
NICCY

northern ireland commissioner
for children and young people

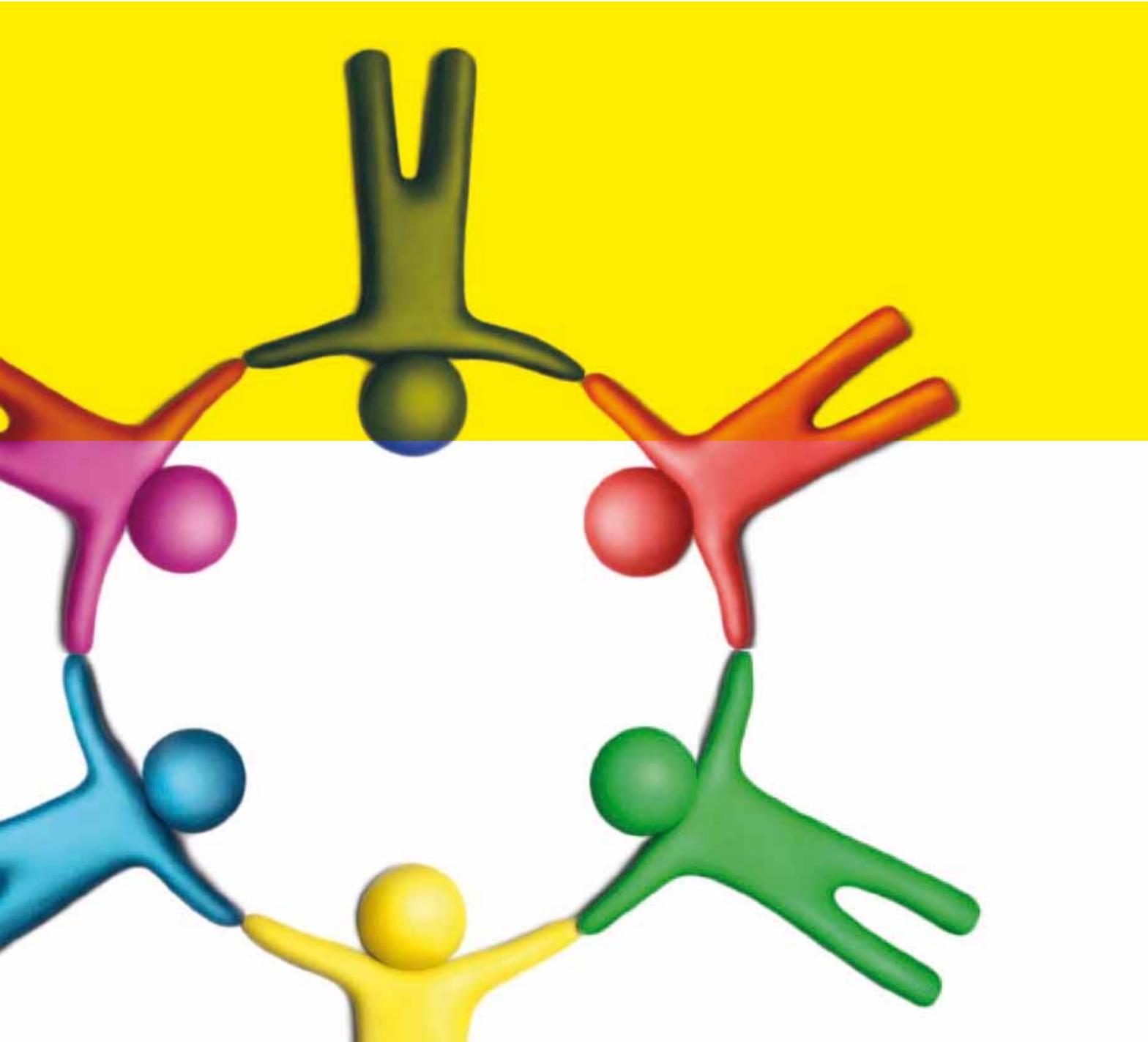
‘Who speaks for us?’

**Review of Advocacy Arrangements
for Disabled Children and Young
People with Complex Needs**





The views expressed herein are those of the Author.



contents

Glossary of Terms	04
Executive Summary	05
Introduction and Background	09
Methodology	13
Literature Review	17
Identification of need	29
Awareness of rights and services	39
Existing Advocacy Arrangements	41
Effectiveness of services	53
Conclusions and Recommendations	57
Appendix A:	
Bibliography	60
Appendix B: Workshop Attendees	61



Glossary of Terms

ASBAH

Association of Spina Bifida and Hydrocephalus

CLC

Children's Law Centre

DARs

Dispute Avoidance and Resolution Service

DDO

Disability Discrimination (NI) Order

DE

Department of Education

DfES

Department for Education and Skills

DHSSPS

Department of Health, Social Services and Public Safety (NI)

DLA

Disability Living Allowance

DoH

Department of Health (UK)

DSD

Department for Social Development

ECNI

Equality Commission Northern Ireland

EHSSB

Eastern Health and Social Services Board

ELB

Education and Library Board

HSSA

Health and Social Services Authority

HSSB

Health and Social Services Board

HSST

Health and Social Services Trust

LACE

Looked After Children in Education

NCVCCO

National Children's Advocacy Consortium

NHSSB

Northern Health and Social Services Board

NICCY

Northern Ireland Commissioner for Children and Young People

NISRA

Northern Ireland Statistics and Research Agency

OFMDFM

Office of the First Minister and Deputy First Minister

ONS

Office of National Statistics

POCVA

Protection of Children and Vulnerable Adults

QUB

Queens University Belfast

SEN

Special Educational Needs

SENDO

Special Educational Needs and Disability Order

SHSSB

Southern Health and Social Services Board

SLA

Service Level Agreement

UNCRC

United Nations Convention on the Rights of the Child

VOYPIC

Voices of Young People in Care

WHSSB

Western Health and Social Services Board

Executive Summary

1.1 Introduction and background to the study

The principal aim of the Office of the Commissioner for Children and Young People (NICCY)¹ is to ‘safeguard and promote the rights and best interests of children and young persons’. The Commissioner is further tasked with keeping under review the adequacy and effectiveness of law and practice relating to the rights and best interests of children and young people, specifically services provided to children and young people by relevant authorities.

NICCY appointed KPMG to undertake a review of the arrangements for advocacy services for disabled children and young people with complex needs in Northern Ireland. This review focuses on advocacy arrangements that provide support and advice in everyday settings, whilst paying cognisance to the other forms of advocacy that are required from time to time.

In particular KPMG were required to:

- Produce a comprehensive literature review relating to the numbers of children in Northern Ireland with disabilities and complex needs, specific issues that impact on these children and their carers, the policy context in which services are delivered and examples of good practice in the provision of advocacy services
- Determine the demographics of disabled children and young people in Northern Ireland
- Obtain the views of disabled children and young people, their parents/carers and professionals working in the field
- Determine the extent and nature of need amongst these children and young people
- Explore the awareness of rights and service provision amongst individuals and their families

- Produce a comprehensive overview of the existing advocacy arrangements for disabled children and young people with complex needs in Northern Ireland, and
- Offer evidence based recommendations for the future development of both policy and practice.

Section Detail

- 1.2 Methodology
- 1.3 Overview of finds
- 1.4 Recommendations

1.2 Methodology

In order to meet these terms of reference KPMG undertook a number of key tasks, as noted below:

- Vetting and ethical approval; each member of the KPMG team was vetted under the Protection of Children and Vulnerable Adults Order (2003). The methodology was also approved by the NICCY ethics committee
- Consultation with Statutory bodies; 11 face to face interviews were conducted with staff responsible for the delivery of Health and Social Services to disabled children and young people. Five telephone interviews were held with staff from Education and Library Boards
- Survey of Parents/Carers; 918 surveys regarding use and awareness of advocacy services were distributed to parents and carers of disabled children and young people with complex via statutory and voluntary bodies. 163 surveys were returned
- Literature Review; a range of literature relating to the statutory policy and the rights of children and people with disabilities was reviewed, as well as statistics relating to the number of disabled children and young people in Northern Ireland with complex needs

¹ The Commissioner for Children and Young People (NI) order 2003

Executive Summary

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- Consultation with children and their parents/carers; a consent form requesting permission to interview children and young people was issued with every survey. 28% of respondents agreed that a member of the KPMG could speak to their child, 64% of parents/carers agreed to be interviewed themselves. In addition to this, following a referral from a parent who had received a survey, a principal of a Special School also agreed that a number of the children could be interviewed. Makaton sign language and drawings were used during the interviews to support communication. In total 33 children and 17 parents were interviewed, and
- Consultation with the voluntary sector; 21 voluntary organisations were invited to attend a workshop relating to advocacy services for disabled children and young people with complex needs. Representatives from 9 organisations attended. A further three voluntary organisations were consulted with either face-to-face or, on the telephone.

1.3 Overview of findings

1.3.1 Literature Review

Based on population statistics, ONS data and data from each of the Health and Social Services Boards, there are an estimated 522 disabled children and young people in Northern Ireland with complex needs. There are a number of United Nations Conventions and government policies which provide a strong policy backing for the provision of advocacy services for disabled children in Northern Ireland. For example, the

United Nations Conventions of the Rights of the Child (UNCRC) as ratified by the UK government in 1991, states that children have the right to obtain and make known information and to express their views. Furthermore, the DHSSPS Care at its Best report noted that, hospitals providing children's services should encourage pro-active approaches such as advocacy. The Department of Health (DoH, UK) published best practice guidelines in the provision of advocacy services. The guidelines note the need for advocacy to be independent from those who provide other services and that it should be led by the views and wishes of the child.

1.3.2 Identification of need

The majority (95%) of children whose parent/carer responded to the survey lived at home, the remainder either lived in foster care or in residential or hospital settings. 13% of those who responded said that their child currently makes use of an advocacy service. Almost half (49%) of whom stated it was in relation to care management issues. Broadly speaking the survey results showed that parents would like their child to have access to advocacy at key times of their lives, such as when leaving school or, changing schools. 64% of respondents said that they would like their child to have advocacy as they grow older, 31% of respondents said that their child would need an advocate to speak up for them when they are no longer able to care for them.

1.3.3 Awareness of Rights

The primary research indicated that there was very little awareness of rights among parents and carers. Only one of the parents interviewed

made reference to any of the organisations with a statutory obligation to protect the rights of children. Five of the children interviewed, noted that they understood the UNCRC and the implications it had for them. There was also a range of understanding among parents about what services were available, 12% of those surveyed said they were not aware of any advocacy services and around 3% of parents said that they didn't know what advocacy really was.

1.3.4 Existing advocacy arrangements

Evidence from the primary research and the consultations with the statutory and voluntary sector showed that there was great variation in the availability of advocacy services across Northern Ireland. 67% of the parents surveyed said that their Social Worker provided an advocacy role. This can create a conflict of interest as the Social Workers are employed by organisations who are responsible for the provision of services. A number of the voluntary organisations such as the Cedar Foundation and Barnardos provide services under a Service Level Agreement (SLA) with local Trusts, as such these services are only available in certain areas (e.g. the Eastern Health and Social Services Board area and the Southern Health and Social Services Board area). Voluntary organisations are often restricted in the level of service they can provide due to funding issues.

1.3.5 Effectiveness of Services

Results from the primary research showed that generally speaking, those who have made use of

advocacy have found it to be very useful. The services that were identified have tended to have been developed organically from a locally identified need rather than a strategic Board or Departmental strategy. Many of the young people interviewed (22%), would have liked more advocacy support during transitional stages of their life or, would have like to have received this support sooner.

1.4 Recommendations

A number of recommendations arose as a result of this review, an overview of which will be provided in the following paragraphs. The recommendations fell into the broad categories of Co-ordination of Services, Service Planning and Equity of Access, as summarised in the following paragraphs:

Co-ordination of Services

1. DHSSPS should ensure that the delivery of advocacy services for disabled children is coordinated at a strategic level. NICCY has already written to the DHSSPS seeking its support for the development of an advocacy network in Northern Ireland and suggesting it would be beneficial to better co-ordinate existing provision and to ensure standards are maintained and developed across the sectors and agencies involved. This network should be inter-departmental to ensure that all aspects of services for disabled children are included.
2. The introduction of the new regional Health and Social Services Board in April 2009 means services will be coordinated and delivered at a strategic level. The new Board should review

Executive Summary

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how advocacy services could be co-ordinated, funded and delivered at a strategic level.

3. The DHSSPS should undertake an awareness campaign to raise the profile of advocacy and its uses, emphasising the need for advocates to be independent and free of conflicts of interest. By way of example this could include providing those who work with disabled children and young people with literature regarding advocacy guidelines or, someone from the DHSSPS acting as an information officer, being responsible for the provision of information and advice relating to advocacy for those in working statutory and voluntary services.
4. Where good practice is identified, DHSSPS should ensure that information is made available that would allow others to replicate or use the model to develop effective advocacy services. This could be good practice within Northern Ireland (such as the Sixth Sense project) and further a field such as the publication of the DoH advocacy guidelines.
5. All statutory organisations with a remit to protect the rights of disabled children should ensure that their services are publicised and promotional material is accessible.

Service Planning

6. An accurate and complete register of all disabled children in Northern Ireland should be compiled and maintained by the new HSSB, in line with the Children Order (Northern Ireland) 1995.

7. All relevant government departments (i.e. DHSSPS, DE and DEL) should ensure that existing services are appropriately funded in order to meet the needs of all children within their remit and to allow organisations to publicise their services.
8. Those responsible for funding advocacy services need to be aware of the resource implications of long term advocacy in order to maintain it effectively and to meet the needs of disabled children with complex needs.

Equity of Access

9. In order to achieve equitable access to advocacy, services should be made available to all children with complex needs at the point when they enter either educational or health and social services.
10. The establishment of the new Health and Social Services Board should ensure that advocacy services are strategically planned and delivered to achieve a regional service and not a series of localised and varied services. Evidence from the review of literature, the responses to the survey and interviews with disabled children and young people with complex needs indicate that all disabled children and young people with complex needs would benefit from statutory funded advocacy services.

Introduction and Background

2.1 Introduction

In the following paragraphs we have provided an overview of the Office of the Commissioner for Children and Young People, the terms of reference for this review and acknowledgements for those who have helped us to complete the review.

Section Detail

- 2.1 Introduction
- 2.2 Terms of Reference
- 2.3 Acknowledgements

2.1.1 NICCY

The Office of the Commissioner for Children and Young People (NICCY) was created in accordance with ‘The Commissioner for Children and Young People (Northern Ireland) Order’ 2003.

The principal aim of the Commissioner is to ‘safeguard and promote the rights and best interests of children and young persons’. The Commissioner is further tasked to ‘keep under review the adequacy and effectiveness of law and practice relating to the rights and welfare of children and young persons’, specifically, those ‘services provided for children and young persons by relevant authorities’¹. All this is done with explicit reference to the United Nations Convention on the Rights of the Child, as ratified by the UK government in 1991². The principal aim of the Commissioner is to ‘safeguard and promote the rights and best interests of children and young persons’ within Northern Ireland.

Of particular relevance to this review is Article 9 of ‘The Commissioner for Children and Young People (NI) Order’ which states that the Commissioner

may review the operation of ‘advocacy, complaint, inspection and whistle-blowing arrangements of relevant authorities for the purpose of ascertaining whether, and to what extent, the arrangements are effective in safeguarding and promoting the rights and best interests of children and young persons’.

2.1.2 Scope of the Review

The remit of the Commissioner’s Office is children and young people from birth up to 18 years of age, or 21 years if the young person is disabled or in the care of Health and Social Services.

The issues associated with disabled children and young people have been brought to the attention of NICCY via a number of different avenues to date; through individual complaints, through research into children’s rights by QUB and through lobbying by concerned professionals, carers and relatives.

Research commissioned by NICCY, and undertaken by QUB, on the state of children’s rights in Northern Ireland highlighted a number of issues, relating to the lives of disabled children. It is intended that this review will particularly focus on the need for greater participation of children and young people with disabilities in making decisions about their own health care and, more generally, their lives.

Influenced by these findings as well as similar issues, found in Monteith et al (2002) and the Social Services Inspectorate Report 2005, NICCY has commissioned this review of advocacy services for disabled children and young people with complex needs, in Northern Ireland.

¹ Article 7 (2) (3), The Commissioner for Children and Young People (Northern Ireland) Order 2003

² Kilkelly et al (2004) Childrens Rights in Northern Ireland (NICCY)

Introduction and Background

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For the purpose of this review, the concentration is on children and young people aged up to, but not including, 21 years of age and who are residing in any of the following settings:

- Home
- Foster Care
- Residential Care
- Hospital.

The review has also recognised that there are differing degrees of advocacy ranging from support in every day living decisions to legal advocacy providing support in litigation. This review will focus on advocacy arrangements that provide support and advice in every day settings, whilst also paying cognisance to the other forms of advocacy that are required.

2.2 Terms of Reference

The terms of reference indicate the following specific objectives:

- Producing a comprehensive literature review, covering:
 - Definitions of (complex) disabilities
 - Existing data on numbers and geographic spread of disabled children and young people (with complex needs) living in Northern Ireland
 - Issues affecting both disabled children and young people with complex needs and their families/carers
 - The needs of these individuals
 - The purpose, and nature, of advocacy arrangements
 - Relevant policies within NI
 - Examples of good practice within NI
 - Examples of good practice from other jurisdictions, both in terms of policy and practice
- Relevant research/reviews within NI, the UK, Ireland and Europe – from academic, statutory and voluntary sources
- Recommendations of previous work in the field.
- Determining the demographics of disabled children and young people with complex needs within NI (with reference to both living at home and those in the care of relevant authorities).
- Obtaining the views of disabled children and young people (via appropriate means); their parents/carers and professionals working within the field.
- Determining the extent and nature of need amongst these children and young people and their families/carers (across all identified settings) – reference should be made to the full gambit of need including the material, social, emotional, educational and physical fields.
- Exploring awareness of rights and service provision amongst these individuals and their families.
- Producing a comprehensive overview, and evaluation, of existing advocacy arrangements for disabled children and young people with complex needs within NI. The effectiveness of current advocacy arrangements should be evaluated in terms of both (a) achieving stated aims and (b) meeting individuals' needs. Consideration should be paid to both policy and practice, with specific reference made to notable developments (positive or negative) within either field.
- Offering evidence-based recommendations for the future development of both policy and practice.

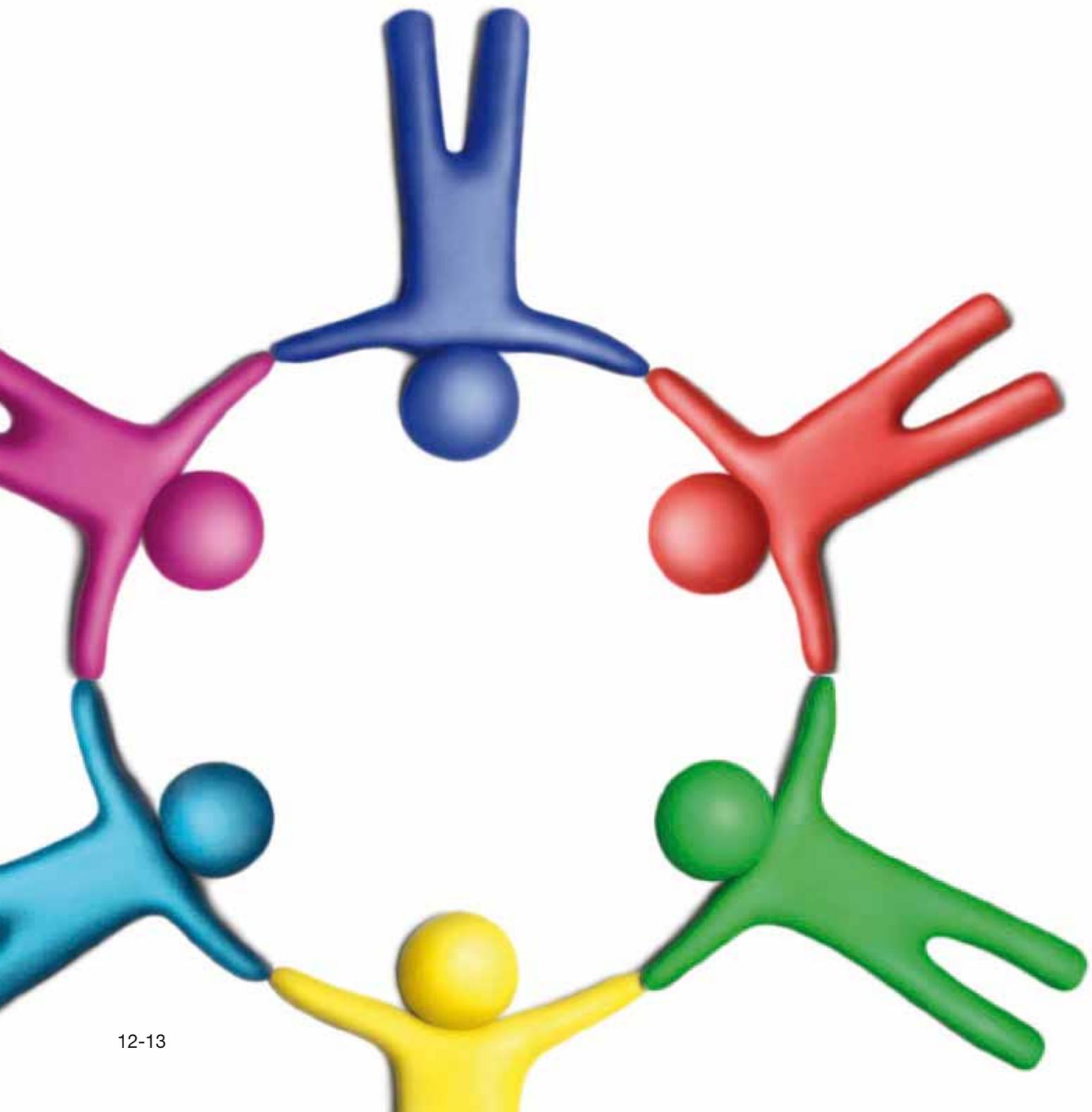
Within this KPMG were required to:

- Evaluate the appropriateness of existing (and planned) policies and determine the extent to which desired policy outcomes are being fulfilled. Reference should be made to Children's Services Plans.
- Ascertain if regional differences exist with regard to the provision, nature and effectiveness of advocacy arrangements for disabled children and young people with complex needs.
- Make specific reference to the different needs of, and potentially different levels of provision for, disabled children and young people residing in different types of setting.
- Offer a comparative analysis of the advocacy arrangements available to different groups of young people, e.g. those at home, in care, hospital or community settings.
- Offer a review of any other systems in place to ensure the voice of the disabled child or young person is heard.
- Address the issue of children from NI who are currently residing outside NI, having been placed there by a HSS Trust.
- Ascertain to what extent inter-agency working is (a) taking place and (b) proving effective within these areas.
- Through creative direct communication with the same, ascertain the views of children, young people, parents/carers and relevant professionals regarding:
 - The effectiveness and appropriateness of existing services;
 - The nature and extent of unmet need;
 - Desired developments within the field; and
 - Examples of good practice and how this might be replicated.

2.3 Acknowledgements

This review required a significant amount of consultation with children and young people and their carers/parents. We would like to thank them for their assistance in undertaking this review. In addition there are a number of groups we would like to thank for their assistance:

- All Health and Social Services Trust staff and voluntary organisation staff, who consulted with us and helped us to distribute the surveys.
- The parents and young people who consulted with us, including the children at Ceara Special School and the Sixth Sense Group who took the time to talk to us.
- The parents and carers at the Newry Parents group who also assisted us by distributing surveys and completing them.
- The parents who assisted with the early drafts of the survey.
- The guides from Ballygilbert who assisted in drafting the children's report.



Methodology

3.1 Introduction

A number of tasks were undertaken to meet the terms of reference of the review, as follows:

Section	Detail
3.1.1	Vetting and Ethical Approval
3.1.2	Strategic context and literature review
3.1.3	Consultation with statutory bodies
3.1.4	Survey of parents/carers
3.1.5	Consultation with children and their parents/carers
3.1.6	Consultation with representatives from the voluntary sector.

3.1.1 Vetting and Ethical Approval

Prior to conducting the review each member of the research team applied to be vetted to work with children and young people through the Protection of Children and Vulnerable Adults (NI) Order 2003 (POCVA). The methodology and related research tools were also approved by the NICCY ethics committee.

3.1.2 Strategic Context and Literature Review

To provide a strategic context within which the review was undertaken, a range of key documents relating to children's services and advocacy, both from Northern Ireland and around the world were reviewed. A complete list of documents reviewed can be found in the bibliography. To estimate the number of children and young people with complex needs in Northern Ireland a range of

key statistics from the Northern Ireland Statistics and Research Agency (NISRA) and the Office of National Statistics (ONS) were also examined.

3.1.3 Consultation with Statutory Bodies

Prior to anyone from the KPMG team conducting any consultations NICCY issued a letter to the Chief Executives of each of the Health and Social Services Trusts and the Education and Library Boards. The letter explained the purpose of the review and asked for their co-operation and assistance in its completion.

KPMG contacted each Community and Combined Trust to arrange a meeting with a representative from the departments with responsibility for children and young people under the age of 21 who had complex needs. Eleven face-to-face consultations were held with Trust managers with a remit for service commissioning and development. The meetings discussed the advocacy services available within the Trust for disabled children and young people generally, and in particular for those with complex needs. We also requested a copy of any written documents in relation to advocacy services. We then requested assistance with forwarding the survey to parents/carers of all disabled children and young people with complex needs known to the Trust.

Following this KPMG contacted the special needs departments of each of the five Education and Library Boards and asked for an individual to be nominated to discuss advocacy services within the Board. Telephone consultations were then

Methodology

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undertaken with the nominated individual to discuss the policies and procedures in place within the Board area in relation to advocacy.

- A consent form permitting us to contact the parent or the child and to request a copy of the report when it was completed (Appendix D).

3.1.4 Survey of Parents/Carers

In order to gather further information on the range and effectiveness of advocacy services a survey was developed to be completed by parents or carers of disabled children with complex needs. The survey and associated letter and consent form was approved by the NICCY Ethics Committee, subject to changes following a pilot.

The survey was then piloted with parents in Derry and Belfast, who had agreed to participate in the study and following some suggested amendments, it was then forwarded to the Trusts for onward distribution to the families. The distribution by Trusts ensured compliance with data protection guidelines. The pack also contained:

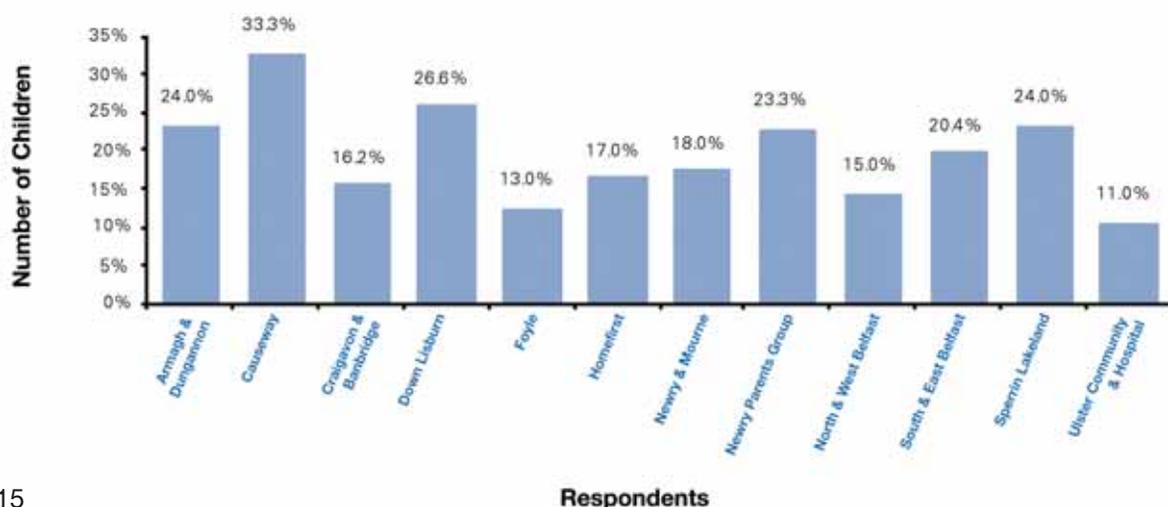
- A cover letter explaining the purpose of the research
- An information leaflet on the Northern Ireland Commissioner for Children and Young People (Appendix C)³
- A discussion guide showing possible questions which would be asked if they consented for their child to be interviewed (Appendix E)

Survey packs were then compiled and forwarded to each Trust for onward distribution to parents and carers. Trusts were asked to print the cover letter on their own headed paper ensuring that the return date was three weeks from the date on which they issued the survey.

Surveys were also distributed through the Newry Parents Support Group for children with Downs Syndrome. Members of the KPMG team attended a meeting of the group and discussed our review with the parents prior to distributing survey packs to each parent who wished to participate. A number of other organisations were invited to participate in a similar manner but were unable to do so within the project timescales.

A total number of 918 surveys were distributed to parents/carers and the overall response rate was 18.4% (163 surveys were returned for 169 children). The corresponding Trust/Group response rates varied from 11% to 33.3%, as illustrated in the chart below.

Chart 1: Trust/Group Response Rates



Notably the surveys issued are almost twice the number of estimated children and young people with complex needs (see section 4). It was noted that during the interviews with the Trusts there was no universal definition of complex needs as each one used the term slightly differently. However, when arranging with the Trusts to distribute the surveys we encouraged them to use an inclusive approach when defining disabled children and young people with complex needs, to ensure that no disabled children with complex needs were excluded from the research.

3.1.5 Consultation with Children and their Parents/Carers

Each parent/carer who received a survey pack also received a consent form permitting KPMG to contact them or their child to discuss advocacy services in more detail. Of the 163 parents and carers who responded, 64% consented to being contacted personally and 28% provided consent to speak with their child. We then contacted the parents who had agreed that we could speak to the children. All children for whom we had consent and were able to communicate were interviewed. In total 16 children and 15 parents/carers were interviewed, following survey responses. The

topics discussed with the children followed the discussion guides which were issued with the survey pack, although the interviews were led by the interviewee and were tailored to meet the abilities and understanding of each individual child. Communications methods such as Makaton and drawing were also used during the interviews to support and increase the level of understanding. Following a referral from Armagh and Dungannon HSST, we also consulted with members of the Sixth Sense group at Barnardos in Armagh. We consulted with four young adults at the Sixth Sense group, and as each participant was over the age of 18 they consented personally to participate in the discussion. A parent who had agreed to be interviewed also referred the KPMG team to Ceara Special School in Lurgan who agreed to participate in the study and distributed information leaflets and consent forms to parents. We also spoke to 12 children at Ceara Special School in Lurgan and parental consent forms were completed by parents prior to the school visit. Again the discussions broadly followed the questions shown in the discussion guide, but were tailored to the individuals participating in each group. Of the children interviewed, 55% were female and 45% were male.

The table below provides an overview of those who we consulted with.

Table 1: Number of Consultations

	Parents/Carers	Children	Total
Number of people interviewed in a group	-	16	16
Number of individual interviews	17	17	30
Total number of interviews	17	33	50

³ All appendices are available on the NICCY web site www.niccy.org

Methodology

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As shown in the table below the majority of children interviewed were aged between 6 and 18. None of those interviewed were aged five or under and only four were aged over 18.

Table 2: Age of the Children Interviewed

	Percentage
0 – 5	0%
6 – 10	33%
11 – 14	27%
15 – 18	27%
Over 18	13%
Total	100%

The table below provides information relating to where the children who were interviewed lived. As shown below the majority of the children interviewed lived within the SHSSB area, this is because more parents from this area agreed for their child to be interviewed than parents from other areas. No parents from the NHSSB area provided consent to interview their children

Table 3: Board area of children who were interviewed

Board Area	% of interviewees
Eastern HSSB	16
Northern HSSB	0
Southern HSSB	78
Western HSSB	6
Total	100

3.1.6 Consultation with Representatives from the Voluntary Sector

An invite was issued to 21 voluntary sector organisations who work with children, people with disabilities or offer advocacy services (see Appendix G) to attend a half day workshop, on 14 February 2007. A total of 12 people attended representing nine organisations.

The programme for the day followed three broad discussion topics:

- Advocacy, what’s out there?
- What is needed?
- How can these needs be met?

The representatives of the voluntary sector were divided into two groups and each group was facilitated to discuss the topics in depth. In addition further contact was made with a range of other organisations who did not attend the workshop, to ascertain their views or, work relating to advocacy with disabled children who complex needs.

Literature Review

4.1 Introduction

An important element of this review is to provide an overview of government policy on advocacy for disabled children in Northern Ireland and also the identification of any examples of best practice. In this review we will also describe what is meant by advocacy and complex needs and review the number of disabled children with complex needs in Northern Ireland. This is important not only to gauge the appropriateness of the range and level of existing services but also to make recommendations for future provision. This will be followed by a review of the literature relating to advocacy for disabled children and the identification of examples of best practice.

Section Detail

4.2 Defining Advocacy

4.3 Defining Complex Needs

4.4 Population/Demographics

4.5 Strategic Context

4.6 Examples of good practice/Existing Services

4.7 Conclusion

4.2 Defining advocacy

There are a few ways in which advocacy could be defined, Article 9 (i) of the Commissioner for Children and Young People (2003) defines advocacy services as:

“arrangements for making persons available to (i) represent the views, wishes and needs and interests of children or young persons in relation to whom any functions of the authority are exercisable and (ii) to provide such children and young persons – (a) with information, advice and support to enable or assist them to express their

*views and wishes to the authority; and (b) with advice about their rights and best interests.”*³

Comhairle⁴ is a statutory agency in the South of Ireland responsible for supporting the provision of information, advice and advocacy on social services. Comhairle describe advocacy as:

“a means of empowering people by supporting them to assert their view and claim their entitlements”.

Therefore, broadly speaking advocacy is, helping someone to speak up for themselves or, speaking on their behalf. We have used this definition throughout the primary research process.

Advocacy 2000⁵ have described the themes of a good independent advocacy service as:

- Safeguarding people who are vulnerable and discriminated against or whom services find difficult to serve
- Empowering people who need a stronger voice by enabling them to express their own needs and make their own decisions
- Enabling people to gain access to information, explore and understand their options, and to make their views and wishes known
- Speaking on behalf of people who are unable to do so for themselves.

4.3 Defining disability and Complex Needs

The UN Convention on the Rights of Persons with Disabilities (2006) notes that *“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory*

³ The Commissioner for Children and Young People (Northern Ireland) Order 2003

⁴ www.comhairle.ie

⁵ ‘Principles and Standards in Independent Advocacy Organisations and Groups’, Advocacy 2000)

Literature Review

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impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

The Disability Discrimination Act (1995) and the subsequent Disability Discrimination (NI) Order 2006, define disability as “a physical or mental impairment which, has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities”. In case law “substantial” is taken to mean more than minor or trivial.

Complex needs is a term that is often used in medical and social care contexts, but often is not clearly defined. The Prince’s Trust ⁶ defined children with complex needs as:

“ those who face particularly severe disadvantage. In many cases this will mean that they have interlocking problems, where the total represents more than the sum of the parts.”

Glendenning et al ⁷ provided a medical based definition of complex needs:

“Children with complex health care needs have additional care needs specifically related to the use of the medical technology itself. This group of children typically require technical and/or medical equipment in the home, both because of their need for intensive on-going care, and to compensate for the loss of a vital bodily function such as the ability to breathe or feed independently.”

Others would use the term ‘complex needs’ to describe children with more than one disability, for example with both a physical and a learning disability. Generally speaking, disabled children and young people with complex needs are usually those with the most severe and profound disabilities and who are often excluded from many aspects of everyday life. Each HSST in Northern Ireland uses different assessments of complex needs, and as such there are differing eligibility criteria to access various HSST services (McConkey et al 2007⁸). For the purposes of this study the Prince’s Trust definition of complex needs was used.

4.3.1 Children in need

On a broader note the Children’s Order (NI) 1995 have defined children in need as:

“For the purposes of this Part a child shall be taken to be in need if—

- a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by an authority under this Part;
- b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
- c) he is disabled.”.

⁶ Prince’s Trust, Reaching the Hard to Reach.

⁷ Glendenning et al 1999

⁸ McConkey R, Barr O. & Baxter R (2007) Children with Complex Healthcare Needs

4.4 Population/Demographics

Under schedule to 2 of the Children’s Order (NI) 1995 each Health and Social Services Board (HSSB) in Northern Ireland is required to maintain a register of disabled children in their area. The UN Committee on the Rights of the Child General Comment (No. 9) also notes that;

“in order to fulfil their obligation, it is necessary for state parties to set up and develop data gathering mechanisms, which are accurate, standardized and allow disaggregation, and which reflect the actual situation of children with disabilities.”

Whilst these registers are useful sources of data, the Boards only maintain the register for children up to the age of 18. Furthermore due to a number of technical and operational difficulties one Board has not been able to establish a register. It is not known how this Board plan services for disabled

children when they do not have a mechanism for recording the number of disabled children within their area.

Those Boards who do maintain a register (EHSSB, SHSSB and WHSSB), recognised that there are a range of difficulties associated with the register, such as the definition of disabled and note that there are limitations on the usefulness of the data that can be extracted from it. Furthermore, some of the Boards record the data up to the age of 18 and others up to the age of 19. It is our understanding that the DHSSPS are in the process of establishing an NI wide register. The NHSSB was not able to provide any data relating to a disability register, but did provide the number of children up to the age of 18 who were receiving Disability Living Allowance. As shown in Table 4, there are an estimated 12,173 children up to the age of 19 in Northern Ireland, based on information provided by the Health Boards.

Table 4: Number of Children on Disabled Register in Northern Ireland

Board (age)	Total population of children	Total number of children with a disability	% with a disability
Eastern HSSB (0 -19)	182,692	4,587	2.5
Northern HSSB (0-18)	110,604	**3,038	2.7
Southern HSSB (0-18)	94,243	2,356	2.5
Western HSSB(0-19)	90,376	2,148	2.3
Total	477,915	12,173	2.5

**Number of children 0-18 claiming Disability Living Allowance

Source: HSSBs Children’s Services Plans

Literature Review

...continued



As shown overleaf each HSS Board has captured their data slightly differently and has used different definitions of both children and disability, so therefore the results will vary slightly between Boards.

Given the difficulties in providing an exact definition of complex needs it is not surprising that the exact numbers of disabled children and young people in Northern Ireland with complex needs is unknown. However, there are a number of ways to estimate the size of this population. Firstly, there are over 522,000 young people in Northern Ireland under the age of 21⁹. The Office for National Statistics (ONS) noted that the rates of disability among children in the UK were 18%¹⁰. This rate includes all categories of health problems and disabilities ranging from mild health care problems such as asthma to profound physical and learning disabilities, as such not all of these children would be known to Social Services. Furthermore, ONS estimate that 10 in every 10,000 children in Northern Ireland are severely disabled.

Based on the ONS estimates we can calculate that there around 522 severely disabled young people in Northern Ireland (under the age of 21). Using the population figures from the table above (under 18/19) of 477,915 and applying the ONS estimate, approximately 478 children are calculated.

Therefore, considering the additional young people aged between 18 and 21 we estimate that there are likely to be in the region of 500 disabled children with complex needs under the age of 21 in Northern Ireland.

4.5 Strategic context

4.5.1 Children's Rights

The United Nations Convention on the Rights of the Child (UNCRC) was ratified by the UK government in 1991. Articles 12 and 13 of the UNCRC notes that, the child has the right to obtain and make known information, and to express his or her own views, unless this would violate the rights of others. This is important because it not only notes that children have the right to express themselves but, also to obtain information that allows them to make informed choices. Article 23 of the UNCRC states that children with disabilities have the right to enjoy *“a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.”* Paragraph one of article 23 should be considered as the leading principle of the implementation of the convention for children with disabilities, as it states that the measures taken by state parties regarding the realisation of the rights of children with disabilities should be directed to this goal.

The UN Convention on the Rights of Disabled Persons was adopted in December 2006, although it is not yet ratified by the UK government. Article 7 of the UN Convention on The Rights of Persons with Disabilities notes that states should take necessary actions to ensure that disabled children enjoy basic human rights and are treated equally with able-bodied children. Article 24 notes that states are required to ensure that disabled children are not excluded from free primary and secondary education on the grounds of their disability. The Convention also states that the best

⁹ NISRA, Census data mid year estimates 2005.

¹⁰ Office of National Statistics, The Health of children and young people, 2004.

interests of the child should always be of primary consideration. Furthermore the Convention also states that people with disabilities have the right to access cultural and social activities. It also notes that States should ensure that disabled children have equal access to sporting and leisure activities, including those provided in a school setting.

Importantly, Article 26 of the Convention on Disability notes that States must take measures to ensure that disabled people achieve and maintain independence and have full inclusion and participation in all aspects of life. States are required to ensure that services and programmes are available, particularly in the areas of health, education and social services.

Article 18 of the Children's Order (NI) 1995, notes that it is the duty of every authority to provide for children in need and their families, by "*providing a range and level of personal social services appropriate to those children's needs*". The article goes on to say that before giving assistance the authority should "*consider the means of the child and the parent*". Therefore, the Order places a legal responsibility on statutory service providers to provide suitable services for children in need and to consider the circumstances of the child and their family before doing so.

The Disability Discrimination (NI) Order 2006 (DDO) makes it unlawful to discriminate against people in respect of their disabilities in relation to employment, the provision of goods and services, education and transport. It is a civil rights law. Among other things the DDO places duties on service providers and requires reasonable

adjustments to be made when providing access to goods, facilities, services and premises.

The duties on service providers have been introduced in three stages:

- Since 2nd December 1996 - It has been unlawful for service providers to treat disabled people less favorably for a reason related to their disability
- Since 1st October 1999 - Service providers have had to make 'reasonable adjustments' for disabled people, such as providing extra help or making changes to the way they provide their services
- Since 1st October 2004 - Service providers may have to make other 'reasonable adjustments' in relation to the physical features of their premises to overcome physical barriers to access.

The Equality Commission Northern Ireland (ECNI) has responsibility for enforcing legislation on disability in Northern Ireland. ECNI has a wide range of powers to ensure compliance with disability legislation, including powers of enquiry and investigation. They can provide assistance to people who feel they have been discriminated against because of their disability; this can vary from giving advice to arranging for legal representation. It also has a legal duty to work towards the elimination of discrimination against disabled people, to promote the equalisation of opportunities for disabled people, to encourage good practice in the treatment of disabled people, and to keep under review the working of the Disability Discrimination (NI) Order 2006.

Literature Review

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Therefore, there is a strong human rights context to the provision of advocacy services for disabled children. Not only have disabled children the right to make informed choices and to have access to education, but they should also have access to sporting and leisure activities. They also have the right to participate fully in making decisions that impact upon their life.

ECNI do not provide an advocacy service for people with disabilities. The Special Educational Needs and Disability Order (SENDO) 2005 Northern Ireland, increases the rights of children with Special Educational Needs (SEN) to attend mainstream schools and introduces the disability discrimination laws to the whole education system. The law also gives increased rights of appeal for parents to the SEN and disability tribunal where there is a disagreement with the Education and Library Board about their child's special educational needs. It provides increased rights to advice and information and places duties on schools and education and library Boards to improve the accessibility of schools and increased information provided to pupils ¹¹.

Related to this is Protocol One (Article 2) of the European Convention on Human Rights which states that no person should be denied the right to education.

The Equality Commission can provide advice and guidance on the aspects of SENDO which they are responsible for (mainly the disability discrimination aspects). It has the power to issue codes of practice to schools and the Further and Higher education sector on providing accessible education to disabled people.

4.5.2 The Bamford Review

In Northern Ireland the Bamford Review ¹² noted that often people with learning disabilities are particularly vulnerable to human rights violations and their rights and interests must be identified under the legislation and within regional policy mandates. It notes that advocacy can support individuals to express themselves and have their view heard. It is concerned with empowerment, autonomy and of safeguarding citizenship rights and the inclusion of people who would otherwise be marginalized. The review also notes that *“advocacy services are unevenly and poorly developed in Northern Ireland”*. The increasing demand for advocacy services in Northern Ireland is an indication of the need to support the rights of people with a mental health problem or a learning disability.

Furthermore, often health and social care staff or, relatives act as advocates for people with disabilities. This however, can cause a conflict of interest and has increased the demand for independent services. McConkey & Smyth ¹³ (2000) noted The Bamford Review goes on to state that there should be a range of advocacy support services available from a range of suppliers and that advocacy should be available in a hospital and community setting. Finally the Review recommended that:

“there should be a regional strategy for the development and funding of independent advocacy support in Northern Ireland. This will involve a number of Northern Ireland departments and should be co-coordinated by the Department of Health, Social Service and Public Safety.”

¹¹ www.education-support.org.uk

¹² The Bamford Review of Mental Health and Learning Disability (Northern Ireland) 2006.

¹³ McConkey R. and Smyth, M. (2000). Not so Different. Experiences and views of parents and school-leavers with severe learning disabilities. University of Ulster and EHSSB.

4.5.3 The Children's Strategy

The OFMDFM strategy 'Our Children and Young People – Our Pledge' ¹⁴, notes that if we are to improve the lives of children and young people in Northern Ireland then we should develop “a culture where the views of our young people are routinely sought in matters which impact on their lives”. The strategy goes on to note that government needs to adopt a needs-driven and evidence based practice, a key element of doing this is to involve children, young people and carers in the assessment of their needs. The strategy states that it will take into account any recommendations from the Bamford review in order to implement its pledges.

4.5.4 Care at its Best

Care at its Best, Social Services Inspectorate report reviewed the care of disabled children in hospital in Northern Ireland ¹⁵. The report noted that over 40 children and young people had been living in specialist learning disability hospitals for periods of over three months. Twenty-three of these children were accommodated in adult wards. Whilst this is generally regarded as unacceptable on social, health, safety grounds and child protection grounds, the Standards for Hospital Services in England states that age is less important than the needs and preferences of the children and young people. However, it is not clear if these children stated any preferences or if any support was available to children living in hospitals to enable them to voice their preferences. The report also noted that often social and health care assessments do not include the views of children and parents and often any care plans that are

developed are not shared with the parent of the child. Finally, the report recommends that:

“Hospitals providing children's and young peoples services should encourage pro-active approaches, such as advocacy initiatives, which promote the rights of children and young people and enable their voice to be heard in matters that concern them”.

More recently the case of children living in hospital for periods of three months or more has been highlighted by the media in Northern Ireland. This has raised the profile of the needs of these children and it is our understanding that an investigation is currently underway. It is our understanding that plans are being put in place with individual children to rectify the situation.

4.5.5 Children and Young People funding package

In March 2006 the Secretary of State announced a funding package of just over £60 million to help under-achieving young people achieve their potential through improvements in their education and fostering their health and well-being through the delivery of services necessary to ensure that every child has a great start to life. Within this package £0.66m has been allocated for the provision of peer-mentoring and advocacy services to empower young people in care to engage actively in the process of ensuring that the system works in their best interests.

¹⁴ Our Children and Young People - Our Pledge, A ten year strategy for children and young people in Northern Ireland 2006 – 2013. Office of the First Minister and Deputy First Minister 2006.

¹⁵ DHSSPS, Social Services Inspectorate, Care at its Best. 2005



4.5.6 Care Matters

In March 2007 the DHSSPS launched the consultation document Care Matters, in accordance with the Green Paper Care Matters which was launched by the Department for Education and Skills (DfES) in England. It focuses on children's issues and marginalized children's issues and complements the Children and Young People's Funding package. It notes that some children in care will need additional support in order to enable them to access advocacy services, if they wish to complain about services or seek information relating to their rights. It goes on to state that the government see access to advocacy services as very important and that additional funding has been made available for regional services through the Children and Young People funding packages. However, it does not note if additional funding will be made available to support children with disabilities and complex needs access services.

4.5.7 The Beattie Report

The Beattie Report on post-school education and training for young people with special needs in Scotland¹⁶ proposed that 'disadvantaged' young people should have a key worker to liaise between different agencies and act as an appropriate advocate on their behalf. It recognised the particular difficulties that young people with disabilities face during transitional times in their lives.

Whilst the UN Convention on the Rights of the Child, as ratified by the UK in 1991 and Northern Ireland Government policies state the right for

children to have a say on issues that affect them it is less clear how children with disabilities and complex needs can exercise this right. Evidence suggests that on the whole children with disabilities have not been offered support in expressing their views. Whilst there are some statutory services available in Northern Ireland, they appear to be fractured and uncoordinated. Examples of those services that do exist are noted in the following paragraphs and discussed further throughout the rest of the review.

4.5.8 Literature relating to advocacy

Whilst there is a wealth of literature relating to advocacy generally, there is very little information relating to advocacy for disabled children. There are a number of self help guides aimed at supporting parents of children with special needs to become advocates for their child¹⁷. A number of these are specifically aimed at helping parents find the right education for their child. However, they do not provide information on how the child can advocate for themselves.

There are also a number of reports and strategies from non-governmental organisations which have directly consulted with disabled young people (including those with complex needs) on specific issues. Such consultations have allowed disabled young people to put forward their opinions. For example, the "Is anyone listening?"¹⁸ report consulted with disabled teenagers regarding their access to leisure. Whilst, it is important that disabled young people are consulted on issues that affect them, this does not replace the need for accessible services that disabled young people

¹⁶ The Beattie Report, Implementing Inclusiveness, Realising Potential. Scottish Executive, 1999

¹⁷ For e.g. www.wrightslaw.com

¹⁸ Is anyone listening, Monteith et al, , Barnardos, 2002

¹⁹ Young disabled people moving into adulthood in Scotland, JRF November 2002.

can use at times that are important to them on issues that matter to them. For example a Joseph Rowntree Foundation Study¹⁹ in Scotland found that disabled young people faced particular difficulties during transitional periods in their lives, such as leaving school and starting work or college. It was found that disabled young people can be particularly isolated during this time compared to their able-bodied peers and that young people with communication difficulties became particularly marginalized. The study also noted that the provision of appropriate advocacy for both the young people and their parents can be particularly useful during these transitional periods. It also recommended the development of more advocacy and befriending schemes.

All of the Northern Ireland HSS Boards also have procedures that allow children and young people participate in the planning of children's services, usually through the four Area Children and Young People Committees. However, the SHSSB have supported this consultation process by providing a user involvement worker whose role is to support young people with disabilities participate in the planning of services for children with disabilities. Often the benefits of advocacy schemes are recorded anecdotally and focus on individuals receiving goods or services that may not have done otherwise. However, one evaluation of an advocacy scheme run for parents with learning disabilities²⁰ found that often advocates took on a range of roles, including:

- A reduction in stress for parents, as advocates often acted as buffers
- Helping to define and communicate what they really wanted

- Interpretation of information in ways that families could understand
- Helping families to develop confidence in dealing with officials.

The evaluation found that the scheme not only succeeded in supporting families deal with officials but also improved the way in which officials dealt with families. Therefore, the full range of benefits of advocacy are often over looked.

4.6 Examples of Existing Services

The literature points to a few examples of advocacy schemes delivered by both voluntary and statutory bodies that provide services for children with disabilities. Further examples of good practice that were identified during the fieldwork will be discussed further in Section 7. At no stage during this review were the services noted below evaluated by the research team, there were included here as they appeared to meet standards of best practice noted elsewhere by organisations such as the Department of Health (UK).

4.6.1 Northern Ireland

Mencap (UK) have developed a three year strategy for advocacy. In the strategy they have stated the aim to develop advocacy services for '*people with profound and multiple disabilities*' as well as children and young people. In addition to the strategy they also operate a number of advocacy schemes in Northern Ireland for people with learning disabilities. In particular they run two schemes for people moving from specialist learning disability hospitals into the community.

²⁰ Booth and Booth, 1997, *Advocacy for parents with learning disabilities: developing advocacy support*. Joseph Rowntree Foundation.

Literature Review

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They also run training courses to support people with learning disabilities to speak up for themselves, one of these is the Shout Out project which supports and trains young people with learning disabilities to speak up for themselves or their peers.

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

One of the Wraparound projects aims to support young people to participate in the development of services that affect them. As such the SHSSB established a Disabled Children and Young People Working Group under the Southern Area Children and Young People Committee. One of the outcomes of this working group has been the establishment of user involvement in the planning of services for disabled children, which in itself has led to the development of two advocacy groups in the Board area. Around 90 disabled children and their siblings have participated in the project and a user involvement worker has been appointed to help disabled children and young people participate in a meaningful way. The Barnardos Sixth Sense project will be discussed in greater detail in Section 7.

4.6.2 Practice from elsewhere

Comhairle (the Citizens Advice agency in the Republic of Ireland) is a good example of the regional co-ordination and funding of advocacy services. Following the launch of the National Children's Strategy (2000) in the Republic of Ireland (ROI), the Department of Social and Family Affairs made 1 million available for the provision of advocacy for disabled people. This funding is delivered across the ROI by Comhairle. It not only provides an accessible advocacy service but, also provides advice and guidance to voluntary organisations wishing to deliver advocacy services. Comhairle also have legislative responsibility to develop and deliver advocacy services for disabled people in the ROI. They note that advocacy can be particularly empowering for disabled people who are often disadvantaged and advocacy should enable them to be aware of their rights and to make informed choices and to contribute to policy making that effects their lives. They also note that advocates and advocacy services should always use language that is acceptable to people with disabilities. Specifically, Comhairle have provided six principles of Good Advocacy Practice for organisations:

- The advocacy project has a clear purpose and specific target group
- Members of the target group have equal access to the service
- Potential for conflicts of interest is reduced
- Advocates are trained, supported and supervised to agreed standards
- Mediated rather than adversarial processes are used where possible, and
- Projects follow best practice in terms of governance and financial transparency.

The Citizens Information Board in the Republic of Ireland noted that ²¹,

“the lack of guaranteed funding constitutes one of the biggest threats to the development and continuation of independent advocacy services”.

As such the way in which Comhairle are funded appears to be good practice, however we have not been able to identify any evaluations of the services themselves.

Furthermore, in England and Wales, following the “Valuing People” White Paper²² £2.3 million was made available to fund the development of self-advocacy groups. The DoH allocated £650,000 per annum for three years to be distributed to local groups to develop citizen advocacy specifically for people with learning disabilities.

Unlike the ROI, no single organisation in Northern Ireland has a legislative responsibility to co-ordinate, fund and deliver advocacy services regionally. As noted previously there are a number of other organisations who have legislative responsibility to provide advice and advocate for children in relation specific matters such as discrimination, however services are not coordinated or funded regionally.

In England the Children Act 1989 states that if a child or young person articulates that a concern or problem is not being resolved and a complaint is likely to be made, local authorities should ensure that help and assistance is given if the children or young people would like an advocate to speak for them.

In the UK the National Children’s Advocacy Consortium ²³ (NCVCCO) is an organisation established in England and Wales to promote the strategic development of advocacy services. Its aim is to ensure that every child has access to an independent and confidential advocacy service. NCVCCO has been established for over 60 years and its members come from the voluntary and community sector, including:

- Homestart
- Barnardos
- Gingerbread, and
- YMCA.

Over the years NCVCCO has received funding from a range of government departments to run local and national projects, such as, the establishment of local voluntary and community networks and the provision of advice for small community groups through its head office. NCVCCO also co-ordinates responses to consultations and sits on national advisory panels on matters relating to children and families. The Department of Health in the UK published guidelines which set standards for children’s advocacy services ²⁴. The standards were developed to assist bodies commissioning services and voluntary organisations who may be providing the service. The standards state that local authorities commissioning the services should adhere to the standards except in exceptional circumstances. They note that advocacy services should work separately from organisations that have a statutory responsibility for looked after children and those in need.

²¹ The Jigsaw of Advocacy. The Citizens Information Board, 2003. www.citizensinformationboard.ie

²² Valuing People: A New Strategy for Learning Disability in the 21st Century. Department of Health, 2001.

²³ www.ncvcco.org

²⁴ National Standards for the Provision of Children’s Advocacy Services, DoH, 2002

Literature Review

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The standards also note the importance of informal advocacy such as parents, siblings and friends. They are:

- Standard 1:
Advocacy is led by the views and wishes of children and young people
- Standard 2:
Advocacy champions the rights and needs of children and young people
- Standard 3:
All advocacy services have clear policies to promote equality issues and monitor services to ensure that no young person is discriminated against due to age, gender, race, culture, religion, language, disability or sexual orientation
- Standard 4:
Advocacy is well publicised, accessible and easy to use
- Standard 5:
Advocacy gives help quickly and when they are requested
- Standard 6:
Advocacy works exclusively for children and young people
- Standard 7:
The advocacy service operates to a high level of confidentiality and ensures that children, young people and other agencies are aware of its confidentiality policies
- Standard 8:
Advocacy listens to the views and ideas of children and young people in order to improve the service provided
- Standard 9:
The advocacy service had an effective and easy to use complaints procedure
- Standard 10:
Advocacy is well managed and is value for money.

4.7 Conclusions

As evidenced in the preceding paragraphs, there is strong policy and legislative backing for advocacy services for disabled children in Northern Ireland, but little evidence within the literature of coordinated and accessible services for individual children with disabilities. Estimates based on disability rates and data from the HSSBs, suggest that there are in the region of 500 disabled children and young people with complex needs in Northern Ireland under the age of 21. It is not clear how those Boards and Trusts who do not maintain a register of disabled children plan services for disabled children their area.

There are examples of best practice in the funding of advocacy services, particularly in the ROI, where advocacy is funded and delivered from a central source with strategic support and input from government. Furthermore the DoH in the UK has published a set of standards in the provision of advocacy services for children and young people²⁵, they are designed to help agencies and staff provide advocacy for children.

²⁵ National Standards for the Provision of Children's Advocacy Service. Department of Health , 2002.

Identification of need

5.1 Introduction

As noted in our methodology we undertook a range of methods to identify the level of need for advocacy services for disabled children and young people with complex needs, these included:

- A survey of parents/carers
- Consultations with parents/carers
- Consultations with children and young people, and
- Consultations with Voluntary Sector organisations.

Three main themes arose from the fieldwork as will be discussed in the following paragraphs:

Section Detail

- 5.2 What is the profile of the children who require advocacy?
- 5.3 What type of advocacy do children require?
- 5.4 When do children require advocacy?
- 5.5 Conclusion.

5.2 What is the profile of the children who require advocacy?

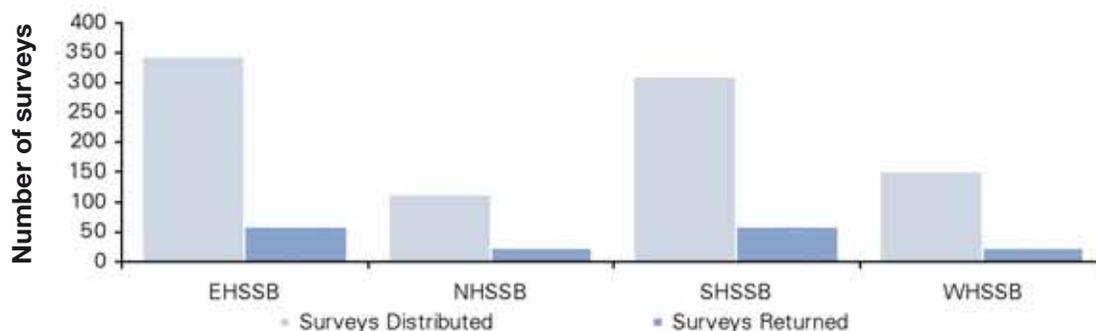
Parents who completed the surveys were requested to provide some background information on the children. As noted in section 3, surveys were distributed via the HSSTs and a parents group, 163 surveys were received for 169 children.

The source of all data contained in the following charts is the parents/carers survey.

5.2.1 Board Area

Chart 2 provides an overview of the response rate to the survey by Health and Social Services Boards. The chart indicates that there are currently more children with complex needs in the Eastern and Southern Board areas (33% in each area) than in the Western and Northern Board areas (16% and 19% respectively).

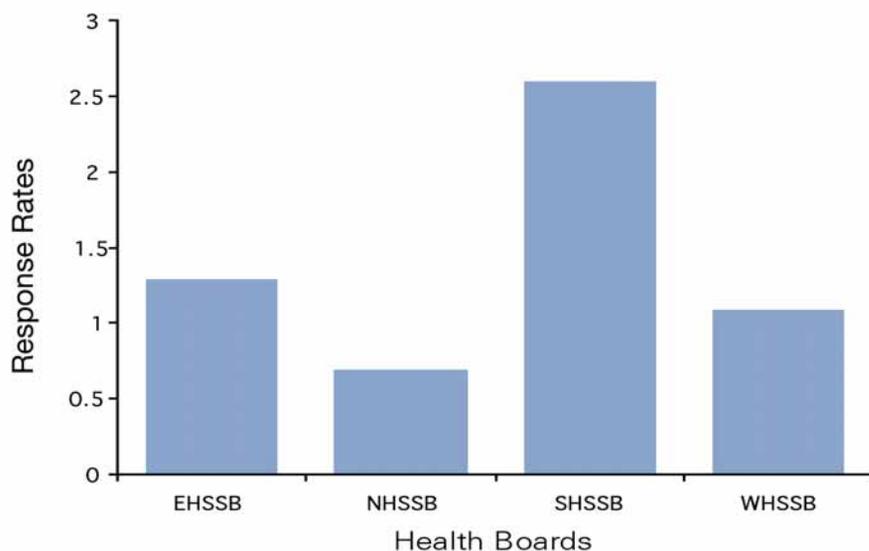
Chart 2: Number of surveys distributed by Board Area



Identification of need ...continued



Chart 3: Response rate as a percentage of all children with disabilities in each Board



5.2.2 Gender and Age

Chart 3 above provides an overview of the response rate from the parents survey of each board as a percentage of the population of disabled children. As shown above, the surveys represented between 0.7% and 2.6% of the total number of disabled children in each Board area.

Of the surveys returned, 63% of the children were boys and 37% girls. 18% of the children under the age of 5, 38% were aged 6-10, 18% were aged 11 - 14, 25% were aged 15 - 18 and 1% were young people aged 18 – 21, as shown in the charts below.

Chart 4: Gender of Children

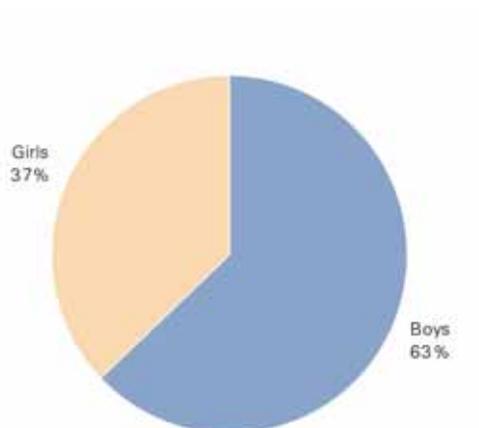
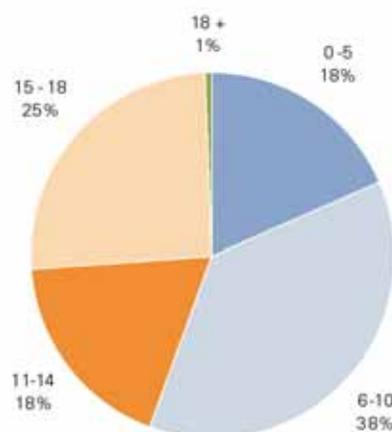


Chart 5: Age of children



5.2.3 Accommodation

95% of the children and young people for whom we had a response lived at home with their parents/carers, while 2% lived in a residential school. 1% of the children lived in foster care, residential care and in hospital. Two children were identified who lived in hospital – one in Muckamore Abbey and one in a secure unit in England, both are aged 16.

The UN Committee on the Rights of the Child General Comment No.9 (2006) ‘The rights of Children with Disabilities’ urged all state parties to; *“establish an accessible, child sensitive complaint mechanism and functional monitoring system”* and to use *“an institution only as a measure of last resort, when it is absolutely necessary and in the best interests of the child”*.

During the course of carrying out this review, issues emerged about children and young people who are accommodated within the hospital setting at Muckamore Abbey. Details emerged in January 2007 which indicated that 17 children under 18 years of age were resident within the hospital on a long term basis. In two cases young people had been living in Muckamore Abbey for approximately 7 years, with the majority of children having spent between one and three years living there. Detention of these children on such a long term basis must raise questions in relation to who was advocating on their behalf. The Commissioner for Children and Young people highlighted her concerns about the inappropriateness of maintaining children on a long term basis within a hospital setting when their primary care needs were not necessarily of a medical nature.

It appeared to the Commissioner, and this was confirmed to her by the parents that the children remained in Muckamore because of the absence of appropriate alternative care in the community. The review team is aware that the Commissioner in her role as Advocate, met with the Minister for Health, and Senior Civil Servants to seek an early resolution to the continued inappropriate placement of the children within a hospital setting. However the Commissioner has expressed her disappointment at the response of the department to meeting the needs of the young people currently resident in Muckamore Abbey.

Within Muckamore Advocacy is provided for the adult residents by Bryson House and Mencap, there was no evidence to suggest that this service is available to Children and Young People. The information provided to the Commissioner about the children and young person who were placed (and this proved to be on a long term basis) suggests their needs changed and evolved. However if re-assessments were made, their care package was not adjusted to meet their changing needs.

The Commissioner believes that children and young people living in this setting should have access to an independent advocate who can act on their behalf in care planning, transition and assessment of their needs.

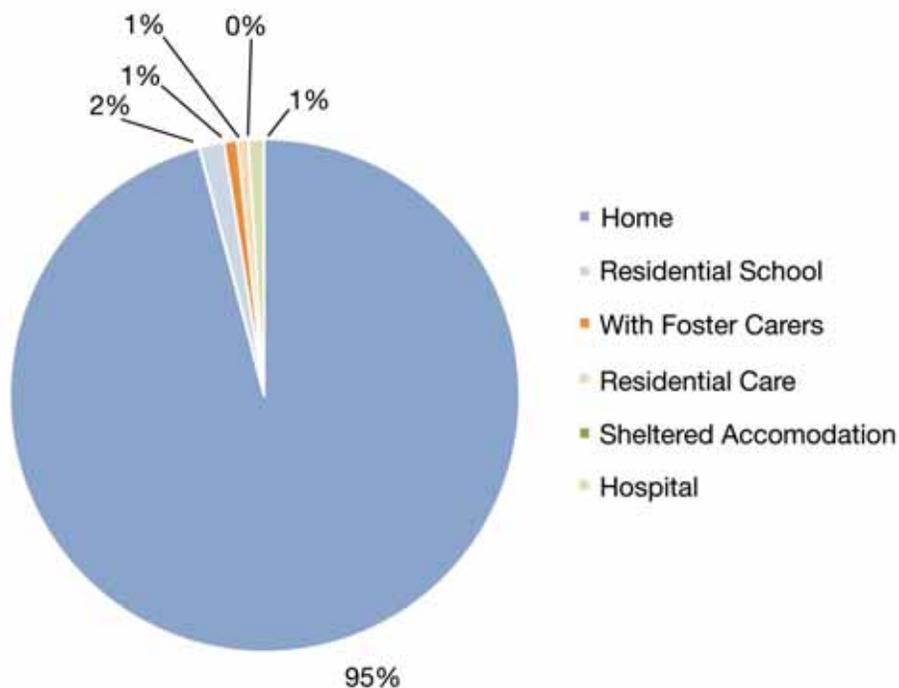
The child in the secure unit in England was the only child or young person identified throughout the research as living outside of Northern Ireland whilst being the responsibility of a Health and Social Care Trust in Northern Ireland. Information regarding the child’s circumstances provided by

Identification of need ...continued



a Northern Ireland based social worker suggests that the child remains in England due to social circumstances, as opposed to the lack of available facilities in Northern Ireland.

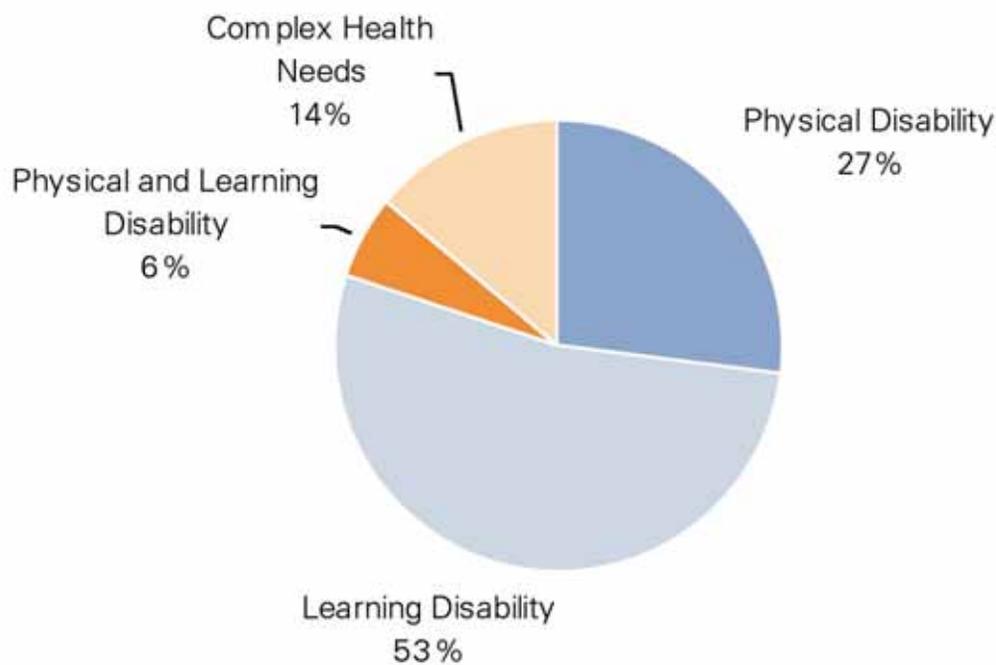
Chart 6: Where do the children live?



5.2.4 Needs of the Children

The parents provided a brief description of their child's primary disability. For 53% of the children their primary disability was a learning disability, while 27% had a physical disability. 6% of the children had both physical and learning disabilities and 14% had complex health needs as their primary disability.

Chart 7: A brief description of the children's needs



5.3 What type of advocacy do children require?

The type of advocacy that the children required varied greatly. For example, our consultations with the children and young people demonstrated that younger children (usually those younger than 10), were happy for their family to speak up for them and to make most of their big decisions for them. Furthermore, parents of younger children who responded to the survey were less likely to note that they required an advocate than those of older children.

If I want anything I ask mummy

The parents of younger children also noted how important it is that they advocate on their behalf, for example one mother who responded to the survey noted:

Our son cannot speak for himself so he needs his parents to speak up on his behalf.

14% of parents who completed the survey commented that they are best placed to undertake the role as their child's advocate, while others stated that they just wanted to be parents, they did not want to have to undertake an advocacy role as well.

Identification of need

...continued



5% of the parents who responded to the survey noted that their children had very little or no communication noted that they will never be able to speak up for themselves, or understand any information that is given to them. The parents noted that these children will always require someone to advocate on their behalf and that they worry about what will happen to them when they are no longer able to care for them.

I worry what will happen when he is older.

One of the voluntary organisations that we consulted with noted that providing advocacy for the people with limited methods of communications requires a long term commitment and it is important to build up a trusting relationship with the child to be able to advocate on their behalf.

50% of the parents/carers surveyed said that their child has no advocate, and 15% of which commented that they had never heard of advocacy. These parents expressed concern that they are unable to adequately advocate on their child's behalf and that some families have no input from either statutory or voluntary bodies. During our consultations with the children we noted that older children (especially those with greater communication skills) wanted to be informed of the choices that are available to them so they could make informed decisions about things that affect them. Some children even suggested how they would like to be kept informed.

An email service or website would be good to let people know what is available to them.

I would like a chat room like my sister uses to talk to other people.

The children who were interviewed in school said that people had come into school to inform them of different things that they might like to do in college when they leave school. The children thought this would be a good way of keeping everyone informed and gave them a direct point of contact if they had any questions.

Good Practice 1

The parents also felt that they needed to be better informed about what services they are entitled to apply for on behalf of their children.

They ask us what we think our child should have – they don't tell us what is available.

Qualitative information from the surveys and interviews with parents and carers revealed that many parents felt they were not provided with enough information about the range of services available to their child. The majority of parents interviewed (88%) felt that they did not have enough information about services.

We always find out about the summer activities on offer when the summer is nearly over.

We consulted with young people who were members of the Barnardos Sixth Sense Advocacy group and Barnardos staff who are responsible for the service. The young people receive training and support to learn how to advocate for themselves. The length of this process varies depending on the needs and abilities of the child. In addition the group are provided with a range of assistive technologies to help those with minimal or limited communication express themselves.

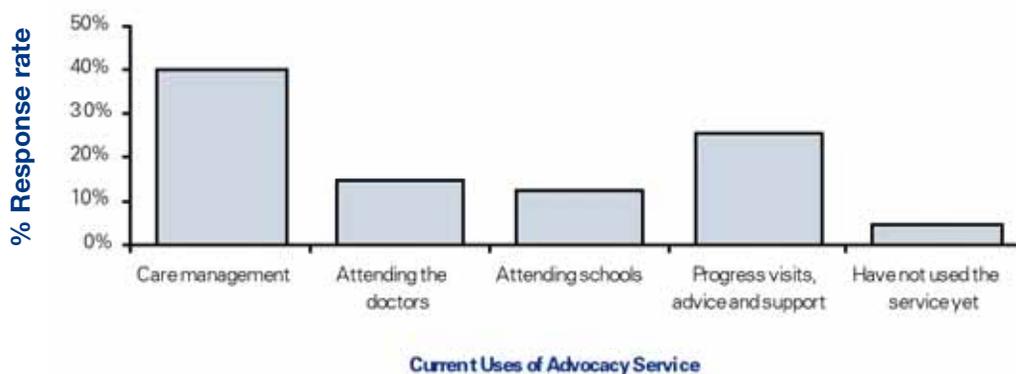
Good Practice 2

5.4 When do children require advocacy?

One of the key themes arising from both the survey and the consultations was that children would like to be able to access an advocacy service at key life stages. In our survey we asked parents “In what circumstances did your child need advocacy?” Of those who responded 49% noted that it was during key stages of their child’s education such as moving school or looking for options after leaving school.

The type of advocacy services required is determined by the reason the need exists. The parents/carers completing the survey were asked to indicate what their children currently used advocacy services for.

Chart 8: Current Uses of Advocacy Services



As shown in chart 8 above, those parents and carers who indicated that they currently use an advocacy service used it most often in relation to care management issues, they also identified the importance of using advocacy in terms of providing advice and support.

Identification of need

...continued



Parents and carers also provided information about their use of advocacy in the past, even if they are no longer using the service.

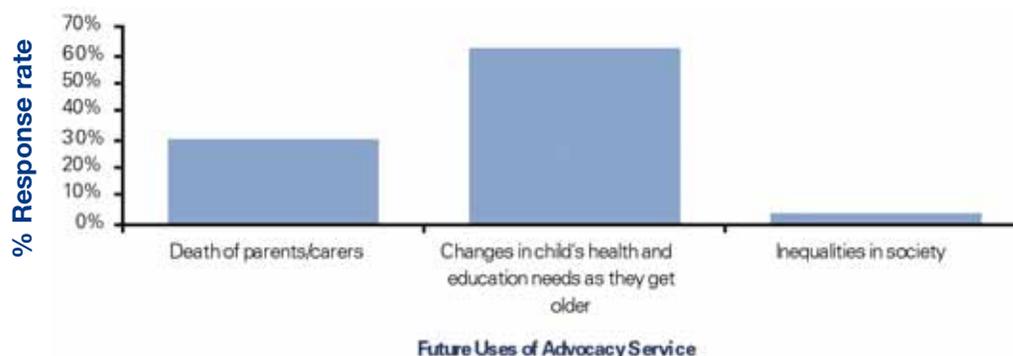
Chart 9: Past Uses of Formal Advocacy Services from HSS Trusts of Education & Library Boards



Of the parents who responded to the survey 13% (23) stated that they had used a formal advocacy service in the past. As shown above the advocacy was most likely to be in relation to educational or care management issues. It was not clear from the survey responses the type of circumstances in which the advocacy was used.

Parents and carers were then asked if they could foresee a time when their child would need advocacy in the future, even if they have never used advocacy to date.

Chart 10: Use of Advocacy Services in the Future



The responses from the survey indicated that children and their parents/carers required advocacy services to help them by providing information, advice and support when attempting to access services such as education, health, care management, respite and social security. 64% indicated that their children would require advocacy services in the future as they got older and the needs of their child changes, mainly in relation to the child's education and health needs. 31% of parents also noted the importance of advocacy services when they are no longer there to look after their child.

The transition period of preparing to leave school and looking for employment or college courses was important to many of the young people who were interviewed. 60% of those who were interviewed felt that there were not enough options open to them or that they were not fully informed of all the available options. In addition, the focus of transition workers appears to be on older children, whereas younger children are also experiencing transitions such as nursery to primary school and primary school to secondary school.

Some of the young people interviewed (41%) felt that they were not given the information they required early enough to make proper decisions.

I think the last year in school is too late to plan for the future.

Whilst the parents of six of the younger children felt that they would have liked more information to make informed choices about what school

their child goes to, others noted that they had no choice. One mother noted that only one mainstream school out of six was physically accessible to her daughter and that she has a long journey there and back which makes her school day very long and she is therefore unable to participate in any after school activities. Another parent commented that the school her son was attending was unable to provide suitable schooling for him after the age of 16, so he was unable to stay in the school, regardless of the fact that both the child and his parents wanted him to stay. Both these parents noted in their surveys that their children did not use any advocacy services. Almost a quarter (24%) of the young people interviewed said people came into their school to help them find work placements when they were leaving secondary school. While the children agreed that these people had helped them find a job or a training placement, further probing identified that in some of the cases, the children or their parents had actually identified the suitable job, and the placement worker helped to arrange practicalities of the young people starting work. 39% of parents who responded to the survey also noted that they required advocacy when accessing or attempting to access health and social services. A number of the parents (22%) expressed frustration and confusion when trying to get any appropriate services for their child and a constant source of frustration was that parents in different Trusts received different services.

Parents were asked if they had ever requested advocacy services from their local Health Trust of Education Board, 15% had done so. Of those who had requested services 50% had asked their

Identification of need ...continued



local Health Trust, 34% their Education and Library Board and the remaining 16% did not state who they had requested the services from.

Four responses to the survey were received from carers of four children and young people who lived in a residential or hospital setting. From the responses to the survey it was difficult to ascertain if their advocacy needs were different from other children. The surveys were completed by both carers and parents and none of the respondents had noted that they had requested advocacy services in the past. Each of these children appeared to have a wider range of support workers than those who lived at home with their parents, such as nurses, care workers and house parents. It is possible that these children have a wider network of informal advocates than those living at home. However it is not clear from the results of the survey if these children have any specific advocacy needs relating to their living arrangements. None of these carers/parents who responded on behalf of children who lived in hospital or residential setting granted permission to speak to the children.

5.5 Conclusions

As discussed in chapter 4, we estimate that there are around 522 disabled children and young people with complex needs in Northern Ireland. Results from the survey suggest that these children and young people require advocacy services to support them in meeting their educational, health and social services needs. 50% of the parents surveyed stated that their child had no advocate. They also need advocates to keep them informed of their options and rights, particularly at key stages of their lives, such as when leaving school.

Parents and children and young people noted the importance of informal advocates such as siblings and the parents themselves. It was not clear from the survey if children living in a residential or hospital setting have different or additional advocacy need than those living at home. Evidence from the surveys and consultations shows that children and young people particularly require advocacy at key stages of their lives such as when leaving school. The Department of Health noted²⁶ that timeliness and efficiency were essential factors in an advocacy service as it is important that children receive information and support when it matters to them.

²⁶ Department of Health , National Standards for the Provision of Children's Advocacy Services, 2002.

Awareness of rights and services

6.1 Introduction

This element of the study was informed by both the parents survey and the consultations with parents and the young people themselves. The following paragraphs discuss the parents and the children's awareness of the rights of the child, as well as their awareness of services.

Section Detail

- 6.2 Awareness of rights
- 6.3 Awareness of services
- 6.4 Conclusion

6.2 Awareness of rights

Despite the existence of legislation such as the ECHR as incorporated by the Human Rights Act 1998, the Children (NI) Order 1995, Disability Discrimination (NI) Order 2006 and SENDO (2005) there appeared to be a relatively low level of awareness of rights among parents and carers.

Only one parent mentioned the United Nations Convention on the Rights of the Child, although a few mentioned that they were aware of NICCY and some of its work, during the consultations. None of the parents consulted with noted any of the legislation that was established to protect the rights of disabled children such as the Disability Discrimination (NI) Order 2006, SENDO, or any of the organisations with a statutory obligation to uphold these rights such as the Equality Commission. Although a few parents noted various difficulties they had experienced with the education system none of the parents appeared to be aware of their rights under SENDO.

As with the parents the level of awareness of rights varied greatly among the children. Five of the young people who were interviewed had

an understanding of their human rights or the UNCRC.

Those who attended the sixth sense group had learnt about their rights and the UNCRC as part of their advocacy training, some of them had visited the United Nations in Geneva. Each of them understood that it meant that they should have equitable access to services. To some, rights meant being able to access further education courses and for others it meant being able to go shopping on a Saturday.

Good Practice 3

Another young person who agreed to be interviewed was a member of the NICCY panel and was well aware of the UNCRC and what it meant. For them it meant being treated fairly in school and being able to access social activities such as youth clubs. The NICCY study on the rights of children in Northern Ireland²⁷ also noted a lack of awareness of children's rights among children and parents. It also noted the paucity of information that is available regarding the rights of children and young people in Northern Ireland and that any existing information is rarely available in a child friendly format. It was also noted that advocacy services for children are under developed in Northern Ireland with particular gaps in relation to services for children with educational needs and complex medical problems.

6.3 Awareness of services

There was a wide range in the level of understanding among parents of what advocacy services for children were. A number of parents who completed the survey (22%) felt that they provide for all their child's needs and they have no need for an advocate.

²⁷ Kilkelly et al (2004) Children's Rights in Northern Ireland (NICCY)

Identification of need ...continued



I am unsure that a 3rd party would have the detailed knowledge that I have of my child's needs.

Authorities can offer help and assistance but no one knows my child like I do

Around 5% of parents stated that they encouraged their child to voice their opinions and make their needs be heard.

I want to be my son's parent not his advocate.

50% (82) of parents who completed the survey did not have an advocacy service. Of these 15% stated that they were not aware of any services. Our consultations with parents showed that there was a general lack of awareness of how to access such services, even among those who lived in a Trust area that provided advocacy services. In the surveys and consultations around a third of parents (30%) expressed frustration in attempting to navigate their way through Health and Social Services to access any services, this was also true for advocacy. Many of these parents said that their social worker did not tell about services that may have been useful and usually found out about them from other parents, whilst others noted how difficult it can be to work out what services and benefits you are entitled to.

Parents find it very difficult to access the services which their children should have.

Most parents blunder on from one service to another. It can be like pass the parcel.

Another issue noted in the survey was that 33% of parents who completed the survey recorded that their social worker provided them with an advocacy service. The Department of Health Standards for Advocacy and the Bamford Review

have noted that advocates should be independent to avoid any conflicts of interest. Among the parents that we consulted with there was a mixed response to social workers providing advocacy, some were very happy with the services provided by their social worker because they worked with the child to provide services, others were frustrated by the lack of support provided by their social worker and felt the need for an independent advocate for their child. Around 75% of the parents who were interviewed noted the need for an independent advocate.

My child would not understand advocacy and to be honest I don't either.

A few parents (3%) also noted that they were not really sure what advocacy was. This was also reflected in the consultations with parents.

How can I find out about this and what would it involve?

6.4 Conclusion

Generally speaking there was little awareness of children's rights amongst parents and carers. Only one of the parents or carers interviewed made reference to any of the organisations with a statutory obligation to protect the rights of disabled children such as the Equality Commission. Some (30%) of the children were very aware of their rights and what they meant to them, although most didn't. There was also a range of understanding among parents regarding the range and the level of services that are available. 12% of parents noted that they were not aware of any services and a further 3% of parents surveyed noted that they did not really understand what advocacy was.

Existing Advocacy Arrangements

7.1 Introduction

In order to review the range and level of existing services KPMG surveyed parents and consulted with statutory bodies and voluntary organisations. The findings from each will be discussed in the following paragraphs.

Section Detail

- 7.2 Who provides advocacy?
- 7.3 Level and range of services
- 7.4 Conclusion

7.2 Who provides advocacy?

Parents who responded to the survey were asked if they currently used any advocacy services and if so, who provides it. The following paragraphs

provided an overview of the services as identified in the surveys and the consultations with parents, and voluntary and statutory bodies.

7.2.1 Statutory Services

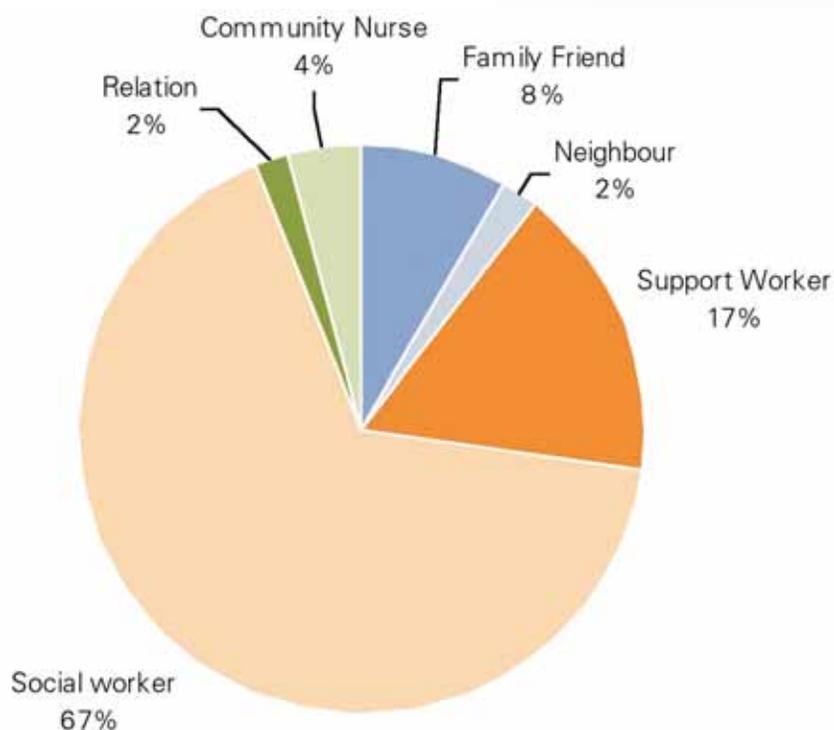
Through survey responses and consultations with voluntary and statutory service providers we identified 7 HSS Trusts who provide some form of independent advocacy service. However, service providers and parents were not always aware of the services offered in their area. We asked parents whether their child currently has an advocate. As shown in the table below, 50% of the respondents to the survey indicated that their child does have an advocate.

Table 5: Does your child currently have an advocate?

Age	0-11 Percentage	12+ Percentage	Total Percentage
Children with an advocate	46%	56%	50%
Children with no advocate	54%	44%	50%
Total			100%

Younger children were less likely to have an advocate than older children, as 54% of children aged under 11 years did not have an advocate compared to 44% of those aged over 11 years. We then asked parents to identify who the advocate was, as shown in the diagram overleaf 67% of those who said they had an advocate identified that their Social Worker provided the advocacy.

Existing Advocacy Arrangements ...continued



In total 88% of those who parents identified as providing advocacy services were employees of statutory bodies, (social workers, support workers and nurses). During the consultations half of the children noted that teachers, classroom assistants and principals were undertaking advocacy roles in relation to the educational needs of the child. Whilst some parents were happy with this

arrangement, during our consultations, others expressed concern (47%), that the advocates were not independent and therefore cannot truly stand up for the child against their employer. As the table below shows the parents of younger children were more likely to identify some one from a statutory organisation as an advocate than parents of older children.

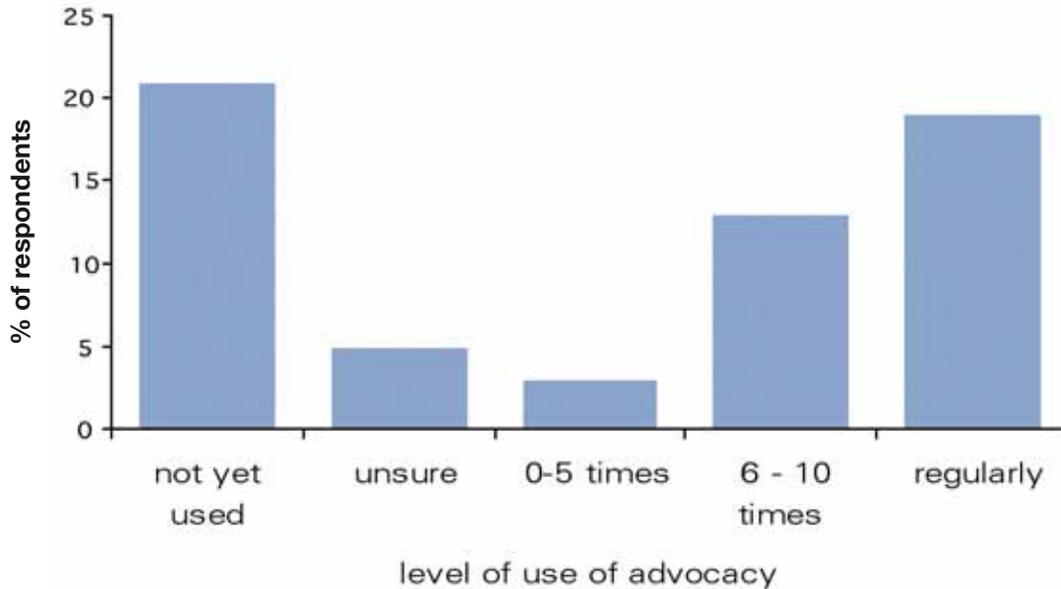
Table 6: Who advocates on behalf of your child?

Age	Age	
Advocate	0-11	12+
Family Friend	4	4
Neighbour	0	2
Support Worker	7	10
Social Worker	38	29
Relation	2	0
Community Nurse	2	2
Total	100	100

During our consultations parents reported that the services provided by statutory organisations tended to be related to the provision of advice on benefits applications, the provision of services to meet the care needs of the child and providing information on social activities and voluntary organisations that were available to help the child. In many cases the role undertaken was not truly one of advocacy, as it was not independent of statutory bodies and generally speaking was not child centred.

Parents were asked how frequently they used their advocacy service. Of those who said their child used an advocacy service, 19% said it was an ongoing service, 13% said they used it regularly, 3% said they had used it between 6 and 10 times, 5% had used advocacy up to four times and the remainder of parents were either unsure of the number of times they had used the service or had yet to make use of it, as shown in the table below.

Table 7: Showing frequency of advocacy use



Results from the parent’s survey also showed that those who are currently receiving advocacy services are generally satisfied, with 64% stating that they are very useful. However, this was not reflected during our interviews with parents. Eight of parents who identified their Social Worker as

Existing Advocacy Arrangements ...continued

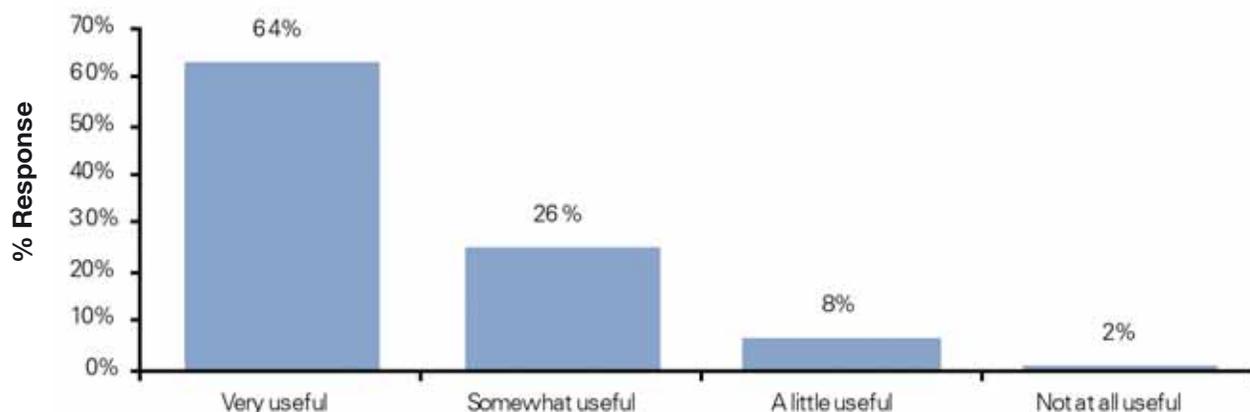


providing advocacy in the survey reported during the interviews that they were not happy with the level of service they were receiving. However, this tended to relate to the number of times they saw the Social Worker or their access to other services such as respite rather than advocacy itself. This perhaps reflects a degree of confusion among parents and carers on what advocacy services for children and young people are, as these parents tended to report dissatisfaction with the Health and Social Services generally rather than advocacy itself. It should also be noted that all of the parents who said their child had made use of an advocacy service said that the service was free.

appropriate services for children and families, it is not in line with best practice (as advocated by organisations such as DoH) as they are not independent and would not necessarily be led by the wishes and views of the children and young people. Furthermore, the effectiveness of this approach can vary greatly even within each Trust. Parents also reported during the consultations that the effectiveness of this as an approach to providing advocacy depended on the effectiveness of the individual Social Worker.

During the consultations with the HSSTs one quarter of Trusts noted that they had a Parents

Chart 12: Usefulness of Advocacy Services



7.2.2 Statutory Providers view on advocacy arrangements

Our consultations with staff from the HSS Trusts also revealed that all of them considered the role of staff such as Social Workers and Key Workers to include advocacy. As noted previously whilst these staff may be effective in acquiring

Forum which fed into the HSSB Children's Services Planning processes. Trusts in the SHSSB area also noted the Disabled Children and Young People Working Group, that operates as part of the Children's Services Plan.

The Disabled Children's and Young People Working Group are a separate working group within the Southern Area Children's Services Plan. A number of Young People with disabilities participate in the working group. They advocate on behalf of all disabled young people in the area on the provision of services and are consulted with when services are being planned. The Barnardos Sixth Sense advocacy project emerged from this working group.

Good Practice 4

Many of the Trusts noted that parents are still regarded as the main advocates for children with disabilities, particularly for young people. As such a number of Trusts would consult with the parents' forum when planning services rather than the children themselves. However, other studies such as McConkey and Smyth²⁸ (2000) have shown that parents are not always the best advocates for children with disabilities, furthermore it is best practice to consult directly with children (where ever possible) in matters that affect them. Approximately, 40% of the HSS Trusts felt that the Social Workers provided advocacy services in as much as they provided information and services to families. This was also reflected by the 67% of the parents who responded to the survey stating that their Social Worker was their advocate.

Foyle Trust also noted that it employed two advocates who support families of disabled children particularly in relation to care management reviews and accessing other services. Whilst the advocate is an employee of the Trust they remain separate from those who are directly responsible for service provision. The

advocate informs the Trust of progress of each case by providing the Trust with monthly updates reports. The Trust recognises that this is an over subscribed service that many more families would like to make use of and are considering the possibility of increasing the service.

Good Practice 5

However, it is interesting to note that none of the parents who completed the survey noted this service. During the consultations with statutory bodies and the voluntary sector workshop it was noted that some Trusts (around one quarter) purchase advocacy services from external organisations, such as Bryson House or the Cedar Foundation. These services normally adopt a person centred approach which focuses on identifying and meeting the needs and wishes of the young person, however the majority of these services were provided for over 16s and were not available to younger children.

The Education and Library Boards noted their policy of directly consulting with children and young people with disabilities regarding issues that concern them. They undertake advocacy work through their special education officers, board education welfare officers and their educational psychologists. These people work with the child and the parents during discussions of the child's educational needs. They work directly with the child, but also assist the parents with the completion of forms relating to the statementing process. Again the ability of these individuals to advocate for the children themselves may be questioned as the advocates are simultaneously providing a service to the parent and being paid by the organisation who they may be called upon to advocate against.

²⁸ McConkey, R. and Smyth, M. (2000). Not so different. The experiences and views of parents and school-leavers with severe learning disabilities. University of Ulster and EHSSB

Existing Advocacy Arrangements ...continued



Each ELB also noted that their Dispute Avoidance and Resolution Service (DARs) was responsible for mediating when there is a disagreement in the statementing process and that they are responsible for providing children and their families with information regarding suitable schools. DARs is independent from the Boards, confidential and it is designed to provide an opportunity to identify points of disagreement and to find a way forward. There is a DARs contact in each ELB who is independent of the Boards' special education system.

7.2.3 Voluntary services

A number of parents also provided qualitative information relating to other advocates their child may have, such as siblings and voluntary organisations. It was reported in the surveys and during the consultations with the children and young people siblings were also noted as important advocates.

My brother gets me things, like toys.

Many of the children interviewed (24%) noted that their siblings provided them with a lot of support and took them out or helped them about the house. This was particularly true of children with older siblings.

My son has two older siblings who continually advocate on his behalf at home, from small things like what clothes he should wear to larger issues such as holidays.

16% of parents said that their child had received advocacy services from voluntary organisations, such as:

- Positive Futures
- Mencap
- ASBAH and
- Barnardos.

It is also likely that some of the voluntary services identified by parents are funded by the HSS Trusts, although this was not clear from the survey results or consultations with statutory bodies.

7.3 Level and range of services

As noted in Section 3, a half day workshop with representatives from the voluntary and community sector was held. 21 organisations were invited to attend and 12 representatives from 9 organisations attended.

Representatives were invited to discuss issues that they believed were important in advocacy services and also to provide more detail on the services provided by their organisation. Each of those who attended were involved in providing advocacy at some level. Table 5 provides an overview of the services provided by those organisations who attended.

Table 8: Advocacy Provision by Voluntary Organisations attending the workshop

Organisation	Overview of advocacy service	Age range	Geographical area covered
Bryson House	Long-term advocacy service for people with physical and learning disabilities.	16 years+	SEBHSST NWBHSST
Disability Action	Advice and Support for Young disabled People accessing employment and training	16+	All of NI
Aspergers Network	Advice and support to people with Aspergers and their families across NI. Social outings for people ages 5+.	all	All of NI
Mencap	Range of support and training services for people with learning disabilities and their families	all	All of NI
Northern Ireland Children's Hospice	Support relating health care for life-limited children	0-18	All of NI
Cedar Foundation	Support in finding employment and training (transitions)	all	Mostly Greater Belfast
NI Cancer Fund for Children	Support (practical and emotional) for young people and a family programme providing support and advice	all	All of NI
NI Regional Genetics Service	Genetics counselling	all	All of NI
Parents and Carers Council on Disability	Parents support for those with disabled children sharing information and advice	all	SHSSB (mostly)

Existing Advocacy Arrangements ...continued



A representative from the Children's Law Centre (CLC) was also consulted with. An overview of the services provided by CLC is shown at 7.3.2.

During the workshop attendees were asked to provide more information on the services they provide. It was generally acknowledged that a range of advocacy services for disabled children do exist in Northern Ireland and most of the voluntary organisations present confirmed that they provided advocacy services, both formally (such as supporting individual when attending care management meetings) and informally (such as providing support and information when looking for training courses or social clubs).

Each voluntary organisation varied in its referral process, some could only receive referrals from statutory organisations due to funding restrictions, whilst others accepted referrals from a range of sources including approaches from individuals. The majority of voluntary organisations noted that they were operating at full capacity and hence they were unable to advertise their services more widely as they would not be able to cope with the demand. The group generally agreed that currently there was not the capacity within the voluntary sector to meet the needs of all the children in Northern Ireland with complex needs without further funding.

There was also a general agreement that the voluntary sector did not promote its services very well. This lack of promotion of organisations offering advocacy services was reflected in our survey as many children with complex needs and their families were not aware of any advocacy services.

Five of the organisations offered services to children with particular disabilities rather than to all children and young people (e.g. children with Aspergers), and some organisations provided the services during a particular time frame, such as transition periods, which can make it difficult for parents to know who to contact.

Five of the organisations that were represented in the workshop either provided services to Trusts under a Service Level Agreement (SLA) or their organisation received core funding from the DHSSPS. For example Bryson House has an SLA with South and East Belfast HSST and North and West Belfast HSST to provide an independent advocacy service to people with learning disabilities aged over 16 years. Bryson House has a number of trained advocates who work with people on a long term basis to represent them in a range of situations such as: care management hearings, to help them find suitable accommodation and training and/or employment. During our consultation with Barnardos we also received information relating to the Assistive Technology Suite that was developed within the Sixth Sense group. This suite uses technology to assist disabled young people with communications difficulties advocate for themselves.

Voices of Young People in Care (VOYPIC) also provide advocacy services to young people with experience of or leaving care, which includes children with disabilities. Their advocates provide guidance on a range of issues relating to care and leaving care. VOYPIC work with the local HSSTs and have recently received funding from the DHSSPS to extend its services.

Other advocacy services were identified during the course of the desk based research, not all of which were directed towards children with disabilities. For example the Parents Advice Centre, provides advice and support to parents on a range of issues relating to children, but does not advocate directly for children. Also SENAC provide parents with advice and support when appealing a Statement of Special Educational Needs. Whilst SENAC have a particular expertise around providing advice in relation to assessment and statementing their remit covers most aspects of special educational needs including assisting parents whose children are at the school based stages of SEN and were appropriate sign posting parents to other organisations. Include Youth also run projects (such as LACE and Give and Take) which train young people to speak up for themselves or provide training for vulnerable young people. However, as these projects are not specifically designed for young people with disabilities and as such disabled young people with complex needs may face difficulties trying to access them. Other organisations such as PAPA provide training and information to professionals and carers although they do not deliver services directly to children and young people themselves.

Furthermore there are a wide range of voluntary organisations which provide social and/or sporting activities for children with disabilities such as Inclusion Matters (part of PHAB NI, who provide social activities, personal development and youth work opportunities for able-bodied and disabled children aged 3 to 25). Other voluntary organisations that provide activities for children with disabilities include Mencap, Disability Sports

NI and Happy Days. These organisations to some extent also provide an informal advocacy role, as they provide a social outlet for children and help to widen their social circle.

7.3.2 Legal Advocacy in Northern Ireland

There are a number of organisations who provide a legal role in supporting children rights in Northern Ireland, as discussed in the following paragraphs.

The Children's Law Centre

There are few organisations in Northern Ireland that provide legal advocacy for disabled children. The Children's Law Centre (CLC) is a registered charity and was established with the specific aim to help children, young people, parents and professionals to work with and understand the law relating to children and young people in Northern Ireland. As well as providing a free phone advice service for all young children, the CLC also undertake casework in a range of areas including:

- Human Rights and Children
- Children's Rights and the Provision of Services
- Educational Rights
- The rights of children in care and leaving care
- The rights of children in the youth justice system
- Discrimination law (in relation to the protection of children and young people)
- Employment of Children, and
- Social Security relating to children.

A large proportion of the CLC's work relates to the provision of advocacy in matters relating to disability, particularly in relation to Special

Existing Advocacy Arrangements ...continued



Educational Needs (SEN) and the statementing process and in relation to care packages for children with complex needs.

The Law Centre Northern Ireland

The Law Centre Northern Ireland also offers a legal advocacy services to disabled children and their families. Most of the casework they undertake for disabled children relates to access to community care, such as respite services, adaptations to the home or issues relating to disability benefits. The Law Centre accepts referrals from a range of sources including its members, voluntary organisations and direct enquiries from members of the public.

Guardian ad Litem

Guardian ad Litem also undertake a legal advocacy role for children who under the care of the state. They provide legal guardians whose roles are to ensure that the child's needs are appropriately represented during legal proceeding at that the best interests of the child are at the centre of any legal decisions impacting on the child. In 2005/2006 around 13% of the children supported by Guardian ad Litem had a disability.

The Equality Commission

The Equality Commission Northern Ireland was established to advance equality, promote equality of opportunity, encourage good relations and challenge discrimination through promotion, advice and enforcement. The Equality Commission have a team of legal officers who conduct cases in the filed of discrimination on an in-house basis. They also provide initial legal advice, support and information to potential claimants in all areas of discrimination, including disability.

The Northern Ireland Human Rights Commission
The Northern Ireland Human Rights Commission also has the power to assist individuals when they are bringing court proceedings and to intervene in proceedings. It also receives inquiries from people who believe their human rights have been violated. This would include people with disabilities who have been denied their human rights because of, or relating to, their disability.

NICCY

Under Article 11 of the Commissioner for Children and Young People (Northern Ireland) Order 2003, the Commissioner may provide assistance to a child or young person in making a complaint to a relevant authority. The majority of NICCY's casework, in pursuit of its principal aim of safeguarding the rights and best interests of children, is via the provision of an advocacy based, complaints resolution service. This assists individual children and young people resolve complaints against relevant authorities, and although has only happened in a small number of cases to date, this can also include helping them to take legal action and taking legal action on their behalf, or in NICCY's own name. Within NICCY, one team is specifically focused on dealing with both individual casework and providing legal and general advice and assistance where necessary, working co-operatively and collaboratively, where possible, with the relevant authorities in order to try and effect speedy change for the child or young person involved.

Generally speaking, with the advocacy cases to date which have involved disabled children with complex needs, concerns have been raised to NICCY by parents and carers

regarding inadequacies in provision of advocacy arrangements. Concerns have been expressed that young people who have the capacity to make decisions about their everyday life are not being encouraged and empowered to make these decisions. Those who do not have the capacity to make decisions about their everyday life may require assistance in exercising their rights to express their needs and wishes; this should be done in a manner which maintains respect for their private life.

Parents and carers have often felt that statutory healthcare providers have not had in place an ethos which provides, either in theory or in terms of practical arrangements, young disabled children with complex needs an opportunity to have their rights, needs and wishes advocated.

Article 23 of the UNCRC states that a child with a mental disability should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. NICCY have advocated on behalf of young people who have been reliant on their parents to understand and advocate for their needs, yet the parents feel they have not been listened to or taken seriously in this role. One parent told NICCY that she felt that her child did not exist as a person in the eyes of some professionals dealing with her, as she could not speak for herself, and when her mother attempted to advocate for her, she felt she was not being taken seriously.

It is NICCY's general view that more information and access to appropriate advocacy services would be beneficial, as carers are often occupied with caring for their child and would welcome the expertise and understanding of someone to meet the child, see them and speak to them if possible, and represent their needs and wishes when appropriate.

7.4 Conclusions of existing services

Based on our consultation with parents and statutory bodies and our workshop with those from the voluntary sector we were able to develop a high level overview of the level and range of existing services:

- A number of consultees from statutory organisations (91%) and parents who were surveyed (88%) noted that people such as Social Workers and other staff from HSSTs often undertook an advocacy role. The independence of HSST staff as advocates is an issue, as conflicts of interest could arise as they may be required to advocate against their own organisation. Furthermore, this is not inline with best practice, as identified by the Department of Health (DoH)
- There are a range of advocacy services available; some are aimed at specific groups of people (e.g. those with Asperger's) or, are only available in certain areas (e.g. in the SHSSB area)
- Around 12% of parents surveyed were unaware of any existing advocacy services

Existing Advocacy Arrangements ...continued



- There are regional variations in statutory provision, results from both our parents survey and consultations were not able to identify any advocacy services for disabled children and young people in the Causeway Trust area
- Only one service that had assistive technologies available to help young people with communications difficulties was identified, this was based in the SHSSB
- Voluntary Organisations are often limited in the range and level of services they provide due to funding restrictions
- Voluntary sector provision is stretched and organisations are often reluctant to advertise their services as they do not want to ‘waste’ their funds in not delivering services and could not meet the demands of additional clients
- Some organisations are specifically building up self-advocacy and ensuring that the appropriate information is provided. At the moment this is provided at local levels and not available across NI (Barnardos and Bryson House), and
- Often the voluntary sector services that are provided are funded through the local HSS Trusts or Boards.

Effectiveness of services

8.1 Introduction

The effectiveness of the identified services will be assessed in two ways. Firstly the extent to which they meet the needs of the children and young people as noted during our fieldwork and secondly the ability of the services to meet the aims and objectives of the statutory organisations that provide them.

Section Detail

8.2 Extent to which the children's needs are being met

8.3 Extent to which the services met the aims and objectives of statutory bodies

8.4 Conclusion.

8.2 Extent to which children's needs are being met

50% of respondents to the survey had used advocacy, 42% of those who had used an advocacy service found it very useful. However 67% of these who said they have an advocacy service noted that their Social Worker was their advocate. During the consultations it was noted that the level of satisfaction with social work services varied, with most parents (53%) saying that they rarely saw their social worker unless they contacted them. However, some examples were given of social workers helping older children in the transition from school to college or work. As noted in section five parents completing the survey and children that were consulted with noted that there are key times and events when they would like to access an advocacy service. Many of the children (22%) noted that they would

like an advocate during transitional stages of their lives, such as moving schools or leaving school. Six of the young people noted that they don't receive support early enough when preparing to leave school or, they felt that they were not made aware of all the options that are open to them. 50% of the Trusts interviewed noted that they provide transition workers to support children moving into adult services and the group of children interviewed at school noted that someone from a voluntary organisation came into to school and supported them in finding work placements and further education courses. Results from the primary research suggest that there are many children who would like this type of service but do not know how they would access it. McConkey et al (2007)²⁹, also noted the importance of transition planning for children with complex needs, including the transition from hospital to community, school entry, school transfer and leaving school.

As noted in section 5, parents who completed the survey also noted that they would like to use advocacy when dealing with care management issues. The primary research identified two such services, one in Foyle and the advocacy services from Bryson House, both of these tend to be geared towards those aged over 16 and have limited availability. Whilst the primary research identified very few children who live in a hospital setting (1%), the Bryson House service was the only advocacy service identified during the primary research for those living in a hospital setting and was only available in the Eastern and Southern HSSBs.

²⁹ McConkey, R. Barr, O. and Baxter, R. (2007) Children with complex physical healthcare needs, unpublished report.

Effectiveness of services

...continued



One Assistive Technology suite to assist children and young people with communication difficulties to advocate for themselves, was identified. However, again this service is localised, as it is provided through the Sixth Sense project in Armagh and is only available to children and young people in the SHSSB area.

As discussed in the previous section many of the services that do exist appear to be localised, meeting the needs of children within a particular geographical area or a specific disability group. Therefore, provision of services across Northern Ireland is uneven and the extent to which children's needs are being met appears to depend on where they live.

8.3 Extent to which services met the aims and objectives of statutory bodies

Each of the four Health Boards have published their Children's Services Plans, all state a number of aims and objectives and outcome statements. In particular one specific outcome statement is relevant to this study:

"All children and young people are involved in decisions that affect them."

The provision of advocacy services would contribute to this outcome in that advocacy should help children make informed decisions and that their voice is heard. As identified in previous chapters progress towards this outcome is patchy and inconsistent across Northern Ireland. Some Boards (such as the SHSSB) have made a

concerted effort towards this on a group level by actively supporting the young people's committees on the Children's Services Planning. However, progress on an individual level the standard and range of services that are available would not contribute to the overall aims and objectives of the HSSBS.

Furthermore, the OFMDFM strategy for children and young people, notes that the key element in developing a needs driven practice is to involve children in the assessment of their needs. By creating children's committees within the Children's Services Plan the HSS Boards have begun to address this at a regional level. However, evidence from our primary research indicates that the provision of advocacy services is too uneven and localised to contribute towards a needs driven practice at an individual level.

Many of the advocacy services that are being delivered by the voluntary sector are being supported by statutory organisations through a range of funding streams. Whilst this helps to achieve an independent service, it is patchy and uncoordinated, which restricts the extent to which these services can assist statutory bodies in meeting aims and objectives.

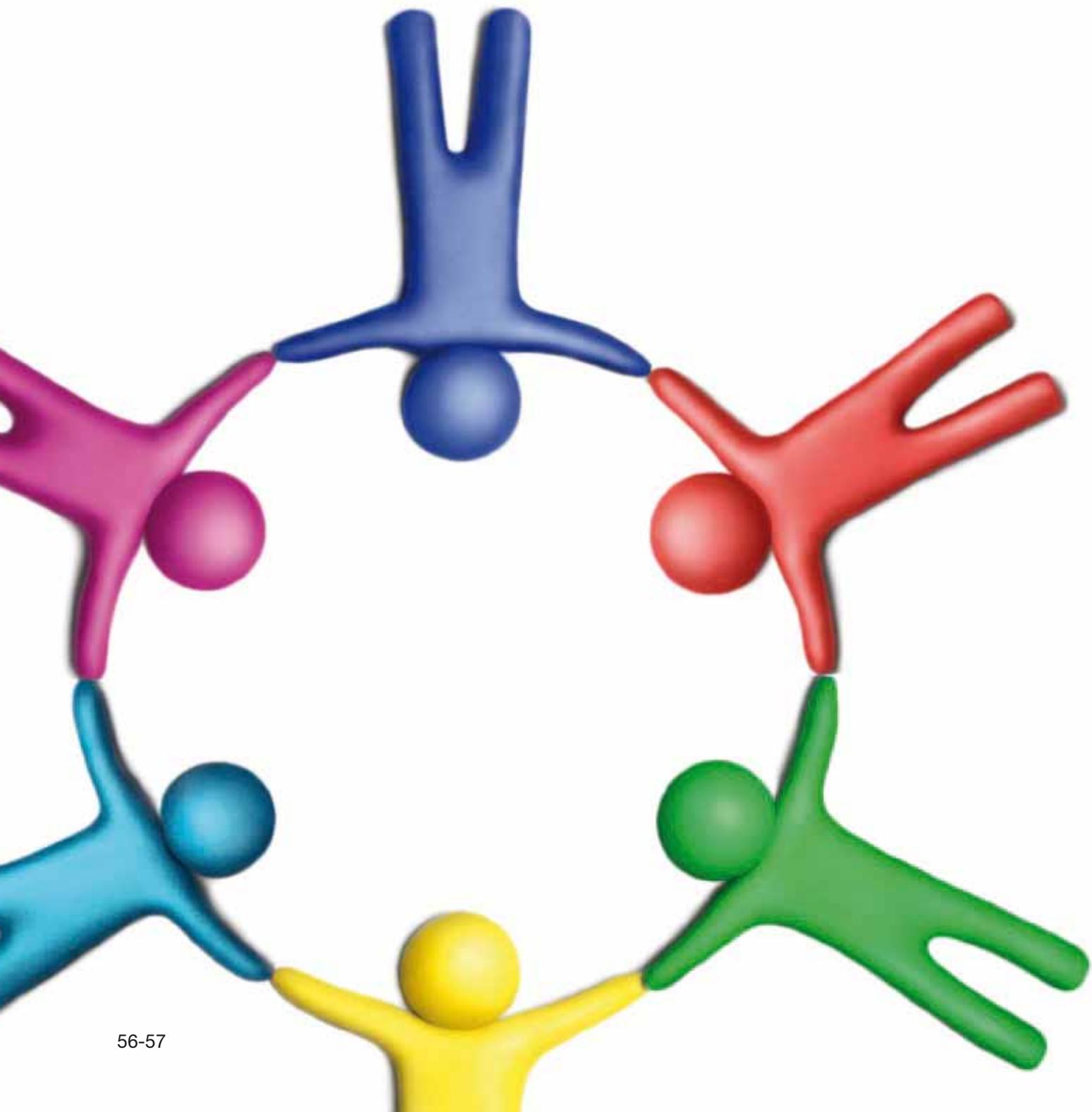
8.4 Conclusions on effectiveness of services

Based on consultations with parents, young people and statutory bodies and the workshop with representatives from the voluntary sector we were able to develop a high level overview of the level and range of existing services.

- Where advocacy is provided there are generally

high-levels of satisfaction among children and their parents, the services tend to support children in accessing other health and social care services or provide information relating to education and training.

- Many of these services that do exist have been developed organically from an identified local need, rather than by strategic Board or Departmental policy development, (as discussed in section 7).
- There are a range of advocacy services available
 - Some are aimed at specific groups of people (e.g. those with Asperger's)
 - Some are limited geographically.
- Children and young people who were interviewed specifically noted that there was a lack of support and advocacy during transitional times such as leaving or changing schools. Many of those interviewed (24%) felt that they were not informed of all the options open to them.



Conclusions and Recommendations

9.1 Conclusions

The following paragraphs provide a brief overview in relation to each of the key issues addressed in the Terms of Reference.

There are a range of policy documents relating to the rights of children and young people and as such there is a strong contextual background for the provision of advocacy services for children with disabilities and complex needs. However, there was no evidence of a strategic framework for advocacy service planning and delivery at a regional level.

It was difficult to determine the number of disabled children with complex needs in Northern Ireland due to variances in the definition of complex needs and the lack of available data. However, based on population statistics and the rates of profound disability we estimate that there around 500 children (up to the age of 21) with disabilities and complex needs in Northern Ireland. Not every Health and Social Services Board maintains a register of disabled children, even though it is a requirement in the Children (Northern Ireland) Order 1995.

The results from our survey and consultation process demonstrated that there are reasonably high levels of need for advocacy services for children with disabilities in Northern Ireland. Advocacy is particularly important for young people during transitional stages of their life.

Both parents and staff from statutory service providers identified people such as Social Workers as advocates. This goes against best practice as advocates should be independent from those providing the services ³⁰.

There was a general lack of awareness of children's rights among parents/carers and children. Most parents and many children interviewed did not understand the concept of human rights. We did identify some examples of good practice of informing children and young people their rights, such as the Sixth Sense Group in Armagh.

The level and range of advocacy services varied greatly across Northern Ireland. Some Trusts have established independent advocacy services and others considered that the social workers should be able to fulfil this role. Those services that do exist appear to have been developed in response to identified local needs rather than a strategic approach to meeting the advocacy needs of disabled children and young people across Northern Ireland. Consequently the extent to which needs are being also varied greatly. Voluntary sector provision appears to be stretched and unable to develop services any further or publicise services without further funding.

³⁰ McConkey, R. Barr, O. and Baxter, R. (2007) Children with complex physical healthcare needs, unpublished report.

Conclusions and Recommendations ...continued



9.2 Recommendations

A number of recommendations arose as a result of this review, an overview of which will be provided in the following paragraphs. The recommendations fell into the broad categories of Co-ordination of Services, Service Planning and Equity of Access, as summarised in the following paragraphs:

Co-ordination of Services

1. DHSSPS should ensure that the delivery of advocacy services for disabled children is coordinated at a strategic level. NICCY has already written to the DHSSPS seeking its support for the development of an advocacy network in Northern Ireland and suggesting it would be beneficial to better co-ordinate existing provision and to ensure standards are maintained and developed across the sectors and agencies involved. This network should be inter-departmental to ensure that all aspects of services for disabled children are included.
2. The introduction of the new regional Health and Social Services Board in April 2009 means services will be coordinated and delivered at a strategic level. The new Board should review how advocacy services could be co-ordinated, funded and delivered at a strategic level.
3. The DHSSPS should undertake an awareness campaign to raise the profile of advocacy and its uses, emphasising the need for advocates to be independent and free of conflicts of interest. By way of example this could include providing those who work with disabled children and young people with literature regarding

advocacy guidelines or, someone from the DHSSPS acting as an information officer, being responsible for the provision of information and advice relating to advocacy for those in working statutory and voluntary services.

4. Where good practice is identified, DHSSPS should ensure that information is made available that would allow others to replicate or use the model to develop effective advocacy services. This could be good practice within Northern Ireland (such as the Sixth Sense project) and further a field such as the publication of the DoH advocacy guidelines.
5. All statutory organisations with a remit to protect the rights of disabled children should ensure that their services are publicised and promotional material is accessible.

Service Planning

6. An accurate and complete register of all disabled children in Northern Ireland should be compiled and maintained by the new HSSB, in line with the Children Order (Northern Ireland) 1995.
7. All relevant government departments (i.e. DHSSPS, DE and DEL) should ensure that existing services are appropriately funded in order to meet the needs of all children within their remit and to allow organisations to publicise their services.

8. Those responsible for funding advocacy services need to be aware of the resource implications of long term advocacy in order to maintain it effectively and to meet the needs of disabled children with complex needs.

Equity of Access

9. In order to achieve equitable access to advocacy, services should be made available to all children with complex needs at the point when they enter either educational or health and social services.
10. The establishment of the new Health and Social Services Board should ensure that advocacy services are strategically planned and delivered to achieve a regional service and not a series of localised and varied services. Evidence from the review of literature, the responses to the survey and interviews with disabled children and young people with complex needs indicate that all disabled children and young people with complex needs would benefit from statutory funded advocacy services.



Appendix A:

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Appendix B:

Workshop Attendees

21 Voluntary sector Bodies were invited to attend a workshop on the Review of advocacy services, attendees included representatives from:

- Disability Action
- The Cedar Foundation
- The NI Cancer Fund for Children
- Aspergers Network
- Bryson House
- The NI Children's Hospice
- Mencap
- The Parent's and Carer's Council on Disability
- NI Regional Genetics Service.

The Children's Law Centre were also consulted with.



‘Who speaks for us?’





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