

Services and Resources for Children and Young People with Special Educational Needs and Disability (Local Offer)

Consultation Report November 2013

Executive Summary

Reading Borough Council is required by the Children and families Bill to implement reforms for children and young people with Special Educational Needs and Disabilities (SEND) and their families. One aspect of the reforms is the duty for Local Authorities to publish a Local Offer of all Education, Health and Social services available to families in their area. This local offer must be used to review and develop services to improve the lives of children, young people and their families.

National guidance on how to develop the code requires authorities to consult widely. This report covers one aspect of this consultation; a survey, mostly of parents on their thoughts on what should be included in Reading's Local offer and how it should be published.

This report, prepared from 71 responses, is divided into three sections:

- Section 1 Information to include in the Local Offer and how it should be presented and accessed.
- Section 2 Lists of services to include in the local offer from respondents experiences
- Section 3 Gaps in provision identified by the respondents

Each of these sections covers a wide range of education, health and social care service across public, voluntary and private sectors and covers all stages of a child's and families development and experiences from birth to age 25.

In addition, specific detailed feedback (compliments and complaints) has been collated and forwarded to managers of the relevant services.

Background

The Department of Education (DfEE) is working on transforming the lives of children and young people with Special Educational Needs and Disabilities (SEND) through reform of the processes of assessing, planning and joint commissioning services across Education, Health and Social Care. The changes are detailed in a revised Draft SEN Code of Practice and are being introduced

through legislation within the Children and Families Bill, due to become law in September 2014.

As part of these reforms the Draft SEN Code of Practice Oct 2013 states:

- “Local authorities must publish a local offer, setting out in one place information about provision they expect to be available for children and young people in their area who have SEN, including those who do not have EHC plans.
- The local offer has two key purposes:
 - To provide clear, comprehensive and accessible information about the provision available; and
 - To make provision more responsive to local needs and aspirations by directly involving children and young people with SEN, parents and carers, and service providers in its development and review.”

The reforms apply to all children and young people aged 0-25 which brings together services for adults and children and applies across education, health and social services, including voluntary sector and private services. The need for holistic of working with families and the creation of a Single Education, Health and Care Plan is a new culture for educational establishments, health services and local authorities. Each will need to publish what they offer, who is eligible for their service and how it can be accessed. The national guidance on the Local Offer in the Draft Code requires local authorities to consult with a wide range of stakeholders including parents, carers, children, young people, organisations providing services and those who work closely with families.

Early in 2013 the four Berkshire Authorities working together through the Raising Participation Partnership: Reading, Wokingham, West Berks and Slough, decided to work jointly on this project. This consultation is based on a set of questions developed by Slough through the joint group. This “Pan-Berks Local offer Group” group includes parent and voluntary sector representation to ensure the resulting Local Offers for each authority are co-produced.

This set of responses will be used to develop Reading’s Local Offer. Initially this will be a directory of services accessed through web pages of information and advice. Once the website is populated (we are aiming for May 2014) there will be further consultation on the content and layout/pathways of information prior to the law coming into place in September 2014. This website will be the “one stop shop” for information, regularly updated and expanded as services develop. The intention is for all professional, parents, organisations and those

coming into regular contact with SEN families to know about and use this resource when advising parents or looking for services to work with around the children and young people that they support.

What we consulted on

The questionnaire asked for each stage of a child's development:

- What services were accessed?
- What services the respondent would like to have had available?
- What information might have been useful?

The life stages/milestones asked about were:

- Birth
- Early Years and Childcare
- Starting School
- School Years
- Diagnosis or when you felt your child needed extra support
- Leaving School and Post 16 options
- Becoming an Adult

The same questions were asked about Caring and Short Breaks:

- Support for my child at home
- Respite for me
- Leisure Activities for my Child
- Support, Advice and Information for me

There were supplementary questions about information range and accessibility

- What other information would you like in the Local Offer?
Education, Health, Social Care, Housing, Employment, Benefits and Other.
- How would you like to access information in the Local Offer?
- How information can best be made available for those with communication difficulties?
- How you would like to give feedback on the Local Offer?

How we consulted

The consultation period was between July and October 2013.

Hard copy questionnaires were posted to the home addresses of 933 children aged 0-17 who have a Statement of SEN or were known to the RBC Children's LDD Social Care team. A further 111 questionnaires were posted to 18-25 year olds known to the Adult Learning Disabilities Social Care team.

The questionnaire was available on-line on the RBC website. This was publicised by the Disability Information Service (DISC), notably with direct emails to 580 parents, carers and some professionals on the DISC mailing list and also promoted via DISC newsletter and in other promotional emails.

Who responded

There were 71 responses.

90% described themselves as Parents, 7% as carers, 7% as professional or volunteer. Some recorded themselves in more than one category.
78% female and 22% male.

73% were aged 25-49 and 20% aged 50-69. The 6% who answered "under 18" were probably misled by the confusing layout of the question.

Ethnicity:

- White British 66%
- Black, Black British, Mixed Black 16%
- Asian, Asian British, Mixed Asian 9%
- White other 9%

What Information would you like included in the Local Offer?

This section advises us on the information pages of the Local Offer website

Early Years

- More information with suspected autism. Would have liked pre- school staff to have been more up front so that diagnosis could have been made earlier.
- Information on charities and support groups so that we didn't feel so alone
- Information on child care funding
- Early intervention panel
- More about prognosis and what the future might hold.

Education

- List of resourced schools.
- List of wheelchair accessible schools
- SEN rights
- What happens to a statemented child on leaving school, what opportunities are there.
- What happens special school
- What my child can do to progress to be independent
- SEN rights under the code of practice
- Courses for carers.
- More understanding on all aspects ie statements and annual reviews
- Rights of the child.
- Support for child and family when excluded
- What therapies local schools offer, and who to contact if you think you need additional support.
- Further education information after 6th form.
- Recourse when not happy/have a query when school is an academy.
- Is the local offer applicable to LAC children living outside Reading LA
- Highlighting support for SEN children and relevant ofsted inspection comments.
- The views of other parents of children with SEN about the school.
- How to apply for a placement into a special school
- How school intended to meet my child's different needs and keep him safe.

- What the Senco's role is.
- A list of schools that offer exceptional ways of inclusion or some sort of rating of schools
- More help with annual reviews at the beginning.

Health

- Contact points for specific facilities offered by the NHS, eg wheelchair service and Hydrotherapy.
- Up to date news on Autism (research, cure, things that help), what can help autism, diet, news, medicines, what to try next.
- Childhood epilepsy and apnoea attacks.
- Diagnostic pathways information about how special needs are met at the RBH dentist
- How to access services such as: wheelchair, incontinence support, respite, and orthotics.
- SLT OT. Also when referral pathways changed.
- List of disability friendly dentists and doctors
- Typical waiting times for speech and language, OT and Camhs
- At birth did not have any information on what to look out for regarding development ie if not developing accordingly eg behaviour, movement, and speech delays.
- Support for older mums who are treated like they are supposed to know everything.
- A flow chart outlining the main routes that a young child might follow in terms of health checks, developmental milestones and educational progress.
- Visual timetable offered to me for my child given by doctors or paediatricians.
- Earlier diagnosis may have been useful to know how to handle behaviour.
- Practical information to supplement physiotherapy services, eg dealing with splints and other aids.
- Information on epilepsy
- Single leaflet on support available (Autism)
- Advice on physical potty training
- What an audiogram is? Information on aids to help listen to the television with the rest of the family.

Social Care

- Clear statement of what's offered, and what people might expect to receive (at least minimum and maximum or how you qualify). Some realistic contact details or further information not just contact LDD.
- Decision making must be transparent.
- Finances for education and health
- Clear referral process
- Realistic timescale about how long referrals take eg to receipt of direct payments and employing someone.
- RBC structure for support (organogram)

Housing

- What are the options for us as a family on a low income.
- What are the options for our kids if they have a desire to be independent.
- If I can get help with getting a bigger home or extra toilet.
- Disabled bedroom news.
- How to fill in a housing form.
- Independent living, disability facilities grant.

Employment

- Support for carers who have problems working due to caring responsibilities eg flexible working.
- Information about positions that are flexible for carers around the kids.
- Employment options for disabled young people.
- Childcare in the school holidays
- Who to go to, to help find work eg DEA, Grants and apprenticeships
- Information on flexible working.
- What support can be given to keep you in your job.
- Support when applying for jobs.

Benefits

- What you are entitled to.
- How to access the family fund
- What benefits are young disabled entitled to.
- Financial support for childcare.
- Help with rent and council tax.
- Child benefit and disability money.
- Financial support for holiday activities and afterschool clubs
- Clear transparent information as to who qualifies and who to contact.
- Will the main carer have to give up work when the child leaves school?
Will my son receive benefits to pay me to look after him.

Becoming an adult

- What's available for young adults when they go into adult services - support from care manager/broker

Accessing Information

This section advises us how to publish and make available the Local Offer

How would you like to access information on the Local Offer?

Website 78%

Hard Copy 31%

Helpline 16%

Other 2% (Home visits, newsletter by post, face to face)

How should the information be made available for those with communication difficulties?

Most were replying as parents/carers and said that they would communicate to their child/young person. Some would like to use pictures on the site as an aid. Some want a key worker or drop in centre where they can discuss face to face. This was mentioned by those who use Makaton or need an interpreter.

Suggestions on information access and presentation

- Internet to look up schools in the area
- One stop info point re what is available for me and my child
- A full list of all services available with contact details
- An organogram showing Reading Council services.
- Someone available to talk to face to face about services available
- Information put up at local leisure centres where SEN is available.
- Advice and clear information on how to navigate through the social care and education maze.
- When arranging meetings eg direct payments information, don't assume parents/carers don't go to work.
- Information on entitlements at point of diagnoses
- A flow chart or some clear guidance document about routes to securing a statement.
- A pack/email which can be applied in the first instance and then email updates that keep information updated.
- Cut down on colours and graphics.
- Information should be available in different Asian languages.
- Helpline to talk to people in Asian languages.
- Face to face
- Via schools and Health Visitors.
- Pictures online for my daughter to accompany detailed text for me.

- By appointment for an interview with a knowledgeable key worker who be a consistent link during the child's formative years and until they leave school.
- PECS
- Makaton

How would you like to give feedback on the Local Offer?

Via: Website 62%
Hard copy questionnaire 36%
Meetings 15%
Phone call 13%
Other 4%



Lists of Services to include in Local Offer:

This section compiled from the question "Services I have accessed" acts as a check list for compiling the Local Offer directory

Education and Learning

Portage
Pre-school support teaching
Brookfields and The Avenue
Addington
Manor primary school
Lambs lane resource unit
Teachers
SENCO
EP Collier resource unit
School admissions service
ASD advisory teacher
West Berkshire Autism Resource at Theale Green
School parent coffee mornings
Chess home learning
Kumon courses
Blessed Hugh Farringdon resource unit
Berkshire college of agriculture

Childcare/EYFS

Dingley playgroup
Mencap
Newbridge Nursery - Snowflakes
Childminder (special needs)
Mainstream nurseries
One to one nursery support funding
Language development playgroup in Henley

Education Support Services

OT
Speech and Language Therapy
Portage
Educational psychologist
Parent Partnership
Massage therapy
Outreach teacher (Brookfields ??)
Adviza / connexions
Behavioural support team
Teacher of the deaf



Brookfields school advisory service
School nurse

Health

Paediatrician
Dingley (RBH)
Physiotherapy
Midwife
Health Visitor
Baby Clinics
Breast Feeding clinic
OT
Speech and Language Therapy
Socom - Dingley (Chasac)
Neurologist JR Hosp
Camhs
Audiology
Tass counsellor Camhs
Orthotics
Wheelchair clinic
Hydrotherapy
Hospital social worker
Chiropractor
Osteopathic children's centre London
Brainwave centre Bridgewater
Child psychology and child psychiatry
GP's
ENT clinic at RBH
Psychotherapy
Dietician
Cognitive Psychologist at JR
Dolphin ward
Language development clinic
Genetics at Churchill hospital,
Great Ormond Street hospital
Cramal facial at the JR
Talking Therapies
Mental health provision for older primary and younger secondary age pupils

Family Support

New parent group CC
LDD/social care team
Respite
OT
Peapods
Disc newsletter



Parenting special children (courses)
Time out for special needs course
Diagnosis support service (parenting special needs)
Webster Stratton course
Mencap Bubble club
West Berks Downs Syndrome Group
Epilepsy Action telephone advice line
BAS
Social worker
Family Link
Solicitor
Adoption
PACT adoption support
Children's centres
Home Start
Housing
DLA/Benefits
Baby massage
Young Carers
Outreach team
ACRE Family Outreach service
Greenslade home sitting
ASD coffee morning at Katesgrove
School parent coffee mornings
National deaf children's society
Cerebra
Crossroads
Cressingham
Reading Families Forum
Family Therapy
Parenting courses (incredible years) for those with ADHD kids
Positive parenting course
Family worker
Berkshire carers
Carers UK
NAS
Link up
Glut1 DS Yahoo group - to communicate with other parents with similar diagnosis
Scope
Unique - chromosomal disorder charity
Early Bird autism course
National deaf children's society (residential course at Mary Hare)
OT suppliers (Breezy chair)
Teen triple p course
Hope solutions
Family Intervention project
Personal assistant
Direct payments
Mencap
Contact a family
FIS

Leisure and Recreation

TVAP

Disc newsletter

Thumbs up club

Special needs swim Rivermead

Blagdon road nursery holiday club

Rhyme time at various libraries

RAFT

Brookfields afterschool holiday club

Friday club - Rivermead

Disability Challengers

After school clubs

Prospect park football

Meadway leisure centre, football and swimming

Tree house after school club

BAS Trampolining club

BAS Swimming at Rivermead

Krazy Playdays

Smiles

Mencap Clubs

Marshlands Square holiday club

Disabled friendly playgrounds

Camp Mohawk

Passport to Leisure

Places eg Legoland with special arrangements for autistic and special needs children.

Swimming at Loddon Valley

CATSYPP

Sensory rooms - academy sport

University sports park holiday clubs

Accessible cycling

Youth clubs

Wyfold RDA

Oxford family support for children with heart defects

Becoming an adult

Connexions

Year 12 specialist unit

Transition plan

Reading college, skills for living course

Reading University disability service

Socom specialist unit for ASD

Support worker and respite care

Camhs

Earley Day café - Crescent resource centre

Readibus

Transport

Brookfields school transport provided by RBC
Readibus



Gaps in provision

This section, taken from the question "Services that I would have liked to access but were not available" has been divided into:

Perceived Gaps where a service does exist in Reading at the moment but the responder may not be aware of it or their child may not be eligible.

Real Gaps are where we think there is no such service in Reading at the moment. If the service does exist please contact Gill Seagrove to include it in the Local Offer gill.seagrove@reading.gov.uk

Education and Learning

Perceived gaps

- Organised play centres that integrate play with child development professionals (SALT's, Health Visitors)
- Professional advice, not only teacher feedback
- I would like them to be in boarding school but can't afford it
- Class specific to autism
- Pre-school support teacher
- After school club - wrap around care
- Special ASD School
- Swimming lessons for disabled children
- List of resourced schools.
- Help to transition from nursery to school. I had to deal with this myself and completely re-organise childcare arrangements and give up work to make this work.
- A group for special pre-school children that runs once a week and focused on speech and language via games and music.

Real gaps

- Paediatrician and Neurologist should be able to trigger an assessment for a statement
- Realistic appraisal of what I would actually be able to receive
- List of wheelchair accessible schools
- Social skills training for children
- More support and understanding rather than keep excluding my son from school (LR 24)
- Would like my little girl to be in a school where teachers like her and accept her with her condition

- Someone to call when child was excluded frequently. Financial support as lost income when child was excluded from school.

Childcare & Early Years

Perceived gaps

- Organised play centres that integrate play with child development professionals (SALT's, Health Visitors)
- After School Club
- Holiday club
- ASD course
- ASD advisory worker to signpost me and to talk to
- Help with behaviour strategies
- Play groups for children with ASD
- Information on how to access funded childcare
- An SEN playgroup with a high level staff and understanding parents
- Childcare provision for children with behaviour difficulties
- More childcare options for parents of disabled child
- Support for nursery in SEN and physical disabilities (including financial help and statement)

Real gaps

- Connections between health visitor and pre-school.
- Adults at Nursery better trained with SEN childcare
- Parents of SEN children working in a nursery to help spot traits early and understand parents rather than judge

Education Support Services

Perceived gaps

- A support group with in the school setting for SEN parents eg coffee morning
- Occupational therapy (not massive report full of suggestions)

Real gaps

- Peto style treatment
- More speech therapy and OT available in school so teachers understand why the child has difficulty and not that they are naughty or stupid.
- Regular visits from visually impaired support team (early years)
- Social skills group, so my son did not have to endure the severe and persistent bullying

- Specialists going into school to explain how diagnosis affects learning and behaviour and how OT would benefit whole child and class
- Services without ridiculous waiting times
- More advice on coping with challenging behaviour at home
- SLT course of therapy and training for staff
- Cognitive Therapy to help with ongoing issues and inflexible thinking.

Health

Perceived gaps

- Breast Feeding Clinic
- Sleep clinic
- Speech Therapy
- First Aid Training to know how to respond to seizures
- Wheelchairs and McLaren buggies with buggy board for the younger sibling
- Targeted OT support, not what just happens to be in store
- Help with eating difficulties and disorders
- Speech & Language without waiting for six months for the first appointment
- Advice post diagnosis with ASD
- Sympathetic GP

Real gaps

- Paediatrician instead of GP within 1st year of life - more chances of early diagnosis
- VUR runs in the family so would have like proper ante-natal kidney scan
- Annual review with paediatrician for Autistic children.
- SoComm more resource
- Knowledge about sickle cell.
- Paediatric epilepsy nurse. Would have been great to have the reassurance of a phone call or a visit from a nurse.
- NHS speech therapy - more resource
- Equipment for the home 'OT seems unable to order new equipment due to budget concerns.
- More Physiotherapy at RBH including Hydrotherapy
- Camhs cognitive behavioural therapy approach
- Peer support groups for birth trauma counselling.

- Ongoing regular assessment with paediatrician after age 5. Diagnosis on statement made 8 years ago, this is all council consider when making decisions.
- Re-assessment at regular intervals to see if any other conditions reveal themselves eg ADHD and Hypertonia.

Family Support

Perceived gaps

- RAFT
- Any courses or study to be able to assess my child
- Organised play centres that integrate play with child development professionals (SALT's, Health Visitors)
- Resource of other parents/details of similar problems. Ways of getting into contact with other parents of disabled children especially for working parents. Support at home after birth
- Emotional support after birth
- Reading Mencap clubs
- Family Support
- More information from Reading Borough Council
- A group for special pre-school children that runs once a week and focused on speech and language via games and music.
- Peer support
- Support for adoptive parents
- Counselling support for family/parents
- More holiday clubs, play clubs and after school provision for children with SEN.
- Respite night sitter occasionally.
- More parent groups closer to home.
- Peer support for parents of children with mild disabilities.
- Help with all form filling and explanations what it all means
- General information about what is available to make life easier ie concessions etc
- Time for sibling
- Emotional support
- More respite during holidays and weekends to make it possible for me to attend family celebrations and festivals.
- Sibling support.
- Information for wider family members.
- Someone to help you research or take time to sit and talk to you and listen for once.

- Personal assistant able to deal with personal care and medical needs at home and in the community.
- Babysitters trained to deal with special children.
- Support group for Tourette's Syndrome
- Help with adjusting the home and daily life
- Supportive toilet seat
- Safety assessment of the home. Adaptions that could be made eg: windows, cords, kitchen etc
- One to one help at home
- Home sitting that can give medication
- Advice on implementing routines in a way accessible to my child eg: picture prompts.

Real gaps

- Realistic appraisal of what I would actually be able to receive
- Child development courses
- Single point of contact for when our childminder, scout leaders and others all raised concerns over our son's behaviour.
- Peto style support; Lycra suit trial music therapy
- An option to not use direct payments and have Reading council organise the accounts and recruitment.
- We could have liked a council employed carer to help us with our son and for it to be the same person rather than an agency who would send any old body off the sheet (street?)
- Supporting siblings, parent groups, building links with local shops, café's etc to promote use of these services without feeling embarrassed.
- Securing the home and garden. fences and corners of house secured, so child can wander outside
- Early Bird courses
- Help with finding out what benefits you are entitled to ie social worker. What is a reasonable expectation, how to get things, how long will it take?
- A leaflet describing support available including, government grants, carers allowance, DLA
- Discussing services / advice received with an independent party - in order to assess whether info given was accurate / good / info omitted.
- Carers fund which doesn't allow for parent/carers of children under 18.
- Someone to help from the beginning with paperwork and stand on board with you.
- More respite, after school service and holiday club, parent groups etc, closer to home, low charge. (Whitley Wood)

- I would be good if there were some way without breaking any data protection laws of getting into informal contact with parents who have children with similar difficulties, through the pre-school support teacher.
- Key worker joint worker of professionals so appointments do not clash
- Description of all the options available. How many places, when and who to contact.

Leisure and Recreation

Perceived gaps

- Activities for mildly disabled children
- Very little social support for older teenagers
- Safe/SEN play areas
- Inclusion at local social clubs and venues ie short breaks
- Scope support short breaks for complex needs, evenings and /or weekends
- Anything for complex needs.
- Ability to choose times and dates for respite care
- riding for disabled.
- After school activities that cater for SN children of mainstream ability.

Real gaps

- Mainstream groups where staff are trained in autism
- Boccia,
- Buddying scheme
- Help to take out socially eg personal assistant or Me2 type service for complex needs
- Services without ridiculous waiting times
- High functioning children, are they eligible for specialist services. Universal services not trained to deal with lack of concentration and safety.

Becoming an adult

Perceived gaps

- Shared housing
- Services that help him become independent
- I'd like to know about staying on at school/college
- Individual support, the right course and working out different funding

- Careers advice and guidance
- Key worker
- Information on training and employment opportunities for SN child.
- Help at college
- Transition from school to college with a support worker.

Real gaps

- Very little social support for older teenagers
- Advice on coping with challenging behaviour
- College transport
- Independent living help/groups
- Work options for someone with a medical condition

Transport

Real gaps

- Transport for short breaks once got older, and transport from after school club
- Dedicated transport for disabled users. Readibus is very stretched and taxi's don't guarantee same drivers
- Transport to sporting activities

Feedback on Services

This section is for relevant managers in each of the categories to respond to as they see fit. It is not intended to include this section in the published consultation report

Early Years

- The nursery educational psychologist (Sue) made to feel my son's behaviour was my fault (a parenting problem)
- I had a pre-school support worker who came to the house and pre-school to help my son play and interact. She was also a vital support for me to act as a sounding board and emotional support. Unfortunately this fell away when he started school.
- Support for my child at home 'did it with the help of pre-school teacher Christine Hissitt'
- There was very little coherence between the different agencies, and even less cross border between Oxfordshire and Reading. Things took time but there were enough people to make up for the jobsworths and the down right liars that I encountered during the process of getting my son a statement. (AM58)

Schools and SEN

- Brookfields school transport provided by RBC - thankyou
- School admissions were most helpful
- A single supportive case worker would have helped, during statementing process
- Parent partnership have been invaluable
- Paediatrician and Neurologist should be able to trigger an assessment for a statement. They told me my daughter would need a high level of support at school, I then had to persuade the head to get the ed psych to assess her and then write in myself formally requesting the statement.
- Manor Primary School is fantastic for children with additional needs, put more money in to it!
- I feel were well served and have nothing but praise for this stage in my son's career (AM 58)
- Daughters TA time was used to support her and another child who did not have a statement. My daughter's behaviour deteriorated significantly



- and she was physically assaulted by this child, leading to me withdrawing her from the school. (RB 9)
- Courses for my son to attend as an alternative to school
 - The large playing field next to Moorlands school could be better utilised for youth activity.
 - Would have liked EP to visit his school and been able to get school to implement recommendations from report. Instead school just said 'oh he's improved we don't need to do anything'.
 - I do not feel that the education offered for children with EBSD of 11 years and older is good enough in the Reading area (SG).
 - Very disappointed with case officer support in last few years - a faceless name on paper. Feel fighting council not being supported. Aren't they there to help? Why don't they attend annual review.
 - Behaviour support team were very judgemental until a diagnosis was sought by myself
 - The school have been great, so was Ann Davies in the SEN dept.
 - Parent Partnership needs boosting.
 - Annual meeting with case officer-1st one we had was great, sadly left after 18 months. Never seen one since (5 years) didn't even have a named case officer for a year. Statement was not amended after one annual review until we had the next one a year later. Really worried about secondary school, no-one to help (RT).

Social Care

- Reading adoption services (no useful outcome) - (SG)
- I have had access to Family Intervention Project who helped me loads
- We accessed the Reading short breaks service. Unfortunately the breaks were so short (2 hrs) but we could not perceive them as time out or respite, but they were useful for our son who got a different adult to play with.
- Have not accessed any respite services for me, because I don't know if there is anything available or if I qualify.
- Resource for PD in Reading social worker who is interested in my child and actually does what he says he will. OT support which is targeted to my child and not just a delivery service for whatever happens to be in the equipment store and may be approximately right (AC)
- When our son left nursery to go to Brookfields I felt the small amount of support we were getting from social services was taken away.
- Service from Cressingham is very intermittent
- More resources, more social workers

- If you have ever tried to get any information out of the LDD team you will know how pointless it is to refer people there for information!!!! (AC)
- Social workers would need to be looked into, never do what they're meant to, never know the answer to a question, never know the full story, even what's going on that has been proven in TAC meetings when the manager had no idea what the situation is. (KC)

Health

- Getting a pre-schooler through the horrible side effects of beginning epilepsy medication (such as repeated fitting, severe lethargy) was very hard. Difficult to get hold of consultant when there were problems. Would have been great to have the reassurance of a phone call or a visit from a nurse.
- SoComm we were referred by the consultant paediatrician but were rejected due to lack of resources. NHS speech therapy - we were referred on 4 separate occasions, always being told we need to wait and see. First referred after 2yr check up as poor speech, eye gaze and poor pincer grip. At 6 years developed a stammer due inability to cope in classroom, chased SLT, only offered therapy after 16 months. Age 12 on transfer to secondary school, diagnosed with an ASC when suffering severe anxiety and depression (anon 42)
- At birth had a good experience with information from RBH.
- Health visitor Jo Webb was brilliant put me on groups and courses with baby.
- These children should be under supervision of specialist, rather than GP's. My GP almost didn't want to help my son.
- Takes a lot of discussions, arguments with doctors to get them to do analysis tests to find and identify problem. Most of the time left one to one with problem, no support just useless talks about nothing. (UA 51)
- Camhs seems to be very under resourced to deal with mental care and related therapies in Reading.

Shortbreak/Leisure

- Meadway disabled swim lessons not well organised
- Disc should be more newsy - their emails are not information
- Better disabled parking at Hexagon, difficult to drive out as limited vision of oncoming traffic.
- More activities for children with mild activities.
- Smaller social activities so the social aspect is less overwhelming.
- More hydrotherapy post 5 years.
- Family on low income with more than one child for family holiday.

Voluntary Sector

- BAS have been my main support and provider of information

