



# **Children with a Disability Register and Network**

Developing our Network - November 2010

*“There are three essential ingredients for successful parent participation:*

- *good information*
- *honest consultation*
- *effective participation”*

***The How to Guide on Parent Participation – Together for Disabled Children  
(March 2010 Version 2.0)***

**The Children with a Disability Network aims to create a support-based environment providing information for, and working in partnership with, the families and carers of children and young people with disabilities.**

The core objectives of the Network are to:

1. Improve access to information for families and carers of children and young people with disabilities
2. Develop a Network for families and carers based on support
3. Work in partnership with families and carers in developing and evaluating services
4. Provide a platform for families and carers to voice their views by way of consultations and a two-way communication strategy
5. Promote opportunities for children and young people with disabilities and their families and carers
6. Encourage family learning
7. Maintain a register of disabled children and provide information to develop consistent and transparent approaches to disabled children’s service provision throughout the local authority

**Through these objectives there will be 4 clear and positive outcomes the Network will achieve:**

- **Improved access to information for parents and carers about support services in the community and wider**
- **Increased family emotional wellbeing through accessing additional support services**
- **The local authority working in partnership with parents/carers in designing and evaluating services**
- **Facilitating a Network for parents/carers that is beneficial**



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## 1. Introduction to the Network

*By law all local authorities must offer to keep details of children and young people with disabilities in their area on a register to help with planning and monitoring services. We are aiming to create something that is much more than just a register; a Network that works for and is driven by parents and carers.*

### ***A growing Network that helps to identify means of support***

Our Children with a Disability Network is developing over the coming months to create a supportive environment by providing information for, and working in partnership with, the families and carers of children and young people with disabilities.

The core aims of the Network are built around sharing useful information on local services, support groups and organisations. Continually growing in local and wider knowledge, the information provided should be both clear and impartial. Families and carers can choose to receive a quarterly newsletter sharing news and information.

There are regular opportunities to talk in person with the Disability Network Coordinator at drop-in and parent forums. Additionally there are frequent opportunities to meet with other families and carers at support groups as well as information events and workshops.

### ***Working in partnership with families***

A strong emphasis is placed on partnership between the Network Coordinator and families and carers in steering the Network. The development of the Network will be a regular feature at the Aiming High Parents Forum and continue to be an ongoing process. Furthermore contacting the Network Coordinator directly is encouraged and your views and opinions are valued.

Providing a platform for families and carers to voice their opinions is also a core objective of the Network. By seeking parents/carers views on new developments or proposed changes, their feedback is fed into service design at various steering and planning groups by way of the Network Coordinator.

### ***Spreading the word***

Promoting opportunities for children and young people with disabilities and their families and carers is also a high priority for the Network. Facilitating learning and training in response to your feedback and needs will be a regular feature. Similarly there is a focus on sharing information on upcoming events and activities for children and young people with disabilities and their families.



A goal for early 2011 is to develop a recognised Network Card initiative that may help increase recognition a child's disability and offer access to local, regional and national schemes.

***Get involved***

Joining the Network is voluntary and free of charge. **All information supplied is held confidentially on a protected database. We will seek permission before sharing any personal information with other professionals.**

***The Network coordinator***

I joined the Social Work Team for Children with Disabilities (SWTCD), which is part of Children's Services, as the Network coordinator in August 2010. My background includes working on both a strategic level and the frontline with disabled children and young people in Hounslow for a number of years; as such their best interests are my overriding priority. Sitting in with but not a part of the SWTCD affords me a favourable position to voice the opinions of the Network across Children's Services.

I look forward to meeting families and hearing their views on how the Network should develop over the coming months.

A handwritten signature in black ink, appearing to read 'S Devlin', with a long horizontal flourish extending to the right.

Steve Devlin  
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## 2. The need for the Network: joining our statutory duties with our goals as a local authority by listening to our customers

*The reasoning is simple: all businesses are looking to achieve the best value for money. People and families are our customers and providing quality services is our business. It makes good sense to combine statutory duty with first-class services, to ensure consultation with the right service users and to achieve the best use of existing resources efficiently.*

### 2.1 Meeting our statutory duties

Like all local authorities in England, The London Borough of Hounslow (**LBH**) has certain duties it is required to fulfil. There are 2 pieces of legislation the Network works toward fulfilling; **The Children's Act 1989** and **The Equality Act 2010**.

#### 2.1.1 Schedule 2 of The Children's Act 1989

2 (1) Every local authority shall open and maintain a register of disabled children within their area.

(2) The register may be kept by means of a computer

The register is an excellent platform from which a genuine information and support Network can develop. The families of the registered children are also perfectly placed to provide evaluation and feedback on services. This extended group of parents and carers can be called upon for consultation and accessed easily.

By developing this Network of families LBH can clearly demonstrate it is working toward the statutory duties as defined in the **Equality Act 2010 Public Sector Duty**.

#### 2.1.2 Extracts of the Equality Act 2010 Public Sector Duty – Section 149, Part 11, Public Sector Duty (Applicable points in *bold-italic*)

(1) A public authority must, in the exercise of its functions, have due regard to the need to-

- (a) Eliminate discrimination, harassment, victimisation and eliminate any other conduct that is prohibited by or under the Act;
- (b) Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;**
- (c) Foster good relations between persons who share a relevant protected characteristic and persons who do not share it;**

(3) Having due regard to the need to advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it involves having due regard, in particular, to the need to-



- a) remove or minimise disadvantages suffered by persons who share a relevant characteristic that are connected to that characteristic;
- b) take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it;
- c) *encourage persons who share a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.***

(5) Having due regard to the need to foster good relations between persons who share a relevant protected characteristic and persons who do not share it involves having due regard, in particular, to the need to:

- a) Tackle prejudice, and
- b) *Promote understanding.***

**Equality Act 2010 (Statutory Duties) Regulations 2011  
Draft Statutory Instrument**

**Better performance duties proposed in Equality Act 2010: The public sector  
Equality duty: Promoting equality through transparency. A consultation.'**

Publication of information

A public authority must publish information relating to its performance of the section 149 (1) duty-

- (a) - not later than 4 April 2011; and
- (b) - subsequently at intervals of not more than one year beginning with the date of publication of the last set of information.

The information shall include, in particular-

(a) – information relating to the protected characteristics of its employees, if the public authority has 150 employees or more;

***(b) - assessments of the impact of its policies and practices, and the likely impact of its proposed policies and practices, on the furtherance of the aims set out in paragraphs (a) to (c) of the section 149 (1) duty;***

***(c)- the information that it took into account when it assessed the impact of its policies and practices, and the likely impact of its proposed policies and practices, on the furtherance of the aims set out in paragraphs (a) to (c) of the section 149 (1) duty; and***

***(d) details of any engagement that it undertook with persons whom it considered to have an interest in furthering the aims set out in paragraphs ( a) to ( c ) of the section 149 duty.***



The **Equality Act 2010** applies to the families of the registered child in 2 ways: firstly by meeting the criteria as defined in section 5 of this report the child is by definition registered disabled with the local authority and is therefore covered under the act. Secondly the family members of the registered child are at risk of discrimination by association; in other words they may be discriminated against because *“The person does not have the protected characteristic but they are treated less favourably than others because of a protected characteristic of a friend, spouse, partner, parent or another person with whom they are associated.”*<sup>1</sup>

The Network works toward meeting the statutory duties as defined above by embedding the needs of families with a disabled child in service design. Later in this section our customers, by way of direct feedback and results from the National Indicator 54 Survey, clearly communicate that they feel they are disproportionately represented and under-consulted in service design as “there is no consistent approach”<sup>2</sup> By encouraging this group of families to participate consultatively the Network promotes inclusion in impact assessments, that their views are equally represented and any engagement is recorded in doing so.

Parents with disabled children have anecdotally reported during conversation and at parents forums that services are designed with accessibility factored-in too late; more often this is also limited to physical accessibility. The needs of families with disabled children extend further where many more factors need to be considered including environment and anxiety levels, transport and travel time, suitability of purpose and other social and economical factors. Section 2.2 of this report highlights Priority 6.4 of the LBH Children and Young People’s Plan which places an emphasis on facilities being accessible to all young people, regardless of barriers. By ensuring that services are designed with the needs of families with a disabled child included, the Network will resultantly promote better access to participation for disabled children.

### **2.1.3 Working within National Framework**

#### **Parenting And Family Support: Guidance For Local Authorities In England – (DCSF March 2010)**

A. The case for supporting parents and families and the challenge for local areas

3. Key principles underpinning parenting and family support

Support for parents and families should:

- See parents as partners – they are the driving force behind design and delivery;
- Be evidence based;
- Focus on improving outcomes for children and families;
- Be matched to rigorously assessed need;
- Be accessed through a variety of routes; including universal services;
- Address issues with parenting, adult-child and adult-adult relationships;



- Look at and address the needs of all the key adults in a child’s life.
- Empower and enable families

The objectives of the Network have a good fit with this piece of national guidance for local authorities. Section 4 of this report outlines how we see our parents as partners and how easier access to information and support, accessed through a variety of routes, focuses on both improved outcomes and empowerment.

<sup>1</sup> Equality Act 2010: What Do I Need To Know? Quick Start Guide To Discrimination By Association And Perception For Voluntary And Community Organisations – Government Equalities Office (2010)

<sup>2</sup> Parental feedback – F. LBH Disability Network Report 2008

## **2.2 Working towards our Children and Young People’s Plan**

The Network has been designed to both work within and contribute toward the goals of the LBH Children and Young People’s Plan. The core objectives of the Network fit into these key priorities by:

- Developing relationships within the community including schools, clinical departments and LBH initiatives to promote access to support and information
- Improved emotional wellbeing through better access to support and supportive organisations
- An emphasis on sharing information including local authority and other organisations, services and support groups
- Developing an effective communication and evaluation strategy for families including consulting the children and young people on the register
- Channelling parental opinion into service design and share across Children’s Services
- Highlighting opportunities for children and young people

### **Hounslow Children and Young People’s Plan Review 2010**

<b>Priority 2: Improving the mental and emotional well-being of children and young people in Hounslow</b>
<i>Key priority for 2010 – 2011: To strengthen identification and early support services for children and young people and families with mental health and emotional issues.</i>
<b>Priority 6: Developing places to go and things to do that children and young people enjoy</b>
<i>6.4: Ensuring activities and facilities are accessible to all young people regardless of any barriers</i>





<b>Priority 7: Engaging and involving children and young people in decision-making and participation within the community</b>
<i>7.2: Improving the participation of children and young people with disabilities and/or learning difficulties and those from hard to reach groups</i>
<i>“A guiding principle of the Aiming High strategy is to promote friendships and new support Networks to develop”</i>
<i>Key priority for 2010 – 2011: Improve the participation of children and young people with disabilities and/or learning difficulties.</i>

## **2.3 What our customers are telling us**

It makes good sense that a strategy designed to better support and consult our families is driven by what they have already told us.

The core objectives have been defined both in response to parental and carer feedback from anecdotal feedback from the **Disability Network Report May 2008** and the **Aiming High Local Authority satisfaction survey (National Indicator 54)**.

### **Parental Feedback - Disability Network Report May 2008**

The final section of the Children with a Disability Network Report – May 2008 focused on anecdotal feedback from parents and carers.

The statements that follow are taken from a wider list of feedback including assessment and decision making, education and short-breaks. These particular statements have been selected as the Children with a Disability Network will impact directly on them.

<b>Information and Support</b>	
<b>A</b>	Parents value the chance to meet with other parents, most want support groups for themselves and want these to be specific to their child’s needs.
<b>B</b>	Parents value workshops as a vehicle for learning new skills as well as meeting other parents facing similar challenges
<b>C</b>	Parents value impartial information. This is a key vehicle to helping them find the right service and make the right links for their child.
<b>D</b>	Parents whose first language is not English are not routinely offered interpreting and translation help.
<b>E</b>	Parents like one-stop shops and the possibility of seeing familiar faces and not having to repeat their story.
<b>F</b>	There is no consistent strategy to involve parents and children in service design and evaluation.

<b>Leisure</b>	
<b>G</b>	Parents feel strongly about lack of accessible playgrounds and indoor play.



<b>H</b>	There is a need of having befriending schemes that give children an opportunity to develop and enhance social and life skills and participate in community based activities.
<b>I</b>	Parents would really value having a discounted Leisure Card.

<b>Suggestions to improve services</b>	
<b>J</b>	Development of an advocacy and support service for young people with disabilities & special needs and their families.
<b>K</b>	Training staff in anti-discriminatory practice and raising awareness on disability issues.
<b>L</b>	Issuing all registered children with an ID card.

## **NATIONAL INDICATOR 54 – AIMING HIGH FOR DISABLED CHILDREN RESULTS FOR HOUNSLOW**

This section is a snapshot of the results from the National Indicator 54 Aiming High Disabled Children (NI54) satisfaction survey on Care and Family Support, Education on Health services.

The results have been filtered down from several questions to where the level of satisfaction fell either below the National Level for England (NLE) and/or the London Borough of Enfield (LBE). Enfield has been used as a comparison for 2 reasons; firstly it is comparable in disability, ethnicity, population and resource demographics. Secondly it was identified as one of 21 AHDC Pathfinder boroughs.\*

\*Pathfinder boroughs “have been chosen following a rigorous selection process. All pathfinders have been assessed as having the capacity to deliver immediate improvements to the short breaks services that they offer, while at the same time developing and sharing information and best practice in short break service commissioning and provision.” **Transforming Short Breaks for Families with Disabled Children – 21 Local Areas Announced as Pathfinder** - AHDC Press Release 14 January 2008.

<b>M</b>	There is someone I can go to for help and support in getting services
	<b>Health and Social Services</b>
<b>N</b>	I had to give the same information several times
	<b>Social Services</b>
<b>O</b>	Whether consulted or asked opinion when decisions were being made about care and family support services received for child in the last 12 months
	<b>Social Services</b>
<b>P</b>	Whether asked for opinion or feedback on care and family support services received for child in the last 12 months
	<b>Social Services</b>



<b>Q</b>	Whether child asked for opinion or feedback on the care and family support services received over the last 12 months
	<b><i>Social Services</i></b>
<b>R</b>	Whether think changes were made as a result of child's opinions or feedback
	<b><i>Social Services</i></b>
<b>S</b>	Difficulty accessing services
	<b><i>Health and Social Services</i></b>
<b>T</b>	How often information received about health care services for child in last 12 months was relevant to parent and child
	<b><i>Health</i></b>
<b>U</b>	How often information received about health care services for child in last 12 months was accurate and up to date
	<b><i>Health</i></b>
<b>V</b>	The decisions made were suitable for my child's needs
	<b><i>Health</i></b>
<b>W</b>	On the whole we were happy with the decisions that were made
	<b><i>Health</i></b>
<b>X</b>	How often information received about schools and education services for child in last 12 months was clear to understand
	<b><i>Education</i></b>
<b>Y</b>	Whether think changes were made as a result of opinions or feedback given
	<b><i>Health and Education</i></b>
<b>Z</b>	All of the child's services needs were met
	<b><i>Health, Education and Social Services</i></b>



### 3. Aiming high

*“The Government expects all local areas to build on good practice in engaging parents of disabled children, such as parent’s forums with the support of staff, who have skills to support participation, to engage, support and train parents to influence the design and delivery of services” (Section 2.40)*

#### ***Aiming High for Disabled Children – The National Core Offer***

There is a shared area of work with the current Aiming High programme. The Network should initially work within and enhance the Aiming High programme; in the longer-term the Network will contribute to the Aiming High legacy and beyond.

With the future of Aiming High undecided by the government, it is prudent to start planning ahead for how services may look. Much great work has taken place in Hounslow with regard to working in partnership with parents in designing services. The continued support and input Aiming High has had from parents, via the steering group and parent’s forum, has been crucial to the programme development. The Network will benefit enormously from continuing such valuable parent participation in the immediate and the post-Aiming High future.

The Network’s core objectives clearly demonstrate a commitment to improving access to information, support and parent participation. Section 4 gives a more detailed description of how these objectives are met; the remainder of this section details the Aiming High national framework that the Network works within, and the delivery standards it contributes toward.

#### **Aiming High for Disabled Children – Delivering the core offer standard**

##### **Information – Delivery Milestones**

- Information services such as CIS/FIS routinely include up to date information for parents of disabled children
- There are elements of an integrated system, e.g. a newsletter, a website, etc
- Families are able to access timely and relevant information that meets their needs
- Information is accessible to parents with a range of needs and in appropriate community languages
- Parents and young people are assessors of information and it is consistently reviewed and amended by them

##### **Participation – Delivery Milestones**

- The opportunity to contribute to decisions about local service development
- Clear reporting channels are in place and two-way feedback is regularly sought and received on a ‘you said, we did basis’



- There is evidence of the effects of an active strategy to ensure that the widest number of parents are encouraged to participate in ways that meet their needs including families seen as hard to reach
- Parents are recognised as equal stakeholders and treated as such
- There is a large and varied group of parents involved in representing the views and experiences of parents (including age range, condition, hard to reach and families not in receipt in services)
- Parents know the local forum feeds into and influences local decision-making processes
- There is regular two-way communication with the wider population of families to inform them about the activities and outcomes resulting from the parent participation work
- The local authority and PCT value the input of parents (and young people) to service planning and their involvement is central to all planning and decision-making



## 4. How we aim to meet our objectives – responding to parent/carer feedback

*These are the first steps on a journey that will be steered by parents and carers. The actions listed in this section outline how the Network works toward meeting the objectives. Throughout its development, it is important that parent and carer direction is embedded in the Network; prioritising what parents and carers feel will have the most impact. There is real need to strive for an equal representation of parental input, especially from families who face barriers in communicating their needs.*

### 4.1 Developing a two-way communication strategy

Through Aiming High there has been a marked increase in the both quantity and quality of information made available about short breaks for families. Consultation with the Aiming High team has highlighted that the direct mailing of a newsletter to 1200 families 4 times a year and a dedicated telephone line are the primary communication channels. Figures from the Aiming High team indicate this has come at a cost of £15,000 for the period April 2010 to April 2011.

The Network Coordinator has received feedback that many service users have not always received the Aiming High information using the existing model for a variety of reasons. One of the challenges for the Network is to work towards changing the expectation that information is *received* from the local authority, by making it easier for parents to *find* the right information. While this will not be an easy or rapid process it makes better sense to have information available from a centralised source and available on demand.

To facilitate this transition the priorities must be to:

- Ensure information is simple to access
- Available on demand from a variety of channels including the web and telephone
- Well publicised
- Supported by active outreach to families that may be difficult to engage with or previously found it hard to seek information from the local authority
- Presented in the best format and fully accessible
- Maintain the expectation that there will be timely response to an enquiry
- Be cost effective



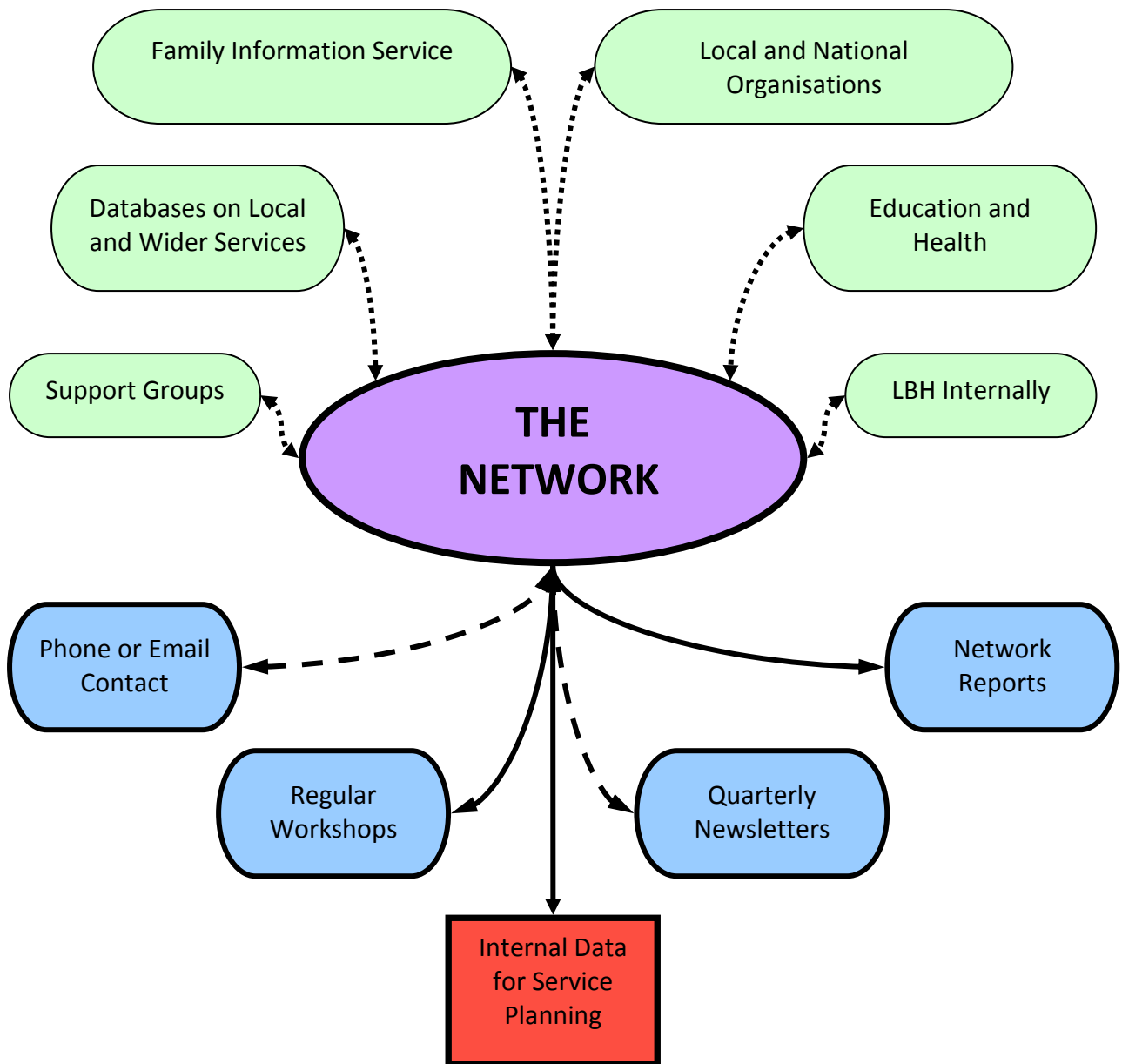
Sections 4.2 to 4.4 outline how the Network will facilitate a variety of mechanisms for two-way communication. The main points are summarised below:

- There are 3 channels for communicating with the Network coordinator

- A dedicated telephone line
- A direct email contact
- Network webpage with publicised dates for meeting the network coordinator in person

- There will be a link from the Network webpage to the Family Information Service webpage
- The Network will produce quarterly newsletters which will also highlight the communication channels with the Network coordinator
- There will be regular workshops with outcome notes published in the Network webpage
- There will be a focus on participation and a mechanism for parent/carer evaluation and two-way feedback

## 4.2 Sharing information and identifying support



**You said:** *“difficulty accessing information” “important for parents to keep learning”*

**You wanted:** *“visible...accessible” “an overview of local services and organisations”*

Key to the successful development of Network is sharing information.

The Network is a hub for information to be collected and passed on in the most useful way. Information for parents and carers is shared between sources such as:

- Internally the Network will work with a growing list of services across the local authority. This list may include the Adult Services, Customer Service Officers,





DCATCH, Early Support and Intervention Teams, Education and SENCO's, Equalities and Human Rights Health, Parent Partnership, Portage, etc

- The Family Information Service (FIS) continually looks to find useful information, such as activities, childcare and much more. The Network coordinator works with the FIS to not only share this information but to keep it updated. It is important that enquires are answered in an acceptable time frame; to work towards this enquires can be made directly to the FIS team but also to the Network coordinator who can access the FIS database. The FIS is also working hard behind the scenes to update the [younghounslow.info](http://younghounslow.info) website so information can be accessed at any time. The FIS can be contacted at:

[www.hounslow.gov.uk/fis](http://www.hounslow.gov.uk/fis) - 0800 783 1696 - [fis@hounslow.gov.uk](mailto:fis@hounslow.gov.uk)

- Additionally the Network coordinator has access to alternative databases on both local service providers and out of borough agencies and organisations. Although out of borough, these services may be accessible to Hounslow residents. These additional databases will grow with members sharing experiences with the Network coordinator and ultimately other Network members
- The Network coordinator will be a regular presence at various forums and groups within the community. These include parents forums, parent support group drop-in sessions (PiT Stops) and condition-specific support groups
- The Network recognises that the best source of information sharing is often parents and carers directly. Encouraged at every level are families talking directly to the coordinator and each other at various opportunities such as parent's forums and workshops
- Where possible the Network will help to point parents/carers in the direction of a support group where experiences can be shared. Additionally if there is a need, a confidential peer-to-peer email Network or voluntary "buddying" scheme could be facilitated. Suitable parents who have had experiences of services across the borough, both within and external to LBH, could volunteer to provide constructive and practical support to less experienced families
- Local and national agencies and organisations with long histories of providing opportunities for children and young people with disabilities. Building strong relationships with these organisations will be a key part of the Network coordinators role

## **Families accessing information**

If sharing information is the backbone of the Network, then this next section is its voice. The ways in which information is communicated to parents/carers are outlined in this section. Initially there will be 5 main ways of communicating information:



- A Network webpage will be created where information, important dates and resources can be accessed. Currently under development the webpage is likely to comprise a main information page including the 3 main channels for contacting the Network coordinator, a calendar for important dates, a news page for downloadable versions of the newsletter, a resources page and links to useful sites. The webpage is expected to go live early 2011
- There are 3 channels for contacting the Network:

- A dedicated telephone line
- A direct email contact
- Network webpage with publicised dates for meeting the network coordinator in person

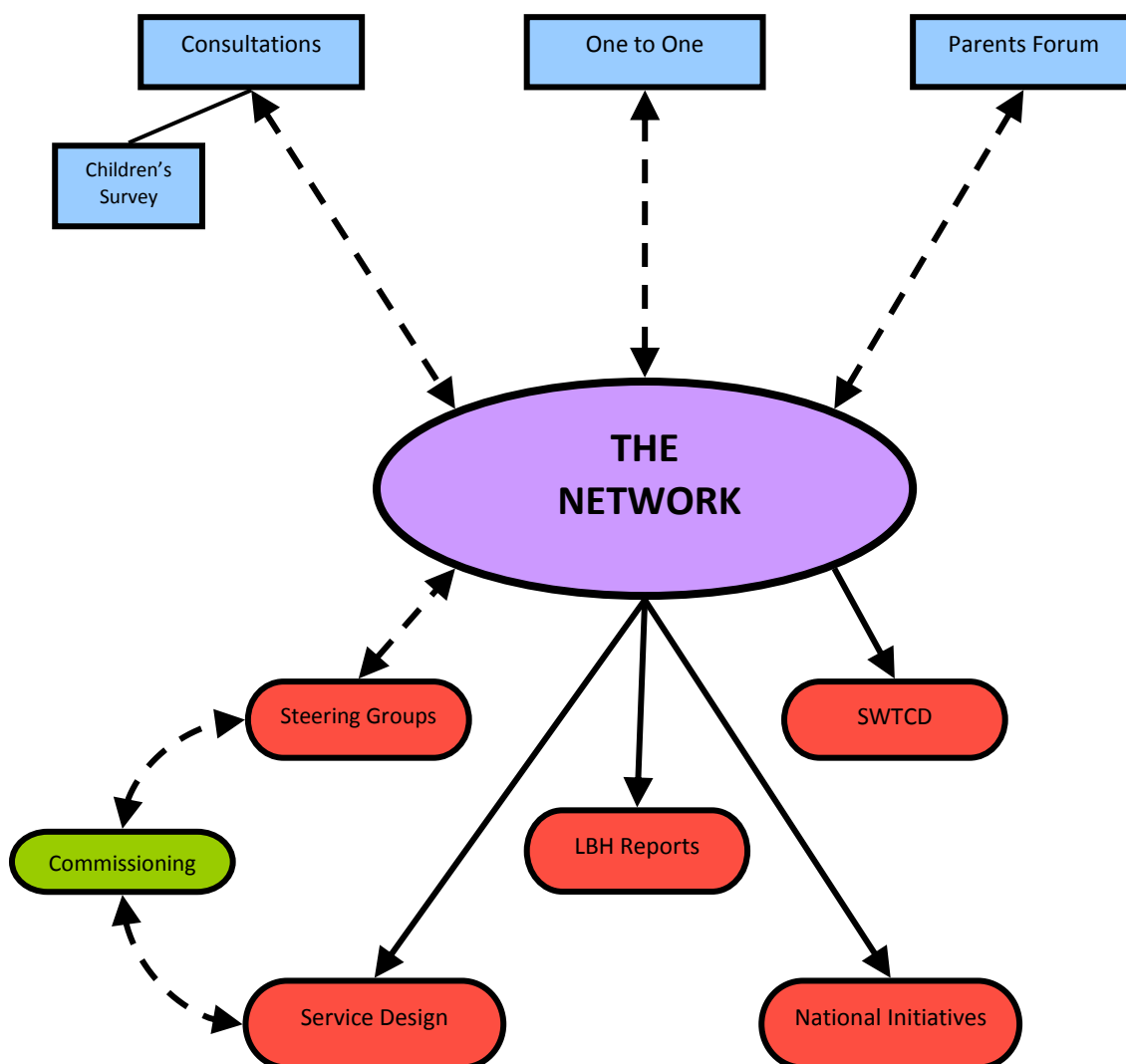
- A quarterly newsletter that aims to provide accessible, digestible but most crucially useful information. The focus will be on exploring services within the community, responding to parent's questions and community news. There will also be a section of the newsletter dedicated to Transition. The standard expectation is that this will be available as a downloadable resource from the Network webpage and primarily communicated via email (the estimated annual cost for mailing hardcopies via Royal mail is approximately £2650) However arrangements can be made to have this mailed to a residential address or presented in an alternative format or language
- A large focus of the Network is to help identify different means of support for families. This will be both universally in terms of the Newsletter and regular news updates but also on an individual basis. Every effort will be made to look holistically at the whole families needs where possible. This might include support groups, youth clubs, voluntary services such as counselling or advice and targeted council initiatives. *The means of support identified by the Network will lean toward services within the community including the voluntary and private sector – these services are not to be confused with statutory services that are available to families that meet the criteria of social care*
- Regular workshops and information events offer both the opportunity to meet other families but also provide a practical learning experience. The topics covered will be driven by parent/carer suggestions. Workshops will be a combination of one-off multiple activity days and extended forums with key speakers. When planning these events consideration will be made to make them as accessible as possible. While not everybody will be able to make the events in person, key points will be communicated through a variety of media including downloadable or emailed options
- Periodic progress reports will be made available for Network members to feedback on. Throughout the Network's development parents/carer will be invited to give their input and opinion on the progress
- There are 3 clear channels to ask a question to the Network coordinator: via email, over the phone or better still in person at a support group, parents forum or workshop. Questions can be asked on behalf of parents/carers internally or at events. Where useful, these questions may be published in newsletters or on the Network website



- Statistical information is available for appropriate agencies and planning teams. Each year an interim and annual report will be available detailing changes in the Network status. It is beneficial both to families and to agencies to have as much “real” information on children with disabilities as possible so to present an accurate representation of need in Hounslow
- Information could be available in different languages or at forums/workshops in different communication formats on request where possible

<i>Objectives</i>	1, 2, 5, 6, 7
<i>Responding to feedback</i>	<b>A, B, C , D, J, M, T - Z</b>
<i>LBH CYPP Key Priority</i>	2, 7.2

### 4.3 Working in partnership to influence and evaluate service design across children's services



**You said:** *“There is no consistent strategy to involve parents in service design and evaluation”*

**You wanted:** *“regular information on how views are shared with service planners and how it specifically influences decisions.”*

The Network is a team where parents are both player and manager. Throughout its development the Network should be responsive to, and steered by, parents and carers needs. Parental/carers influence extends beyond shaping the Network; it is collected and elevated where most needed. Priority 6.4 of the LBH CYPP places the importance of ensuring activities and services are available to all young people regardless of barriers. The needs of disabled children and their families should be embedded in mainstream service design from conception. Core objective 3 of the

Network works practically toward achieving this by bringing parents/carers to the forefront of service design as standard practice.

The ways in which parent/carer input is fed in to the Network includes:

- Participation – at least one consultation is held each year as standard and where changes that may affect services are considered, additional consultations may be held. When opening consultations there will be clarity about its purpose – what it is about, who the results will have an impact on and what the outcomes might be. A response to consultation will be issued, opening the communication channels where feedback can be offered both ways
- There will be a focus on the feelings and opinions of the children and young people who are registered to the Network. It is a goal to work towards developing consultations in partnership with the parents and carers
- As described in the previous section there are 3 clear channels to talk to the Network coordinator
- The Network coordinator will be a regular presence at various parents' forums and support groups. A key part of their role is to record parental/carer opinions during discussions and take note of specific feedback
- There will be an ongoing process to identify and overcome the barriers some families face with communicating their needs. The Network should aim to provide an equal platform for families that find it difficult to engage with services. To assist with this a variety of accessible communication channels, including alternative formats and languages, can be made available via the Network website and email. Families should feel that confident that Network coordinator has an impartial position to Social Services and can ask questions or supply information informally
- To further assist overcoming the barriers of engaging with the Network, the Network coordinator will outreach via schools or other community organisations to identify alternative channels to families that find it hard to engage. The Network coordinator will liaise with other LBH services regular to further identify families on the periphery that may benefit from the Network service

How parent/carer opinion is used:

- The views of the Network are passed on internally at LBH when considering future services design. This may be via a consultation or as part of the Network reports, in which anecdotal and statistical information is reported. The Network may share useful information and express parental input between departments. In addition to service design the Network can facilitate parent/carer opinion for communication, democratic, equality and quality control purposes. Members of the Network are service-users of varying levels and are ideally placed to share their views to external organisations, such as OFSTED
- The Network coordinator and members of the Network will attend the LBH Disability Community Forum where questions can be asked and issues discussed with Council Members directly. The Network coordinator will facilitate two-way feedback with the wider Network on the Forum



- The Network coordinator is a member of various planning and steering groups, such as the Aiming High steering group, Inclusion sub-group and the Transition steering group. The main focus is to represent the views of the Network
- As the Network develops, parents and carers experiences locally can be shared in national initiatives, research and surveys. Just as local satisfaction results have been factored into projects, such as Aiming High, the Network coordinator seeks to liaise with national agencies and schemes to have the experiences in Hounslow represented
- The Network coordinator attends team meetings with the SWTCD management and team. This provides an opportunity to share general parental/carers opinion and feedback into the team. Additionally the Network coordinator will seek to meet with teams across Children’s Services to raise awareness of the Network and raise issues as appropriate
- Crucially, and in line with its core objectives, the Network development is driven by its member’s views. Regular feedback can be given at parent’s forums and the opportunity to discuss progression. To this extent the Network can remain dynamic and responsive to suggestion; for example should parents feel there is a need for a web-forum, social Networking or web microsites linked to the Network page then this may be explored
- A formal end of year review will be issued with the yearly consultation and a response will be made available for all members
- With a centralised position, the Network can offer an ‘information funnel’ with regard to joined-up thinking. By capturing both data and perspective on families in Hounslow, the Network has scope to liaise across agencies and departments

<i>Objectives</i>	3, 4, 7
<i>Responding to feedback</i>	<b>A, F, M, O, P, Q, R</b>
<i>LBH CYPP Key Priority</i>	2, 6.4, 7.2



#### 4.4 Promoting opportunities

**You said:** *"We want to have the same opportunities as other families, to have a normal life".*

**You wanted:** *"...to be in a situation with our children where everyone understands and you don't have to feel awkward."*

Key to the LBH Children and Young People's Plan is participation; and the Network aims to have an impact on this by signposting opportunities where possible.

- **Increasing the visibility of services:** As the Network develops there will be an ongoing commitment to learning about and sharing existing services that may be useful to families. An opening statistical report (September 2010) of the Network highlighted 2 points; many main carers are not accessing support groups and many children and young people do not attend clubs or groups. If there is a need for more families to be accessing these services but are unsure of how to, by collecting and sharing information the Network may contribute to the visibility of these groups or additional services
- **Network Card:** A goal for spring 2011 is to launch a recognised card scheme aimed at possible discounts, fast-tracking services or possible even free services. Initially focusing on local recognition, but with wider expansion ultimately, this voluntary initiative has proved successful for other boroughs. Like many aspects of the Network it will develop in partnership with families needs; feedback on where it would be most useful and additional places willing to recognise it will be key to development. At the other end of the scale, the card will offer proof that the holder is recognised as having a disability

The gateway to the Network member's suggestions and feedback on this scheme will be opened in the December 2010 Newsletter

- **Rebranding - Giving the Network an identity:** another goal for early 2011 is to rename the Network to coincide with the launch of the Network Card. The name and logo will be for the Network members to choose and design
- **Exploring new ideas:** The project work of the Network can be driven by suggestions from members

Examples of this could be:

1. It has been long recognised that there is a continuing need to raise awareness of disability in a variety of public settings. A training scheme for parents/carers or young people to become "community disability awareness champions" could be considered. This might see parents/carers young people work alongside the disability Network coordinator going into retail outlets, leisure centres, educational environments, etc to present short and cost-effective disability awareness



2. Providing access to computers and the web at PiT Stops by working alongside Parents in Touch

<i>Objectives</i>	3, 5, 6
<i>Responding to feedback</i>	<b>B, H, I, K, L</b>
<i>LBH CYPP Key Priority</i>	6.4, 7.2





## 5. Access to the Network

*Caring for a disabled child or young person can place significantly increased pressures on families and carers. There can be repetition when it comes to form-filling and continually giving details. This section should provide clarity and certainty about who might benefit from being part of the Network and how to join.*

### 5.1 Who can join?

#### The Disabled Children's Register

Children and young people who live in or are the responsibility of the London Borough of Hounslow aged between 0 and 18 years old and as defined as disabled under the Equalities Act 2010 can be placed on the Disability Register. These young people can be from Pathway 1, 2 or 3 as defined by the **Aiming High Common Access Framework (See Appendix A)**

Parents and carers of all children and young people on the register can opt to receive the Network Newsletter.

#### The Network

To be eligible for the Network and qualify for a Network card, the child or young person must meet the criteria for the Disabled Children's Register AND for Pathways 2 or 3 of Aiming High Common Access Framework.

### 5.2 How to join the Network:

Registration can be made by:

- Filling out an application form – this can be sent by the Network coordinator via mail, received from a social worker (who can help with completing the form) or downloaded from the Network webpage
- Registering over the phone or in person with the Network coordinator.
- Alternative languages or formats – applications can be made individually with the Network coordinator on request in other formats or languages.



## 6. Measuring impact

*The Network should offer clear and measurable benefits; at the same time it should be flexible, responsive to member feedback and open to change. From this point forward the Network can be measured and reviewed against a simple and sensible framework that joins opinion with data-based evidence.*

There are 4 performance indicator measures used to ensure the Network is working toward its objectives. Each outcome is split into 2 categories; the first category is measured on member satisfaction and the second measured statistically.

A target score can be applied to each indicator point and can be measured and set yearly or quarterly. Where applicable the satisfaction statement is based on the NI54 question used to drive the Network (as described in section 2).

The measurability process begins with a short satisfaction survey to establish a baseline for comparison. It is important that the statements are applied only to current Network members and responses are limited to Network-only involvement. Guidance will accompany the survey to ensure responses are within the parameters for each statement.

Below are 2 tables; the first is the **Objectives Performance Indicators** table detailing which performance indicators are used to measure each core objective. The second table is the **Network Performance Indicator Framework** which contains descriptions of each measurement.

<b>Objectives Performance Indicators</b>		
<b>Objective</b>		<b>Performance Indicator</b>
1	Improve access to information for families and carers of children and young people with disabilities.	<b>A, B, D</b>
2	Develop a Network for families and carers based on support.	<b>A, B, D</b>
3	Work in partnership with families and carers in developing services.	<b>C</b>
4	Provide a platform for families and carers to have a voice by way of consultation and direct feedback.	<b>C</b>
5	Promote opportunities for children and young people with disabilities and their families and carers.	<b>A, B, D</b>
6	Encourage family learning.	<b>A, B, D</b>
7	Provide data from the Children with a Disability register for planning and monitoring.	<b>A</b>

Network Performance Indicator Framework				Type	Source	Measurement Frequency	Baseline Survey Score (November 2010) %	Previous Score (date)	Target Score (date)
Performance Indicator	Outcomes	Indicator Point	Measurement						
A1	Improved Access to Information for Parents and Carers	1.1	"There is someone I can go to for help and support in getting care and family support services." (NI54 - Q58.4)	Satisfaction statement	Annual Consultation	Yearly			
		1.2	"I don't know what help is available/entitled to" (NI54 - Additional Feedback)	Satisfaction statement	Annual Consultation	Yearly			
		1.3	"It is easier to get information about support services in the community that I can access"	Satisfaction statement	Annual Consultation	Yearly			
A2	Improved Access to Information for Parents and Carers	2.1	Newsletters Sent	Statistical	Database	Quarterly			
		2.2	Network Web Page Hits	Statistical	Web Team	Quarterly			
		2.3	FIS Enquiries	Statistical	FIS Tracking	Quarterly			
		2.4	Coordinator Direct Enquiries	Statistical	Network Coordinator	Quarterly			
B1	Increased Parent/Carer Emotional Wellbeing	1.1	"Being able to access information or services makes me feel better supported"	Satisfaction statement	Annual Consultation	Yearly			
		1.2	"I can talk to someone who has had similar experiences to me"	Satisfaction statement	Annual Consultation	Yearly			
B2	Increased Parent/Carer Emotional Wellbeing	2.1	% parents/carers who attend a support group	Statistical	Database	Yearly			
		2.2	% parents/carer who have attended a parents forum	Statistical	Annual Consultation	Yearly			
C1	LBH and Parents/Carers Working in Partnership	1.1	"I have been consulted or asked opinion when decisions were being made about care and family support services received for child in the last 12 months" (NI54 - Q53)	Satisfaction statement	Annual Consultation	Yearly			
		1.2	"I have been asked for opinion or feedback on care and family support services received for child in the last 12 months" (NI54 - Q54)	Satisfaction statement	Annual Consultation	Yearly			
		1.3	"I think my child has been asked for opinion or feedback on the care and family support services received over the last 12 months" (NI54 - Q56)	Satisfaction statement	Annual Consultation	Yearly			
		1.4	"Care and family support do not listen to parents" (NI54 - Additional Feedback)	Satisfaction statement	Annual Consultation	Yearly			
		1.5	"I feel that as the parent/carer of a child with a disability or additional needs, that I am heard and my opinion is valued when it comes to designing or evaluating services"	Satisfaction statement	Annual Consultation	Yearly			
C2	LBH and Parents/Carers Working in Partnership	2.1	Number of members in network	Statistical	Database	Quarterly			
		2.2	Network Coordinator attendance at parents forums	Statistical	Recording	Yearly			
		2.3	LBH attendance at PiT Stops	Statistical	Recording	Yearly			
		2.4	Demographic diversity to be consistent with borough population - to ensure equal representation of families	Statistical	Database	Yearly			
D1	Provide Clear Benefits to Parents/Carers	1.1	"Being part of the network is beneficial"	Satisfaction statement	Annual Consultation	Yearly			
D2	Provide Clear Benefits to Parents/Carers	2.1	Number of Network Cards issued	Statistical	Database	Yearly			
		2.2	Number of Workshops held	Statistical	Recording	Yearly			
		2.3	Average attendance at Workshops	Statistical	Recording	Quarterly			
		2.4	Project attendance	Statistical	Recording	Yearly			



## **7. Reporting**

The Network will report frequently; both internally and for public purposes.

An opening report was made in September 2010 on the current Network status following the appointment of the current Network coordinator. The first 6 months of this period will include some maintenance on the password-protected database that is managed by (and accessed by) the Network coordinator. This will include a period where the current database is migrated to an upgraded service.

An interim report will be produced at 6 month intervals within the Network year (running August to August) with an Annual Report completed and made available at the end of each year.

Confidential details will not feature as part of the reports.

Each year a reminder to update current details will be sent to all Network members.



## 8. Resources

*The Network is committed to achieving value for money. A clear demonstration of this commitment is the way in which current provision is utilised and the improved signposting of existing services. At every stage in-house or centrally funded resources and materials are used. There are no additional on-costs outside of departmental spend expected.*

### Resources: August 2010 - August 2011

Category	Item	Quantity	Supplier	Funding Source	Distribution	Comments
Administration	Welcome letter	1000	Internal	Internal	Mailed	Produced using desktop software
	Applications	1000	Internal	Internal	Various	Produced using desktop software
	Reports	500	Internal	Internal	Electronic	Produced using desktop software
Media	Newsletter	2500	Internal	Internal	Primary electronic with limited mail	Produced using desktop software
	Posters	1000	External	Aiming High	In person	One-off cost
	Flyers	5000	External	Aiming High	In person	One-off cost
	Welcome pack	500	External	Aiming High	Mailed	One-off cost
Events	Parent's forums	5	Internal	Internal	n/a	LBH venues
	Refreshments	5	Internal	Internal	n/a	
	Workshops	1	Internal	Internal	n/a	
	Refreshments	0	n/a	n/a	n/a	
	Network card launch	1	External	Aiming High		One-off cost
	Refreshments	40	External	Aiming High		One-off cost
Projects/Training	Training		External	Aiming High	n/a	Utilising existing funding
IT	Database migration	1	Internal	Internal	n/a	Internal IT
	Database maintenance	n/a	Internal	Internal	n/a	Tasked to Network Coordinator
Travel	Fuel		External	Internal	n/a	Essential travel only by most economical means
	Travel		External	Internal	n/a	Essential travel only by most economical means
	Parking		External	Internal	n/a	Essential travel only by most economical means
Production	Network card	1000	Internal	Internal	Mailed or in person	Produced in-house using existing resources

**END OF REPORT**

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**APPENDIX A – Aiming High Common Access Framework – Pathways of Need**

	Dimension	Pathway 1 Level of Need	Pathway 2 Level of Need	Pathway 3 Level of Need
Band A	Mobility	Able to walk unassisted, but with difficulty or poor co-ordination.	Walks, but only with aids or assistance. May use a wheelchair sometimes.	Full time wheelchair user and/or Mobility severely restricted without special provision.
	Vision	Severe or profound problem with one eye. Less than half visual field loss. Able to function independently.	Able to read print with simple aids or assistance. Defect of at least half visual field. May be eligible for registration as partially sighted.	Unable to read large print without intensive educational assistance or sophisticated aids. Registered.
	Hearing	Severe or profound hearing loss in one ear. Hearing loss 20-40 dB	Hearing loss 41-70 dB	Hearing loss >71 dB
	Functioning and Learning ability	Overall functioning slightly below expected level for age. May have a mild or moderate learning disability	Overall functioning around half expected level for age. Has a moderate learning disability	Overall functions significantly below expected level for age. Have a severe learning disability or a moderate learning disability and diagnosed ASD.
	Health	Known health condition, which is under control but occasionally interferes with everyday activities in a minor way.	Health condition that limits normal activities, including self-care and personal hygiene, access to services. May interfere with opportunities for development or education.	Diagnosed health condition, which is severe and potentially life threatening, and results in frequent hospital admissions that limits accessing developmental or educational activities. May be in receipt of Continuing Care or palliative care from Health Services.
Band B	Communication	Delayed language development only.	Delayed/ disorganised verbal communication causing difficulty. Speech supplemented by alternate communication method.	Uses communication other than words, e.g. symbols, makaton, BSL.
	Personal care	Child requires minimal support beyond that of their peers with everyday care needs; this will include toileting, washing and dressing.	Child requires practical support beyond that of their peers with everyday care needs; this will include toileting, washing and dressing.	Child requires assistance beyond that of their peers with all everyday care needs; this will include toileting, washing and dressing and can be problematic and need skilled intervention.
Band C	Safety and Supervision	Requires occasional supervision beyond that expected for their age. Poor sense of danger or risk of excitability.	Needs supervision to perform daily activities significantly greater than that expected for developmental age. Limited perception of danger to self or others.	Needs constant supervision during the day and night. Would place themselves or others at risk without supervision.
	Behaviour and Social Integration	Some mild, transient or frequent behaviour difficulties. Able to use local non-specialist universal services. Able to sustain limited peer relationships and social integration with support. Child requires support to access services.	Behaviour problems severe or frequent enough to require some specialist advice or provision. Significant support required to achieve social integration. Only able to sustain peer relationships with support. Child requires services to prevent or alleviate stress in the family.	Long-term behaviour difficulties make it difficult for the child to function appropriately most of the time, and maybe of risk to the child or carers without special provision. Dependence upon carer for social integration. Limited awareness of impact of behaviour upon others. Services required to prevent high risk of accommodation for the child.

Children and young people who meet one or more of the criteria within Band A are likely to meet that Pathway. Children and young people who meet one or more of the criteria within both Bands B and C are likely to meet that Pathway.