

Wraparound:

the Health Impact Assessment of the  
All-Inclusive Wraparound Scheme

Summary Report

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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The Intellectual Property Rights for the Rapid appraisal tool for Health Impact Assessment in the context of participatory stakeholder workshops, and the development of this tool as a result of the Health Impact Assessment of the All-Inclusive Wraparound Scheme, are held by Ms Erica Ison.

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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 by developing new ways of working in partnership with the families 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 significant 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

## **Part one: The All-Inclusive Wraparound Scheme [1]**

### **The All-Inclusive Wraparound Scheme**

The Wraparound [1] was introduced into the Southern Health and Social Services Board (SHSSB) in October 2002. It will run until March 2004.

#### **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 0-18 years) and their families and carers across the SHSSB.

#### **Aim**

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.

#### **Funding**

Wraparound has received a funding allocation from the Programme for Government Executive Programme Funds of £1.5m over three years.

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, representative of 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 a Health Impact Assessment (HIA) on Wraparound using the funds allocated to evaluation for Year 2001/2002.

## Projects

There are eight projects included in Wraparound.

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

## Definition of health

The Wraparound is based on a definition of health that recognises that health is 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\***

### **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. [3]

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

Like Wraparound, HIA is multi-disciplinary, intersectoral and participatory. Its underpinning values are sustainability, promotion of health, democracy, equity, equality and the ethical use of evidence. HIA 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* [4]

- 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?

The Wraparound HIA uses a rapid appraisal method ie one that has a limited timeframe and uses information and data that are readily available.

#### **Resource box**

*Health Impact Assessment: an introductory paper* [www.publichealth.ie](http://www.publichealth.ie) [5]  
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) [4]

### **The rationale for conducting a HIA on Wraparound**

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.

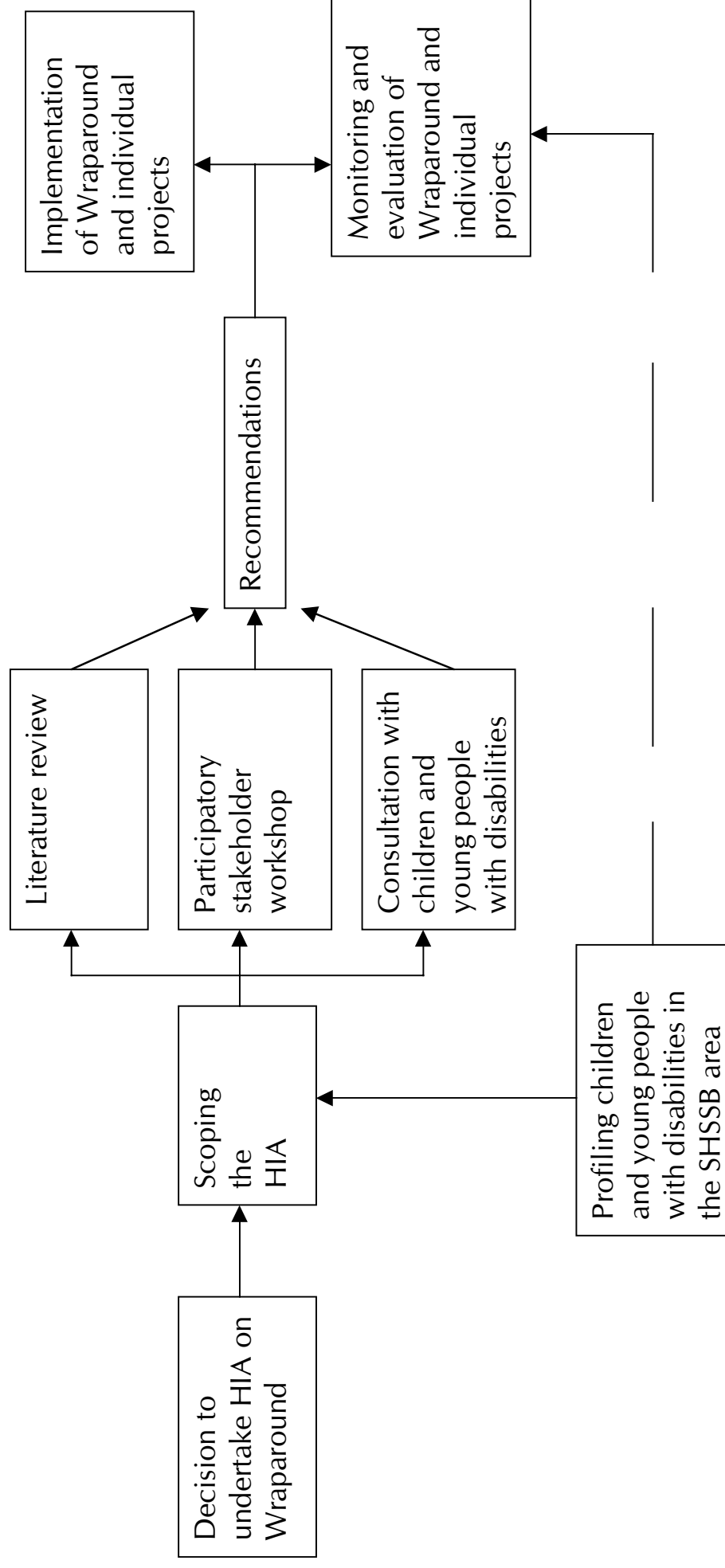
The aims of the HIA on Wraparound are:

- 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
- through the information gathered by the evaluation and monitoring system, to support future service developments.

On the next page there is a summary of the process followed in the HIA of the All-Inclusive Wraparound Scheme.

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



## **Scoping**

The 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 time scale for the HIA was set as follows:
  - participatory stakeholder workshop- April
  - presentation of headline findings at Stakeholder Forum and production of newsletter- May
  - production of report- Summer 2002
- the geographical area was the SHSSB
- the population covered by the HIA was the children and young people with disabilities and their families and carers 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.

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

- Literature review
- Routine information sources
- 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 were reviewed. The literature review identified

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

### **Routine information sources**

The routine information sources provided Census data on the whole population of the SHSSB [6], and the 0-19 age group [7, 8] (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 [9]. Three levels of service activity were examined through the Korner returns [10], the Child and Adolescent Mental Health Service records [11] and an audit of the physiotherapy service at the Child Development Clinic [12]. The additional care needs of these children and young people were indicated by analysis of the Family Trust Fund Database [13]. The survey of the Travelling community [14] highlighted health issues within this socially excluded community.

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 eg 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.

### **Participatory stakeholder workshop**

Partnership working and participation are central to Wraparound. The *Rapid appraisal tool for HIA in the context of participatory stakeholder workshops* [4] provided a process for including all partners 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 and carers , health disciplines and disabilities. The task group discussed at length who could be invited and the support that they would need to attend.

A mailing list for invitations to the HIA workshop was centrally collated by the SHSSB from:

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

To promote representation from a range of disciplines, information was targeted across services. To promote the inclusion of parents and carers, 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
- 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)
- mail out of a letter of invitation to the HIA workshop

- mail out 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 at 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 [P35]

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 were circulated to members of the ETG and at the Stakeholder Forum one month after the workshop. These findings are included in the full report [15].

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 the Southern Education and Library Board, District Councils), policy makers, elected representatives and individuals.

Five hundred copies of the full report [15] and 3000 copies of this summary report have been produced. The dissemination channels for these reports include: existing Wraparound structures, the Wraparound mailing list, libraries of universities in the UK and Ireland, and the Northern Ireland Assembly and Dail Eireann, key policy makers, web sites, networks of HIA practitioners and professional journals.

Both this report and the full report [15] 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 the full report [15]. 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.

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

The newly appointed user participation worker consulted with children and young people with disabilities to gain their views and ideas about Wraparound. Two group consultations and a series of consultation with individual young people have informed this section. Information from the consultations are included in the full [15] and summary reports, following participants' agreement that:

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

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 three: Findings of the participatory stakeholder workshop**

The participatory stakeholder workshop generated substantial amounts of data. The ways in which these data were organised are outlined below. Examples of how the data were presented are included in this report. All the workshop data is included in the full report [15].

#### **Organisation of the data**

The data from the graffiti board was 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 health impacts of disability on children are included below for illustration.

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

- physical health
- mental health
- quality of life
- social inclusion.

The impacts were coded as positive (P), negative (N) or unclear if neither entirely positive or negative (?). The findings for project C are included below for illustration.

The graffiti board and health impact data were presented in tables, identifying issues and using illustrative comments. As far as possible comments were grouped using common 'Issue' headlines in order to facilitate comparison between tables. The number of times a comment was made was indicated in brackets.

A commentary was made 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 were written up as principles to guide the implementation of Wraparound. These principles are included in part four, which also includes data from the work group task of identifying recommendations.

## **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 or 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 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' and carers' relationship and the quality of life for siblings. Key issues that emerged were the impacts on mental or psychological health (19), exhaustion (9), financial worries (8) and concern for future with regard to transitions in the child or young person's life and the death of their parents or carers.

Participants commented that family members and 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 is 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:

- 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. Cluster analysis of data from the Family Trust Fund has been used to identify broad groups of children with disabilities requiring extra care. These broad groups may provide a useful framework for service planning.

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

Strong themes emerged from the graffiti board: access to and 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.

### Section 1: Graffiti board

#### 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).

Health Impact	Comment
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, 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 it is necessary to integrate the child with other children and put in supports to facilitate this; exclusion from summer schemes due to rigid inclusion criteria or resources not being available results in children with disabilities seeing themselves as different]</li> <li>• social attitudes (2) [social isolation or 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 / 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 flow between medical and 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 PSE1
Education	<ul style="list-style-type: none"> <li>• time lost out of education due to illness and attending hospital appointments and 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>



**Section 2: Health impacts**  
 Project C (User participation)  
 No direct effects on physical health identified

Direct effects on mental health

Issue	Impacts
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 re '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

Issue	Impacts
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> increase knowledge of childrens' services providers about what services are needed at an early stage; understand their needs first time (4)</li> <li>• <b>P</b> reorient service [statutory services and individual professionals need to rethink service delivery and listen to family experiences and promote 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> scope is too wide with regard to age range, developmental levels and disabilities (3)</li> <li>• <b>?</b> undiagnosed or 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 to 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 19years – 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

Issue	Impacts
Service delivery	<ul style="list-style-type: none"> <li>• <b>P</b> may lead to the development of new ways of communicating with severely disabled children to obtain their views</li> <li>• <b>?</b> how professionals interpret complex needs</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 who are difficult to engage or 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>

## **Part four: Recommendations**

### **Development of the recommendations**

#### **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 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.

The recommendations for the Wraparound scheme and the strategic recommendations for the Wraparound projects are included in this part. The full report [15] includes operational recommendations for the Wraparound projects.

## Section 1: Recommendations from the consultation with children and young people with disabilities

*‘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 web site 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 participatory stakeholder workshop discussions about barriers to and conflicts around the implementation of Wraparound a set of principles has been developed for key areas of service quality.

### **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.

#### **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.

#### **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 ie 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.

#### 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.

#### 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.

#### 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's roles and territoriality.

- To be respectful towards children, parents and carers, staff and other agencies.
- To back commitment to partnership working with parents and carers with practical supports (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 service and clinical communication systems between all relevant actors that are supported by information technology.
- To develop integrated services.



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

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	CSP	Childrens Services Planning
CB	Craigavon and Banbridge	E	Evaluation		
NM	Newry and Mourne	PT	Project team		

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.

#### 1 Information

	Recommendation	Lead
1.1	Improve service information and sign posting of services	PT
1.2	Develop a Wraparound web site 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

## 2 Share the learning

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

## 3 Work plans

Recommendation		Lead
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 post holders with reference to existing staff and services	All

## 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

## 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 parents and children and young people can be heard but with opportunities to identify their views separately, particularly in the teenage years	All

## 6 Transition

	Recommendation	Lead
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 and options at transition and disseminate this to all stakeholders	CSP

## 7 Capacity building and training

	Recommendation	Lead
7.1	Conduct capacity building and training needs review for each project using a common pro-forma	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

## 8 Workers' health

Recommendation		Lead
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

Recommendation		Lead
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 care.	PT

## 10 Lobbying

Recommendation		Lead
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

Recommendation		Lead
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

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

Project A [One stop child development clinic outreach to each Trust area ]

<b>Focus</b>	<b>Recommendation</b>
1 Capacity building	1.1 Develop communication training for staff
	1.2 Run road shows for staff regarding referral criteria to service etc

Project B [Royal National Institute for the Blind and Southern Education and Library Board]

<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)

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

Focus	Recommendation
1 Partnership working: children	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 and 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 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

Project D [Autism specific service provision with the SHSSB]

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

Project E [Mencap family and play advisor]

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

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

**See ‘Recommendations for Wraparound scheme’**

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]

**See ‘Recommendations for Wraparound scheme’**



## Appendix I Membership of the Evaluation Task Group

Dr Brid Farrell [Chair]	Public Health Directorate, Southern Health and Social Services Board
Mr Richard Black	Disability Programme, Newry and Mourne Health and Social Services Trust
Mr Liam Burns	Mencap
Mr 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
Sr Frances Connolly	Orana Family Centre, Newry
Sr Loretto McKeown	Orana Family Centre, Newry
Ann Mallon	Mencap
Ms Valerie Maxwell	Children's Services Planning, Southern Health and Social Services Board
Mr Martin Sweeney	Learning Disability Programme, Armagh and Dungannon Health and Social Services Trust
Mr George Thompson	Community Development Team, Craigavon and Banbridge Health and Social Services Trust
Ms Mary Wright	AFASIC

## Appendix II 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).
- 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 ( $n \sim 100$ ). ('Even though some people felt rushed, there were not many who said they did not have the opportunity to express themselves in the workshop evaluation.')
- Try to allow reasonable amounts of time for relaying information about the scheme and HIA 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 before the HIA.
- The lack of partners' knowledge about some projects at an early stage in the Wraparound scheme 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 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 workshop had already started was distracting, noisy, and for some downright annoying.'

[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 parents and carers 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 & 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 groups 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.'

- 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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