

# Wraparound:

the Health Impact Assessment of the  
All-Inclusive Wraparound Scheme

The Southern Health and Social Services Board

The Institute of Public Health in Ireland

August 2002

## Wraparound: the Health Impact Assessment of the All-Inclusive Wraparound Scheme

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## Preface

The All-Inclusive Wraparound Scheme (Wraparound) [1] seeks to improve the quality of life for children with disabilities and their families and carers by developing new ways of working in partnership with the families and carers of children with a disability.

I am particularly pleased that we have been able to complete a Health Impact Assessment early in Wraparound [1]. Health Impact Assessments are described in the new Public Health Strategy for Northern Ireland *Investing for health* [2] as a key tool for facilitating cross-sectoral action, promoting health and reducing inequalities. Using this approach will enable us to ensure that we are making the best use of the resources associated with Wraparound. It will facilitate service developments to reflect the best evidence of what works for children with a disability and their families and carers and accommodate partnership working with families and carers, professional staff and the voluntary sector. Hopefully it will also make decision making in Wraparound open and transparent to all partners and the general community.

This report contains a huge amount of information about the needs and difficulties faced by families and carers of children with disability. It combines local information with published evidence together with the views of parents, carers, children, professional staff and the voluntary sector.

The Health Impact Assessment presents a challenging agenda for all concerned with services for children with a disability that we will seek to address in the next two years. Our hope is to repeat the exercise in November 2003 and measure progress.

Finally, I would like to thank all the people who have contributed to the Health Impact Assessment. In particular I would like to thank the Evaluation Task Group of Wraparound led by Dr Brid Farrell, Ms Jacqui Mc Garvey, Ms Iris Elliott from the Institute of Public Health in Ireland and Ms Erica Ison who acted as an external consultant to the Health Impact Assessment.

Brian Dornan  
Director of Social Services,  
Southern Health and Social Services Board

## CHROMOS

Reluctantly you journey to the outer world  
Too frail for the rigours of labour  
Your ailing, feeble body falters  
Inching its way in breech position.  
Birth comes with deafening silence.  
Your sloe-like pallor confirms months of agony, suspicion, fear;  
Shifting, darting, oblique glances imprison me  
Inwardly screaming, begging to be told.  
No-one hears.  
No-one wants to hear.  
'It's a boy', they say with feigned assurance.  
'Has he Down's?' I ask.  
No-one answers.

Your imperfections turn my mundane, tranquil existence into a  
frenzy of silent screaming,  
Blind panic, trapped in a windowless, doorless dungeon.  
Despair.  
Deep grief envelops me.  
'A child of God, a saint for a son', they chorus.  
Pious platitudes reverberate around me.  
Why does he have to be?  
His is not the child I carried,  
This alien they foist upon me.  
My life freezes.  
No future.  
No hopes.  
No horizons.

Yet He who ordained this trial  
Was to graciously support me.

Your winters count to six now.  
Unwittingly these years uncover  
The mettle from which I'm made.  
Your being is the kingpin of our home;  
In us you have tapped that which lay dormant before your coming.  
Together we have climbed the peaks,  
Endured the troughs,  
Cavorting with death, yet running away again,  
Growing stronger, ever happy.  
Loving unconditionally.

Today we strolled together in the glen,  
You pulled your hand from mine  
To greet an abandoned, homeless man by the river.  
You hugged him with all the power of your precious being.  
His moist, sad eyes looked up at mine.  
'Nobody ever kissed me before', he slurred.  
Six winters ago they told me you would die;  
That you were handicapped.  
Today you touched and loved the unwanted.  
If you are handicapped  
What then, are we?

Sodilva Murphy

## Executive Summary

The All-Inclusive Wraparound Scheme [1] (Wraparound) seeks to develop new and distinctive way of multi-agency, multi-professional working that will make a difference to the lives of children with disabilities (aged 0-18years) and their families and carers across the Southern Health and Social Services Board (SHSSB). The aim of Wraparound is to enable children with disabilities to have access to information, assessment and, where appropriate, services which provide the social, health and educational support necessary to maximise their potential to lead socially included lives.

Children with disability are defined as 'children who have a physical, sensory or learning disability or prolonged condition which impacts on daily living in such a way that, without the provision of adequate support services, they would not achieve their optimal potential for personal development and social inclusion.' [3]

There are eight projects included in Wraparound.

- One stop child development clinic outreach to each Trust area
- Royal National Institute for the Blind (RNIB) and Southern Education and Library Board
- User participation of children with disabilities in strategic planning of services
- Autism specific service provision with the SHSSB
- Mencap family support and play advisor
- Newry and Mourne Health and Social Services Trust (HSST) and Orana Family Support Centre project
- Craigavon and Banbridge Community HSST and Banbridge Willowgrove project
- Armagh and Dungannon HSST and Oaklands project

Wraparound was introduced into the SHSSB in October 2002. It is funded until March 2004 by allocation from the Programme for Government Executive Programme Funds of £1.5m.

Wraparound is operationalised through the work of five task groups. These task groups are intended to represent all service providers and parents and carers. The role of the Evaluation Task Group (ETG) is to develop an evaluation and monitoring framework for Wraparound and to facilitate its implementation. The ETG agreed to conduct an Health Impact Assessment (HIA) on the Wraparound scheme using the funds allocated to evaluation for Year 2001/2002.

**Part one describes the Wraparound and its location, the Southern Health and Social Services Board.**

HIA was the method chosen to bring together all groups with an interest in Wraparound to review how it will effect the health and wellbeing of children with a disability and their families and carers. These groups include parents and carers, children and young people with disabilities, voluntary agencies and health service workers as well as groups such as local communities and non-health sector services.

HIA is 'a combination of procedures or methods by which a policy, programme or project may be judged as to the effects it may have on the health of a population.' [4]

The public health strategy for Northern Ireland *Investing for health* [2] strongly supports the development of HIA.

The HIA of Wraparound provided participants with an opportunity to discuss ways in which Wraparound:

- protects and improves health and well-being
- could be improved to maximise benefit to and minimise negative effects on health and wellbeing
- who in the SHSSB area will gain from Wraparound
- whether and how the health and wellbeing of particularly vulnerable or disadvantaged individuals or groups will be effected by the initiative.

Wraparound was considered a good candidate for HIA because:

- it is at an early stage of implementation and so there is scope to influence the way in which it is implemented

- all partners and key decision makers are represented in the task groups and Stakeholder Forum and so there is an agreed structure and process for recommendations of the HIA to be discussed and agreed
- it is important that Wraparound is soundly and comprehensively evaluated and monitored using standards that reflect the interests and concerns of all stakeholders
- it is a new and innovative approach to the development and delivery of services for children with disabilities, their families and carers.

The Wraparound HIA used a rapid appraisal method (*the Rapid appraisal tool for Health Impact Assessment in the context of participatory stakeholder workshops* [5]) ie one that has a limited timeframe and uses information and data that are readily available.

**Part two outlines the stages of the HIA conducted on the Wraparound and the evidence used to inform its recommendations.**

The aims of the HIA on Wraparound are:

- to identify the positive and negative health impacts of Wraparound on all stakeholders
- to produce clear comments and recommendations about Wraparound's development and delivery
- to inform the development of an evaluation and monitoring framework
- to support future service developments through the information gathered by the evaluation and monitoring system.

The HIA used a number of evidence sources:

- literature review
- routine information sources
- participatory stakeholder workshop
- consultation with children and young people.

All of the evidence is included in this report to promote transparency, and to create a resource for those interested both in service provision for children and young people with disabilities and their families and HIA.

**Part three outlines the findings of**  
**1 the participatory stakeholder workshop**  
**2 the consultation with children and young people with disabilities.**

An iterative process was used to develop the recommendations from the HIA. As data became available from each of the evidence sources, the recommendations were reviewed to ensure comprehensiveness, coherency and accuracy.

The recommendations are presented in four sections:

- recommendations from the consultation with children and young people with disabilities
- principles to guide the implementation of Wraparound (accessibility, coverage, sustainability, equity, social inclusion, effective innovation, flexible service delivery, negotiation and partnership)
- recommendations for the Wraparound scheme
- recommendations for the Wraparound projects at strategic and operational levels.

The recommendations have been developed, discussed, negotiated and agreed in the Wraparound Stakeholder Forum. The forum includes both formal representation of all stakeholders and has an open membership policy.

**Part four reports on the recommendations of the HIA.**

A monitoring and evaluation framework is included in this report. The framework has been developed by the ETG, based on the findings of the literature review and discussions about monitoring and evaluation at the HIA workshop. The ETG will oversee the implementation of the framework until 2004.

A further HIA will be conducted toward the end of 2003, to inform the continued development of services to children and young people with disabilities and their families. The second HIA will:

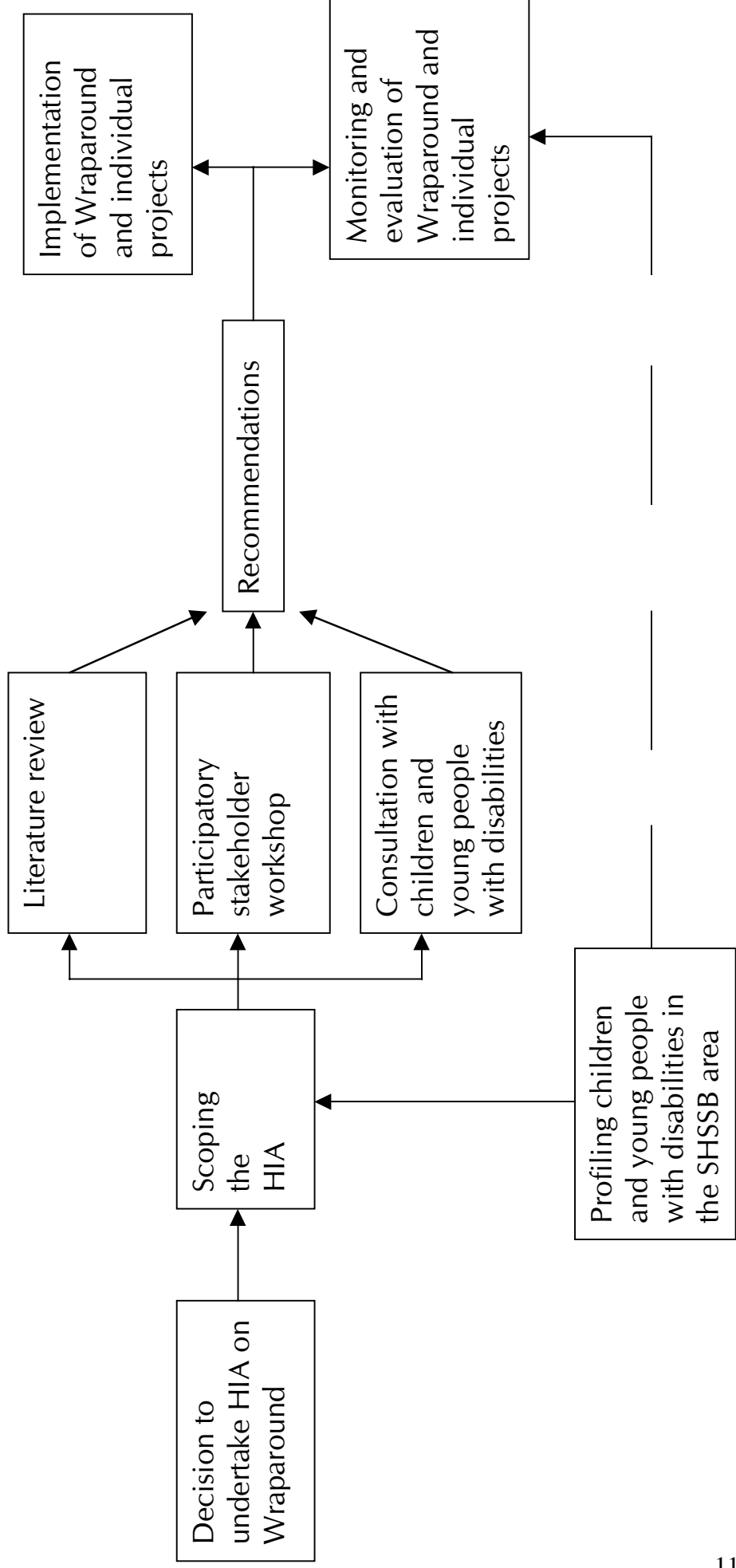
- review the accuracy of the impacts anticipated in this HIA
- review the appropriateness of the recommendations

- review the implementation of the recommendations
- assess the health impacts of Wraparound.

**Part five outlines the framework that will be used to evaluate and monitor Wraparound.**

A summary report of the Health Impact Assessment of the All-Inclusive Wraparound Scheme is also available [6].

# The Health Impact Assessment process of Wraparound



## **Part one: The All-Inclusive Wraparound Scheme**

## The All-Inclusive Wraparound Scheme [1]

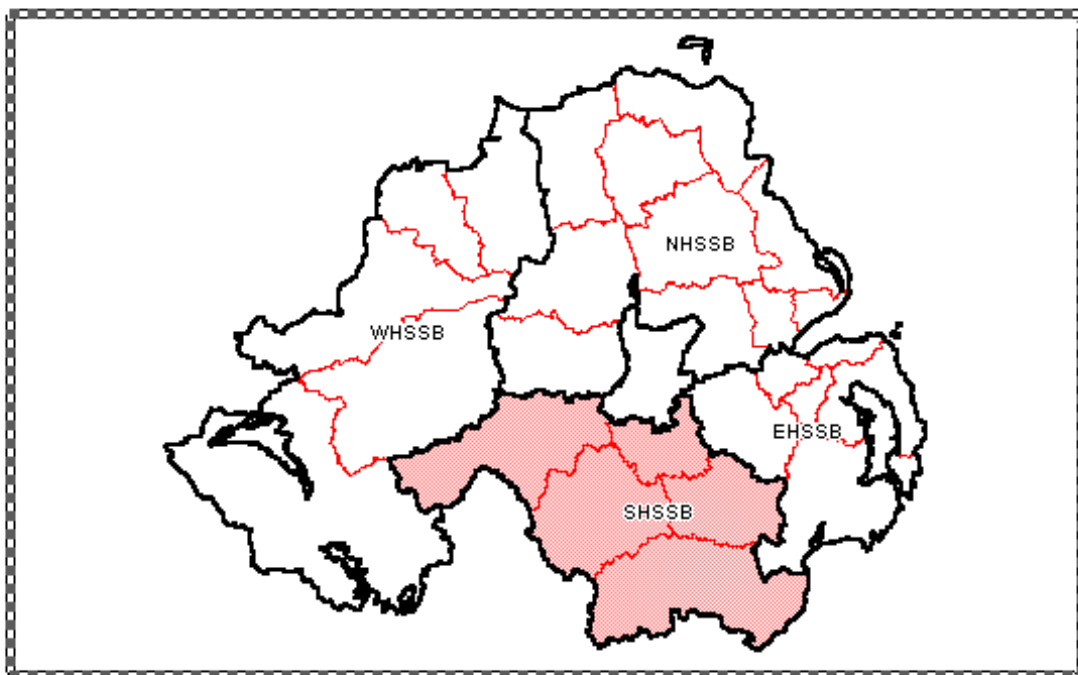
### The All-Inclusive Wraparound Scheme

The All-Inclusive Wraparound Scheme [1](Wraparound) was introduced into the Southern Health and Social Services Board (SHSSB) in October 2002.

### The place

The SHSSB is situated in the southerly most part of Northern Ireland and borders Lisburn and Down District Councils to the east, Cookstown, Fermanagh and Omagh District Councils to the west and County Monaghan and Louth in Ireland. Within it there are three Health and Social Services Trust (HSST) administrative areas: Newry and Mourne, Armagh and Dungannon and Craigavon and Banbridge. The Southern Board contains the five District Councils of Armagh, Dungannon and South Tyrone, Craigavon, Banbridge and Newry and Mourne.

Map of Northern Ireland District Councils /Health Boards



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## **Vision**

Wraparound seeks to develop new and distinctive way of multi-agency, multi-professional working that will make a difference to the lives of children with disabilities (aged 0-18years) and their families and carers across the SHSSB.

## **Aim and objectives**

The aim of Wraparound is to enable children with disabilities to have access to information, assessment and, where appropriate, services which provide the social, health and educational support necessary to maximise their potential to lead socially included lives.

The objectives of Wraparound are to:

- 1 Provide services within a coherent, multi-agency, multi-disciplinary model to children and young people who have identified and assessed needs.
- 2 Provide children across the SHSSB area with equal access to services.
- 3 Consider children defined within the scope of Wraparound as 'children first' [7] ie wherever possible, they should have access to services provided for children in general.

## **Funding**

Wraparound has received a funding allocation from the Programme for Government Executive Programme Funds of £1.5m over three years. It will run until March 2004.

Children with disability are defined as 'children who have a physical, sensory or learning disability or prolonged condition which impacts on daily living in such a way that, without the provision of adequate support services, they would not achieve their optimal potential for personal development and social inclusion.' [3]

**The Evaluation Task Group** (see Appendix I for list of members) Wraparound is operationalised through the work of five task groups (Armagh and Dungannon, Craigavon and Banbridge, Newry and Mourne, Communication and Evaluation). These task groups are intended to represent all service providers and parents.

The role of the Evaluation Task Group (ETG) is to develop an evaluation and monitoring framework for Wraparound and to facilitate its implementation. The ETG agreed to conduct an HIA on Wraparound using the funds allocated to evaluation for Year 2001/2002.

### **Partners**

Wraparound was developed by the following groups: SHSSB, Southern Education and Library Board, Craigavon and Banbridge Community HSST, Newry and Mourne HSST, Armagh and Dungannon HSST, Craigavon Area Hospital Group Trust, Orana Family Resources Centre, Barnardos Willowgrove Project, Mencap, National Children's Homes, Parents and Professionals for Autism (PAPA), Royal National Institute for the Blind (RNIB), Disability Action, Northern Ireland Pre-school Playgroup Association (NIPPA) and the Young Men's Christian Association (YMCA).

### **Projects**

There are eight projects included in Wraparound. These are listed below, with their expected outcomes:

*A One stop child development clinic outreach to each Trust area*

- Provide 42 child development clinics per year between four locations (Newry – 10, Willowgrove - 4, Armagh & Dungannon - 12, Lurgan - 16) instead of the current 42 clinics provided in Lurgan
- Provide a seamless service at a one-stop centre where families can access medical, nursing, dentistry, professions allied to medicine (PAMs) and social care and support including respite in partnership with Child Development Clinics, local trusts and the voluntary sector
- Improve user satisfaction with more locally accessible services

*B Royal National Institute for the Blind (RNIB) and the Southern Education and Library Board*

- Train professionals and carers working with pre-school children who are visually impaired (including children with additional difficulties)
- Support, inform and advise parents of pre-school children with a visual impairment (including children with additional difficulties)
- Provide local services for children within the SHSSB area, which will include mobility training, daily living skills and communication skills
- Enhance the pre-school experience of young children with a visual impairment in the SHSSB area, therefore making the transition to primary school a much smoother process.

*C User participation of children with disabilities in strategic planning of services*

- Improve partnerships between service planners and users of the service
- Mainstream user participation
- Develop a range of models and methods of user involvement appropriate to the different age ranges and types of disabilities
- Facilitate the integration of these user involvement methods by the participating agencies including health and social services, education, voluntary and community sectors, probation, policing and housing.

*D Autism specific service provision with the SHSSB*

- Provide 'specialist general advice' to families regarding, for example, information about autism, self-help groups and services available
- Provide advocacy for the child and /family
- Promote therapeutic interventions either directly with the child or indirectly through teaching families and others eg teaching appropriate therapeutic strategies

### *E Mencap family support and play advisor*

- Improve social and emotional development of the children through providing better information for families about the role of play in addressing behavioural difficulties
- Develop an increased sense of community and reduce isolation of families
- Increase child confidence and self esteem of parents, children and carers
- Develop a more person-centred approach
- Enable more children with disabilities and complex needs to gain a sense of fun and leisure
- Enhance partnership and co-operation between statutory and voluntary agencies.

### *F Newry and Mourne HSST and Orana Family Support Centre*

- Enable families to access the whole range of services on a localised basis
- Deliver a seamless service with additional familial outreach provision which would offer parents and carers and children a range of respite and support services
- Provide
  - Twelve places per day available for age range 0 – 5 years in sessional day care
  - Two places per day available for age range 4 years 2 months – 14 years in after-school and summer schemes
  - Four places available per day in residential respite unit
  - Ten families being supported by outreach workers
  - Four sessions per month for PAPA group
  - Develop places in an adolescent group.

### *G Craigavon and Banbridge Community HSST and Banbridge Willowgrove project*

- Increase residential provision by one night per week for children with a learning disability
- Provide residential respite on one night per week for children with physical disability

- Increase the number of family placements by five and extend the range of services provided by family links to include day-care, sitting service and befriending
- Develop after-school provision for children and young people who did not want to be identified with 'specialist' provision
- Look at the personal and social development function of respite for all the young people involved
- Extend the pool of sessional staff and develop their volunteer base
- Extend early years provision through training and support for staff, and additional support staff within the scheme and purchasing equipment and toys
- Develop a dedicated sponsored child-minding scheme of up to twenty childminders for children with disability, in the context of a broader range of non-specialist family supports
- Develop the Carer and User Volunteer Support project (a partnership between the Trust and the Craigavon and Banbridge Volunteer Bureau) to recruit and deploy volunteers in schemes and activities to promote the inclusion of children with disabilities (sensory, physical and learning) in play and leisure activities.

#### *H Armagh and Dungannon HSST and Oaklands project*

- Develop an integrated assessment and diagnostic service which will deliver high quality information to carers, trigger appropriate referrals to professionals and service providers and by extension offer well designed innovative and effective packages of care to young children and their families
- Allocate a keyworker to each child who will be responsible for designing, commissioning and co-ordinating the care package, linking directly with the assessment team and the relevant service providers, agencies and professionals
- Create clarity within the primary care system about referral pathways and communication channels.

## **Definition of health**

The health of the children and their families using Wraparound is influenced by the children's disability. However, health is also determined by a broader range of factors including:

- **socio-economic status** eg income and poverty, employment and social exclusion
- **physical environment** eg housing regeneration, crime, transport, noise, air and water quality
- **social and community environment** eg social and community networks, access to services such as education and leisure
- **individual or family lifestyles** eg diet, physical activity, smoking, alcohol, sexual behaviour, drugs and mental health
- **fixed or constitutional** eg age, sex and genes.

**Part two: The Health Impact Assessment of  
the All-Inclusive Wraparound Scheme**

## The Health Impact Assessment of the All-Inclusive Wraparound Scheme\*

### Introduction to Health Impact Assessment

Health Impact Assessment (HIA) is

a combination of procedures or methods by which a policy, programme or project may be judged as to the effects it may have on the health of a population. [4]

The public health strategy for Northern Ireland *Investing for health* [2] includes a chapter on HIA.

Like Wraparound, HIA is multi-disciplinary, inter-sectoral and participatory. Its underpinning values are sustainability, promotion of health, democracy, equity, equality and the ethical use of evidence. Although HIA can be retrospective ie conducted after the implementation of a proposal, it is ideally conducted prospectively ie before or at the beginning of implementation in order to influence decision making.

The benefits to proposals of using HIA are that:

- the potential for health gain is increased
- the best available evidence is used
- there is community participation in decision making
- decision making is accountable and transparent.

There are five main stages in the process of HIA:

- 1 Screening – Which proposals should be subject to HIA?
- 2 Scoping – What are the boundaries for this particular HIA?
- 3 Appraisal - What are the health impacts of this proposal? and What changes could we suggest to minimise the negative and maximise the positive?
- 4 Decision-making – Which recommendations to change the proposal should we adopt?

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\* Information on HIA in this Part is taken from the *Rapid appraisal tool for HIA in the context of participatory stakeholder workshops* [5]

- 5 Monitoring and evaluation – What are the health outcomes of implementing the proposal as modified by the HIA and can we improve the process of HIA?

There are three types of appraisal: rapid, comprehensive or in-depth and intermediate. The Wraparound HIA uses a rapid appraisal method ie one that has a limited timeframe and uses information and data that are readily available.

The HIA of Wraparound provided participants with an opportunity to discuss ways in which Wraparound:

- protects and improves health and wellbeing
- could be improved to maximise benefit to and minimise negative effects on health and wellbeing
- who in the SHSSB area will gain from the Scheme
- whether and how the health and well-being of particularly vulnerable or disadvantaged individuals or groups will be effected by the initiative.

#### **Resource Box**

*Health Impact Assessment: an introductory paper* [www.publichealth.ie](http://www.publichealth.ie) [8]  
Health Development Agency England HIA web site

[www.hiagateway.org.uk](http://www.hiagateway.org.uk)

*Investing for health* [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk) [2]

*The Rapid Appraisal Tool for Health Impact Assessment in the context of participatory stakeholder workshops* can be downloaded from the Tool Kit Section of [www.hiagateway.org.uk](http://www.hiagateway.org.uk) [5]

### **The rationale for conducting a Health Impact Assessment on Wraparound**

HIA was the method chosen to bring together all groups with an interest in Wraparound to review how it will effect the health and wellbeing of children with a disability and their families. These groups include parents and carers, children and young people with disabilities, voluntary agencies and health service workers as well as groups such as local communities and non-health sector services.

Wraparound was considered a good candidate for HIA because:

- it is at an early stage of implementation and so there is scope to influence the way in which it is implemented
- all partners and key decision makers are represented in the task groups and Stakeholder Forum and so there is an agreed structure and process for recommendations of the HIA to be discussed and agreed
- it is important that Wraparound is soundly and comprehensively evaluated and monitored using standards that reflect the interests and concerns of all stakeholders
- it is a new and innovative approach to the development and delivery of services for children with disabilities and their carers.

Partnership working and participation are central to Wraparound and the *Rapid appraisal tool for Health Impact Assessment in the context of participatory stakeholder workshops* [5] provided a process for including all partners in the HIA.

The aims of the HIA on Wraparound are:

- to identify the positive and negative health impacts of Wraparound on all stakeholders
- to produce clear comments and recommendations about Wraparound's development and delivery
- to inform the development of an evaluation and monitoring framework
- to support future service developments through the information gathered by the evaluation and monitoring system.

### **Scoping**

The Evaluation Task Group (ETG) was responsible for the scoping of the HIA. In discussion with the consultant Erica Ison, the ETG set the following boundaries for the HIA:

- the HIA was conducted on the whole Wraparound scheme
- user participation was the overarching theme
- the timescale for the HIA was set as follows:
  - participatory stakeholder workshop: April
  - presentation of headline findings at the Stakeholder Forum and production of newsletter: May

- production of report: summer 2002
- the geographical area was the SHSSB (see Part one)
- the population covered by the HIA was the children and young people with disabilities and their families in the SHSSB and the workers involved in Wraparound
- the target groups were children and young people with disabilities, their families and carers, workers and volunteers in the services
- the vulnerable groups were children with complex disabilities, children without diagnosis, children living in rural areas and members of the Traveller community
- as no additional resources were available, the HIA focussed on the existing resources allocated to Wraparound.

There are 98,200 children and adolescents under the age of 19 years in the SHSSB. The pre-school, primary and post-primary population, by District Council area is detailed below [9].

Age	Armagh	Dungannon	Craigavon	Banbridge	Newry and Mourne	SHSSB
0-4	3600	3500	6000	2700	7300	<b>23100</b>
5-9	4300	4000	6300	2800	7500	<b>24900</b>
10-14	4600	4100	6400	3100	7800	<b>26000</b>
15-19	4400	3900	5800	2900	7200	<b>24200</b>
<b>Total</b>	<b>16900</b>	<b>15500</b>	<b>24500</b>	<b>11500</b>	<b>29800</b>	<b>98200</b>

The ETG agreed to conduct the HIA using the following methods:

- Literature review (see Appendix II)
- Routine information sources (see Appendix III)
- Participatory stakeholder workshop
- Consultation with children and young people.

## Methodology

### *The literature review*

Unpublished and published literature from Northern Ireland and published literature from England, Scotland, Wales and Ireland on services for children with disabilities was reviewed in order to inform the HIA of the Wraparound. The literature review identified

- what services are available
- what recommendations for good practice have been made
- what gaps exist in services.

A search of the literature was conducted using Medline, CINAHL and ASSIA databases. The librarian from Queens University Belfast also identified relevant papers from research databases. Further papers were retrieved from references cited in papers from the initial search. Inclusion criteria were:

- Published in England, Scotland, Wales or Ireland
- Published between 1992-2002
- Described services for children with disabilities and their families
- Made recommendations for good practice
- Identified key gaps in services

Abstracts which dealt with predominantly adult services, psychiatric services, education services, highly specialised genetic services or research on populations outside England, Scotland, Wales or Ireland were excluded. Prevalence data was also excluded as being outside the scope of this review.

In addition, members of the ETG collected a range of unpublished literature and information.

### *Routine information sources*

Information from a range of sources in the SHSSB was collated and reviewed. The sources were:

- 1 The Child Health System (March 2002) [10]
- 2 Referrals to the child and adolescent mental health services (1998-2000) [11]
- 3 Survey of the Traveller community (2000-2001) [12]

- 4 Korner<sup>1</sup> returns relating to disability (2000, 2001) [13]
- 5 Audit of the physiotherapy caseload at the Child Development Clinic (2001) [14]
- 6 Family Trust Fund Database (May 2002) [15]

The routine information sources provided Census data on the whole population of the SHSSB [16], and the 0-19 age group [9, 17](current and projected size, location). Children and young people with disabilities were profiled through information about diagnosis and service use, where reliable data were available. Three levels of service activity were examined through Korner returns [13], the Child and Adolescent Mental Health Service records [11] and an audit of the physiotherapy service at the Child Development Clinic [14]. The additional care needs of these children and young people were indicated by analysis of the Family Trust Fund Database [15]. The survey of the Traveller community [12] highlighted health issues within this socially excluded community.

#### *Participatory stakeholder workshop*

Partnership working and participation are central to Wraparound. The *Rapid appraisal tool for Health Impact Assessment in the context of participatory stakeholder workshops* [5] provided a process for including all partners in the HIA and fitted with the ETG's time frame for conducting an HIA. Erica Ison, who developed the selected tool, agreed to act as consultant to the HIA.

#### Stakeholder identification

The ETG decided that the HIA workshop needed to be as representative and inclusive as possible for example of the statutory, voluntary and community sector including non-health sector, parents, health disciplines and disabilities. The ETG discussed at length who could be invited and the support that they would need to attend. A central mailing list for invitations to the HIA workshop was collated by the SHSSB from:

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<sup>1</sup> Korner returns are quarterly records that are statutorily required by the Regional Information Branch of the Department of Health Social Services and Public Safety Northern Ireland. They are used to monitor community and social services activity.

[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

- lists provided by the partners represented on the ETG
- service and telephone directories (health and non-health sector services)
- websites (elected representatives).

To promote representation from a range of disciplines, information was targeted across services. To promote the inclusion of parents, organisations extended individual invitations. The umbrella organisation Contact a Family was approached and agreed to mail information to its list of families and support groups.

The ETG agreed to fund the transport and childcare costs of participants and any additional supports required in order to make the workshop accessible to all.

#### Preparation for the workshop

Preparation is essential to the success of the HIA Workshop. The preparation phase included the following activities:

- development of workshop programme based on the tool [5]
- collation of the workshop mailing list
- collation of profile information about Wraparound and the SHSSB area (the first time such information had been collated and reviewed)
- mailout of a letter of invitation to the HIA workshop
- mailout of profile information to participants as soon as they registered
- booking and briefing of an accessible venue
- setting up a system for administering individual child care and transport claims
- review of access needs and organisation of supports for the workshop
- allocation of participants to ten discussion groups
- recruitment of facilitators
- development of facilitators information
- briefing of facilitators in the morning of the workshop
- public relations.

### Workshop tasks

The workshop took place over four hours, between 12 noon and 4pm on 15 April 2002. All participants were invited to a healthy lunch from 12-1pm.

### Graffiti board

Over lunch participants were encouraged to post responses on a graffiti board to the questions:

- 1 What are the health issues for children and young people with disabilities?
- 2 What are the health issues for the families and carers of children and young people with disabilities?

### Work groups

Participants were organised into ten facilitated work groups. Each group was asked to look at specific components of Wraparound: one statutory and one voluntary sector project. All groups discussed project C on user participation.

### Presentations and group work

Following presentations on *the All-Inclusive Wraparound Scheme*, *Children with disabilities in the SHSSB*, *Good practice in services for children with disabilities*, participants discussed the barriers to and conflicts around the implementation of Wraparound.

A presentation introducing HIA and the workshop programme by Erica Ison informed further work group discussion on:

- identifying the health impacts of Wraparound
- identifying recommendations to change Wraparound to maximise positive health impacts and minimise negative health impacts.

### Developing recommendations

See Recommendations section.

### Reporting and dissemination

The workshop was evaluated using a brief questionnaire which included a general question about services for children with disabilities in the SHSSB. The findings of the evaluation (see

Appendix V) were circulated to members of the ETG and at the Stakeholder Forum one month after the workshop.

At the Stakeholder Forum a presentation on the initial findings of the HIA workshop was given and stakeholder responses to this were recorded. An edition of the Wraparound newsletter was produced to report on the workshop, the evaluation and the initial recommendations. This was available at the Stakeholder Forum. In total, 2000 copies were circulated using the Wraparound mailing list of approximately 250 voluntary organisations, statutory service providers (health and non-health sector eg Southern Education and Library Board, District Councils), policy makers, elected representatives and individuals.

Five hundred copies of this report and 3000 of a summary report have been produced. The dissemination channels for these reports are outlined below:

Wraparound (1)	Members of Wraparound project team, task groups and service providers
Wraparound (2)	Wraparound mailing list (summary only)
DHSSPSNI	<i>Investing for health</i> team Library
Northern Ireland Assembly	Health Committee (summary only) Ministerial Group on Public Health (summary only) Library
Libraries UK	The British Library, Queens University Belfast, University of Ulster
Libraries Ireland	Trinity College Dublin, University College Dublin, Dublin City University, National University of Ireland (Cork, Galway, Maynooth), University of Limerick, the National Library of Ireland, Department of Health & Children, Dail Eireann
Web Sites	Institute of Public Health in Ireland (this links to a number of international public health and HIA web sites) <a href="http://www.publichealth.ie">www.publichealth.ie</a> Health Development Agency, England HIA Gateway <a href="http://www.hiagateway.org.uk">www.hiagateway.org.uk</a>
HIA Networks	The Institute will circulate information about the reports using its HIA international and national mailing lists

Journals	Articles about the HIA will be submitted to professional journals
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Both this report and the summary report are available on audio-cassette. They can be made available on disc, in larger print, via email or in minority languages for anyone not fluent in English.

#### Decision making

The recommendations of the Wraparound HIA have been developed, discussed, negotiated and agreed in the Stakeholder Forum. The forum includes both formal representation of all stakeholders and has an open membership policy.

#### Monitoring and evaluation

A Monitoring and Evaluation Framework is included in this report. The framework has been developed by the ETG, informed by the findings of the literature review and discussions about monitoring and evaluation at the HIA workshop. The ETG will oversee the implementation of the framework until 2004.

A further HIA will be conducted toward the end of 2003 to inform the continued development of services to children and young people with disabilities and their families. The second HIA will:

- review the accuracy of the impacts anticipated in this HIA
- review the appropriateness of the recommendations
- review the implementation of the recommendations
- assess the health impacts of Wraparound.

#### *Consultation with children and young people*

The newly appointed user participation worker consulted with young people with disabilities to gain their views and ideas about Wraparound.

#### Process for including consultation into the HIA report

Following the HIA workshop, the findings in relation to project C *User participation of children with disabilities in strategic planning of services* were forwarded to the colleague managing this project and the project worker, Ms Rosemary Murray.

Two group consultations and a series of consultation with individual young people have informed this section. Before these consultations there were discussions between Rosemary and the Institute which focussed on:

- key questions that would inform the HIA
- write-up of the findings of the consultation
- negotiation with the participants about how the material that they shared would be included in the HIA report.

The findings of the consultations are written up below, following agreement from participants that

- 1 this is an accurate reflection of their views
- 2 the findings can be included in this report.

#### Description of consultation

Two consultation sessions with groups of young people with disabilities were held. There was also consultation with individual young people with disabilities and one such session is described below.

#### Consultation session 1 (CS1)

Five members of a Gateway club in the SHSSB met with Rosemary during an evening club. The group consisted of 3 females and 2 males, aged 17-19 years who had the following disabilities: learning disability and epilepsy, spina bifida and hydrocephalus (2 participants), a spinal condition and a learning disability. One participant lives with foster parents.

#### Consultation session 2 (CS2)

The first formal meeting of the *Service user involvement in Children's Service Planning project* was held on 1 July 2002 at the Market Place Theatre, Armagh. Eleven young people aged 15-20 years who have a range of learning and physical disabilities attended the three hour meeting. The programme is outlined below.

Aims of the service user involvement work

(Ann Godfrey, Children Services Planning SHSSB)

Alternative methods of communication using creative technology

(Nigel Hampton, KeadyArty)

Consultation with young people

(Teresa Gerraghty and Gina McDonald, Children's Law Centre)  
Two Gateway volunteers, one of whom has a disability, supported participants. Marion Cully, community development worker with Armagh and Dungannon HSST, attended.

#### Consultation session 3 (CS3)

A meeting was held with a 17 year old male with muscular dystrophy. He is in mainstream second level education and wants to continue to participate in the project on an individual basis with occasional group participation.

## **Part three: Findings**

## Findings of the participatory stakeholder workshop

### **Presentation of the data**

In this part of the report the findings of the graffiti board (Section 1) and the work group task on health impacts (Section 2) are presented. The data are presented in tables, identifying issues and using illustrative comments. As far as possible comments have been grouped using common 'issue' headlines in order to facilitate comparison between tables. The number of times a comment was made is indicated in brackets.

The data from the graffiti board have been themed as:

- health impacts of disability on children
- health impacts of having a child with a disability
- health needs of children with disabilities
- health needs of family members and carers.

The data on the health impacts of each project have been themed as impacts with direct effects on:

- 1 physical health
- 2 mental health
- 3 quality of life
- 4 social inclusion.

The impacts are coded as positive (P), negative (N) or unclear if positive or negative (?).

There is commentary on the key themes and issues raised and how these weave with data from the literature review.

Data from the work group task of identifying barriers and conflicts (see appendix IV) have been written up as principles to guide the implementation of Wraparound in Part Four. Also in Part Four, the work group data on recommendations are written up with relevant sections of the literature review.

## Section 1: Graffiti board

### **Commentary**

Participants' contributions to the graffiti board indicated that they were using a holistic model of health. Comments were made on social, mental/psychological, financial, emotional, physical and sexual dimensions of health.

#### 1 Health impacts of disability on children

Comments on the graffiti board indicate that the disability which a child or young person has has fewer health impacts than the societal context and the quality and level of service provision and delivery.

#### 2 Health impacts of having a child with a disability

The graffiti board recorded substantial health impacts on family life, the parents' or carers' relationship and the quality of life for siblings. Key issues that emerged were the impacts on mental and psychological health (19), exhaustion (9), financial worries (8) and concern for the future with regard to transitions in the child or young persons' life and the death of their parents or carers.

Participants commented that family members or carers have a higher incidence of physical and mental health problems and other indications of social need than the general population. The number of children with disabilities in a family was another significant factor: the 'full impact of having more than one disabled child in families is not fully acknowledged or understood'.

The literature confirms that the birth of a child with disability has far reaching effects on individual parents, marital relationships, siblings and the family unit as a whole. The quality of life for all members of the family is affected as parental priorities adapt to cope with the practical, emotional and time demands of caring. Employment opportunities for both parents are often reduced with resultant financial implications at a time when the need for resources, both personal and material is increased.

The mental and physical health of parents are affected, in particular that of the mother who is often the main carer on a daily basis. However, recognition is increasing of the needs of fathers in these families and the difficulty of engaging fathers in support services.

Both parents experience a grief reaction and a period of adjustment to losing the child whom they had expected and adapting to the child that has been born. Ethnicity, social class and religious beliefs all affect the parents' ability to cope and adapt to this situation.

The health impacts of having a child or children with disability in a family can vary considerably according to how the family appraises the situation of having a child with disability. This variation is not explained by the severity of the disability. The literature identified families at particular risk as:

- those who had had a recent stressful life event
- those where the father is unemployed
- those in which the child has both mental and physical disabilities
- those in which the mother uses a high proportion of passive coping strategies.

### 3 Health needs of children with disabilities

Participants identified a range of health needs in terms of both disability services and mainstream health services.

During the workshop participants commented that the needs of children with disabilities depended on the type and complexity of the disability or disabilities.

The health needs of children with a disability are for excellent health care, including identification, diagnosis, detailed assessment and therapeutic intervention. An analysis of the Family Trust Fund Database was conducted to identify the extra care needs of children with disabilities (see literature review in Appendix II). Following cluster analysis, the children were classified into five broad groups, which may be useful when planning services. Some of the extra care needs of children with a disability include dental care and feeding and swallowing problems. Once the child grows up, long-term care needs and quality of life into adulthood are a source of anxiety for parents, together with concerns about sexuality, employment and vulnerability to abuse or the risk of abusing others.

#### 4. Health needs of family members and carers

Strong themes emerged from the graffiti board namely: access to and the quality of respite care (21), access to a range of services and facilities (14), co-ordination between services and workers (11), information (9), levels of resources (10) and support (8). Comments were made in relation to both disability services and mainstream health services.

The type and extent of the needs of family members and carers fluctuates over the course of a child's life, depending on internal family factors and extraneous circumstances and demands. Families and carers need both practical and emotional support. Informal support networks from extended family and friends, support from voluntary organisations and statutory services all have a part to play. Parents ought to have a choice in the delivery of services appropriate for their family lifestyle.

## 1. Health impacts of disability on children

It was noted that the health impacts of disability vary with the disability and children's access to information about the condition(s).

<b>Health Impact</b>	<b>Comment</b>
Disability	<ul style="list-style-type: none"> <li>● care (4) [moving and handling, positioning, rehabilitation]</li> <li>● coping with pain (2)</li> <li>● physical limitations</li> <li>● lack of mobility can affect health</li> <li>● lack of extra support in home leads to lack of outdoor activity – exercise and fun</li> <li>● reaching potential within limits of disability</li> <li>● prevention: deformities, chest conditions</li> </ul>
Social	<ul style="list-style-type: none"> <li>● access (3) [access to built environment]</li> <li>● segregation (3) [as far as possible need to integrate the child with other children and put in supports etc to facilitate this; exclusion from summer schemes due to rigid inclusion criteria or resources not available results in children with disabilities seeing themselves as different]</li> <li>● social attitudes (2) [social isolation / rejection]</li> <li>● fitting in with modern society</li> <li>● friendships</li> <li>● long, long, long summer school holidays</li> <li>● my health setting me apart from other children without disabilities</li> </ul>

Mental and psychological	<ul style="list-style-type: none"> <li>• self image and self esteem ( 3) [recognition of individuality and uniqueness; beautiful people: feeling good about themselves ; mental health – low self esteem]</li> <li>• lack of mental health support for children with learning disability</li> <li>• depression</li> </ul>
Emotional	• emotional (2) [ stress; social capabilities eg friends, socialising; impact of discrimination]
Future	(1)
Financial	(1)
Commitment	(1)
Family health	• being cared for by stressed out parents (child protection issues)
Co-ordination	<ul style="list-style-type: none"> <li>• un-joined up service provision</li> <li>• co-ordination ( 7) [services – appointments, procedures, reviews, service provision following assessment ; need to streamline services ‘Too many procedures and reviews – need to be more child friendly’ ; multiple assessments by multiple agencies ; information ; between medical, social support and education ; better communication between professionals (3) eg between clinics and social care]</li> </ul>
Health interventions	• coping with constant doctors appointments, treatment, physiotherapy etc
Hospital care	• hospitalisation affects all other developments
Education	<ul style="list-style-type: none"> <li>• time lost out of education due to illness and attending hospital appointments / therapy and implications of catching up with missed work</li> <li>• segregated education</li> </ul>
Local services	<ul style="list-style-type: none"> <li>• lack of respite care in local area</li> <li>• travel daily Armagh - Belfast to school: impacts on many aspects of their lives</li> </ul>

## 2. Health impacts of having a child with a disability in the family for family members and carers

Health Impact	Comment
Family life	<ul style="list-style-type: none"> <li>• time for other members of the family (6) [no 'quality time' for other children; other family members also suffer ; emotional needs of siblings]</li> <li>• strain on relationships (2) [become over protective other siblings can become frustrated – don't want to bring their friends – denial; blame disabled child for not being able to do things ie shopping]</li> <li>• support the family to function as a family and not have the families left vulnerable and trying to take the lead in their care</li> <li>• a normal family life</li> <li>• marital problems</li> <li>• sibling rivalry</li> </ul>
Mental and psychological	<ul style="list-style-type: none"> <li>• 19 comments [stress (9) – 'Families supporting children with disabilities are under considerable stress. They need specialist support for their mental health needs,'; mental health (3); depression (2) – caused by feeling of isolation; anxiety]</li> <li>• worries about the future</li> <li>• fear of the unknown</li> <li>• emotional needs of siblings</li> </ul>
Exhaustion	<ul style="list-style-type: none"> <li>• 9 comments [physical, emotional exhaustion ; strain of chronic care ; care 24/7 ; lack of time out / for selves and need for timeout]</li> </ul>

Financial	<ul style="list-style-type: none"> <li>● poverty (3)</li> <li>● financial support, pressures (5)</li> <li>● inequalities in health</li> </ul>
Social	<ul style="list-style-type: none"> <li>● social exclusion (2)</li> <li>● isolation</li> </ul>
Physical	<ul style="list-style-type: none"> <li>▪ back care, prevention of injury</li> <li>▪ nutrition</li> <li>▪ stress-related illness: cancer, high blood pressure</li> </ul>
Transition	<ul style="list-style-type: none"> <li>● transition between early years to children's services (1) and children's to adult's services (6) [services focussing on transition ; limited opportunities at transition; needs at transition]</li> <li>● continuum of care – what happens when parents and carers no longer here?</li> </ul>
Co-ordination	<ul style="list-style-type: none"> <li>● un-joined up service provision (3)</li> <li>● 'There still are gaps where some staff don't know who are inputting to the child'</li> <li>● 'Being involved with so many professionals – confusion about who does what for my child?'</li> </ul>

### 3. Health needs of children with disabilities

Health Needs	Comment
Like all children	<ul style="list-style-type: none"> <li>• same as other children, including constructive play and interaction</li> <li>• coping with everyday health and mental health problems, everyday illness</li> </ul>
Physical	<ul style="list-style-type: none"> <li>• nutrition [diet (3);obesity]</li> <li>• dental (2)</li> </ul>
Independence	<ul style="list-style-type: none"> <li>• need to be allowed to be as independent as possible in all aspects of life</li> </ul>
Sexual	<ul style="list-style-type: none"> <li>• young people with disabilities need opportunities and assistance to develop their sexual identity and sexual lives</li> </ul>
Access	<ul style="list-style-type: none"> <li>• access (4) [to good quality, appropriate healthcare; waiting lists instead of quick and efficient health services for children when needed]</li> </ul>
Resources	<ul style="list-style-type: none"> <li>• equal access to resources / funding (4) [lack of services for children]</li> </ul>
Co-ordination	<ul style="list-style-type: none"> <li>• co-ordinated multi-agency response to assessed needs</li> <li>• teamwork (2) [team approach, consistency of team members]</li> </ul>
Continuity	<ul style="list-style-type: none"> <li>• continuity of care (2) [assessment of need and follow up intervention and ongoing review]</li> </ul>
Transport	<ul style="list-style-type: none"> <li>• transport (2) [to clinics, outpatients]</li> </ul>
Attitudes of workers	<ul style="list-style-type: none"> <li>• lack of understanding / awareness among professionals, people working with children</li> <li>• need to take children's views into account – feel valued and included</li> <li>• 'To be treated by professionals in a sensitive manner. They are used to dealing with the 'disease' this is normal for them.'</li> <li>• ensuring the child or adult is put at ease regarding health appointments</li> </ul>

Mainstream services	<ul style="list-style-type: none"> <li>• access to mainstream healthcare [similar to non-disabled counterpart (2)]; lack of confidence by professionals; tendency to focus on child's disability rather than illness]</li> <li>• dental care</li> </ul>
Information	<ul style="list-style-type: none"> <li>• good information (2)</li> </ul>
Specific services	<ul style="list-style-type: none"> <li>• equipment (3) [getting equipment needed; delays eg wheelchair service]</li> <li>• children with complex needs [lack of appropriate support / stimulation; lack of supported placement either in school or home]</li> <li>• lack of physiotherapy / occupational therapy for children in mainstream secondary schools</li> <li>• dealing with double incontinence: lack of knowledgeable support in the community</li> <li>• facilities to help with self care / independence</li> <li>• respite</li> </ul>

#### 4. Health needs of family members and carers

Health Needs	Comment
Respite	<ul style="list-style-type: none"> <li>(21) [local provision; home-based provision (babysitting/crossroads support, specialist childminders/helpers eg something like Home Start but for the disabled child and available for 1-2 hours at least per week; more needed; parents and carers need more consideration with regard to respite care and need to know their children or adults are happy and content in the environment they are placed in ; allocation and provision of respite care is haphazard and unregulated; care / respite should not be assessed on monetary value ie where care is needed it should be provided irrespective of area you live, nature of disability – no money in fund !; transport to respite]</li> </ul>
Access	<ul style="list-style-type: none"> <li>(14) [need ease of access to services – support, advice, treatment, therapy ; access to the curriculum ; equality of access ; appropriate services as and <u>when</u> needed (2) eg respite and day care; more flexible services to individual needs; 24 hour on call support]</li> <li>insufficient time to attend doctors appointments / follow up for medical problems</li> </ul>
Co-ordination	<ul style="list-style-type: none"> <li>(11) [communication (2) ; ‘a more simple and holistic approach to healthcare for the disabled is needed ie all services based in one area and under the same roof’ (2) ; between multi-professionals and agencies (5) ; family key worker needed]</li> </ul>
Information	<ul style="list-style-type: none"> <li>(9) [lack of information ; easy access ; easy and understandable (2) ; having support with practical help and information that is relevant and appropriate ; appropriate knowledge of issue / condition (2) ; information on services]</li> </ul>

Resources	<ul style="list-style-type: none"> <li>• (10) [poor; lack of relevant resources and facilities (4) including lack of mainstream play facilities for children with disabilities; lack of child / dependent care; limitations in funding for necessary equipment ; resources for augmentative communication ; waiting lists (2) ; access to education with suitable resources and equipment - 'not having to 'fight' for services']</li> </ul>
Support	<ul style="list-style-type: none"> <li>• (8) [with inherent difficulties ; whilst child is growing and developing ; lack of professional support, at the right times and the right way, support services]</li> <li>• 'Support in all activities of daily living. But that these people also have a responsibility to in partnership look after their child '</li> </ul>
Training	<ul style="list-style-type: none"> <li>• (4) [training for trainers on a one to one basis; for trainers to train informed carers; specific topics (2): lifting and handling, parenting skills]</li> </ul>
Equity	<ul style="list-style-type: none"> <li>• equity of service (2) [therapy resources - physical disability]</li> </ul>
Respect	<ul style="list-style-type: none"> <li>• parents, carers and children should be listened to and treated with respect (4) [health care professionals will listen to families; 'A parent is a professional too !! whilst we don't hold certificates we do hold the life-time 'honours' – our children; recognition of their expertise]</li> <li>• consultation (2) [how to facilitate eg respite care, transport]</li> </ul>
Mainstream services	<ul style="list-style-type: none"> <li>• attending local doctor with everyday illness eg long waiting times etc</li> <li>• GPs, hospital doctors and nursing staff need training about children with learning disabilities</li> </ul>

## Section 2: Health impacts

**Project A (One stop child development clinic outreach to each Trust area)**

No 'direct effects on physical health' were identified

Direct effects on mental health

<b>Issue</b>	<b>Impact</b>
Access	<ul style="list-style-type: none"> <li>● <b>P</b> improve access to play advisor</li> <li>● <b>P</b> make access to respite care easier</li> <li>● <b>P</b> provide access to a good mental health therapist</li> <li>● <b>P</b> improve access to services due to local provision (2)</li> <li>● <b>P</b> reduce travelling for families, leading to better attendance (2), less cost and stress</li> <li>● <b>P</b> reduce waiting time</li> <li>● ? timing</li> </ul>
Partnership	<ul style="list-style-type: none"> <li>● <b>P</b> empower carers (2) and child</li> <li>● <b>P</b> enable employment for carers</li> <li>● <b>N</b> some parents may not want to be involved in support groups</li> </ul>
Health child	<ul style="list-style-type: none"> <li>● <b>P</b> alleviate stress</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>● <b>P</b> alleviate stress (2) [access to services]</li> <li>● <b>P</b> reduce stress on siblings</li> <li>● <b>N</b> can increase parental anxiety and stress (2) as family / carer expectations rise</li> </ul>
Health workers	<ul style="list-style-type: none"> <li>● <b>N</b> could increase workers' stress</li> </ul>
Nature of Wraparound	<ul style="list-style-type: none"> <li>● <b>P</b> families feel part of something special</li> <li>● <b>P</b> can overload families with bad news on one day</li> <li>● <b>N</b> some prefer more anonymous service</li> </ul>

Direct effects on quality of life

Issue	Impact
Access	<ul style="list-style-type: none"> <li>● <b>P</b> reduce waiting time and provide quicker assessment</li> <li>● <b>N</b> poor transport (2) [not on a main bus route]</li> <li>● <b>N</b> take up professional time in travelling to outreach</li> </ul>
Partnership	<ul style="list-style-type: none"> <li>● <b>P</b> increase partnership with other agencies</li> </ul>
Service delivery	<ul style="list-style-type: none"> <li>● <b>P</b> should improve 'face to face' communication</li> <li>● <b>P</b> improve access to information</li> <li>● <b>P</b> provide integrated care pathway</li> <li>● <b>P</b> provide professional key worker (2) [co-ordinates care package; provides continuity; links on behalf of child]</li> <li>● <b>N</b> not all diagnostic services available</li> <li>● ? room space</li> <li>● ? clinical environment</li> <li>● <b>N</b> clinics have to be relocated in Armagh</li> <li>● <b>N</b> outreach centre is not a specifically built centre: from professionals' point of view – making do</li> <li>● ? will assessment lead to provision of needs</li> <li>● <b>N</b> raise expectations but service will lead to assessment not provision</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>● <b>P</b> respite prevents family / carer breakdown and improves quality of life</li> </ul>

Nature of Wraparound	<ul style="list-style-type: none"> <li>• <b>P</b> use holistic approach</li> <li>• <b>P</b> develop services around child</li> <li>• <b>P</b> provide range of services</li> <li>• <b>P</b> provide one stop integrated service</li> </ul>
Equity	<ul style="list-style-type: none"> <li>• <b>N</b> may be perceived inequality of services</li> </ul>
Resources	<ul style="list-style-type: none"> <li>• <b>N</b> not enough adequate facilities and resources</li> </ul>

#### Direct effects on social inclusion

<b>Issue</b>	<b>Impact</b>
Nature of Wraparound	<ul style="list-style-type: none"> <li>• <b>P</b> de-stigmatise 'attitudes' about respite care services as child development clinic based in respite unit</li> </ul>

**Project B (Royal National Institute for the Blind and Southern Education and Library Board)**

No direct effects on physical health identified

Direct effects on mental health

<b>Issue</b>	<b>Impact</b>
Health child	<ul style="list-style-type: none"> <li>• <b>P</b> improve children’s self-esteem and confidence</li> <li>• <b>P</b> develop for young people as individuals</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>• <b>P</b> reduce isolation for parents of visually impaired children</li> <li>• <b>P</b> address parental anxiety</li> <li>• <b>P</b> lead to family becoming closer</li> <li>• <b>P</b> provide opportunities for improving play activities between children and parents</li> <li>• <b>P</b> improve parent’s confidence</li> <li>• <b>N</b> increase parental anxiety</li> <li>• <b>?</b> over-protective parents</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>• <b>P</b> increase parents’ mutual education and support</li> </ul>

Direct effects on quality of life

<b>Issue</b>	<b>Impact</b>
Capacity building	<ul style="list-style-type: none"> <li>• <b>P</b> provide co-ordinated training for those involved</li> <li>• <b>N</b> provide time-limited benefit only if training is once off</li> </ul>
Partnership	<ul style="list-style-type: none"> <li>• <b>P</b> improve work between professional and parent and child</li> </ul>
Awareness	<ul style="list-style-type: none"> <li>• <b>P</b> make professionals and carers more informed and aware</li> </ul>

Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> improve diagnosis (5) [possibly improved diagnosis; possibly earlier diagnosis (2); acceptance of early diagnosis – positive early intervention for parents and child]</li> <li>• <b>P</b> promote holistic management and care because early intervention can connect all professionals involved</li> <li>• <b>P</b> improve recognition / focus</li> <li>• <b>P</b> provide better information for needs assessment</li> <li>• <b>P</b> improve information (2) [about services for blind and visually impaired; increased knowledge of services – process, families, individual]</li> <li>• <b>P</b> lead to better follow up</li> <li>• <b>P</b> lead to better communication (2)</li> <li>• <b>P</b> enhance advocacy role</li> <li>• <b>N</b> restricted age group</li> <li>• <b>N</b> could have long waiting list when referred on</li> </ul>
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#### Direct effects on social inclusion

<b>Issue</b>	<b>Impact</b>
Access	<ul style="list-style-type: none"> <li>• <b>P</b> greater access to these services for young people and families in home or home area</li> </ul>
Service use	<ul style="list-style-type: none"> <li>• <b>P</b> assist children going into school environment and promote educational opportunities</li> </ul>
Health child	<ul style="list-style-type: none"> <li>• <b>P</b> promote inclusion of young people</li> </ul>
Stigma	<ul style="list-style-type: none"> <li>• <b>P</b> raise awareness about visual impairment (2)</li> <li>• <b>N</b> increase stigma by labelling the child at an early age</li> </ul>

### Project C (User participation of children with disabilities in strategic planning of services)

No direct effects on physical health identified

Direct effects on mental health

<b>Issue</b>	<b>Impacts</b>
Health child	<ul style="list-style-type: none"> <li>● ? can services be changed to reflect the views obtained? If not, this will have a negative impact (3) [frustration and disappointment]</li> <li>● N increase in stress: people feeling that they must be involved</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>● N increase anxiety of parents about 'letting go'</li> <li>● N may lead to conflict between parents and children (2) [parents feeling uncomfortable with children's new awareness]</li> <li>● N raise expectations and stress by building expectations, if only short term initiative</li> </ul>

Direct effects on quality of life

<b>Issue</b>	<b>Impacts</b>
Service delivery	<ul style="list-style-type: none"> <li>● <b>P</b> improve service: improve health as a result of participation (3) [effective services targeted more appropriately; more responsive service]</li> <li>● <b>P</b> highlight problems in services and other agencies (housing, education etc)</li> <li>● <b>P</b> improve knowledge of children’s services providers about what services are needed (4) [at an early stage; understand their needs (first time)]</li> <li>● <b>P</b> reorient service [change of statutory service and professionals’ thinking – now listen to family experiences; promoting inclusion]</li> <li>● <b>?</b> if funding fails after number of years, parents might be reluctant to involve children</li> <li>● <b>?</b> is this possible within the timeframe?</li> <li>● <b>N</b> too wide an age range, developmental levels, and disabilities (3)</li> <li>● <b>?</b> undiagnosed / rare conditions</li> </ul>
Partnership	<ul style="list-style-type: none"> <li>● <b>P</b> increase networking between agencies, leading to the development of closer relationships, new links and new ideas</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>● <b>P</b> skill up volunteers</li> <li>● <b>P</b> skill up children (4) [increase in ability; improve communication skills (3)]</li> <li>● <b>P</b> skill up parents, increase their learning from the children</li> <li>● <b>P</b> could be the development of new ways of working with people with disabilities</li> </ul>
Nature of Wraparound	<ul style="list-style-type: none"> <li>● <b>P</b> lead in the long term, a more healthy society if young disabled people can make a contribution</li> </ul>
Health child	<ul style="list-style-type: none"> <li>● <b>N</b> short term involvement until 19 years – what then? (2)</li> </ul>
Conflict	<ul style="list-style-type: none"> <li>● <b>N</b> priority conflict</li> </ul>

Direct effects on social inclusion

<b>Issue</b>	<b>Impacts</b>
Service delivery	<ul style="list-style-type: none"> <li>● <b>P</b> may lead to the development of finding new ways of communicating with severely disabled children to obtain their views</li> <li>● <b>?</b> how professionals interpret complex needs: communication, at what level</li> <li>● <b>P</b> provide different ways to allow users to participate (to suit needs of users)</li> <li>● <b>P</b> increase ownership by engaging users at an early stage</li> <li>● <b>P</b> mainstream user involvement</li> <li>● <b>P</b> develop structure for user involvement</li> <li>● <b>N</b> unrepresentative</li> <li>● <b>N</b> some groups difficult to engage and consult – may not be targeted</li> <li>● <b>N</b> difficult not to work with those who are easiest to consult with</li> <li>● <b>N</b> children with more complex needs [in danger of not getting at needs; parental advocacy needed for these]</li> <li>● <b>N</b> one disability dominates user participation</li> </ul>
Health child	<ul style="list-style-type: none"> <li>● <b>N</b> tokenism (5)</li> <li>● <b>N</b> to ‘wheel’ children in for the sake of a meeting would have negative effect on family and individual children</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>● <b>N</b> process not family inclusive</li> </ul>

### Project D (Autism specific service provision with the SHSSB)

No direct effects on physical health were identified, but it was anticipated that the project will impact on general health development. No direct effects on social inclusion were identified.

#### Direct effects on mental health

<b>Issue</b>	<b>Impact</b>
Health child	<ul style="list-style-type: none"> <li>▪ <b>P</b> improve mental health</li> <li>▪ <b>P</b> take pressure off</li> <li>▪ <b>N</b> parents will be aggrieved if their child is not selected</li> </ul>
Health family and carers	<ul style="list-style-type: none"> <li>▪ <b>P</b> take pressure off</li> </ul>

#### Direct effects on quality of life

<b>Issue</b>	<b>Impact</b>
Partnership working	<ul style="list-style-type: none"> <li>• <b>P</b> increase effective partnership</li> <li>• <b>P</b> produce positive dynamic by professionals, carers and facilitator working together to understand more about autism</li> </ul>
Service delivery	<ul style="list-style-type: none"> <li>• <b>N</b> early recognition not addressed</li> <li>• <b>N</b> diagnosis [difficult to diagnose; delay in diagnosis will not be picked up by this project; need for a follow up service after diagnosis otherwise early intervention will have no impact]</li> <li>• <b>N</b> raise expectations</li> <li>• <b>N</b> exclude those children waiting on services due to rigid criteria</li> <li>• <b>?</b> waiting list</li> </ul>

	<ul style="list-style-type: none"> <li>• <b>N</b> 2/3 tier system</li> <li>• <b>N</b> potential for frustration within the service</li> </ul>
Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> provide early diagnosis and early intervention with a lead contact (up-to-date information)</li> <li>• <b>P</b> provide strong support through project workers advocacy for child and family or carer</li> <li>• <b>P</b> give formal diagnosis</li> <li>• <b>P</b> provide family advisors (2)</li> <li>• <b>P</b> give structured multi-professional assessment: a change from the current ad hoc system</li> <li>• <b>P</b> help families with autistic children</li> <li>• <b>P</b> produce better outcomes</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>• <b>P</b> parent would learn better techniques</li> <li>• <b>P</b> training</li> <li>• <b>N</b> lack of training</li> </ul>
Resources	<ul style="list-style-type: none"> <li>• <b>N</b> too specific – robbing others</li> <li>• <b>N</b> gaps in funding</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>• <b>P</b> recognise needs of other children</li> <li>• <b>P</b> lead to better employment opportunities and better pensions</li> </ul>

### Project E (Mencap family support and play advisor)

Direct effects on mental health

<b>Issue</b>	<b>Impacts</b>
Health family and carer	<ul style="list-style-type: none"> <li>● <b>P</b> improve parental mental health (coming to terms with diagnosis) through contact with others)</li> <li>● <b>P</b> increase confidence of parents</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>● <b>P</b> enable children to learn through play</li> <li>● <b>P</b> empower/enable parents to 'play' (skill development) (2)</li> <li>● <b>P</b> enhance parent / child bond – emphasis on positive play</li> </ul>
Awareness raising	<ul style="list-style-type: none"> <li>● <b>P</b> raise awareness of importance of play</li> </ul>
Nature of Wraparound	<ul style="list-style-type: none"> <li>● <b>N</b> raise expectations (3), causing disappointment and frustration</li> </ul>

Direct effects on quality of life

<b>Issue</b>	<b>Impacts</b>
Access	<ul style="list-style-type: none"> <li>● <b>P</b> increase accessibility of Mencap advisors</li> </ul>
Transition	<ul style="list-style-type: none"> <li>● <b>N</b> support is strong during early years, and reduces as child grows</li> </ul>
Resources	<ul style="list-style-type: none"> <li>● <b>N</b> inadequate resources: cannot deal with all children and demand</li> </ul>

Capacity building	<ul style="list-style-type: none"> <li>• <b>P</b> provide practical support to play workers – who in turn feed back to parents / education system</li> <li>• <b>?</b> may reduce the specialist work with child</li> </ul>
Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> provide advocacy</li> <li>• <b>P</b> provide support</li> <li>• <b>P</b> provide information</li> <li>• <b>N</b> question the age range 0-5</li> <li>• <b>N</b> provides advice, but not necessarily real help</li> <li>• <b>N</b> not clear how links made with social services</li> <li>• <b>N</b> need clarification of roles – play advisor/worker, family advisor, link with autism support</li> </ul>

Direct effects on social inclusion

<b>Issue</b>	<b>Impacts</b>
Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> takes focus off 'disability' for child</li> </ul>
Health child	<ul style="list-style-type: none"> <li>• <b>N</b> child with disability(ies) stick out like a sore thumb</li> <li>• <b>N</b> peers who do not have disability(ies) have moved on</li> </ul>

### Project F (Newry and Mourne HSST and Orana Family Support Centre)

No direct effects on physical health were identified, but 'general health development' was anticipated

Direct effects on mental health

Issue	Impacts
Access	<ul style="list-style-type: none"> <li>● <b>N</b> frustration at inequality of access [location; accessibility to all parents]</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>● <b>P</b> provide family with respite from children (stress free time) enabling other children to have 'time for them' and to feel included</li> <li>● <b>P</b> improve marital health and relationships in the family</li> <li>● <b>P</b> improve sibling health by reducing stress and promoting development</li> </ul>

Direct effects on quality of life

Issue	Impacts
Service delivery	<ul style="list-style-type: none"> <li>● <b>P</b> looked after in safe environment</li> <li>● <b>P</b> first time day-care facilities available</li> <li>● <b>P</b> first outreach project to help with practical issues (2) [home support service]</li> <li>● <b>P</b> provide local early years services with parents and children</li> <li>● <b>P</b> provide greater choice of services</li> <li>● <b>P</b> provide more services for physical disability</li> <li>● <b>P</b> provide service for siblings</li> <li>● <b>P</b> lead to changes in attitudes and beliefs where best service is</li> </ul>

Health family and carer	<ul style="list-style-type: none"> <li>• ? show people what life is like living without the child</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>• P improve language</li> <li>• P develop skills [communication (2), sensory, personal development, social (2)]</li> </ul>
Nature of Wraparound	<ul style="list-style-type: none"> <li>• P provide tailored service (2) [flexibility to fit in with family life]</li> </ul>
Resources	<ul style="list-style-type: none"> <li>• N no additional funding for existing services</li> </ul>

Direct effects on social inclusion

<b>Issue</b>	<b>Impacts</b>
Health child	<ul style="list-style-type: none"> <li>• P increase social contact in different settings</li> </ul>
Service delivery	<ul style="list-style-type: none"> <li>• P make Orana 'disability friendly'</li> <li>• N promote integration (2) [might be mixing children with mental and physical disabilities and have negative impacts on children]</li> <li>• N service limitations do not address expectations beyond the Newry and Mourne area</li> </ul>

## Project G (Craigavon and Banbridge Community HSST and Banbridge Willowgrove project)

No direct effects on physical health or social inclusion identified

Direct effects on mental health

<b>Issue</b>	<b>Impact</b>
Health child	<ul style="list-style-type: none"> <li>• <b>P</b> increase self esteem</li> <li>• <b>P</b> increase social support</li> <li>• <b>P</b> increase social contact</li> </ul>
Health family and carer	<ul style="list-style-type: none"> <li>• <b>P</b> family development</li> <li>• <b>P</b> increase parents' self esteem</li> <li>• <b>P</b> increase social support</li> <li>• <b>P</b> increase social contact</li> </ul>

Direct effects on quality of life

<b>Issue</b>	<b>Impact</b>
Partnership working	<ul style="list-style-type: none"> <li>• <b>P</b> provide support for families and children following diagnosis and treatment by developing links with professional agencies</li> </ul>
Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> provide respite and short breaks for children</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>• <b>P</b> provide opportunities for parents to learn new skills</li> </ul>

## Project H (Armagh and Dungannon HSST and Oaklands project)

No direct effects on physical health or quality of life identified

Direct effects on mental health

<b>Issue</b>	<b>Impacts</b>
Health family and carer	<ul style="list-style-type: none"> <li>• <b>P</b> give parents time for other children or themselves</li> <li>• <b>P</b> give peace of mind</li> <li>• <b>P</b> provide confidence in the care child receiving</li> </ul>
Nature of Wraparound	<ul style="list-style-type: none"> <li>• <b>P</b> promote respect</li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>• <b>P</b> increase knowledge and skills</li> </ul>

Direct effects on quality of life

<b>Issue</b>	<b>Impacts</b>
Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> provision key worker</li> </ul>

## Findings of the consultation with children and young people with disabilities\*

‘We would like to be asked about our views on things and about what we think is best for us. We would like to be involved in the planning of services.’ [CS1]

### **Thoughts on consultation**

‘This is a very positive development for young disabled people.’

All the young people who participated in the consultation were positive about the project and the idea of being involved in the development of services for children and young people with disabilities. During CS1 and CS3 participants said that this would be the perfect opportunity for young people to express their views and talk about their experiences and in CS3 the participant said that it may mean that issues that matter to young people with disabilities would be addressed. Participants (professionals and young people) agreed that the session (CS2) was a very relaxed and enjoyable experience. Another young person said that if she had the same opportunity to talk to medical professionals at her hospital appointments she would feel much more informed about her condition and her treatment. She thought that this might also make her feel more relaxed about future appointments.

‘This could mean better lives for everyone with a disability.’

One of the challenges for the project will be the inclusion of young people with more profound disabilities. As one participant commented: ‘We must make sure that they are not left out.’ [CS1]

When asked about the impact of the project on their families and carers, the participants in CS1 were reluctant to speak on their behalf: ‘We can’t speak for our parents and families.’

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\* The group consultation sessions are coded as Consultation Session 1: CS1 and Consultation Session 2: CS2. The individual consultation session is coded as CS3.

All participants wished to continue to be involved in the project and wanted to meet again in the near future.

'We don't know enough about it but we are looking forward to finding out more.'

### **Barriers to user participation**

The following barriers were identified:

- Lack of money. (CS1)
- Transport. (CS1 and CS2) (This was highlighted when one young person was unable to attend CS2 due to the fact that the taxi, which was sent to his home, was unsuitable for his motorised wheelchair.)
- Communication difficulties. (CS1)
- Physical access to buildings. (CS1)
- Young people not being listened to and taken seriously. (CS1)

### **Issues for children and young people with disabilities**

'Don't make assumptions – people with disabilities can talk for themselves, do things for themselves, and think for themselves.'

#### *Community Health Services*

- Not feeling listened to by doctors. (CS1, CS2)
- Short appointments (15 minutes). (CS2)
- Better experience of the adult clinic because young people are spoken to directly. (Members of the group said that at the children's clinic it was like the parent's appointment). (CS2)
- Lack of access in some GP surgeries. (CS2)

#### *Hospital*

- Limited disabled parking spaces near hospital buildings. (CS2)
- High parking charges. (CS2)
- Long distance between car parking and hospital for someone using walking aids or in a wheelchair. (CS2)
- Time consuming and tiring journey to Belfast for appointments. (CS2)

- Mixed experience of care. One participant experienced nursing staff in a mainstream service being rude – the participant thought that it was because she was different. On the other hand, a young person who has recently undergone major surgery said that the doctors and nurses she met were very nice to her. (CS2)
- Lack of hospital service provision in the Armagh area. This impacted on families as parents have to stay in the hospital with the disabled child regardless of the needs of other family members. (CS2)
- It was the general consensus of the group that experiences in hospital eg the service provided by doctors and nurses could have been better. (CS2)

### *Therapists*

- School based therapy provision is good. (CS2)
- Lack of comprehensive services in Armagh, Newry and Craigavon. (CS2)
- Lack of services and schemes in the summer. Some services stop or the availability of services is dependant on ability. In particular the young people reported that the nine weeks without a physiotherapy service during the summer impacted negatively on their physical health. (CS2)

### *School*

- Teachers in mainstream primary education are not trained to help young people with special needs to learn. (CS2)
- Attitudes of teachers in mainstream schools are not good. One young person said that she felt that she was treated as the class ass and she was not encouraged to do what she felt she was able to do. (CS2)
- Access for wheelchairs is a problem in mainstream schools.(CS2)
- School is the place where friends meet, as there is no way of getting together outside of school. (CS2)
- Favourite activities are art, science and computers. (CS2)

### *Attitudes*

- The perceptions of some service providers that people with disabilities present a risk and their reluctance to include them. (CS3)

### *Emotional Health*

- Sometimes having a disability can 'get you down'. (CS3)

### *Social Life*

- Lack of leisure and social opportunities for young disabled people especially evening activities. (CS2)
- Life in rural areas is boring. (CS2)

### *Access*

- Lack of access to buildings for wheelchair users. (CS2)
- The means testing of adaptations to dwellings. (CS3)

### *Transport*

- Lack of independent transport. (CS2)
- Lack of transport can lead to appointments being cancelled. (CS2)
- Lack of access to driving instruction. (CS3)

### *Societal Conflict*

- Riots in the summer are frightening and stop people from getting about.

### *Training*

- Training provides enjoyable freedom and independence. (CS2)
- Training leads to finding a good career. (CS2)

## *Work*

- Preference for permanent work. (CS2)
- Need more employment opportunities for young people with disabilities. (CS2)
- Work provides opportunities for making new friends. (CS2)

'This was a really good experience. We were all given an opportunity to put our point across without anyone talking back to us or making excuses.'

## **Part four: Recommendations**

## Recommendations

### **Development and presentation of the recommendations**

#### Development

##### *Stage 1*

The recommendations identified at the workshop were written up for each project.

##### *Stage 2*

A number of recommendations were repeated for several projects and / or were judged to be appropriate to the whole Wraparound Scheme by members of the ETG. These recommendations were developed as a set of strategic 'umbrella' recommendations for Wraparound. This set was included in the HIA edition of the Wraparound newsletter.

##### *Stage 3*

Project level recommendations were grouped as 'strategic' or 'operational'.

##### *Stage 4*

The full set of recommendations was reviewed by members of the ETG and Erica Ison, in light of the evidence from the literature review.

##### *Stage 5*

A set of principles for the implementation of Wraparound were drawn up based on the data from the work group task of identifying barriers and conflicts. The principles were underpinned with evidence from the literature review.

##### *Stage 6*

Recommendations were written up from the consultation with children and young people with disabilities.

##### *Stage 7*

A final review of the recommendations was conducted by the members of the ETG, taking on board comments made at the Stakeholder Forum held in May 2002.

## Presentation

The recommendations are divided into four sections.

- Section 1 Recommendations from the consultation with children and young people with disabilities.
- Section 2 Principles to guide the implementation of Wraparound.
- Section 3 Recommendations for the Wraparound scheme.
- Section 4 Recommendations for the Wraparound projects.

The lead with responsibility for implementing Section 3 recommendations is indicated using the following task group, project team and service codes:

AD	Armagh and Dungannon	C	Communication
CB	Craigavon and Banbridge	E	Evaluation
NM	Newry and Mourne	PT	Project team
CSP	Childrens Services Planning		

The lead responsibility for implementing Section 4 recommendations rests with the task group responsible for that project, unless otherwise stated.

The Stakeholder Forum will have a role in overseeing the implementation of all recommendations, informed by the task group reports presented at each meeting.

Relevant sections of the literature review are included throughout part four. In sections 3 and 4 findings from the literature review are linked to specific recommendations and referenced in the Bibliography (Appendix VII).

## Section1: Recommendations from the consultation with children and young people with disabilities

The literature identified the need to involve children in planning their own futures and underlines that user input is essential to the planning, development, management and evaluation of services for children with a disability

‘Talk to us as young people and don’t go to anyone else – don’t ignore us!’

Issue	Recommendation
Communication	<ul style="list-style-type: none"> <li>• Develop a website for the project which could give young people the freedom to express their views and enable professionals to access young people’s views. (One of the participants has experience of web design and is interested in contributing this skill.)</li> </ul>
Transport	<ul style="list-style-type: none"> <li>• Work with transport providers to develop a transport system that would enable young disabled people to be more independent. At the moment they are always dependent on parents for transport. Public transport is not accessible. There is a need for better wheelchair accessible transport including taxis.</li> <li>• Promote independent travel by providing driving instruction for young people with disabilities</li> </ul>
Community support	<ul style="list-style-type: none"> <li>• Develop better community support for young people with disabilities eg volunteers for Gateway</li> </ul>
Social life	<ul style="list-style-type: none"> <li>• Improve the choice of social activities (something more than the cinema)</li> <li>• Improve accessibility of parks or outdoor adventure areas</li> </ul>
Awareness raising	<ul style="list-style-type: none"> <li>• Increase public awareness of disability</li> <li>• Address service provider concerns about having people with disabilities use their facilities</li> </ul>
Finance	<ul style="list-style-type: none"> <li>• Review the means testing of adaptations to buildings</li> </ul>
Support	<ul style="list-style-type: none"> <li>• Address the emotional needs of young people with disabilities regarding the impact of having a disability on their mental health</li> </ul>

## **Section 2: Principles to guide the implementation of the All-Inclusive Wraparound Scheme**

From the discussions about barriers to and conflicts around the implementation of Wraparound a set of principles has been developed for key areas of service quality. It is intended to develop these emerging principles into a charter for services for children and young people with disabilities and their families and carers, informed by evidence from the literature. (The Health Care Needs Assessment for Community Health Services [18] includes a charter for children with disabilities and their families and standards for service provision and outlines the characteristics of an ideal service for children with disabilities and their families / carers. See Appendices 2-4 of the literature review in Appendix II).

### Principles

#### 1 Accessibility

- To deliver accessible services, with particular regard to their location, transport links (including health service transport) and waiting times
- To promote staff awareness of how to develop service accessibility.

Studies of services for children with disabilities and their families stress the importance of accessibility, developing a comprehensive multi-agency information pack, allocating a key worker, having clear service access criteria and a gradual transfer from child to adult teams. Services are ideally provided locally, although there may be a need to travel to tertiary centres to access highly specialised services.

#### 2 Coverage

- To deliver inclusive services for children with different types and complexity of disability, children who are not registered as disabled and those who have acquired disabilities
- To have transparent, objective justification for referral to and use of services.

It is important to avoid compromising quality in endeavours to provide inclusive and comprehensive services. The literature notes that a good service which attempts to do too much may evolve into one that does many things poorly. The specification of minimum standards for existing provision can consolidate services' good practice.

### 3 Sustainability

- To create a profile that will raise awareness of Wraparound
- To generate momentum and thus support for this way of working
- To develop capacity amongst all partners, including different types of staff eg domiciliary staff
- To operate at a reasonable work level eg avoiding 'overload'
- To address a range of resource issues such as: matching allocated resources to realistic service levels, staff recruitment, allocating dedicated time to partnership working and ensuring equitable, transparent resource allocation
- To empower all stakeholders to contribute to the development and continuation of services.

Continued resourcing of Wraparound is necessary for its sustainability. The literature highlights the trend toward commissioners making evidence based decisions about the development and purchasing of services. The evaluation of Wraparound will be central to making the case for further resources.

The literature also highlights that services are sustained not only by the level of resources but also the way in which resources are used. The Health Care Needs Assessment [18] review of therapy provision found that the service could be improved by:

- better definition of therapy goals
- short programmes with defined objectives followed by a period of observation
- more effective liaison with educational services
- better teaching of parents and carers regarding the methods and goals of therapy
- the use of therapy aides
- provision of secretarial and clerical help.

#### 4 Equity

- To develop equitable and accessible services for children with different types of disability.

#### 5 Social inclusion

- To promote social inclusion within services
- To promote the social inclusion of children with disabilities and their families and carers in society.

#### 6 Effective innovation

- To develop innovative and varied ways of working with children with disabilities and their families, particularly those experiencing exclusion due to health and social factors
- To reduce the stigma of provision.

#### 7 Flexible service delivery

- To promote flexibility in health and non-health sector services in order to develop user-oriented provision and improve access.

The level and nature of support required by each family fluctuates over the course of a child's life, depending on internal family factors and extraneous circumstances and demands. Also, coping strategies and styles vary from individual to individual and between families. Services need to be flexible and responsive to deal with these differences and meet the current, individual needs of each child and family.

Parents and carers ought to have a choice in the delivery of services appropriate for their family lifestyle. It is this individualised approach which makes planning and provision of services more difficult and challenging, yet more rewarding for commissioners.

#### 8 Negotiation

- To acknowledge and work positively with conflict by promoting a culture of negotiation between all partners

- To minimise conflict by promoting clarity in relationships between stakeholders (eg regarding roles, responsibilities expectations), and working inclusively with new partners
- To build capacity for facilitation and mediation.

The provision of comprehensive and accessible information promotes informed communication and reduces misperceptions and misunderstandings. The literature highlights the need for training for professionals to improve their communication skills and methods of communication.

## 9 Partnership

- To develop strong partnerships with children, parents and carers, staff and other agencies, through a managed process that would address organisational and professional cultures including 'custom and practice', attitudes and perceptions of each other roles and territoriality
- To be respectful towards children, carers, staff and other agencies
- To back commitment to partnership working with parents and carers with emotional and practical support (transport, childcare, accessible venues), capacity building programmes and innovative and safe methods
- To back commitment to partnership working with staff by allocating time for this work
- To develop effective, dynamic, transparent services and clinical communication systems between all relevant actors that are supported by information technology
- To develop integrated services.

The literature review states that there is no single ideal model of parent and carer-professional partnership. In practice, parents and carers may have quite different relationships with a range of professionals and indeed with the same professional over time. The most important factor is an acknowledgement of the skills and attributes of both parents and professionals and an acknowledgement of the skills and attributes of both parents and carers and professionals and an agreement to work together for the good of the child.

Increasing acknowledgement is being given to the fact that parents become experts as they gain knowledge and experience in the specialised care of their child over time. In particular, the parents and carers of technology dependent children and children with rare disabilities rapidly become more knowledgeable than many of the professionals in the care of their children.

Professionals are moving to a partnership approach and seeking to empower parents, enabling them to take control of their family life and yet supporting them in their caring role. This may require a shift in emphasis for professionals as they become more empathic to parents and carers.

Further, partnership working needs to develop between professionals, in the context of multi-disciplinary teams, and between the agencies involved with the child and their family and carers. All agencies have a part to play but should take a lead role at certain stages in the person's life in order deliver integration and co-ordination of care and avoid fragmentation.

### Section 3: Recommendations for the All-Inclusive Wraparound Scheme

Where there is evidence from the literature review [see Appendix II] supporting recommendations it is cited below the recommendations.

#### 1 Information

	Recommendation	Lead
1.1	Improve service information and sign posting of services	PT
1.2	Develop a Wraparound website including local information, a service directory and links to information about specific disabilities	C
1.3	Develop a multi-media plan to profile the Wraparound scheme and individual projects to professional, partners agencies, children, young people and parents	C
1.4	Develop a communication system for cascading information to all stakeholders	C
1.5	Develop systems to increase projects awareness of other services	C

#### *Evidence about information*

Information enables parents to access services [19]. In a study of needs of families and children with severe physical disability, Sloper & Turner [20] identified information about services as one of the areas of highest unmet needs. In a study of respite care needs, Treneman et al [21], found that information was needed about what services were available. In an evaluation of community learning disability services for children with a learning disability [22], one of the improvements suggested by GPs and parents was an information pack.

## 2 Share the learning

	<b>Recommendation</b>	<b>Lead</b>
2.1	Develop a plan to disseminate learning from Wraparound in order that outcomes of this initiative inform and influence other service providers	PT

## 3 Work plans

	<b>Recommendation</b>	<b>Lead</b>
3.1	Develop and disseminate clear, transparent realistic work plans for each project	All
3.2	Standardise referral criteria for services (mainstream and Wraparound)	All
3.3	Clarify roles of new postholders with reference to existing staff and services	All

### *Evidence about work plans*

McConachie's conceptual framework for the evaluation of services for children with disabilities [23] highlights the importance of specifying the aims of the service to define exactly what it will do. Hall et al [18] state in their recommendations for minimum service provision that proper business plans with costings and coverage need to be developed.

#### 4 Partnership with families and carers

	Recommendation	Lead
4.1	Develop plans to engage families (including siblings) and carers as active partners in service planning and delivery using a range of creative methods.	All
4.2	Provide emotional and practical support to promote participation eg transport, appropriate childcare	All + PT
4.3	Develop parents participation in existing Wraparound structures eg Stakeholder Forum and task groups	All

##### *Evidence about partnership with families and carers, recommendation 4.1*

Hall et al [18] state in their list of characteristics for an 'ideal' child development, disability and rehabilitation service that a consumer/empowerment philosophy of care helps parents and carers to cope rather than de-skilling them. Such empowerment would be strengthened if this philosophy were extended to engaging parents in service planning. In a study of respite care needs, Treneman et al [21] concluded that parents should be involved in service planning. Shah [25] acknowledged parents' role in developing more culturally appropriate services. In a study of parental involvement in the KIDS Family Centre, Dale [26] highlighted the importance of parents' rights to choose services and forms of intervention. Engaging parents in service planning offers them the potential to develop some of the services they could choose. At the 1995 European Academy of Childhood Disability workshop [24], the inclusion of families' views in service aims was discussed.

##### *Evidence about partnership with families and carers, recommendation 4.2*

In a study of service needs of families and children with severe physical disability, Sloper and Turner [20] found that the domiciliary services of child minding and practical services such as transport were identified as areas of highest unmet need.

## 5 Partnership working

	Recommendation	Lead
5.1	Name individual parents and parent groups as partners	All
5.2	Review existing partnership network	All
5.3	Develop strategies for contacting new partners	All
5.4	Develop strategies for strengthening current partnerships	All
5.5	Identify ways in which both children / young people and parents can be heard, but with opportunities to identify their views separately, particularly in the teenage years	All

### *Evidence about partnership working, recommendation 5.1*

Appleton et al [27] identified the conditions necessary to introduce the co-ordination of care as follows:

- the primary identity and culture for local children’s services should not be determined by one agency
- a new identity for children’s services should be created in each agency. Each agency needs to understand and support the role of the other agencies involved and to ensure that individual children and families receive co-ordinated care and education.

Goh and Holland [28] proposed a framework for commissioning services for people with learning disabilities in which different agencies (health, education, social services) are involved, but each takes the lead at different stages in the child’s life. In a study by Mukherjee et al [29] investigating the communication flows about pupils with special health needs at mainstream schools, good communication included joint meetings between health and education staff, shared documentation and local policy development (eg anaphylaxis protocols). Recommendations made by health professionals in the study included the clarification of roles of the different professionals involved and improvements in information flows from health services to schools. These findings about the importance of, for

example, joint meetings, shared documentation, clarification of roles, good communication and information flows, could be applies to any of the partnerships formed to care for any child who has a disability. Indeed, in Sloper and Turner's study of service needs for families and children with severe physical disability [20], one of the problems identified was the unclear delineation of roles. Improved co-ordination and communication were crucial. At the 1995 European Academy of Childhood Disability workshop [24], the co-ordination of separate agencies was discussed.

#### *Evidence about partnership working, recommendation 5.2*

Appleton et al [27] in their study of care co-ordination for children with disabilities identified the need to involve children in planning their own futures. Hall et al [18] state in their *Charter for disabled children and their families* that the family should feel they have been listened to, and that their concerns and aspirations have been taken seriously.

## **6 Transition**

	<b>Recommendation</b>	<b>Lead</b>
6.1	Establish a working group to look at the area of transition from child to adult services and early years to child services	CSP
6.2	Clarify and develop information about service paths / options at transition and disseminate this to all stakeholders	CSP

#### *Evidence about transition*

The European Academy of Childhood Disability workshop in 1995 [24] identified the need to change the emphasis of care as the child grows older. Fiorentino et al's study of the transition from school to adult life for physically disabled young people [30] revealed that the child's time of leaving school could be particularly stressful for both

parents and child. Moreover, loss of contact with social services can occur whilst the young person is away at college. They also distilled some key messages from their work:

- young people should receive a fourteen plus assessment irrespective of whether they have a statement
- it is vital to involve the primary care team throughout childhood and adolescence
- the age of transfer to adult services should be flexible
- a range of adult services is needed because it is not possible for one service to cater for all needs
- transition plans should reflect service availability.

In McKenzie & Murray’s evaluation of community learning services for children with a learning disability [22], parents and GPs suggested that the adult team should be involved from the age of twelve onwards. In the *Charter for disabled children and their families*, Hall et al [18] state that the child’s future needs should be discussed with the parents and child as soon as possible and that there should be a planned hand over to a relevant co-ordinated adult service in line with the requirements of current legislation. ‘Ideal’ child development, disability and rehabilitation service involves a well-planned transition from school to adult life and arrangements for adult-oriented services to take over care. In their study of care co-ordination for children with disabilities, Appleton et al [27] highlight the need to involve children in planning their own futures.

## 7 Capacity building and training

	<b>Recommendation</b>	<b>Lead</b>
7.1	Conduct capacity building / training needs review for each project using a common proforma	PT
7.2	Develop a strategy for ongoing training of workers (multi-disciplinary, under- and post-graduate and in-service), partner agencies and groups, children, young people and parents	PT
7.3	Develop training for mainstream services in primary and secondary care	All

*Evidence about capacity building and training, recommendation two*

Hall et al [18] identify the importance of the provision of ongoing training for professionals which would be enhanced by a team spirit of learning, the desire to keep up to date and a search for continuous improvement. In addition, Hall et al [18] state that, where necessary, training should be provided to professionals who break the news of disability to parents following a diagnosis. Sloper & Turner [20] found one of the areas of highest unmet need was teaching parents how to help the child. Appleton et al [27] recommend the recruitment and training of care coordinators. McConachie et al [31] point out that one of the benefits of having child development teams based at a child development centre is that the centre forms a base for in-service training. It is possible that such a centre could also provide a base from which professionals in primary and secondary care could be trained (see recommendation three in this section).

## 8 Workers health

	<b>Recommendation</b>	<b>Lead</b>
8.1	Establish a staff health monitoring system particularly for stress	PT
8.2	Work with occupational health departments to explore workplace health protection and promotion programmes relevant to Wraparound which can be operationalised in partnership with the health promotion department, SHSSB	PT

## 9 Equity

	<b>Recommendation</b>	<b>Lead</b>
9.1	Develop criteria for access to Wraparound services in order to promote social inclusion	PT
9.2	Develop a monitoring system so that the allocation of resources can be assessed objectively to ensure equity. This should include access to and uptake of, respite.	PT

*Evidence about equity, recommendation one*

In McKenzie & Murray’s evaluation of community services for children with a learning disability [22], parents and GPs suggested that inequity in services should be addressed through access criteria. In a review of the role of commissioners in evaluating child disability programmes, Davidson [32] emphasised that the views of families about access and use of the service were critical. Similarly, Logan [33] emphasises the need to set service standards to monitor performance from a multidisciplinary standpoint which includes parental views. These two papers highlight the importance of including parents in the development of criteria governing access and service monitoring.

*Evidence about equity, recommendation one two*

McConachie [23] urges service providers to consider how resources and procedures relate to the aims of service provision. This suggests the importance of not only establishing equity as a fundamental principle of Wraparound services but also of the individual projects that comprise Wraparound. Both Hall et al [18] and Treneman et al [21] found that parents want a choice of respite care, which provides a positive experience for both the child and the carers. McConkey & Adams [34] urge service providers to look at usage and preference in order to plan future respite services. Providing services that parents do not prefer will affect uptake and thereby restrict access to a service that was repeatedly mentioned as a need on the Graffiti Board responses.

**10 Lobbying**

	<b>Recommendation</b>	<b>Lead</b>
10.1	Develop an awareness raising strategy targeting policy and decision makers about funding, and the Wraparound approach to services	SHSSB
10.2	Lobby the Northern Ireland Assembly Health Committee	SHSSB

**11 Access**

<b>Recommendation</b>		<b>Lead</b>
11.1	Review transport access to services and develop strategies to develop non-stigmatised, improved transport in partnership with transport providers	PT
11.2	Review arrangements for equipment repair and provision and work with relevant partners to improve the delivery of these services	PT

*Evidence about access*

In their study of the service needs of families and children with a severe physical disability, Sloper & Turner [20] identified practical services such as transport as one of the areas of highest unmet need. This is particularly important in a rural area such as that covered by the SHSSB.

## Section 4: Recommendations for the All-Inclusive Wraparound Scheme projects

Project A [One stop child development clinic outreach]

Strategic level	Recommendation
1 Capacity building	1.1 Develop communication training for staff 1.2 Run road shows for staff about referral criteria to service etc

*Evidence about communication training, recommendation 1.1*

A particularly delicate point in the communication between parents and professionals is the disclosure of the diagnosis of disability. The *Charter for disabled children and their families* developed by Hall et al [18] states that, where necessary, training should be provided for the health professionals who are responsible for breaking the news to parents. Ongoing training for professionals is also stressed [Hall et al 20]. Sloper & Turner [35], in their study of parental satisfaction with the disclosure of disability, identified three key elements in the communication:

- a sympathetic, understanding, approachable and direct manner in the communicator
- being given sufficient information
- being given the opportunity to ask questions.

Quine & Rutter in their study of doctor-parent communication concur [36]. They identified three main components in parental satisfaction with the way the news of impairment was communicated, namely:

- being told as soon as possible if something is wrong with a child

- a sympathetic approach in the communicator
- being given information, which then helps to reduce parental anxiety.

Any training for professionals giving parents a diagnosis should include these key elements.

### Operational level

Focus	Recommendation
2 Use of service	2.1 Provide a choice for user to attend local or area clinic
	2.2 Introduce confirmation of attendance
	2.3 Develop a multi-disciplinary approach to decisions about when a child needs fast tracked to the child development clinic and to team meetings
3 Access	3.1 Provide crèche for siblings
	3.2 Provide signing
	3.3 Provide easy phone access
	3.4 Improve building access
	3.5 Refurbish accommodation
	3.6 Provide hospitality for parents and carers
	3.7 Appoint guide or intermediary for parents
4 Information	4.1 Provide internet access
	4.2 Promote a two way flow of information between children, family and professionals
5 Parents networks	5.1 Provide opportunities for parents to be mutually supportive

### *Evidence supporting the recommendations*

In a study of parental involvement in a family centre for pre-school children with special needs [26], Dale highlights the importance of parents having the right to select services and forms of intervention.

### *Evidence about use of service, recommendations 2.1-2.3*

The European Academy of Childhood Disability workshop [24] identified promoting multidisciplinary team-working as one of the main areas for improvement. McConachie et al [31] highlighted that two of the benefits of a child development centre where services could be based were:

- a physical space in which team members can meet
- the potential for team-building and communication.

In Youngson-Reilly et al's study of multidisciplinary teams working with children with a visual impairment [38], the following benefits of team-working were identified:

- increased numbers and speedier referrals
- speedier implementation of services
- improved liaison between professionals.

However, Mukherjee et al [29] investigating communication about pupils with special needs in mainstream schools found that it was important:

- to be clear about the roles of the relevant professionals
- to maintain information flows among professionals (particularly between NHS and school).

Good practice in communication included:

- joint meetings between health and education staff
- shared documentation.

These findings may be relevant to multidisciplinary team-working.

*Evidence about parents' networks, recommendation 5.1*

Hall's review of child development teams in Britain [18], found that parents need links with other families who have disabled children. The 'Charter for disabled children and their families' developed by Hall et al [18], states that every family should be offered a meeting with another parent whose child has the same problem. In Pain's [19] study of the ways parents cope with a child with disabilities, parents identified sharing with other parents as an important information source.

Project B [RNIB and the Southern Education and Library Board]

**Strategic level**

<b>Focus</b>	<b>Recommendation</b>
1 Partnership working	1.1 Develop multi-agency approach and share professional expertise 1.2 Develop partnerships with: early years providers, school services (often Belfast based) and primary health care workers (particularly health visitors and GPs)

### *Evidence about partnership working, recommendation 1.1*

In the health care needs assessment for child health community services, Hall et al [18] identified inter-agency collaboration (health, social services, and education) as important to providing a comprehensive service for children with a disability. In addition they suggest that there should be co-operation with other agencies to ensure liaison over the needs of individual children. With respect to commissioning services for people with learning disabilities, Goh & Holland [28] proposed a model in which health, social services, and education all have a role to play but that different agencies lead at different stages in the child's life. The European Academy of Childhood Disability workshop [24] discussed the co-ordination of separate agencies.

### *Evidence about partnership working, recommendation 1.2*

In Fiorentino et al's study of transition from school to adult life for physically disabled young people [30], one of the key messages was that the primary care team must be involved throughout childhood and adolescence. Hall's review of child development teams in Britain [39], found that parents need easy access to other agencies such as education. In the *Charter for disabled children and their families* [18], Hall et al concluded that every parent should know about pre-school educational help (eg home teachers, Portage), their rights under education legislation and the procedures involved in assessment and statements of special educational need.

### **Operation level**

<b>Focus</b>	<b>Recommendation</b>
2 Partnership working	2.1 Develop a culture of valuing everyone and their contribution
	2.2 Use accessible language to enable communication between users and providers of services
	2.3 Involve parents at early diagnosis stage
3 Resources	3.1 Support co-ordinator with mobile phone, computer etc

*Evidence about partnership working, recommendation 2.1*

The principles guiding the *Charter for disabled children and their families* [18], stress the need for professionals to listen to and respect the parents of the disabled child. In Sloper's [40] review of models for service support for parents of disabled children, one of the important characteristics of an effective service model is acknowledging and recognising parents' own expertise about their child and their family.

*Evidence about partnership working, recommendation 2.3*

In the light of the finding by Quine & Rutter [36] that parents want to know as soon as possible if something is wrong with their child, and that by Pain [19] that information assisted in the parents' emotional adjustment to their child's disabilities, it would seem that parental involvement at early diagnosis is necessary for their wellbeing. Giving parents information early is also important for the child's wellbeing. Pain [19] found that information enabled parents to access services and benefits for the care of their child. Information also helped parents to manage the child's behaviour.

Project C [User participation of children with disabilities in strategic planning of services]

<b>Strategic level</b>	<b>Recommendation</b>
1 Partnership working: children and young people	1.1 Develop a strategy for accessing ‘hard to reach’ children eg those not in existing groups and those with severe disability 1.2 Extend representation on task group
2 Partnership working: agencies	2.1 Ensure commitment at all levels of agencies to: ownership of concept; planning, reviewing and monitoring of partnership with children and young people; to taking their views seriously 2.2 Develop systems so that users will influence planning processes for getting views back to policy makers, planners and providers 2.3 Establish a statutory requirement to have users on all planning groups 2.4 Develop systems to feedback to users on the results of their participation, including open and honest explanation about the reasons why some things have been achieved and some have not
3 Methods	3.1 Conduct a review to identify similar schemes and contact for advice about methods 3.2 Conduct a review of models about how to engage young people, both disabled and non-disabled
4 Selection and representation	4.1 Ensure that all children’s voices are heard by monitoring representativeness of children participating in project

**Operational level**

<b>Focus</b>	<b>Recommendation</b>
5 Partnership working: generic	5.1 Use existing networks, experiences and activities 5.2 Address practical barriers: transport, childcare, language 5.3 Be clear about the potential scope for service development and priority setting in order to avoid raising unrealistic expectations
6 Partnership working: children and young people	6.1 Establish the principle that it is the children's choice to participate 6.2 Access the views of peers who do not have disabilities
7 Partnership working: families	7.1 Be pro-active in engaging individual families to: - access the views of children who cannot express their own needs - address their concerns about the appropriateness of working with children and young people in this way and convince them of the value of their children getting involved
8 Methods	8.1 Develop a range of exciting methods for communication and consultation, recognising that some young people have 'meeting phobia' and using advocates and sub-groups

*Evidence about recommendations five to eight*

Hall et al [18] argued that user input is essential to the planning, development and management of services. Appleton et al in their study of care co-ordination [27] stated that the child needs to be involved in planning for their future, which will include their needs for service provision. In an editorial, Logan [33] pointed out that one way to achieve 'patient' satisfaction is to involve users in the planning of the services they receive.

Project D [Autism specific service provision with the SHSSB]

<b>Strategic level</b>		
<b>Focus</b>	<b>Recommendation</b>	<b>Lead</b>
1 Respite care	1.1 Increase respite provision, and improve appropriateness	PT

*Evidence about respite care, recommendation 1.1*

Treneman et al [21] found parents want a choice of respite care, which should be a positive experience for both the child and the carers, and recommend that parents be involved in planning respite services. McConkey & Adams [34] urge service providers to look at usage and preference in order to plan future respite services. Hall et al's *Charter for disabled children and their families* [18] stated that every parent should know about respite care and there should be a range of respite provision.

**Operational level**

<b>Focus</b>	<b>Recommendation</b>
2 Boundaries	2.1 Establish siblings groups and young carers groups
3 Capacity building	3.1 Develop a training role for one of the three specialists to work with primary health care workers
4 Service delivery	4.1 Develop good co-ordination with the early diagnostic service
	4.2 Develop multi-professional diagnostic service
	4.3 Develop follow-up after diagnosis
	4.4 Improve communication between professionals
	4.5 Develop a good profile for specialists among families and health professionals
	4.6 Work with family as a whole
	4.7 Develop a feedback mechanism for the service and improve existing user involvement

*Evidence about capacity building, recommendation 3.1*

Fiorentino et al [30] emphasise the need to involve the primary care team throughout childhood and adolescence.

*Evidence about service delivery, recommendation 4.4*

When Mukherjee et al [29] investigated communication about pupils in mainstream schools who have special health needs, one of the recommendations was to improve information flows among professionals in the different agencies. Face-to-face contact between staff was particularly important. Another issue highlighted was the communication among professionals within a single agency.

*Evidence about service delivery, recommendation 4.6*

In their study of service needs for families and children with severe physical disability, Sloper & Turner [20] underlined the importance of interventions that focus on the family as a whole. McConachie [41] argued that the aim of child disability services was to offer comprehensive and co-ordinated assessment, advice, information and relevant support for children with developmental difficulties and their families. In a later paper, McConachie [23] extends this delineation of broad aims for child disability services thus: ‘Family support, that is, helping the child and the family toward achieving good adaptation and quality of life’. Hall [39] identified one of the drivers for multidisciplinary services as ‘the chronic and complex nature of the child’s problem in the context of that particular family’. Beresford [42] reviewed parents’ coping skills to inform intervention programmes, and identified two prongs to an intervention programme:

- intervention at the level of personal and socio-ecological coping resources
- interventions to enhance parents’ coping skills.

*Evidence about service delivery, recommendation 4.7*

The European Academy of Childhood Disability workshop [24] on services for children with disabilities, it was recommended that family’s views should be included in the service aims. Hall et al [18] suggest as a minimum for service provision that user input is essential to the planning, development and management of services.

Project E [Mencap family support and play advisor]

**Strategic level**

<b>Focus</b>	<b>Recommendation</b>
1 Service Delivery	1.1 Improve communication and co-ordination to avoid overlap between services

*Evidence about service delivery, recommendation one*

Hall et al [18] identify the importance of inter-agency collaboration (health, social services, and education) to providing a comprehensive service. In addition, in the list of characteristics of an 'ideal' service for children with disabilities, it is suggested that there be co-operation with other agencies to ensure liaison over the needs of individual children. At the European Academy of Childhood Disability workshop [24], the co-ordination of separate agencies was discussed. When Mukherjee et al [29] investigated the communication flows about pupils with special health needs at mainstream schools, good communication included joint meetings between health and education staff and shared documentation. One of the recommendations made by the health professionals in the study was clarification of the roles of the different professionals involved.

**Operational level**

<b>Focus</b>	<b>Recommendation</b>
2 Boundaries	2.1 Expand upper age limit to 18 years 2.2 Clarify the roles and responsibilities of multi-agency clinics, and between voluntary, community and statutory and expectations; and groups of children to be reached by service eg into age blocks
3 Service delivery	3.1 Increase participation of profound disability children in play group 3.2 Ensure specialism not lost

*Evidence about boundaries, recommendation 2.1*

Hall et al [18] suggest that an 'ideal' child community health service should offer a comprehensive service for the children from birth to 18 or 19 years.

*Evidence about boundaries, recommendation 2.2*

The clarification of roles of different professionals was an important point to emerge from Mukherjee et al's [29] study of communication about pupils in mainstream schools with special health needs.

Project F [Newry and Mourne HSST and Orana Family Support Centre]

### Operational level

Focus	Recommendation
1 Service delivery	1.1 Ensure sufficient administration support
	1.2 Address early diagnosis
	1.3 Develop outreach with schools

*Evidence about service delivery, recommendation 1.1*

Hall et al [18] suggest that an 'ideal' child development, disability and rehabilitation service should have a secretary or administrator as part of the team.

Project G [Craigavon and Banbridge Community HSST and Banbridge Willowgrove Project]  
**See 'Recommendations for Wraparound Scheme'**

Project H [Armagh and Dungannon HSST and Oaklands Project]

### Operational Level

Focus	Recommendation
1 Service delivery	1.1 Conduct holistic assessment of needs
2 Partnership working	2.1 Assessment: involve carer in assessment of what is 'complex'

*Evidence about service delivery, recommendation 1.1*

Sloper's [40] identified one of the important characteristics of an effective service model as an holistic approach to assessing and meeting family needs.

*Evidence about partnership working, recommendation 2.1*

In Sloper's review of models of service support for parents of disabled children [40], one of the important characteristics of an effective service model was a focus on parents' own concerns and understanding parents' own perceptions of their hierarchy of needs.

**Recommendations not taken forward**

<b>Project</b>	<b>Recommendation</b>	<b>Rationale</b>
D	Expand service age range from 3 to 5 years	Resources not available
	Develop a training role for one of the workers	

## **Further recommendations**

The HIA Workshop and subsequent Stakeholder Forum generated a number of recommendations for service provision not included in Wraparound. In order to avoid losing these ideas they are recorded below to inform subsequent service development.

### Hospital provision

- Copy hospital letters (in- and out-patient) to parents
- Improve co-ordination, communication and planning between hospital and community services.

### Service delivery

- Use key workers, selected by the family or carer, to co-ordinate a holistic and comprehensive assessment, and continuity in ongoing care. (The concept of a key worker is supported by [31], [27], [22], [20], [40] and [19].)
- Look at the needs of an individual child within the context of their family. (Assessing a child's needs in the context of the whole family is supported by [39])
- Develop supports for all family members eg non-disabled siblings
- Provide services during summer months.

### Specific services

- Develop project for children with hearing impairment
- Set up sign language classes for parents of deaf children
- Develop a flexible out of hours service
- Develop local specialist teams for children with disabilities locally (There is currently one paediatric nurse for the whole of SHSSB.)
- Increase the accessibility of education services
- Provide specialised schooling
- Conduct neo-natal screening for hearing loss. (This is supported [43].)
- Improve communication support
- Develop links with Banbridge community village.

## **Part five: Monitoring and evaluation framework**

## Monitoring and evaluation framework

### **Challenges for the monitoring and evaluation framework (MEF)**

There are a number of challenges in monitoring and evaluating Wraparound. In the inclusive spirit of Wraparound, it is important to involve stakeholders in the monitoring and evaluation process. The literature on evaluation of services for children with disabilities raises a number of key issues. These are summarised below and have informed the development of the framework.

#### *Scope of the evaluation*

Evaluation can be considered for:

- one particular intervention
- overall assessments of Quality of Life (QOL) of child's life or family functioning, parental satisfaction, adjustments and coping
- measuring processes of care eg uptake of services, knowledge of target population, reach of services.

#### *Measurement*

Measurement challenges include:

- the need to assess what a child can and cannot do and relating this to their age
- the assessment of how multiple disabilities interact eg mild hearing loss may cause major problems when combined with a mild learning disability
- the effect of the attitudes of the child, parents and teachers on the perceived extent of the disability
- the early stage of development of instruments to measure positive health changes in children
- outcome measures which measure functional ability can rarely be used in routine practice
- difficulty in measuring changes in QOL in children with a disability
- the optimum amount of therapy is not known
- there is an absence of evidence on service effectiveness.

#### *Interventions*

The literature on parents' satisfaction with aspects of service delivery can be used to develop quality criteria. This includes:

A key events

B processes of service delivery.

A An example of key events is 'news breaking'. Parental assessments of the empathy of the professional and the clarity of expression at the first consultation correlate with long term parental satisfaction and mental health.

B Examples of processes of service delivery are:

- true parental involvement in assessing information, providing care and decision making
- education and information about the condition and services
- treatment and evaluation of progress
- care co-ordination between agencies
- continuity of care
- family centred care
- family coping skills.

*Development of a MEF*

The framework needs to have clear, agreed goals for professionals and families on areas such as communication, social skills, sleep disturbance and learning key skills.

It is important that the framework assesses:

- service quality
- issues of adaptation and participation for the child
- support for families to prevent disruption.

This can be done by:

- assessing 'process' issues such as service uptake and knowledge of target population by using multiple data sources
- assessing consumer satisfaction by interviews and questionnaires using standardised instruments
- agreeing standards based on research such as *A Charter for disabled children and their families* [18].

### Timetable for the development of the MEF

- July - Development of proposed MEF
- August Inclusion of proposed MEF in HIA report
- September Dissemination of HIA report
  - Discussion of proposed MEF in task groups
  - Review of proposed MEF
- October Discussion and adoption of MEF at Stakeholder Forum

### Monitoring and evaluation framework

A matrix will be constructed for each Wraparound project with the dimensions of partners (children, parents, workers and agencies) and principles (accessibility, coverage, sustainability, equity, social inclusion, effective innovation, flexible service delivery, negotiation and partnership). The guidance will include methods and tools, which can be used for evaluation and monitoring.

Project E				
Project D				
Project C				
Project B				
Project A	Children	Parents	Workers	Agencies
Accessibility				
Coverage				
Sustainability				
Equity				
Social inclusion				
Effective innovation				
Flexible service delivery				
Negotiation				
Partnership				

## **Appendices**

## Appendix I Membership of Evaluation Task Group

Dr Brid Farrell [Chair]	Public Health Directorate, Southern Health and Social Services Board
Mr Richard Black	Disability Programme, Newry & Mourne Health and Social Services Trust
Mr Liam Burns	Mencap
Ms Mary Duffin	Mencap
Ms Valerie Doyle	Children's Services Planning, Southern Health and Social Services Board
Ms Iris Elliott	Institute of Public Health in Ireland
Ms Ann Mallon	Mencap
Ms Valerie Maxwell	Children's Services Planning, Southern Health and Social Services Board
Mr Martin Sweeney	Learning Disability Programme, Armagh & Dungannon Health and Social Services Trust
Mr George Thompson	Community Development Team, Craigavon & Banbridge Health and Social Services Trust
Ms Mary Wright	AFASIC

Appendix II Literature Review\*  
**Services for children with disabilities and their families**

## **Introduction**

Children with disabilities form a varied and disparate group. This poses challenges for professionals, voluntary organisations and parents for planning and co-ordination of services. Over the past years, thinking has changing from service-based models to child-focused and family-focused models.

The aim of this paper is to review published literature from England, Scotland, Wales and Ireland on services for children with disabilities in order to inform the HIA of Wraparound. The paper will identify, from the literature, what services are available, what recommendations for good practice have been made and what gaps exist in services.

The working definition of disability for the purposes of this review is: 'Children who have a physical, sensory or learning disability, prolonged illness or condition which impacts on daily living in a way that, without the provision of adequate support services they would not achieve their optimal potential for personal development and social inclusion'. (Age range 0-18 years). This covers a wide range of conditions and illnesses with the common theme of requiring services to attain potential.

## **Method**

A search of the literature was conducted using Medline, CINAHL and ASSIA databases. The librarian from Queen's University Belfast also identified relevant papers from research databases. Further papers were retrieved from references cited in papers from the initial search. Inclusion criteria were:

- Published in England, Scotland, Wales or Ireland
- Published between 1992-2002

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\* The reference numbers used in the literature review relate to the literature review references in Appendix 5, not the Bibliography in Appendix VII of this report.

- Described services for children with disabilities and their families  
OR
- Made recommendations for good practice OR
- Identified key gaps in services.

Abstracts which dealt with predominantly adult services, psychiatric services, education services, highly specialised genetic services or research on populations outside England, Scotland, Wales or Ireland were excluded. Prevalence data was also excluded as being outside the scope of this review.

### **Services available**

Impact on parents and families of caring for a child with a disability

The birth of a child with disability has far reaching effects on individual parents, marital relationships, siblings and the family unit as a whole<sup>1,2</sup>. The quality of life for all members of the family is affected as parental priorities adapt to cope with the practical, emotional and time demands of caring for a child with a disability. Employment opportunities for both parents are often reduced with resultant financial implications at a time when the need for resources, both personal and material is increased.

Families vary considerably in how they appraise the situation of having a child with a disability and this variation is not explained by severity of disability<sup>2</sup>. Coping strategies are multi-factorial and it is impossible to predict at an early stage what levels of support and services will be required. In addition, the level of support required by each family fluctuates over the course of a child's life, depending on internal family factors and extraneous circumstances and demands. This has led to services becoming more individualised and focused on the current needs of each child and family.

Informal support networks from extended family and friends, support from voluntary organisations and professional support from statutory services all have a part to play. Parents ought to have a choice in the delivery of services appropriate for their family lifestyle<sup>3</sup>. It is this individualised approach which makes planning and provision of services more difficult and challenging, yet more rewarding for commissioners.

An evolving group within the wider category of children with a disability comprises those children who are dependent on complex technology for their survival – a group that would not have survived into childhood in previous years. The special skills required to cope with technology in an uncertain and changing environment brings about a new set of extra care needs for these children and parents. Because of the rarity of these conditions, parents rapidly become more knowledgeable than many professionals in the care of their technology dependent children.

The birth of a child with a disability also affects the physical and mental health of the parents, in particular the mother, who is often the main carer on a daily basis<sup>2</sup>. Recognition is increasing, however, of the needs of fathers in these families and the difficulty of engaging fathers with support services. Both parents suffer a grief reaction and a period of adjustment to losing the child whom they had expected and adapting to the child that has been born<sup>1</sup>. Ethnicity, social class and religious beliefs all affect the parents' ability to cope with and adapt to this situation.

## Needs

Parents of children with disability need both practical and emotional support. Increasing acknowledgement is being given to the fact that these parents become experts as they gain knowledge and experience in the specialised care of their child over time. Professionals are moving to a partnership approach and seeking to empower parents, enabling them to take control of their family life and yet supporting them in their caring role. This may require a shift in emphasis for professionals, as they become more empathic and sensitive to parents.

Not all parents are the same however. Coping strategies and coping styles vary from individual to individual and between families<sup>2</sup>. Services that are developed need to be flexible and responsive enough to deal with these differences and meet individual needs. 'Pick and mix' rather than 'one size fits all'.

In an analysis of the Family Fund Database, Roberts and Lawton reviewed the records of almost 40,000 applicants to the Fund in

order to identify the extra care needs of these children with disabilities<sup>4</sup>. Cluster analysis then identified 5 broad groups of children with disabilities requiring extra care aged between 1 and 16 years and three groups of infants under 1 year old. These broad groups may provide a useful framework when planning services for children with disabilities (see Appendix 1 of this literature review).

### Worries and concerns

Most parents worry about their children and are concerned for their welfare, however, parents of children with a disability have extra cares and concerns. These include such things as dental care, feeding and swallowing problems. Looking to their child's future, parents are often concerned about sexuality, employment and vulnerability to abuse or the risk of abusing others. Long-term care needs and quality of life into adulthood is also a source of anxiety<sup>1</sup>.

In a study by Case in 2000<sup>1</sup>, social issues of concern for parents of children with disability were explored under the headings of: diagnosis, professionals, therapy, aesthetics, body, time, support and advice.

For both parents and young people, transition periods such as starting and leaving school are particular times of stress. A survey of 87 young people with physical disability identified a number of key messages<sup>5</sup> for the transition from school to adult life.

- Young people with physical disability should receive a fourteen plus assessment regardless of whether they have a 'statement'
- A period away at college can result in loss of contact with social services
- The age of transfer to adult services should be flexible
- One service can not cater for all: a range of adult services is needed
- Transition plans must reflect service availability
- The primary health care team must be involved throughout childhood and adolescence

Services to meet the needs of disabled children and their families

In October 1995, the European Academy of Childhood Disability held a workshop with a wide range of professionals, parents and voluntary groups to review how services were provided for children with disabilities across Europe. At least two representatives from 17 countries attended this workshop. The report of this workshop<sup>6</sup> provides the most comprehensive information that we have on service provision.

Two key issues for improvement in services were identified as:

- Promoting multidisciplinary team working
- Developing a goal orientated programme for each child and family.

Five discussion sessions took place under the following headings:

1 How comprehensive are local health services?

- Service delivery and accessibility
- Which clinical problems are services for and which doctors are involved?
- The role and availability of therapy
- The changing emphasis of care as the child grows older
- The transfer of care to adult services

2 Rare diseases

3 The co-ordination of separate agencies

4 The inclusion of families' views in service aims

5 Services for children who have severe behaviour problems

### **Multidisciplinary team working**

This key theme emerges in most of the literature about children with a disability. In a paper entitled *Child development teams: are they fulfilling their purpose?*<sup>7</sup>, Hall states that 'what dictates the need for multidisciplinary services is the chronic and complex nature of the child's problem in the context of that particular family'.

In a comprehensive study of 242 multidisciplinary child development teams throughout the UK<sup>8</sup>, management and funding of teams emerged as the two major issues. Teams varied widely in their composition and organisational structure with no single ideal model. However, some important components of multidisciplinary child development teams emerged from the survey: the ideal service should be based in a child development centre. The benefits of a centre include; physical space for team members to meet, opportunities for team building and communication, the potential to act as a base for in-service training and as a community resource for children and families. The survey also found that a keyworker should be assigned to each family, that parents want copies of assessment reports and that assessment should not be prolonged but lead to an individual programme plan.

In a study of 12 multidisciplinary teams for children with disabilities<sup>9</sup>, Yerbury identified seven issues for multidisciplinary team working. These are listed below.

- Team management
- Team models and leadership
- Dual accountability
- Developmental stage of team
- Team meetings
- Multidisciplinary co-operation
- Child development centres

A small study of two teams for children with visual impairment<sup>10</sup>, found that a multidisciplinary team approach led to a faster, more streamlined system and improved liaison between professionals. However, one of the main constraints to multidisciplinary team working is lack of time.

The importance of a Child Development Centre, or at least a common base, is a recurring theme in the literature regarding services for children with disabilities. However, a common base alone will not necessarily produce improved multidisciplinary working. In a study of 20 parents of pre-school children with disability, who were about to start nursery school, Appleton et al piloted a study of care co-ordination<sup>11</sup>. This concept appears similar to that of the key-worker with an added intra-agency emphasis. Care

co-ordinators from a range of professions were trained to assess the needs of child and family, provide ongoing support and co-ordinate case reviews with school staff. No single agency was seen as lead agency.

In 1994, Goh and Holland published a paper proposing a framework for commissioning services for people with learning disabilities<sup>12</sup>. This recognised that all agencies had a part to play, but suggested that each should take the lead role at certain stages in a person's life. Health services should lead commissioning services for the pre-school child, passing to education services when a child started school, with social services leading commissioning for adult services. The aim of this framework was to avoid fragmentation, while acknowledging the need for integration and co-ordination of care.

### **Child and family focused services**

In an editorial article<sup>13</sup>, McConachie proposes that the aim of child disability services should be: 'To offer comprehensive and co-ordinated assessment, advice, information and relevant support for children with developmental difficulties and their families'.

Services to meet the needs of children with a disability and their families should ideally be well co-ordinated and easily accessible. There should be early intervention and assessment of the child and wider family. This will require communication between professionals from a range of disciplines<sup>14</sup>.

Medical, nursing and therapy input should include counselling and genetic advice where relevant and testing for undetected medical problems such as reduced vision or hearing<sup>14</sup>.

Liaison with education services should provide support, advice and education of teachers and other education staff with regard to the child's particular disability. This process is not always straightforward, as professionals often do not understand each other's role. Information flows within agencies and between agencies is often unco-ordinated<sup>15</sup>.

Social services departments should provide information and support about financial benefits and information about equipment and support services.

In all services, individual parental choice should be available. Aspects of good practice are considered in more detail in the section on page 117.

### **Service evaluation**

The literature search yielded six papers or articles that addressed the issue of service evaluation.

Particularly in the field of medicine, commissioners are increasingly required to develop and purchase services that are evidence based. Funding is often dependent on proof or evidence that a service is effective. This may be relatively straightforward when evaluating single drug treatments through randomised controlled trials (RCTs), but becomes extremely difficult when dealing with complex interventions such as those for children with a disability. Evaluation is often difficult due to complex interdisciplinary and interagency teams or pathways of care. The views of families regarding access and use of services are an important aspect of service evaluation<sup>16</sup>.

In an editorial article<sup>17</sup>, Logan commented that the combination of chance effects on rare events makes it difficult to disentangle chance effects from real differences. For example: the child with a disability already has a rare condition. Many factors – physical, emotional, social and others - combine to determine the child's development. Against that background it is difficult to attribute progress to a single intervention in isolation from all other factors. Logan advocates the need to set service standards against which to measure performance and stresses that these standards should be determined from a multidisciplinary point of view, including the views of parents.

McConachie goes on to develop the idea of standards in a paper entitled *Conceptual frameworks in evaluation of multidisciplinary services for children with disabilities*<sup>18</sup>. She proposes two broad aims for child disability services:

- Excellent medical care, including identification, diagnosis, detailed assessment and therapeutic intervention
- Family support, that is, helping the child and family toward achieving good adaptation and quality of life.

The paper goes on to make some recommendations about evaluation of child disability services.

- Take time to reflect on practice
- Specify aims to define what exactly the service is aiming to do
- Think about how resources available and procedures followed relate to aims
- Monitor how decisions on change are being implemented (Reorientation of services takes time and effort)
- Set individual goals for children and a timescale for review of measurable objectives.

The published literature includes some practical examples of service evaluations that have taken place. In Scotland, McKenzie and Murray carried out an evaluation of community disability services for children with a learning disability<sup>19</sup>. They obtained views from twelve Trusts which provided Community Learning Disability Services, thirty parents of children with learning disability and eleven GPs. Although this was not a random sample, it did cover views from providers, GPs and parents. The key suggestions for improvement in the service centred round locally accessible specialist learning disability services, including clinical psychology and psychiatry services to address behaviour problems, provision of a comprehensive multiagency information pack, allocation of key worker, clear service access criteria and gradual transfer from child to adult teams.

A second paper by Cass and Kugler<sup>20</sup> considered service evaluation and development within a paediatric disability team. Although this audit was based on a single team based in a specialist tertiary centre, it provides some useful comments about service evaluation. The authors make the important point that in paediatric disability services, the effects of intervention may be indirect, having their influence through family support and counselling rather than through direct therapy with the child. They also comment that effects may be delayed and that services often try to achieve negative outcomes, for

example avoiding complications such as contractures or behavioural problems.

Cass and Kugler also stress the importance of setting goals and objectives, realising that these may change over time. They make the point that secondary services are often under pressure to be comprehensive, but that a good service which attempts to do too much too soon may evolve into one that does many things poorly. They suggest that by specifying minimum standards for existing services, these can be consolidated before determining what additional resources are available for new developments.

The report of the European Academy of Childhood Disability workshop<sup>6</sup> discusses the need for evaluation and makes general rather than specific comments. Most authors agree on the need for service evaluation but there is no clear structure for achieving this.

### **Good Practice**

Recommendations for good practice in services for children with disability can be distilled from a number of studies. Most of the research in this area consists of small qualitative studies that often can not be generalised to a wider population. However, when these studies are considered together, the recurring themes can form a basis for recommendations for good practice.

In 1992, Sloper and Turner published a paper on the service needs of families and children with severe physical disability<sup>21</sup>. The authors obtained views from 107 families on a range of issues including service contacts, helpfulness of services and needs for help. This research identified a number of key areas that could inform good practice.

Some years later, Hall conducted a review of child development teams in Britain, based on published literature, personal experience and the conclusions of a seminar for those working in the field<sup>7</sup>. Although this was a non-random sample of participants it reflected a broad view of the topic.

A third paper, again by Sloper, reviewed models of service support for parents of disabled children asking 'What do we know? What do

we need to know?'<sup>22</sup>. She identified important characteristics of effective service models. Taking these three papers together, it is possible to produce the composite list of general recommendations for good practice given below.

Services for children with disabilities and their families should be:

- 1 Holistic in the approach to assessing and meeting family needs
  - Be individualised, needs-led approach
  - Empower parents and carers
  - Be based on a good relationship between parents and carers and professionals
  - Work in partnership with parents and carers
  - Provide emotional support
  - Recognise parents and carers perceptions of need
  - Allow parental and carer choice of services
  - Show respect to parents and carers
  - Acknowledge parental and carer expertise
- 2 Multidisciplinary, with well trained staff who have good communication skills and who can be sensitive and empathic
- 3 Locally accessible, while recognising the need to travel to tertiary centres to access highly specialised services
- 4 Well co-ordinated, with named key worker providing consistent point of contact
- 5 Providing information and advice about:
  - available services, including other families with children with disability and voluntary groups
  - procedures for assessment and review
  - the child's condition and how to help them
- 6 Providing aids and adaptations quickly
- 7 Providing financial and material help with transport and housing
- 8 Providing practical help with breaks from care

## Good communication

One of the most common recurring themes in studies of good practice surrounds communication. This has training implications for professionals as they seek to improve their communication skills and methods of communication. In one sense, breaking bad news is always going to be extremely traumatic. However, the manner of the communicator and method of communication can help to soften the blow.

Sloper and Turner interviewed 103 parents to determine parental satisfaction with disclosure of disability<sup>23</sup>. They found that a good communicator should have a sympathetic, understanding, approachable and direct manner. Parents should be given sufficient information and the opportunity to ask questions.

Quine and Rutter studied doctor-parent communication at the first diagnosis of severe mental and physical disability by questioning parents<sup>24</sup>. This stratified sample of 166 children was drawn from all disabled children in two health districts in the south-east of England. Their findings echoed those of Sloper and Turner with regard to the sympathetic approach of the communicator and the importance of information in reducing anxiety. Their study also found that parents want to know as soon as possible if something is wrong.

## Early diagnosis

Watkin, Beckman and Baldwin also found that early diagnosis of impairment is important to parents. They surveyed parents of 208 children with hearing impairment about the need for neonatal hearing screening and consequent early diagnosis of hearing loss<sup>25</sup>. Although these parents already knew their child's diagnosis, in retrospect they would have welcomed a neonatal hearing screen if it had been available.

## Information

A study by Pain in 1999 entitled *Coping with a child with disabilities from the parents' perspective: the function of information*<sup>26</sup>, found that information assisted the process of emotional adjustment to a child's disabilities and enabled parents to access services and

benefits. It also improved management of the child's behaviour. Personal communication was the preferred method, with written information as back up. Information from teachers, other parents and voluntary organisations also played an important role.

### Communication in specific situations

Some studies address the importance of communication in certain specific situations. Shah makes the case for providing culturally appropriate services<sup>27</sup>, while Mukherjee et al studied communicating about pupils in mainstream school with special health needs<sup>15</sup>.

### Models of service

Three papers refer to the issue of parent partnership models of service support. Case<sup>1</sup> and Hall<sup>14</sup> describe similar theoretical models in detail. At one end of the spectrum lies the expert model, where the professional is regarded as the expert and the parent is the passive recipient of advice and instruction. The opposite extreme regards the parent as empowered to choose between a range of options, including refusal of professional advice and help. Sloper<sup>22</sup> examines how the balance between parent and professional might be worked out in practice.

There is no single ideal model of parent-professional partnership. In practice, parents may have quite different relationships with a range of professionals and indeed with the same professional over time. The most important factor is an acknowledgement of the skills and attributes of both parents and professionals and an agreement to work together for the good of the child.

### Standards for services

*A Health Care Needs Assessment for Community Child Health Services*, led by Hall<sup>14</sup>, contains a proposed 'Charter for disabled children and their families'. This sets out standards for referral and follow-up, the diagnosis and the disability, treatment and therapy, information and medical care and support. The document also lists recommended minimum service provision through European countries for children with disability, taken from the report of the European Academy of Childhood Disability workshop<sup>6</sup>. The

proposed charter and standards for minimum service provision are reproduced in full in Appendices 2 and 3 and should provide a useful basis for local service planning.

### **Key gaps**

In order to identify gaps in a service, it is necessary to begin by examining the ideal level of support and then compare existing levels against this to demonstrate the shortfall. This type of Health Care Needs Assessment has recently been carried out for Community Child Health Services, which include services for children with a disability<sup>14</sup>. This is currently available online at <http://hcna.radcliffe-online.com/cchs.htm> and will be published during 2002.

The Health Care Needs Assessment recommends that each district should have a Child Development, Disability and Rehabilitation Service (CDDRS). Difficulties arise when trying to determine optimum staffing levels as many professionals see children with disability as part of a broad range of work, making it difficult to accurately apportion time and resources spent on disability services. The Health Care Needs Assessment suggests characteristics of an ideal service, based on a range of studies. Many of these characteristics have already been discussed elsewhere in this paper, but are listed in full in Appendix 4.

### Therapy provision

The Health Care Needs Assessment also makes the following important point about therapy provision:

A difficult problem in defining the ideal service is to determine and provide optimal therapy. There is constant pressure from parents for more therapy input. Understandably, parents feel that more must equal better. The evidence on this point is unhelpful. A disability service can always absorb more physiotherapy, occupational therapy and speech therapy but, even without substantial extra resources, the service can be improved by:

- better definition of therapy goals
- short programmes with defined objectives followed by period of observation

- more effective liaison with educational services
- better teaching of parents and carers regarding the methods and goals of therapy
- the use of therapy aides
- provision of secretarial and clerical help.

The workshop held by the European Academy of Childhood Disability<sup>6</sup>, reviewed the role and availability of therapy in one of the discussion sessions. The need for 'therapy to adapt to life' rather 'life to therapy' was seen as preferable by most of the participants. The consensus opinion was that treatment should be aim-orientated with a clear understanding of the short and medium term purposes of therapy. More is not always better, and parents should not be given unrealistic expectations of what can be achieved. As the child grows older, local services must be clear about prognosis, possible intervention and how children can be best prepared for life.

### Respite care

Availability of respite care is perhaps one of the greatest gaps in services for children with disability. Treneman et al (1997) studied respite care needs, both met and unmet<sup>28</sup>. This study of 308 families showed that parents of children with greatest dependency were the greatest users of respite care, however greater variation in use of respite care was seen among those with medium dependency.

In Northern Ireland, McConkey and Adams conducted a study of matching short break services for children with learning disabilities to family needs and preferences<sup>29</sup>. The study reviewed use of short break services by 476 families over a twelve-month period. Six different types of service were available:

- Hospital-based overnight care
- Overnight stays in residential home
- Domiciliary service in the family home
- Breaks provided in another family home
- Residential holidays
- Breaks provided through leisure schemes organised after school or in holidays.

Seventy-six of these parents were than interviewed about the use of short breaks.

Some common themes emerge from these two studies on respite care:

- Current levels of respite provision are insufficient
- Parents require information about respite care
- Parents want flexibility and choice
- Parents should be involved in planning services
- Hospital settings are not a favoured option
- Parents prefer services which benefit the child in addition to giving parents a break
- Two special groups of children posed particular challenges for respite services: those with complex medical needs and those with behavioural problems.
- Specialist provision should be available for these two vulnerable groups.

Parents often have difficulty in entrusting their child to the care of others. This is particularly relevant when the child has a communication difficulty. Building relationships and establishing confidence is an important aspect of these support services.

## **Conclusion**

This paper reviews the literature about services for children with disability and their families. It should provide a basis for further discussion with professionals, parents, voluntary groups and children themselves about the future direction of services in the Southern Health and Social Services Board All-Inclusive Wraparound Scheme.

## Literature Review APPENDIX 1

Clusters of children with similar combinations of extra care needs: description of cluster and associated principal disabling conditions among children aged < 12 months old

(Adapted from: *Acknowledging the extra care parents give their disabled children* by Roberts and Lawton<sup>4</sup>)

Cluster (% of sample )	Description	Associated principal disabling conditions
1  60%	Multiple care needs resulting from internal organ malformations and disorders. Crises, feeding and toileting problems common	Heart disease Other lung disease Kidney/renal disease Digestive system disorder Urogenital disorder Alimentary tract disorders
2  23%	Specific extra care needs, most commonly because of the need for input to ensure potential is reached or medical crises.	Down's syndrome Asthma Blindness Deafness
3  17%	Multiple care needs resulting from central nervous system disorders, particularly associated with feeding problems and fits.	Cerebral palsy Learning difficulties Microcephalus Meningitis Epilepsy Other central nervous system disorders

\*Based on a sample size of 3602.

Clusters of children with similar combinations of extra care needs: description of cluster and associated principal disabling conditions among children aged 1-16 years. (Adapted from: *Acknowledging the extra care parents give their disabled children* by Roberts and Lawton<sup>4</sup>)

Cluster (% of sample <sup>#</sup> )	Description	Associated principal disabling disorder
<b>1</b> 24%	Chronically sick or fragile children who suffer pain. Multiple care needs and crises	Cancer Leukaemia Arthritis Burns Brittle bones Blood/circulation disorders AIDS
<b>2</b> 29%	Multiple care needs arising from cognitive difficulties. Behaviour/feeding are problematic.	Autism Behavioural disorders Learning difficulties Down's syndrome Microcephalus Chromosome disorder Severe speech disorders
<b>3</b> 14%	Multiple care needs without behavioural difficulties.	Cerebral palsy Microcephalus Global delay Down's syndrome Hydrocephalus Spinal muscular atrophy Other central nervous system
<b>4</b> 21%	Multiple care needs. Behaviour frequently problematic.	Behavioural disorders Learning difficulties Muscular dystrophy Severe speech disorders Skin disorders Deafness Perthes Disease
<b>5</b> 12%	Largely self-caring. Distinct areas of help required. Linked to crises.	Asthma Cystic fibrosis Urogenital disorder Epilepsy Heart disease Blindness Deafness

<sup>#</sup> Based on a sample size of 32,534

## Literature Review Appendix 2

### A Charter for disabled children and their families [14]

#### **Principles**

- The family should feel that they have been listened to and heard and that their concerns and aspirations have been taken seriously and that their responsibility to their child is respected.

#### **Referral and follow-up**

- There should be a prompt response to the first referral (within one week) and the degree of urgency and parental anxiety should be considered when arranging the first appointment.
- The child should either receive regular medical follow-up or open access to the consultant in the event of new problems.
- There should be arrangements for children with complex medical needs to be seen urgently on request. The family should know whom to contact in the event of new problems.

#### **The diagnosis and the disability**

- The process of 'news-breaking' should follow established guidelines, whichever professional undertakes the task. Where necessary, training should be provided. There should be arrangements for an early follow-up appointment and/or home visit and telephone support should be available.
- The parents and child should know the correct name, label or description for the child's condition, and its prognosis and functional implications.
- Investigations should be carried out according to current best professional practice. Even if no exact diagnosis can be made, the family should know what tests have been done and what the results mean. If the situation changes, any new investigations should be explained.
- The child's future needs (eg for care in adolescence and adult life, or for terminal care in the case of progressive disease) should be discussed with the parents and the child as soon as possible. There should be planned handover to a relevant, co-ordinated adult service, in line with the requirements of current legislation.

## **Treatment and therapy**

- If the child takes any medication, the parent should know what, why, for how long and how much. They should have a medication card to summarise complex drug or multiple therapy.
- The family should know what sort of therapy or teaching the child is receiving, what it is intended to achieve and how they can help. There should be defined and achievable goals. Parents and child should understand what system of prioritising need is used by therapists and the reasons for any delays in commencing a treatment programme.
- The family should know what other methods might be offered by others for treating the child's condition (including both orthodox and controversial therapies and alternative medicine) and why the team/therapists are not using them for the child; they should be aware that some treatments of dubious efficacy can be disturbing and distressing to children. Families who try other methods should continue to receive support.

## **Information**

- Every family should be offered: full information about the child's condition including implications and prognosis; a meeting with another parent whose child has the same problem; the name and phone number of the organisation for children with this condition.
- Every family should be offered expert information about the genetic aspects of the child's condition, either by a clinical geneticist or a well-informed paediatrician. This information should not be omitted even when the condition is thought to be non-genetic by the professionals.

## **Medical care and support**

- The growth of every child should be monitored; every child should have access to expertise on feeding problems and techniques and nutritional support.
- Every child should be offered hearing and vision assessments as appropriate.
- Every parent should know about: day care (day nurseries etc) and respite care (short breaks). There should be a range of respite provision and other relevant local support services.
- Every child should be offered prophylactic dental advice and access to dental specialist services if needed.

- Every parent should know about benefits and the Family Fund.
- Every child with cerebral palsy associated with a risk of hip dislocation and/or scoliosis should receive regular orthopaedic checks and hip and spine X-rays as appropriate.
- Every child should be offered a full immunisation programme unless there are recognised contraindications.
- Every parent should know about: pre-school educational help (home teachers, Portage etc); their rights under the Education Act; and the procedures involved with assessment and Statements of Special Educational Need. Limitations in resource provision should be explained. There should be an impartial source of advice on services.
- The family should be provided with all equipment and aids appropriate to the child's needs.
- There should not be undue delays in providing or repairing the equipment; if delay is unavoidable, the family should be kept informed
- The family should be invited and encouraged to identify other important service needs. They should be able to offer suggestions and there should be a clear complaints procedure.

## Literature Review Appendix 3

Recommended minimum service provision through European countries for children with disability [14]

### **Philosophy**

- Services should be needs-led.
- Use terms such as normalisation and therapy with care and with adequate explanation.
- Some services should be available as a basic right and not require validation.

### **Process**

- Care programmes should be goal orientated and individually adapted.
- Early identification is the key to early intervention and service availability.
- Services should be provided by local, well co-ordinated teams.
- User input is essential to planning, development and managing services.
- Appropriate support for behaviour problems should be an integral part of service provision.
- Disability services must be locally-based with ready access to tertiary support.

### **Structure**

- Children with rare disabling conditions may need considerable tertiary care but should also receive support from a local disability service.
- Better information on numbers of disabled children and services available is needed at local levels.
- Integration into mainstream education is to be encouraged where appropriate.
- Inter-agency collaboration (health, education, social services) is important to providing a comprehensive service
- Proper business plans with costings and coverage need to be developed.

## Literature Review Appendix 4

### Child development, disability and rehabilitation service [14]

There are sufficient disabled children in each district to justify the existence of a Child Development, Disability and Rehabilitation Service (CDDRS).

The findings from a range of studies suggest that the ideal service has the following characteristics.

- Offers a comprehensive plan for the management of children from birth to 18 or 19 years, with disabling conditions of any kind, whether mild or severe.
- Defines goals for intervention that can maximise the potential for growth and development, increase participation in a range of social situations (rather than to achieve specific developmental milestones) and increase the likelihood that the individual with a disability will lead a useful and happy life.
- Has a consumer/empowerment philosophy of care that helps the parents and carers to cope rather than 'de-skilling' them and considers the needs of the whole family rather than just those of the child. This implies no standard package of assessment or care, but options presented fairly to each family.
- Undertakes regular self-appraisal and strives to meet the standards set out in the Charter (see above)
- Co-operates with other agencies to ensure liaison over the needs of individual children.
- Has a base from which services are organised and delivered.
- Provides facilities for prolonged assessments when the diagnosis and intervention needs are unclear - ideally, funded jointly with departments of education and social services.
- Provides an effective public health and management group (district handicap team or similar) with participants of sufficient seniority to make and implement decisions for the whole district.
- Includes as core staff: paediatrician, psychologist (clinical and/or educational), social worker, member of each therapy discipline, links with teaching, health visitors, paediatric community nurses and links with voluntary sector but develops a team individualised for each family.

- Offers referral to tertiary and speciality services for complex and uncommon problems and a combined clinic setting when multi-disciplinary decisions have to be made. Children who need such services include those with, for example, swallowing and feeding problems, cleft lip and palate, the dual impairment of deafness and blindness, arthrogyphosis, and neural tube defects (spina bifida).
- Has a secretary or administrator as easy point of contact for parents, providing a 'single front door', ie access to all the services needed without a complex bureaucracy.
- Offers families a key worker or case manager. The key worker can be provided by any of the statutory agencies.
- Ensures well-planned transition from school to adult life and arranges for adult-oriented services to take over care.
- Undertakes teamwork with child and adolescent psychiatrists and child psychologists to prevent and deal with behavioural and emotional difficulties, particularly in those with severe learning disabilities.
- Provides mainstream services for children with learning disabilities (mental handicap) by the paediatric team and uses a Community Learning Disabilities team as an expert resource (CMHT).
- Keeps a register of disabled children or collaborates with Social Services' register staff and has arrangements to share data between agencies wherever possible, remembering the requirements of the Data Protection Act 1998 (parents' permission for registration must be obtained).
- Has the ability to analyse register data to obtain a local profile of disability and need.
- Provides ongoing training for health professionals - a team spirit of learning, keeping up to date and seeking continuous improvement.

## Literature Review Appendix 5

### References

- 1 Case S. Refocusing on the parent: what are the social issues of concern for parents of disabled children? *Disability and Society*. 2000; 15(2):271-292.
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- 5 Fiorentino L, Datta D, Gentle S, Hall DMB, Harpin V, Phillips D, Walker A. Transition from school to adult life for physically disabled young people. *Archives of Disease in Childhood*. 1998; 79:306-311.
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- 9 Yerbury M. Issues in multidisciplinary teamwork for children with disabilities. *Child: Care, Health and Development*. 1997; 23(1):77-86.
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- 16 Davidson LL. Evaluating child disability programmes: the role of commissioners. *Child: Care, Health and Development*. 1999; 25(2):129-39.
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29 McConkey R, Adams L. Matching short break services for children with learning disabilities to family needs and preferences. *Child: Care, Health and Development*. 2000; 26(5):429.

Ref	Publication	Study type	Participants	Comments
1	Case,S. <i>Refocusing on the parent: what are the social issues of concern for parents of disabled children?</i> 2000	Questionnaire administered by post	114 parents throughout UK  Non-random sample	Introduction gives parent-professional relationship models  Nine topics in questionnaire 1 Diagnosis 2 Professionals 3 Therapy 4 Aesthetics 5 Body 6 Time 7 Support 8 Advice 9 Personal details (optional)
2	Beresford,BA. <i>Resources and strategies: how parents cope with the care of a disabled child.</i> 1994	Review  220 references		KEY STUDY Looks at coping skills of parents and uses this to inform intervention programmes 'there should be two prongs to an intervention programme. These are: intervention at the level of the personal and socio-ecological coping resources; and interventions to enhance parents' coping skills'.

3	Dale, N.J. <i>Parental involvement in the KIDS Family Centre</i> . 1992.	Action research Guided interview using a questionnaire	50 mothers of preschool children with special needs	'A key feature is that parents have the right to select services and forms of intervention'
4	Roberts, K. Lawton, D. <i>Acknowledging the extra care parents give their disabled children</i> . 2001.	Quantitative analysis of Family Fund Database Also focus groups	Sample size 32,534 aged 1-16 3900 infants < 12 months	Large sample size providing representative data.  Uses cluster analysis to identify five broad groups of children with disabilities in 1-16 age group, and three broad groupings in infants under one year old. See Appendix 1

5	<p>Fiorentino, L. Datta, D. Gentle, S. Hall, DMB. Harpin, V. Phillips, D. Walker, A. <i>Transition from school to adult life for physically disabled young people.</i> 1998</p>	Semi-structured face-to-face interview	87 young physically disabled people	<p>Key messages:</p> <ul style="list-style-type: none"> <li>• Young physically disabled people should receive a 14+ assessment regardless of whether they have a 'statement'</li> <li>• A period away at college can result in loss of contact with social services</li> <li>• The age of transfer to adult services should be flexible</li> <li>• One service can not cater for all: a range of adult services is needed</li> <li>• Transition plans must reflect service availability</li> <li>• The primary health care team must be involved throughout childhood and adolescence</li> </ul>
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6	<p>Anon. <i>Services for children with disabilities in European Countries.</i> 1997.</p>	<p>Report of European Academy of Childhood Disability workshop held in Paris in 1995</p>	<p>At least two representatives from seventeen different European countries. Included professionals, voluntary groups, users and carers</p>	<p>Covers services throughout Europe Main issues for improvement:</p> <ul style="list-style-type: none"> <li>• Promoting multidisciplinary team working</li> <li>• Developing a goal orientated programme for each child and family</li> </ul> <p>Five discussion sessions took place</p> <ol style="list-style-type: none"> <li>1 How comprehensive are local health services</li> <li>• Service delivery and accessibility</li> <li>• Which clinical problems are services for and which doctors are involved</li> <li>• The role and availability of therapy</li> <li>• The changing emphasis of care as the child grows older</li> <li>• The transfer of care to adult services</li> </ol> <ol style="list-style-type: none"> <li>2 Rare diseases</li> <li>3 The co-ordination of separate agencies</li> <li>4 The inclusion of families' views in service aims</li> <li>5 Services for children who have severe behaviour problems</li> </ol>
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7	<p>Hall, D. Child development teams: are they fulfilling their purpose? 1997</p>	<p>Review of Child Development Teams (CDTs) in Britain</p>	<p>Article based on published literature, personal experience and conclusions of a national seminar</p> <p>Non-random sample of participants</p>	<p>Discusses wide range of practice in CDTs</p> <p>The changing expectations of parents</p> <p>The need for further research and evaluation</p> <p>Difficulties in comparisons across the country</p> <ul style="list-style-type: none"> <li>● Variations in target groups</li> <li>● Difficulties of optimal staffing levels</li> </ul> <p>'what dictates the need for multidisciplinary services is the chronic and complex nature of the child's problem in the context of that particular family'.</p> <p>Parents need:</p> <ul style="list-style-type: none"> <li>● Information about the child's condition and disability in general</li> <li>● Emotional support</li> <li>● Links with other families who have disabled children</li> <li>● Easy access to other agencies such as education</li> <li>● Prompt efficient supply and repair of equipment</li> <li>● Many other services</li> </ul>
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8	<p>McConachie,HR. Salt,A. Chadury, Y. McLachlan,A. Logan,S. <i>How do Child Development Teams work? Findings from a UK national survey.</i> 1999</p>	<p>Basic survey questionnaire about team composition, management and processes</p>	<p>242 multidisciplinary teams</p>	<p>Management and funding of teams is a problem.          Very varied team organisational          Often no clear aims or standards          Research suggests:          1 Services should be based in Child Development Centre. Benefits of centre:  <ul style="list-style-type: none"> <li>• Physical space for team members to meet</li> <li>• Team building and communication</li> <li>• Base for in-service training</li> <li>• Community resource for children and families</li> </ul>         2 Keyworker          3 Parents want copies of assessment reports          4 Assessment should not be prolonged but lead to individual programme plan</p>
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9	Yerbury, M. <i>Issues in multidisciplinary teamwork for children with disabilities.</i> 1997.	Interview  Case study  Consultation	12 district multidisciplinary teams  Three teams by interview with parents  Two further districts consulted (London and rural)	Issues highlighted: 1 Team management 2 Team models and leadership 3 Dual accountability 4 Developmental stage of team 5 Team meetings 6 Multidisciplinary co-operation 7 Child development centres
10	Youngson-Reilly, S. Tobin, M.J. Fielder, A.R. <i>Multidisciplinary teams and childhood visual impairment: a study of two teams.</i> 1995	Semi-structured face-to-face interview	Two teams for visually impaired children	Benefits of team working: ● Increased numbers and speedier referrals ● Speedier implementation of services ● Improved liaison between professionals Problem areas: ● Lack of time

11	<p>Appleton, P.L. Boll, V. Everett, J.M. Kelly, A.M. Meredith, K.H. Payne, T.G. <i>Beyond child development centres: care co-ordination for children with disabilities.</i> 1997.</p>	Structured interview	20 sets of parents and 12 care co-ordinators	<p>Need to involve children in planning their own futures</p> <p>Creating the conditions for introducing care co-ordination:</p> <ul style="list-style-type: none"> <li>• The primary identity and culture of the local children's services would not be determined by one agency</li> <li>• A new identity for children's services would be created in which each agency</li> <li>• Understands and supports the role of each other's agency</li> <li>• Ensures that individual children and families receive co-ordinated care and education</li> </ul> <p>Care co-ordinators recruited and trained and objectives set.</p> <p>Achievements reviewed under headings:</p> <ol style="list-style-type: none"> <li>1 Empowerment</li> <li>2 Defined populations</li> <li>3 Matching need to service</li> <li>4 Interagency collaboration</li> <li>5 Named care co-ordinators</li> </ol>
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12	Goh, S. Holland, A.J. <i>A Framework for commissioning services for people with learning disabilities.</i> 1994.	Proposed framework for commissioning services	<p>Framework for commissioning services</p> <p>Proposes that Health, Education and Social services have a part to play at all stages of life but that different agencies should lead commissioning at different stages:</p> <p>Health – pre-school child</p> <p>Education – school child</p> <p>Social Services – adulthood.</p> <p>Acknowledges assessment of individual need</p>
13	McConachie, H. <i>Organisation of child disability services.</i> 1997	Editorial article	<p>Suggested aim of child disability services:</p> <p>To offer comprehensive and co-ordinated assessment, advice, information and relevant support for children with developmental difficulties and their families.</p> <p>Funding – many different agencies and professionals leading to fragmentation</p> <p>Management of services – no clear management and accountability structure</p>

14	<p>Hall, DMB. Stewart-Brown, S. Salt, A. Hill, P. <i>Draft Health Care Needs Assessment – Community Child Health Services.</i> (Web reference no date.)</p>	<p>Health care needs assessment</p>		<p><b>HIGHLY RELEVANT</b>  Comprehensive health care needs assessment for community child health services. Contains sections on children with disability.  See Appendices 2-4</p>
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15	<p>Mukherjee, S. Lightfoot, J. Sloper, P.  <i>Communicating about pupils in mainstream school with special health needs: the NHS perspective.</i> 2002.</p>	<p>Qualitative research  Semi-structured interview</p>	<p>22 health professionals from one NHS Trust</p>	<p>Examined</p> <ul style="list-style-type: none"> <li>● health professionals roles and practices</li> <li>● issues of patient confidentiality</li> </ul> <p>Examples of good practice in communication:</p> <ul style="list-style-type: none"> <li>● Joint meetings between health and education staff</li> <li>● Shared documentation</li> <li>● Local policy development eg anaphylaxis protocols</li> </ul> <p>Examples of difficulties in communication:</p> <ul style="list-style-type: none"> <li>● Parents as conduits of information</li> <li>● Face-to-face contact between staff</li> <li>● Lack of knowledge of respective roles</li> </ul> <p>Other issues:</p> <ul style="list-style-type: none"> <li>● Ethos of individual schools</li> <li>● Communication within health services</li> </ul> <p>Recommendations from participants:</p> <ul style="list-style-type: none"> <li>● Clarification of roles of different professionals</li> <li>● Information flows from health services to schools</li> </ul>
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16	Davidson, L.L. <i>Evaluating child disability programmes: the role of commissioners.</i> 1999.	Review		<p>Key issues:</p> <ul style="list-style-type: none"> <li>• RCTs are difficult to conduct when dealing with complex interventions</li> <li>• Evaluation is often difficult due to complex interdisciplinary and interagency teams or pathways of care.</li> <li>• Views of families re access and use of service are critical</li> </ul>
17	Logan, S. <i>Evaluating services for children with disabilities and their families.</i> 1999.	Editorial article		<p>This is a difficult area of research. The combination of chance effects on rare events makes it difficult to disentangle chance effects from real differences. Patient satisfaction is important. There is a need to set service standards against which to measure performance. These need to be determined from a multidisciplinary point of view, including parental views.</p>

18	<p>McConachie,HR.  <i>Conceptual frameworks in evaluation of multidisciplinary services for children with disabilities. 1999.</i></p>	<p>Discussion of frameworks for evaluation</p>	<p>Two broad aims for child disability services:</p> <ul style="list-style-type: none"> <li>● Excellent medical care, including identification, diagnosis, detailed assessment and therapeutic intervention.</li> <li>● Family support, that is, helping the child and family toward achieving good adaptation and quality of life.</li> </ul> <p>Suggestions for evaluation of child disability services:</p> <ul style="list-style-type: none"> <li>● Take time to reflect on practice</li> <li>● Specify aims to define what exactly the service is aiming to do</li> <li>● Think about how resources available and procedures followed relate to aims</li> <li>● Monitor how decisions on change are being implemented. Reorientation of services takes time and effort</li> <li>● Set individual goals for children and a timescale for review of measurable objectives</li> <li>● Adopt a charter of standards or write clinical guidelines and then audit these, rather than a small satisfaction questionnaire</li> </ul>
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19	McKenzie, K. Murray, G.C. <i>An evaluation of community learning disability services for children with a learning disability.</i> 2001.	Telephone survey about services  Survey questionnaire  Interview	12 Trusts which provided Community Learning Disability Services  30 parents of children with learning disability  11 GPs  Non random samples	Parents and GPs made suggestions about improved services: <ul style="list-style-type: none"> <li>● Local specialised learning disability service for children</li> <li>● Information pack</li> <li>● Clinical psychology and psychiatry service</li> <li>● Care manager for each child</li> <li>● Service access criteria to address inequity</li> <li>● Involvement of adult team from age 12 onwards</li> <li>● Link nurse for GPs and schools</li> <li>● Summary of common health and behaviour needs of client group</li> </ul>
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20	Cass, H. Kugler, B. <i>Service evaluation and development: experience of a paediatric disability team.</i> 1999.	Describes structures and process for evaluation	One specialised tertiary service.	Useful framework and approach to evaluation 'impact of clinical intervention is often qualitative rather than quantitative' Provides structured approach to evaluation and development of services Goals and objectives are important. Also important to recognise that these may change 'A good service that attempts too much too soon may evolve into one that does many things poorly'.
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21	<p>Sloper, P. Turner, S. <i>Service needs of families and children with severe physical disability.</i> 1992.</p>	<p>Self-report questionnaires and interviews</p>	<p>107 families of children with severe motor disability</p>	<p>Looks at unmet need – KEY STUDY. Problems:</p> <ul style="list-style-type: none"> <li>● Large number of contacts but still unmet need</li> <li>● Unclear delineation of roles</li> <li>● Consistent with findings for other groups of disability</li> </ul> <p>Areas of highest unmet need:</p> <ul style="list-style-type: none"> <li>● Information about services and child's condition</li> <li>● Domiciliary services of child minding and emergency provision</li> <li>● Improving mobility, communication and teaching parents how to help the child</li> <li>● Practical services re housing adaptations and transport</li> </ul> <p>Families at particular risk:</p> <ul style="list-style-type: none"> <li>● Recent stressful life events</li> <li>● Father unemployed</li> <li>● Child suffered mental and physical problems</li> <li>● Mother used high proportion of passive coping strategies</li> </ul> <p>Link person most important for those families with most problems and fewest internal family resources</p> <p>Most important factors:</p> <ul style="list-style-type: none"> <li>● Accessible and appropriate help</li> <li>● Interventions focusing on family as a whole</li> <li>● Improved co-ordination and information</li> </ul>
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22	<p>Sloper, P. <i>Models of service support for parents of disabled children. What do we know? What do we need to know?</i> 1999.</p>	Review	61 references	<p>Important characteristics of effective service models:</p> <ul style="list-style-type: none"> <li>• Holistic approach to assessing and meeting family needs</li> <li>• Recognise importance of relationship building between parents and professionals</li> <li>• Consistent, single point of contact for the family</li> <li>• Flexible, individualised, needs-led approach</li> <li>• Focus on parents own concerns and recognise the importance of understanding parents own perceptions of the hierarchy of their needs</li> <li>• Empowering parents rather than taking control away from them</li> <li>• Acknowledging and recognising parents own expertise with regard to their child and family</li> </ul>
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23	Sloper, P. Turner, S. <i>Determinants of parental satisfaction with disclosure of disability.</i> 1993.	Interviews with parents and self report questionnaire	103 parents of children with a disability	Key elements for satisfaction with communication of disclosure of disability: <ol style="list-style-type: none"> <li>1 Sympathetic, understanding and approachable manner, direct and communicated well</li> <li>2 Given sufficient information</li> <li>3 Opportunities to ask questions</li> </ol>
24	Quine, L. Rutter, DR. <i>First diagnosis of severe mental and physical disability: a study of doctor-parent communication.</i> 1994.	Parental satisfaction survey questionnaire	166 children (stratified sample of all disabled children in two health districts)	Three main components in satisfaction with the way news of impairment is given: <ol style="list-style-type: none"> <li>1 Parents want to know as soon as possible if something is wrong</li> <li>2 Feeling that the person who communicated the information had a sympathetic approach</li> <li>3 Information and the part that sharing it can play in reducing anxiety</li> </ol>
25	Watkin, PM. Beckman, A. Baldwin, M. <i>The views of parents of hearing impaired children on the need for neonatal hearing screening.</i> 1995.	Parental survey questionnaire	Parents of 208 children	In retrospect, parents would welcome a neonatal hearing screen leading to early diagnosis of hearing impairment.

26	Pain, H. <i>Coping with a child with disabilities from the parents perspective: the function of information.</i> 1999.	Semi-structured interviews	20 parents Non random sample	<p>Information was found to:</p> <ol style="list-style-type: none"> <li>1 Assist the process of adjusting emotionally to their child's disabilities</li> <li>2 Enable parents to access services and benefits</li> <li>3 Improve their management of their child's behaviour</li> </ol> <p>Information sources:</p> <ul style="list-style-type: none"> <li>• Personal communication (preferred)</li> <li>• Written word as back-up</li> <li>• 'Home books' – teacher-parent comments</li> <li>• Sharing from other parents</li> <li>• Information from voluntary organisations</li> </ul>
27	Shah, R. <i>Improving services to Asian families and children with disabilities.</i> 1997.	Article suggesting a service improvement		<p>Acknowledging the need for culturally appropriate services</p>

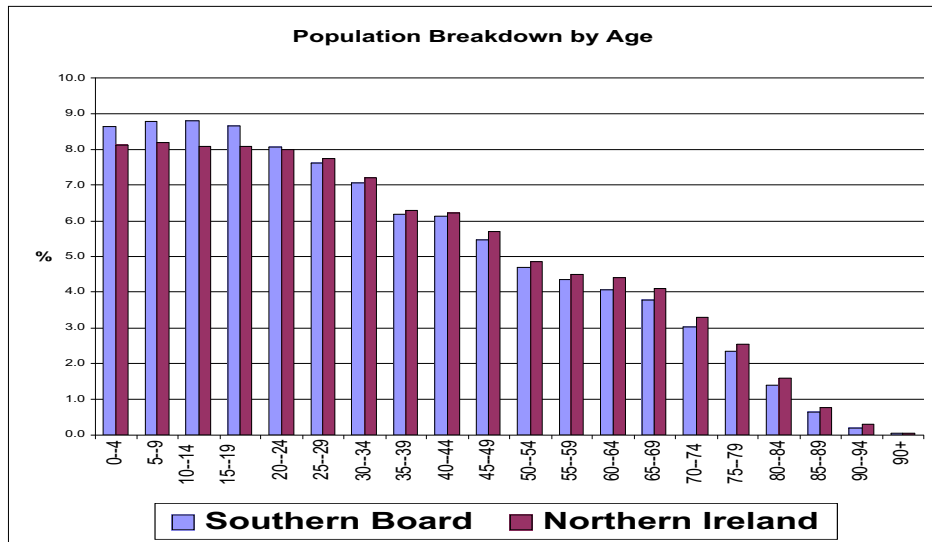
28	Treneman, M. Corkery, A. Dowdney, L. Hammond, J. <i>Respite care needs – met and unmet: assessment of needs for children with disability.</i> 1997.	Postal questionnaire	308 families of children with disabilities	Particular problems exist for children with complex medical needs and behaviour problems Parents want choice of respite Information about available services is needed Respite care should be a positive experience for both child and family Parents should be involved in planning services
29	McConkey, R. Adams, L. <i>Matching short break services for children with learning disabilities to family needs and preferences.</i> 2000.	Census over 12 month period Followed by interviews with families	476 families who had received short break services 76 parents interviewed	Examined six types of short breaks: 1 Hospital-based overnight care 2 Overnight stays in residential home 3 Domiciliary service in the family home 4 Breaks provided in another family home 5 Residential holidays 6 Breaks provided through leisure schemes organised after-school or in holidays Looked at usage and preference to assist in planning for the future

## Appendix III Routine information sources

### Information on the general population

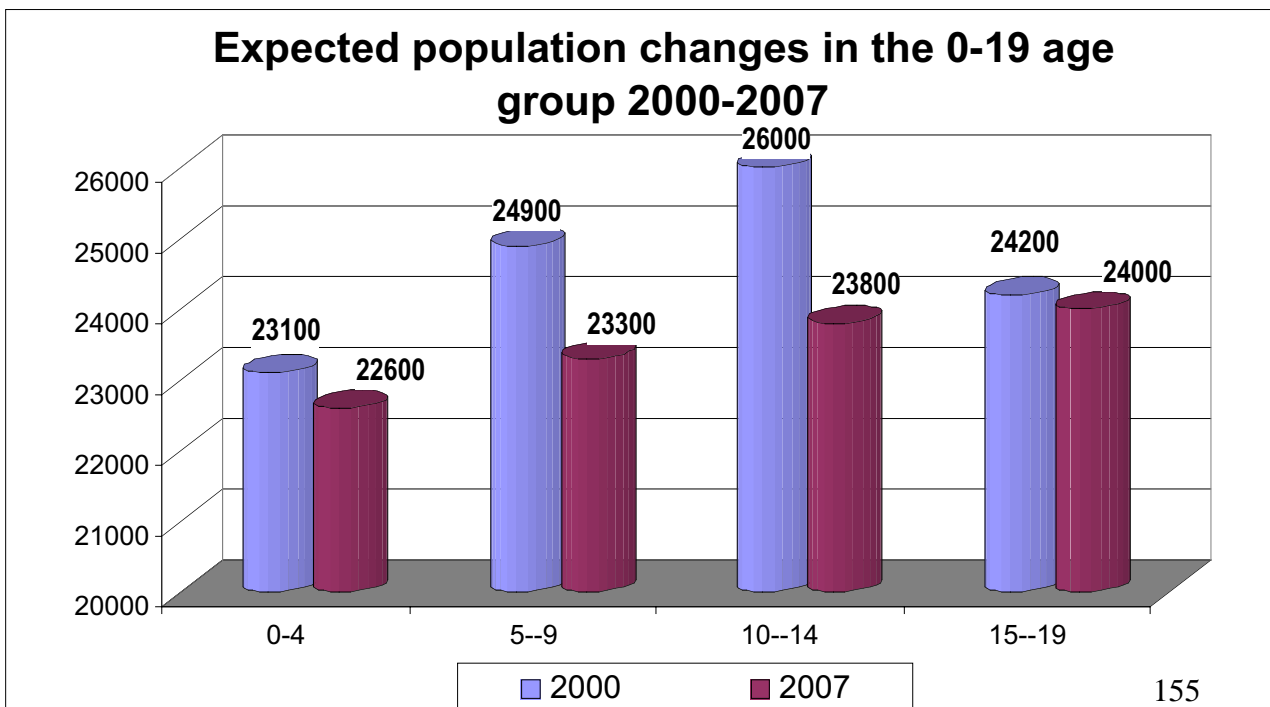
Population breakdown by age group

Below is the profile of the SHSSB population and the Northern Ireland population broken down by age group [16].



Predicted population changes in the SHSSB

Population projections for the 0-19 population for the year 2007 predict that the number of children in the 0-14 age groups will reduce by 2007. This reflects the 22% reduction in total births to SHSSB residents between 1984 and 2000 [17].



## **Local information on children with a disability**

Data from a range of information sources in the SHSSB is detailed below. The sources are:

- The Child Health System (March 2002) [10]
- Referrals to the Child and Adolescent Mental Health Services (1998-2000) [11]
- Survey of the Traveller community (2000-1) [12]
- Korner<sup>2</sup> returns relating to disability (2000, 2001) [13]
- Audit of the physiotherapy caseload at the Child Development Clinic (2001) [14]
- Family Trust Fund Database (May 2002) [15]

The information is presented, wherever possible, for pre-school, primary and post primary age groups.

There are significant limitations to existing information systems relating to children with a disability. These include:

- data quality eg incomplete or out of date
- multiple diagnoses present
- no diagnosis made e.g. the cause of the disability may be unknown
- a disability may have different manifestations in different individuals eg Autistic Spectrum Disorder (ASD) may be associated with severe disability and handicap but there are also individuals who fulfil the criteria for ASD who may experience fulfilling lives without any professional support, or with episodic treatment only at times of high stress
- some disabilities only become apparent at older ages eg following school entry
- some information systems eg Korner returns group conditions together such as physical disability without identifying the underlying cause.

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<sup>2</sup> Korner returns are quarterly records that are statutorily required by the Regional Information Branch of Department of Health Social Services and Public Safety Northern Ireland and used to monitor community and social services activity. [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

- some information systems eg Korner returns group conditions together such as physical disability without identifying the underlying cause.

*Child Health System [10]*

Information from the Child Health System on selected conditions is shown in the following tables. No particular significance should be attached to the range of conditions selected: Down's syndrome, spina bifida, autism, blindness / low vision, hearing problems / other hearing loss, cerebral palsy and muscular dystrophy. These conditions were included because the quality of data was better for these compared to other conditions. ICD 10 codes were used to identify children with these conditions.

<b>Down's Syndrome</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	16	21	30	26	38	19	150

ICD 10 Codes: Q90-90.9

<b>Spina Bifida</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	4	5	8	11	15	11	54

ICD 10 Codes: Q05-Q05.9

<b>Autism</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	10	3	122	15	44	11	205

ICD 10 Codes: F84.0 F84.1 299.8 F84.5

<b>Blindness/Low Vision</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	2	3	59	33	103	59	259

ICD 10 Codes: H54-H54.7

<b>Hearing Problems/Other Hearing Loss</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	2	10	134	105	184	160	595

ICD 10 Codes: H90 – H90.8 H91 –H91.9

<b>Cerebral Palsy</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	9	1	28	20	41	26	125

ICD 10 codes:G80.0-G80.9 343-343.9

<b>Muscular Dystrophy</b>							
Age	0-4		5-11		12-18		0-18
Sex	Male	Female	Male	Female	Male	Female	Total
Number	1	1	12	2	16	0	32

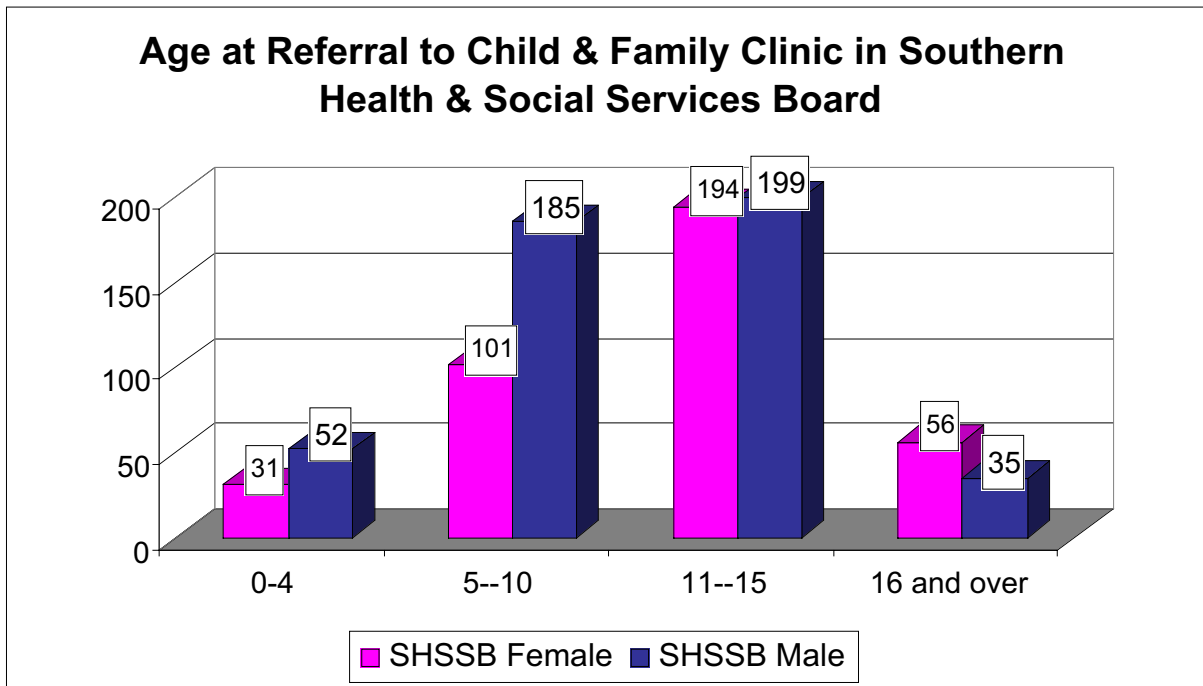
ICD 10 codes: G71.0-G71.9 359-359.9

*Referrals to child and adolescent mental health services [11]*

Between January 1998 and January 2000, a total of 859 referrals were received by the Child and Family Clinic.

<b>Trust</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
Armagh & Dungannon	139 (56%)	109 (44%)	248(29%)
Craigavon & Banbridge	199 (52%)	186 (48%)	385(45%)
Newry & Mourne	139 (62%)	87 (38%)	226(26%)
SHSSB	477 (56%)	382 (44%)	859

The age of referral is shown in the following diagram



*Traveller children with a disability* [12]

In a survey of 253 Traveller children in the SHSSB, undertaken by Children’s Services Planning between 2000-2001, 6% of the survey sample reported a disability.

Age	Male	Female
0 – 4	3	2
5 – 9	1	1
10 – 14	1	3
15 – 19	3	1
<b>Total</b>	<b>8</b>	<b>7</b>

Reported disabilities in the survey included deafness, curved spine, cardiac abnormalities, asthma, learning difficulties, heart complaint, arthritis, special needs, not being able to use their arm properly, hyperactive, speech problems, Hurlers syndrome and kidney problems.

*Korner returns relating to disability services (2000, 2001) [13]*

The Korner returns record the numbers of people in contact with each HSST's disability service by age group.

<b>Learning disability</b>			
Trust	0 - 4	5 - 15	16 – 24
Armagh & Dungannon	21	57	73
Craigavon & Banbridge	20	112	93
Newry & Mourne	32	108	79

KMH 2

<b>Physical disability</b>			
Trust	0 - 4	5 - 15	16 – 24
Armagh & Dungannon	11	71	44
Craigavon & Banbridge	20	74	66
Newry & Mourne	25	52	39

KPH2(1)

<b>Blind people</b>			
Trust	0 – 4	5 - 15	16 – 24
Armagh & Dungannon	0	4	4
Craigavon & Banbridge	0	7	5
Newry & Mourne	0	7	12

KPH2(3)

<b>Partially sighted</b>			
Trust	0 – 4	5 - 15	16 – 24
Armagh & Dungannon	1	8	5
Craigavon & Banbridge	1	4	4
Newry & Mourne	2	19	13

KPH2(3)

<b>Deaf with speech</b>			
Trust	0 – 4	5 - 15	16 – 24
Armagh & Dungannon	0	4	10
Craigavon & Banbridge	0	6	4
Newry & Mourne	0	1	8

KPH2(3)

<b>Deaf without speech</b>			
Trust	0 - 4	5 – 15	16 – 24
Armagh & Dungannon	1	3	13
Craigavon & Banbridge	6	9	12
Newry & Mourne	1	3	9

KPH2(3)

<b>Hard of hearing</b>			
Trust	0 - 4	5 – 15	16 – 24
Armagh & Dungannon	4	14	14
Craigavon & Banbridge	1	6	2
Newry & Mourne	2	16	18

KPH2(3)

*Audit of the physiotherapy caseload at the Child Development Clinic [14]*

Primary conditions by location

Condition	Lurgan	Armagh	Dungannon	Newry
(n=)	n (%)	n (%)	n (%)	n (%)
Dev. Delay (79)	37 (47)	18 (23)	12 (15)	12 (15)
CP quad (19)	6 (32)	7 (37)	5 (26)	1 (5)
CP Di. (29)	9 (31)	8 (28)	4 (14)	8 (27)
CP Hemi. (69)	21 (30)	12 (18)	18 (26)	18 (26)
Spina Bifida (19)	6 (32)	1 (5)	4 (21)	8 (42)
Down's Syndrome (40)	9 (23)	10 (25)	5 (13)	16 (39)
Muscular Dystrophy (5)	3 (60)	1 (20)	0 (0)	1 (20)
Other Syndromes (28)	16 (57)	5 (18)	3 (11)	4 (14)
Other Conditions (108)	52 (48)	24 (22)	16 (15)	16 (15)

### Children numbers by school provision

	Pre-school	Primary	Secondary	Learning Support Centre
Lurgan	100	43	9	7
Armagh	42	27	9	8
Dungannon	29	24	12	2
Newry	51	19	12	2
Total = 396	222	113	42	19

### *Family Trust Fund Database [15]*

The Family Trust Fund Database is an independent organisation funded by the national governments of England, Wales, Scotland and Northern Ireland. The Trust supports families of children aged under 16 who are severely disabled or seriously ill by providing grants and information related to the care of the child. These include children with physical disability, learning disability, sensory impairment and those with high care needs. Anonymised information for Southern Board residents was obtained from the Trust database.

There are some limitations associated with this information.

- Families on the database are self-selecting and may not be representative of children with a disability
- Information is only collected during the initial assessment and is not updated
- There may be over-representation of low income families owing to a financial cut-off operated by the Trust

A total of 166 conditions in 1059 children were recorded on the database. Autistic Spectrum Disorder, Asthma, Learning Disability and Down's Syndrome accounted for a third of cases.

The breakdown of cases by age and sex is shown in the following table:

	Age-group			Total
	0-4	5-11	12-18	
Female	55	174	157	386
Male	63	323	287	673
Total	118	497	444	1059

Appendix IV Barriers and conflicts exercise data

<b>General Comments</b>	
<b>Area</b>	<b>Issue</b>
Nature of Wraparound	<b>Boundaries</b>
	<b>Profile</b>
	<b>Momentum</b>
	<b>Workload</b>
	<b>Impact on users</b>
	<b>Custom and practice</b>
Resources	<b>Level</b>
	<b>Ongoing</b>
	<b>Personnel</b>

<b>Comment</b>
<ul style="list-style-type: none"> <li>• children not registered as disabled</li> <li>• acquired disabilities – difficulty access services</li> <li>• definitions of child (age limits)</li> </ul>
<ul style="list-style-type: none"> <li>• lack of awareness about Wraparound (don't understand term)</li> </ul>
<ul style="list-style-type: none"> <li>• maintaining impetus / support</li> </ul>
<ul style="list-style-type: none"> <li>• overload (2) [nature of Wraparound; multi-disciplinary nature]</li> </ul>
<ul style="list-style-type: none"> <li>• dependence</li> <li>• creating unrealistic expectations</li> </ul>
<ul style="list-style-type: none"> <li>• difficulties in thinking 'outside of the box' – danger of simply providing more of the same</li> <li>• tradition versus innovation : reluctance to change [changing custom and practice; changing attitudes; fear of unknown; difficult to change professional attitudes to how services have been provided]</li> </ul>
<ul style="list-style-type: none"> <li>• lack of resources (5) [no additional staff or facilities]</li> </ul>
<ul style="list-style-type: none"> <li>• fear among professionals about 3year funding - why invest time etc apathy</li> </ul>
<ul style="list-style-type: none"> <li>• recruitment [suitably trained staff]; increasing expectations on existing staff</li> </ul>

Resources	Time Allocation	<ul style="list-style-type: none"> <li>• facilitate partnership [allocated time to involve everyone]</li> <li>• equity [budget management / jealousies and rivalries; achieving equity between different agencies / organisations; how resources are allocated]</li> </ul>
Services	Delivery	<ul style="list-style-type: none"> <li>• suitability of appointments</li> <li>• inflexibility of services: health, education, social services etc</li> <li>• lack of co-ordination of services each in a box need to be integrated</li> <li>• school services – often Belfast-based</li> </ul>
	Use	<ul style="list-style-type: none"> <li>• stigma</li> </ul>
	Communication	<ul style="list-style-type: none"> <li>• communication (9) [sharing information between all relevant agencies; problems with information reaching the right / appropriate people; poor; no formal/informal information; lack of / poor PR (2); IT /equipment / systems;</li> <li>• communications: method, language, timing, individual or two-way</li> <li>• clinical information: What can be shared? Who needs to give permission?</li> </ul>

Partnership working	Conflicts	<ul style="list-style-type: none"> <li>● importance of partnership</li> <li>● previous experience of working in partnership conflictual</li> <li>● conflicts between: <ul style="list-style-type: none"> <li>– users – parents and carers and professionals</li> <li>– professionals (role clarification)</li> <li>– original partners and expansion of partners (why were we not originally involved)</li> <li>– SHSSB and trusts</li> <li>– Trusts and voluntary sector</li> <li>– parents expectations and what trusts will / can provide</li> <li>– range of disabilities / voluntary</li> <li>– parents own personal conflict in approaching service provider</li> </ul> </li> <li>● lack of shared vision</li> <li>● conflict of cultures / ways of working (2) [bureaucratic, statutory ways and structures]</li> <li>● way we plan services and rush</li> </ul>
	Cultural differences	<ul style="list-style-type: none"> <li>● how it operates, each partner understanding their role, effective partnership</li> <li>● roles [perception, images of roles]</li> </ul>
	Ownership	<ul style="list-style-type: none"> <li>● territorial</li> </ul>

Partnership families and carers	Engagement	<ul style="list-style-type: none"> <li>● acceptance of diagnosis</li> <li>● realistic expectations</li> <li>● under-representation and understanding by parents in process</li> <li>● good parent participation</li> <li>● parents feel vulnerable at raising issues</li> <li>● 'provider' led services – needs assessment</li> </ul>
	Methods	<ul style="list-style-type: none"> <li>● perceptions about meetings: boring, what in it for them, capacity building</li> <li>● need to make 'meetings' fun, interesting and focussed about outcomes</li> </ul>
Partnership workers	Resources	<ul style="list-style-type: none"> <li>● time for user involvement eg other commitments</li> <li>● multi-disciplinary team</li> <li>● relationships</li> <li>● management</li> </ul>
Partnership agencies		<ul style="list-style-type: none"> <li>● education and response</li> </ul>
Information	Systems	<ul style="list-style-type: none"> <li>● managing and collating information</li> </ul>
Capacity building	Training	<ul style="list-style-type: none"> <li>● for domicilliary care providers</li> <li>● for families</li> </ul>

### Specific Projects

<b>Project</b>	<b>Issue</b>	<b>Comment</b>
<b>A</b>	1 Flexibility	1 Flexibility of clinic appointments reduced
	2 Transport	2 Ambulance availability
	3 Location	3 Appropriateness eg Armagh or Dungannon
<b>D</b>	Waiting lists	PAMS waiting lists
<b>F</b>	Resources	Resources not available to fully implement the service – resources unrealistic
	Training	Specialist training – frequency of application of these skills updates
<b>B</b>	Parental acceptance	

## Appendix V Health Impact Assessment workshop evaluation

### Participants

The HIA workshop was attended by 101 people. This number includes ten facilitators, the chair Jacqui McGarvey, facilitator Erica Ison and observer Iris Elliott. The participants are from the following groups.

Group	Number
Parent or carer	5
Non-health statutory organisation (education, housing, local authority)	6
Voluntary sector	31
Statutory health sector	54
Not identified	1

Twenty-seven people who registered for the workshop did not attend. (Six parent/carers, five non-health statutory organisation workers [District Council and Housing Executive], four voluntary organisation representatives and 12 health sector workers). The number of parents and carers more than halved from registration to participation. (These numbers were made up by participants who did not register, but turned up on the day.) It was noted at the stakeholder meeting in May 2002 that several representatives from the voluntary sector were parents also.

### Evaluation forms

Fifty-one evaluation forms were completed. Percentages given below are percentages of completed evaluation forms.

### Quality of the venue

Thirty-two respondents rated the venue 'very good' (63%), 14 (27%) 'good', and 5 (10 %) 'satisfactory'. Two positive comments were made about the food. Three people commented that the venue was overcrowded, with one person making a related comment that the noise between groups in the studio theatre was 'difficult'. One person thought that the presence of the media caused interference for people at the back of the room. [See 'Organisation' below.]

### Quality of organisation

The organisation of the workshop was rated 'very good' by 31 respondents (61 %), 'good' by 16 (31%), and 'satisfactory' by 4 (8 %). One person suggested that the agenda should have been sent out in advance.

### Ability to participate

The majority of participants were able to participate as much as they wanted to ie 45 (88%). Four people were not able to participate as much as they wanted to (8%), with one commenting that their group was too big (12 people). Two people did not complete this section.

### Usefulness of sessions

Participants were asked to comment on the usefulness of different sessions during the workshop, using a grading system Very Good (VG), Good (G), Satisfactory (S), Poor (P) and Very Poor (VP). Sections not completed are recorded as NC. These responses are summarised in the table below, with comments. (Percentages are give in bold.)

Activity	VG	G	S	P	VP	NC	Comment (NC)
Graffiti board	15 <b>30</b>	13 <b>25</b>	13 <b>25</b>	5 <b>10</b>		5 <b>10</b>	Missed: 2, <b>4</b> No time to read, consider: 2, <b>4</b>
Introductory presentations	19 <b>37</b>	25 <b>49</b>	6 <b>12</b>	1 <b>2</b>			
Barriers and conflicts	19 <b>37</b>	26 <b>51</b>	5 <b>10</b>		1 <b>2</b>		
Impacts	18 <b>35</b>	22 <b>43</b>	9 <b>18</b>	1 <b>2</b>	1 <b>2</b>		
Recommendations	18 <b>35</b>	22 <b>43</b>	8 <b>16</b>	1 <b>2</b>	1 <b>2</b>	1 <b>2</b>	

## Other comments on the workshop

This section was completed by 36 participants (71% of respondents).

### General Comments

The general comments made about the workshop were largely positive, as illustrated above. Participants found the overall experience of, and discussion during, the workshop 'useful', 'enlightening', 'valuable' and 'excellent'. Comments were made about the sheer amount of information gained, and the pace at which it was shared: 'Fast pace, a lot covered very quickly'. One participant would have preferred to receive more information about the projects under discussion, another observed that 'many people were confused about the whole Wraparound proposal – it could have been explained more clearly'. Further, 'getting my head around terminology' was a challenge.

### Method

Several participants commented on the value of having a diverse group of stakeholders including a range of professionals, agencies and local councillors. This 'effective mix of people at each table', 'good guidance' and strong facilitation ('facilitator excellent and really promoted discussion and sharing of ideas') produced a 'highly intensive' experience in which there was 'excellent sharing of information'. The need to expand stakeholder involvement to both disabled and non-disabled young people, in creative and appropriate ways, was identified. And a number of comments were made that more parents, family members and carers need to be involved. One participant wrote that it was 'good to know that all comments will be noted'.

### Process

Participants commented that the process of the workshop was well managed and facilitated, and the tasks were 'very appropriate'. The inclusion of a range of stakeholders led to a 'greater awareness of what others are doing and what they would like'. This discussion raised the need for inter-agency meetings about service provision 'so that the professionals know exactly what is available, so that they all

have a good knowledge base'. At the moment some thought that professionals did not know enough about Wraparound, and its relevance to existing clients.

The manner of allocating projects to workshop groups received both positive and negative comments. Some participants would have liked to discuss the projects that they were specifically working on (and about which they felt informed). Several stated that they felt that they were not sufficiently informed about the projects that they were discussing, and that this difficulty was magnified by the fact that some of the projects had not started. One participant was concerned that such discussion could generate 'uninformed and potentially dangerous' recommendations. Others welcomed the opportunity to have others comment on 'their' projects, anticipating that 'others could see and identify barriers/conflicts etc that I may have not wanted to see (being honest)'.

One participant raised that difficulty that focussing on specific projects left little space for commenting on the whole Wraparound proposal.

### Organisation

The overall evaluation reflects positively on the organisation of the workshop ('everything ran like clockwork'). However, several participants thought that there were too many people at the event, and in the workshop groups, and that the main workshop venue (the studio theatre) was 'crowded' and 'noisy', restricting 'comfort and sometimes communication'. The strong acoustics of the theatre magnified these problems leading one participant to suggest 'the smaller discussions should be held in a room without 'echoes''.

### Time

Time featured in several evaluation forms. The timetable left some participants feeling rushed, and that the expectations were too high in terms of assimilating information, conducting discussions and covering the number of topics. There was one suggestion of holding the workshop over a full day, balanced by another participant's comment that the workshop was very long and ran very late into the evening.

## Comments on services for children with disabilities in the SHSSB

Thirty three participants (65% of respondents) completed this section.

### Process

A lot of comments were made on the process of service delivery, specifically on communication and partnership working.

Participants thought that communication can be poor between agencies, professionals, management and front-line workers and between services and families. Both workers and families and carers may not be aware of existing service provision. Information about existing and new services needs to be developed and disseminated.

Partnership working is key to the development and delivery of services: 'we need to begin to develop partnership with parents, providers, professionals, carers and consultants'. There was specific mention of parents of school age children, and of the Southern Education and Library Board Youth Service. With regard to the involvement of families and carers it is important to be inclusive, to 'take into account every family and not just those who shout loudest'.

Participants highlighted the need for improved co-ordination in service development by using existing structures (such as the Children Services Planning and the inter-agency, multi-professional strategy planning forum), and linking Wraparound with local Trust staff in order to identify how it will impact on their work. The need to clarify roles and responsibilities was stressed. One participant noted the importance of equity of provision across the three Trusts in the SHSSB.

### Specific Service Needs

Participants identified a number of specific service needs in terms of groups of children with disabilities, stages of service delivery, types of provision and relevant non-health care services. These are summarised below:

<b>Issue</b>	<b>Comment</b>
Groups	<ul style="list-style-type: none"> <li>• Hearing impaired / deaf children (2)</li> <li>• Children without a diagnosis</li> <li>• Children with severe learning disabilities with high care needs including nursing care</li> <li>• Young people 18/19+</li> </ul>
Stages	<ul style="list-style-type: none"> <li>• Diagnosis: waiting times, slow process</li> <li>• Provision for families while awaiting a diagnosis (support, information)</li> </ul>
Provision	<ul style="list-style-type: none"> <li>• Respite including leisure holidays</li> <li>• Domiciliary care</li> <li>• Physiotherapy</li> <li>• Palliative care</li> <li>• Community children's nursing</li> </ul>
Non-healthcare Services	<ul style="list-style-type: none"> <li>• Leisure: parks, cinemas [access needs to be looked at for example movement of wheelchairs]</li> </ul>

## Resources

Comments relating to resources highlighted the need to extend funding after the three years of Wraparound in order to 'offer continuity and develop services'. Participants identified the current need for further resources for respite, specialist care, outreach support and care for children with complex and nursing needs.

## Evaluation and monitoring

One participant comment on the need to develop an evaluation framework for Wraparound, agreed with parents and professionals, as soon as possible.

## Appendix VI Learning from the Health Impact Assessment

‘Partnerships take time to deliver results.’

People who were closely involved in developing and organising the HIA of Wraparound were asked to reflect on the experience, to inform:

- the development of HIA
- the development of the Rapid Appraisal Tool
- the organisation of the second HIA in 2003.

This group included members of the project team, the ETG, administrative staff, the literature reviewer and facilitators of the Workshop work groups.

‘The HIA provided a forum for parents, carers, children and young people with disabilities to highlight issues in an organised and productive manner.’

### **General Comments**

The HIA was ‘a very worthwhile exercise’, particularly because it:

- helped projects, stakeholders and other interested parties to develop a sense of focus for Wraparound
- helped everyone to identify the real priorities within a very complex programme
- enabled a wide range of perspectives to help the development of individual projects and challenge the thinking behind project objectives, in a non-threatening environment (ie small groups)
- enabled agencies to identify opportunities to create partnerships which will impact on the health of children and young people
- provided an opportunity for agencies to learn from one another thereby empowering everyone to further develop services
- gave professionals an in depth view of the issues affecting children and young people and their families and carers.

### **HIA Organisation**

#### 1 Preparation

- Preparation is key to the success of the use of this tool [4]. Whilst the actual workshop is ‘rapid’, the preparation for the workshop

and the organisation, analysis, write-up and dissemination of the findings takes a great deal of time and other resources. To influence decision making about the continuance and development of Wraparound, the next HIA needs to be well timed and supported.

## 2 Information

- Mail agenda out to participants beforehand (this is recommended in the tool).
- We need to use existing information systems better.

## 3 Timing

- Ideally, undertake HIA as part of the design process.
- Try to ensure that the timing of the workshop suits participants.
- Increasing the usual participatory stakeholder workshop length by an hour helped to manage the large number of people (n ~ 100). (Even though some people felt rushed, there weren't many who said had not had the opportunity to express themselves in the workshop evaluation.)
- Try to allow reasonable amounts of time for relaying information about the scheme, HIA etc and for discussion. This would help to inform the new people who are continually becoming involved and would address the issue of people not reading the materials forwarded in advance of the HIA.
- The lack of partners' knowledge about some projects at an early stage in Wraparound meant it was very difficult to link into the HIA process.

## 4 Facilitators

- Briefing the facilitators before the workshop made the workshop facilitator more confident they would be able to handle the tasks.

## 5 Location of the graffiti board

- Consider locating the graffiti board outside the workshop room.

## 6 Publicity

- Consider the potential disruption of PR activity. 'The TV crew was excellent for publicity and it was tremendous you got them there - very well done. However, their insistence on filming the graffiti board when the Wraparound workshop had already started was distracting, noisy and for some downright annoying.'

[NB Wraparound was covered in a consumer health programme on Northern Ireland television.]

## 7 Feedback in workshop

- Find a better way of giving feedback on the graffiti board to participants in the workshop: 'very rich information was obtained through this informal exercise - and it would have been good to give them some of that back.'
- Ask the facilitators to feedback through the workshop facilitator. (This mechanism does require co-ordination with main workshop facilitator and discipline on behalf of the small group facilitators to make sure the results are handed to main facilitator in a legible format according to the instructions given.)

## 8 Partnership

There was agreement on the value of involving all partners, particularly parents and carers, in the workshop. However their representation needs to be increased for the next HIA.

- 'The carers being included in the workshop was good. It's one way of re-adjusting the perspectives of professional and carers alike and moving to more of an understanding of the other's position - it is only from this place that we can move forward and find solutions that are acceptable to all parties...However, I am aware that sometimes members of the public feel constrained when they have to work with professionals in this way - this was certainly expressed at the Wraparound workshop. This needs more work and in general I would like to find ways of integrating public, communities, carers and professionals without the former group feeling (or even being made to feel) unconfident, second class, non-expert, unheard, etc...We need their tacit knowledge sometimes more than anyone else's.'

- 'The participation of service users will impact greatly on the development of services which will in turn impact on the physical and mental health of children and young people in the SHSSB area.'
- Working with voluntary groups was extremely helpful and facilitative throughout the HIA.
- 'The HIA did not succeed in reaching out to all groups who could make an important impact to the process, because some people considered it to be irrelevant. It also raised issues about the stigma of disability and the lack of representation of various groups. This would need to be addressed by the second round of HIA in order to optimise interest, inclusion and ownership of Wraparound.'
- Some professional staff (the minority I think) were reluctant to get enthusiastic about Wraparound.

'I am amazed at the amount of good, relevant information that came from the event. The only question is what to do with it all?'

## 9 Dissemination

- 'The newsletter was an excellent way of keeping people informed during the interim period before the main report is produced. People often want to know the headline results fairly early on after they've participated and this was a good way of doing it. It keeps people's interest up and makes them feel their contribution has been valued and is being used. The newsletter was also well produced and eye-catching, which makes people want to read it.'
- It is important to feed HIA results into the task groups quickly to allow the opportunity to adjust programmes to meet the new objectives stemming from the HIA.

'What a great experience to work with "leaders" who are happy to change their way of working because of being able to see the big picture and who can sell the project to colleagues'

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