



Parents' points of view: an evaluation of the M'Lop Tapang special needs programme, Cambodia

School of Health and Society

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Chapter 1: Table of contents

Chapter 1:	Table of contents	1
Chapter 2:	List of tables	3
Chapter 3:	List of figures	4
Chapter 4:	Abstract	7
Chapter 5:	Funding	8
Chapter 6:	Background	9
Section 1:	Vision	9
Section 2:	Mission	9
Chapter 7:	Introduction	10
Chapter 8:	Method	16
Chapter 9:	Ethical considerations	17
Chapter 10:	Results	18
Section 1:	Cambodia country profile	18
Section 2:	Characteristics of survey respondents	20
Section 3:	Characteristics of the children of the respondents	23
Section 4:	Access to education prior to joining the Special Needs Programme	25
Section 5:	Reported impact of the Special Needs Programme	26
1: Imp	act on the carers or parents	28
2: Pare	ent or carer learning	30
2. Dar	ant or carer requests for more support	21

Chapter 11:		Discussion	
Chapter	12:	Recommendations	35
1:	Reco	ommendation One	35
2:	Reco	ommendation Two	35
3:	Reco	ommendation Three	35
4:	Reco	ommendation Four	36
5:	Sum	mary	36
Chapter	13:	Gallery	37
Chapter	14:	References	42
Chapter	15:	Appendix One	46
Sectio	n 1:	Proposed family meetings format	46
Chapter	16:	Appendix Two	48
Sectio	n 1:	Learning something new with and from one another	48
Sectio	n 2:	All about me!	49
Sectio	n 3:	Person centred assessment of a child's individual specific needs	50
Imp	ortant	points to be aware of	52

Chapter	2:	List	of	tab	les
Ullable	4.	LIGI	vı	luv	

Table 1: Sumr	mary of recommendation	ons 36
	man, or recommissionadis	

Chapter 3: List of figures

Figure 1: Progress in the programme = smiles all around
Figure 2: Practising gross motor skills
Figure 3: Practising gross motor skills through sport
Figure 4: All children in the special needs programme have health follow-up 15
Figure 5: Dependent children in the respondents' families
Figure 6: Education level of respondents
Figure 7: Occupation of parent or carer
Figure 8: Male and female children attending the special needs programme at M'Lop Tapang
Figure 9: Diagnosis of child(ren) of respondent
Figure 10: Quote from the Mother of a 12 year old boy26
Figure 11: Quote from the Mother of an 11 year old girl
Figure 12: Massage to improve the wellbeing of children during home visits 27

Figure 13: Reported respondent stress prior to special needs programme
involvement
Figure 14: Reported stress after special needs programme involvement 29
Figure 15: Join the dots! Practising fine motor skills
Figure 16: Using Lego® to practise fine motor skills
Figure 17: Practising fine motor skills through fun activities
Figure 18: 1 to 1 learning for specific fine motor development
Figure 19: Learning to count and practising fine motor skills
Figure 20: Learning colours
Figure 21: Learning colours and counting skills
Figure 22: Music time! Participating in the arts programme
Figure 23: Cymbals and drums! The arts programme is very popular at M'Lop
Tapang
Figure 24: Jigsaws are fun and help with fine motor development, counting and
shape recognition40

Figure 25: Painting helping to develop fine motor and colour recognition skills 41
Figure 26: 1 to 1 support from a member of the Special Needs Programme
team 41

Chapter 4: Abstract

M'Lop Tapang is a registered non-governmental organisation working in South West Cambodia and providing services to 5000 vulnerable children and 2500 families.

This evaluation was commissioned to review M'Lop Tapang's special needs programme.

Interviews were conducted with 35 parents / carers of children who receive services from M'Lop Tapang's special needs programme¹. Nearly all of these parents / carers reported that they had noticed improvements in their children's behaviour or functional ability since attending the programme. Significantly, almost all also reported a dramatic reduction in stress as a result of their child attending the programmes.

While the study revealed many positive aspects of M'Lop Tapang's special needs programme it also highlighted areas for improvement, particularly in areas of parental learning and education.

¹ https://www.facebook.com/watch/?v=1742087122495658

Chapter 5: Funding

This report and the Special Needs Programme at M'Lop Tapang, Cambodia are made possible with the generous support of the Carraresi Foundation in Memory of Augusto Carraresi.

Chapter 6: Background

Section 1: Vision

M'Lop Tapang is a registered non-governmental organisation working in South

West Cambodia. M'Lop Tapang envisions an environment where all children

are allowed to grow up in their families feeling safe, healthy and happy;

a society where all children are respected and treated equally; a community

where all children are given choices about their future.

Section 2: Mission

M'Lop Tapang strives to provide a safe haven for vulnerable children of

Sihanoukville, offering care and support to any child at risk. M'Lop Tapang

offers access to education, reintegration with families, life-skills training and

creative and recreational activities, while ensuring protection from all forms of

abuse. The efforts of M'Lop Tapang allow underprivileged children to embrace

their childhood so they can become responsible adults as well as positive,

independent members of society.

9

Chapter 7: Introduction



Figure 1: Progress in the programme = smiles all around

M'Lop Tapang has been providing services to the Sihanoukville region since 2003. During that time there has been significant environmental and societal changes (Jackie Ong & Smith, 2014), which can bring both benefits and risks to vulnerable members of the community (Sandy, 2009). In a country where most families lack access to even the most basic health, education and social services, Cambodian families with children having learning disabilities have even fewer options (Cordier, 2014; Mak & Nordtveit, 2011; Nuth, 2018). Most

of these children face significant discrimination within the community and are often left isolated in their homes with care predominantly, being provided by their families (Cordier, 2014). When compared to the general population, evidence exists to support the theory that children, young people, their parents, families and carers experience poor health along with lower levels of physical activity (Walsh, 2008; Wouters et al 2019). They are also known to have higher barriers when accessing education and healthcare (Hilgenkamp et al 2012) which further impact upon the feelings of stress and anxieties experienced by the children and their families. The needs of the carers within these families often remains hidden, in part due to the experience of stigma experienced from having a child with a disability (Cordier, 2014). Sivberg (2002) demonstrates that caregivers and families with children that have learning disabilities such as 'Autism' experience greater levels of stress and anxiety in comparison to those who do not. This stressful experience can have a negative impact on the whole family and those involved in delivering education and care strategies (Gray 1993, 2002).

Social stigma and a family's 'place' within community and society and perceived stigma associated with their child's specific needs may impact upon the family's ability to access support services offered, such as those available at M'Lop Tapang. Listening to caregiver/parent feedback and 'getting it right', are both key to helping to understand the perceived and very real barriers to positive child and caregiver experiences at home and within their wider society. It is important therefore to ensure that we make 'every contact count' (Public Health England, 2017) when listening to the voices and choices made by parents and

caregivers for their children and young people. All children are capable and rich in potential, deserving to be at the centre of ideas, initiatives and plans which involve them and their families. This evaluation study aimed to illuminate the vital role of parents by focussing on their views and experiences.

M'Lop Tapang's Special Needs Programme has been operating since 2007. A designated team works with children and their families at M'Lop Tapang's Education Centre as well as with children and families in the local community. The programme is provided for free to the families.



Figure 2: Practising gross motor skills

M'Lop Tapang's special needs programme provides daily classes at its

Education Centre for children with physical, behavioural and developmental

disabilities, offering regular medical care, nutritional support, organised sports activities, as well as group and individual learning programmes.

The programme is the only one of its kind in the Sihanoukville area. For children unable to attend these daily classes home visits are provided on a regular schedule that includes social and medical support, physical therapy, and parental education.



Figure 3: Practising gross motor skills through sport

Through our Outreach activities we have found, and continue to find, a number of children with physical, behavioural and developmental disabilities. In a review of the literature, Venetsanou, & Kambas, (2010) found that socioeconomic factors contribute to developmental delay in young children and note the significant influence of intervention programmes that promote movement.

Movement programmes and family interaction between caregivers/parents and the children and young people are evidenced as being a positive activity that helps prepare them for interpersonal functioning within and out with the family setting (Floyd and Olsen, 2020).

The development of interpersonal skills amongst the special needs programme users can positively impact upon social functioning, communication, self-care skills and relationship building. It is recognised that social skills are just as important as the development of cognitive skills, having an influence upon well-being and adjustment for children and young people with disabilities (Kasari, 2016; Piaget 1936, 1945, 1957).

Many of the children involved in the M'Lop Tapang Special Needs Programme suffer from undiagnosed learning disabilities. There are very few services in all of Cambodia for children with special needs and the programme is the only one of its kind in the Sihanoukville area.



Figure 4: All children in the special needs programme have health follow-up

Chapter 8: Method

35 caretakers/parents of children who have received Special Needs services were interviewed for this study.

We used a self-created questionnaire and a member of our research team sat down with the interviewees to complete the form. Interviews were conducted in the community and at M'Lop Tapang's Education Centre.

Cambodia country profile data was obtained from the World Bank² and this was used as a comparator for the data obtained from the caretakers/parents involved in the interviews.

The data obtained from caretakers/parents was analysed using SPSS.

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² https://data.worldbank.org/country/cambodia

Chapter 9: Ethical considerations

The method for this service evaluation was considered and approved by the M'Lop Tapang Executive Management Team under the ethical principles set out in The M'Lop Tapang local Child Protection Policy.

Chapter 10: Results

Section 1: Cambodia country profile

Before describing the data obtained from the caretakers/parents who were

interviewed in this study, it is necessary to describe the Cambodia country

profile so that the responses from the families in this study can be put into

context. The latest data available from the World Bank is from 2018/20193:

• Population: 16.25 million

Gross National Income per capita: \$1390 USD

• Life expectancy at birth (2018): 69 years

The Gross National Income per capita is a very crude measure upon which to base comparisons in the context of families supported by M'Lop Tapang. It is

gross national income divided by mid-year population, converted to US Dollars

using the World Bank Atlas method.

Since 1990, Cambodia has seen a steady reduction in the under 5 years of age

mortality rate (per 1000 live births). In 1990 this was 116 per 1000 live births

and in 2018 this has been decreased to 28 per 1000 live births. That said, by

3

https://databank.worldbank.org/views/reports/reportwidget.aspx?Report_Name=CountryProfile&Id=b450fd57&tbar=y&dd=y&inf=n&zm=n&country=KHM



Section 2: Characteristics of survey respondents

Of the 35 parents and carers who participated in this evaluation, 75% were female with a mean age of 39.6 years of age. 77% of the interviewees were married, 9% were divorced, and 14% were widows/widowers. The interviewees had a monthly (mean) income of \$308 USD.

The majority of participants (71%) cared for up to three children. However almost a quarter (23%) had between four and six children and two participants (6%) had more than seven children dependent upon them (**Figure 5**).

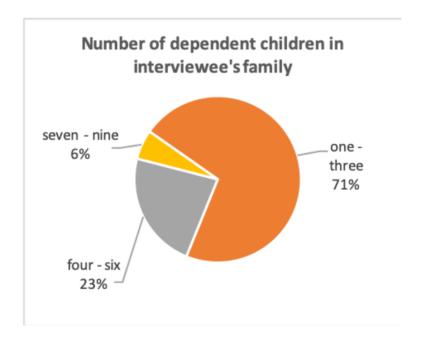


Figure 5: Dependent children in the respondents' families

The participants in this study had a range of educational experiences. Notably, more than a quarter of those who participated (26%) had no formal schooling and the same number were only in receipt of primary school education.

Therefore, more than half of those interviewed had not received education beyond a pre-adolescent age. In addition to considering the information presented in **Figure 6**, it is important to note that many parents and carers in this study would have been in receipt of education in the 1980's. At that time education provision in Cambodia saw the initial renewal of education provision which sought to extend opportunities for its children (Dy, 2004). Positively, 26% of participants had attended secondary school, with 11% of those completing high school and university.

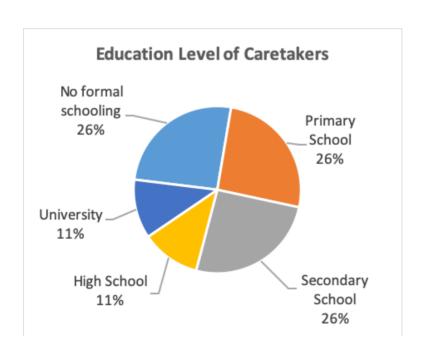


Figure 6: Education level of respondents

Figure 7 presents the distribution of occupations across the participating group. A little more than a quarter of participants (26%) were full time housewives, and 9% of interviews worked within the government. The majority of participants worked in the service sectors as shop sellers (23%), moto-taxi drivers (11%), cleaners (11%), hairdressers (9%). Other interviewees were occupied in employment that was not listed (11%).

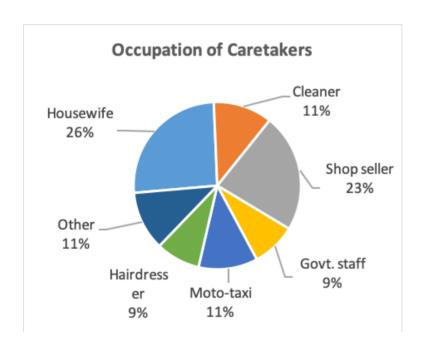


Figure 7: Occupation of parent or carer

Section 3: Characteristics of the children of the respondents

In total 35 children and young people participated in the study with their parent(s) or guardian (caretaker), out of a potential 48 participants from the programme as a whole. Of the participants, 63% of the children were male and 37% were female (**Figure 8**).

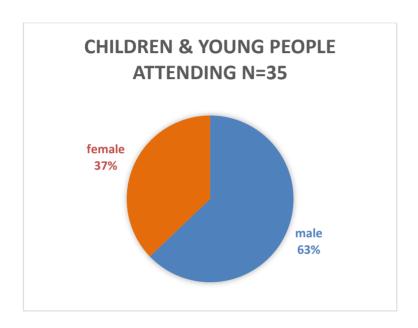


Figure 8: Male and female children attending the special needs programme at M'Lop Tapang

The mean age was 9.5 years old (range 3 to 17 years old). 85% were undertaking the Special Needs Programme exclusively at the M'Lop Tapang Education Centre, 9% at home and 6% both at the Education Centre and at home.

Figure 9 presents the diagnosis of the children attending the special needs service at M'Lop Tapang.

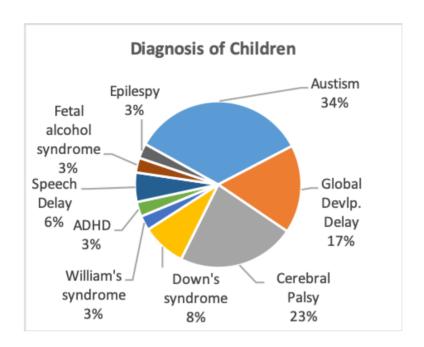


Figure 9: Diagnosis of child(ren) of respondent

Section 4: Access to education prior to joining the Special Needs Programme

66% of the children had never attended public or private school before joining M'Lop Tapang Special Needs Programme. The most common reasons were:

- too young (9%)
- the school did not accept them (26%)
- the parents never tried to send them (65%).

For the children not going to school, more than 50% of the caretakers reported that their children spent most of their time at home watching TV or playing on a mobile telephone. It is interesting to note that it was said that only 9% of children played with other children.

One third of the children had attended local public schools before joining MT Special Needs Programme. Of those that had attended school before, 83% stopped going.

The most common reasons for stopping were that "my child couldn't learn" or that "the school did not have the skills to teach them".

Section 5: Reported impact of the Special Needs Programme

100% of those interviewed stated that their child likes being part of the programme, and all but one of the parents/caretakers reported that they had seen positive changes in their children since starting with MT's Special Needs programme. Most parents/caretakers interviewed have seen improvements in more than one area:

- 86% reported positive changes in their child's in ability to feed/dress themselves;
- 74% reported positive changes in their child's speech;
- 74% reported positive changes in their child's health/nutrition;
- 71% reported positive changes in their child's ability to focus;
- 49% reported positive changes in their child's behaviour/ relationships with others; and
- 34% reported positive changes in the child's physical mobility.

"Now he knows to call us 'Ma' or 'Pa' and he knows the names of his younger siblings too"

Figure 10: Quote from the Mother of a 12 year old boy

"She can speak 2 or 3 words now, she can put on her own clothes and she knows to go to the toilet when she needs to pee. Before is she needed to pee she would just do it in front of everyone but now she uses the bathroom."

Figure 11: Quote from the Mother of an 11 year old girl

When asked, most of the parents/caretakers also stated that they had specific goals for their children that they would like MT's Special Needs team to help with. Most of these goals centred around simple life skills, e.g., brushing their teeth, dressing themselves, feeding themselves. A few of the parents' goals were less realistic, i.e. "Please help my girl to be normal."



Figure 12: Massage to improve the wellbeing of children during home visits

1: Impact on the carers or parents

94% of the parents/caretakers interviewed reported that having their child attend MT's Special Needs programme has greatly decreased their stress.

We asked them to rate their stress level before (**Figure 12**) and after (**Figure 13**) their child started attending the programme using a scale of 1-10 (1 being least amount of stress and 10 being the most amount of stress)

- 100% of the parents/caretakers interviewed also reported that they have more time to do other things since their child started attending MT's Special Needs programme;
- 75% reported that they have more time to do their housework;
- 71% reported that they have more time to work and to earn money; and
- 57% reported that they have more time to spend with their other children

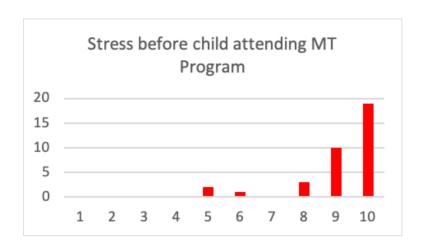


Figure 13: Reported respondent stress prior to special needs programme involvement

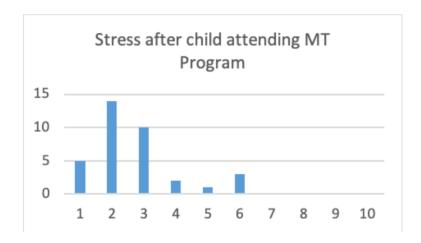


Figure 14: Reported stress after special needs programme involvement

2: Parent or carer learning

When asked about the time when they first learned about their child's diagnosis, almost half of the parents/caretakers interviewed said that they learned before enrolling with M'Lop Tapang, 20% found out after their children started with the Special Needs programme, and 31% reported that they still did not know. Surprisingly, nearly two thirds of those interviewed stated that they did not gain any new knowledge about their child's condition since starting the programme.

The Special Needs programme launched an organized family meeting a couple of years ago. The goal of these meetings was for families to share and learn from each other. However, 83% of those interviewed reported that they did not learn anything from other families.

The implication of diagnosis is that as children, young people and their families have a definitive diagnosis of the condition that they are living with, they have limited access to appropriate support and treatment to help them to understand and manage the condition (Baron-Cohen, et al., 2009; Couteur, et al., 2008).

An increase in prevalence therefore equates to an increase in required resources and associated costs to meet the increased needs (Briggs, 2014) and the Special Needs Programme is striving to achieve this level of support.

3: Parent or carer requests for more support

Initially when asked, most parents were very hesitant to say they wanted more support and that they were just so grateful already for what MT was doing. When we explained that their response would help shape the programme in the futures,74% of the parents/caretakers interviewed requested more support from the Special Needs team. The most common requests for additional support included:

- Help with transportation to and from MT's Education Centre
- Full time (all day) classes versus part time (morning or afternoon)
 classes
- More home visits
- More variety of activities in programmes
- Help with child-specific goals (e.g. Feeding self, dressing, improving speech)

Chapter 11: Discussion

Average family income is higher than in another recent study we did that focused on impact of providing free medical care. The reason for this is that the Special Needs Programme, unlike other M'Lop Tapang programmes, is open to all local families and not just those living in poverty. The decision to open to all families is based on the fact that there are no other services for children living with Special Needs in the Sihanoukville area.



Figure 15: Join the dots! Practising fine motor skills

With the exception of one interviewee, all of the families perceived positive changes in their children since they joined the programme. The changes were often seen in different areas of the child's daily life.

The self-perceived stress levels of the parents/caretakers were significantly reduced with their child being part of the programme. Having children attend the programme also allowed the parents more time to engage in other activities.



Figure 16: Using Lego® to practise fine motor skills

Surprisingly, even though each family meets with Special Needs staff and visiting medical and child development specialists, the majority of parents/caretakers reported that they had not learned anything new about their child's condition since being part of the programme or hadn't learned anything from other parents.

For the 30% that reported that they still did not know the child's medical diagnosis, this may be due to not having Khmer language words for conditions like "Autism", "Down syndrome (Trisomy 21)", "Fetal Alcohol Syndrome (FAS)" and others.

It is interesting to note that of all of the children whose parents/caretakers took part in this study, 34% have an initial diagnosis of an Autism Spectrum Disorder (ASD). This is reflected in the number of boys involved in this study (63%) and mirrors the global evidence from the literature which suggests that the prevalence of ASD continues to increase across the world in the second decade of the 21st century (Chiri & Warfield, 2012; Baron-Cohen, et al., 2009) with an estimated rate of 1 in 63 being reported (Baron-Cohen, et al., 2009). The ratio of individuals with ASD is reported to be 7:1 male to female (Whiteley et al., 2010).

Approximately 82% of children and young people with Autism have co-existing disorders such as language disorders, Attention Deficit Hyperactive Disorder (ADHD) which also affects their behaviour (Levy *et al.*, 2009). In addition, children and young people with Autism often have coexisting health care needs such as seizures, gastrointestinal problems, allergies and sometimes intellectual disabilities which require continued support (Liptak, Stuart *et al.*, 2006).

Chapter 12: Recommendations

1: Recommendation One

Re-evaluate family meetings format. This may require more training to the staff on how to effectively run these kinds of meetings. A proposed structure is set out in **Appendix One**.

2: Recommendation Two

Present study findings to Special Needs staff and visiting medical/behavioural specialists on high percentage of parents/caretakers who reported not learning anything new. There may be a need to create new teaching styles that will support all participants in the special needs programme to work with and learn from one another. This can be based upon working together and sharing information and detailed in **Appendix Two**.

3: Recommendation Three

Explore/evaluate parent/caretaker requests for more support. While some of the requests (i.e. help with child-specific goals, more variety of activities) may be achieved within the existing programme and at low cost, other requests

(transportation, more all day programmes) would require investments in vehicle, infrastructure/increased classroom space, and staffing levels.

4: Recommendation Four

Share this service evaluation with our working partners in Cambodia as well as nationally and internationally.

5: Summary

Table 1: Summary of recommendations

Recommendation	Detail
One	Re-evaluate family meetings format.
Two	Present study findings to Special Needs staff and visiting medical and behavioural specialists
Three	Explore and evaluate parent and carer requests for more support.
Four	Share this service evaluation with M'Lop Tapang's partners working in Cambodia.

Chapter 13: Gallery



Figure 17: Practising fine motor skills through fun activities



Figure 18: 1 to 1 learning for specific fine motor development



Figure 19: Learning to count and practising fine motor skills



Figure 20: Learning colours



Figure 21: Learning colours and counting skills



Figure 22: Music time! Participating in the arts programme



Figure 23: Cymbals and drums! The arts programme is very popular at M'Lop Tapang



Figure 24: Jigsaws are fun and help with fine motor development, counting and shape recognition



Figure 25: Painting helping to develop fine motor and colour recognition skills



Figure 26: 1 to 1 support from a member of the Special Needs Programme team

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Chapter 15: Appendix One

Section 1: Proposed family meetings format

Occilon	1. I roposca family incentings format
1. Se	et the agenda of the meeting when possible
	a. Focus upon a specific topic for the meeting
2. Pa	arents introduce themselves and their children
3. Pr	ofessionals introduce themselves
4. Pr	ofessionals lead discussion about 'what is going well'
	a. Group compliments to support positive reinforcement
5. Pr	ofessionals lead discussion about 'what could be better'
	a. Group discusses potential solutions in order to learn from each other
	b. Perhaps small group discussion
6. Br	eak out into a family fun activity that includes:
	a. Play
	b. Art
	c. Messy play
	d. Music

7. Come back together and review any developments and set the agenda for next time

Chapter 16: Appendix Two

Section 1: Learning something new with and from one another

This can be used as part of the family meeting structure & format

- Ask the parents and children to complete a 1-page profile for each of the children (All about me). This will allow the parents / caretakers and children to tell everyone a little bit about themselves.
- In a group, ask them to present what they have done and support this with positive encouragement and reinforcement
- Ask the parents and children to complete the 'Person Centred Assessment of the Child's Individual Specific Needs'
- This can be kept as part of the child's records
- Ask each parent to share their child's
 - o Likes
 - o Dislikes
 - Their very special interests
 - o How they manage 'difficult times & behaviour'

All about me!!



1. What is your name?
My name is
? \$\int 2. How old are you?
I am years old.
3. What color is your hair?
My hair is
◆ ◆ 4. What color are your eyes?
My eyes are
5. What color is your shirt?
My shirt is
6. What color are your shoes?
My shoes are
? ₹ 7. How are you today?
I am

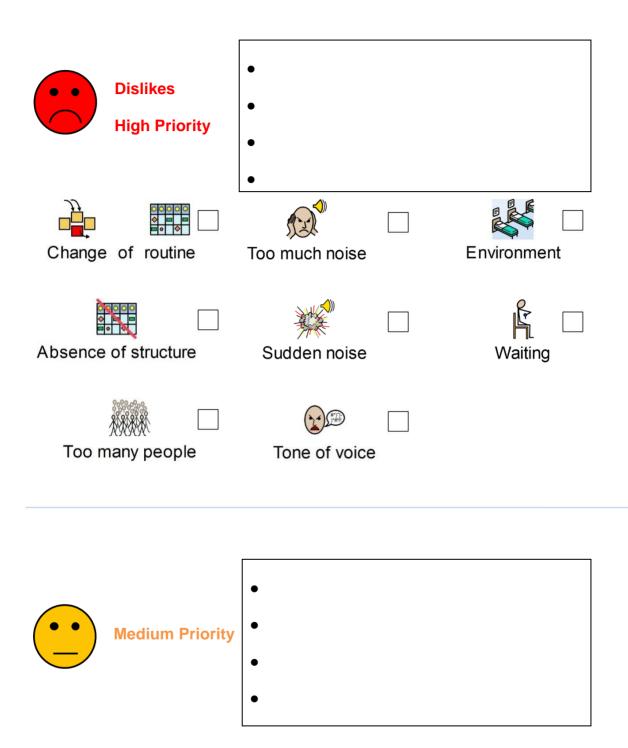
Section 3: Person centred assessment of a child's individual specific needs

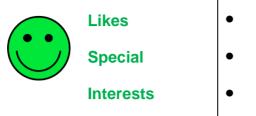
(Kennedy & Binns et al 2016)

This summary is to be placed at the front of the child's health, care or education plan

Child & family name:			
Child with:	Date of	f birth:	
Autism			
Learning Disability	Age:		
Medical Complexity □			
Contact details:			
Home address			
Mobile telephone			
Translator / Interpreter requir	ed?		
Yes □ No □			
Date of attendance			
Assessment completed by w	ho?		
Professional ☐ Parent	:/Carer □	Other □	
Signature		Print name	
Professional status Date completed			

Important points to be aware of







Comments:

- •
- •
- •
- •





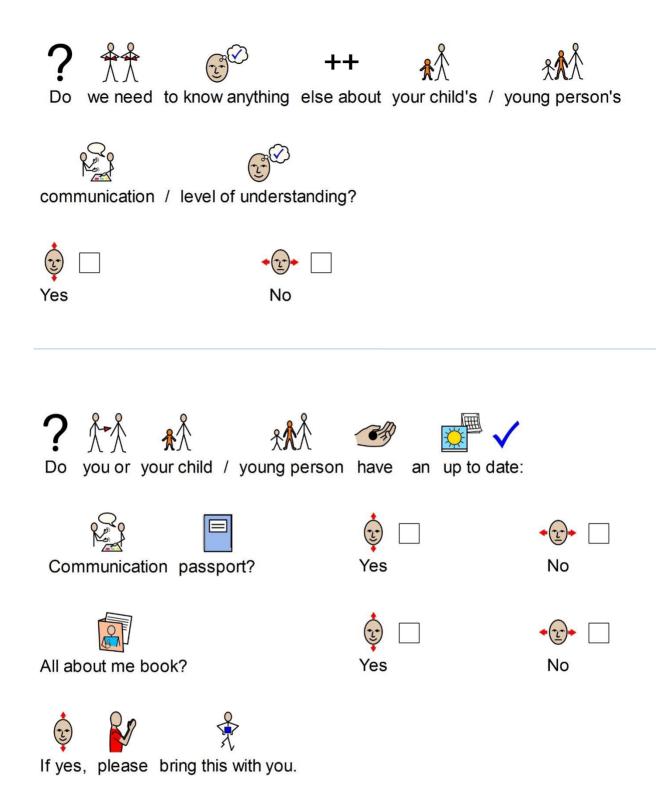
Past Hospital Experiences

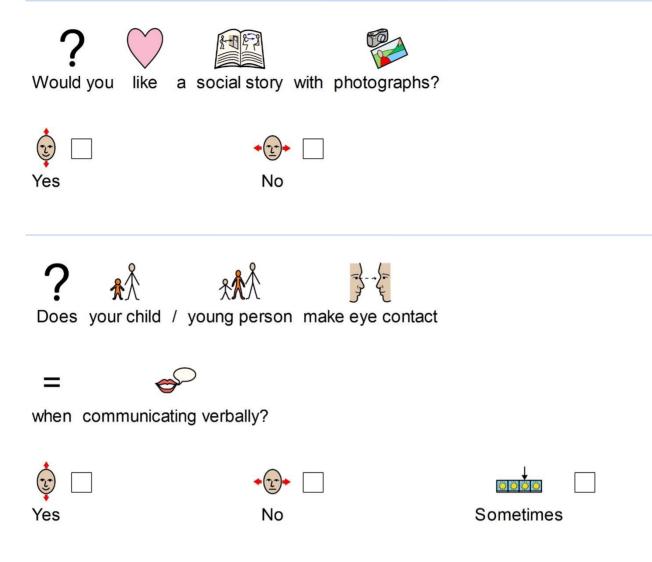
Has your child / young person been in hospital before?

Yes	No
Comments	
•	
•	
•	



? What method of communication	tion does your child / you	ng person use?
Pictures	Sign language	Verbal
Auditory	1 Abcd Single words	③ ← □ Sensory
Translator required		
Comments		
•		







Yes No

Comments			
•			
•			











Does your child / young person use a behaviour system?



e.g. traffic light system

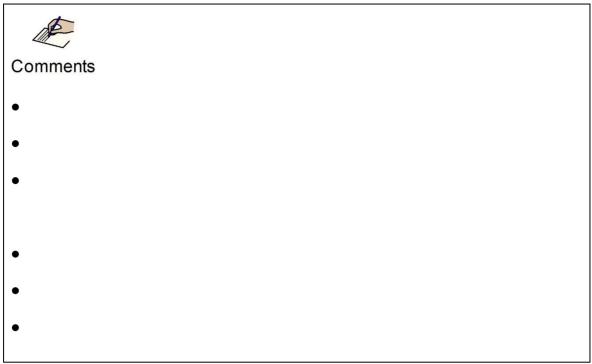
At school	Yes	No	Sometimes
At home	yes	No	Sometimes

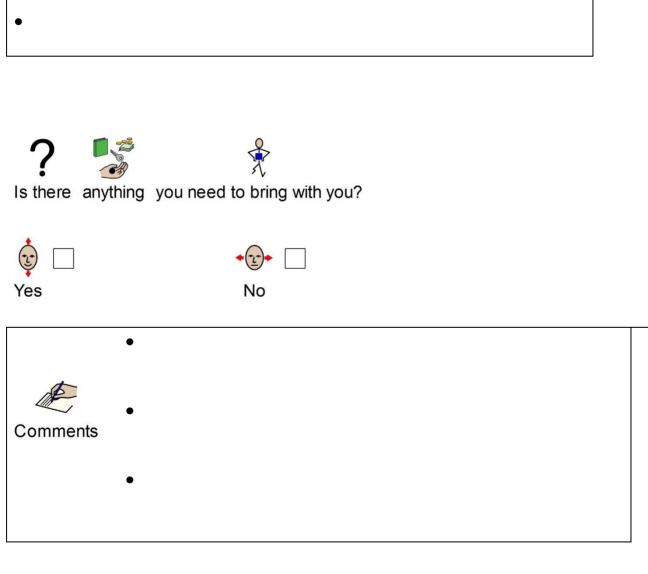
Comments

•
•



? *** What does your child / yo	ung person like playing w	ith?
Books	Group games	Playing alone
Musical games	Computer games	Sensory play
Television	Imaginative play	Drawing/colouring
iPad	DVD	





?	young person have any mobility problems?	
Ç ☐ Yes	No	
Comments		
? Å Å Do you have a	رُدُ ؟! any mobility problems?	
Yes	No	
Comments		



? *** *** *** *** *** *** *** *** *** *	experience of pain?
Communicate pain verbally	Point to area of pain
Screams	Hitting self
Hitting others	Unable to communicate pain
Don't know	

Comments	
•	
•	
•	
•	
•	
•	



Poes your child / young p	erson easily become
Anxious	Frustrated
Challenging	Non-compliant
Comments •	

Phow does your child's / y	oung person's behaviour present itself?
Angry	Aggressive
Withdrawn	Self harm
Comments	



?			* *		3
Does	your child	/	young person	allow	contact?













Will your child / young person engage with nursing / medical procedures?

		Yes	No No	Sometimes	Don't know
	Attending Clinics e.g. out patients				
Comments	•				
RANGE TO SERVICE TO SE	Tolerate being in busy waiting areas				
Comments	•				

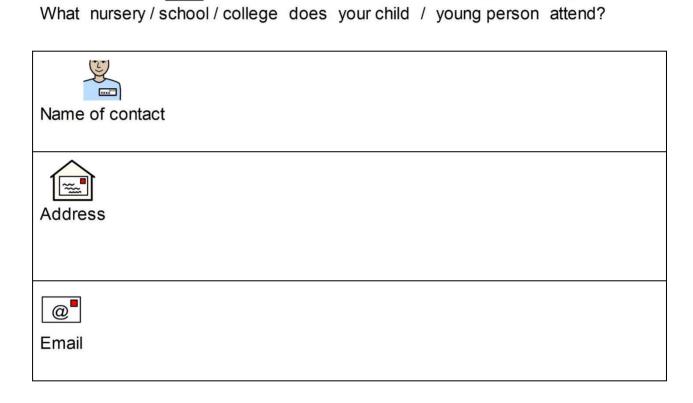
		Yes	◆ (<u>r</u>)•	Sometimes	Don't know
	Examined by doctor / nurse				
Comments	•				
	Weight / Height				
Comments	•				
	Taking medicine				
Comments	•				

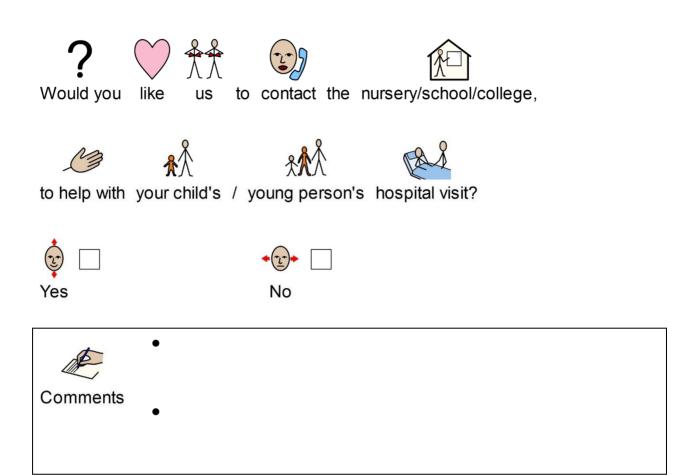
	Taking	ý Yes	No	Sometimes	Don't know
	tablets				
Comments	•				
°C	Temperature				
	•				
Comments	•				
© 120 80	Blood pressure				
	taken				
	•				
Comments	•				

		Yes	No No	Sometimes	Don't know
	Needle procedures • blood tests • Injections • cannulas				
Comments	•				
	Local anaesthetic cream				
Comments	•				

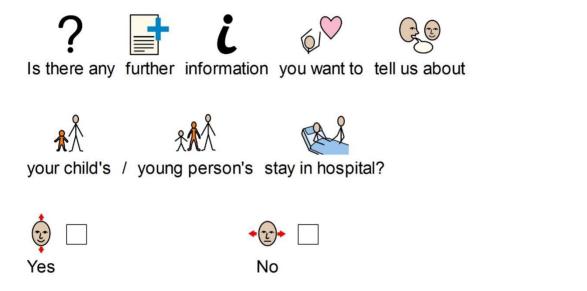
		Yes	No No	Sometimes	Don't know
	Plasters				
Comments	•				











Comments	
•	
•	
•	
•	
•	



Shoemaker D, Chhim S, Dom S, Ngov C, Kennedy R, Peach D & Rowland AG (2020). Parents' points of view: an evaluation of the M'Lop Tapang special needs programme, Cambodia

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