

## **APPENDIX A**

## QUESTIONNAIRE FOR PARENTS

**For office  
use only**

1. Respondentnumber

V1

2. Card number

V2

**Please mark the applicable answer**

3. Question 1

Age of father

30 – 35	1
36 – 40	2
41 – 45	3
46 – 50	4
Older than 50	5

V3

4. Question 2

Age of mother

30 - 35	1
36 - 40	2
41 - 45	3
46 - 50	4
Older than 50	5

V4

5. Question 3

Number of children in the family

One	1
Two	2
Three	3
Four	4
Five	5
More than five	6

V5

6. Question 4

Birth position of the disabled child in the family.

First	1
Second	2
Third	3
Fourth	4
Fifth	5
Fifth +	6

V6

7. Question 5

Birth position of the brother/sister in the family

First	1
Second	2
Third	3
Fourth	4
Fifth	5
Fifth +	6

V7

8. Question 6

Home language

Afrikaans	1
English	2

V8

9. Question7

Where does the disabled child live?

At home	1
At boarding school and comes home for weekends and holidays	2
At boarding school and only comes home for holidays	3

V9

10. Question 8

Did any member of your family ever receive help in order to adapt to the fact that one of the children is disabled?

Yes	1
No	2

V10

If yes, from whom?

Doctors	1
Therapists	2
Teachers	3
Other parents of disabled children	4
Other Specify	5

V11

V12

V13

V14

V15

**Answer the following questions**

11. Question 9

Describe your child's disability

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V16

V17

V18

12. Question 10

Who informed the other children about their brother's/sister's disability?

\_\_\_\_\_ V19

13. Question 11

What was the brothers/sisters told regarding the disability of their disabled sibling?

\_\_\_\_\_ V20

\_\_\_\_\_ V21

\_\_\_\_\_ V22

**Mark the applicable answer**

14. Question 12

How will you describe your family in terms of their adaptation to the fact that one of the children is disabled?

Very well adapted	1
Well adapted at times	2
In general it is difficult	3

V23

15. Question 13

Do you think that at this stage your family needs additional help in adapting to the fact that one of the family members is disabled?

Yes	1
No	2

V24

If yes, please explain why you think so?

V25

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V26

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V27

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## VRAELYS VIR OUERS

### Slegs vir kantoorgebruik

1. Respondentnommer

V1

2. Kaartnommer

V2

**Merk asseblief wat van toepassing is**

3. Vraag 1

Ouderdom van vader

30 - 35	1
36 - 40	2
41 - 45	3
46 - 50	4
Ouer as 50	5

V3



#### 4. Vraag 2

Ouderdom van moeder

30 - 35	1
36 - 40	2
41 - 45	3
46 - 50	4
Ouer as 50	5

V4

#### 5. Vraag 3

Aantal kinders in die gesin

Een	1
Twee	2
Drie	3
Vier	4
Vyf	5
Meer as vyf	6

V5

### 6. Vraag 4

Geboorte posisie van die gestremde kind in die gesin

Eerste	1
Tweede	2
Derde	3
Vierde	4
Vyfde	5
Vyfde +	6

V6

### 7. Vraag 5

Geboorte posisie van die broer / suster

Eerste	1
Tweede	2
Derde	3
Vierde	4
Vyfde	5
Vyfde +	6

V7

### 8. Vraag 6

Huistaal

Afrikaans	1
Engels	2

V8

9. Vraag 7

Waar bly die gestremde kind?

By die huis	1
In die koshuis en kom naweke en vakansies huis toe	2
In die koshuis en kom slegs vakansies huis toe	3

V9

10. Vraag 8

Het u gesin ooit hulp gehad om aan te pas by die feit dat een

Van die kinders gestremd is?

Ja	1
Nee	2

V10

Indien ja, van wie het u hulp ontvang?

Dokters	1
Terapeute	2
Onderwysers	3
Ander ouers van gestremde kinders	4

V11

V12

V13

V14


Ander	5
Spesifiseer	

V15

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**Beantwoord die volgende vrae asseblief volledig**

11. Vraag 9

Beskryf u kind se gestremdheid

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V16

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V17

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V18

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12. Vraag 10

Wie het die ander kinders in die gesin ingelig oor die gestremdheid van hul broer / suster?

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V19

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### 13. Vraag 11

Wat is aan die gestremde kind se broers / susters gesê aangaande die gestremdheid?

	V20	
	V21	
	V22	

### Merk wat van toepassing is

### 14. Vraag 12

Hoe sal u u familie beskryf in terme van aanpassing by die gestremdheid?

Baie goed aangepas	1
Goed aangepas met tye	2
Oor die algemeen is dit moeilik	3

V23

### 15. Vraag 13

Dink u dat u gesin op hierdie stadium addisionele hulp nodig het om aan te pas by die feit dat een van die gesinslede gestremd is?

Ja	1
Nee	2

V24

Indien ja, verduidelik asseblief waarom u so dink?

V25

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V26

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V27

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## **APPENDIX B**

## VRAE VIR DIE ONDERHOUD MET DIE SIBBE

1. Ek wil vandag met jou gesels oor jou broer(s) en/of suster(s). Hoeveel broer(s) en/of susters het jy?

- Vertel my meer van hulle
- Hoe kom julle oor die weg?

2. Vertel my meer van naam van gestremde kind.

3. Het iemand jou al ooit vertel wat presies fout is met \_\_\_\_\_ ?

- Het jy al op jou eie meer probeer uitvind daaroor?

- 

Wat dink jy sal in die toekoms gebeur met \_\_\_\_\_ ?

4. Hoe voel jy daaroor om so 'n broer/suster te hê?

5. Wat sê jy vir jou vriende of vreemde mense as hulle jou uitvra oor \_\_\_\_\_ ?

- Hoekom sê jy dit vir hulle?
- Hoe dink jy voel hulle oor \_\_\_\_\_ ?

6. Baklei jy en jou broer(s) en/of suster(s) ooit?

- Wat veroorsaak gewoonlik dat julle baklei?
- Wat gebeur gewoonlik as julle baklei?
- Hoe tree jy gewoonlik op in so 'n situasie?
- Hoe reageer jou ouers as julle baklei?

7. Wat dink jy dink jou vriende van jou?



- Hoekom dink jy dink hulle so?
- Hoe voel jy daaroor?

8. Is daar van julle familieledede buite julle gesin, bv. 'n ouma/oupa en ooms/tannies wat soms help met \_\_\_\_\_ ?

- Hoe help hulle julle gesin?
- Hoe dink jy voel hulle oor \_\_\_\_\_ ?

9. Praat jy en jou ouers ooit oor \_\_\_\_\_ ?

- Wat bespreek julle as julle oor hom/haar praat?
- Is daar soms sake waaroor julle nie saamstem nie?
- Wat gebeur gewoonlik in so 'n situasie?

10. Wat se veranderings moet jy in jou lewe maak as gevolg van \_\_\_\_\_ ?

- Hoe voel jy daaroor ?
- Is daar dinge wat jy nie kan doen nie as gevolg van \_\_\_\_\_ ?
- (Ja) Soos wat?

of

- (Nee) Is daar dinge wat moeilik is as gevolg van \_\_\_\_\_ ?
- Is daar dinge wat jou nou meer irriteer as toe jy jonger was?
- Dink jy dat dit verkeerd is om so te voel?

11. Watter ander mense, bv. die bure, vriende of die kerk, ondersteun julle gesin?

- Wat doen hulle om julle te ondersteun?
- Hoe dink jy voel hulle oor \_\_\_\_\_ ?

12. Baklei jy en \_\_\_\_\_ ooit?

- Wat veroorsaak gewoonlik dat julle baklei?
- Hoe tree jy gewoonlik op in so 'n situasie?
- Hoe reageer jou ouers as julle baklei?

13. As jy jou lewe kon verander het, watter drie dinge sou jy wou verander of vir watter drie dinge sou jy wens?

- Hoekom?

## QUESTIONNAIRE FOR SIBLINGS

1. I want to talk to you about your brother(s) and sister(s).

- How many brother(s) and sister(s) do you have?
- How do you get along with each other?

2. Tell me more about x.

3. Has anyone ever told you what exactly is wrong with x ?

- Have you ever tried to find out more about the disability on your own?
- What do you think will happen to him/her in the future?

4. How do you feel about having a brother/sister like that?

5. What do you tell your friends/strangers when they ask you about x ?

- Why do you tell them that?
- How do you think they feel about x ?

6. Do you and your brother(s) and sister(s) ever fight?

- What usually causes a fight?
- What usually happens when you fight?
- How do you usually act in a situation like that?
- How do your parents react when you fight with your brother(s) and/or sister(s)?

7. What do you think your friends think about you?

- Why do they think that?
- How do you feel about that?

8. Are there family members outside of your immediate family circle, e.g. your grandparents and uncles/ aunts, that sometimes do things to help your family with x ?

- How do they help your family?
- How do you think they feel about x ?

9. Do you and your parents ever talk about x ?

- What do you discuss when you talk about him/her?
- Are there things that you sometimes disagree on?
- What usually happens in a situation like that?

10. What changes do you have to make to your life because of X ?

- How do you feel about that?
- Are there things that you can't do because of x ?
- (Yes) What are they?

or

(No) Are there things that are difficult to do because of x ?

- Are there things about x that irritate you now more than it did before?
- Do you think it is wrong to feel this way?

11. What other people, e.g. neighbours, family friends and people from the church, support your family with x ?

- What do they do to support your family?
- How do you think they feel about x?

12. Do you and x ever fight?

- What usually causes a fight?
- What usually happens when you fight?
- How do you usually act in a situation like that?
- How do your parents react when you and x fight?

13. If you could change your life, which three things would you like to change/ which three things would you wish for?

- Why?

## APPENDIX C

## **RESULTS – SUBJECT 3; 15 YEARS**

### **1. *I want to talk to you about your brothers and sister.***

- *How many brothers and sisters do you have?*

Uhhh.. I have two older brothers .. and one older half brother .... and my sister, younger sister.

- *How do you get along with each other?*

Oh we get along very well, because uhm ..... oh .. there's a big line of respect. I respect my brothers and they respect me and I respect my little sister and she respects me. So we hardly squibble .. it's very rare.

### **2. *Tell me more about Mpepu.***

Oh, I think she's a very great thing in all our lives, because she is ... she reminds us of the simplicity of life. We don't really need all the things that we think we need... and uh... she's a very important part of our lives.

### **3. *Has anyone ever told you what exactly is wrong with Mpepu?***

My parents have told me exactly what is wrong with her. Her right brain is damaged .. there was a lack of oxygen when she was born .... and it's impaired her muscles a little bit and her balance and her ability to excel academically .... I don't know, she's going to ..... she's pretty big for her age, you know? She uhh.... mentally I think she's growing, she's growing pretty slowly. We still refer to her as "Baby", because that's .. she's got around a three, four years old ... mentality .. so .....

- *Have you ever tried to find out more about the disability on your own?*

Uhhh.. I feel that I know enough about it.

- *What do you think will happen to her in the future?*

That's a real tough question, because .... ai..... especially in South Africa .... I mean the schools here are, aren't really ... the ... developed and are .... uh .. it's just not good enough, because I don't know..... while we were staying in the US, even in one year she developed so quickly ... she was so self-sufficient. I don't know, ever since she's come back here, she's just ... she's regressing....

**4. *How do you feel about having a sister like that?***

I think it's great, because it's just ... uhm .. like I said... it reminds me to just stay simple and to learn what actually counts most.

**5. *What do you tell your friends or strangers when they ask you about Mpepu?***

Oh, I'm very honest. I'm not ashamed of her at all. I tell them .. what's wrong with her and ... how much I love her and how much I like being around her. I've never been ashamed of my sister.

- *How do you think they feel about Mpepu?*

Uhm.... it's one thing I've learnt ... you shouldn't really care ..'cause if you do, it will affect my ... the way I treat my little sister. So I don't really think about that.

**6. *Do you and your brothers ever fight?***

Not at all. We disagree, but we respect each other.



- *How do your parents react when you do fight?*

Uhm .. it depends on the situation, if my parents feel that I have been disrespectful towards my older brothers, they will reprimand me for the way I behaved, but they wouldn't allow my brothers to react in any way they would like to.

**7. *What do you think your friends think about you?***

They think of me as a successful person ... they know I am serious and that I know what I want .....

- *How do you feel about that?*

I guess I don't mind.

**8. *Are there family members outside of your immediate family circle, e.g. your grandparents and uncles/aunts, that sometimes do things to help your family with Mpepu?***

No, they live too far. My grandmother does love her, but she lives too far to really help.

**9. *Do you and your parents ever talk about Mpepu?***

Not really, but we will talk about her character ... you know ... she has a sly character ...

- *Are there things that you sometimes disagree on?*

I get irritated very easily and I don't like it if they go on about things.

**10. What changes do you have to make to your life because of Mpepu?**

No, I've never had to miss out on something because of Mpepu .....

- *Are there things that you can't do because of Mpepu?*

No .. not that I'm aware of..

- *Are there things about Mpepu that irretate you now more than before?*

There's never been a situation that I had to stay home because of Mpepu, so there has never been a situation in which i have been irretated.

**11. What other people, e.g. the meighbours, family friends or people from the church, support your family with Mpepu?**

Nobody comes to mind .... but my aunts and uncles ... they just really enjoy her company, but there is no actual financial support .. or maybe more moral support when she was younger .... just to deal with the situation ...

**12. Do you and Mpepu ever fight?**

Oh we used to, but I think she has matured a little bit now. Sometimes she just doesn't really want to do anything ..... so we fight a bit ..... but we don't really fight ....

- *What usually causes a fight?*

Uhhh..... I ..... sometimes she is disobedient. You have to know her character ... she's very ... she's very stubborn.

- *What usually happens when you fight?*

She's got very strong hands .... Being a very short person, she relies on them. She can't really rely on her feet, but she relies on her hands. She scratches ..... but this doesn't really happen since she's matured.

- *How do you usually act in a situation like that?*

When I was younger ... not in serious, but I would scratch backb but now I just walk away from her.

- *How does your parents react when you fight?*

Uhm .... my mother .... she'd be more angry at me, because ... she knows that I could control my impulses more....

**13. *If you could change your life, which three things would you like to change or which three things would you wish for?***

I'd like to see my brothers more often .. because .. they're not around the house a lot. Uhm ... I'd like to be more mobile. My parents work a lot ... like right now ..... they'll be back after seven .... there goes my Friday afternoon