties not to discriminate against disabled people by treating them less favourably or failing to make reasonable adjustments. Public authorities also have a duty to have due regard to the need to promote disability equality.

Section 149(3) explains what having due regard to need (b) entails. Section 149(4) explains further, by reference to section 149(3)(b), that taking steps to meet the needs of disabled people that are different from the needs of people who are not disabled includes, in particular, steps to take account of their disabilities. Section 149(5) explains further what need (c) entails. Complying with section 149 may involve treating some people more favourably than others, but that does not permit conduct which would otherwise be prohibited by the 2010 Act (section 149(6)).

The Council for Disabled Children advises that in practice this means that at the outset all children (disabled and non-disabled) should have access to universal services. Local areas should work towards eliminating discrimination and promoting equality of opportunity by building capacity in local services so that they are accessible by all children.

Where this may not be practical, for example for children on the autistic spectrum or children with multiple impairments who may require a high level of support and activities tailored to their needs, the Council for Disabled Children advises setting up specific services, such as youth activities or sports opportunities, for a specified group of children as a way of meeting the duties under the Equality Act. Given the need to ensure the most disabled children are not disadvantaged, a mixture of universal and specific services will be required in every area.

#### **2.2.10.4) Children Act 1989**

Disabled children can access services through Part III of the Children Act 1989 ('Local Authority Support for Children and Families'). All disabled children are children 'in need' for the purposes of section 17 of the Children Act 1989. The duty on local authorities under s17 of the 1989 Act is to provide a range and level of support services for children in need in their area, where possible to support them in the context of their families. Local authorities are required to assess and prioritise the way they meet the needs of children in their area.

Local authorities are permitted to use eligibility criteria and to take into account available resources when deciding whether to provide services following assessment. However, they should have due regard to their duties under the Equality Act in reaching this decision.

Where the local authority assess a child's needs they should do so in accordance with the statutory guidance, Framework for the Assessment of Children in Need and their Families

Services provided under Section 17 of the Children Act 1989 should safeguard and promote the welfare of children 'in need'. Services should be designed to:

- Minimise the effect on disabled children of their disabilities, and
- Give disabled children and their families the opportunity to lead lives which are as 'normal' as possible.<sup>1</sup>

Such services include services to a child at home, social or recreational activities, help with holidays and where necessary the provision of accommodation.

The Council for Disabled Children advises that:

- the definition of 'disabled' children in the Children Act 1989 is broad and that all 'disabled children' are children 'in need' and are entitled to an initial assessment.
- It is important that children are not seen as being in fixed bands. The banding of children undermines the principle of identifying and meeting individual assessed need.
- eligibility cannot just be based on the severity of the child's impairment but should take into account the other 2 sides of the assessment triangle (parenting capacity and family and environmental factors).
- The term 'disabled' child exists in law, but severe disability or complex needs does not. If you are targeting particular resources on children with severe disabilities, it is more helpful to state that 'this resource, such as one-to-one support will be provided to children whose needs cannot be met by mainstream or universal services.

#### **2.2.10.5) The Chronically Sick and Disabled Persons Act 1970 (CSDPA)**

The Council for Disabled Children advises that the interface between the CSDPA 1970 and the Children Act 1989 is not straightforward. CSDPA 1970 is one of the central pieces of legislation about the provision of social care services to disabled people. The Act covers both adults and children.

**A High Court case (*R (JL) v Islington LBC*)** re-stated that services under s2 of the CSDPA 1970 are available to disabled children.<sup>2</sup> Once an authority has assessed the needs of a disabled child and decided that the provision of services under CSDPA 1970 s2 is necessary in order to meet that child's needs, there is then a specific duty on that authority to provide those services; *R v Gloucestershire CC ex p Mahfood*.<sup>3</sup>

To make sense of the duty under section 2 CSDPA 1970, **local authorities need to have a process to decide which children will be eligible for CSDPA services**. This process needs to be fair and rational, and local authorities can take resource constraints into account when making this decision.

The CSDPA 1970 only becomes important if a local authority has assessed a child's needs under Section 17 of the 1989 Act and has identified needs, but is considering not providing services to meet those needs. If the needs can be met through the provision of one or more of the services listed in Section 2 of the CSDPA, then the local authority is under a duty to provide them. Local authorities must be careful that their eligibility criteria allow for consideration of the CSDPA 1970 before a final decision is made on whether to provide services.

<sup>1</sup> The term 'normal' is found in Schedule 2 to the 1989 Act, but in keeping with Aiming High for Disabled Children this should be read as meaning a right to lead 'ordinary lives'.

<sup>2</sup> As specifically stated in CSPDA 1970 s28A

<sup>3</sup> (1995) 1 CCLR 7

**Welfare Services which can be considered for Disabled Children under s.2 of the CSDPA**

- the provision of practical assistance for a disabled child in his/her home (Homecare services); the provision for a disabled child of, or assistance to that disabled child in obtaining, wireless, television, library or similar recreational facilities;
- the provision for a disabled child of lectures, games, outings or other recreational facilities outside his/her home or assistance to that person in taking advantage of educational facilities available to him/her;
- the provision for a disabled child of facilities for, or assistance in, travelling to and from his/her home for the purpose of participating in any services provided by a local authority under Part III of the Children Act 1989 or services which are similar to those which could be provided by a local authority;
- facilitating the taking of holidays by a disabled child, whether at holiday homes or otherwise and whether provided under arrangements made by the authority or otherwise;
- the provision of meals for a disabled child whether in his/her home or elsewhere;
- the provision for a disabled child of, or assistance to the child in obtaining, a telephone and any special equipment necessary to enable him/her to use a telephone.
- the provision of assistance for a disabled child in arranging for the carrying out of any works of adaptation in his/her home or the provision of any additional facilities designed to secure his/her greater safety, comfort or convenience;

**Disabled Children A Legal Handbook** highlights that local authorities may encourage families to apply for disabled facilities grants to meet some or all of the costs of adaptations, however it is important to note that the fact that a grant may be available does not detract from the core duty under the CSDPA. This means that if the costs of the works that are required exceeds the current maximum mandatory grant, or the work is required to a second home (e.g. because the parents have separated) then the council will have to consider making the additional sums available to comply with the duty.

Works may include adaptations to minimise the risk of danger posed by a disabled child's behavioural problems.

Blatant failures to take action to ensure that a property is suitable for the needs of a disabled person may result in a violation of both the private and family life rights within the European Convention on Human Rights article 8 see 2.2.10.10.

The Council for Disabled Children advises that the **Islington Judgement** highlights the following issues in relation to eligibility criteria:

- Eligibility criteria must not be applied before there has been adequate assessment of the child and family's needs.
- Local authorities should ensure that they separate assessment of need from decisions on the provision of services; they must not allow their eligibility criteria to confuse or distort the assessment process.
- Eligibility criteria should never be applied mechanistically. Decisions should always take into account the particular circumstances and needs of the child and family.
- Local authorities should be aware of the specific legal powers and duties they are using when making decisions about services.
- Eligibility criteria must take full account of the statutory provision under which the local authority is acting.

- Eligibility criteria are appropriate in those situations where local authorities are using their discretionary powers to meet needs (for example, under section 17 or section 20(4) of the Children Act 1989) but not in situations where they have established there is a duty to meet need (for example under section 20(1) of the 1989 Act and section 2 of the Chronically Sick and Disabled Person's Act 1970).
- Eligibility criteria should be informed by the local authority's duties under equality legislation which include duties to eliminate discrimination, to promote equality of opportunity and to encourage participation by disabled people in public life.

#### **2.2.10.6) Carers legislation**

Under carers legislation individuals providing substantial and regular care to a disabled person have a right to request an assessment. The Council for Disabled Children advises that while parents should be told that they have a right to an assessment, it is hoped that their needs as well as the needs of most children can be met without the need for such an assessment. (See section 4 Short Break Practice Guidance Draft)

#### **2.2.10.7 Children Act 2004**

The Children Act 2004 created important new duties on local authorities to safeguard and promote the welfare of all children in their area (section 11) and to co-operate with other agencies, including Primary Care Trusts, to achieve the 'Every Child Matters' outcomes (section 10). These duties must be considered whenever a local authority is carrying its functions towards children.

#### **2.2.10.8) Childcare Act 2006**

Section 12 of the Children Act 2006 requires local authorities to provide information about child care and other services which help to support parents with their children. There is a specific requirement to provide information which is helpful and accessible to disabled children, young people and their families. The Council for Disabled Children advises that local authorities need to be clear that all disabled children are entitled to universal services and information, advice and assistance and need to be aware of the reasonable adjustments being made to ensure that all children can access these services wherever possible.

#### **2.2.10.9) Breaks for Carers of Disabled Children Regulations**

The regulations took effect from April 2011, making it a legal duty for local authorities to provide a range of Short Breaks and a 'Short Breaks Services Statement'. Paragraph 6(1)(c) of Schedule 2 of the Children Act 1989 requires Local Authorities to provide services to assist carers of disabled children that will give them breaks from caring for a disabled child.

To meet the requirements of the Regulations Local Authorities must have regard to the needs of Carers in respect of their capacity to care for, or continue to care for their disabled child, and must provide a range of services designed to meet this need. [*'Carer' means a person who provides care for a disabled child and who is either the child's parent or a person who has parental responsibility for that child. 'Disabled' has the meaning given in section 17(11) of the 1989 Children Act (2)*]

Local Authorities were required by 1<sup>st</sup> October 2011 to publish a statement for carers about the Short Breaks available to disabled children and young people outlining:

- The range of services provided;
- Threshold to access Short Breaks services;
- How the range of services are designed to meet the needs of carers in Central Bedfordshire

**A range of services must be provided which are sufficient to assist carers to continue to provide care or to do so more effectively:** In particular local authorities must provide:

- Daytime care in the homes of disabled children or elsewhere;
- Overnight care in the homes of disabled children or elsewhere;
- Educational or leisure activities for disabled children outside of their homes;
- Services available to assist carers in the evenings, at weekends and during school holidays.

Local authorities must provide a service to carers of disabled children in order to :

- Allow them to care more effectively
- Allow carers to undertake education, training, regular leisure activities and/or day to day tasks.

The Statement is reviewed bi-annually by the Local Authority and disabled children and their parents and carers to ensure their needs are being met.

#### **2.2.10.10) Human Rights Act**

##### **Article 8 – Right to Respect for Private and Family Life**

- Everyone has the right to respect for their private and family life, home and correspondence.
- Right may be restricted, provided such interference has a proper legal basis, is necessary in a democratic society and pursues one of the following recognised legitimate aims:
  - national security
  - public safety
  - the economic wellbeing of the country
  - the prevention of disorder or crime
  - the protection of health or morals
  - the protection of the rights and freedoms of others.

Interference must be necessary (not just reasonable) and should not do more than is needed to achieve the aim desired.

**Private life** – The concept of ‘private life’ is broad. In general, it means that a person has the right to live their own life with such personal privacy as is reasonable, taking into account the rights and freedoms of others. The right is very wide-ranging, covering issues such as privacy, relationships with other people, life in the community, culture and language. Issues that may be particularly relevant include:

**Participating in community life:** private life may be involved if someone is unable to participate in the life of the community or access essential economic, social, cultural and recreational activities.

**Family life** – The right to respect for family life includes the right to have family relationships. It also includes the right for a family to live together and enjoy each other’s company.

**Article 14 – Prohibition of Discrimination:**

Article 14 of the European Convention on Human Rights gives people the right to protection from discrimination in relation to all the other rights guaranteed under the Convention. It means that everyone is entitled to equal access to those rights. People cannot be denied equal access to them on grounds of their personal 'status'.

**How does Article 14 work?**

Article 14 only works to protect people from different treatment in exercising their other Convention rights. It does not give people a general right to protection from different treatment in all areas of their life. The structure of Article 14 means that a person needs to be able to identify another Convention right in order to make use of the non-discrimination protection.

**2.2.10.11) Section 3 of the Local Government Act 1999 ('the 1999 Act') and the statutory guidance issued under it**

Authorities should be responsive to the benefits and needs of voluntary and community sector organisations of all sizes (honouring the commitments set out in Local Compacts) and small businesses.

Paragraph 7 says that 'Authorities should seek to avoid passing on disproportionate reductions – by not passing on larger reductions to the voluntary and community sector and small businesses as a whole than they take on'.

- An authority intending to reduce or end funding (where 'funding' means both grant funding and any fixed term contract) or other support to a voluntary and community organisation or small business should give at least three months' notice of the actual reduction<sup>5</sup> to both the organisation involved and the public/service users.
- An authority should actively engage the organisation and service users as early as possible before making a decision on: the future of the service; any knock-on effect on assets used to provide this service; and the wider impact on the local community.
- Authorities should make provision for the organisation, service users, and wider community to put forward options on how to reshape the service or project. Local authorities should assist this by making available all appropriate information, in line with the government's transparency agenda.

**Section 27(2) of the Children and Families Act 2014 ('the 2014 Act')**

Section 27(1)(a) of the 2014 Act imposes a duty on a local authority to keep under review, among other things, its social care provision for children with disabilities. Section 27(2) requires it to **consider the extent to which that provision is sufficient** to meet the social care needs of the young people concerned. Section 27(3) of the 2014 Act imposes a duty on a local authority to consult with a wide range of local bodies when it exercises the functions imposed by section 27.

**DAT & Anor. R (on the application of) v West Berkshire Council [2016] EWHC 1876**

Mrs Justice Laing commented:

*"I would accept Mr Broach's submission that there is an exceptional public interest in ensuring that when local authorities cut spending in a way which affects vulnerable children, they are seen to observe the relevant legal provisions, particularly where, as here, the amounts at stake are, in relation to the budget as whole, not large, and where there was flexibility in the money available*

to accommodate a smaller cut.”

*I am not satisfied by the terms of the new reports prepared for decision 2 that the Council was invited to consider the use of reserves, or, if it did, why it decided not to use them, since apart from the allusion to 'difficulty', the report does not explain whether or not it would be proper to draw on the reserves, and does not tell members what the 'difficulty' is; whether it is insuperable, or could be overcome.*

**2.3. Summary of Existing Data and Consultation Findings – Employment  
 Considering the impact on CBC Employees – Not Applicable**

- **Age:** e.g. 16-19 / 20-29 / 30-39 / 40-49 / 50-59 / 60+ **N/A**
- **Disability:** e.g. Physical impairment / Sensory impairment / Mental health condition / Learning disability or difficulty / Long-standing illness or health condition / Severe disfigurement **N/A**
- **Carers:** e.g. parent / guardian / foster carer / person caring for an adult who is a spouse, partner, civil partner, relative or person who lives at the same address **N/A**
- **Gender Reassignment:** People who are proposing to undergo, are undergoing or have undergone a process (or part of a process) to reassign their sex by changing physiological or other attributes of sex **N/A**
- **Pregnancy and Maternity:** e.g. Pregnancy / Compulsory maternity leave / Ordinary maternity leave / Additional maternity leave **N/A**
- **Race:** e.g. Asian or Asian British / Black or Black British / Chinese / Gypsies and Travellers / Mixed Heritage / White British / White Irish / White Other **N/A**
- **Religion or Belief:** e.g. Buddhist / Christian / Hindu / Jewish / Muslim / Sikh / No religion / Other **N/A**
- **Sex:** Women / Men **N/A**
- **Sexual Orientation:** e.g. Lesbians / Gay men / Bisexuals / Heterosexuals **N/A**
- **Other:** e.g. Human Rights, Poverty / Social Class / Deprivation, Looked After Children, Offenders, Cohesion, Marriage and Civil Partnership **N/A**

**2.4. To what extent are vulnerable groups more affected by this proposal compared to the population or workforce as a whole?**

The proposal focuses on services for children who have a disability and their families. They are, by definition, a vulnerable group and may experience challenging circumstances. The proposal may have the potential to impact adversely on children who meet the Equality and Children Act definitions of disability (and their families), but who do not meet the thresholds for diagnosed profound or severe impairment.

Analysis of existing service user data indicates that 157 children (47%) will continue to receive a specialist service and 179 (53%) will be signposted and supported to access mainstream services and opportunities.

Further consideration needs to be given as to the extent to which these families receive services on a:

- discretionary basis under section 17 or section 20(4) of the Children Act 1989) or
- statutory basis under section 20(1) of the 1989 Act and section 2 of the Chronically Sick and Disabled Person’s Act 1970 or the Breaks for Carers of Disabled Children Regulations)

A consultation with families and voluntary organisations will help to ascertain the likely impact of the proposals and the extent to which families feel that they are able to access mainstream services and opportunities.

**2.5. To what extent do current procedures and working practices address the above issues and help to promote equality of opportunity?**

Recognising the important contributions made by Occupational Therapy Services and the Disabled Facilities Grant, £10k ongoing funding has been identified in order to retain an element of top up provision for these services in relation to disabled children.

**Information to help children with additional needs:**

Local parents have worked with the Council to produce a directory which contains detailed information about a range of services, equipment providers, benefits and support groups.

**A Community Physical Activity Assistant** has been appointed with a focus on increasing access to a range of leisure activities for disabled children.

**Additional Opportunities in Disability Hubs.** Consideration is being given to the ways in which activities can be provided in the Disability Hubs.

**Facilitating culture change amongst professionals** Support will need to be provided to encourage professionals to consider the varying options available in relation to universal services.

**Consultation Process**

- 1) The consultation process was developed and informed as a result of **focus groups** that were held with families in June 2016 which were facilitated by the **Special Needs Action Panel (SNAP)**. SNAP's purpose is to improve the services that are provided to children and young people with additional needs or disabilities, aged from birth to 25 years, who are living in Central Bedfordshire.
- 2) The Head of the Children with Disabilities Service attended the **Equality Forum** on 16 June to discuss the proposal. Further details can be found at section 5 of the EIA.
- 3) A **formal Central Bedfordshire Council consultation process** was launched in December 2016. This included parents / carers, disabled children, voluntary organisations and other stakeholders.
- 4) **SNAP Survey 2017** – The Special Needs Action Panel also launched an independent survey with parents

**Overview of Findings SNAP Focus Groups 2016 -**

**Summary**

From SEN questionnaire 2014 gathering parent carer views, when asked “How satisfied or dissatisfied are you with the social care support and services provided by CBC if you currently use them for your child/young person with special educational needs” from 131 responses there was a net satisfaction rate of 17.86% in regard to respite and short breaks.

Which Services help families most and why?	
<b>Services for Children</b> <ul style="list-style-type: none"> <li>• Families United Network (FUN) – Saturday Club                             <ul style="list-style-type: none"> <li>• Holiday Club</li> </ul> </li> <li>• Autism Bedfordshire (AB) – Summer Clubs                             <ul style="list-style-type: none"> <li>◦ Loads of Autistic Fun(LOAF)</li> </ul> </li> <li>• Opportunity Playgroup</li> <li>• Kingfisher</li> <li>• Core Assets Respite Services</li> <li>• CHUMS</li> <li>• Bedford and District Cerebral Palsy Society (BDCPS)</li> <li>• Special Needs Out Of School Club (SNOOSC)</li> </ul>	<b>Why?</b> <p>Independence                      Confidence                      Reduced Anxiety                      Life skills                      New opportunities                      Peer relationships                      Break from parents                      No bullying                      Fun</p> <p>"It is the only place my mainstream child can go and have the opportunity to play and interact with other children who suffer from the same issues as he does"                      Parent</p>
<b>Services for Young People</b> <ul style="list-style-type: none"> <li>• FUN – Saturday Club</li> <li>• Youth Club</li> <li>• Kids in Action</li> <li>• Otters Swimming Club</li> <li>• BDCPS – JJ's                             <ul style="list-style-type: none"> <li>◦ Holiday Club</li> </ul> </li> <li>• Mencap – Youth Club                             <ul style="list-style-type: none"> <li>◦ Holiday Club</li> </ul> </li> <li>• HI 5's</li> <li>• Boost Sports Club</li> <li>• Kingfisher</li> <li>• Community Support Team</li> <li>• Special Needs Out Of School Club (SNOOSC)</li> </ul>	<b>Why?</b> <p>Self Confidence                      Self Esteem                      Social Skills                      Independence                      Social Interaction                      Family Participation                      1-1 carers of peer age                      Activities at an appropriate age/ability level                      Families starting to Let Go</p> <p>"Continuity is so important for our children and changes without a long timescale don't give the young person time to adjust" Parent</p>
<b>Services for Families</b> <ul style="list-style-type: none"> <li>• FUN – Saturday Club</li> <li>• Carers in Beds</li> <li>• Otters Swimming Club</li> <li>• Outside In</li> <li>• The Avenue</li> <li>• Mencap Holiday Scheme</li> <li>• LOAF</li> <li>• BDCPS – Carers Breakfast</li> <li>• Special Needs Out Of School Club (SNOOSC)</li> </ul>	<b>Why?</b> <p>Respite for Siblings and Parents                      Support                      Training                      Family Social Time                      Sharing Experiences                      Learning from Others                      Sense of Community                      Relieve Stress over 6 week Summer Holiday</p> <p>"We don't go to groups for a rest, none of us chose this"                      Parent</p> <p>"Continual support and guidance cannot be measured" Parent</p>

*“If it weren’t for these services my children would be Looked After”*

You cannot influence the attitude of parents of mainstream children and young people who may see the children with additional needs as taking up more resources. *“A parent was accessing universal services with their child who has Downs Syndrome. The child took longer to get on and off the equipment. The other parents were tutting and complaining that their children were compromised as they therefore got fewer turns in a session. The parent of the little girl had to sit and endure.”* Parent

*“Specialist provision gives me confidence as a mum that the needs of the my children will be met, that the staff will have specialist knowledge, skills and experience enabling them to support and care for my children with dignity, compassion and enthusiasm. For my children it means that they have an amazingly good time unhindered by staff that do not understand them or are unable to communicate with them. In contrast universal services do not have the knowledge, skills and experience to support my children, this means I needs to invest time ensuring these qualities are brought up to an acceptable standard. In addition, I worry when the children are at these provisions that they are not being supported adequately, the children may react adversely to inexperienced staff making it a negative experience for all involved.”* Parent

### **It is important to remember**

Short break provision holds families under pressure, together. They provide dignity, self-esteem and support in addition to respite. They are **more** than clubs. They are essential to the well-being of our families the cuts will be keenly felt. *“As families we did not choose this.”* Parent

## **Central Bedfordshire Council Consultation Process December 2016 – March 2017**

### **Parents and Carers - Summary:**

#### **Overview proposals for change:**

- The majority of respondents (50%) indicated that they disagreed with the proposal to increase cost effectiveness. A third of respondents (36%) agreed with the proposal and 13% remained neutral.
- The majority of respondents (54%) indicated that they agreed with the proposal to protect services for those in greatest need. A third (38%) indicated that they disagreed and 9% remained neutral
- Opinion towards the proposal for introducing new service models for those with lower levels of need was more balanced with 44% of respondents indicated that they disagreed and 37% agreeing with 19% remained neutral
- The majority of respondents 56% of respondents indicated that they disagreed with the proposal to introduce a new eligibility criteria, with 23% agreeing and 21% remained neutral
- A significant majority (79%) of respondents indicated that they disagreed with the proposal to change the funding model.
- the key areas of **value of short breaks** are:
  - **Children:** Having fun (56%), developing friendships (55%), social skills (53%) and building self confidence (44%).
  - **Teenagers:** Building self confidence (62%), independence (56%), social skills (54%), self esteem (51%), developing friendships (49%) and gaining practical life skills (46%).
  - **Families:** Rest (65%), family participation (46%), friendships (44%) and continuity (41%)

**Eligibility Criteria:**

- The majority of respondents (46%) indicated that the criteria clearly explained how to work out if their child would meet the threshold for support, with 36% disagreeing and 19% remained neutral
- The majority of respondents 44% indicated that the criteria did not clearly explain how their child's needs would be met. 31% agreed the criteria was clear and 25% remained neutral
- The majority of respondents 51% indicated that criteria did not clearly explain the standards of service delivery. 26% agreed that the criteria was clear and 26% remained neutral

**Service Development - Greater use of Universal Services**

- 63% of respondents felt it was important to use specially trained staff from voluntary organisations to visit the library, leisure centre, swimming pool to run sessions for children and teenagers with disabilities.
- 57% of respondents felt it was important to use specially trained Council staff who are permanently based at the library, leisure centre, swimming pool to run sessions for children and teenagers with disabilities
- 56% of respondents felt it was important to use multi-purpose rooms and facilities at universal services to run sessions for children and teenagers that are dedicated to their needs. (i.e. not open to the general public).
- 40% of respondents felt it was important to provide opportunities to integrate children and teenagers into universal services. (i.e. shared access with the general public).
- The majority of respondents (60%) did not agree with signposting children with lower level needs to universal services 24% agreed and 16% remained neutral.

**Concerns included:**

- Access to well trained and knowledgeable staff (74%)
- Attitudes of parents of mainstream children and teenagers (68%)
- Attitudes of mainstream children and teenagers (72%)
- Mixing children and teenagers of the same age but with different ability levels (54%)
- Ensuring that the premises is developed with children and teenagers with disabilities in mind i.e. separate changing facilities, specialist equipment, safe access, parking etc. (66%)
- Intimate care (47%)

**Service Sustainability**

- Ensure that we are putting the needs of children and teenagers at the heart of service provision by working with voluntary organisations to ensure there is no overlap or duplication of services (67%)
- Develop standards with partners including voluntary organisations to ensure that outcomes for children and teenagers are being achieved (56%)
- Help voluntary organisations to work together to share expertise and knowledge (59%)
- Help families to attend short break sessions by ensuring there is adequate provision in their local area to reduce travelling time (55%)
- Look at ways of managing vacant short break places to ensure that all opportunities have been taken up (53%)
- Provide advice and support to enable teenagers over the age of 16 and their parents to access direct payments (43%)

**Voluntary Organisations****Autism Beds - Summary**

- impact of being forced to reduce/remove services will **inflate demand for costly social care**

**support** directly from the council. Currently, Central Bedfordshire receives £135k worth of services annually for an SLA that costs £35k. The SLA **anchors our funding pot and attracts grants.**

- **£30k wasted annually on overnights not attended** and the tens of thousands that families tell us that they have in their accounts to spend on **direct payments, that go unspent due to lack of suitable choices**
- **diagnosis of autism legally entitles children to the level of** support described in the Central Bedfordshire Short Breaks Statement
- terminology without definition is extremely subjective
- proposing specialist Services would need to be withdrawn from: • Siblings of children with disabilities • Other children – i.e. children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and the Children Act 1989
- By limiting targeted services to those already in receipt of social care support, the council is effectively **'blocking up the door'** to this group of disabled children
- council will be at risk legally of **not understanding the level of need** and therefore **not fully understanding if they are providing adequate or sufficient short breaks/support.**
- new threshold criteria for CWD will only be an effective tool to measure and assess need if the social worker is trained, experienced and competent
- over the last 7 years have trained thousands of staff from Central Bedfordshire's leisure centres, libraries, swimming pools and play schemes. Have encouraged and supported members to integrate. Parents, staff and Children say that **the barriers are being 'add on' group of people, that there is a lack of understanding, co-operation and empathy towards their needs and this dissuades members from continuing.**
- **Staff induction, training, supervision and appraisal** of working with/for children with disabilities would need expert care. Staff retention and turn over would need specialist training built into the common induction standards framework.
- this **may not work/breakdown, be underused;** how to monitor unmet need due to the inadequacies of the universal services and how to still meet the need.
- facilities design may need to be adjusted to risk of sensory overload and the council's recognition that these steps are seen as a **'hassle' for mainstream providers**

### **Families United Network - Summary**

- Short break services **already represent excellent cost effectiveness** for the Council. Voluntary organisations secure funding from other sources in order to financially maintain their services for Central Bedfordshire families. This enables the local authority to fulfil its short break obligations at a much reduced cost.
- Goodwill of volunteers will be eroded
- Short breaks help keep families together, **not just surviving, being resilient and thriving**
- Legal duty to provide shortbreaks – what other options have been considered?
- Will there be sufficient services to meet need?
- Will CBC meet obligations to treat disabled children's best interests as primary consideration
- Will all children have social work assessment? Is there capacity for this?
- Lack of appropriate and effective support for 'lower and moderate need' families **can lead to these families becoming 'higher need'** and then requiring much greater levels of support
- **will mostly disadvantage the children with moderate needs and their families.** Their needs within an educational setting have been deemed significant enough to require an EHCP or Statement demonstrates that they have significant difficulties that inevitably will also be impacting on their family carers on a daily basis.
- cannot be assumed that if a child is able to manage within a mainstream school, then they are

able to manage within a universal leisure activity.

- **will require significant initial and ongoing investment** in staff training, and will need very effective communication between the provider, service users and the wider community
- **eligibility criteria do not take into account the caring capacity of the child's family members or other family environmental factors**
- **need plenty of notice** for service providers and families to make the transition successfully to personalised funding with a **clear plan and timeline**
- Families need a **clearly explained pathway on how and when to request an assessment** for short break services, and be given sufficient time to do this before any changes to their child's access to provision.
- Universal services need to be more flexible and able to deal with resistance from other families
- Who can families turn to if universal service doesn't meet their needs?
- Have universal services been consulted?
- Need better information sharing and collaborative decision making between organisations

### **Bedford and District Cerebral Palsy Society – Summary**

- BDCPS provide a good service which is very cost effective for the Council in terms of what is being delivered. The full cost of the support is greater. The Council need to see this as a life line which supports some very complex children to stay living at home. The funding to BDCPS is a small amount compared with one overnight in a residential service of having to go out of area.
- the children who BDCPS are working with have specialist needs which make it difficult to manage in some environments
- The funding from the Council provides a platform from which other grants can be applied for. BDCPS require this if they are to continue to provide the support
- Given the right support in universal services– equipment, staff, this could provide some good opportunities for disabled children to access local services. This will require quite a shift in thinking
- They would have to build confidence with the parents by providing a safe place with well trained staff as the physical and learning needs of this group of children and young people make them vulnerable
- We would disseminate information and encourage families to engage in exploration of personalisation as a means of meeting their needs if it is appropriate and supportive in their case.
- Fully funded we could continue to develop appropriate and meaningful services with good outcomes. Less funding threatens our existence as we could not ethically take on complex young people without safe staffing levels
- We would struggle as a very small core team working across all roles to produce good tender proposals that would compete with nationals or other charities that have personnel with specific tender and funding roles.
- Provide adequate funding to support the voluntary sector to provide services that meet the needs of families and avoid costly long term need and family break down. Think long term benefit for the council as well as for the families. A residential place costs approx. 6 times a year more than the funding that each charity has been receiving on an SLA.

### **Additional Information**

- large increase in users over the 8 year period, the figures have almost doubled, primarily due to an increase in the service coverage
- documented increase in the numbers of young people with disabilities and a recognition that

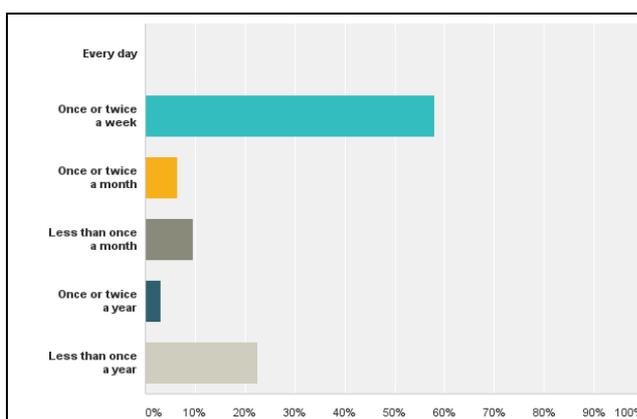
these are becoming more complex. Category 5, is highest level of need of support

Category of Need - No. of young people using BDCPS	2009	2017
1	12	19
2	3	9
3	19	16
4	3	17
5	0	6

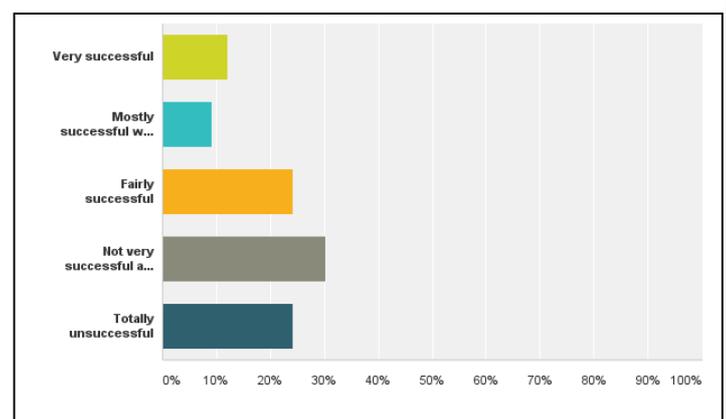
- currently train staff to meet the needs of young people for emergency rescue medication for epilepsy, oxygen, suctioning, gastro feeding, feeding difficulties, administration of regular medication, manual handling for care needs, first aid, safeguarding and communication difficulties. In the process of aiming to secure tracheostomy care training.
- CBC funding has failed to keep track of the development of services, the increase in users and in the complex care needs of those users. Funding from another local authority for holiday childcare for the same period has increased in line with needs and demand for the service
- Less funding threatens our existence as we could not ethically take on complex young people without safe staffing levels.
- Quantitative data does not help us as our numbers will never be large due to the complex needs of many of the young people using our services. Would like to see a model that takes this kind of service cost and provision into account and appreciates the difficulty of producing effective and real data that demonstrates the outcomes. Would like to see more interaction in terms of observation of outcomes at service provision levels.
- Provide adequate funding to support the voluntary sector to provide services that meet the needs of families and avoid costly long term need and family break down. A residential place costs approx. 6 times a year more than the funding that each charity has been receiving on an SLA, with probably the same if not better in some cases outcomes.

### SNAP Survey 2017 Summary

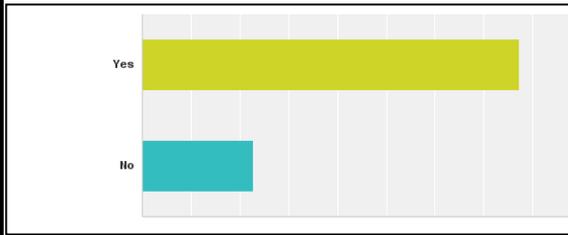
#### Attendance at mainstream activity? supporting your child?



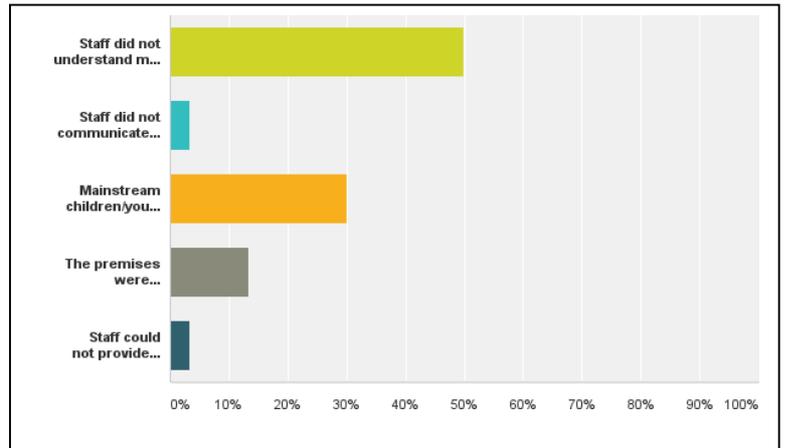
#### How successful were providers at supporting your child?



**Difficulties**

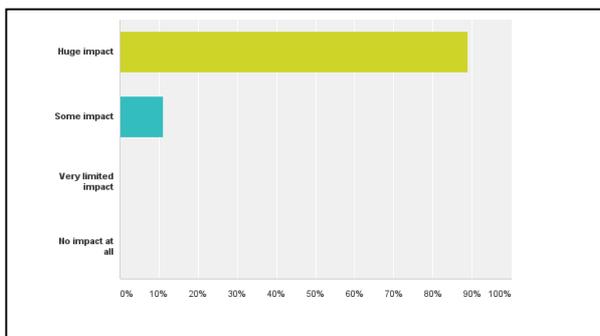


**What was not good about service?**

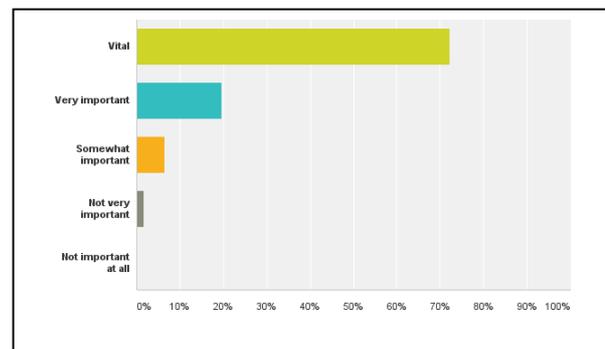


Answer Choices	Responses
Staff did not understand my child/young person's needs or know how to support them	50.00% 15
Staff did not communicate well with us as parents and generally did not ask for our views	3.33% 1
Mainstream children/young people and their parents did not understand my child and were not tolerant of their needs	30.00% 9
The premises were inappropriate for my child's needs and did not provide the right environment/facilities	13.33% 4
Staff could not provide intimate care	3.33% 1
<b>Total</b>	<b>30</b>

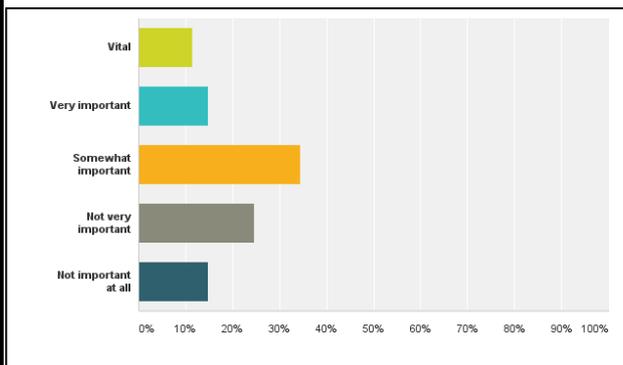
**Impact if clubs not available?**



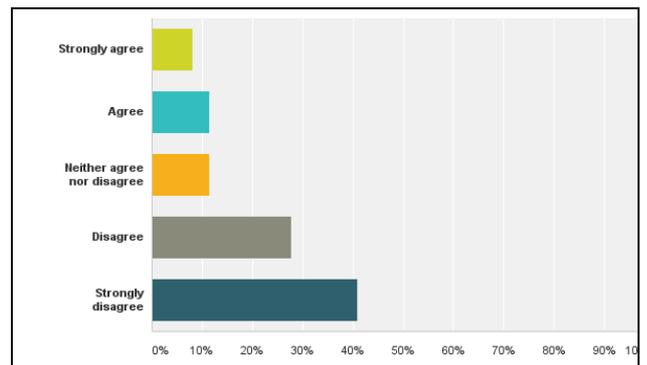
**How important is it to access specialist clubs?**



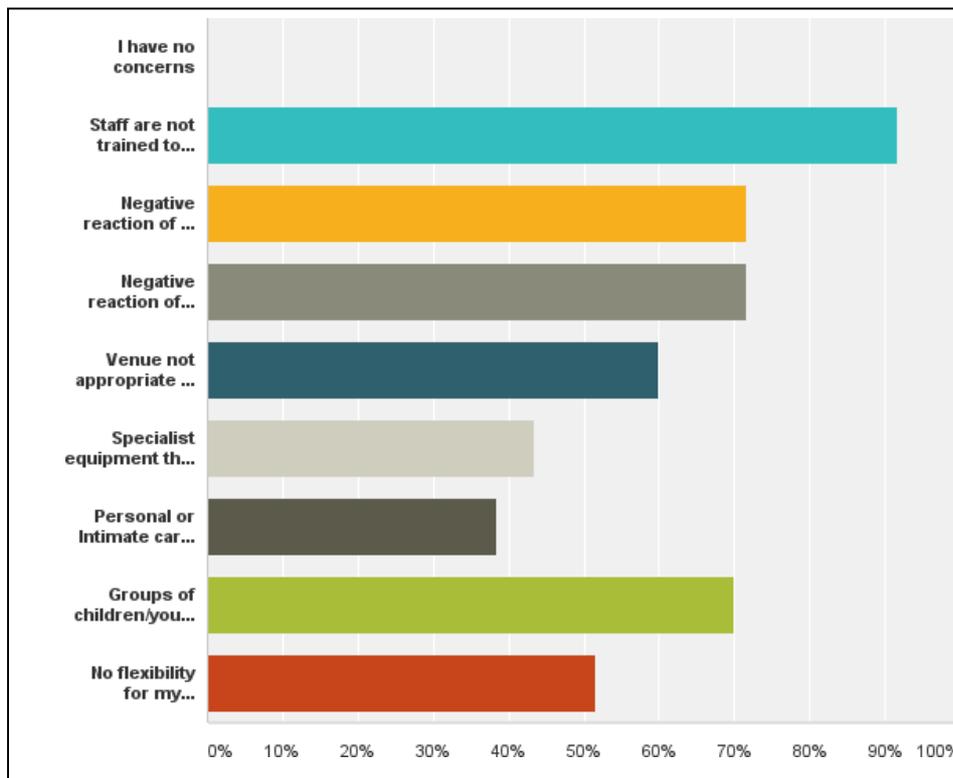
**How important to access mainstream?**



**Signposting less complex needs to mainstream?**



**Concerns about accessing mainstream clubs**



Answer Choices	Responses
I have no concerns	0.00% 0
Staff are not trained to support my child/young person appropriately	91.67% 55
Negative reaction of the other typical children/young people	71.67% 43
Negative reaction of parents of the typical children/young people	71.67% 43
Venue not appropriate to meet my child/young person's needs	60.00% 36
Specialist equipment that my child/young person needs is not available	43.33% 26
Personal or Intimate care is not provided	38.33% 23
Groups of children/young people are too large for my child/young person	70.00% 42
No flexibility for my child/young person to attend with children outside their own age group	51.67% 31
<b>Total Respondents: 60</b>	

<p><b>2.6. Are there any gaps in data or consultation findings?</b> Non identified</p>
<p><b>2.7. What action will be taken to obtain this information?</b> Not applicable</p>

**Stage 3 - Providing an overview of impacts and potential discrimination.**

Stage 3 – Assessing Positive & Negative Impacts					
Analysis of Impacts	Impact		Discrimination		Summary of impacts and reasons
	+ve	- ve	YES	NO	
3.1 Age	/	/	/	/	
3.2 Disability	√	√	?	?	<ul style="list-style-type: none"> <li>• Eligibility criteria requires further clarification and details about how different needs will be met</li> <li>• Proposing specialist services would need to be withdrawn from children who do not meet the categories for the highest levels of need, but who may still meet a definition of disability under the terms of the Equality Act 2010 and the Children Act 1989</li> <li>• Numbers of disabled children are increasing and becoming more complex</li> <li>• Short breaks help keep families together, not just surviving, being resilient and thriving</li> <li>• <b>Children:</b> Having fun (56%), developing friendships (55%), social skills (53%) and building self confidence (44%).</li> <li>• <b>Teenagers:</b> Building self confidence (62%), independence (56%), social skills (54%), self esteem (51%), developing friendships (49%) and gaining practical life skills (46%).</li> <li>• ensure there is adequate provision in the local area to reduce travelling time</li> <li>• Lack of appropriate and effective support for 'lower and moderate need' families can lead to these families becoming 'higher need' and then requiring much greater levels of support</li> <li>• Voluntary Sector groups are highly valued for their expertise and support</li> <li>• The SLA anchors the funding pot for voluntary organisations and helps to attract grants.</li> <li>• Universal services need to be more flexible and able to deal with resistance from other families</li> </ul>

					<ul style="list-style-type: none"> <li>the barriers are being 'add on' group of people, that there is a lack of understanding, co-operation and empathy towards their needs and this dissuades members from continuing.</li> <li>Staff induction, training, supervision and appraisal of working with/for children with disabilities would need expert care.</li> <li>important to use multi-purpose rooms and facilities at universal services to run sessions for children and teenagers that are dedicated to their needs. (i.e. not open to the general public).</li> <li>will need very effective communication between the provider, service users and the wider community</li> <li>eligibility criteria do not take into account the caring capacity of the child's family members or other family environmental factors</li> <li>need plenty of notice for service providers and families to make the transition successfully to personalised funding with a clear plan and timeline</li> </ul>	
3.3	Carers	√	√	/	/	<ul style="list-style-type: none"> <li>72% of parents / carers experience mental ill health such as anxiety, depression or breakdown due to isolation</li> <li>Value of short breaks: Rest (65%), family participation (46%), friendships (44%) and continuity (41%)</li> <li>Paragraph 6(1)(c) of Schedule 2 of the Children Act 1989 requires Local Authorities to provide services to assist carers of disabled children that will give them breaks from caring for a disabled child.</li> </ul>
3.4	Gender Re - assignment	/	/	/	/	
3.5	Pregnancy & Maternity	/	/	/	/	
3.6	Race	/	/	/	/	
3.7	Religion / Belief	/	/	/	/	
3.8	Sex	/	/	/	/	
3.9	Sexual Orientation	/	/	/	/	
3.10	Other e.g. Human Rights, Poverty / Social Class /					<p><b>Article 3</b> The child's best interests must be a top priority whenever anything is done that affects children.</p> <p><b>Article 23</b> Every disabled child has the right</p>

<p>Deprivation, Looked After Children, Offenders, Cohesion Marriage and Civil Partnership</p>					<p>to a full life and to active participation in the community. <b>Article 31</b> Every child has the right to rest, play and leisure  Disabled people are a particularly vulnerable group in society and need additional support. A disproportionate number of families with disabled children live in poverty</p>
---	--	--	--	--	---

**Stage 4 - Identifying mitigating actions that can be taken to address adverse impacts.**

<p><b>Stage 4 – Conclusions, Recommendations and Action Planning</b></p>			
<p><b>4.1 What are the main conclusions and recommendations from the assessment?</b></p>			
<p>Consideration of research and consultation findings indicates that disabled children and their families are, by definition, a vulnerable group and can experience challenging circumstances. The proposal may have the potential to impact adversely on children who meet the Equality and Children Act definitions of disability (and their families), but who do not meet the thresholds for diagnosed profound or severe impairment.</p>			
<p>Further consideration needs to be given as to the extent to which these families receive services on a:</p>			
<ul style="list-style-type: none"> <li>• discretionary basis under section 17 or section 20(4) of the Children Act 1989) or</li> <li>• statutory basis under section 20(1) of the 1989 Act and section 2 of the Chronically Sick and Disabled Person’s Act 1970 or the Breaks for Carers of Disabled Children Regulations)</li> </ul>			
<p>The support and expertise provided by the voluntary sector is highly valued by families, providing opportunities for rest and family participation, whilst enabling children and young people to enjoy themselves and develop.</p>			
<p>Although there is a desire for services to be provided closer to home there is a concern, based on previous experiences, that Universal Services are not currently able to meet the needs of disabled children. There is a desire for specialist services to be protected and for the Council to also take account of the needs of children with lower levels of need in order to ensure that crisis is avoided and families are able to continue providing care at home.</p>			
<p>Many families have indicated that the voluntary sector could have an important role to play in helping to ensure that if changes are made that provision at universal service locations is delivered in an appropriate way. The need to ensure sufficient time to plan and deliver such changes has also been highlighted.</p>			
<p><b>4.2 What changes will be made to address or mitigate any adverse impacts that have been identified?</b></p>			
<p>Consideration will be given to whether the proposed changes could be implemented over a longer timescale with the ongoing involvement of the voluntary sector.</p>			
<p><b>4.3 Are there any budgetary implications?</b></p>			
<p>The proposed budget efficiencies may not be attainable in the current financial year.</p>			
<p><b>4.4 Actions to be taken to mitigate against any adverse impacts:</b></p>			
Action	Lead Officer	Date	Priority
Develop service plan proposal including analysis of need and clear pathways to appropriate services	Ken Harvey	Ongoing	High

Review timescales for completion	Ken Harvey	Ongoing	High
Review eligibility criteria with reference to consultation	Ken Harvey	Ongoing	High

**Stage 5 - Checking that all the relevant issues and mitigating actions have been identified**

<b>Stage 5 – Quality Assurance &amp; Scrutiny:</b>
<b>Checking that all the relevant issues have been identified</b>
<b>5.1 What methods have been used to gain feedback on the main issues raised in the assessment?</b>
<b>Step 1:</b>
<b>Has the Corporate Policy Advisor (Equality &amp; Diversity) reviewed this assessment and provided feedback? Yes</b>
<b>Summary of CPA’s comments:</b>
The CPA (E&D) has been fully involved in the development of the EIA.
<b>Step 2:</b>
<b>5.2 Feedback from Central Bedfordshire Equality Forum - 16 June 2016</b>
The Panel received a report starting with the premise that Council resources must be targeted to areas of greatest need and that all services must deliver value for money. Comments were made, including:
<ul style="list-style-type: none"> <li>• The focus should be on the children with the highest needs</li> <li>• SNAP represented a very helpful group of parents with a constructive approach</li> <li>• Respite for families with disabled children was vital and procedures were in place to identify families at risk who needed respite most acutely.</li> </ul>
Panel members were encouraged to send in any further comments on the consultation.

**Stage 6 - Ensuring that the actual impact of proposals are monitored over time.**

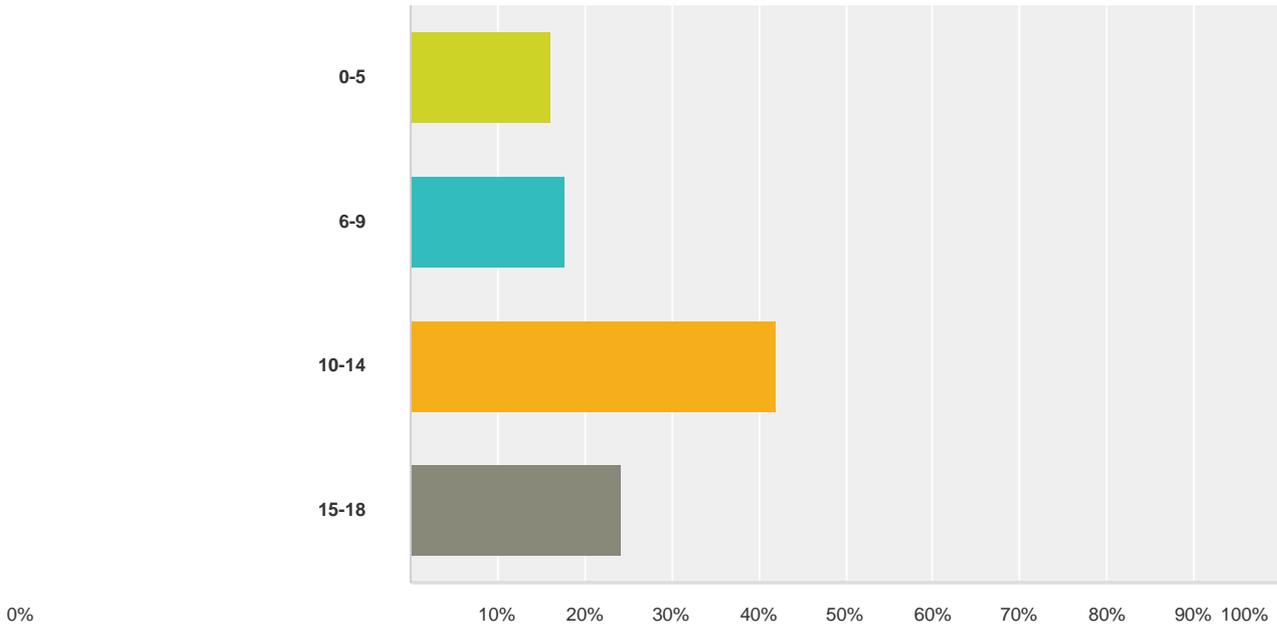
<b>Stage 6 – Monitoring Future Impact</b>
<b>6.1 How will implementation of the actions be monitored?</b>
<b>6.2 What sort of data will be collected and how often will it be analysed?</b>
<b>6.3 How often will the proposal be reviewed?</b>
<b>6.4 Who will be responsible for this?</b>
<b>6.5 How have the actions from this assessment been incorporated into the proposal?</b>

**Stage 7 - Finalising the assessment.**

<b>Stage 7 – Accountability / Signing Off</b>
<b>7.1 Has the lead Assistant Director/Head of Service been notified of the outcome of the assessment</b>
Name: _____ Date: _____
<b>7.2 Has the Corporate Policy Adviser Equality &amp; Diversity provided confirmation that the Assessment is complete?</b>
Date: _____

### Q1 How old is your child?

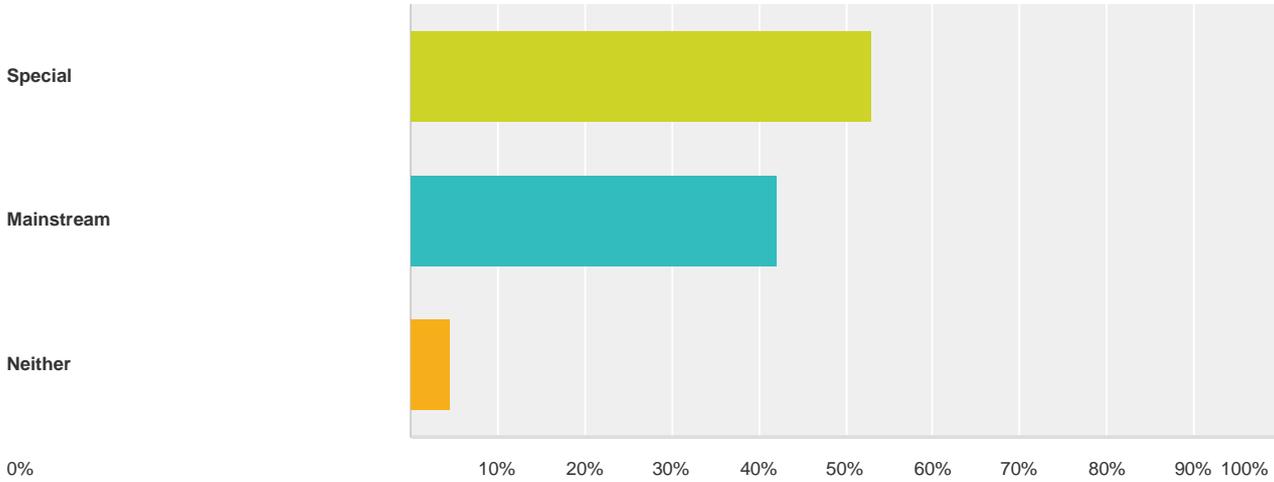
Answered: 62 Skipped: 2



Answer Choices	Responses
0-5	16.13% 10
6-9	17.74% 11
10-14	41.94% 26
15-18	24.19% 15
<b>Total</b>	<b>62</b>

### Q2 Does your child attend a mainstream or a special school/college?

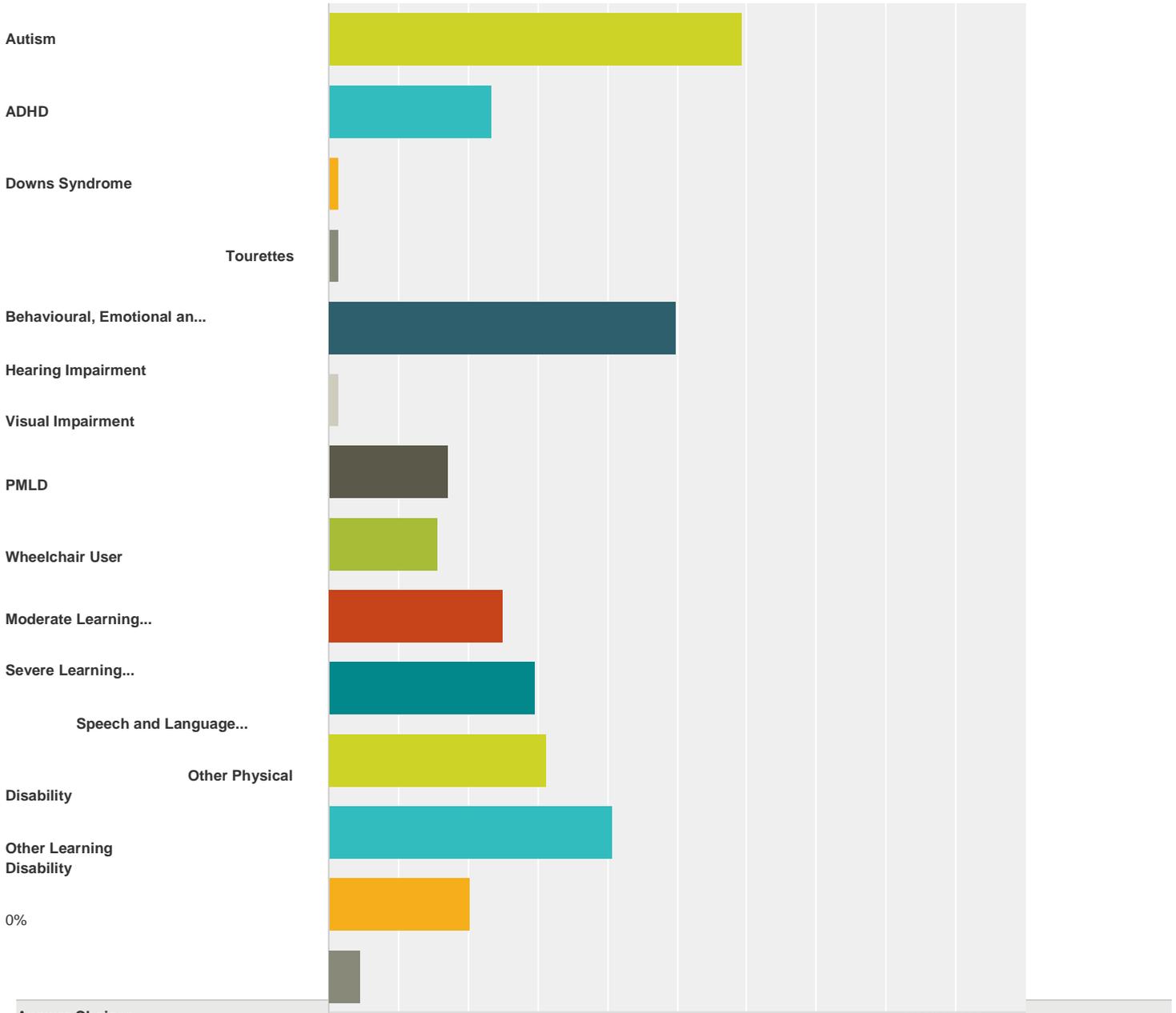
Answered: 64 Skipped: 0



Answer Choices	Responses
Special	53.13% 34
Mainstream	42.19% 27
Neither	4.69% 3
<b>Total</b>	<b>64</b>

### Q3 What are your child/young person's primary additional needs or disabilities (please tick all that apply)?

Answered: 64 Skipped: 0



Answer Choices	Responses	Count
Autism	59.38%	38
ADHD	23.44%	15
Downs Syndrome	1.56%	1
Tourettes	1.56%	1
Behavioural, Emotional and Social Difficulties	50.00%	32

Hearing Impairment	1.56%	1
Visual Impairment	17.19%	11
PMLD	15.63%	10
Wheelchair User	25.00%	16
Moderate Learning Difficulties	29.69%	19
Severe Learning Difficulties	31.25%	20
Speech and Language Delay/Difficulties	40.63%	26
Other Physical Disability	20.31%	13
Other Learning Disability	4.69%	3
<b>Total Respondents: 64</b>		

**Q4 Has your child/young person ever attended any mainstream clubs or activities that are open to all children or young people, e.g. swimming clubs, scouts or guides, youth clubs, after school clubs, sports activities etc. ?**

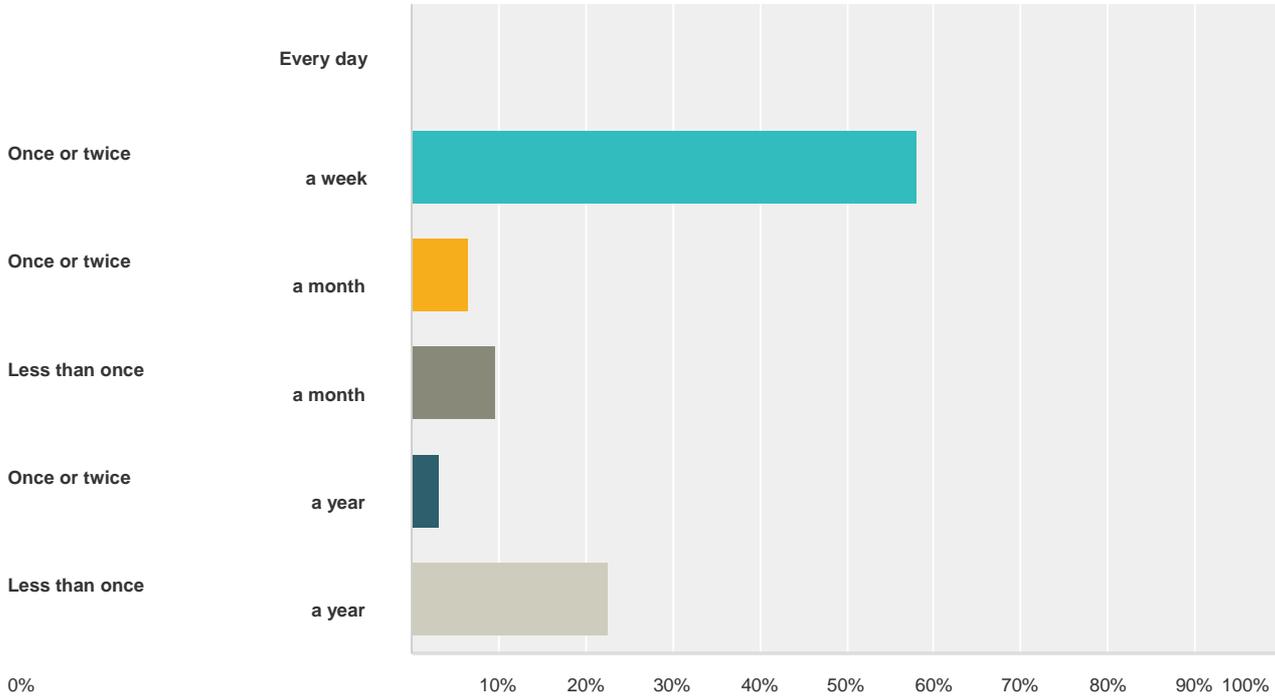
Answered: 64 Skipped: 0



Answer Choices	Responses	
No – go to Q 10 on Page 2.	48.44%	31
Yes – please answer Qs 5-9	51.56%	33
<b>Total</b>		<b>64</b>

### Q5 How often does your child/young person attend a mainstream club or activity?

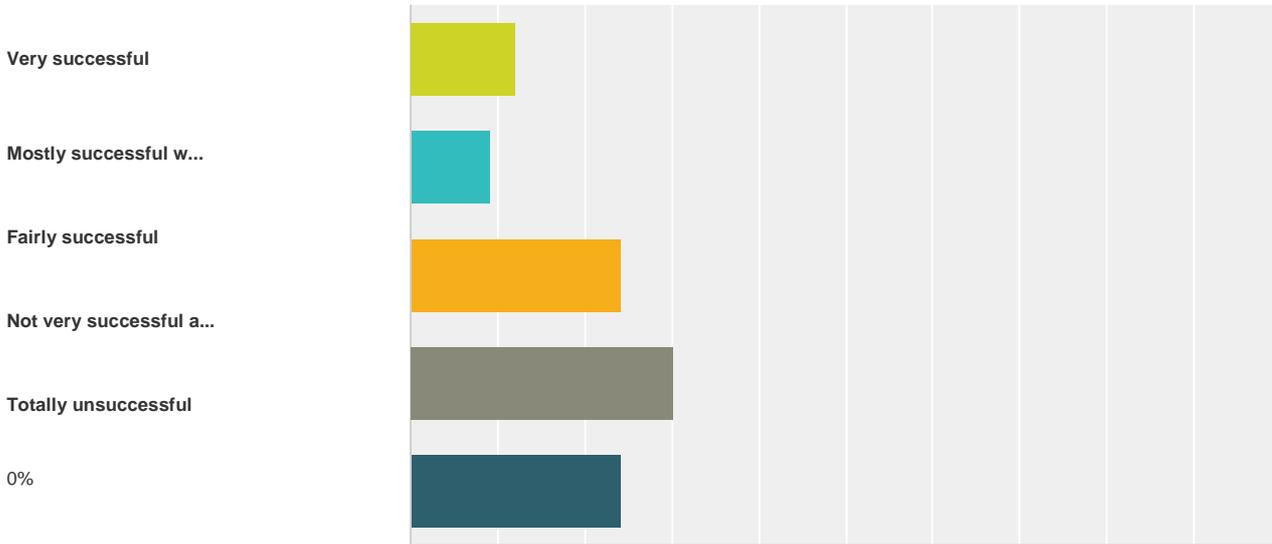
Answered: 31 Skipped: 33



Answer Choices	Responses	Count
Every day	0.00%	0
Once or twice a week	58.06%	18
Once or twice a month	6.45%	2
Less than once a month	9.68%	3
Once or twice a year	3.23%	1
Less than once a year	22.58%	7
<b>Total</b>		<b>31</b>

**Q6 As a whole, how successful were the providers of these clubs and activities at supporting and integrating your child/young person into their service?**

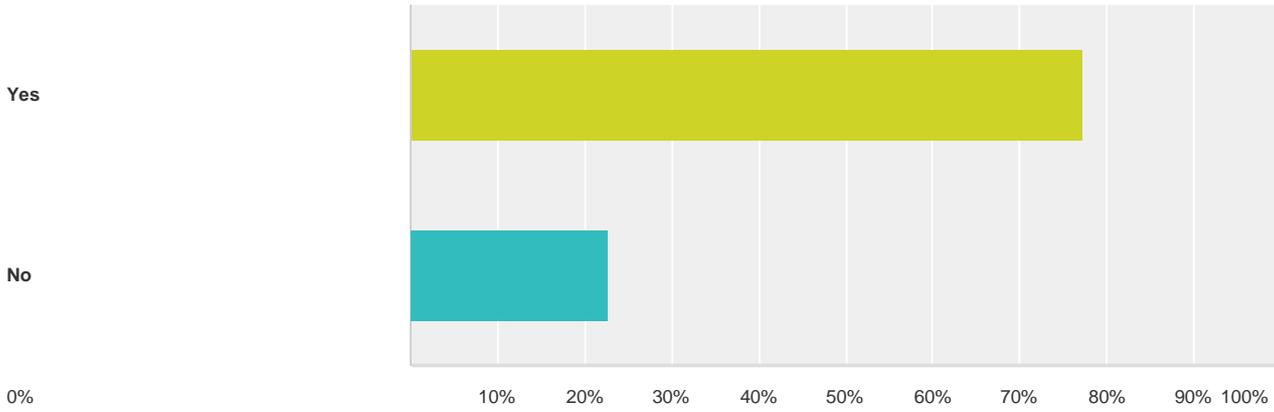
Answered: 33 Skipped: 31



Answer Choices	Responses
Very successful	12.12% 4
Mostly successful with a few minor exceptions	9.09% 3
Fairly successful	24.24% 8
Not very successful at all	30.30% 10
Totally unsuccessful	24.24% 8
<b>Total</b>	<b>33</b>

**Q7 Have there been any difficulties that you or your child/young person have encountered when trying to access mainstream clubs or activities?**

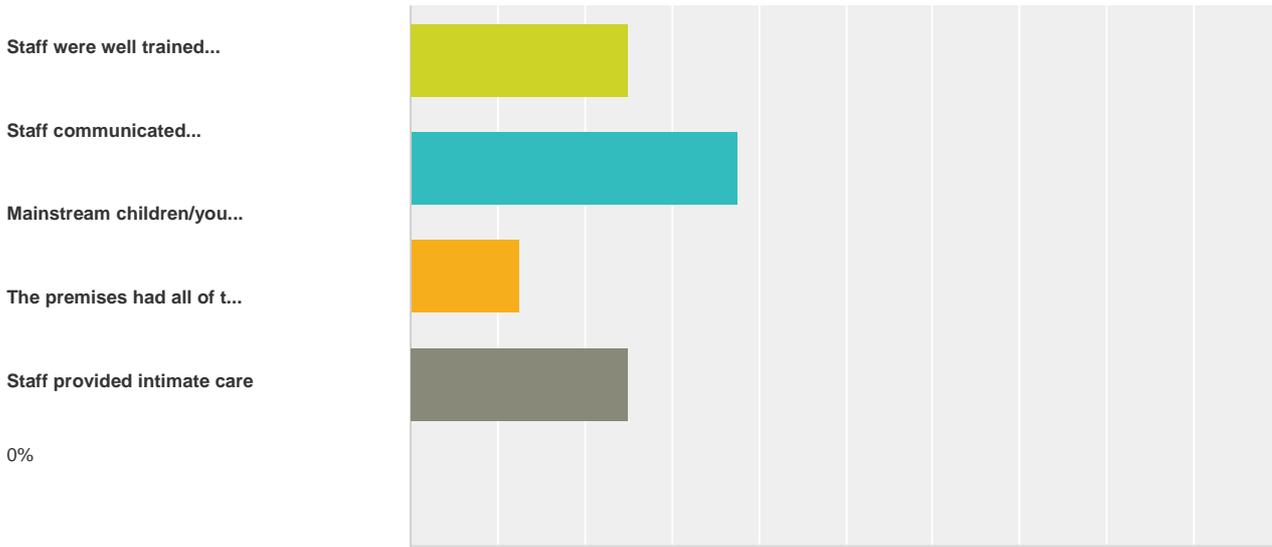
Answered: 35 Skipped: 29



Answer Choices	Responses	
Yes	77.14%	27
No	22.86%	8
<b>Total</b>		<b>35</b>

### Q8 What was good about the service?

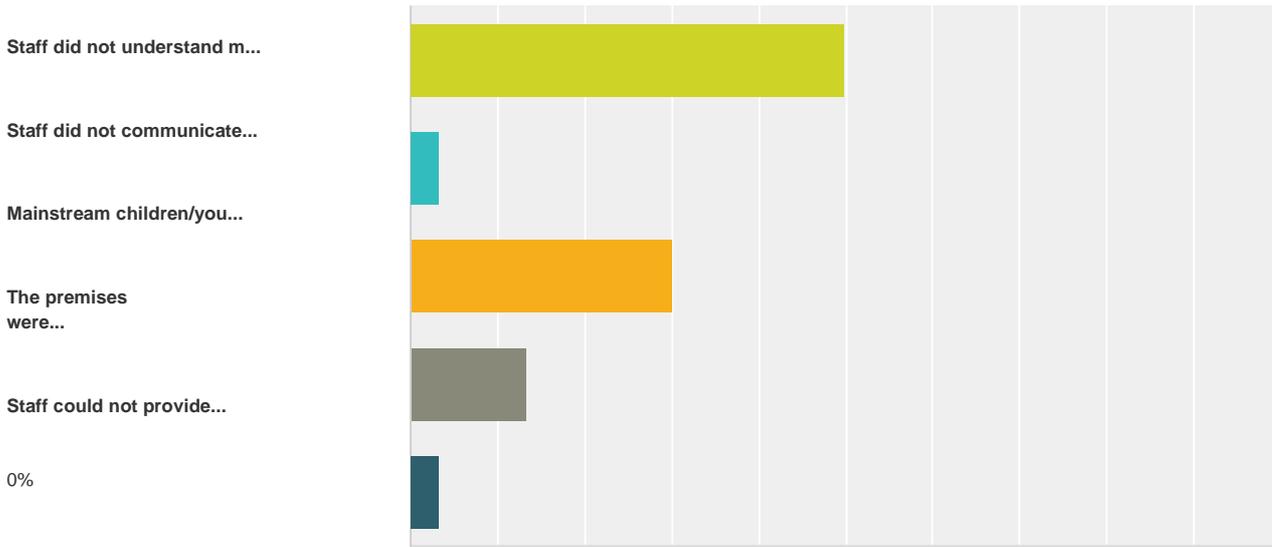
Answered: 16 Skipped: 48



Answer Choices	Responses
Staff were well trained and knowledgeable about my child/young person's needs and supported them well	25.00% 4
Staff communicated well with us as parents and we worked in partnership	37.50% 6
Mainstream children/young people and their parents were patient and understanding about my child's needs	12.50% 2
The premises had all of the features and resources it needed to meet my child's needs (e.g. security, changing facilities, parking etc.)	25.00% 4
Staff provided intimate care	0.00% 0
<b>Total</b>	<b>16</b>

### Q9 What was not good about the service?

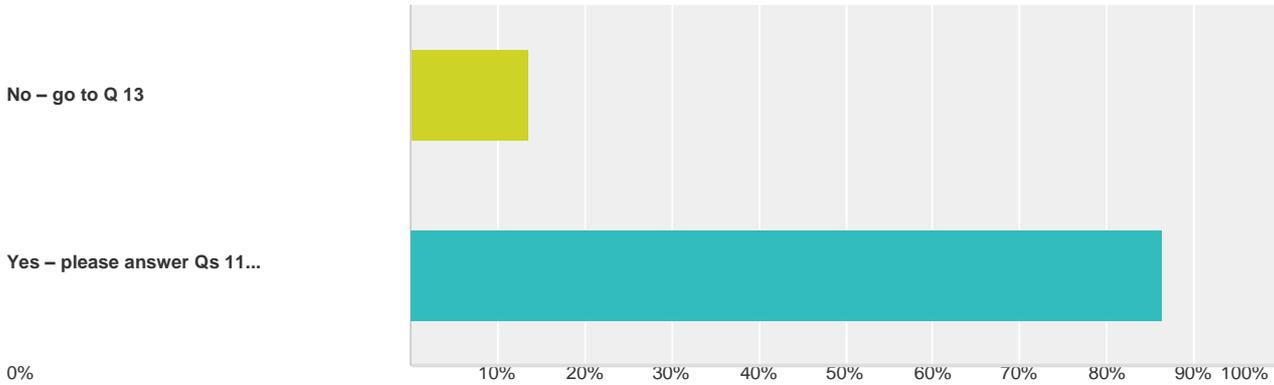
Answered: 30 Skipped: 34



Answer Choices	Responses
Staff did not understand my child/young person's needs or know how to support them	50.00% 15
Staff did not communicate well with us as parents and generally did not ask for our views	3.33% 1
Mainstream children/young people and their parents did not understand my child and were not tolerant of their needs	30.00% 9
The premises were inappropriate for my child's needs and did not provide the right environment/facilities	13.33% 4
Staff could not provide intimate care	3.33% 1
<b>Total</b>	<b>30</b>

**Q10 Does your child access any specialist clubs or activities designed specifically for those with additional needs or disabilities?**

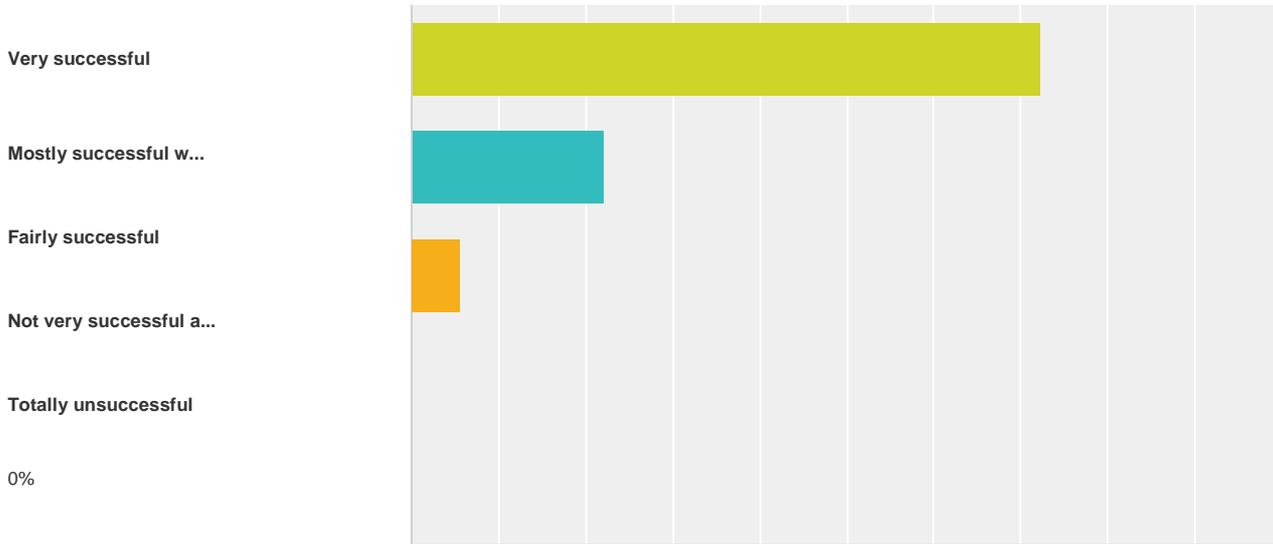
Answered: 59 Skipped: 5



Answer Choices	Responses	
No - go to Q 13	13.56%	8
Yes - please answer Qs 11 and 12	86.44%	51
<b>Total</b>		<b>59</b>

**Q11 How successful were the providers of these specialist clubs and activities at supporting and meeting the needs of your child/young person?**

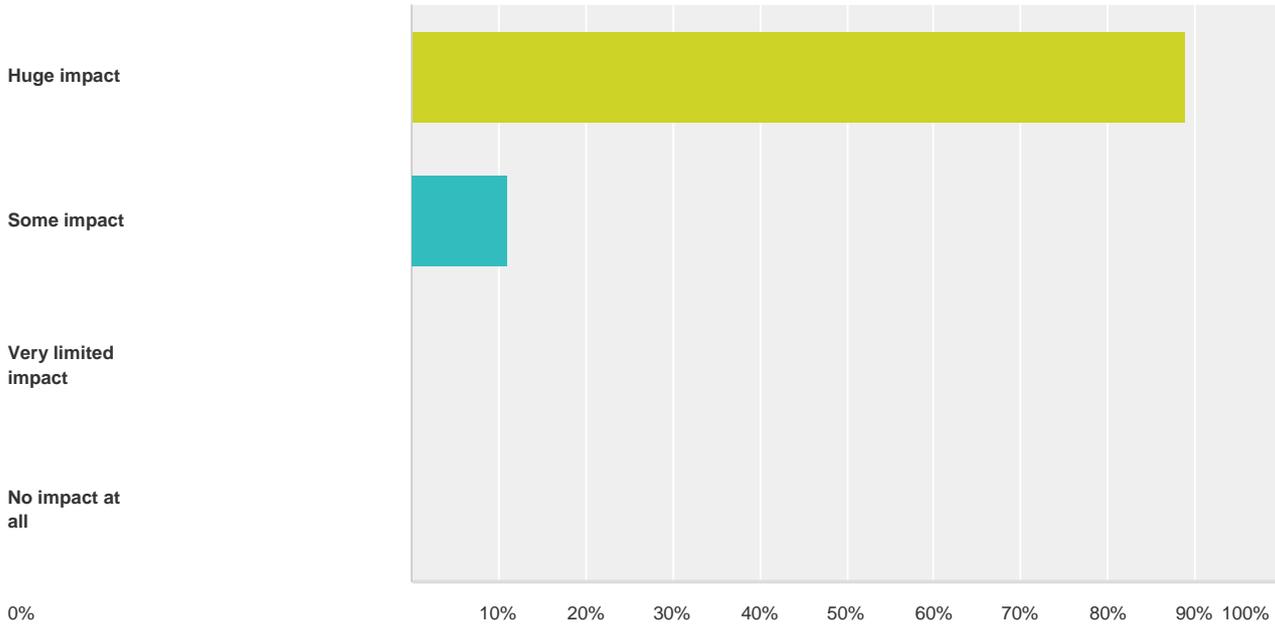
Answered: 54 Skipped: 10



Answer Choices	Responses
Very successful	72.22% 39
Mostly successful with a few minor exceptions	22.22% 12
Fairly successful	5.56% 3
Not very successful at all	0.00% 0
Totally unsuccessful	0.00% 0
<b>Total</b>	<b>54</b>

**Q12 If these specialist clubs and activities were no longer available to your child/young person, what would the impact be on them and your family?**

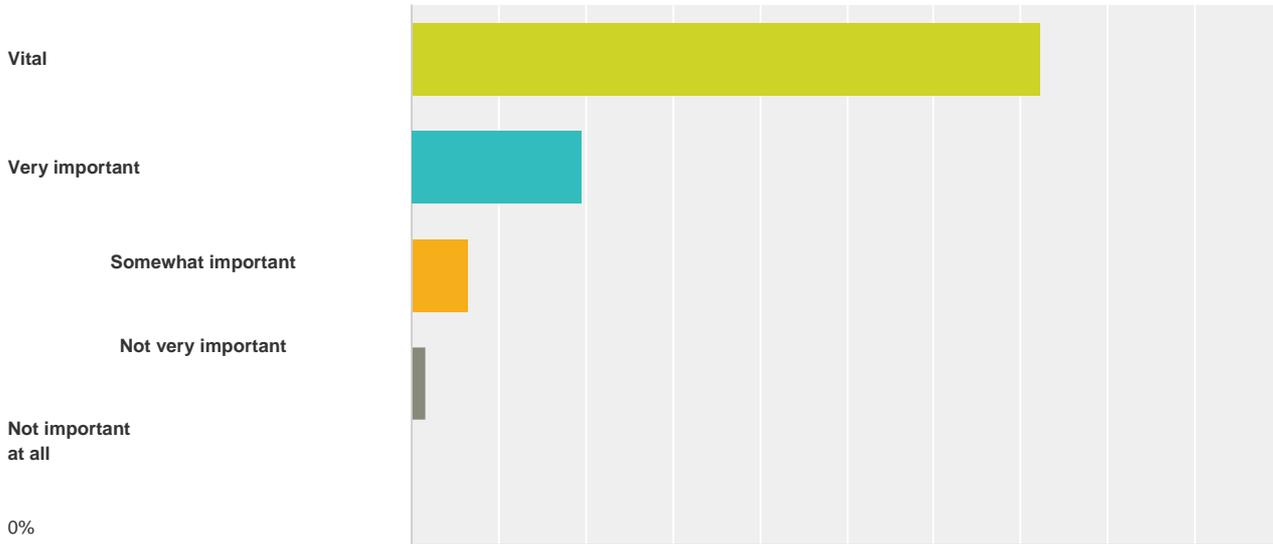
Answered: 54 Skipped: 10



Answer Choices	Responses	Count
Huge impact	88.89%	48
Some impact	11.11%	6
Very limited impact	0.00%	0
No impact at all	0.00%	0
<b>Total</b>		<b>54</b>

**Q13 How important is it to you that your child/young person is able to access clubs and activities that are specifically for those with additional needs or disabilities?**

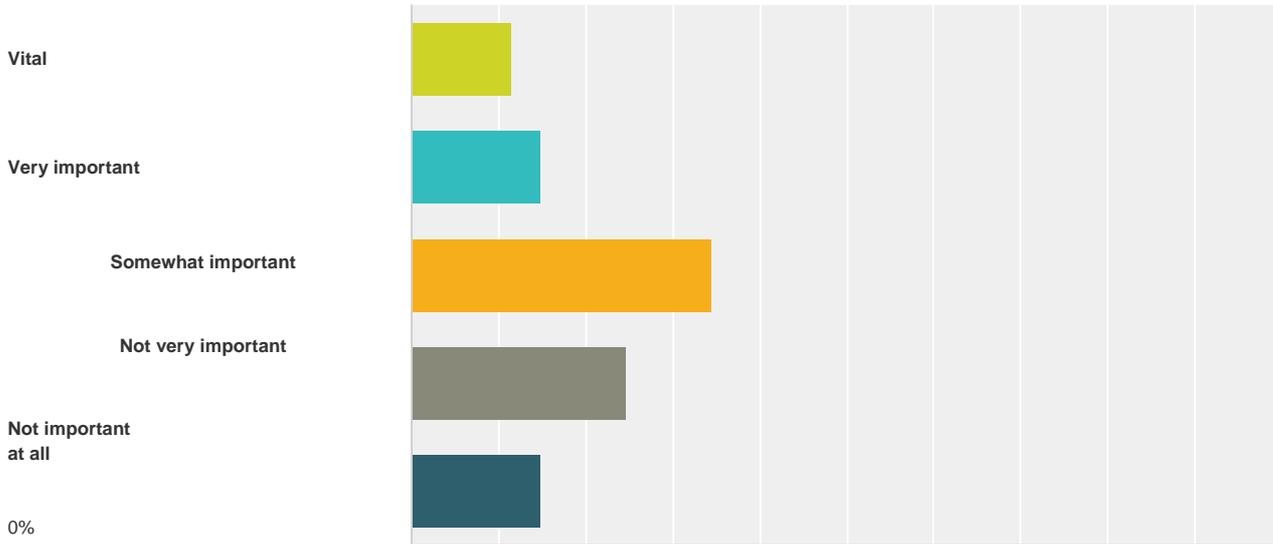
Answered: 61 Skipped: 3



Answer Choices	Responses	Count
Vital	72.13%	44
Very important	19.67%	12
Somewhat important	6.56%	4
Not very important	1.64%	1
Not important at all	0.00%	0
<b>Total</b>		<b>61</b>

**Q14 How important to you is it that your child/young person is able to be access mainstream clubs and activities alongside typical children/young people?**

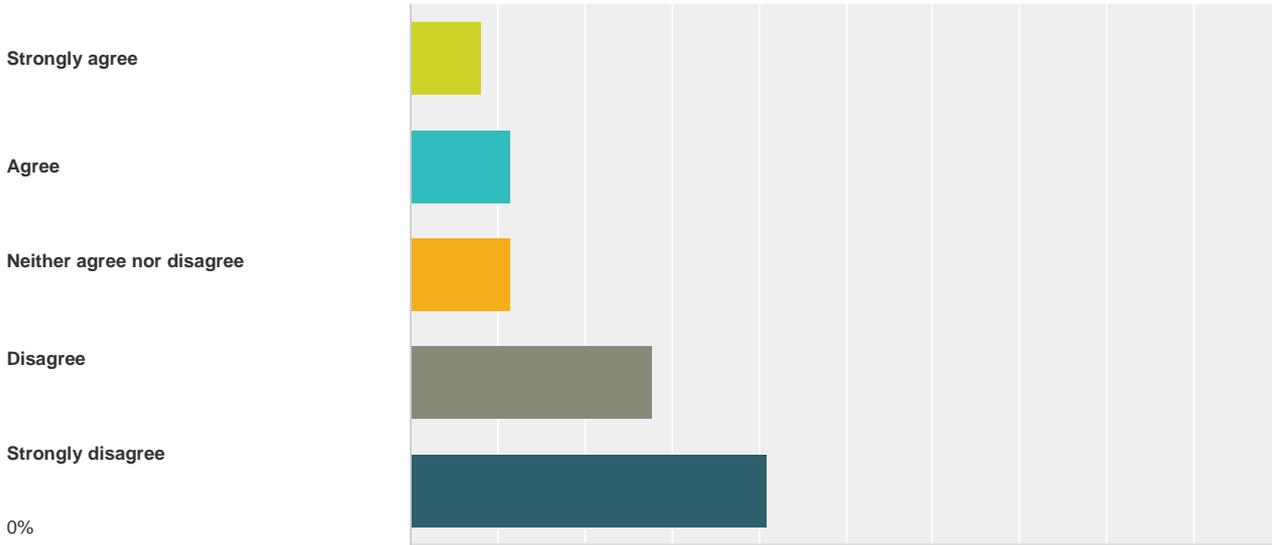
Answered: 61 Skipped: 3



Answer Choices	Responses
Vital	11.48% 7
Very important	14.75% 9
Somewhat important	34.43% 21
Not very important	24.59% 15
Not important at all	14.75% 9
<b>Total</b>	<b>61</b>

**Q15 To what extent do you agree that children/young people with less complex additional needs or disabilities should be required to use mainstream clubs and activities, rather than specialist services?**

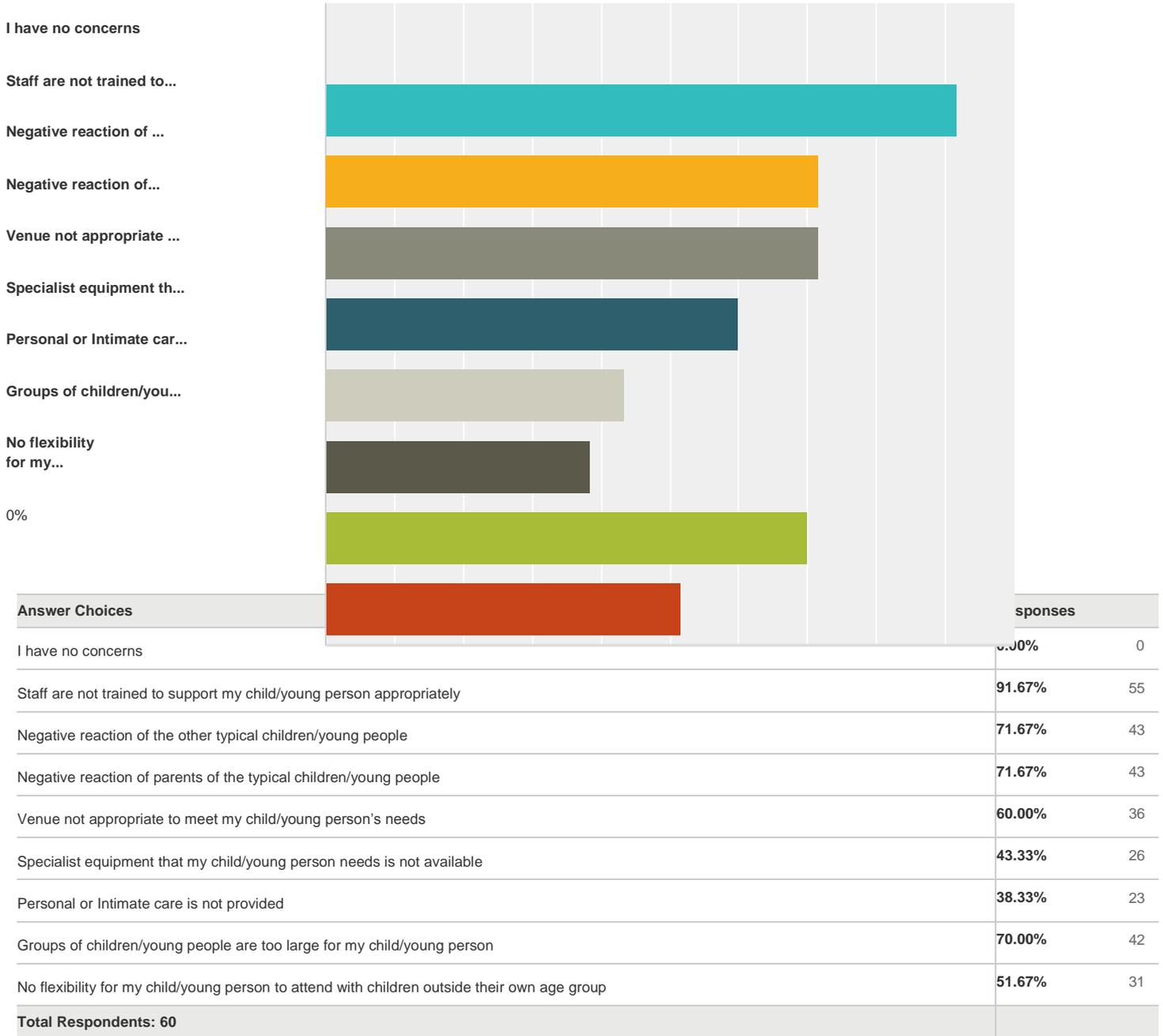
Answered: 61 Skipped: 3



Answer Choices	Responses	
Strongly agree	8.20%	5
Agree	11.48%	7
Neither agree nor disagree	11.48%	7
Disagree	27.87%	17
Strongly disagree	40.98%	25
<b>Total</b>		<b>61</b>

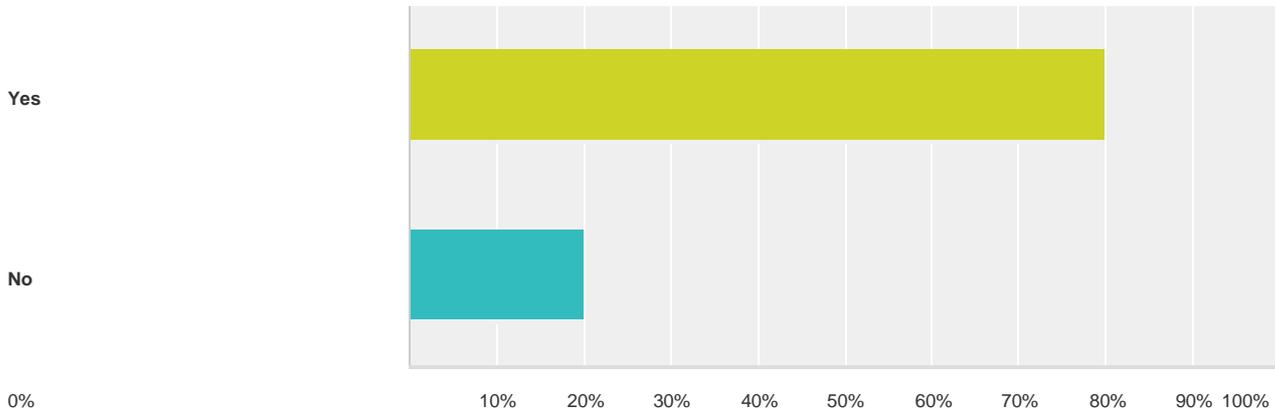
**Q16 What concerns, if any, do you have about children/young people with additional needs or disabilities being required to access mainstream clubs and activities alongside typical children/young people, instead of specialist services?**

Answered: 60 Skipped: 4



### Q17 Are you aware of the Central Bedfordshire Council short breaks survey?

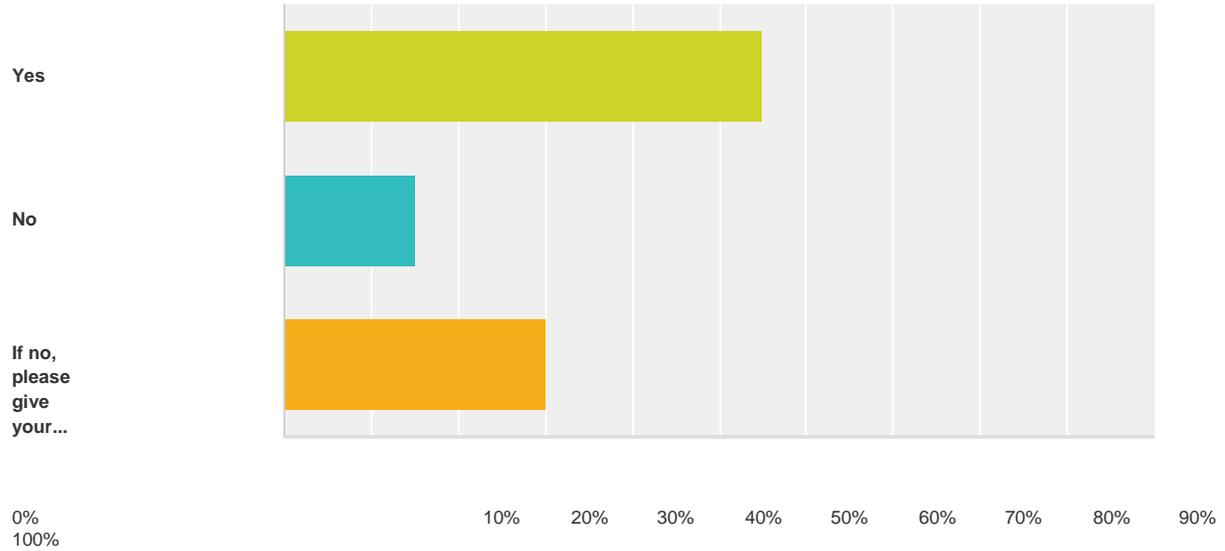
Answered: 60 Skipped: 4



Answer Choices	Responses	
Yes	80.00%	48
No	20.00%	12
<b>Total</b>		<b>60</b>

### Q18 Did you complete it?

Answered: 60 Skipped: 4



Answer Choices	Responses	
Yes	55.00%	33
No	15.00%	9
If no, please give your reasons	30.00%	18
<b>Total</b>		<b>60</b>