



OUTCOME MEASURES

FOR

CHILDREN AND YOUNG PEOPLE

WITH

SENSORY IMPAIRMENT

FAMILIES SURVEY

March 2010

CONTENTS

	Page
1. SUMMARY	3
2. ANALYSIS OF THE QUESTIONNAIRE SAMPLE	4
Table 1: Age of C&YP	4
Table 2: Gender	4
Table 3: Ethnicity	5
Table 4: Languages used at home	5
Table 5: Disability	6
Table 6: Additional needs	6
Table 7: Setting	6
3. ANALYSIS OF THE MAIN HOPES EXPRESSED BY FAMILIES	7
Table 8: Hopes expressed by families classified according to main ECM outcomes	7
Table 9: Hopes expressed by families classified according to ECM sub-outcomes	9
APPENDIX: QUESTIONNAIRE TOOL	14

1. SUMMARY

As part of the NatSIP work on the development of outcome measures for children and young people with sensory impairment, a London regional group, led by Helen Forbes-Low and Elizabeth Clery, was tasked with consulting families to determine the outcomes that are most important to them.

A questionnaire survey was employed which asked parents to list their five main hopes for their child/young person. The questionnaire appears in the Appendix.

103 questionnaire returns were received. Details of the sample are presented (ref. Tables 1 - 7). The main hopes of parents were collated and classified according to the ECM outcomes framework (ref. Tables 8 –9). A commentary is provided where appropriate.

The information obtained from the families' survey will be used to inform the future selection of outcomes beyond the initial pilot set of seven measures.

Nat SIP FAMILIES SURVEY

2. ANALYSIS OF THE QUESTIONNAIRE SAMPLE

Respondents

There were 103 questionnaire returns. (N.B. Not all sections were completed by each respondent).

Table 1: Age of C&YP

Age range	No. of C&YP
0 – 11 mths	8
1 yr. 0 mths – 1 yr. 11 mths	2
2 yr. 0 mths – 2 yr. 11 mths	8
3 yr. 0 mths – 3 yr. 11 mths	10
4 yr. 0 mths – 4 yr. 11 mths	4
5 yr. 0 mths – 5 yr. 11 mths	5
6 yr. 0 mths – 6 yr. 11 mths	4
7 yr. 0 mths – 7 yr. 11 mths	1
8 yr. 0 mths – 8 yr. 11 mths	11
9 yr. 0 mths – 9 yr. 11 mths	4
10 yr. 0 mths – 10 yr. 11 mths	6
11 yr. 0 mths – 11 yr. 11 mths	4
12 yr. 0 mths – 12 yr. 11 mths	7
13 yr. 0 mths – 13 yr. 11 mths	11
14 yr. 0 mths – 14 yr. 11 mths	6
15 yr. 0 mths – 15 yr. 11 mths	5
16 yr. 0 mths – 16 yr. 11 mths	2
17 yr. 0 mths – 17 yr. 11 mths	1
18 yr. 0 mths – 18 yr. 11 mths	2
Total	101

Table 2: Gender

Gender	No. of C&YP
Male	57
Female	44
Total	101

Table 3: Ethnicity

Ethnicity	No. of C&YP
White British	53
White Irish	1
Any other White background	8
Caribbean	2
African	7
Any other Black background	2
Indian	4
Pakistani	7
Bangladeshi	0
Any other Asian background	5
White and Caribbean	2
White and Black African	2
White and Asian	2
Any other mixed background	2
Chinese	0
Any other ethnic group	4
Total	101

Table 4: Languages used at home

Languages	No. of Families
English	33
English & BSL	2
English & Tagalog	1
English & Swahili	2
English & Tamil	3
English, Tamil & Makaton	1
English, Creole & BSL	1
English & Yurabi	1
English & Polish	1
English & Urdu	2
English & French	1
English, Polish, Portuguese & Makaton	1
Farsi	1
Italian	1
Portuguese	1
Swahili	1
Tamil	1
Yonba	1
Yurabi	1
Total	56

Table 5: Disability

HI	Mild	Mod.	Mod./Sev.	Sev.	Sev./Prof.	Prof.	Total
	1	13	3	18	3	20	
VI	Mild	Mod.	Mod./Sev.	Sev.	Blind		
	5	10	6	1	13		35
MSI							8
Total							101

Table 6: Additional needs

Additional needs were specified for 52 C&YP

Additional needs	No. of entries
Physical	16
Speech and language	24
Moderate learning difficulty	13
Severe learning difficulty	7
Medical condition	23
ASD	3
EAL	2
Behaviour	2
Global delay	1
Total entries	91

Table 7: Setting

Setting	No. of entries
Home	14
Pre-school	13
Mainstream School	36
Mainstream Resourced Base	28
Special School	7
Further Education	3
Total entries	101

3. ANALYSIS OF THE MAIN HOPES EXPRESSED BY FAMILIES

Table 8: Hopes expressed by families classified according to main ECM outcomes

The analysis is based upon 103 questionnaire returns. (N.B. Not all parents entered 5 'Main Hopes' – some offered more, some less)

A breakdown by type of SI has been provided to help in deciding whether particular outcomes might be more appropriately targeted to the nature of the disability.

The potential for further analysis clearly exists e.g. according to broad age bands.

A full detailing and classification of the 'Main Hopes' behind the summary data presented in both tables 8 and 9 is available for working group reference.

N.B. The 'All SI' group includes entries from two respondents who did not specify their child's type of SI. This accounts for the disparity between the total number of entries for All SI (521) and the combined total number of entries for HI, VI and MSI (510).

ECM OUTCOMES	MAIN HOPES							
	ALL SI		HI		VI		MSI	
	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries
Be Healthy	85	16.3%	45	15.2%	29	16.8%	11	27.5%
Stay Safe	24	4.6%	13	4.4%	7	4.0%	4	10.0%
Enjoy and Achieve	213	40.9%	122	41.1%	70	40.5%	17	42.5%
Make a positive contribution	123	23.6%	71	23.9%	44	25.4%	5	12.5%
Achieve economic well-being	76	14.6%	46	15.5%	23	13.3%	3	7.5%
Total	521	100%	297	100%	173	100%	40	100%

Commentary

Overall, Enjoy and Achieve has the highest percentage of 'Main Hopes' entries, (nearly double that of the outcome with next highest) and Stay Safe by far the lowest.

The profile of the percentage of entries against the main ECM outcomes is very similar for HI and VI.

Whilst Enjoy and Achieve is again the highest ranking outcome for MSI, there is a greater emphasis on Be Healthy and Stay Safe within this group in comparison with HI and VI. It should be noted, however, that the sample of MSI was low (only 8 cases) which brings into question the reliability of the data.

Table 9: Hopes expressed by families classified according to ECM sub-outcomes

N.B. Whilst the ECM sub-outcomes are based on those set out within the ECM framework, they have been extended/ amended in certain cases to reflect the nature of the 'Main Hopes' expressed by families.

ECM OUTCOMES	MAIN HOPES							
	ALL SI		HI		VI		MSI	
Be Healthy	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries
Physically healthy	23	4.4%	10	3.4%	7	4.0%	6	15.0%
Mentally and emotionally healthy	58	11.1%	32	10.8%	20	11.6%	5	12.5%
Sexually healthy	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Healthy lifestyles	4	0.8%	3	1.0%	2	1.2%	0	0.0%
Choose not to take illegal drugs	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Stay Safe								
Safe – non specific	2	0.4%	1	0.3%	1	0.6%	0	0.0%
Safe from maltreatment, neglect, violence and sexual exploitation	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Safe from accidental injury and death	4	0.8%	2	0.7%	2	1.2%	0	0.0%
Safe from bullying and discrimination	8	1.5%	6	2.0%	2	1.2%	0	0.0%
Safe from crime and anti-social behaviour in and out of school	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Safe from crime and anti-social behaviour in and out of school	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Have security, stability and are cared for	10	1.9%	4	1.3%	2	1.2%	4	10.0%

ECM OUTCOMES	MAIN HOPES							
	ALL SI		HI		VI		MSI	
Enjoy and Achieve	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries
Ready for school	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Attend school - appropriate placement with appropriate support	28	5.4%	17	5.7%	9	5.2%	2	5.0%
Enjoy - school	4	0.8%	0	0.0%	4	2.3%	0	0.0%
Enjoy - recreation	9	1.7%	4	1.3%	5	2.9%	0	0.0%
Enjoy - quality of life	9	1.7%	3	1.0%	5	2.9%	0	0.0%
Achieve – Speech, Language and Communication	31	6.0%	24	8.1%	2	1.2%	5	12.5%
Achieve – Age appropriate development	9	1.7%	7	2.4%	2	1.2%	0	0.0%
Achieve – Learning and academic achievement	55	10.6%	32	10.8%	18	10.4%	4	10.0%
Achieve – Self-help skills, life skills and independence	55	10.6%	25	8.4%	23	13.3%	5	12.5%
Achieve - personal and social development	7	1.3%	6	2.0%	1	0.6%	0	0.0%
Achieve - Be Successful	6	1.2%	4	1.3%	1	0.6%	1	2.5%
Make a positive contribution								
Engages in decision making and support the community and environment	3	0.6%	2	0.7%	0	0.0%	1	2.5%
Engage in law-abiding and positive behaviour in and out of school	2	0.4%	1	0.3%	1	0.6%	0	0.0%

ECM OUTCOMES	MAIN HOPES							
	ALL SI		HI		VI		MSI	
	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries	No. of entries	%age of entries
Make a positive contribution cont.								
Develop positive relationships	52	10.0%	26	8.8%	24	13.9%	0	0.0%
Develop positive relationships – Family life	25	4.8%	15	5.1%	7	4.0%	2	5.0%
Develop self-confidence and successfully deal with significant life changes and challenges	41	7.9%	27	9.1%	12	6.9%	2	5.0%
Develop enterprising behaviour	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Achieve economic well-being								
Engage in further education, employment or training on leaving school	58	11.1%	36	12.1%	17	9.8%	2	5.0%
Ready for employment	3	0.6%	3	1.0%	0	0.0%	0	0.0%
Live in decent homes and sustainable communities	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Access to transport and material goods	6	1.2%	1	0.3%	5	2.9%	0	0.0%
Live in households free from low income	9	1.7%	6	2.0%	1	0.6%	1	2.5%
Total	521	100%	297	100%	173	100%	40	100%

Commentary

This sub-outcome level of analysis provides a potentially more useful steer in the selection of future outcomes for benchmarking than that in Table 8.

Initial inspection reveals the following sub-outcomes have the highest overall percentage of entries:

Rank	%age of entries	ECM Outcome	ECM Sub-Outcome
1=	11.1%	Be Healthy	Mentally and Emotionally Healthy
1=	11.1%	Achieve Economic Well-Being	Engage in further education, employment or training on leaving school
3=	10.6%	Enjoy and Achieve	Learning and academic achievement
3=	10.6%	Enjoy and Achieve	Self -help skills, life skills and independence
5	10.0%	Make a Positive Contribution	Develop positive relationships
6	7.9%	Make a Positive Contribution	Develop self confidence and successfully deal with significant life changes and challenges

The rank 5 outcome 'Develop positive relationships' is interesting in that an item about friendships did not appear in the top 21 priority set derived from consultation across SI Services.

It is possible at this level of analysis to pick out outcomes with more disability weightings e.g. Enjoy and Achieve: Achieve speech, language and communication (8.1% for HI, 1.2% for VI); Enjoy and Achieve: Achieve self-help skills, life skills and independence (8.4% for HI, 13.3% for VI).

NatSIP SURVEY FOR FAMILIES

This is an outcome measurement tool that ensures that sensory services meet/ respond to the priority outcomes for children and young people (CYP) identified by families. This is part of a three stage approach:

- 1) Gathering views of families
- 2) Analysing the views of families
- 3) Using these views to inform service development.

Stage One - Gathering views of families

Aim: To gather feedback from families about their wishes and hopes for their child or young person.

Ask the question:

‘What are your five main hopes for your child/ young person?’

(Please do not lead or influence parents/carers but if they are struggling responses may include independence, happiness, emotional well being, social life, friendships, doing well educationally, future employment/ training/ care...)

You may like to consider the points below before undertaking this survey.

- Decide on the number of families to answer the above question. (We suggest a minimum of twenty families).
- Ensure that the choice of families represents a range of ages, level of service involvement, disabilities, ethnic groups and hard to reach families

How to complete the survey

- Ask the question face to face or over the telephone
- Record the responses (sheet attached)
- Complete the profile on each CYP (sheet attached)

NatSIP SURVEY FOR FAMILIES

'What are your five main hopes for your child/ young person?'

Profile of child / young person (CYP)

Age of CYP		Gender (please circle)	Male / Female
-------------------	--	-------------------------------	---------------

Ethnicity (please tick)			
White British		Any other Asian Background*	
White Irish		White and Black Caribbean	
Any other White background*		White and Black African	
Caribbean		White and Asian	
African		Any other mixed background*	
Any other Black background*		Chinese	
Indian		Any other ethnic group*	
Pakistani		*Please specify	
Bangladeshi			

Language(s) used at home	
---------------------------------	--

Classification of Sensory Loss			
Please refer Appendix 1- Classification of Sensory Loss			
Discuss with parent / carer and tick one option in each column			
Visual Impairment (VI)		Mild Sensory Loss	
Hearing Impairment (HI)		Moderate Sensory Loss	
MSI (VI & HI)		Severe Sensory Loss	
		Profound Sensory Loss	
		Unilateral Sensory Loss	
Comment (if appropriate):			

Additional needs (Please tick as many as necessary)	
Physical	
Speech and language	
Moderate learning difficulty	
Severe learning difficulty	
Medical condition	
Autistic Spectrum Disorder	
Other, please specify	

Current Education Setting (Please tick)			
Early Years -home		Special School including nursery	Mainstream School including nursery
Early Years – playgroup or similar		Further Education	Mainstream Resourced Base including nursery
Educated otherwise (please specify)			

Appendix 1 Classification of sensory loss*

Mild sensory loss:	hearing:	unaided threshold 21-40 dBHL
	vision:	better than 6/18 Snellen/Kay better than 0.5 LogMAR but with visual field loss
	multi-sensory:	dual impairment with a mild loss in both modalities
Moderate sensory loss:	hearing:	unaided threshold 41-70 dBHL
	vision:	within the range 6/18-6/36 Snellen/Kay within the range 0.5-0.7 LogMAR
	multi-sensory:	dual impairment with a moderate loss in both or the most affected modality
Severe sensory loss:	hearing:	unaided threshold 71-95 dBHL
	vision:	within the range 6/36-6/60 Snellen/Kay within the range 0.8-1.2 LogMAR
	multi-sensory:	dual impairment with a severe loss in both or the most affected modality
Profound sensory loss:	hearing:	unaided threshold in excess of 95 dBHL
	vision:	blind 6/60 or less Snellen/Kay blind 1.3 LogMAR or worse
	multi-sensory:	dual impairment with a profound loss in both or the most affected modality
Unilateral sensory loss:	either unilateral hearing or monocular vision	

* Taken from South East Sensory Impairment Partnership (SESIP) Eligibility Criteria (2009) and the British Society of Audiology.