

Childhood Disability

Background:

Over recent years there has been a continuing positive focus from Government and all agencies working with disabled children on the development of child and family centred services, where the emphasis is on a “needs – led” approach to provision of services to meet identified needs and outcomes for each child and their families / carers.

The “Children and Families Act 2014”(2), together with the “SEN Code of Practice 2014”(3) have clearly identified the needs and wishes of disabled children and their families as central to all planning and provision of services.

The development of “Education Health and Social Care Plans” is central to the promotion of collaborative and “joined-up” working between agencies on behalf of children and families, and the requirement to publicise “the Local Offer”(4) ie services available from all sources in an area, has greatly enhanced the choice of parents and families.

The increase in the uptake of Direct Payments, and the development of Personal Budgets, both in Social Services and Health, has enhanced the choices available to children and families in achieving services to meet the identified outcomes for the disabled child(ren) in the family, and to develop robust “respite” options for parents / carers.

Following self-referral, or referral by a professional / agency, an assessment of need is conducted by an “Early Help Assessor” or a Social Worker, and the process continues with the application of “threshold criteria”, which should identify the level of intervention required (if any), and therefore which service is most likely to be appropriate to respond to the assessed needs and outcomes required.

Historically disabled children were likely to have poorer outcomes compared with their peers including lower educational attainment, poorer access to health services resulting in poorer health outcomes, more difficult transitions to adulthood, and poorer employment outcomes. Also, families with a disabled child are more likely to have one or both parents out of work, and to suffer family break up. Siblings of disabled children may also be more likely to suffer from emotional and behavioural problems.

Hopefully the greater collaboration between agencies, and the more detailed planning of co-ordinated responses to need will dramatically change the future expectations for young people with a disability.

What are the needs of the population?

It is challenging to assess the total need of the population of disabled children, as the degree and type of disability can lead to a range of different professional and service responses. More recently service responses are hopefully based on an agreed eligibility criteria and a set of publicised service thresholds.(5)

The key measures of need are:

- The number of children receiving a Social Work service from the Disabled Children's Team – this will generally be children with more complex needs, in crisis situations or where there are multiple challenges affecting their family.
Current children with an allocated Social Worker number 120.
- The number of children known to the Disabled Children's Team receiving support from Family Support Workers, Occupational Therapists or others ie Day Care Co-ordinators, Volunteer/Buddy Co-Ordinator, via Playschemes, After School Clubs etc to support their independence.

These will generally be children with longer-term needs who will receive continued support and monitoring throughout their lives. The numbers fluctuate but currently numbers are:

- FSW's: 60 active family support scenarios
- Occupational Therapists: 90 "active" cases; 50 "equipment reviews"; 20 "waiting list"
- Others: 650 on database of involvement re playschemes, after school clubs, Saturday Club, Transitions Group, etc.
- The number of children with a disability who are subject to child protection plans – given the additional stresses experienced by families of disabled children, this identifies those families in crisis, needing the most urgent support to safeguard the wellbeing of children.

Currently the Disabled Children's Team support 7 children on Child Protection Plans.

- The number of children who are "looked after" in placements via the Disabled Children's Team. Currently 3 children are LAC.

- The number of children with a Statement of Special Educational Needs or Education Health and Care Plan. These will often be children with challenges affecting their emotional wellbeing, mental health or with learning disabilities. These children will general be supported to attend an appropriate school, and will have clear plans for their independence and development.

Currently the numbers are as follows:

Students with an Education Health and Social Care Plan = 130

Students with a Statement of Educational Needs = 485

Total: 615

- The number of Early years children with Special Educational Needs / Disability who receive “Top-up Funding” which started from 01.04.2014.

The below table shows – column 2 - the number of New applications that were submitted to the funding panel, and this figure includes the refused applications. Some refused applications are re-submitted at a later date. The third column shows the number of Top-up funding applications awarded Top-up funding.

| Academic year | Total no of New applications (incl. Refused applications) | No of TUF applications awarded TUF |
|---------------|---|------------------------------------|
| 2013/14 | 111 | 109 |
| 2014/15 | 79 | 76 |
| 2015/16 * | 70 | 67 |
| | 260 | 252 |

- The number of children known to the Lifetime Care service – these are children with life-limiting conditions who require intensive medical support to remain at home. Currently there are 45 children known to Lifetime in North Somerset who are life limited/life threatened (including 3 with care packages) and 10 who have an acute nursing need
- MAISEY (Multi-Agency Information and Support in Early Years)

Monthly MAISEY Meetings ensure that the many services available to children with additional needs consider the services and provision as a whole and are co-ordinated around individual needs.

MAISEY Meetings exist to monitor that Plans are in place and working, and any actions from this professional's meeting will be discussed with parents by the most appropriate professional.

MAISEY will identify extra help needed for individual children, and who will take this forward, by making appropriate referrals, or arranging for training of parents / carers and child care Providers.

MAISEY will update discussion on the services available, and will address planning of provision from early identification of need until school entry, ensuring that transfer to pre-school and school is as successful as possible.

Children will only be discussed at MAISEY if parents have given written consent.

Currently 156 Children from North Somerset with complex needs are discussed at MAISEY. Of these there are 61 children (22 in north and 39 in south) who have level 1 or 2 top up funding and are likely to require social care input in the future. Also, of these 156 children there are 19 children (8 in north and 11 in south) who have severe and complex needs, including PMLD and ASC with severe and challenging behaviour.

At any point, a child known to our services may be present in a number of these groups, or may move between them as their family situation changes, their expectations of independence change, or their condition alters. This makes whole-system planning a genuine challenge to all partner organisations.

Current services, strategies and the community voice:

Needs are assessed and services commissioned by the Disabled Children's Team, with support from Schools, Health Visitors, Springboard and others in undertaking Early Help Assessments:

North Somerset Council Disabled Children's Team

How to contact us

- The Firs Resource Centre 01934 427615
- St. Barnabas 01275 884101

Who are we?

We are a multi-disciplinary workforce consisting of social workers, occupational therapists, family support workers, day care co-ordinators, and volunteer co-ordinators; play leader and play workers and “buddies”.

What do we do?

- We deliver support services to children with a range of additional needs and their families within the home and community settings.
- We work with children and young people to ensure we meet their identified needs as early as possible
- We aim to ensure children are effectively safeguarded, promote their health and wellbeing, to access learning and fun activities.
- Children’s views and voices are at the heart of all we do.
- We support families to provide the best possible care for their children.

How do we do this?

Staff are trained and competent to deliver and support a wide range of activities which include:

Day Care co-ordinators organise and run short break activities e.g.

- Summer and winter play schemes
- Weekend activities
- Day trips to locations chosen by children and young people.

Volunteer Co-ordinator

- Recruit, train & support volunteers and buddies who support young people to access social and leisure activities in the community.

(Services delivered by Day Care are inspected by OFSTED)

DCT Family Support Workers

- Deliver support services to children with complex additional needs and their families within the home and community settings.
- During holiday times run Family Fun afternoons at Kingston Seymour Specialist Playground or Kingston Seymour Village Hall during October and February half term.
- Provide family support services during school holidays to children and young people assessed as having the highest level of need.

- Deliver parenting courses during term times.
- Undertake Early Help Assessments

(The Family Support Team are inspected by the Care Quality Commission)

Who do we work with?

The Team works with:

- Family Information Service to provide a wide range of information to families
- Voluntary sector e.g. North Somerset Mencap; Scouting organisation, Portishead Churches, Lions and Rotary Clubs, Springboard
- Schools and colleges
- Community Paediatricians
- Physiotherapists
- Specialist nurses
- Specialist education officers

How do you access a service from the team?

Family Support Worker: this service requires an assessment via a early help or single assessment.

Family Fun: open access to all members of the family.

Play schemes: open access: contact day care co-ordinators.

Buddy Scheme: this service requires an assessment via statement of educational needs, health or social care assessment or Early Help.

Saturday Club, Transitional Saturday Club @ The Firs: open access on a booking system via the Firs Resource Centre.

Saturday Drop in @ St. Barnabas: open access

After School Clubs: open access

Information via: The Firs Resource Centre or St. Barnabas.

DCT Occupational Therapy Service

The DCT Occupational Therapy Service aims to help disabled children and their families to live safely and independently in their own homes.

Who are we?

We are experienced Children's Occupational Therapists (OTs) employed by NSC and registered with the HCPC. We work with children with complex needs from 0-18 years old at home, in their educational and short break settings.

What do we do?

- promote functional independence skills in daily living tasks eg: bathing, toileting, eating
- Promote access to essential facilities in the family home eg: access to bedroom and bathroom
- Promote a safe environment in the family home eg: safe moving and handling techniques

How do we do this?

After an assessment of your child's needs, the OT will agree an action plan with you and your child. This may include:

- Advice and guidance eg: alternative methods of managing daily living tasks
- Provision of equipment eg: a supportive seating system to enable hand function, a mobile hoist and slings for safe manual handling
- Provision of minor adaptations eg: grab handles in the bathroom to help get in/out of the bath safely and independently
- Provision of major adaptations via a Disabled Facilities Grant (DFG) eg: building a level access shower room in the family home

Who do we liaise with to help you and your child?

- other Social Care professionals eg: social workers, family support workers
- Health professionals eg: doctors, physiotherapists, child health OTs, speech and language therapists, specialist nurses
- Education eg: special and mainstream schools and pre-schools/nurseries,
- Vulnerable Learners Service
- Housing eg: Housing Adaptations Team, Home Choice, Care and Repair, Architects
- Voluntary Sector eg: Springboard Nursery, Charlton Farm Children's Hospice

- Equipment providers

DCT Social Workers

Social Workers work with most complex disabled children and young people and their families

- They work closely with the child, parents/carers to undertake an assessment to identify your child's needs
- Work in partnership with health, education and other professionals who share responsibility to meet your child's needs
- Social workers follow statutory child in need processes
- We will talk to you about your child's needs and whether they are eligible for services including short breaks.
- Direct payments and personal budgets offer parents and young people choice over the type of service which best meets their needs.

Offering Support to a wide range of children and families: Case Study - Summer Playscheme 2015:

During the summer of 2015 the Day Care Development Team provided a Summer Playscheme for 5 weeks, Monday, Tuesday, Thursday and Friday running from 09:30 to 16:30 with the option of wrap around 08:00 to 09:30 and 16:30 to 18:00. On 3 Wednesday's Transitions trips were provided to young people in Year 9 and above, to Weymouth, Drayton Manor, and the Forest of Dean.

A total of **81** children and young people were supported at Playscheme, Transitions trips, and at community based playschemes.

The Team, including 53 peer aged playworkers, volunteers and "buddies", were able to provide flexible provision to the majority of these children; this included changes of dates, additional dates and longer sessions.

As recorded on the parental consent form, the Team catered for children identified with the following:

- Challenging behaviour – 53
- Personal care needs – 44
- Physical disability – 29
- Speech and Language/communication difficulties – 54
- Mental health – 9

According to the parental consent forms, children and young people supported had the following diagnoses:

| | | | |
|------------------------|----|--|----|
| Anglemans Syndrome | 1 | Anhydrosis | 1 |
| Asthma | 1 | Attachment disorder | 2 |
| Autism | 38 | Bilateral Tranchrectasis | 1 |
| Cerebral palsy | 6 | Chromosome deletion | 4 |
| Cleft pallet | 1 | Coeliac | 1 |
| Diabetes | 1 | Down Syndrome | 11 |
| Dravets Syndrome | 1 | Dyslexia | 2 |
| Dyspraxia | 2 | Epilepsy | 18 |
| Fragile x Syndromes | 2 | Front Temporal lobe cortical Dysplasia | 1 |
| Gastrostomy | 1 | GDD | 13 |
| Heart condition | 3 | Heart Disease | 1 |
| Hole in the heart | 1 | Hyper mobility | 1 |
| Hypoxemia | 1 | Immunity problems | 1 |
| Lardosis | 1 | Lower muscle tone | 1 |
| Migraines | 1 | Pathological Demand Avoidance | 2 |
| Pace maker | 1 | Picka | 1 |
| Prada-Willi Syndrome | 1 | Retts Syndrome | 2 |
| Scoliosis of the spine | 2 | Sensory Processing Disorder | 3 |
| Severe Allergies | 1 | | |

Other service provisions:

- During every school holiday period the Day Care Co-ordinators, and Volunteer Co-ordinator organise a variety of community based activities for disabled children and young people.
- Additionally throughout the year a variety of Clubs and events are held, including Saturday Club, Wicked Wednesday, and the “Team We Can Club” at the Campus Community Centre.
- After School clubs are held at Nailsea and Clevedon on a Tuesday. A Saturday “Drop-in” is also held monthly at St Barnabas Community Centre at Portishead.

Parent’s views:

Consultation with parents some time ago, as part of the Aiming High initiative(i), identified their priorities as more breaks in school holidays, evenings and

weekends, and overnight; more breaks supported by buddies; and breaks provided by activities open to all children.

Co-production and Engagement

Following a partnership approach to the Aiming Higher initiatives, the Council has continued to engage with children with disabilities, their families and the groups that represent them. This has been evidenced particularly in our response to the Children and Families Act 2014 and our work to redesign and procure short break services.

We work closely with groups representing children and young people with disabilities, including both Supportive Parents and Our Voice Counts. Both organisations are included in the Programme Board which is managing our response to changes in the SEND system, and we have formed a number of Parent Reference Groups to oversee specific strands of work including EHCPs, the Local Offer and Short Breaks. In return, senior officers have attended open meetings of representative groups to answer questions and engage with a broader group of parents.

We have also worked to ensure that children and young people's voices are heard in this process of change, commissioning Playworks UK to deliver high quality engagement with children and young people via their school or day care settings.

More recently a Young Persons Reference Group has been proposed, and the first Meeting of the Group is scheduled for Tuesday 28th June 2016, with young people with a variety of abilities to communicate their views are being supported to attend.

High Risk Groups

A group of young people who have historically missed out on services are those young people with Asperger's Syndrome. Young people with this condition can have very high levels of anxiety and often need the involvement of Child and Adolescent Mental Health Services. They can also present with challenging behaviour within the family home particularly during their teenage years. This can result in deterioration in the health of the parent both physical and mental particularly if their child's needs are unable to be met in the community and the full responsibility for the care of the child falls on them.

Young people with long-term physical disabilities are an often overlooked group who rely on their families for much of their support, with few services specifically targeted to reach them. This is particularly true as they transition to adulthood when support around preparation for independence and potential employment is not consistently available.

Young people with single or multiple sensory impairment, either alone or as part of a wider range of challenges are not able to access specific services to support this aspect of their life with a disability.

Future Needs

There is a need to maintain good quality local community services to prevent breakdown in family, with the inherent stress for all involved, and to minimise the need for complex residential provisions.

Challenges for consideration

There is an urgent need for data sharing on the numbers of children who are now surviving as a result of advances in medical care. This information is needed to inform medium and long term financial planning and service developments. These children are likely to have long term health and social care needs and require adaptations to family homes, hoists, wheelchairs and other specialist equipment. In order to meet their social care needs data needs to inform the requirements for children to receive short break overnight care and other long term residential care which impacts on adult services. In addition there is a need for a skilled workforce to work with the children in the community and this will include foster carers and other support workers.

There is a need for data to be made available on the number of children who are excluded from out of school activities because of their personal and medical health care needs.

We need to ensure that our processes where children transition to adulthood are designed to be effective and to facilitate advance planning of future support needs.

There is also a need for specific data to be available centrally to identify the numbers of children in North Somerset with specific conditions e.g. how many children have epilepsy, Downs Syndrome, Cerebral Palsy, and single and multiple sensory impairment.

What will work?

On the basis of evidence gathered from co-production and research into work undertaken by other Local Authorities, we are currently working to review our assessment processes at present to ensure they:

- Link with the early help agenda, ensuring access to preventive support wherever it is needed.

- Recognise the strengths and support networks families already have, seeking to preserve and protect them.
- Link to a resource allocation system which helps parents to decide whether they would prefer to receive support via a Direct Payment, or a Personal Budget.
- Signpost families to our Local Offer to facilitate them accessing peer support, local groups and a wider range of opportunities outside the statutory sector.

This will allow us to better respond to needs on an individual level, and also to begin to understand the broader picture of need across the population more readily, and to provide a range of responses based on the immediate level of need.

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References

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2. HM Government (2014) *Children and Families Act 2014*
(<http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>)
3. Dept. for Education (2015) *Special Educational Needs and Disability Code of Practice: 0-25 years* (<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>)
4. North Somerset Online Directory: Local Offer (<http://nsod.n-somerset.gov.uk>)
5. North Somerset's Safeguarding Children Board (2015) *Threshold Criteria for Children in Need and Child Protection Referrals to Children's Social Care*
(<http://www.northsomersetlscb.org.uk/uploads/files/750.pdf>)