

# Highland Children's Forum

Representing Children in Need in the Highlands



Dalton



## Children with Learning Disability

## Health Consultation

## Introduction

This consultation with children with learning disabilities about health issues was carried out by the Highland Children's Forum's Children's Consultation Worker, for the inspection of health services in Highland for those with learning disability (April 2005).

The time scale for the consultation was such that the children who took part all lived within 30 miles of Inverness and so this sample is not necessarily representational of children's experience elsewhere in the Highlands.

The consultation was explained to parents and their consent sought. Children were asked to complete a front sheet (Appendix 1) identifying the areas of learning/health difficulty that were true for them. They were then asked to think of a day when they were feeling healthy (feeling good for those who were not sure what feeling healthy was) and to draw themselves feeling healthy. The children were then asked about what things helped them feel healthy. The children were able to write their own responses or could have them scripted, whichever they preferred. The children were then shown stickers representing various health professionals, and asked to choose which of these people helped them stay healthy. The children were then offered emotion stickers and asked to choose which face they would be showing when visiting each of these people. Stickers about the hospital and medication were offered in a similar way. The children's comments and some of their drawings are included in this report.

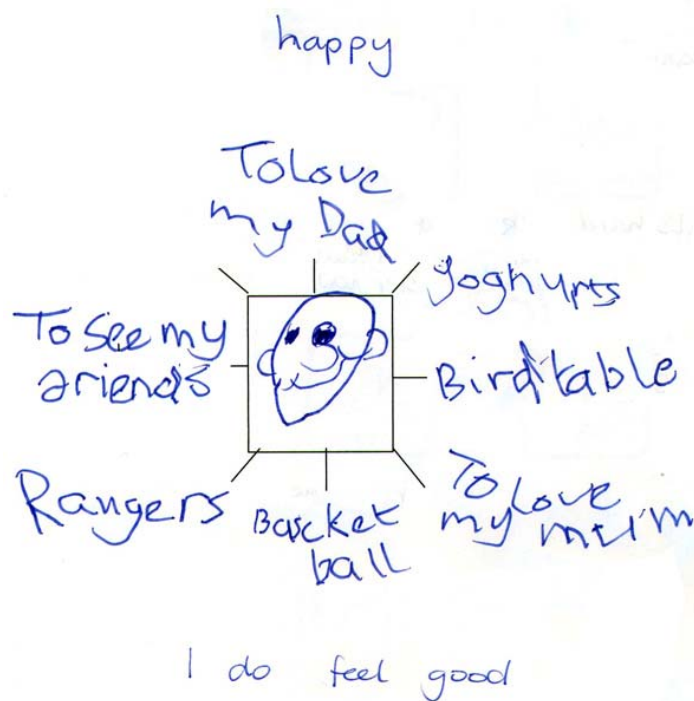
The discussion with children is all in this font, to separate this from comments made by their parents.

The pre-school children's stage of communication and understanding prevented their taking part personally, but their parents were asked questions relating to the quality indicators (Appendix 2) the responses in full are included in this report.

The Children's Consultation Worker visited the children's ward to find out about the admission of children with learning disabilities. A summary of these findings is also included.

The results of the consultation are shown in graphical form on Appendix 3. The number of children taking part is too small to claim any statistical significance for these graphs, they are none the less an interesting snapshot of children's experience.

## Ross: Aged 15 - Accident with brain injury



Ross felt healthy, but was not sure how he knew he was healthy

He knew more about feeling good and shared the things that made him feel good, "To love my Mum" and being able to make a bird table which was in the garden for all to see.

Ross loved the hospital staff.

He found occupational therapy was not fun as it was hard, but it is easier now.

make him feel good

Ross and the things that

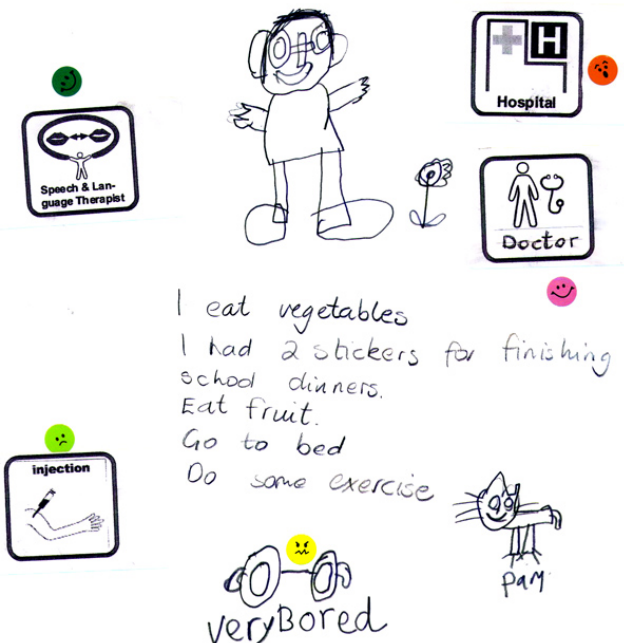
Ross found physiotherapy difficult, because it was hard work. He called the physio a "physioterrorist" - but said "of course I love her". Ross also said he loved one of the nursery nurses

Ross worried about speech and language therapy as he felt he could not get it right, it was difficult

Ross does not like giving blood samples - they hurt!

Ross' mum completed a hospital questionnaire (Action for Sick Children) and gave the hospital 10 out of 10 for quality of care

## Mary - aged 12, with severe learning disability and visual impairment



Mary knew all about being healthy, they had done it at school.

Mary could not remember attending the hospital as a young child when she had had many out patient appointments (for special boots, hearing and vision), but did remember going in twice to A&E!

It was sore and worrying as she did not know what would happen, they might hurt you! On one occasion she needed stitches and on another an X-ray. All of this had been worrying and scary.

### Mary Feeling Healthy

Mary also went for a "jelly belly scan". Mum came too. The jelly was cold. The staff were all nice. Sweets help!

Audiology has a playstation, but Mary finds ophthalmology appointments "really, really boring"

Mary does not like visiting people in hospital as she doesn't like looking at sick people.

Mary likes seeing the speech and language therapist and her GP.

She does not like getting injections.

Mary's mum reported problems getting speech therapy for Mary. She had gone to a special school initially, just to get speech therapy. Mary was not happy (she told me she was bullied and only had one friend). Mary moved to the local primary and the speech and language therapist who lived near by called in to the school on her way to work. Mary's speech improved enormously when she was with other children who spoke all the time.

## Matthew - aged 7 with autistic spectrum disorder

It was a lovely sunny day and Matthew wanted to go out on his bike, so was not very enthusiastic about the consultation

Matthew liked visiting the dentist.

He enjoyed visiting the GP as he had a Pegasus (toy flying horse) to play with

Matthew did not like the hospital but he liked the nurses.



Matthew Feeling Healthy, with Wonderful Teeth

Mum said "Matthew liked visiting the dentist as he is given lots of time to explore the room and he gets a ride in the dentist's chair. He also gets some little mirrors on sticks to take home and play with."

Matthew had gone to A&E 3 times after falls. Mum said "The reception staff and triage nurses were very understanding of how important it was to deal with Matthew quickly because of his limited understanding and inability to wait for long periods without becoming distressed." She did not feel the doctors showed the same understanding.

## Daibhidh aged 13 with autistic spectrum disorder

Daibhidh



Daibhidh had had an unpleasant experience getting injections at the school. It had involved waiting in a line. He had felt worried and scared.

Daibhidh feels he now understands why he needed the injection, but didn't know then. He thinks it would have been "less unpleasant" if he had known.

Daibhidh felt puzzled at appointments. He said that professionals talked to his parents, not him, he was not included and things were not explained. He is told "what is done not what for".

Daibhidh says he forgets if told early, he needs told on the day. People should ask more questions.  
Daibhidh Feeling Puzzled

Daibhidh is now afraid of the dentist, after being so upset about his school injection.

Daibhidh's mother felt that professionals saw the ASD label and not the child, so did not speak directly to him. She felt that Daibhidh needed questions that were not open questions, but were more in depth than yes no answers.

Mum reported that dietician did ask Daibhidh direct questions but he was bored with the rest of the appointment. There has been good follow up and mum can even phone from the supermarket to check the ingredients of certain foods. The child does not need to listen to all the dietary information.

Mum felt there was a break down in communications between services, especially with the school nurse records which don't go to the GP. Mum felt GP's had a valuable role in knowing the whole child through all stages and so was a vital cog in the multi-agency approach especially at the transition from child to adult services.

## Gina aged 11 with Mearles Irlen Syndrome and suspected autistic spectrum disorder



Gina at SALT

Gina knew all about being healthy, what food to eat, getting enough sleep and doing exercise. She knew about vitamins and minerals too.

Gina was happy to see the paediatrician and psychiatrist, the dietician and ophthalmologist.

Gina enjoyed speech and language therapy.

Gina had no opinion about the GP

She was puzzled about seeing the psychologist as she did not know what it was for.

Gina's mum reported felt that Gina's combination of problems had led to her not being diagnosed early for some of them. She had had a stigmatism and the focus on this had meant her Mearles Irlen Syndrome had been missed. Gina avoided eye contact and had behavioural difficulties at school, but these could have been due to her visual problems, not seeing the blackboard and copying from neighbours or shouting out, they could have been down to ASD. There was a feeling that professionals settled for one diagnosis and did not look at things another way to see if there was another diagnosis too.

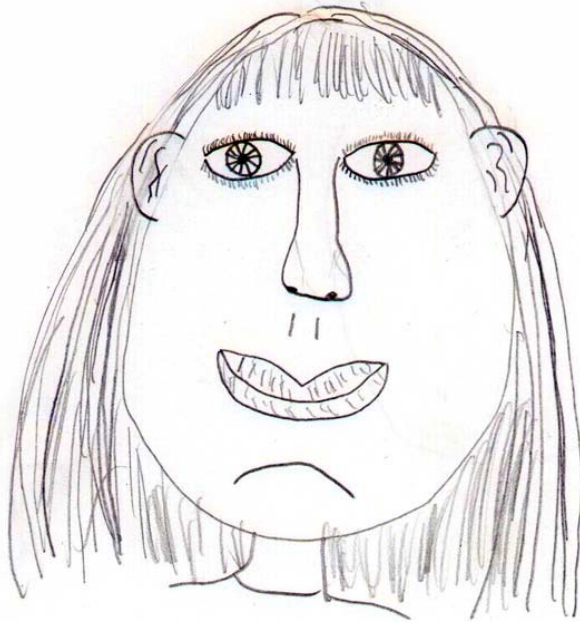
"I needed someone who could advise me on how to cope with children's breakdown in mental health and no-one could answer me."

Mum reported that when Gina was depressed no one seemed to think there was a problem. When she finally went to Newcraigs it was at least 2 years after the crisis point and it was because of the absurd behaviour not the hopelessness and wanting to kill herself.

"It is more that the kids get picked up when it interferes with other people and not when it could be dangerous to self.

My son had a breakdown the month before my daughter and my solution to that was to finally take him out of school, at that point questions were then asked by education but the SW and GP backed my decision for his mental well being."

## Alice aged 11, with autistic spectrum disorder



Alice did not think she knew about being healthy but said that people made a fuss about what she ate, "I don't eat enough soup and things - it has something to do with a balanced diet"

"I know vegetables are healthy but I don't really like them."

"I know exercise is good for you. I like swimming. I would like to try new kinds of exercise."

"I like sleeping, I am a little bit cranky when I stay up late."

Alice, A Self-portrait,

### Feeling Healthy

Speech and language therapy give Alice pictures that tell a story and she has to put them in the right order, it is quite difficult.

"The people are nice and ask me about the things I do at school."

Alice also visits the orthodontist at the hospital.

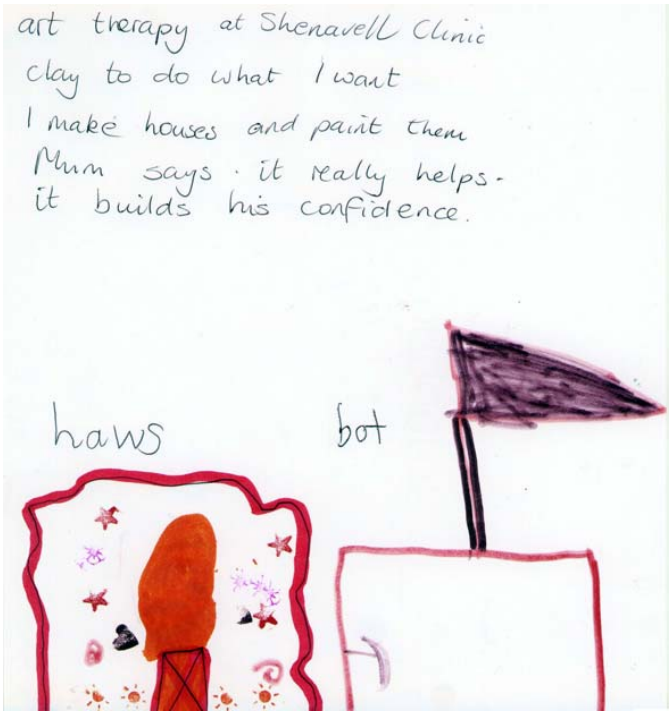
"It is like being at the dentist, not bad. They just check your teeth. One time they gave me an Xray - I had to put my mouth on this yellow thing - they told me what to do. I just felt normal."

I don't remember pain when the nurse gave me an injection, but I had to put cotton wool on it, it was bleeding."

"I didn't like the gloopy medicine, it was yuch, it doesn't taste nice to me."

Alice's mum said as well as the injection, Alice had had to give a blood sample once and had become most upset about the anaesthetic cream and patch, and had insisted on its removal, but had not reacted to the pain of the blood sample.

## Cameron, aged 8, with ADHD, learning difficulty and possibly autistic spectrum disorder



Cameron had good ideas about staying healthy, including cleaning your teeth.

He said he felt "not that good when you get your teeth done, you're grumpy".

Cameron takes Ritalin and something to help him sleep and is happy to take these. He doesn't like injections!

Cameron visits the Birnie where he sees the speech and language therapist and the paediatrician. He enjoys his visits and knows the SALT helps him

"to talk"

### Cameron's Clay House and Boat

Cameron also visits the Shenavell Centre to see an art therapist which he really enjoys, he gets to make things out of clay.

Cameron's mum is really pleased with the art therapy and feels it has helped Cameron express himself, she felt the art therapist had opened up things in Cameron that she hadn't known.

Cameron and his family have moved up from England and felt the transition had been very smooth. She felt the doctors here had wanted to look deeper into Cameron's problems and not just stop at the ADHD diagnosis, but look at ASD. She felt that Cameron had been helped by this and was pleased with the level of service.

## Response from Mother of Kerry, aged 4 ½ with global developmental delay and epilepsy

Q1 1 Involvement of children with learning disabilities and their families through self-representation and advocacy

Mum felt involved in the planning of services, but felt having a coordinator would be very helpful.

She had not been involved in formal evaluation but had contributed to discussions about improving services.

Speech and language therapy is a problem, there is none for Kerry just now and she has no speech, just a few signs.

Kerry has occupational therapy just now as a pre-school child but this will stop or lessen when she becomes a school child, but Kerry's needs are such that she will require regular assessments and new equipment. Kerry has been waiting ages for a stand up frame.

Kerry has support workers who slot in when they can rather than when Kerry needs them. Not all support workers can give Kerry her medication, so the help is not really person centred.

Kerry's Mum knew of advocacy services but not particularly for health.

Q1 4 Children with learning disabilities have a range of additional and complex needs, often life-long that require good integrations of general and specialised services, across different age ranges and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

Kerry's Mum felt services were not very well integrated, she has to do the integrating. Physiotherapist is very good at supporting and speaking to others.

Kerry's family have moved from Southern Ireland to Northern Ireland and then to the Highlands. When moving to Scotland, Kerry was put back at the end of waiting lists, she is waiting for referral to wheelchair and other services. Kerry is also waiting for a special bed. There was a big waiting list for the learning disability nurse, OT and physio, even for a social worker.

There was early intervention for Kerry, starting when she was 12 days old. In Scotland, the Birnie Centre has been fantastic and Kerry did get to see the OT, physiotherapist and so on there.

Discharge from hospital has been quite good each time and when a suction unit was needed for going home this was sorted out by the Community Paediatric team.

Kerry sees OT, SALT, Epilepsy team, visual impairment and consultant. Consultant is fantastic, can always get in touch, knows Kerry and the family really well.

There are not sufficient health services in the special school!

Crisis is not unusual for Kerry who is often admitted to hospital or is poorly at home. This presents problems for the whole family. This is when a coordinator would be most help.

Respite is available using different options.

Administration of medicines is not a problem in school, but is with support workers.

#### QI 5 In-patient

The quality of accommodation and services is a key contributor to quality of life. People who use services are entitled to make choices and decisions about their life and to live in the least restrictive setting.

#### In hospital

Safety - Kerry has seizures which can be very subtle and so cannot be left unwatched, Mum and Dad take turns to be with her the whole time. Hospital doctor did not always listen to parents who knew seizures best, and wanted to change medication.

Sensory play was brought to Kerry's bed and she loves the snuzzlein room

The hospital is far too hot, but the food and accommodation for parents is good. Not enough space for things like buggies and wheelchairs.

No problems with visiting

#### QI 6 Planning Services and Partnership Working

To address health inequalities and plan services for children with learning disabilities, information on the needs of the population is essential. A strategic approach across NHS boards, Community Health Partnerships and local authorities is required for effective partnership working. The needs of children

with learning disabilities should be part of all planning activity and strategy documents.

Equity of access to services not happening, there are gaps in SALT and OT, plus vision support is losing funding. More children with complex needs are surviving, more resources are needed.

Shared assessment would be a big improvement, especially when moving areas as need to start with each service from the beginning again.

Long term planning is needed to cater for the increasing number of children with complex needs, look at the wider picture of health, housing, education, play and so on. There needs to be coordination. More indoor play facilities needed.



The Doll's House Birnie Centre Playgroup

## **Response from Mother of Emily aged 4, partially sighted and possibly on autism spectrum, although diagnosis not yet confirmed**

QI 1 Involvement of children with learning disabilities and their families through self-representation and advocacy

Emily's mum felt consulted about planning of all services except for speech and language therapy, where you were just told. She has not been involved in evaluating services and has no complaints. Person centred planning was happening.

The key worker was a useful support and would be an advocate if needed.

QI 4 Children with learning disabilities have a range of additional and complex needs, often life-long that require good integrations of general and specialised services, across different age ranges and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

Emily is receiving pre-school visual and behavioural support and mum has good expectation of a successful transition in to school.

Early intervention in speech therapy has been sporadic, Emily was getting weekly SALT as recommended, but is now only getting support once a month. The previous speech therapist had provided information about what parents could do at home, the new therapist does not do this.

As well as SALT, vision support and pre-school teachers, Emily is seen annually in Glasgow.

Emily waited 4 months for an appointment with the eye specialist, but once she had been diagnosed, support was given. Emily's parents have been waiting 8 months to see a geneticist.

Emily's behaviour has given cause for concern but no one is quite sure what the problem is yet, she is under ongoing assessment.

QI 6 Planning Services and Partnership Working

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with learning disabilities should be part of all planning activity and strategy documents.

There does not appear to be equity in speech and language therapy, Emily received more in Lewis than she does in Inverness.

Shared assessment would be a great idea as everyone wants to know everything from the start and it can take up to an hour.



The Sensory Area, Birnie Centre Playgroup

# Response from Mother of Sophie aged 4, with epilepsy, cerebral palsy and developmental delay

QI 1 Involvement of children with learning disabilities and their families through self-representation and advocacy

Sophie's mum felt that she had been very involved with the planning of services for Sophie, her opinion was always sought.

She had a complaint but this was sorted satisfactorily.

Sophie lives 30 miles from the hospital and person centred planning means that most services come to her, but if she needs to attend the hospital, transport is provided.

Sophie's mum has not felt the need for advocacy.

QI 4 Children with learning disabilities have a range of additional and complex needs, often life-long that require good integrations of general and specialised services, across different age ranges and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

Sophie's mum felt that there was joint care planning and clinical review.

There has been a lot of support for Sophie's transition into school.

Sophie has moved up from Edinburgh and although the notes were delayed, the services were in place for her in advance.

Sophie's problems began when she was 12 weeks old. She had gastro-enteritis and was very poorly. The GP who knew the family was away and 3 different locums came out in 24 hours, but failed to register a problem, and had put on the notes "hysterical mother". By the time Sophie's parents took her into A&E she was in shut down, had stopped breathing and took an epileptic fit. Sophie was in hospital for 6 weeks and all the support she needed for going home was organised in hospital. Sophie's mum felt that apart from the locums' errors, early intervention had been effective.

Sophie has not had to wait for treatment. Crisis response has been good (since), for example when Sophie took an epileptic fit.

Sophie is beginning to show signs of behaviour problems, which has been discussed with social worker.

QI 5 In-patient

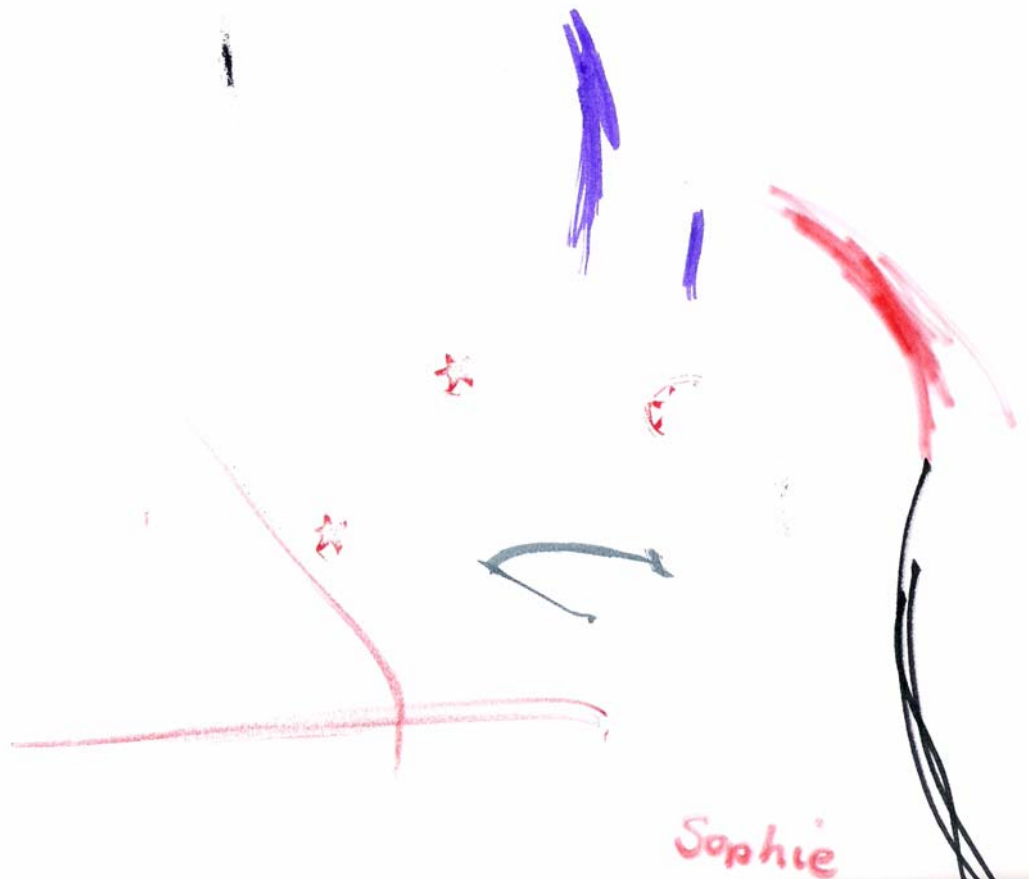
The quality of accommodation and services is a key contributor to quality of life. People who use services are entitled to make choices and decisions about their life and to live in the least restrictive setting.

Sophie's mum had felt welcome when in hospital and had stayed the whole time and been given a maternal chair to stay beside Sophie for the critical 72 hours.

#### Q1 6 Planning Services and Partnership Working

To address health inequalities and plan services for children with learning disabilities, information on the needs of the population is essential. A strategic approach across NHS boards, Community Health Partnerships and local authorities is required for effective partnership working. The needs of children with learning disabilities should be part of all planning activity and strategy documents.

Sophie's mum was quite happy with the support offered and had had access to everything needed. She felt that shared assessment was an excellent idea.



## **Response from Mother of Euan aged 2, Spina bifida, hydrocephalus, holoprosencephaly, diabetes insipidus, gastrocnemius fed, intermittent catheterisation, dislocated hip**

Q1 1 Involvement of children with learning disabilities and their families through self-representation and advocacy

Mostly Mum has to do the planning and keep track of appointments, treatments and so on. Mum can phone if there is a problem. Euan was an in-patient most of last year.

Mum has not had a complaint as such although Euan was in a lot of pain post-operatively and he was back and forth to the hospital, it took ages for an appropriate response. Euan had to go back to theatre to have his operation reversed. Mum felt that she was not believed about how much pain Euan was in.

Person centred planning doesn't always work in hospital, there are set times when Euan's catheterisation should occur, but because the nurses cannot do it, he has to wait for a doctor, which causes him some discomfort.

Q1 4 Children with learning disabilities have a range of additional and complex needs, often life-long that require good integrations of general and specialised services, across different age ranges and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

Euan is seen by 3 medical teams, in Aberdeen Hospital, Raigmore Hospital and in the community

Euan is seen by at least 24 different health professionals.

Euan's mum felt the coordination between services was good, letters were copied to everyone. Transition between services, Aberdeen/Inverness/community was good

There was appropriate early intervention for Euan, his spina bifida was known about 6 weeks before birth, he got physio at 3 or 4 hours old! Mum was taught how to do things and has been involved in his treatment since he was 3 weeks old.

Euan has never had a long wait for treatment and is generally seen right away.

There is arranged crisis response for Euan, his first point of call is Raigmore unless there are problems with his shunt in which case he would be given an air ambulance to Aberdeen and would be seen within 4 hours.

Respite for Euan is just beginning now with once a fortnight overnight stays with Katie Kares and two nights a month at the Orchard.

Euan requires regular medicine and medical procedures, including catheterisation 4 times a day and 13 hours of feeding tube per day, along with medicine am and pm. Respite have now been trained to cope with this administration, but the hospital nurses can't.

#### QI 5 In-patient

The quality of accommodation and services is a key contributor to quality of life. People who use services are entitled to make choices and decisions about their life and to live in the least restrictive setting.

Euan's mum is quite happy with safety in hospital, Euan feels quite at home and the regular nurses know him well and can recognise when he is poorly. Euan enjoys the play specialist and gets priority when in isolation.

The hospital is always stuffy, especially at night time. The bedding could be more breathable.

As someone who spends a lot of time in hospital with her child Euan's mum felt that she needed somewhere to go and let off steam and stress and suggested some sort of fitness room for staff and relatives would be useful.

#### QI 6 Planning Services and Partnership Working

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Euan's mum felt access to services had been good.

Shared assessment would be great as at the moment she has to go through the same forms every time he is admitted. Euan has two full folders of notes and the student doctors do not get time to read through all the information. Time should be provided and just the recent notes made available.

There is a long term aim to plan for some autonomy for Euan: some movement although he will not be fully mobile, hopefully some speech so that he can communicate his needs and feelings, and most importantly when he is sore. The hospital did offer respite once.



Art activities at Birnie Centre Playgroup

## Response from Mother of Matthew, aged 17, with autism (mother now volunteers at the Birnie)

Q1 1 Involvement of children with learning disabilities and their families through self-representation and advocacy

Although Matthew as a young person was entitled to be consulted about services he tends not to want to be involved, if asked he would want things to stay the same all the time.

Person centred planning has not been Matthew's experience; he has had to accommodate service providers in the times and places to attend.

Q1 4 Children with learning disabilities have a range of additional and complex needs, often life-long that require good integrations of general and specialised services, across different age ranges and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

The learning disability nurse has been good at coordinating services.

Matthew is facing the transition into adult services, but this is only just beginning to be discussed now.

Matthew did not receive appropriate early intervention. He had been given an assessment pre-school but the paediatrician had found nothing medical wrong and referred him to educational psychology. Matthew was not diagnosed until primary school.

Matthew recently needed to be referred to the skin clinic. The receptionist was made aware of his autism and tried to accommodate the time of his appointment to suit. However, the doctor that Matthew saw did not seem to have understood his autism and treated him like a small child. All the preparation for attending the clinic was left to mum.

Matthew has required support for his behaviour and was referred to a children's clinician for this. He is now moved into adult services and someone has visited him from adult services. Mum feels it is a case of crisis management, help is brought in when his behaviour is bad, but the 4 point plan is not followed consistently in between times. Matthew was not involved in developing this 4 point plan and it was not shared with his support workers and out of school club.

## QI 5 In-patient

The quality of accommodation and services is a key contributor to quality of life. People who use services are entitled to make choices and decisions about their life and to live in the least restrictive setting.

Matthew was a day case 13 years ago. The first time he went in he was given a room of his own but the second time was in an open ward. He became very distressed and the sedative he was given did not work. Preparation for his visit would have helped.

## QI 6 Planning Services and Partnership Working

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Matthew's mum felt shared assessment was a good idea.

Matthew's mum does not know what planning there is for services for Matthew as he goes in to adult services. She feels that what he would need is good preparation for any appointment and a room of his own if he were to be admitted.

## Children's Ward

What happens if a child to be admitted has learning disability?

If the child is referred from the community dentists or any of the consultants, any learning disability is flagged up, there is good communication, and such children are referred directly to the play team.

For example, a child with Asperger's has to come in to hospital. A gradual plan of introduction has been taking place, with the child bringing in a letter (blank) for the play team person, sometimes he has to take it to the lift, sometimes to the clinic, sometimes to the ward and so on. This is gradually building up his familiarity without the stress of having an appointment. When an appointment is required, he does not need to wait in the waiting room as he would find this stressful, but is met in the café and taken in through a back door.

Photographs of the ward and clinics are available for children to use in advance of their appointments. A complete folder of photographs is available for specific tests.



MRI Scanner Model, with Photograph Folder

Child friendly posters describe every test in child's language.

The child is told how things will feel.

" A wee bit coldie, coldie brrrrr.



Child Friendly Posters

The play team meet children in the clinics before admission for surgery. This gives them time to get to know the children. A diary is used to ensure preparation for admission happens.

Person centred planning occurs - children are given a work sheet with the non-negotiable items in print, but the child gets to make plans for everything else. Colourful stickers are used to decorate this plan.



In the treatment room, wall murals are carefully painted to include colours, patterns, different numbers of things to count, describe, find on the wall for distraction. A video player is also available so a favourite video can provide the distraction. They are planning a projector in the anaesthetic room before theatre for children's distraction there.

Treatment Room Wall Mural



Snuzzlein Sensory Room

There is a wonderful sensory room in the hospital and items from it are taken to the bedside of children who cannot be moved.

The adolescents have a nice separate area with age appropriate activities and a living room type space. They are allowed to put up posters and so on.

The accommodation for the parents is very homely and suitably close to the ward. All usual facilities are there.

Acknowledgements:

Grateful thanks to all children and parents who took part in this consultation.

Thanks to Stephanie of the Play Team in the Children's Ward Raigmore Hospital.

Thanks to Louise Corbett and all at the Birnie Centre

Thanks to Sheila Lawtie of Action for Sick Children

Health Consultation process from Wetton, N. (1998), *Healthy and Happy, Confidence to Learn. A Guide to extending health education in the primary school* Health Education Board for Scotland, Edinburgh

# Appendix 1

## Participant Cover Sheet

Name:

School:

Date:

Age:

Tick, are you a boy



or a girl



Tick any of these that are true

I find it harder than other children:

1. To move about or do exercise

2. To learn things

3. To talk and listen to other people

4. To control my actions and behaviour

5. To control and understand my feelings

6. I have difficulty seeing or hearing

7. I am ill and need to take medicine

## Appendix 2

### Parent Questionnaire QIS Inspection Health Services for the Learning Disabled

QI 1 Involvement of children with learning disabilities and their families through self-representation and advocacy

Describe your experience of the following:

- Consultation and planning of services
- Evaluation of services and complaints
- Person Centred planning
- Advocacy services

QI 4 Children with learning disabilities have a range of additional and complex needs, often life-long that require good integrations of general and specialised services, across different age ranges and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

Describe your experience of the following:

- Joint care planning and clinical review
- Age transitions
- Transitions between and within other services
- Appropriate early intervention
- Discharge from hospital
- Range of services used
- Access/waiting times
- Sufficient health services to allow integration into mainstream schools
- Crisis response
- Respite
- Behaviour
- Administration of medicines

## QI 5 In-patient

The quality of accommodation and services is a key contributor to quality of life. People who use services are entitled to make choices and decisions about their life and to live in the least restrictive setting.

Describe your experience of the following:

- Safety - play areas etc
- Homely-ness
- Play areas
- Smell/noise/heat etc
- Personal space and property
- Visits
- Clothes

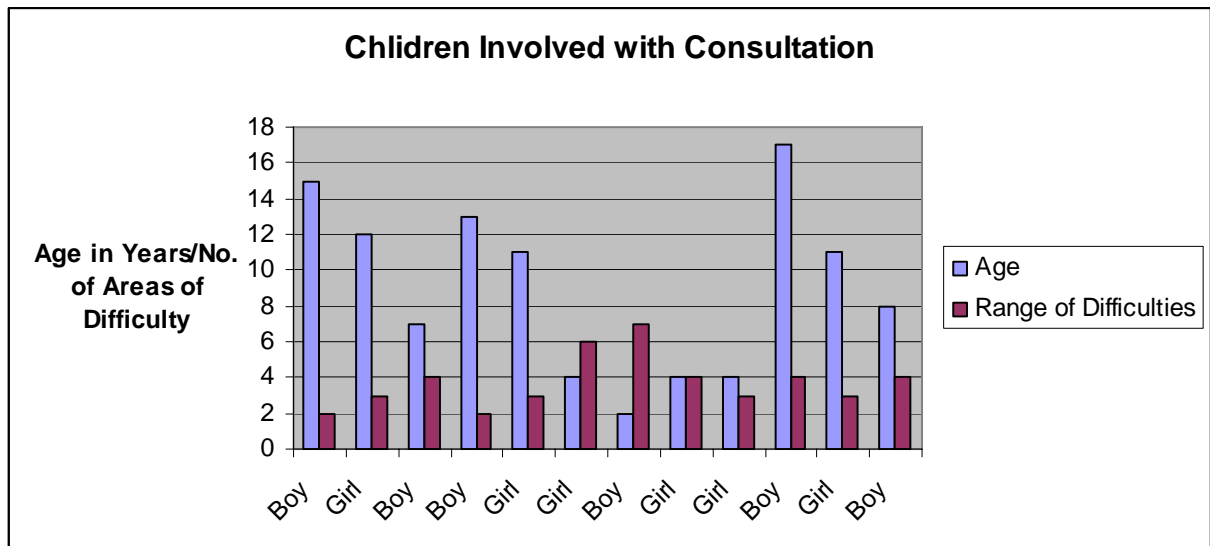
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Describe your experience of the following:

- Equity of access to services
- Shared assessment
- Plan for learning disability - what do you know - what does it need
- Respite care - in hospital
- Child Protection

## Appendix 3 Graphical Representation of Results

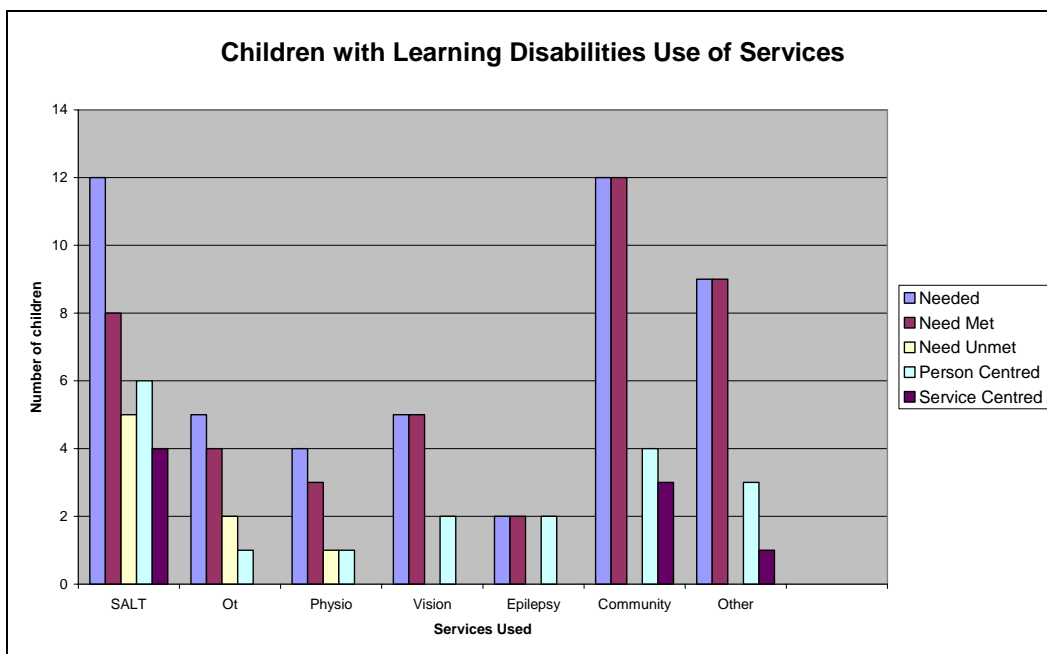


The above graph indicates the age, gender and identified range of difficulties experienced by the children who took part. The “range” is the number of difficulties, from the following list of 7, that children felt were true for them.

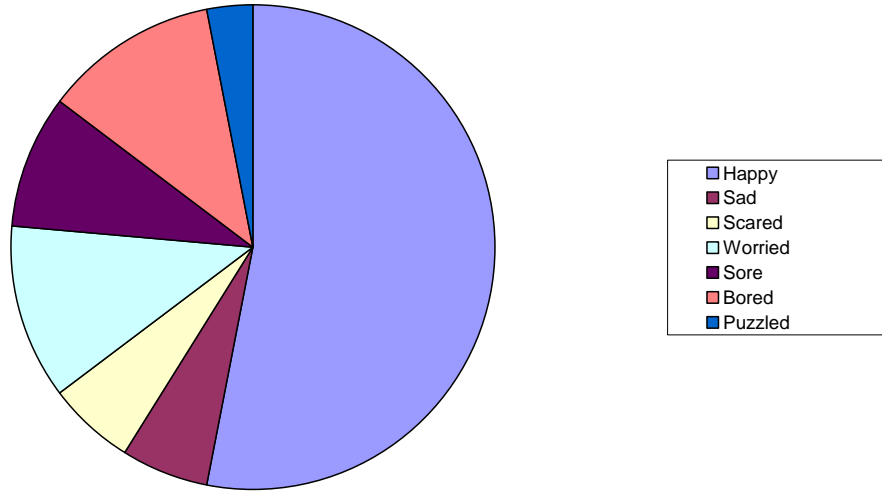
“I find it harder than other children:

To move about or do exercise, to learn things; to talk and listen to other people; to control my actions and behaviour; to control and understand my feelings.

I have difficulty seeing or hearing. I need to take medicine”



### Children with Learning Disabilities - Expression of Emotions about Health Services



### Children with Learning Disabilities Experience of Hospital

