the Light House

Consultation with Disabled Children, Parent Carers & Practitioners

COMMENT ON DERBY'S INTEGRATED DISABLED CHILDREN'S SERVICE

I wish to thank all the parents, children and staff who took part in the consultation process, it has provided a valuable insight into the first year of the Light House's operation. Without the hard work of the staff members who have been involved the evaluation would not have been possible.

Thank You All

Jacqui

September 2007

CONTENTS PAGE

Page No.

COMMISSION

PROCESS

FINDINGS

OUTCOMES

INTRODUCTION TO THE SERVICE

The Integrated Disabled Children's Service @ the Light House.

The Light House is both a residential short break centre and a base for the Integrated Disabled Children's Service (IDCS). The service is a multi-disciplinary, multi-agency service and can provide information, advice, sign posting to other services and a route to assessment. If needed, it directly provides services for disabled children and young people and their carers. It is a purpose built resource, specifically for profoundly disabled children with complex needs. It is fully accessible and equipped for disabled children. The building name, the Light House, has become synonymous for the service itself amongst staff and service users. The IDCS provides:

- Nursery education, family and parenting support.
- Groups for parents and pre-schoolers.
- Community based short breaks, clubs and after-school groups.
- Statutory social work, safeguarding and looked after services.
- Transition assessment support.
- Behaviour management, training and support.
- Residential over-night breaks.
- Physiotherapy and Occupational Therapy in special schools.
- Direct work with young people.
- Assessment, care planning and reviewing of care packages.
- Special Needs Toy Library.

INTRODUCTION TO THE SERVICE

Our staff group includes:

- Community Learning Disability Nurse.
- Family Resource Workers.
- Family Workers.
- Residential Nurses.
- Child Care Workers.
- Health Care Assistants.
- Occupational Therapists.
- Physiotherapists.
- Technical Assistants.
- Special Needs Toy Library Project Leader.
- Teacher.
- Teaching Assistants.
- Social Workers.
- Community Care Workers.

Derby City Primary Care Trust (DC PCT) and Derby City Council's Children & Young People's Department (CYPD) jointly fund the IDCS. Prior to implementation of the IDCS, community and residential services for severely disabled young people were provided by a number of service providers including what was then Derby City Council's Social Services Department (SSD), the Local Education Authority (LEA) and the PCT.

The Commission

The IDCS Partnership Management Board commissioned a consultation with children and their parent carers to find out what our customers feel about the new service after the first year of implementation. The Board asked,

- Are children happy in our care?
- Are parents satisfied that the service is moving in the right direction?
- Is there anything we should do better, stop doing, or should do more of?
- Is there a direction we should prioritise over all others?

The consultation aimed to provide some answers to these questions.

As the Manager responsible for the service I am also interested in the variables which contribute to any success or improvement we may have achieved. There are a number of variables which may influence change in practice: the political context; new systems and processes; joint performance targets; structural and environmental change; geographical proximity and professional networks; joint working and alliances, and the desire to use the new service advantages (purpose built environment and staff proximity) to benefit the children. Practitioner Action Learning Sets allowed us to consider these variables. Without this learning there is a chance we cannot maintain practice improvement, so I asked:

- Are practitioners able to identify positive changes for their customers after the integration of services?

The consultation is part of a wider piece of research undertaken for a Doctorate by the IDCS Head of Service. A research proposal was completed and agreed by a CYPD AD and the Derby University Ethics Process.

The Commission

Why consult with disabled children and young people?

Research evidence shows that for disabled young people, having their views respected and being involved in decision-making are highly valued features of service provision. (Morris, 1999, Noyes, 1999, Crisp et al., 2000, Mitchell & Sloper, 2001).

> *'One of the most disabling attitudes faced by children with physical or sensory impairments, and particularly by children with significant learning difficulties, is the assumption that they do not have a view to express or a way of expressing it. Our society operates as if communication only takes place through written or spoken language.'* (Beresford, 1998b, p.36)

The Department of Health states that a child who has a learning disability should not be assumed to lack competence:

> *'Many children will be competent if information is presented in an appropriate way and they are supported through the decision-making process'*. (DoH, 2001c, p4).

Most importantly, consultation and participation in issues that affect their lives is a child and young person's Right. This is enshrined in the Children Act '04. Our service takes the Right's afforded to our children and young people seriously.

PROCESS

Involving Practitioners

Information on the research and consultation was provided at team meetings and staff members were asked to consider how we would recruit people to be involved in the consultation design group and how we would recruit people to be involved in action research learning sets.

Staff volunteers were preferred in the first instance and if there was any need to prioritise, consideration would be given to any qualification training or learning needs a practitioner may have. In effect, all practitioners who took part in the consultation and action research were volunteers.

Bias

Bias is inherent in any social activity. The process accepted that our values and bias would affect the design of the consultation and we would own that fact and analyse the findings in the context of it being a value laden exercise. Consultation involving disabled young people in itself holds a value base of valuing the children and believing in their right to a voice in their service planning.

Consent

Issues of consent were a significant consideration. The children and young people cannot give informed consent for consultation, but this is balanced against their Rights to have their wishes and feelings captured in relation to the service they receive. There was a value in this approach as most of the children involved do not use formal communication methods. Consent and method for these children was led by their abilities and a rationale understanding of what is ethical and possible.

PROCESS

Consent in relation to the parent carer group was relatively straight forward. The parents are used to having their views sought and there are a number of situations in which this already occurs.

Confidentiality and Anonymity

Parents and practitioners were assured that any collation of findings, reports or feedback would not identify the respondents or staff members. No comments would be attributed to anyone involved in the research.

Practitioners were able to stop the recording of the Action Learning Sets at will, and did. They also had draft transcripts to check before a final copy being retained. The transcripts will be used for research use only. Practitioners will have a veto on anything written in reports or the dissertation at draft stage.

Staff involvement in consultation, particularly with children and young people, is a significant part of our organisational culture. Communicating with the children is an everyday part of our work. Therefore, we did not commission consultation involvement from voluntary sector partners.

The consultation process included the design and implementation by a consultation Design Group, which led to the consultation itself involving a sample group of disabled children and their parent carers. The group designed the consultation process which included choosing the sample group, the interview questions, structured observation logs and the logo.

Staff members interviewed parent carers and were the participant observers for the children.

PROCESS

Consultation Sample Group

The 26 children sampled were from a group of children who received a package of support of three or more types of service provision. Many received five or more. The design group considered that this would be the best test of our aim to improve the 'integration' of the service. Of the sample group,

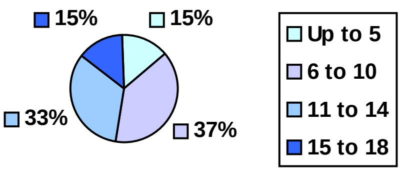
- 45% were from black and minority ethnic communities.
- 11% were currently on the child protection register.
- 15% were currently, or had been previously, subject to care proceedings.

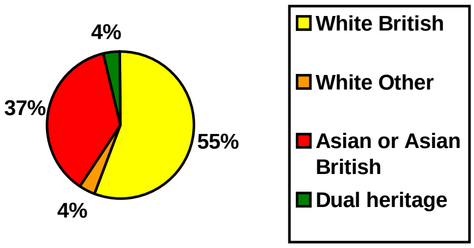
Staff consulted with children in residential and community environments and the format (for all but one) was a Structured Participant Observation and an Affective Communication Assessment (ACA). The other young person was consulted using a semi-structured interview format - he is a young man with a physical impairment who does not have a cognitive impairment.

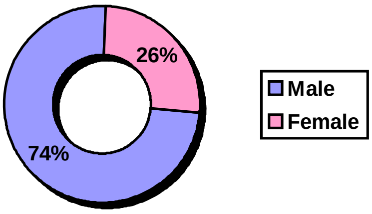
Consultation with Parent Carers took place in the family home. This was arranged at a suitable time and through a semi-structured interview.

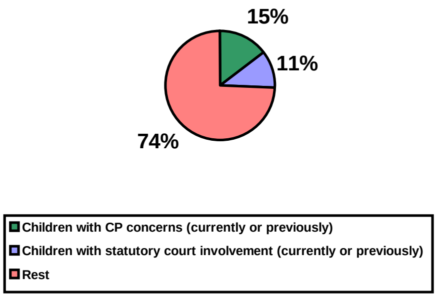
PROCESS

Statistical analysis of sample


AGE


ETHNICITY


GENDER


CHILD PROTECTION

PROCESS

Practitioner Researchers

Using practitioners to consult with children they work with has a firm research base. Bradley confirms the value that the experience and knowledge of the child which the practitioner can bring to the interaction, stating:

> *'The greatest resource available in planning an assessment is the vast array of essential information that is already known about the client's communication abilities and strategies. This knowledge exists in the form of observations that carers have consciously or unconsciously made about their client.'* (Lacey & Ouvrey)

The Data is Affected by the Interviewer

The practitioner's identity (and the meaning this holds for the respondent) will affect the interaction and the responses, with their preferences and prejudices influencing the process. It was felt that the benefits of the interviewer as 'insider' would counterbalance these concerns. This decision was taken for a number of reasons, including pragmatic ones. The group considered that a practitioner known to the family would have an in-depth knowledge of the child and family which would be beneficial to the process in a number of ways. The practitioner:

- Would be party to any crisis, child protection issues or confidential issues and the family would be aware of this.
- Would know the family fairly well and have a pre-established relationship.
- Have knowledge which would mean the parent wouldn't have to explain the child's impairment or needs to someone else.

PROCESS

- Is likely to have participated in the child's consultation or, if not, knows the child well enough to understand and describe the child's findings.
- Is likely to have broad experience of the child's communication method and will have a rapport with the child and possibly the parent.
- Have a means to communicate regularly and routinely with the parent carer's.
- Are CRB checked and we know they are safe with our children.

Pragmatically, we do not have access to independent research staff nor would an independent outsider strategy fit with our organisational culture.

PROCESS

Consultation with children & young people

For some severely disabled children, observation of their behaviour, interactions and body language in a number of settings can provide a wealth of information and can be used to inform the decision-making process. (Morris, 1998a, 2003, Marchant et al., 1999a).

Our consultation included severely disabled children and children with complex communication skills so we decided that the child consultation would be undertaken through structured 'participant' observation, supported by an Affective Communication Assessment (ACA).

The strategies used by Practitioners to collect data included:

- Affective Communication Assessment (ACA).
- Structured Participant Observation (SPO) of the sample group of children.
- Semi-structured interviews with one young person
- Semi-structured interviews with parent carers.
- Practitioner Action Learning Sets.
- Critical reflection.

Affective Communication Assessment

The Affective Communication Assessment (ACA) is a tool used to undertake a baseline assessment of a child's communication, which requires a level of interpretation of sound, expression, behaviour and movement.

PROCESS

Previously a tool used by physiotherapists, it only became known to the residential staff team here when we began designing the consultation. It was well received by the staff group, and has since been adopted as part of the baseline residential assessment.

During the consultation, this tool allowed staff members (who already knew the child well) to assess how the child communicated various wishes, feelings and emotions through movement, gesture and facial expression. Having collected this data, it then enabled the practitioner to check their findings against the knowledge and experience of another practitioner and/or the child's parent carer which enabled a greater understanding of the child concerned.

The ACA is considered to be a benefit to the assessment of the child generally. For children with behaviour that challenges, it is of particular benefit alongside the SCIP Assessment, as many unwanted behaviours are a result of communication frustrations.

It can be an 'aide memoir' and a means to check with parent carers that we understand accurately. It can also aid safeguarding work - in that we are clear when the child's behaviour indicates distress or anxiety.

Structured Participant Observation

Structured Participation Observation (SPO) is just that - observing behaviour or events, instead of asking questions about them. 'Structured' relates to having a pre-decided view on what is intended to be observed and noting the information in a formal way. 'Participation' indicates the person who is

PROCESS

observing is taking part in the event or situation rather than an impassive observer.

The practitioners observed the child in a series of typical situations, such as play, arriving to have a session or a stay, having a meal or getting ready for bed. The information was collected on a form devised for the purpose of making it easy to collate and compare data.

From the collated information, which included anecdotes about the child in the circumstances, we were able to ascertain their views on the situations and the service itself. The process was very successful and we gained a considerable amount of detailed knowledge about the service and the child’s likes and dislikes that we could evidence.

PROCESS

Consultation with Parent Carers

There is a reasonable body of research in which parent carers views on issues related to their children and care provision have been sought in the past. Locally our service has sought parent carers' views regularly over the years. This includes:

- A major consultation event in 2001 for input into an Outline Business Case.
- A BME parent consultation in 2005 contributing to a large Departmental consultation process.
- Open Meetings at the end of 2005 to gain parent carers views/anxieties on the impending new service.
- Yearly Independent Reviews of a child's care plan formally seeks parents' views.
- A limited survey of parent carers is carried out when OfSTED inspect the Residential and Community Support Teams.
- An annual patient survey is completed by our 'health' colleagues.
- Quarterly parent carer representatives meetings produce 'suggestions for service improvements' as part of the service Governance Arrangements.
- Through the Commendation and Complaints processes.

PROCESS

Preparation for Interview

The intention of the parent carer evaluation was to measure improvement (or otherwise) of the service since its inception in March 2006.

The design decisions related to areas for questioning were taken at the outset of the study and were formed through discussion and negotiation in the design group

Reassurance

It was felt that parents may potentially be anxious about a formal interview, eg. anxiety relating to a potential reduction in services particularly residential or community support sessions. This concern influenced the design of process for engaging parents in the interviews.

- Parent Representatives checked the interview script and had the opportunity to make suggestions or amendments.
- An article was written for the IDCS newsletter telling people about the consultation.
- Parent representatives wrote a paragraph for the newsletter encouraging parents to be honest about their concerns.
- A letter informing parents was posted and given by hand. It explained their child's consultation and asked that they assist the consultation by agreeing to be interviewed.
- A second letter was written to parents informing them that the child consultation was finished and that a practitioner would telephone them to arrange a date to feedback on their child's consultation and to undertake their interview.
- Letters were addressed to both parents [as appropriate] which allowed an opportunity for each parent carer to participate in the interview.

PROCESS

Both letters reassured parents that the service their child receives would not be affected by the consultation and of anonymity when the findings are published. A telephone call would give parents the opportunity not to go ahead with the interview and allow the practitioner to negotiate a time which was acceptable to both parents if possible.

Parent Carer Interviews

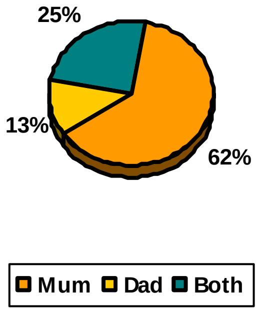
Generally parents were interviewed by their child's short break key-worker, social worker or social care worker. The 'practitioner as interviewer' approach had mixed benefits and dis-benefits. The benefits were as expected: parents appeared to take part well, and provided interesting (and some unpredictable) results. Parents who were in court proceedings or child protection procedures were very open with the practitioners concerned.

The dis-benefits to this approach were that parents may be reluctant to complain in case services were removed, or they might only tell a practitioner what they thought they wanted to hear. We found no evidence to support this hypothesis. The responses were at times constructively critical and supportive in accordance with, but not exclusively, our knowledge of service weaknesses and strengths.

There were 15 interviews with mum, 3 with dad and 6 with both. No parents refused to take part.

PROCESS

Parents Present at Interview



On the day the interviewing practitioner's were given a prompt script to assist their questioning and note comments.

PROCESS

Action Research/Action Learning involving practitioners as learners

The principal sample was a group of 8 practitioner volunteers, including one manager, to form an initial discussion group; the group were volunteers sampled from professional groups in the service, including participants from the consultation design group. The practitioner group were provided with an assurance of anonymity and confidentiality in the final report and given access to written material for comment on inclusion and change. A Managers Action Learning Set also met to provide their perspective on the process of integration.

Three fundamental features of Action Learning are: Action, practitioner participation and a cyclical approach to the study: planning, action, observation and reflection.

An Action Learning approach enables ‘gathering of Information and analysis’ (Carr, 1989) which will enable the gathering and acquisition of intuitive, tacit knowledge from practitioners themselves. The data was acquired and analysed through a cyclical process of reflective action, (Griffiths, 1990) and (Warner & Gould, 2003).

After the findings from our consumers had been collated a practitioner Action Learning Set considered what we have learned from the findings and how this intelligence relates to practitioner experience and knowledge. It also enabled practitioners to consider the findings in detail against their views on how the service has changed.

FINDINGS

What we learned from children and young people

Generally the findings indicated that the children and young people in the sample were happy and content with the services they experienced. The consultation showed that children who challenge our communication abilities are very well able to indicate their wishes and feelings.

Aspects of the service children enjoy

- The wheel chair swing has gone down well.
- Toy and play activities.
- Most children enjoy meal times or food related activities.
- Trips out and away days.
- Planned and routine activities where the children are informed.
- Sensory room.
- Words like happy, pleased, relaxed, content and settled, 'smiley and flapping' appeared many times in the summary of each child's consultation.

Aspects of the service children did not enjoy

- Having teeth cleaned!
- Having rigid behaviours and unwanted behaviours challenged.
- For two children, having personal care needs met.

What we learned from the semi-structured interview with a young man

One young man, Rod[1] took part in a semi-structured interview. He had recent experience of support in the home at night, group activities, child protection and looked after services.

---

[1] Rod and any other children's names are pseudonyms

Rod told the interviewer that he had been kept informed throughout the protection and court process and felt included. When asked about the support he receives he replied “there is nothing I don’t like’.

An example of details from a child’s findings.

Beth[2] a profoundly autistic child of 9 years old communicates through her behaviour and noises. Beth’s findings were more positive in relation to community activities than to her residential stays. The difference in the activities and Beth’s experience and expectations are significant. The things she didn’t like about residential are the things that are good for her, such as structured time, having positive routines and having negative behaviours challenged. Community ‘outreach’ is less structured and very lively at times. Beth enjoys this and finds it less of a challenge.

Having expertise in Autism enables staff to put Beth’s consultation findings into context, without dismissing her wishes and feelings. Residential staff ensure that Beth has the chance to expend energy and run around.

Findings from 6 children specifically indicate that they were happy to receive the service.

> *‘It was really nice for the kids to get picked up from home. They were getting really excited and a couple of them were not just pleased but very chuffed to see the worker and wanting to hug them. So we had a very nice picture that we wouldn’t have captured in any other way’.*
> (IDCS Practitioner, May 2007)

---

[2] Any chid name used is a pseudonym

FINDINGS

What we learned from parent carers

- All parents were satisfied or very satisfied with the services they received.
- All parents said staff were well-mannered and helpful.
- No parents who had experience of the 'old' service felt the new service was inferior.
- Information is easy to get and parents indicated that they would generally ask their social worker, occupational therapist or community support worker.

- **Environment**

  As expected, parents stated that the building or environment and facilities have improved - with good hygiene getting a specific mention. In contrast, some responses indicated that the residential service was too clinical, formal and not homely.

- **Integration of Services**

  Parents liked that all the services were in same building and some respondents stated that they found information easy to get, by telephoning their Social Worker, Occupational Therapist or Community Support Worker. Conversely, new parents find it difficult to get information.

- **Contact**

  There were a number of responses related to difficulties in getting through to teams and a request for a receptionist was made.

FINDINGS

- **Staff**

  Staff were viewed positively.

  Staff are supportive.

  They [the parents] receive moral support as well as care.

  Staff always returned calls to parents.

- **Service provision**

  "I found the service daunting at first but we are now benefiting from it."

  "My CST worker talked to me about behaviour and autism."

  Many said that:

  Their needs were met.

  The service was stimulating and safe for children.

  They are happy with the contact they have with the service and the response they receive.

- **Safeguarding/Child Protection**

  Comments related to child protection were very positive considering the context, they included:

  - "We have all greatly benefited from the services provided"
  - "It helped improve our coping strategies."
  - "Legal and child protection procedures were clearly explained and as a result didn't feel intimidating".
  - "Very stressful at times"
  - "Glad that she doesn't need a social worker anymore".

More critical comments

Less positively, many parents talk about having too many meetings to attend and some mentioned a need for co-ordination of appointments. A few parents wanted longer or more short break sessions than they currently received. One respondent stated that children should not be on a waiting list for a residential short break service.

Provision of information on IDCS services for disabled children is very good and well publicised across a variety of media, written and electronic. However, it was clear that we hadn't publicised some aspects of our service well enough. This includes,

- How we can support parents in crisis or emergencies.
- How we can provide residential care for special dates given enough notice.
- That we don't have a residential waiting list for a service.

It may be that some parents need verbal responses to questions as and when required, rather than the information in leaflets and newsletters we routinely send or the electronic information we have built up on the web.

FINDINGS

Practitioner Research: what we learned

Generally, practitioners were not surprised by the suggestions parents made for improvements to the service.

Whilst practitioners believe we provided a good service, they underestimated parental support and appreciation shown by the consultation. They were surprised and appreciative of the positive comments from parents and the positive results from the children's consultation.

To hypothesise, parents are tired and often don't take the time to formally tell us what we are doing right or what they appreciate until their child leaves us at 18, or they give us presents at Christmas. Often, even if we know parents are appreciative, we don't know why.

Parents don't routinely come to our coffee mornings or respond to open invites to comment in significant numbers UNLESS they are worried about an aspect of provision OR during times of change. Whilst this is understandable given their responsibilities, it means we often only hear the negatives AND we do remember these more than the thanks or the appreciation shown.

It is clear from the consultation findings that integration has been beneficial
The practitioner findings and research analysis provided insight into what made successful integration possible.

- Rather than practitioners becoming homogeneous, respect for each other's roles and responsibilities has grown as they understand each other.
- Growth in trust has led to willingness to 'giving up' some of their tasks to another professional.

FINDINGS

- Use of CAF's has led to a decrease in initial assessments for the social care staff but a growth in specialist assessments.
- Growth of a team culture among fieldwork staff has led to a joint problem solving approach. Sharing of concerns among the child's core group has improved holistic assessment and a sharing of professional risk.
- Combining resources and skills has led to an increase in preventative work; improved ability to support families through stress at a lower tier of intervention.
- Branding, without our noticing, has taken on a significance we didn't expect or see coming. Our culture has developed around 'shine' - the visual recognition symbol for the children who use our service. Staff feel ownership for it and for the Light House. There is a pride in being part of the service.
- A common language has emerged as staff work closer together.
- The value of having the new build is recognised in terms of making working together, networking and communication easier. However some staff groups have been based together before and the level of joint working and interaction was not the same as it is now. Communal ownership and sharing equipment etc has made the difference.
- Integrated systems processes and management are as valuable as working side-by-side.
- There was an expectation of staff and by staff that they would have to change how they worked when we moved into the new building. Staff began to work together within weeks of moving into the building, changing how they worked and taking advantage of the experience and knowledge of the various disciplines relatively quickly.
- Practitioners are very aware of the aspects of the service that are going well and contributing to good outcomes for customers AND equally

aware of the areas that warrant prioritisation and those that need improving but can wait until the priorities have been addressed.

- Practitioners are not interested in standing still, they believe in being the best they can be, they are clearly committed to the children they work for and want to do their best.
- The Light House ‘brand’ has brought a common identity which has been significant to practitioners possibly linked with perception of success.

FINDINGS

Direct outcomes for children and young people

Both the ACA and consultation findings have been placed on each child's file record. Any individual issues previously unknown which emerged from the findings have now been addressed in care plans. Findings from 2 children have been included in their individual assessments and care plans for Court proceedings.

Indirect outcomes for children and young people

- Children and young people have been given a voice in their service delivery and planning.
- They have exercised their Rights under the UN Convention and the 2004 Children Act.
- The importance of participation and the value of these children for the IDCS have both been modelled to practitioners.
- The inherent value of our child customers and the impact on organisational culture of this consultation process in turn safeguards the child in our care.
- The skills and knowledge practitioners have enhanced improves assessment and day to day interaction with the children.
- Improved communication understanding will impact on the numbers of challenging episodes children exhibit.

OUTCOMES

Outcomes following parent carer's consultation

There were immediate changes or enhancements which the service could put in place, following the findings from the consultation and with the resources available.

- The recruitment of a Receptionist.
- An answering machine to improve contact.
- Publicise our emergency or crisis support capability.
- Ask parents to give us lots of notice to enable us to respond to any special dates they would like to book.
- Specifically, a child's Key worker spent time in a child's home within two weeks of a request made at the consultation interview.
- The graphic designer who created 'Shine' was engaged to decorate the residential units.
- Staff 'mug shots' will be sent out to all parents and a 'Who Is Working Today' board with photographs of staff is now placed at the entrance to both units.

Findings indicating improvements required which are out of the IDCS resources or a commissioning response is required.

- Care co-ordinator scheme to co-ordinate meetings and service plans.
- Parking facilities in the surrounding area is poor when sports events are occurring in the park.

OUTCOMES

Future priorities in the light of the 360° study of the IDCS

- Improve pathways for newly diagnosed children that include better communication and working together with our colleagues in a particular area.
- Concentrating work on small children to affect the most change to posture, mobility and behaviour.
- More intense behaviour training and management and support for learning disabled children with challenging behaviour that may or may not have a diagnosis as yet and their parents.
- Building on the family support work that we do for very small children; parenting assessments and work with young families.
- Improving transition work, direct payments and ILF take up for young people.
- Early support and early intervention with a proactive multi agency response.

Feedback and Dissemination

A poster giving a brief summary of the consultation was posted out to all parents who took part with a covering letter. An executive summary is available for all parents who use our service and an article will appear in the Autumn newsletter advising where a copy of this can be obtained.

A poster has been printed, outlining the consultation and participation and is displayed in the building. Others have been provided to the CYPD marketing and communication sections for use in any marketing or consultation event. The Executive Summary and the full Consultation Report was presented to the IDCS Partnership Management Board in September. The Board's membership includes senior managers from the PCT and CYPD and parent representatives.

OUTCOMES

The Head of Service gave feedback in person at a Coffee Morning in September to Parent Representatives and all attending parents.

The Executive Summary and Consultation Report were circulated to Senior Managers in the PCT and CYPD through the Disabled Children's Strategic Commissioning Group and the CYP Executive.

Both documents are available on the Light House website as PDF documents for anyone who is interested.

Jacqui Jensen
Head of Service
Integrated Disabled Children's Service
www.derby.gov.uk/thelighthouse