

Exploring the Palliative Care Needs and Delivery of Services to Young Children with Life-Limiting Neurodevelopmental Disabilities and their Families: A Mixed Methods Study.

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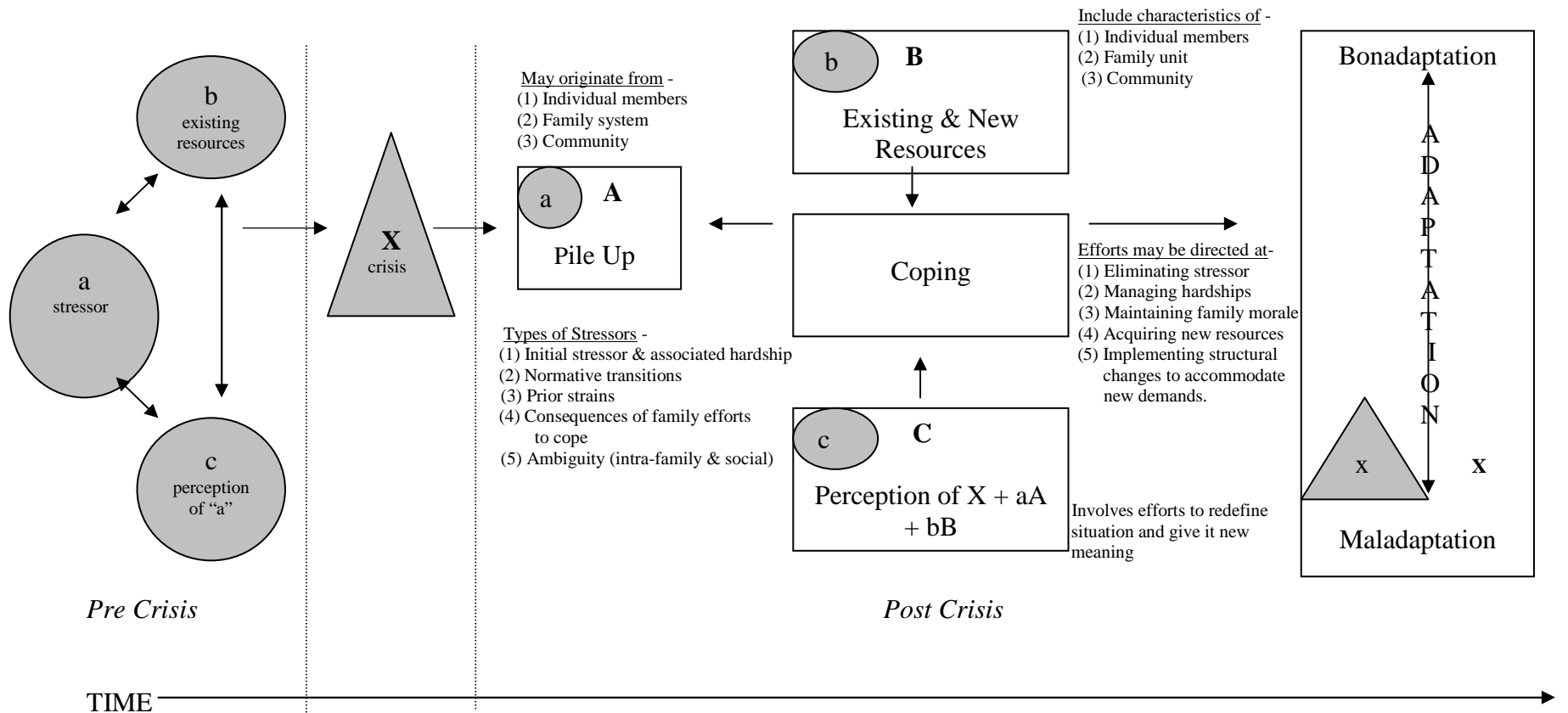
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Appendices

Appendix A: Double ABCX Model of Family Stress and Adaptation



(adapted from McCubbin & Patterson 1983b)

Appendix B: *Introductory Letter for Parents*

School of Nursing
Dublin City University
Glasnevin
Dublin 9
DATE

Dear Parent

I am writing to seek your help with an important research study. My name is Eileen Courtney and I am a nurse and a lecturer in the School of Nursing in Dublin City University. I am part of a research team working on a study on the needs of children who have neurodevelopmental conditions and serious medical problems and their families. We hope that by understanding the challenges that your child and family experience we can help develop services that are best suited to meet the needs of children and families in situations like yours in the future. This project is part of a doctoral programme I am undertaking in Dublin City University.

Please consider taking part in the study. We are sending this request to you through the Jack & Jill Children's Foundation but the research is not related to the Foundation in any way. They have simply agreed to help us by sending this letter to you.

- We do not have your name or address.
- You can choose to take part in the study or not without any fear of negative effects.

If you agree to be part of the study we will ask you to complete a number of short questionnaires. Later, in the second phase of the study, we may write to you again to ask you if you would agree to an interview. You will find information about the study in the leaflet enclosed with this letter. **Please read this carefully, it will give you all the information you need to make a decision about taking part in the study.**

If you agree to be part of the study please complete and return the consent form in the freepost envelope provided. When we receive this we will post you the questionnaires. We will treat all information in the strictest confidence.

We appreciate how busy you are and would be very grateful if you choose to take part in our study. We need your opinions and experiences to make this study a success, and we would greatly value your contribution.

Thank you for taking the time to read this letter and information leaflet. If you have any questions about the study please feel free to contact me by telephone at (01) 700 8525 or by email Eileen.Courtney@dcu.ie. We hope that you will agree to be involved in the study as we cannot progress without your help.

Yours Sincerely

Eileen Courtney.

Dr. Gemma Kiernan, School of Nursing, Dublin City University. Tel: (01) 700 8542.

Dr. Suzanne Guerin, School of Psychology, University College Dublin. Tel: (01) 716 8490

If you have concerns about this study and wish to contact an independent person, please contact –

The Secretary,

Dublin City University Research Ethics Committee,

C/O Office of the Vice President for Research,

Dublin City University,

Dublin 9.

Telephone (01) 700 8000

Appendix C: Information Booklet for Parents

***Services to Children with Complex Neurodevelopmental Disabilities and
Serious Medical Problems and their Families - A Study.***



Information Booklet

What is the study about and why have you contacted me?

What is this study about?

This study is about exploring the needs of children who have complex neurodevelopmental conditions and serious medical problems and their families.



We would like to understand the challenges that your child may experience, and whether there are enough services available to you and your child to meet these needs. We would also like to understand your experience as a parent of a child who has a serious medical problem, and to know what you think about the services that are available.

Why is the study being done?

The aim of this study is to help develop services that are best suited to meet the needs of families in situations like yours in the future.

Who is doing the study?

The study is being carried out by a team of researchers including

- Ms. Eileen Courtney who is a Nurse and Lecturer in Nursing in Dublin City University. You will have most contact with Eileen if you agree to be part of the study.
- Dr. Gemma Kiernan who is a Psychologist and Lecturer in Psychology in Dublin City University.
- Dr. Suzanne Guerin who is a Psychologist and Lecturer in Psychology in University College Dublin.

Why have I been chosen?

You have been chosen because you are the parent of a child who has a serious medical condition what will require ongoing care.

You are one of a number of parents who have asked to be involved in the study.

How did you contact me?

We got your name from a list of families who are involved with the Jack & Jill Children's Foundation. The Foundation agreed to send you this letter on our behalf but they are not involved in the study itself.

The Jack & Jill Children's Foundation did not give us any information about you or your child.

What does taking part in the study mean for me and my family?

What will happen if I agree to be part of the study?

If you agree to be part of the study we will send you a questionnaire to complete and return to us. **If you prefer, you can complete the questionnaire over the phone with Eileen Courtney.** Later Eileen might contact you to see if you would agree to be interviewed, but you do not have to do this. You can choose to only complete the questionnaire. We are grateful for your involvement in any part of the study.

Taking part in the study is completely up to you. You can change your mind at any stage without having to explain why.



What is the questionnaire about? What types of questions will I be asked?

- There are six short questionnaires to complete on paper. You can choose to do this by yourself or over the phone.
- The first part of the questionnaire asks for some background information about yourself and you child (age for example). It also asks about any medical difficulties your child may be experiencing; what kinds of services are available to you, and how well you think these services work. You will also be given the chance to tell us more about your own experiences and what you feel is important in helping you care for your child.
- The other questionnaires are "tick the box" style.
- The second part asks for your opinion on the services you use; the third measures your own general health and wellbeing; the fourth asks about the support you get from friends and family.
- The last two parts ask about the effects of your child's ongoing health difficulties on family life, and about what things you find helpful in managing family life.



How long will it take?

It should take about 45 minutes for you to complete all of the questionnaires.

What will happen if I do not want to be part of the study?

If you choose not to be part of the study we will not contact you again. There will be no change in the services your family receives, and your child's treatment will not be affected in any way.

Are there any benefits to taking part?

There are no personal rewards for being involved in the study except that it will give you a chance to have your say about the services that are currently available to you. However, we hope that the findings of this study will help to develop services in the future that could benefit other families in situations like yours.

Are there any costs to being involved?

The only cost of being involved in the study is the time it takes to fill in the questionnaire.

We will give you a freepost envelope to send back the questionnaire, or telephone you to complete it over the phone if you prefer.

What will happen to the information collected from me?

Confidentiality

We will treat all the information you give us in the strictest confidence. The questionnaire will contain no information that would allow anyone except the researchers to identify you.

We will keep all your information private. We will only break privacy if there is a concern for a child's safety. In this situation we would have to bring this to the attention of your service who would follow this up with you.

Only the researchers will have access to your answers. We will not publish or share your name with anyone else. We will enter the information from your questionnaire into a secure computer and then destroy the paper copy.

When the information from everyone's questionnaire has been analyzed and the study is finished we will destroy the computer records.



Where can I get more information?

If you have any questions about the study please contact -
Eileen Courtney,
School of Nursing,
Dublin City University.
Telephone (01) 700 8525 or Email Eileen.Courtney@dcu.ie

What do I do next?

What do I need to do next?

If you agree to be part of the study please return the Consent Form (yellow form) in the Freepost envelope. We will then send you a questionnaire to complete.

*Thank you for taking the time to read this letter and information leaflet.
We hope that you will agree to be involved in the study.*

Appendix D: Consent Form for Participation in Parents Survey

**Please complete this form if you agree to take part in the study.
You can use the freepost envelope to return the form.**

(1) I know who to contact to discuss or ask questions about this study.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

(2) I understand what the study is about.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

(3) I know that my name will not appear on the completed questionnaire.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

(4) I know that if I change my mind I am free to withdraw from the study, without having to say why, and that this will not affect the services I receive.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I have read and understand the information about this study. I have had the chance to talk to the researchers about any questions I may have. I agree to take part in this study.

Your Signature

(date)

Please turn over

Please choose one option

(1) Please send me a questionnaire by post

Your Name (block capitals) -----

Your Address -----

Telephone Number -----

OR

(2) I would like to complete the questionnaire over the phone. Please contact me to arrange a time that suits me.

Your Name (block capitals) -----

Telephone -----

The best time to call me is -----

Appendix E: Parents' Survey Questionnaire

Study Questionnaires

(1) **Background Information.**

This first part of the questionnaire asks for some background information about yourself and your child. It also asks about the types of services that are available to you. This information is needed so that we can get a picture of your current situation and the types of challenges that you face.

Please try to answer all questions.

(1a) Background Information

(1) What is **your** relationship to the child who has an illness ----- (2) What is your age? -----

(3) How many other children do you have? ----- (4) What are their ages? -----

(5) How old is your child who has an illness? ----- (6) What is your child's diagnosis / condition (if known)? -----

(7) What special difficulties or challenges does your child experience?

| DIFFICULTY | YES | NO | If Answer is "YES" - Please explain what the problem is |
|------------------------|------------|-----------|--|
| Breathing | | | |
| Seizures | | | |
| Pain or Discomfort | | | |
| Eating & Drinking | | | |
| Sleeping | | | |
| Communication | | | |
| Behaviour | | | |
| Mobility | | | |
| Toileting / Continence | | | |
| Other (please name) | | | |

(8) In relation to those difficulties or challenges that your child experiences, can you tell us how well you think the problem is managed by marking the box that best represents your child's situation – If you feel the problem is not well controlled please explain why you think this is the case.

| DIFFICULTY | Very Well Managed | Fairly Well Managed | Not Sure | Fairly Poorly Managed | Very Poorly Managed | Please explain why you think the problem is not well managed |
|---------------------------|--------------------------|----------------------------|-----------------|------------------------------|----------------------------|---|
| Breathing | | | | | | |
| Seizures | | | | | | |
| Pain or Discomfort | | | | | | |
| Eating & Drinking | | | | | | |
| Sleeping | | | | | | |
| Communication | | | | | | |
| Behaviour | | | | | | |
| Mobility | | | | | | |
| Toileting / Continence | | | | | | |
| Other | | | | | | |

Please use the space below to provide any additional information or comments that you feel are relevant to the difficulties or challenges that your child experiences.

(1b) Experiences of Current Services

(9) Please list all of the services that are available to your child

NOTE: These may be community based for example G.P or Public Health Nurse; hospital based for example Consultant Paediatrician or specialist nurse; or may be a voluntary service for example Jack & Jill Children's Foundation

- (a) ----- (e) -----
- (b) ----- (f) -----
- (c) ----- (g) -----
- (d) ----- (h) -----

(10) Please list any services that you feel would benefit your child but which are not available to you at this time

- (a) ----- (e) -----
- (b) ----- (f) -----
- (c) ----- (g) -----
- (d) ----- (h) -----

(11) Is there **one named** person or service that that you can call on to organise care and support when needed?

| | |
|-----|----|
| Yes | No |
| | |

(12) Who is that person (what is their role in your child's care)? -----

(13) In general how difficult do you find it to get the services that your child needs?

| Very Easy | Fairly Easy | Not Sure | Fairly Difficult | Very Difficult |
|-----------|-------------|----------|------------------|----------------|
| | | | | |

(14) In general how difficult do you find it to get **information** about services that your child may need?

| Very Easy | Fairly Easy | Not Sure | Fairly Difficult | Very Difficult |
|-----------|-------------|----------|------------------|----------------|
| | | | | |

(15) In general how well do you think the services **work together** to provide a package of care?

| Very Well | Fairly Well | Not Sure | Fairly Poorly | Very Poorly |
|-----------|-------------|----------|---------------|-------------|
| | | | | |

(16) Do you meet any obstacles / problems when you are trying to get care and support services for your child or yourself?

| All of the Time | Most of the Time | Not Sure | A Little | Never. |
|-----------------|------------------|----------|----------|--------|
| | | | | |

If you meet problems / obstacles to getting the services you need please use the space below to tell us what these are -

| |
|--|
| |
|--|

(17) What effects does meeting these obstacles / problems have on family life?

| |
|--|
| |
|--|

(18) Overall how satisfied are you with the services available to your child?

Very Satisfied Fairly Satisfied Neither satisfied nor Dissatisfied Not very Satisfied Not at all Satisfied.

| | | | | |
|--|--|--|--|--|
| | | | | |
|--|--|--|--|--|

(19) What works well or is good about the services your child receives?

| |
|--|
| |
|--|

(20) What does not work well, or is not good about the services your child receives?



(21) What changes to services do you think would most improve the situation for families like yours?



Please use this space if there are any other comments or information that you would like to provide –

A large, empty rectangular box with a thin black border, intended for providing additional comments or information. The box is currently blank.

(2) Measure of Processes of Care

In this section we would like to ask your opinions about the care you have been receiving **over the past year** from the health care organizations that provide services to your child. This may be your G. P's practice, your local hospital children's department, your local health centre or another organization. The care that you and your child receive may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

People: refers to those individuals who work directly with you or your child. These **may include** doctors, nurses, therapists, social workers, etc.

Organisation: refers to all staff from the health care organization, whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, administrative personnel, etc.

The questions are based on what parents like you have said about the way care is sometimes offered. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

(2) Measure of Processes of Care (MPOC-20)

For each question, please indicate how much the event or situation happens to you. You are asked to respond by circling **one** number from 1 (*not at all*) to 7 (*to a very great extent*) that you feel best fits your experience.

Please note that the zero value (0) is used only if the situation described does not apply to you.

“People” refers to those individuals who work directly with you and your child.

| In the past year to what extent do the PEOPLE who work with you and your child | Please indicate <u>HOW MUCH</u> this event or situation happens to you | | | | | | | |
|--|--|--------------------------|---------------------------------|-----------------------------|--------------------------|-------------------------------|-------------------|-----------------------|
| | To a very great extent | To a great extent | To a fairly great extent | To a moderate extent | To a small extent | To a very small extent | Not at all | Not Applicable |
| Help you to feel competent as a parent? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Provide you with written information about how your child is doing in the service? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Provide a caring atmosphere rather than just give you information? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Let you choose when to receive information and the type of information you want? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Look at the needs of your whole child (mental, emotional and social) rather than just at physical needs? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Make sure that at least one person is someone who works with you and your family over a long period of time? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Fully explain treatment choices to you? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

| In the past year to what extent do the <u>PEOPLE</u> who work with you and your child | To a very great extent | To a great extent | To a fairly great extent | To a moderate extent | To a small extent | To a very small extent | Not at all | Not Applicable |
|--|-------------------------------|--------------------------|---------------------------------|-----------------------------|--------------------------|-------------------------------|-------------------|-----------------------|
| Provide opportunities for you to make decisions about treatments? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Provide enough time to talk so you don't feel rushed? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Plan together so that they are all working in the same direction? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Treat you as an equal rather than just as the parent of a patient? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Give you information about your child that is consistent from person to person? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Treat you as an individual rather than a "typical" parent of child with a complex illness? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Provide you with written information about your child's overall progress? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Tell you about results from tests and assessments? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

| In the past year to what extent does the <u>ORGANISATION</u> where you receive services | Please indicate <u>HOW MUCH</u> this event or situation happens to you | | | | | | | |
|---|--|--------------------------|---------------------------------|-----------------------------|--------------------------|-------------------------------|-------------------|-----------------------|
| | To a very great extent | To a great extent | To a fairly great extent | To a moderate extent | To a small extent | To a very small extent | Not at all | Not Applicable |
| Give you information about the type of services offered at the organization or in your community? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Have information available about your child's condition? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Provide opportunities for the entire family to obtain information? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Have information available to you in various forms? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |
| Provide advice on how to get information or to contact other parents? | 7 | 6 | 5 | 4 | 3 | 2 | 1 | 0 |

Thank you for completing this part of the questionnaire.

(3) The General Health Questionnaire

Please Read This Carefully –

We would like to know if you have had any medical complaints, and how your health has been in general, **over the past few weeks**. Please answer ALL of the questions by simple marking the answer which you think most nearly applies to you.

Remember that we want to know about **present and recent complaints**, not those you have had in the past. It is important that you try to answer ALL Questions.

Have You Recently:

| | | | | | |
|----|---|-------------------|--------------------|------------------------|-----------------------|
| A1 | Been feeling perfectly well and in good health? | Better than usual | Same as usual | Worst than usual | Much worse than usual |
| A2 | Been feeling in need of a good tonic? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A3 | Been feeling run-down and out of sorts? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A4 | Felt that you are ill? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A5 | Been getting any pains in your head? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A6 | Been getting a feeling of pressure or tightness in your head? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A7 | Been having hot or cold spells? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B1 | Lost much sleep over worry? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B2 | Had difficulty staying asleep once you are off? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B3 | Felt constantly under strain? | Not at all | No more than usual | Rather more than usual | Much more than usual |

Have You Recently:

| | | | | | |
|----|---|--------------------|-------------------------|---------------------------|------------------------|
| B4 | Been getting edgy and bad tempered? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B5 | Been getting scared or panicky for no good reason? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B6 | Found everything getting on top of you? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B7 | Been feeling nervous and strung-up all the time? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| C1 | Been managing to keep yourself busy and occupied? | More so than usual | Same as usual | Rather less than usual | Much less than usual |
| C2 | Been taking longer over the things you do? | Quicker than usual | Same as usual | Longer than usual | Much longer than usual |
| C3 | Felt on the whole you were doing things well? | Better than usual | About the same | Less well than usual | Much less well |
| C4 | Been satisfied with the way you carry out your tasks? | More satisfied | About the same as usual | Less satisfied than usual | Much less satisfied |
| C5 | Felt that you were playing a useful part in things? | More so than usual | Same as usual | Less useful than usual | Much less useful |
| C6 | Felt capable of making decisions about things? | More so than usual | Same as usual | Less so than usual | Much less capable |
| C7 | Been able to enjoy your normal day-to-day activities? | More so than usual | Same as usual | Less so than usual | Much less than usual |
| D1 | Been thinking of yourself as a worthless person? | Not at All | No more than usual | Rather more than usual | Much more than usual |
| D2 | Felt that life is entirely hopeless? | Not al all | No more than usual | Rather more than usual | Much more than usual |
| D3 | Felt that life isn't worth living? | Not al all | No more than usual | Rather more than usual | Much more than usual |

Have You Recently:

| | | | | | |
|----|---|----------------|--------------------|------------------------|----------------------|
| D4 | Thought of the possibility that you might make away with yourself? | Definitely not | I don't think so | Has crossed my mind | Definitely have |
| D5 | Found at times you couldn't do anything because your nerves were too bad? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| D6 | Found yourself wishing you were dead and away from it all? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| D7 | Found that the idea of taking your own life kept coming into your mind? | Definitely not | Don't think so | Has crossed my mind | Definitely has |

(4) Multidimensional Scale of Perceived Social Support

This part of the questionnaire measures how much social support and help you feel you have.

We are interested in how you feel about the following statements.

Please read each statement carefully and indicate how you feel by marking the appropriate box.

| | | | | | | | | |
|---|---|------------------------|-------------------|-----------------|---------|--------------|----------------|---------------------|
| 1 | There is a special person who is around when I am in need. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 2 | There is a special person with whom I can share joys and sorrows. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 3 | My family really tries to help me. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 4 | I get the emotional help and support I need from my family. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 5 | I have a special person who is a real source of comfort to me. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 6 | My friends really try to help me. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 7 | I can count on my friends when things go wrong. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 8 | I can talk about my problems with my family. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |

| | | | | | | | | |
|----|---|------------------------|-------------------|-----------------|---------|--------------|----------------|---------------------|
| 9 | I have friends with whom I can share my joys and sorrows. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 10 | There is a special person in my life who cares about my feelings. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 11 | My family is willing to help me make decisions. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
| 12 | I can talk about my problems with my friends. | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |

Any other comments you would like to add? -----

(5) Impact of Illness on the Family Scale

The questionnaire was developed to measure your perception of the effects of your child’s ongoing health difficulties on family life.

Below are some statements that people have made about caring for a child with a serious illness. For each statement please indicate whether you **strongly agree, agree, disagree, or strongly disagree** by circling the number that best describes your feelings. There are no right or wrong answers, please be as honest as you can and answer as many questions as you can.

Who filled out this form? (Circle one) Mother Father Mother and Father

| | | | | |
|--|----------------|-------|----------|-------------------|
| The illness is causing financial problems for the family | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Time is lost from work because of hospital appointments | Strongly Agree | Agree | Disagree | Strongly Disagree |
| I am cutting down the hours I work to care for my child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Additional income is needed in order to cover medical expenses | Strongly Agree | Agree | Disagree | Strongly Disagree |
| I stopped working because of my child’s illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Because of the illness we are not able to travel far from where we live | Strongly Agree | Agree | Disagree | Strongly Disagree |
| We get special treatment from the neighbours because of my child’s illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| We have little desire to go out because of my child’s illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| It is hard to find a reliable person to take care of my child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Sometimes we have to change plans about going out at the last minute because of my child’s condition | Strongly Agree | Agree | Disagree | Strongly Disagree |
| We see family and friends less because of the illness | Strongly Agree | Agree | Disagree | Strongly Disagree |

| | | | | |
|---|----------------|-------|----------|-------------------|
| Because of what we have shared we are a closer family | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Sometimes I wonder whether my child should be treated specially or the same as a normal child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| My relatives have been understanding and helpful with my child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| I think about not having more children because of the illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| My partner / spouse and I discuss my child's problems together | Strongly Agree | Agree | Disagree | Strongly Disagree |
| We try to treat my child as if he / she were a normal child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| I don't have much time left over for other family members after caring for my child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Relatives interfere and think they know what's best for my child | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Our family gives up things because of my child's illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Tiredness / fatigue is a problems for me because of my child's illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| I live from day to day and don't plan for the future | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Nobody understands the burden I carry | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Travelling to hospitals is a strain on me | Strongly Agree | Agree | Disagree | Strongly Disagree |
| I worry about what will happen to my child in the future | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Sometimes I feel like we live on a roller coaster; in a crisis when my child is ill and o.k. when things are stable | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Learning to manage my child's illness has made me feel better about myself | Strongly Agree | Agree | Disagree | Strongly Disagree |

Please answer the next 6 questions if you have other children. If you have no other children you have completed this part of the questionnaire.

| | | | | |
|---|----------------|-------|----------|-------------------|
| It is hard to give much attention to the other children because of the needs of my ill child. | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Having a child with an illness makes me worry about my other children's health | Strongly Agree | Agree | Disagree | Strongly Disagree |
| There is fighting between the children because of my ill child's special needs | Strongly Agree | Agree | Disagree | Strongly Disagree |
| My other children are frightened by my child's illness | Strongly Agree | Agree | Disagree | Strongly Disagree |
| My other children seem to have more illnesses, aches and pains than most children their age | Strongly Agree | Agree | Disagree | Strongly Disagree |
| My other children's school grades suffer because of my child's illness | Strongly Agree | Agree | Disagree | Strongly Disagree |

(6) Coping Health Inventory for Parents.

The Coping Health Inventory was developed to record what parents might find helpful or not helpful to them in the management of family life when one of its members has a medical condition which calls for continued medical care. Coping is defined as personal or collective (with other individuals) efforts to manage the hardships associated with health problems in the family.

To complete this inventory you are asked to read the list of “Coping Behaviours” below, one at a time. For each coping behaviour you use please record how helpful it is by circling ONE number –

- 3 = extremely helpful.
- 2 = moderately helpful.
- 1 = minimally helpful.
- 0 = not helpful.

For each coping behaviour that you did not use please record your reason by checking one of the boxes “chose not to” or “not possible”

Although some may seem similar it is important that all questions are answered.

| Coping Behaviours | How Helpful | | | | Not Used | |
|---|-------------------|--------------------|-------------------|-------------|--------------|--------------|
| | Extremely Helpful | Moderately Helpful | Minimally Helpful | Not Helpful | Chose not to | Not Possible |
| Trying to maintain family stability. | 3 | 2 | 1 | 0 | | |
| Engaging in relationships and friendships which help me feel important and appreciated. | 3 | 2 | 1 | 0 | | |
| Trusting my spouse or partner to help support me and my child(ren). | 3 | 2 | 1 | 0 | | |
| Sleeping. | 3 | 2 | 1 | 0 | | |
| Talking with the medical staff (nurses and social workers) when we see them. | 3 | 2 | 1 | 0 | | |
| Believing that my child will get better. | 3 | 2 | 1 | 0 | | |

| Coping Behaviours | How Helpful | | | | Not Used | |
|--|-------------------|--------------------|-------------------|-------------|--------------|--------------|
| | Extremely Helpful | Moderately Helpful | Minimally Helpful | Not Helpful | Chose not to | Not Possible |
| Working – outside employment. | 3 | 2 | 1 | 0 | | |
| Showing that I am strong. | 3 | 2 | 1 | 0 | | |
| Purchasing gifts for myself and / or other family members. | 3 | 2 | 1 | 0 | | |
| Talking with other individuals / parents in my same situation. | 3 | 2 | 1 | 0 | | |
| Talking good care of all the medical equipment at home. | 3 | 2 | 1 | 0 | | |
| Eating. | 3 | 2 | 1 | 0 | | |
| Getting other members of the family to help with chores and tasks at home. | 3 | 2 | 1 | 0 | | |
| Getting away by myself. | 3 | 2 | 1 | 0 | | |
| Talking with the doctor about my concerns about my child with the medical condition. | 3 | 2 | 1 | 0 | | |
| Believing hat the medical centre / hospital has my child’s best interests in mind. | 3 | 2 | 1 | 0 | | |
| Building close relationships with people. | 3 | 2 | 1 | 0 | | |
| Believing in God. | 3 | 2 | 1 | 0 | | |
| Developing myself as a person. | 3 | 2 | 1 | 0 | | |

| Coping Behaviours | How Helpful | | | | Not Used | |
|--|-------------------|--------------------|-------------------|-------------|--------------|--------------|
| | Extremely Helpful | Moderately Helpful | Minimally Helpful | Not Helpful | Chose not to | Not Possible |
| Talking with other parents in the same type of situation and learning about their experiences. | 3 | 2 | 1 | 0 | | |
| Doing things together as a family. | 3 | 2 | 1 | 0 | | |
| Investing time and energy in my job. | 3 | 2 | 1 | 0 | | |
| Believing that my child is getting the best medical care possible. | 3 | 2 | 1 | 0 | | |
| Entertaining friends in our home. | 3 | 2 | 1 | 0 | | |
| Reading about how other people in my situation handle things. | 3 | 2 | 1 | 0 | | |
| Doing things with family relatives. | 3 | 2 | 1 | 0 | | |
| Becoming more self-reliant and independent. | 3 | 2 | 1 | 0 | | |
| Telling myself that I have many things I should be thankful for. | 3 | 2 | 1 | 0 | | |
| Concentrating on hobbies. | 3 | 2 | 1 | 0 | | |
| Explaining our family situation to friends and neighbours so they will understand us. | 3 | 2 | 1 | 0 | | |
| Encouraging my child with a medical condition to be more independent. | 3 | 2 | 1 | 0 | | |
| Keeping myself in shape and well groomed. | 3 | 2 | 1 | 0 | | |

| Coping Behaviours | How Helpful | | | | Not Used | |
|---|-------------------|--------------------|-------------------|-------------|--------------|--------------|
| | Extremely Helpful | Moderately Helpful | Minimally Helpful | Not Helpful | Chose not to | Not Possible |
| Involvement in social activities with friends. | 3 | 2 | 1 | 0 | | |
| Going out with my spouse / partner on a regular basis. | 3 | 2 | 1 | 0 | | |
| Being sure prescribed medical treatments for my child are carried out at home on a regular basis. | 3 | 2 | 1 | 0 | | |
| Building a closer relationship with my spouse. | 3 | 2 | 1 | 0 | | |
| Allowing myself to get angry. | 3 | 2 | 1 | 0 | | |
| Investing myself in my child(ren). | 3 | 2 | 1 | 0 | | |
| Talking to someone (not a professional) about how I feel. | 3 | 2 | 1 | 0 | | |
| Reading more about the medical problems which concern me. | 3 | 2 | 1 | 0 | | |
| Talking over personal feelings and concerns with my spouse / partner. | 3 | 2 | 1 | 0 | | |
| Being able to get away from my home care tasks / responsibilities for some relief. | 3 | 2 | 1 | 0 | | |
| Having my child with a serious illness seen at the clinic / hospital on a regular basis. | 3 | 2 | 1 | 0 | | |
| Believing that things will always work out. | 3 | 2 | 1 | 0 | | |
| Doing things with my child(ren). | 3 | 2 | 1 | 0 | | |

You have now completed all of the questionnaires. Thank you for your involvement in this study.

Please return this booklet in the prepaid envelope.

Appendix F *Cover Letter for Parents Questionnaire*

School of Nursing
Dublin City University
Glasnevin
Dublin 9
DATE

Dear NAME

Thank you very much for agreeing to take part in our study. We are very grateful for your help. I have enclosed the questionnaire for you to complete. It should take no more than about 30 minutes of your time. Please return the completed questionnaire in the freepost envelope.

As I mentioned in my first letter we are also looking for parents who would be willing to talk to us about their experiences. Interviews would last less than an hour and can take place in your home or at any place and time that suits you. I will need to tape-record the interview to keep an accurate record of what is said but will destroy all tapes once the information is transferred onto computer. Just like the questionnaire we will treat all your information in the strictest confidence, and no information recorded would allow yourself or your child to be identified.

If you would like to talk about taking part in the second stage of the study please complete the enclosed form and return it with your completed questionnaire. **This form is not an agreement to be interviewed** only that you are willing to talk to me about the possibility of being interviewed. I will then contact you by phone to give you more information and answer any questions you might have.

We are very grateful for the time you have already agreed to give to the study and appreciate how busy you are. If you have any further questions about the questionnaire please contact me by telephone at (01) 700 8525 or by email Eileen.Courtney@dcu.ie

Kind Regards

Eileen Courtney

Contact Agreement

Services to Children with Complex Neurodevelopmental Disabilities and Serious Medical Problems and their Families.

Please return this page with your completed questionnaire if you are willing **to discuss being involved** in an interview with the researcher.

You are agreeing only to being contacted about the possibility of being interviewed and are free to refuse or change you mind at any time.

I am willing to be contacted by Eileen Courtney (the researcher) to discuss being interviewed about my experiences of caring for my child and the services available to us.

Name: -----
Block Capitals

Address: -----

Phone Number: -----

Best time to call me is: -----

Many Thanks

Appendix H: Consent to Participate in Interview

Services to Children with Complex Neurodevelopmental Disabilities and Their Families.

Investigators

Eileen Courtney. School of Nursing, Dublin City University.

Dr. Gemma Kiernan. School of Nursing, Dublin City University.

Dr. Suzanne Guerin.. School of Psychology, University College Dublin.

Purpose of the Study

This interview follows on for the survey that you have already completed. The purpose of the interview is to get a deeper understanding of your experience of caring for a child with complex needs and the services you receive. This study will contribute to the development of a detailed and reliable evidence base that relates to the current health services, with a view to improving the delivery of services to families like yours in the future.

Please indicate your consent to be interviewed for this study by completing this form.

I have had a chance to discuss and ask questions about this study.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I understand what the study is about.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I understand that this interview will be tape-recorded.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I know that, in order to minimize the chance of being identified, my name will not appear on any interview transcripts and the researchers will not attribute comments to individual participants.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I know that if I wish, I am free to stop this interview at any time, or withdraw from the study, without having to explain my decision, or suffer any adverse effects.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

My questions and concerns have been answered and I have retained a copy of this consent form.

Therefore, I consent to take part in this research project

signature of participant

(date)

Name in block capitals

(signature of researcher)

(date)

Appendix I: Letter Inviting Participation in Delphi

School of Nursing
Dublin City University
Dublin 9.
Date

Dear NAME

My name is Eileen Courtney and I am currently working on my PhD which involves an exploration of the palliative care needs of young children with life-limiting neurodevelopmental disabilities and their families. The second phase of the study involves a Delphi survey of expert opinion related to the services currently available to such children and their families. As part of the exploratory work for this Delphi I have conducted a series of interviews with experts in the area including individuals from the general paediatric services, intellectual disability services and palliative care services. I write to you now to seek your participation in this second part of the study as you have been recommended as an expert in this field.

I have enclosed some information on the study including what is required of participants. I would be most grateful if you would read this. I appreciate that participation requires more time and commitment than a traditional survey and that you have a busy clinical remit, but there is relatively little Irish research in this area and it is hoped that the overall findings will provide a reliable evidence base and assist in making a case for improvements to the organisation of services for this group of children and their families.

I would be very happy to discuss any aspect of this study with you, either in person or on the telephone. I can be contacted by telephone at (01) 700 8525, or by email at Eileen.Courtney@dcu.ie. Please do not hesitate to contact me should you have any questions.

Alternatively, if you have concerns about this study and wish to contact an independent person, please contact – The Secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9. Telephone – (01) 700 8000.

Many thanks for taking the time to read this letter and the enclosed documentation.

Kind Regards

Eileen Courtney.

Appendix J: Information Leaflet for Potential Delphi Participants

Information for Potential Participants

Exploring the Palliative Care Needs and Delivery of Service to Young Children with Life-Limiting Neurodevelopmental Disabilities and Their Families.

Investigators

Eileen Courtney. School of Nursing, Dublin City University.

Dr. Gemma Kiernan. School of Nursing, Dublin City University.

Dr. Suzanne Guerin. School of Psychology, University College Dublin.

Purpose of the Study

This is the second stage of a larger study exploring the palliative care needs of young children with life-limiting disabilities and their families. The first stage of the study focused on the experiences and perception of parents while the purpose of this stage is to explore expert opinion related to the services provided to these children and their families. We hope that the overall findings will help contribute to the development of a detailed and reliable evidence base that relates to current health service provision, with a view to improving service delivery in the future. The study is funded through the School of Nursing in Dublin City University.

Participation in the Study

The study utilises a Delphi design. This involves the completion of three sequential self-report questionnaires approximately 5-6 weeks apart. The first questionnaire consists of open ended questions related to your opinion of current services. Responses to this questionnaire, along with interview data from parents and other expert health professionals, form the basis of the subsequent questionnaires for the next two rounds.

Subsequent questionnaires are structured, and provide a list of statements on which you are asked to rate your agreement using a Likert scale. Between each round you will be provided with the group summary statistics from the previous round which may, or may not, influence your position related to the statements. You may also be asked to provide more detail on your answers to the previous questionnaire. The purpose of using this design is to develop expert consensus, and explore areas of disagreement, related to service provision.

Because the first questionnaire is open-ended it will take the most time to complete. It is expected that this will be in the region of about 30 - 40 minutes. Subsequent questionnaires should take approximately 20 minutes. It is important that should you agree to participate in the study you complete and return all 3 rounds of the questionnaire.

Involvement in the study is entirely voluntary and you are free to withdraw from the study at any stage without penalty.

Basis on Which You Were Chosen

You are being asked to participate in this study on the basis of your professional expertise in this area. Other health professionals in the clinical field have suggested you as someone with the necessary knowledge and experience to contribute to an expert panel. You are not asked to present the opinion of the organisation in which you work as the study is concerned with *your expert opinion and personal experiences only*.

Confidentiality of Data

If you agree to participate in the study you will be one of a panel of 20 experts. All data will be treated in the strictest confidence and questionnaires will contain no information that allows you to be identified beyond the research team.

However, because this is a highly specialised area, with limited numbers of available experts, it is possible that participants may be able to logically deduce who their fellow respondents may be. In this context it is not possible to guarantee absolute anonymity to respondents (the panel size for the study is relatively small; members have been nominated by other experts; and all members will be identifiable to the researcher). However, neither questionnaires nor summary feedback will include any information by which participants may be identifiable to other members of the expert panel, and all responses will be handled so that their originator cannot be identified beyond the research team.

Confidentiality of data is subject to legal limitations. Paper questionnaires will be destroyed once data has been uploaded onto a secure computer. Computerised data will be held until the study is completed. Following this data will be wiped from the hard drive.

Risks & Benefits of Participation

There are no personal or professional risks to participating in this study. The only cost of being involved is the time it takes to complete the questionnaires.

Neither are there personal rewards for participation, beyond having an opportunity to express your opinion on the status of current services. However you may find the summary feedback provided between rounds useful in terms of current expert group opinion, and it is hoped that the findings of this study will contribute to the development of future services in this area.

If You Agree to Participate

Please complete the attached consent form and return it in the pre-paid envelope. We will then send you on the first of the questionnaires.

NOTE - If there is another health-professional that you consider to be an expert in this area who you believe could make an important contribution to the study I would be grateful if you could include their name and contact details (although it is possible that we may have already contacted them). This form of snowball sampling is necessary to ensure comprehensive multidisciplinary expertise and representation amongst the expert panel.

*Thank you for taking the time to read this.
We hope that you will lend your expertise to this study.*

Appendix K: Consent for Participation in Delphi

Exploring the Palliative Care Needs and Delivery of Services to Young Children with Life-Limiting Neurodevelopmental Disabilities and Their Families

Please indicate your consent to participate in this Delphi study by completing this form.

I have read the information leaflet and know who to contact if I have questions about this study.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I understand that participation involves the completion of more than one questionnaire.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I understand that in order to preserve my anonymity as much as possible my name will not appear on completed questionnaires or on feedback summaries provided between rounds to other panel members.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I am aware that the privacy of information I provide can only be guaranteed within the limitations of the law.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I understand that if I wish, I am free to withdraw from the study at any stage, without having to explain my decision or suffer any adverse effects.

| | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

I consent to take part in this Delphi study.

Signature of participant (date) Name in block capitals

Address to which questionnaire should be posted: -----

Email :----- Contact Telephone No. -----

If there is another health-professional that you believe has significant expertise in this area, please provide us with their contact details below.

Name: -----

Contact Address: -----

Appendix L: Cover Letter for Delphi Round One

School of Nursing
Dublin City University
Dublin 9
DATE

Exploring the Palliative Care Needs and Delivery of Services to Young Children with Life-Limiting Neurodevelopmental Disabilities and their Families

Delphi: Round One.

Dear NAME

Thank you very much for your agreement to form part of the expert panel for this study. I am very grateful for your time, commitment and expertise.

Enclosed is the first round of the study questionnaire. As outlined in the introductory information this round consists only of open-ended questions. Please read the instructions carefully as it defines the terms used in this and subsequent rounds of the questionnaires. When you have completed the questionnaire please return it in the pre-paid envelope. Alternatively, if you would find it more convenient, please feel free to complete the questionnaire as a Microsoft© text document and either post it or email it to me. I would be grateful if you could return the questionnaire at your earliest convenience.

When I have collated the information and opinions of all panel members I will send you on the second questionnaire which will have a more structured format. I expect this to take approximately three weeks (depending upon the volume of the data and how promptly the questionnaires are returned). I will also include the group summary statistics from this round in order that you can consider your opinion relative to that of the group as a whole. Please do not hesitate to contact me if you require any additional information or would like clarification on any aspect of the questionnaire. I can be contacted by phone at (01) 700 8525, or by email Eileen.Courtney@dcu.ie Thanks again for your input into this study.

With best wishes

Eileen Courtney.



Delphi Round One
Instructions for Responding to Round 1.

Please read the following information carefully before completing the questionnaire.

This study is concerned with the palliative care needs of young children (under the age of six) with life-limiting neurodevelopmental disabilities and their families.

In the context of this study a “*Life Limiting Neurodevelopmental Disability*” is defined as a condition of neurodevelopmental origin for which there is currently no cure and which is likely to lead to the child dying prematurely.

The study defines a “*Palliative Care Need*” as a physical, psychological, social or spiritual need that is present in the context of life-limiting or terminal illness. It is the context of the life-limiting condition that designates a palliative care need, although this does not necessarily imply a requirement for specialist palliative care services.

Please complete this questionnaire in the context of these definitions.

This questionnaire consists of three broad subject areas related to the goals of care for this population of children and their families and the way in which current services meet these goals. Please complete all parts of the questionnaire based upon your own personal opinion and experience (the answers you provide are not taken to represent the views of the services in which you work), and include additional sheets if required.

Each question consists of two parts. The left-hand column asks you to identify a particular issue while the right-hand column asks for additional information or further explanation. The answers in both columns are important as they provide an additional way of viewing your responses to ensure they are not misinterpreted.

Thank You.

| | |
|---|--|
| Q.1 Please use the space below to identify what you consider to be the goals of care for children with life-limiting neurodevelopmental disabilities and their families. | For each goal you identify please explain how / why you believe it is important to this population. |
| | |

| Q.2 Based upon your previous answer please describe which goals you feel are achieved in the context of current services and which are not. | If goals are not achieved in the context of current services what do you think is preventing their achievement? |
|--|--|
| | |

| Q.3 What changes do you consider are necessary to current services to improve the care provided to children with life-limiting developmental disabilities and their families? | Please explain what resources would be required in order to achieve these changes. |
|--|---|
| | |

Appendix N: Relationship between Theoretical Framework, Research Questions and Constructs Measured in the Study

| | | Related to Research Questions & Theoretical Construct |
|---------------------------|---|---|
| Instrument | Researcher-Designed Questionnaire | |
| Construct Measured | <i>Range of problems & challenges experienced by the child and the family. Family's experiences of services</i> | |
| | Quantification of child's problems / challenges | (1) What challenges do children commonly experience? |
| | Degree to which problem is controlled / managed | (2) What are the palliative care needs of this group? |
| | Experiences of services | (5) How are services perceived by parents? |
| | | <i>Provides an indication of the impact of the stressor and its associated hardships. aA Factors</i> |
| | MPOC-20 | |
| Construct Measured | <i>The family-centered behaviors of healthcare providers.</i> | |
| Subscale Items | Enabling and Partnership | (5) How are services perceived by parents? |
| | Providing general information | <i>Services should form part of family's expanded resources which help alleviate the demands of the crisis situation. Should also influence the perception of the stressor. [Recovery Factor] Cc Factors</i> |
| | Providing specific information about the child | |
| | Coordinated & comprehensive care | |
| | Respectful & Supportive care | |
| | | |
| Instrument | GHQ-28 | |
| Construct Measured | <i>Range of psychological disorders mainly in the anxiety / depression spectrum.</i> | |
| Subscale Items | Somatic symptoms | (3) Level of psychological distress amongst parents. |
| | Anxiety & Insomnia | <i>Provides an indication of the impact of the stressor and its associated hardships. Also indicates the level of successful adjustment & adaptation achieved. [May indicate severity of stressor, also level of adaptation] xX Factors</i> |
| | Social Dysfunction | |
| | Depression | |
| | Total Score | |
| | | |
| Instrument | MSPSS | |
| Construct Measured | <i>Subjectively assessed social support</i> | |
| Subscale Items | Family | (6) What level of social support is available to parent |
| | Friends | <i>Should act as a post-crisis variable which helps ameliorate the impact of the crisis. Emphasized as one of the most important resources.[Recovery Factor] cC Factors</i> |
| | Significant Other | |
| | Total Score | |

| | | |
|---------------------------|--|--|
| Instrument | IFS | |
| Construct Measured | <i>Quantifies the impact of illness on the family unit</i> | |
| Subscale Items | Financial situation | (4) Impact of care on family life. |
| | Social interaction | <i>Provides an indication of the impact of the stressor and its associated hardships. Indicative of family's perception / meaning of stressor.</i> |
| | Subjective distress | |
| | Positive sense of mastery | |
| | Total Score | <i>Also indicates the level of successful adaptation achieved {Indicative of level of Adaptation achieved}. xX Factors</i> |
| Instrument | CHIP | |
| Construct Measured | <i>Measure of parents responses to the management of family life</i> | |
| Subscale Items | Maintaining family integration | (3) What coping mechanisms are used? |
| | Maintaining social support | <i>Indicates family's efforts to cope and maintain balance & harmony. [Adjustment & Recovery Factor] xX Factors</i> |
| | Understanding medical condition | |
| Instrument | Delphi Questionnaire | |
| Construct Measured | <i>Health professional perceptions of the delivery of current services</i> | |
| Items | Goals of Care | (9) What are the agreed goals of care? (10) How well do services currently function? (11) What changes would improve services? |
| | Delivery of Services | <i>Constitutes part of the community to which the family has to achieve a "fit".</i> |
| | Priorities for Improving Services | |
| | | |

Appendix O *Non-Significant Correlations*

Non-significant Correlations with Negative Family Impact

| Variable | Result (<i>r</i>) | Significance (<i>p</i>) | n |
|---|------------------------------|------------------------------------|----------|
| Parents Age | -.03 | .87 | 48 |
| Number of other children | -.06 | .70 | 48 |
| Factors Related to the Child and their Condition | | | |
| Age of child | .04 | .77 | 48 |
| Total number of problems experienced by child | .23 | .11 | 48 |
| Management of breathing related difficulties | -.26 | .08 | 48 |
| Management of seizures | -.02 | .90 | 47 |
| Management of pain and discomfort | -.22 | .13 | 48 |
| Management of feeding difficulties | .10 | .52 | 46 |
| Management of communication difficulties | .19 | .21 | 46 |
| Management of behavioural difficulties | -.08 | .60 | 46 |
| Management of mobility difficulties | .19 | .21 | 45 |
| Management of continence difficulties | .09 | .54 | 45 |
| Management of other problems | .07 | .64 | 47 |
| Service Related Factors | | | |
| Number of services involved in the child's care | .14 | .34 | 47 |
| Number of additional services needed | .23 | .12 | 47 |
| Difficulty obtaining services | .22 | .14 | 47 |
| Difficult obtaining information about services | .19 | .20 | 46 |
| Level of service integration | .16 | .36 | 47 |
| MSPSS Scale Scores | | | |
| Total MSPSS score | -.21 | .16 | 47 |
| Support from Family | -.21 | .15 | 48 |
| Support from Significant Other | -.09 | .55 | 48 |
| Support from Friends | -.24 | .11 | 47 |
| GHQ-28 Scale & Subscales | | | |
| Total GHQ-28 | .18 | .22 | 47 |
| Somatic Symptoms subscale | .15 | .31 | 48 |
| Anxiety & Insomnia subscale | .23 | .12 | 47 |
| Social Dysfunction subscale | .19 | .19 | 48 |
| Depression & Despondency subscale | .19 | .21 | 47 |
| CHIP Subscales | | | |
| Coping Pattern I (Maintaining Family Integration) | -.29 | .06 | 43 |
| Coping Pattern III (Understanding the Situation) | -.12 | .43 | 45 |

Non-significant Correlations with GHQ-28

| Total GHQ-28 Score | | | |
|--|-----------------------|-----------------------------|----------|
| Variable | Result (r) | Significance (p) | n |
| Parents Age | .00 | .98 | 61 |
| Number of other children | .00 | 1.00 | 62 |
| | | | |
| Factors Related to the Child and their Condition | | | |
| Age of child | -.03 | .85 | 62 |
| Total number of problems experienced by child | .13 | .33 | 61 |
| Management of breathing related difficulties | .02 | .85 | 61 |
| Management of seizures | .02 | .86 | 61 |
| Management of pain and discomfort | -.02 | .87 | 61 |
| Management of feeding difficulties | .13 | .32 | 59 |
| Management of sleeping difficulties | .14 | .28 | 60 |
| Management of communication difficulties | -.15 | .26 | 58 |
| Management of behavioural difficulties | -.19 | .15 | 60 |
| Management of mobility difficulties | -.06 | .61 | 56 |
| Management of continence difficulties | -.06 | .64 | 58 |
| Management of other problems | -.06 | .64 | 60 |
| | | | |
| Service Related Factors | | | |
| Number of services involved in the child's care | .12 | .36 | 61 |
| Difficulty obtaining services | .13 | .32 | 60 |
| Difficult obtaining information about services | .16 | .22 | 61 |
| Level of service integration | .21 | .19 | 60 |
| Frequency with which obstacles to obtaining services are encountered | .15 | .26 | 61 |
| Satisfaction with services | .17 | .02 | 62 |
| | | | |
| MPOC-20 Subscales | | | |
| Enabling & Partnership | -.15 | .24 | 59 |
| Providing General Information | -.09 | .50 | 60 |
| Providing Child Specific Information | -.15 | .27 | 61 |
| Coordinated & Comprehensive Care | -.17 | .19 | 60 |
| Respectful & Supportive Care | -.18 | .18 | 61 |
| | | | |
| MSPSS Scale Scores | | | |
| Total MSPSS score | -.14 | .34 | 61 |
| Support from Family | -.15 | .24 | 62 |
| Support from Significant Other | -.06 | .62 | 62 |
| Support from Friends | -.08 | .52 | 61 |
| | | | |
| CHIP Subscales | | | |
| Coping Pattern I (Maintaining Family Integration) | .04 | .78 | 55 |
| Coping Pattern II (Maintaining Social Support) | -.07 | .62 | 56 |
| Coping Pattern III (Understanding the Situation) | .30 | .82 | 56 |
| | | | |

Non-significant Correlations with GHQ-28 Somatic Symptoms Subscale

| Somatic Symptoms Subscale | | | |
|--|-----------------------|-----------------------------|----------|
| Variable | Result (r) | Significance (p) | n |
| Parents Age | -.07 | .60 | 62 |
| Number of other children | -.19 | .13 | 63 |
| | | | |
| Factors Related to the Child and their Condition | | | |
| Age of child | -.06 | .64 | 63 |
| Total number of problems experienced by child | .08 | .56 | 62 |
| Management of breathing related difficulties | .06 | .64 | 62 |
| Management of seizures | .09 | .15 | 62 |
| Management of pain and discomfort | -.04 | .74 | 62 |
| Management of feeding difficulties | .07 | .61 | 60 |
| Management of sleeping difficulties | .16 | .23 | 61 |
| Management of communication difficulties | -.04 | .75 | 59 |
| Management of behavioural difficulties | -.15 | .25 | 61 |
| Management of mobility difficulties | .06 | .66 | 57 |
| Management of continence difficulties | .09 | .49 | 59 |
| Management of other problems | -.16 | .23 | 61 |
| | | | |
| Service Related Factors | | | |
| Number of services involved in the child's care | .13 | .30 | 62 |
| Difficulty obtaining services | .20 | .13 | 61 |
| Frequency with which obstacles to obtaining services are encountered | .14 | .29 | 62 |
| Satisfaction with services | .21 | .10 | 63 |
| | | | |
| MPOC-20 Subscales | | | |
| Enabling & Partnership | -.25 | .06 | 63 |
| Providing General Information | -.08 | .53 | 60 |
| Providing Child Specific Information | -.10 | .42 | 61 |
| Coordinated & Comprehensive Care | -.10 | .43 | 61 |
| Respectful & Supportive Care | -.07 | .59 | 62 |
| | | | |
| MSPSS Scale Scores | | | |
| Total MSPSS score | -.01 | .95 | 62 |
| Support from Family | .02 | .89 | 63 |
| Support from Significant Other | .02 | .90 | 63 |
| Support from Friends | -.04 | .76 | 62 |
| | | | |
| CHIP Subscales | | | |
| Coping Pattern I (Maintaining Family Integration) | -.10 | .47 | 56 |
| Coping Pattern II (Maintaining Social Support) | -.04 | .73 | 57 |
| Coping Pattern III (Understanding the Situation) | -.02 | .91 | 57 |
| | | | |

Non-significant Correlations with GHQ-28 Anxiety & Insomnia Subscale

| Anxiety & Insomnia Subscale | | | |
|--|------------------------------|------------------------------------|----------|
| Variable | Result (<i>r</i>) | Significance (<i>p</i>) | n |
| Parents Age | -.05 | .72 | 61 |
| Number of other children | .01 | .96 | 62 |
| | | | |
| Factors Related to the Child and their Condition | | | |
| Age of child | .01 | .95 | 62 |
| Total number of problems experienced by child | .20 | .11 | 61 |
| Management of breathing related difficulties | .05 | .70 | 61 |
| Management of seizures | -.02 | .89 | 61 |
| Management of pain and discomfort | -.07 | .57 | 61 |
| Management of feeding difficulties | .14 | .30 | 59 |
| Management of sleeping difficulties | .03 | .84 | 60 |
| Management of communication difficulties | -.12 | .38 | 58 |
| Management of behavioural difficulties | -.22 | .09 | 60 |
| Management of mobility difficulties | .02 | .89 | 56 |
| Management of continence difficulties | -.08 | .57 | 58 |
| Management of other problems | -.23 | .08 | 60 |
| | | | |
| Service Related Factors | | | |
| Number of services involved in the child's care | .06 | .65 | 61 |
| Difficulty obtaining services | .21 | .10 | 61 |
| Difficulty obtaining information about services | .18 | .17 | 60 |
| Level of service integration | .21 | .10 | 60 |
| Frequency with which obstacles to obtaining services are encountered | .23 | .08 | 61 |
| Satisfaction with services | .23 | .08 | 62 |
| | | | |
| MPOC-20 Subscales | | | |
| Enabling & Partnership | -.09 | .51 | 59 |
| Providing General Information | -.12 | .37 | 60 |
| Providing Child Specific Information | -.16 | .23 | 61 |
| Coordinated & Comprehensive Care | -.18 | .12 | 60 |
| Respectful & Supportive Care | -.15 | .26 | 61 |
| | | | |
| MSPSS Scale Scores | | | |
| Total MSPSS score | -.16 | .23 | 61 |
| Support from Family | -.09 | .50 | 62 |
| Support from Significant Other | -.09 | .47 | 62 |
| Support from Friends | -.20 | .13 | 61 |
| | | | |
| CHIP Subscales | | | |
| Coping Pattern I (Maintaining Family Integration) | .08 | .56 | 55 |
| Coping Pattern II (Maintaining Social Support) | -.09 | .51 | 56 |
| Coping Pattern III (Understanding the Situation) | .01 | .97 | 56 |
| | | | |

Non-significant Correlations with GHQ-28 Social Dysfunction Subscale

| Social Dysfunction Subscale | | | |
|--|-----------------------|-----------------------------|----------|
| Variable | Result (r) | Significance (p) | n |
| Parents Age | .06 | .65 | 62 |
| Number of other children | -.06 | .64 | 63 |
| | | | |
| Factors Related to the Child and their Condition | | | |
| Age of child | .00 | .99 | 63 |
| Total number of problems experienced by child | .11 | .40 | 62 |
| Management of breathing related difficulties | -.10 | .45 | 62 |
| Management of seizures | -.05 | .73 | 62 |
| Management of pain and discomfort | .19 | .14 | 62 |
| Management of feeding difficulties | .11 | .39 | 60 |
| Management of sleeping difficulties | -.06 | .66 | 61 |
| Management of communication difficulties | .01 | .97 | 59 |
| Management of behavioural difficulties | -.00 | .98 | 61 |
| Management of mobility difficulties | .03 | .81 | 57 |
| Management of continence difficulties | -.07 | .58 | 59 |
| Management of other problems | -.31 | .07 | 61 |
| | | | |
| Service Related Factors | | | |
| Number of services involved in the child's care | .06 | .65 | 62 |
| Difficulty obtaining services | .02 | .89 | 62 |
| Difficulty obtaining information about services | .16 | .22 | 61 |
| Level of service integration | .21 | .10 | 61 |
| Frequency with which obstacles to obtaining services are encountered | .05 | .72 | 62 |
| Satisfaction with services | .14 | .29 | 63 |
| | | | |
| MPOC-20 Subscales | | | |
| Enabling & Partnership | -.24 | .06 | 60 |
| Providing General Information | -.15 | .26 | 61 |
| Providing Child Specific Information | -.17 | .18 | 62 |
| | | | |
| MSPSS Scale Scores | | | |
| Total MSPSS score | -.11 | .40 | 62 |
| Support from Family | -.22 | .09 | 63 |
| Support from Significant Other | -.01 | .92 | 63 |
| Support from Friends | -.02 | .87 | 62 |
| | | | |
| CHIP Subscales | | | |
| Coping Pattern I (Maintaining Family Integration) | -.24 | .07 | 56 |
| Coping Pattern II (Maintaining Social Support) | -.15 | .25 | 57 |
| Coping Pattern III (Understanding the Situation) | -.13 | .35 | 57 |
| | | | |

Non-significant Correlations with GHQ-28 Depression & Despondency Subscale

| Depression & Despondency Subscale | | | |
|--|------------------------------|------------------------------------|----------|
| Variable | Result (<i>r</i>) | Significance (<i>p</i>) | n |
| Parents Age | .13 | .34 | 61 |
| Number of other children | .20 | .11 | 62 |
| | | | |
| Factors Related to the Child and their Condition | | | |
| Age of child | -.03 | .82 | 62 |
| Total number of problems experienced by child | .11 | .42 | 61 |
| Management of breathing related difficulties | -.07 | .57 | 61 |
| Management of seizures | -.02 | .86 | 61 |
| Management of pain and discomfort | .00 | .98 | 61 |
| Management of feeding difficulties | .05 | .73 | 59 |
| Management of sleeping difficulties | .17 | .19 | 60 |
| Management of communication difficulties | -.23 | .09 | 58 |
| Management of behavioural difficulties | -.13 | .34 | 60 |
| Management of mobility difficulties | -.23 | .08 | 56 |
| Management of continence difficulties | -.13 | .34 | 58 |
| Management of other problems | -.30 | .06 | 60 |
| | | | |
| Service Related Factors | | | |
| Number of services involved in the child's care | .08 | .55 | 61 |
| Number of additional services needed | .19 | .15 | 60 |
| Difficulty obtaining services | .01 | .94 | 61 |
| Difficulty obtaining information about services | -.04 | .79 | 60 |
| Level of service integration | .01 | .93 | 60 |
| Frequency with which obstacles to obtaining services are encountered | .05 | .68 | 61 |
| Satisfaction with services | .01 | .94 | 62 |
| | | | |
| MPOC-20 Subscales | | | |
| Enabling & Partnership | -.08 | .53 | 59 |
| Providing General Information | -.05 | .72 | 60 |
| Providing Child Specific Information | -.13 | .30 | 61 |
| Coordinated & Comprehensive Care | -.14 | .30 | 60 |
| Respectful & Supportive Care | -.19 | .14 | 61 |
| | | | |
| MSPSS Scale Scores | | | |
| Total MSPSS score | -.07 | .58 | 61 |
| Support from Family | -.22 | .09 | 62 |
| Support from Significant Other | -.07 | .60 | 62 |
| Support from Friends | .09 | .50 | 61 |
| | | | |
| CHIP Subscales | | | |
| Coping Pattern I (Maintaining Family Integration) | .09 | .50 | 55 |
| Coping Pattern II (Maintaining Social Support) | -.05 | .70 | 56 |
| Coping Pattern III (Understanding the Situation) | .03 | .85 | 56 |
| | | | |

Non-significant Correlations with Total MSPSS

| Total MSPSS Score | | | |
|--|------------------------------|------------------------------------|----------|
| Variable | Result (<i>r</i>) | Significance (<i>p</i>) | n |
| Parents Age | -.10 | .43 | 61 |
| Number of other children | -.01 | .91 | 62 |
| | | | |
| Factors Related to the Child and their Condition | | | |
| Age of child | -.19 | .15 | 62 |
| Total number of problems experienced by child | -.11 | .41 | 61 |
| Management of breathing related difficulties | -.12 | .37 | 61 |
| Management of seizures | .05 | .71 | 61 |
| Management of pain and discomfort | .00 | .98 | 61 |
| Management of feeding difficulties | -.08 | .57 | 59 |
| Management of sleeping difficulties | .07 | .60 | 60 |
| Management of communication difficulties | -.16 | .23 | 58 |
| Management of behavioural difficulties | .19 | .15 | 60 |
| Management of mobility difficulties | -.10 | .48 | 56 |
| Management of continence difficulties | -.05 | .73 | 58 |
| Management of other problems | .08 | .53 | 60 |
| | | | |
| Service Related Factors | | | |
| Number of services involved in the child's care | .14 | .28 | 61 |
| Number of additional services needed | -.05 | .72 | 60 |
| Difficulty obtaining services | -.03 | .85 | 61 |
| Difficulty obtaining information about services | .07 | .61 | 60 |
| Level of service integration | -.01 | .96 | 60 |
| Frequency with which obstacles to obtaining services are encountered | .03 | .79 | 61 |
| Satisfaction with services | -.03 | .83 | 62 |
| | | | |
| CHIP Subscales | | | |
| Coping Pattern III (Understanding the Situation) | .07 | .59 | 56 |
| | | | |

Appendix P: Non Significant Independent Samples T-tests

Service Experiences

| Grouping Variable: Named Care Coordinator Dependent Variable: Service Experiences | t | df | p |
|--|----------|-----------|----------|
| Difficulty obtaining information about services | -1.6 | 57 | .12 |
| Level of service integration | -.19 | 56 | .06 |
| Satisfaction with services | -1.4 | 57 | .17 |

Child's Difficulties

| Grouping Variable: Child's Difficulties Outcome Variable: IFS Score | t | df | p |
|--|----------|-----------|----------|
| Breathing | 1.10 | 46 | .06 |
| Seizures | -.63 | 45 | .54 |
| Pain & Discomfort | 1.8 | 48 | .08 |
| Eating & Drinking | .66 | 46 | .51 |
| Communication | -.36 | 46 | .71 |
| Behaviour | .72 | 46 | .48 |
| Mobility | -1.42 | 46 | .16 |
| Continence | .58 | 44 | .56 |
| Other difficulty | .85 | 46 | .40 |

Appendix Q: Distribution of IFS Scores and Selection of Interview Participants from Survey Sample

Random Selection of Interviewees.

N = 55 Min = 31 Max = 58 Mean = 45 Range = 27

Low Impact = 31-39: Mean Impact = 40-48: High Impact = 49-58

Respondents' IFS Scores: Low = 20% (11): Mean = 51% (28) High = 29% (16)

Number of valid consent for interview = 41 (i.e returned interview consent & has total IFS score).

Decision – Conduct 12 interviews (30% of eligible participants)

Requirements – 2 x Low Impact (20% of 12)

6 x Mean Impact (50% of 12)

4 x High Impact (30% of 12)

Shaded boxes indicate all participants to participate. Red text indicates interviews conducted.

| | | | | | |
|------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| 41.00 = 2 | 48.00 = 3 | 58.00 = 4 | 40.00 = 5 | 40.00 = 6 | 42.00 = 7 |
| 45.00 = 9 | 31.00 = 10 | 52.00 = 11 | 45.00 = 12 | 48.00 = 13 | 47.00 = 14 |
| 44.00 = 15 | 53.00 = 16 | 31.00 = 17 | 42.00 = 18 | 56.00 = 19 | 35.00 = 20 |
| 37.00 = 21 | 52.00 = 22 | 48.00 = 23 | 42.00 = 25 | 54.00 = 26 | 42.00 = 27 |
| 53.00 = 28 | 48.00 = 29 | 45.00 = 31 | 37.00 = 32 | 44.00 = 34 | 39.00 = 35 |
| 50.00 = 37 | 51.00 = 38 | 49.00 = 39 | 53.00 = 40 | 55.00 = 42 | 41.00 = 43 |
| 39.00 = 44 | 44.00 = 45 | 38.00 = 46 | 44.00 = 47 | 31.00 = 48 | 45.00 = 49 |
| 42.00 = 50 | 48.00 = 51 | 48.00 = 52 | 52.00 = 53 | 41.00 = 54 | 46.00 = 55 |
| 47.00 = 56 | 54.00 = 57 | 52.00 = 58 | 44.00 = 60 | 51.00 = 61 | 39.00 = 62 |
| 35.00 = 63 | | | | | |

Appendix R: *Topic Guide for Parents' Interviews*

- (1) You have already told us in your questionnaire about the particular challenges and difficulties that [child's name] experiences, can you tell me a little bit more about how you manage these day to day?

- (2) How does this influence day-to-day life for your family?
 - a. Management of daily life
 - b. Impact on siblings
 - c. Family relationships

- (3) Can you explain to me what you find most difficult about your current situation?

- (4) Can you tell me about the services that [child's name] and your family receive?
 - a. What services are received and how were these organised?
 - b. How do the services you receive help support you in caring for your child?
 - c. Are there any areas where you feel improvements could be made? Why?

- (5) What do you think would make the situation for families like your easier?

- (6) Is there anything that you would like to add?

Appendix S: Interview Inter-Rater Reliability

(1) Coding Convergence and Divergence on Individual Interviews¹

| Interview No. | Overall Agreement | Number of Items Not Coded | |
|---|-------------------|---------------------------|--------------|
| | | Primary Coder | Second Coder |
| 1 | 96.1% | 8 | 3 |
| 2 | 97.6% | 9 | 3 |
| 3 | 89.6% | 10 | 8 |
| Overall Inter-Rate Agreement = 94.4% | | | |

(2) Agreement on Individual Categories and Codes²

| Subthemes & Coding Categories | Code ID | No. of Times Occurred | No of Times Agreed | No. of Times Not Agreed | Overall Percentage Agreement |
|---|---------|-----------------------|--------------------|-------------------------|------------------------------|
| Child Related Coding Categories | | | | | |
| <i>Ordeal of the Child's Condition</i> | | 42 | 41 | 1 | 97% |
| Physical problem experienced by the child | 01 | 16 | 16 | 0 | 100% |
| Rarity of the child's condition | 02 | 5 | 5 | 0 | 100% |
| Uncertainty / unpredictability of the child's condition | 03 | 8 | 8 | 0 | 100% |
| Unrelenting & repetitive nature of the care provided | 04 | 8 | 7 | 1 | 88% |
| Exclusion of child from social events and opportunities | 05 | 1 | 1 | 0 | 100% |
| Grappling with the enormity of the child's diagnosis | 06 | 4 | 4 | 0 | 100% |
| <i>Child's Exceptionality</i> | | 18 | 18 | 0 | 100% |
| Defying the odds / proving them wrong | 07 | 0 | n/a | n/a | n/a |
| Positive emphasis on the child's achievement | 08 | 4 | 4 | 0 | 100% |
| Emphasis on the child as a unique personality | 09 | 3 | 3 | 0 | 100% |
| Child as a fundamental element of the family unit | 10 | 11 | 11 | 0 | 100% |

¹ This related to text that was not coded by the primary coder but coded by the second, or vice versa. Principally this related to large sections of interview text where a code was applied once by one coder but twice by the other.

² Not all categories were relevant to the interviews that were second coded. Subsequently the percentage agreement for each category is calculated using only the items that were relevant in that particular category.

| Family Related Coding Categories | | | | | |
|---|-----------------|------------------------------|---------------------------|--------------------------------|-------------------------------------|
| <i>Starting Out</i> | | 22 | 20 | 2 | 91.5% |
| The Beginning | 11 | 9 | 9 | 1 | 88.8% |
| Subthemes & Coding Categories | Code I.D | No. of Times Occurred | No of Times Agreed | No. of Times Not Agreed | Overall Percentage Agreement |
| Organising outside life | 12 | 6 | 6 | 0 | 100% |
| Coming home | 13 | 7 | 6 | 1 | 85.7% |
| <i>Keeping the Show on the Road</i> | | 77 | 74 | 3 | 96.1% |
| Facing the day-to-day challenges | 14 | 16 | 16 | 0 | 100% |
| Precision planning and organisation | 15 | 12 | 12 | 0 | 100% |
| Developing and utilising resources | 16 | 21 | 20 | 1 | 95.2% |
| Attempting to maintain a sense of normality | 17 | 9 | 9 | 0 | 100% |
| Adopting a positive perspective | 18 | 11 | 11 | 0 | 100% |
| Anticipating the future | 19 | 8 | 6 | 2 | 75% |
| <i>Shouldering the Burden</i> | | 40 | 37 | 3 | 92.5% |
| Impact on the Mother | 20 | 30 | 27 | 3 | 90% |
| Impact on Siblings | 21 | 4 | 4 | 0 | 100% |
| General Impact on the Family | 22 | 6 | 6 | 0 | 100% |
| <i>Wider Perceptions</i> | | 8 | 8 | 0 | 100% |
| Lack of empathy and sensitivity | 23 | 4 | 4 | 0 | 100% |
| Alteration in fundamental belief system | 24 | 4 | 4 | 0 | 100% |
| Confronting public perceptions | 25 | 0 | n/a | n/a | n/a |

| Service Related Coding Categories | | | | | |
|--|-----------------|------------------------------|---------------------------|--------------------------------|-------------------------------------|
| <i>Hospital Based Services</i> | | <i>21</i> | <i>19</i> | <i>2</i> | <i>86%</i> |
| The hospitalisation experience | 26 | 7 | 6 | 1 | 86% |
| Expertise and consistency | 27 | 5 | 4 | 1 | 80% |
| Accessing acute services | 28 | 9 | 9 | 0 | 100% |
| <i>Community Based Services</i> | | <i>83</i> | <i>78</i> | <i>5</i> | <i>94%</i> |
| Getting what is needed | 29 | 29 | 28 | 1 | 97% |
| Fit between the services and the child / family | 30 | 26 | 23 | 3 | 89% |
| Complexity of respite services | 31 | 2 | 2 | 0 | 100% |
| Subthemes & Coding Categories | Code I.D | No. of Times Occurred | No of Times Agreed | No. of Times Not Agreed | Overall Percentage Agreement |
| Process / orientation of service delivery | 32 | 26 | 25 | 1 | 96% |
| Learning how the system works | 33 | 0 | n/a | n/a | n/a |
| <i>General Services Issues</i> | | <i>19</i> | <i>19</i> | <i>0</i> | <i>100%</i> |
| Communication | 34 | 8 | 8 | 0 | 100% |
| Geography | 35 | 8 | 8 | 0 | 100% |
| Importance of individual attitudes and orientation | 36 | 3 | 3 | 0 | 100% |

Appendix T: Delphi Interview Topic Guide

Delphi Interview

Interview Topic Guide

This interview is concerned with the following topics

- (1) Can you begin by explaining what, in your expert opinion, are the goals of care / the principles that should govern care when a child has a life-limiting neurodevelopmental disability?
 - Explain why each goal is important / relevant in the care of this population.
- (2) In your opinion how do current services meet those goals?
 - Which goals are achieved and which are not?
 - If goals are not achieved in the context of current services why do you think this is so?
- (3) What changes are necessary to current services to improve the care of children with life-limiting developmental disabilities and their families?
 - What is required in order to achieve these changes?



Delphi Survey – Round 2

Exploring the Palliative Care Needs and Delivery of Services to Young Children with Life-Limiting Neurodevelopmental Disabilities and their Families

Please read the following information before completing the questionnaire.

Thank you for completing the first round of this Delphi.

This second round questionnaire is based on the analysis of information provided in the previous round together with information obtained from a national survey of parents and interviews conducted with health professionals working in this area.

The format of this round is different to the previous one. This questionnaire is divided into three sections. In sections 1 and 3 you are asked to rank order issues relative to their importance in the overall care of children with life limiting disabilities' and their families.

In section 2 you are presented with a list of statements on which you are asked to rate your agreement using a simple 5 point Likert scale. Instructions for completing each section are provided at the outset. Please read these carefully before completing the questionnaire.

The questionnaire should take no more than 30 minutes of your time to complete. It is vital to the success and credibility of this study to have a high a response rate, so I would ask that you return this questionnaire even if you did not respond to the previous round.

Please return completed questionnaires in the prepaid enveloped by September 10th.

Thank you.

Section 1

This section relates to the goals of care for children with life-limiting neurodevelopmental disabilities and their families.

Based upon the data collected from parents and the responses from round one the following issues were identified as the important goals of care for children with life-limiting neurodevelopmental disabilities and their families. You are asked to do two things with this list -

1. Please read and review all of the 13 goals on the list. Please rank these goals in order of their importance for the care of these children and families. Assign a weight of one (1) to the *most important*, two (2) to the *second* most important etc. until you have completed all 13.
2. Comment, in one or two statements, on any goal(s) that you wish. You may argue in favour of a goal, against a goal, or request clarification. Brevity and clarity will facilitate analysis.

| Goal Weight | Improvement | Comment |
|-------------|---|---------|
| | <p>The child is cared for at home.</p> <p>Achievement of the best possible quality of life for the child.</p> <p>Provision of appropriate respite services.</p> <p>Achievement of the child's full potential within the limits of the illness.</p> <p>Inappropriate medical interventions are minimised.</p> <p>The family continues to function as a unit and enjoy life.</p> <p>Promotion of normality as much as possible for the child and family.</p> <p>Open & honest communication with the family.</p> <p>The child's life is prolonged.</p> <p>Optimum management of symptoms.</p> <p>Parents are supported with the provision of care.</p> <p>The family is provided with the hope that things will get better.</p> <p>Achievement of a seamless web of care.</p> | |

If there are other comments that you would like to add please include them in the space provided on the next page.

Please use this space if you would like to provide any additional comments on the Goals of Care listed in Section 2

Section 2

This section relates to the current provision of service to children with life-limiting neurodevelopmental disabilities and their families.

Please read each statement carefully and indicate your agreement by marking the box that best represents your view from 5 = *strongly agree* to 1 = *strongly disagree*.

| | <i>Strongly Agree</i> | <i>Agree</i> | <i>Not Sure</i> | <i>Disagree</i> | <i>Strongly Disagree</i> |
|---|-----------------------|--------------|-----------------|-----------------|--------------------------|
| 1. Children with life-limiting neurodevelopmental disabilities and their families are well served by current services. | 5 | 4 | 3 | 2 | 1 |
| 2. A lack of key workers for families results in the ad hoc delivery of services to this population. | 5 | 4 | 3 | 2 | 1 |
| 3. The child and the family are seen as a single unit of care. | 5 | 4 | 3 | 2 | 1 |
| 4. There is a heavy reliance upon charity services to meet the needs of this population. | 5 | 4 | 3 | 2 | 1 |
| 5. There is sufficient psychological support available to parents of children with life-limiting neurodevelopmental disabilities. | 5 | 4 | 3 | 2 | 1 |
| 6. These children often undergo futile investigations and procedures. | 5 | 4 | 3 | 2 | 1 |
| 7. Services are flexible enough to respond to a family crisis at short notice. | 5 | 4 | 3 | 2 | 1 |
| 8. There is poor communication between acute services and community based services in the care of these children. | 5 | 4 | 3 | 2 | 1 |
| 9. Medical teams lack interest in these children because of their limited prognosis. | 5 | 4 | 3 | 2 | 1 |
| 10. Current respite services are sufficient to meet the needs of this population. | 5 | 4 | 3 | 2 | 1 |
| 11. General Practitioners lack the experience and expertise to deal effectively with these children. | 5 | 4 | 3 | 2 | 1 |
| 12. There is sufficient psychological support available to siblings of children with life-limiting neurodevelopmental disabilities. | 5 | 4 | 3 | 2 | 1 |
| 13. There is poor coordination and integration of services involved in the care of these children and their families. | 5 | 4 | 3 | 2 | 1 |
| 14. Medical staff are reluctant to discuss the fact that children are “life-limited” with parents. | 5 | 4 | 3 | 2 | 1 |
| 15. There is good home support for end-of-life care for these children. | 5 | 4 | 3 | 2 | 1 |

| | <i>Strongly Agree</i> | <i>Agree</i> | <i>Not Sure</i> | <i>Disagree</i> | <i>Strongly Disagree</i> |
|--|-----------------------|--------------|-----------------|-----------------|--------------------------|
| 16. Medical teams fail to recognise the palliative needs of the child. | 5 | 4 | 3 | 2 | 1 |
| 17. The services available in the community are dependent upon where the child lives. | 5 | 4 | 3 | 2 | 1 |
| 18. Palliative care is only considered late in the child's condition or in crisis management. | 5 | 4 | 3 | 2 | 1 |
| 19. Out patient appointments are prioritised in favour of these children and their families. | 5 | 4 | 3 | 2 | 1 |
| 20. Children and families suffer because of long delays in obtaining necessary equipment. | 5 | 4 | 3 | 2 | 1 |
| 21. Health services are under-resourced with respect to services required for these children and their families. | 5 | 4 | 3 | 2 | 1 |
| 22. Health professionals acknowledge parents expertise in the care of their child. | 5 | 4 | 3 | 2 | 1 |
| 23. Acute services are not aware of the range of services that are available to these children and their families in the community. | 5 | 4 | 3 | 2 | 1 |
| 24. Access to specialist palliative care services is readily available to these children if it is required. | 5 | 4 | 3 | 2 | 1 |
| 25. The lack of staff within services results in children not receiving the care they need. | 5 | 4 | 3 | 2 | 1 |
| 26. It is easy for parents to access the services their child needs. | 5 | 4 | 3 | 2 | 1 |
| 27. Families receive conflicting information about their child from different services. | 5 | 4 | 3 | 2 | 1 |
| 28. It is difficult to get a holistic view of the child's needs because of the number of different health professionals and services involved in the child's care. | 5 | 4 | 3 | 2 | 1 |
| 29. It is easy for parents to get information about the services that are available to their child. | 5 | 4 | 3 | 2 | 1 |
| 30. Insufficient funding results in the need to ration services to these children and their families. | 5 | 4 | 3 | 2 | 1 |
| 31. There is collaboration between the different services regarding the goals of care for these children. | 5 | 4 | 3 | 2 | 1 |
| 32. Parents are considered equal partners in the setting and prioritising of goals for their child's care. | 5 | 4 | 3 | 2 | 1 |

Section 3

This section relates to suggestions for improving the situation for children with life-limiting neurodevelopmental disabilities and their families.

Based upon the data collected from parents and the responses in round one of the survey the following issues were identified as the most important factors for improving the situation for this population of children and their families.

You are asked to do two things with this list of factors -

1. Please read and review all of the 18 factors on the list. Rank the factors in order of their potential to improve the current situation for children and their families. Assign a weight of one (1) to the factor you believe would make the *most important* contribution, two (2) to the *second* most important factor etc. until you have assigned a weight to all 18 factors.

2. Comment, in one or two statements, on any factor(s) that you wish. You may argue in favour of a factor, against a factor, or request clarification. Once again, brevity and clarity will facilitate analysis.

| Weight | Factor | Comment |
|--------|---|---------|
| | A greater level of communication between the different health professionals involved in the care of the child. A key worker available to every family. | |
| | A single care plan that is used across all services. | |
| | A greater level of coordination and integration of the services involved in the care of the child. | |
| | A single point of contact for information for families. | |
| | Less bureaucracy surrounding family's entitlements. | |
| | Access to specialist palliative care in a timely and efficient manner. | |
| | Parent held medical records. | |

A national directory of the services available to children and their families.

Improved education for community based health professionals.

A specialist paediatric palliative care consultant to act as a resource when required.

A formal coordinator of services for children with life-limiting disabilities in every HSE area.

Affording “medical priority” status to these children in Emergency and Outpatient departments.

Development of community based paediatric palliative care teams.

Improved respite facilities.

Less protracted ordering system for essential equipment.

Improved liaison between acute services and other service providers.

National standards of service and care.

Thank you for completing the second round of this Delphi survey.

Please use the final sheet of the questionnaire if you would like to make any additional comments on the factors listed in section 3 of the questionnaire.

Please use this space if you would like to provide any additional comments on the factors listed in Section 3

A large, empty rectangular box with a thin black border, intended for providing additional comments on the factors listed in Section 3.

Appendix V: Sample of Content Analysis of Delphi Interviews

| Interview Excerpt | Issue Identified |
|--|--|
| Goals of Care | |
| to try and make things a bit easier and for them to get on with their normal day to day activity then they cant give up, even though alot of families do.... they cant give up everything just for this child they may have other siblings, other family members that need help and you cant expect everyone just to focus on the child everyday. | Promotion of normality as much as possible for child and family |
| I suppose the first thing to say is that its not just the goal of the child and the care of the child, it's the child and family I think you cant separate the two because quite often this population of children cant communicate themselves and would have varying development levels so I think it's the two together. Secondly I think the main goals are individual to each child I think they have to arise for a full assessment for the needs of that child and family and I suppose they really from my opinion they would be optimising the quality of life of that child I suppose... | <p>Goal of family focused care</p> <p>Goal of individualised care</p> <p>Optimising quality of life</p> |
| Service Related Issues | |
| Unfortunately the hospital system and the medical system doesn't work that way and it is open to team to team to team and so one of the main goals of care and certainly my role is to try and co-ordinate that care and to try and make it less confusing for the family... I think that is one of the biggest things is in a way trying to simplify life for the family. | Key worker can coordinate care / make system less confusing for family / simplify life for family. |
| I think we do [meet the needs of the family] sometimes, I don't think it's as formal, alot of the time it is informally and I think it can be done a bit ad hoc and in retrospect you look and see are we meeting the needs of this family, are we prioritising and setting appropriate goals I think alot of time we are, but I think it is hugely dependent on the individual that's linked in with the family, the family themselves. | <p>Needs are sometimes met, but it is usually on an ad hoc basis</p> <p>Link person is vital to meeting needs of family</p> |
| Required Changes | |
| there are family out there that do fall through the trap and we don't cover their needs properly and we don't identify proper goals and care for them, I think there are alot of families that weren't sort of were not providing effective care for, I think it comes back to maybe becoming a bit more effective communication between the different disciplines that are linked in with the child, and stating more clearly to the child and family what we think they need, talking to them and letting them know what they need, and nearly documenting it all, and actually setting out a care plan that is not just on their nursing care plan for the hospital, but a care plan for their day to day life at home. | <p>Sometimes fail to meet the needs of families</p> <p>More effective inter-professional communicating needed</p> <p>More effective communication with family needed</p> |
| So I don't know whether there needs to be a review of services in the community so that there is nearly a directory of knowing who is where and what they provide and what their admission criteria are or whatever and then that being provided to the acute setting. Because quite often the acute setting doesn't know what the primary care setting is doing. | Need for a directory of primary care services |