



# SITUATIONAL ANALYSIS FOR PERSONS WITH AUTISM IN CAMBODIA

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Prepared by





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## Foreword



As a state party to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) since December 2012, the Royal Government of Cambodia (RGC) has taken all possible measures in order to embrace and support the interests of persons with disabilities, and empowering them to suitably participate in all aspects within our society.

At the present time, the new law on the Protection of the Rights of Persons with Disabilities is being drafted to ensure the protection, promotion and realization of full and equal rights and freedoms of the persons with disabilities, allowing for equal opportunities and footing with others in our society.

Under the wise leadership of **Samdech Akka Moha Sena Padei Techo HUN SEN**, Prime Minister of the Kingdom of Cambodia, the disability sector has witnessed remarkable developments. These include the development and implementation of relevant laws, policies and regulations; the provision of various services to persons with disabilities; and facilitating meaningful engagement of Organisations of Persons with Disabilities.

Despite this encouraging progress, there are nevertheless a few remaining challenges, such as substandard disability data and legal framework gaps that are related to persons with autism.

The Australia-Cambodia Cooperation for Equitable Sustainable Services (ACCESS) in partnership with the Disability Action Council Secretariat General (DAC-SG) commissioned a consultancy from experts in the disability sector and with the best practice technical expertise in autism in order to conduct a comprehensive analysis of the situation of persons with autism in Cambodia and to provide recommendations for improving supportive services including education, rehabilitation and vocational training.

On behalf of the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY) and the DAC-SG, I sincerely appreciate the work that this team of experts have now successfully completed.

This report on the “Situational analysis for persons with autism in Cambodia” is a foundation for the development of an action plan for autism in Cambodia.

I call on you all to continue your hard work to strengthen intersectoral cooperation and collaboration with relevant ministries and institutions and to develop policies focusing on persons with autism and to improve the effectiveness of supportive services including education, rehabilitation and vocational training and to ensure their full engagement with RGC in realizing poverty reduction and building a fair, equal and inclusive society.

Phnom Penh, 2 May 2022



**EM CHAN MAKARA**

## Acknowledgement

This report on ‘Situational Analysis for Persons with Autism in Cambodia’ was prepared by Dr. Richard Rose, Professor Emeritus, Department of Inclusive Education, University of Northampton, UK for the “Disability Action Council” (DAC) and Ministry of Social Affairs, Veterans and Youth Rehabilitation (MOSVY), Royal Government of Cambodia in partnership with the Center for Child and Adolescent Mental Health (Caritas-CCAMH), with the support of the Government of Australia through the Australia-Cambodia Cooperation for Equitable Sustainable Services (ACCESS).

We acknowledge the role of Dr. Richard Rose in actively coordinating this research with Dr. Bhoomikumar Jegannathan, Child Psychiatrist and his team of mental health professionals Dr. Dalin

Mong, Psychiatrist, Ms. Dearozet Sok and Mr. Puthy Pat, Psychologists working at Caritas-CCAMH who played a key role in enlisting the responders, data collection, transcription, translation and analysis. This work is commendable, particularly in the context of the global pandemic and the constraints of mandatory restrictions, which the team was able to overcome while practicing all the safety precautions advised by local authorities and the Ministry of Health (MoH) of Cambodia.

The DAC and MOSVY would like to express sincere thanks to the Department of Foreign Affairs and Trade (DFAT), the Government of Australia through ACCESS Program for the generous financial and technical support for the development of this important study and the publication of this report.

## Status of the Report

This report presents the processes, findings and recommendations following a situational analysis for persons with autism in Cambodia. Data collected for this analysis were used to address the three objectives identified in the project brief as defined below. The report provides details of the methods of data collection deployed by the team, preparation of this team for conducting fieldwork in a manner that ensured a duty of care and ethical practice, reference to the coding of data and initial findings from the project. It concludes with recommendations for further action in support of the development of provision for persons with autism and their families.

## The Project Brief

The project team was commissioned by The Disability Action Council Secretary General (DAC-SG) and The Australia-Cambodia Cooperation for Equitable Sustainable Services (ACCESS), to provide a situational analysis to improve understanding and fill gaps in knowledge with regards to the population of young persons with autism and their families in Cambodia. The three objectives of the project were defined as:

1. To undertake an assessment and analysis of the support services available to persons with autism;
2. To analyse the situation of persons with autism in accessing support services, that may include facilitators, barriers and challenges; and
3. To make recommendations on options to strengthen support services, including but not limited to education, rehabilitation and vocational skills training.

## Definition and prevalence of autism

The International Statistical Classification of Diseases and Related Health Problems (ICD-10) is one of the more commonly-used diagnostic manuals which is recommended by WHO. The definition of autism as stated in ICD 10:

Autism spectrum disorders (referred to as 'Pervasive Developmental Disorders' in ICD 10) are defined as "A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations".

There are assessment and diagnostic tools other than ICD-10 in common use internationally. These include the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). The definition from this manual is attached to this report as Appendix 5.

Accurate figures related to the prevalence of autism are not easily obtained and there is considerable variation across published studies. The World Health Organization has estimated that worldwide about one in every 160 children has an autism spectrum disorder. The prevalence of Autism Spectrum Disorder (ASD) in many low- and middle-income countries, including Cambodia is unknown. In 2014 The National Institute of Statistics of Cambodia conducted a Demographic and Health Survey 2014 utilising The Washington Group Short Set Disability Questionnaire. Data were obtained from a sample of 16,356 households with 18,012 women and 5,484 men between the age of 15 and 49. From this survey a response rate of 99% was obtained (15,825 households; 74,112 individuals). This survey identified an overall prevalence of

disability of 9.5% of the population five years of age and over.

While the data obtained from this survey is important and can certainly assist with the implementation of disability policy within Cambodia, it has limitations when attempting to understand the situation for persons with autism and their families. The survey was focused upon individuals aged 5 years and older and asked questions about whether the individual had difficulties with seeing, hearing, walking or climbing stairs, remembering or concentrating, performing self-care, or communicating. Persons with autism may experience some or all of these challenges, but a more specific and focused population survey is essential if a greater understanding of the prevalence and needs of individuals with autism spectrum disorders is to be made.

## Team Development

The team assembled (see appendix 1) to undertake this work was selected on the basis of expertise in conducting previous situational analyses, knowledge of the national situation for children and young people with disabilities and their families in Cambodia, and the ability to generate data through engagement with both established service providers and users across the country.

In order to ensure cohesion across the team, weekly meetings were held involving all members. In addition, training sessions were provided for field workers by the project team leader to ensure that all members were conversant with methodological approaches, ethical requirements and able to maintain a focus upon the project objectives.

The work of the project team was allocated according to expertise and knowledge of the local and national situation. This enabled field work to be conducted with a purposive stratified sample and

data to be collected using both English and Khmer language as necessary. Administrative and financial management was co-ordinated through the Centre for Child and Adolescent Mental Health (CCAMH) in Kandal Province.

## Methods Deployed

### Review of Documents

Throughout the project a bank of documents (listed in appendix 2) comprising both official documentation and that provided by organisations and respondents was collated, scrutinised and analysed in order to provide information related to:

1. National policy initiatives related to disability (with particular reference to autism)
2. Cambodian national responses to international agreements and initiatives
3. Research which addresses disability in Cambodia with particular reference to autism.

An initial read through of documentation enabled the research team to gain insights into contextual issues related to provision for persons with autism in Cambodia. The documents were constantly revisited and related to the thematic codes developed for data analysis as outlined below. Where deemed appropriate, reference to sections of these documents has been made within the findings section of this report.

### Field research

Qualitative methods were developed with a purpose of obtaining the first-hand experiences of individuals and organisations who either live with a young person on the autism spectrum or provide professional support to this population within Cambodia.

**Instruments:** Semi-structured interviews and

focus groups were deployed in order to collect data from the field. The choice of a semi-structured approach allowed for flexibility in prompting respondents for more in-depth information as necessary. Instruments were developed by the project team and were piloted in Cambodia in order to ascertain their effectiveness. On the basis of this piloting process, modifications were made before the use of the instruments with the substantive study sample. The interview and focus group instruments were made available to the project team in both Khmer and English, with respondents given an option of which language they would use.

Forms providing informed consent from all respondents were developed and maintained by field workers during and following data collection. (Details of ethical procedures can be seen in appendix 3)

**Sample:** A purposive stratified sample was obtained that took account of the varied population within Cambodia. This enabled data to be obtained from both urban and rural environments through face to face contact in Kandal, Battambang Province and Kampong Cham with a diverse range of service providers and users. Additional data was collected from similar groups in Kampot, Phnom Penh, Prey Veng, Pursat, Sihanoukville, Svay Reang and Takeo Province, though because of travel difficulties resulting from the COVID-19 Pandemic, these data were accessed via electronic platform interviews.

In addition to ensuring data collection from varying environments, consideration was given to the influence of religious bodies, Non-Governmental Organisations (NGO) and Government and administrative authorities as respondents to the

study. The range of respondents can be seen in the table provided in the following section of this report (Field Work Undertaken). A process of snowball sampling has been helpful, whereby respondents have identified further organisations with whom they have engaged and who are providing support to the population with autism in Cambodia.

**Training:** Prior to field work, training was provided to all field workers by the project leader. Initial training was focused upon ethical considerations and the effective management of semi-structured interviews and focus groups. The process, ethical aspects, and the technique of conducting key informant interviews (KII) and focus group discussions (FGDs) and the differences between them were discussed in detail. Following the commencement of data collection, further training was provided in respect of the development and application of thematic codes. All members of the team signed forms of ethical agreement before commencing data collection.

## Field Work Undertaken

Key respondents were obtained as a sample using the following criteria:

1. Organisations or individuals with an established record of making provision for persons with disabilities, including those with autism
2. Organisations with a statutory responsibility for persons with disabilities, including those with autism
3. Parents/carers of individuals with autism

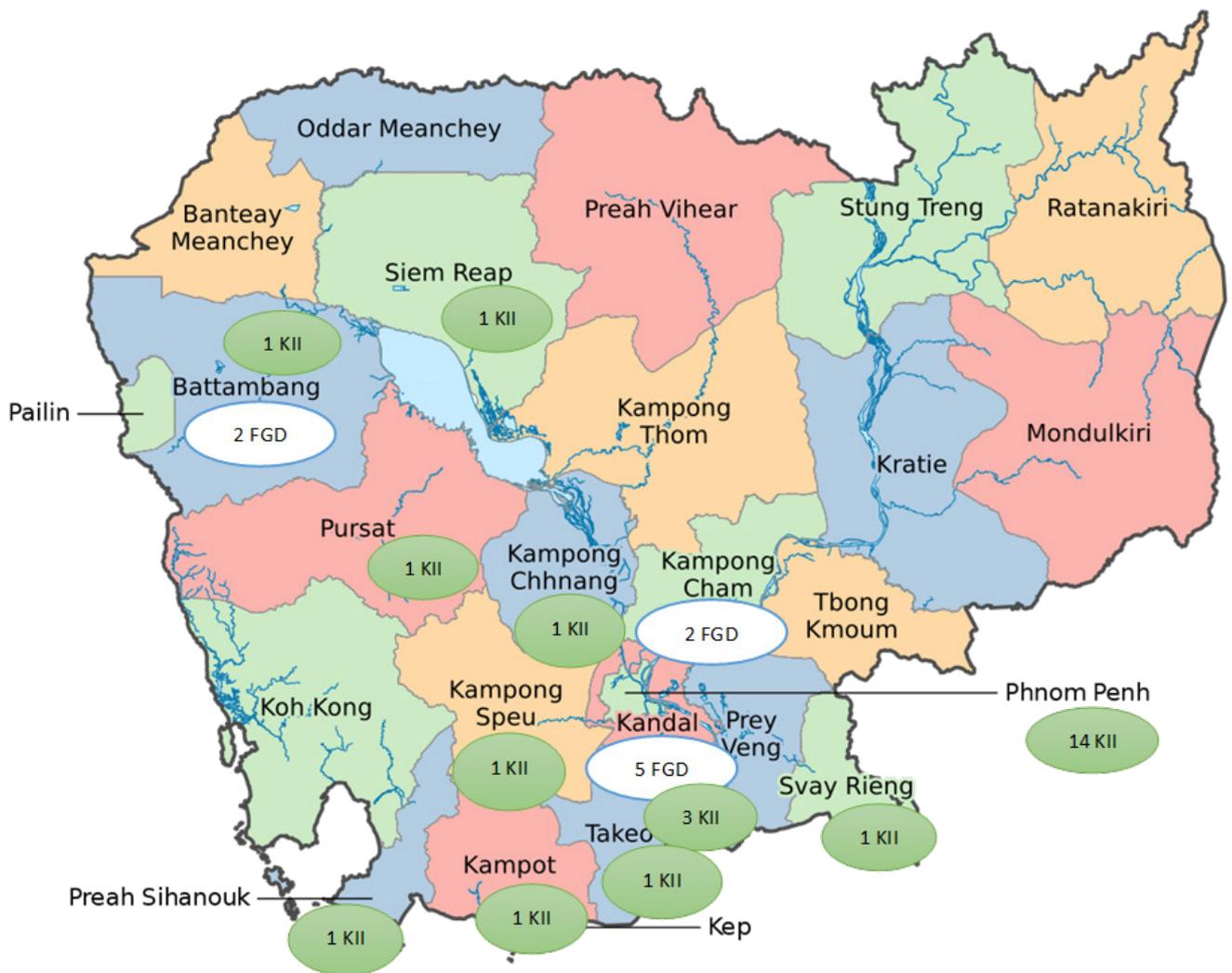
Data were obtained from the respondents and organisations presented in tables 1a and 1b below (Please note that while the names of organisations

are included, those of individuals have not been inserted for ethical reasons.) It has not been possible to interview individuals with autism due

to the challenges of access emanating from the COVID-19 epidemic and limited numbers of potential interviewees with an accurate diagnosis.

The map below shows the distribution of the research sample

**Participants in the study, province wise**



FGD: Focus Group Discussion with parents of children with autism

KII: Key Informant Interview with service providers

**Table 1a Respondents from whom Data have been obtained through interviews**

No.	Status of service provider / organization	Position of interviewee	Language of interview	Brief details of each service provider/ organization
1	Special education department, Ministry of Education, Youths and Sports, Phnom Penh	Head of children with intellectual disability office	Khmer	Special education department, Ministry of Education, Youths and Sports (MoEYS), Phnom Penh. A Government Department providing support for activities to encourage effective teaching and learning, social and emotional development and curriculum standards for teachers and children working with students with special educational needs and/or disabilities.
2	National Institute of Special Education, Phnom Penh	Director	Khmer	National Institute of special education, Ministry of Education, Youths and Sports (MoEYS), Phnom Penh.
3	Disability Action Council Secretary General , Phnom Penh	Deputy Secretary General	Khmer	An institution with responsibility for coordination and advisory on disability, including monitoring, evaluation and enhancing the implementation of disability legal frameworks. An institution with responsibility for promoting the welfare of children and families and persons with disabilities.
4	Mlop Tapang NGO, Sihanouk Ville province	Special need team leader	Khmer	This NGO working is a comprehensive center, dedicated to disadvantaged street children and youth in Sihanoukville, Cambodia. The Center provides shelter, medical care, education, sports, arts, vocational training, counselling, family support and protection from all types of abuse. Through a wide variety of programs focused on challenges across the community of Sihanoukville, the organisation supports at-risk children, youth and their families.

No.	Status of service provider / organization	Position of interviewee	Language of interview	Brief details of each service provider/ organization
5	Karuna Battambang, Battambang province	Program manager,	Khmer	<p>An NGO providing monthly clinical out-reach services. In 2016 and given the constant growth of the social and humanitarian projects, this local organization was created to fulfil a need. It operates in Battambang covering all its provinces.</p> <p>The Missions of the organization are:            Providing center-based care and home-based care at households and communities;            Formal and non-formal education, economic support and basic medical treatment to persons with disabilities, youths, women and children.</p>
6	Peace Village Center (PVC), Takeo province	Center Director	Khmer	An organisation that works collaboratively with other organisations to provide a referral service. Services including therapeutic interventions and education initiatives are provided to a broad range of persons with complex needs. The NGO is supported by Phnom Penh Church Diocese, runs day care center and home-based care support.
7	Epic Art, Kompot province	Country Director and, Special education Team Leader	Khmer	An organisation that promotes the inclusion of people of all abilities and disabilities through the arts. They use the arts as a form of expression and empowerment to bring people with and without disabilities together.
8	Disability Development Services Program (DDSP), Pursat province	Executive Director	Khmer	An NGO that works to promote the welfare of persons with disabilities through empowering and strengthening partnership with relevant stakeholders to access wide range of services including WASH, raise awareness of the community on the rights of persons with disabilities and work towards social inclusion and improve the quality of learning of children with disabilities by working with Department of Education Youth and Sport and other relevant government departments.

No.	Status of service provider / organization	Position of interviewee	Language of interview	Brief details of each service provider/ organization
9	National Special Olympics Cambodia, Phnom Penh	Senior member of executive committee	Khmer	National Special Olympics Cambodia organizes sport activities for children with intellectual disability and autism. Special Olympics provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities. Those activities give them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship.
10	Growing Special Education School, Phnom Penh	Mother of a son with autism and Head of the school	Khmer	A Special Education School first opened in 2017 under the auspices of Child Jesus Parish in South Phnom Penh and addressing the needs of children with autism. There are approximately 100 children on roll. Staff work on physical, sensory, social, and emotional development, and use the Applied Behaviour Approach (ABA) for some of their work.
11	Rabbit School Organization, Phnom Penh, Kandal, Kompong Speu and Siem Reap province	Program Manager	Khmer	A Special School organisation that has been working with children with intellectual disabilities in Cambodia for over 20 years. They promote the rights of Children with Intellectual Disabilities to gain access to education. Started the first integrated class room in a primary school and a vocational training centre in Phnom Penh. Since 2014 has been extending services to other provinces and currently have education projects in Kandal, Kampong Speu and Siem Reap provinces.
12	Pour un Sourire d'Enfant's School, Phnom Penh	Disability Program Manager	Khmer	A school that has a mission to help children escape from destitution and lead them to decent, skilled and well-paid jobs. To achieve this, six main programmes- adapted to the needs of the children have been developed: food, health, protection, education and schooling, vocational training and help for families.

No.	Status of service provider / organization	Position of interviewee	Language of interview	Brief details of each service provider/ organization
13	Government School HHC, Kandal province	Executive Director	Khmer	This school is an organization that promotes and protects the rights of children and youth with Intellectual Disabilities and Autism, empowers families and communities and engages government to be more responsive. The school works to address early disability intervention include early detection, special education and identification with support and training to parents and families to facilitate the maximum development of children, physical rehabilitation, and enrolment of children with disabilities in education system both with quality and equity.
14	KPF Government school Phnom Penh and Kratie province	Primary school teachers	Khmer	Staff at these schools are committed to seeing children and youth with moderate to severe disabilities living dignified lives, with their families, in inclusive communities. Using a community based, self-help approach, the schools build the capacity of families to advocate for the needs of their own children and ensure their rights are respected. They actively engage with communities to facilitate the inclusion of all people with disabilities, in all areas of life. This includes working with government ministries, Disabled Persons Organizations, Parent Groups and other organizations to advocate for the needs of vulnerable children.
15	Organization to Improve Communication and Swallowing Therapy Services in Cambodia (OIC) Phnom Penh	Executive Director	Khmer	Organization to Improve Communication that works to make speech therapy accessible to all those who need it in Cambodia. A Cambodian NGO working to grow speech therapy services in Cambodia and helping those with communication and swallowing difficulties and to provide occupational and speech therapy to children so that they could go to school and participate fully in society.

No.	Status of service provider / organization	Position of interviewee	Language of interview	Brief details of each service provider/ organization
16	National Borey for Infants and Children (NBIC), Phnom Penh	Director	Khmer	An organisation that provides a home to those who are abandoned or orphaned HIV/AIDS-positive persons and others with disabilities.
17	Preash Sihanoukraj Buddhist University, Phnom Penh	Acting rector	Khmer	A non-profit public higher-education institution providing graduate and post graduate training for students including those who will work in the education, health and care sectors.
18	Highest Council for Islamic Religious Affairs Cambodia, Phnom Penh	Assistant	Khmer	Council overseeing the welfare of the Muslim community in Cambodia. An organization that maintains an overview and supports the welfare of all members of the Muslim community in Cambodia, including those with disabilities.
19	Association for Aid and Relief, Japan (AAR Japan), Phnom Penh, Kandal province	Head of Organisation	English	International NGO promoting Inclusive Education, cooperating with schools and communities in Kandal province since 2013 to ensure that children, regardless of their disabilities, have access to school and can learn together while receiving appropriate care and attention to their individual needs. The Inclusive Education program includes establishing a barrier free school environment and providing training for teachers to help them better engage with children with disabilities.
20	Children In Families (CIF), Phnom Penh, Svay Rieng province	Technical Advisor	English	A local NGO, dedicated to providing high-quality family-based care for orphans and vulnerable children in Cambodia. The organisation also provides specific care to children with disabilities and chronic illness through a focused project and engages with the wider community through an outreach and church partnerships projects.
21	National Paediatric Hospital (NPH), Phnom Penh	Paediatrician/ Deputy chief of service	English	A government run hospital providing medical services, including assessment and therapeutic intervention for children and families, including those with disabilities.

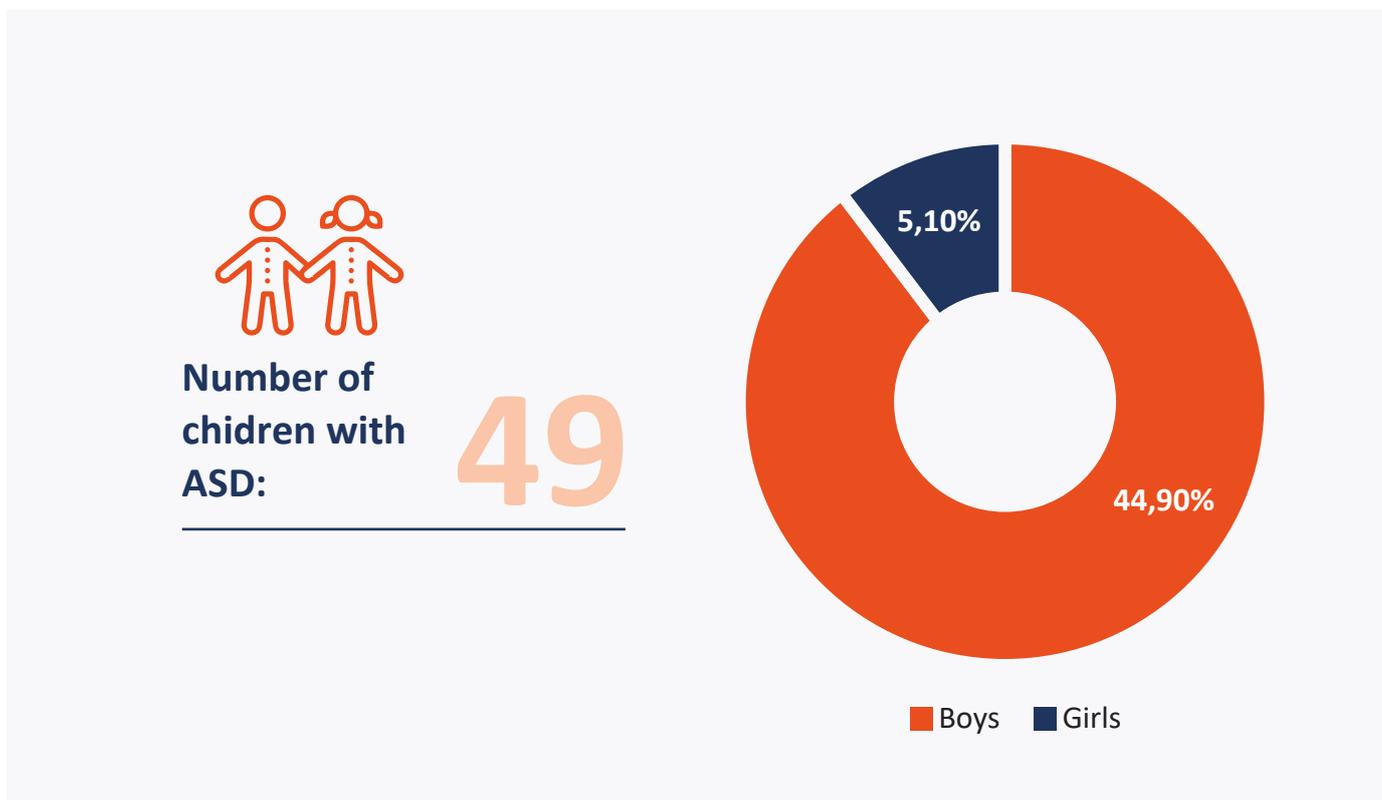
No.	Status of service provider / organization	Position of interviewee	Language of interview	Brief details of each service provider/ organization
22	Founder Karuna Battambang, NGO	Head of Organisation	English	The Mission of the organization is one of: Providing center-based care and home-based care at households and communities; Formal and non-formal education, economic support and basic medical treatment to disabled persons, youths, women and children.
23	Individual parent of child with autism	Mother of an autistic child and as teacher	English	Mother of daughter, 15 years old.
24	Medical Practitioner working for assessment and intervention with persons with disabilities, including autism	Medical practitioner	English	Government employed doctor involved in assessment and intervention programmes for children with disabilities, including those on the autism spectrum.
25	Damnok Toek - Goutte D'eau	Head of Disability Programs	English	Organisation working with rescued trafficked children, including many with disabilities.
26	Parents Association for Children with Intellectual Disabilities	Head of Organisation and a parent	Khmer	Organisation supporting families and arranging activities for persons with a range of intellectual difficulties, including autism

In addition to the interviews conducted with individuals, a series of focus groups were conducted with parents as indicated in the table (1b) below. The number of children represented in this sample is indicated in Figure 1 below

**Table 1b Parent Respondents from whom Data have been obtained through focus groups**

No.	Date of FGDs conducted	Location of focus group	No. of parents attended	Language used
1	25 <sup>th</sup> June 2021	CCAMH	6 parents (2 fathers, 4 mothers)	Khmer
2	9 <sup>th</sup> July 2021	CCAMH	5 parents (3 fathers, 2 mothers)	Khmer
3	12 <sup>th</sup> July 2021	CCAMH	5 parents (1 father, 4 mothers)	Khmer
4	14 <sup>th</sup> July 2021	CCAMH	6 parents (5 fathers, 1 mother)	Khmer
5	16 <sup>th</sup> July 2021	CCAMH	7 parents (4 fathers, 3 mothers)	Khmer
6	22 <sup>nd</sup> July 2021	Kompong Cham	5 parents (0 father, 5 mothers)	Khmer
7	19 <sup>th</sup> August 2021	Kompong Cham	7 parents (5 fathers, 2 mothers)	Khmer
8	2 <sup>nd</sup> September 2021	Battambang	4 parents (1 father, 3 mothers)	Khmer
9	3 <sup>rd</sup> September 2021	Battambang	4 parents (1 father, 3 mothers)	Khmer

**Figure 1. Children with ASD data set**



**Table 2. Demographics of family samples**

No.	Date of FGDs	Location of focus group	No. of parents	Sex/Age of the child	Schooling of the zchild	Informant/ Age of parent	Occupation/ Socio-economic status
Grp1	25 <sup>th</sup> June 2021	CCAMH	6 parents 2 fathers 4 mothers All from Phnom Penh	1.M/4 yrs	1.Pre-school (private school)	1. Informant: Mother (39 years & Father: 50 years old)	1.Business (Rental house and father is company staff-Singaporean.
				2.M/11 yrs	2. Not in school	2. Informant: Father (41 years & Mother: 39 years old)	2. Car Repairer-Father, Mother is rice seller.
				3.M/3 yrs	3. Not in school	3. Informant: Father (50 years & Mother: 40 years old)	3. Both are government staff (Father works at National Bank of Cambodia, Mother works at Ministry of Finance)
				4. M/6 yrs	4.Pre-school (private school)	4. Informant: Mother (35 years & Father: 33 years old)	4. Government staff at Social Security Fund (SSF) and father is company staff.
				5. M/7 yrs	5.Growing Special education school	5. Informant: Mother (37 years & Father: 35 years old)- divorced parents	5.Government staff at Ministry of Environment.
				6. F/4 yrs	6. Not in school	6. Informant: Mother (39 years & Father: 43 years old).	6.Mother: Online seller, Father: Photographer.

Grp 2 9 <sup>th</sup> July 2021	CCAMH	5 parents 3 fathers, 2 mothers	7.M/8 yrs	7. Special school (HHC)	7.Informant: Mother (29 years & Father: 38 years old)	7.Mother is housewife and father is credit officer.
			8.F/5 yrs	8. Pre-school (private school)	8. Informant: Father (41 years & Mother: 37 years old)	8. Government staff at Ministry of Interior -Father, Mother is doctor at Ketomealea hospital.
			9.M/7 yrs	9. Private school (Sovann Phum school at 1st grade)	9. Informant: Mother (40 years & Father: 48 years old)	9. Both are sellers
			10.M/5 yrs	10.Pre-school (Government school)	10. Informant: Father (37 years & Mother: 30 years old)	10.Delivery staff and mother is Pizza company staff.
			11.M/9 yrs	11. Special school (Rabbit school)	11. Informant: Father (45 years & Mother: 40 years old).	11.Government staff at Provincial agriculture of Kompong Cham province and mother is working at Electricity of Cambodia (EDC) at Kompong Cham province.
Grp 3 12 <sup>th</sup> July 2021	CCAMH	5 parents 1 father, 4 mothers	12.M/14 yrs	12.Special school (Rabbit school?)	12.Information unavailable	NA
			13.M/7 yrs	13. Special school (HHC)	13. Informant: Mother (41 years & Father: 42 years old)	13. Mother is seller and father is in sport army.
			14.M/ 4 yrs	14. Not in school	14. Informant: Mother (32 years & Father: 45 years old)	14. Father is driver and mother-housewife).
			15.M/ 6 yrs	15. Pre-school (Private school)	15. Informant: Mother (33 years & Father: 43 years old)	15. Both parents are company staff.
			16.F/4 yrs	16. Special school (HHC)	16. Informant: Grandmother (Father is 37 years & Mother: 36 years old).	16. Both parents are sellers.

Grp 4 14 <sup>th</sup> July 2021	CCAMH	6 parents 5 fathers, 1 mother	17.M/5 yrs	17. Not in school	17. Informant: Father (40 years) & Mother: 40 years old).	17. Father is seller and Mother is government staff (admin) at Ministry of Education.
			18.M/7 yrs	18. Special school (Growing Special Education school)	18. Informant: Mother (38 years & Father: 36 years old)	18. Both parents are grocery sellers.
			19.F/9 yrs	19. Private school (1st Grade)	19. Informant: Father (42 years & Mother: 43 years old)	19. Father is Tuk Tuk driver and mother- housewife).
			20.M/7 yrs	20. Primary school (1st grade) at Takhmao, Kandal province (Private school) (Government school).	20. Informant: Father (36 years & mother: 32 years old)	20. Both parents are government staff at Ministry of Economy and Ministry of Health.
			21.M/7 yrs	21. Primary school (2nd grade) at Prey Veng province (Government school).	21. Informant: Father is 34 years & Mother: 30 years old).	21. Both parents are teachers.
			22.M/3 yrs	22. Pre-school	22. Informant: Father is 33 years & Mother: 29 years old).	22. Both parents are sellers.

Grp 5 16 <sup>th</sup> July 2021	CCAMH	7 parents 4 fathers, 3 mothers	23.M/5 yrs	23.Not in school	23. Informant: Father (36 years & Mother: 35 years old).	23.Father is police and Mother is housewife.
			24.M/5 yrs	24.Not in school	24. Informant: Father (48 years & Father: 31 years old).	24. Father is government staff at Ministry of Foreign Affairs and mother is company staff.
			25.M/ 6 yrs	25.Not in school	25. Informant: Father (39 years & Mother: 36 years old)	25. Father is police and mother is doctor at Meanchey Referral Hospital, Phnom Penh.
			26.M/7 yrs	26. No information	No information	NA
			27.M/7 yrs	27. Pre-school (Private school)	27. Informant: Mother (37 years & Father: 44 years old)	27. Both parents are motorbikes sellers.
			28.M/7 yrs	28. Pre-school (Government school)	28. Informant: Mother (30 years & Father: 33 years old).	28. Both parents are company staff.
			29. M7 yrs	29. Special school (Private school- King Kids)	29. Informant: Father (38 years & Mother: 36 years old).	29. Both parents are cake sellers.

Grp 6 22 <sup>nd</sup> July 2021	Kompong Cham	5 parents 0 father, 5 mothers	30. M/5 yrs	30. Not in school	30. Informant: Mother (28 years & Father: 29 years old)	30. Mother is contracting primary school teacher and father is farmer.
			31. M/6 yrs	31. King Kids Special school (1 day per week on every Sunday)	31. Informant: Mother (33 years & Father: 37 years old)	31. Mother is midwife and father is nurse at Prey Veng province.
			32. M/ 5 yrs	32. Pre-school (Government school)	32. Informant: Mother (22 years & Father: 21 years old)	32. Mother is teacher and Father is farmer.
			33. M/ 6 yrs	33. Primary school (Government school) at Kratie province.	33. Informant: Mother (41 years & Father: 53 years old).	33. Both parents are high school teachers.
			34. M/8 yrs	34. Not in school	34. Informant: Mother (34 years & Father is 42 years old).	34. Mother is seller at home and father is farmer.
Grp 7 19 <sup>th</sup> Aug 2021	Kompong Cham	7 parents 5 fathers, 2 mothers	35. M/6 yrs	35. Primary school 1st grade (Private school) at Kompong Cham province.	35. Informant: Father (43 years & Mother: 40 years old).	35. Father is government staff -Public work and Mother is high school teacher (Khmer literature).
			36. M/9 yrs	36. Not in school	36. Informant: Mother (43 years & Father: 48 years old).	36. Father is gold seller and mother is housewife.
			37. M/ 6 yrs	37. no information		
			38. M/ 7 yrs	38. no information		
			39. M/7 yrs	39. no information		
			40. M/7 yrs	40. no information		
			41. M/5 yrs	41. Pre-school (Private school at Cheurng Prey district)	41. Informant: Father (34 years & Mother: 29 years old)	41. Father is phone seller and mother is vegetables seller.

Grp 8 2 <sup>nd</sup> Sept 2021	Battambang	4 parents 1 father, 3 mothers	42.F/4.5 yrs	42.Special school (Coconut house NGO)	42. Informant: Mother (39 years & Father: 41 years old).	42. Both parents are company staff.
			43.M/7 yrs	43. Primary school (Private school- at 1st grade Panhasas)	43. Informant: Father (35 years & Mother: 30 years old).	43. Father is University teacher and mother is banker).
			44.M/ 7 yrs	44. Primary school (government school at 1st grade)	44. Informant: Mother (39 years) & Father: 52 years old)	44. Father is grocery seller and mother is primary school teacher).
			45.M/ 8 yrs	45. Pre-school (Private Sovann Phum school)	45. Informant: Mother: (38 years & Father: 40 years old).	45. Both parents are sellers (Plates, pots...)
Grp 9 3 <sup>rd</sup> Sept 2021	Battambang	4 parents 1 father, 3 mothers	46. M/7 yrs	46. Primary school (government school at 1st grade)	46. Informant: Elder sister. Father: (45 years old & step mother: 43 years).	46. Father is photographer and mother is fish seller.
			47. M/5 yrs	47. Special school (Coconut house NGO)	47. Informant: Mother (31 years & Father: 38 years old)	47. Father is government staff-social work at district level and mother is housewife).
			48. M/ 7yrs	48. Primary school (government school at 1st grade)	48. Informant: Grandmother Father (31 years old and mother is 40 years) - Divorced parents.	48. Father works at road construction company and mother is company staff (Easycom) Company.
			49. M/5 yrs	49. Pre-school (Private school- Kolbot school)	49. Informant: Father (34 years & Mother: 35 years old).	49. Father is head of company and mother is high school mother (teaching physics and chemistry)
Total	Phnom Penh, Kandal, Prey Veng, Kratie, Kompong Cham and Battambang	49	49 (Boys: 44, Girls: 5)			

Figure 2. Age profile of sample children:

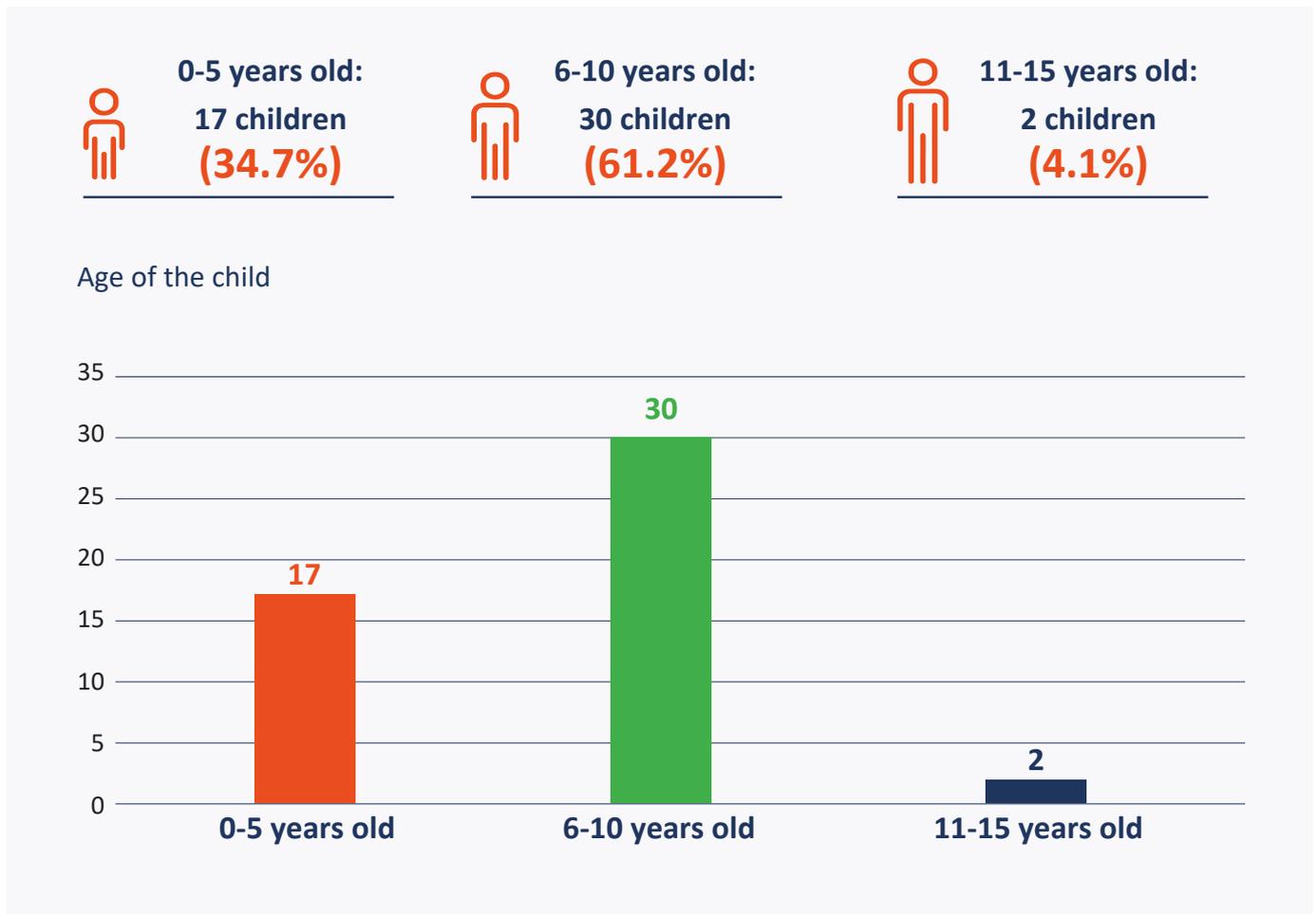


Figure 3, Enrolment in School

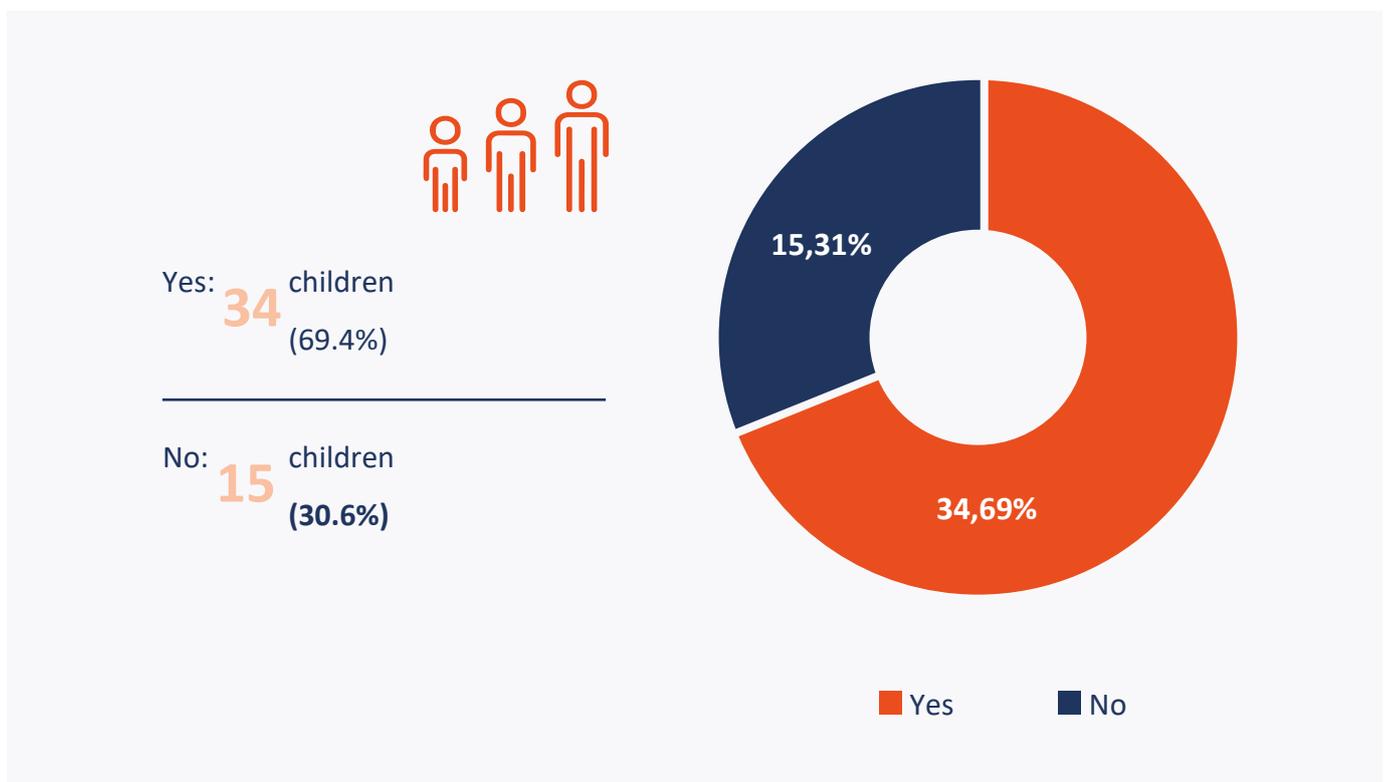


Figure 4. Type of school attended

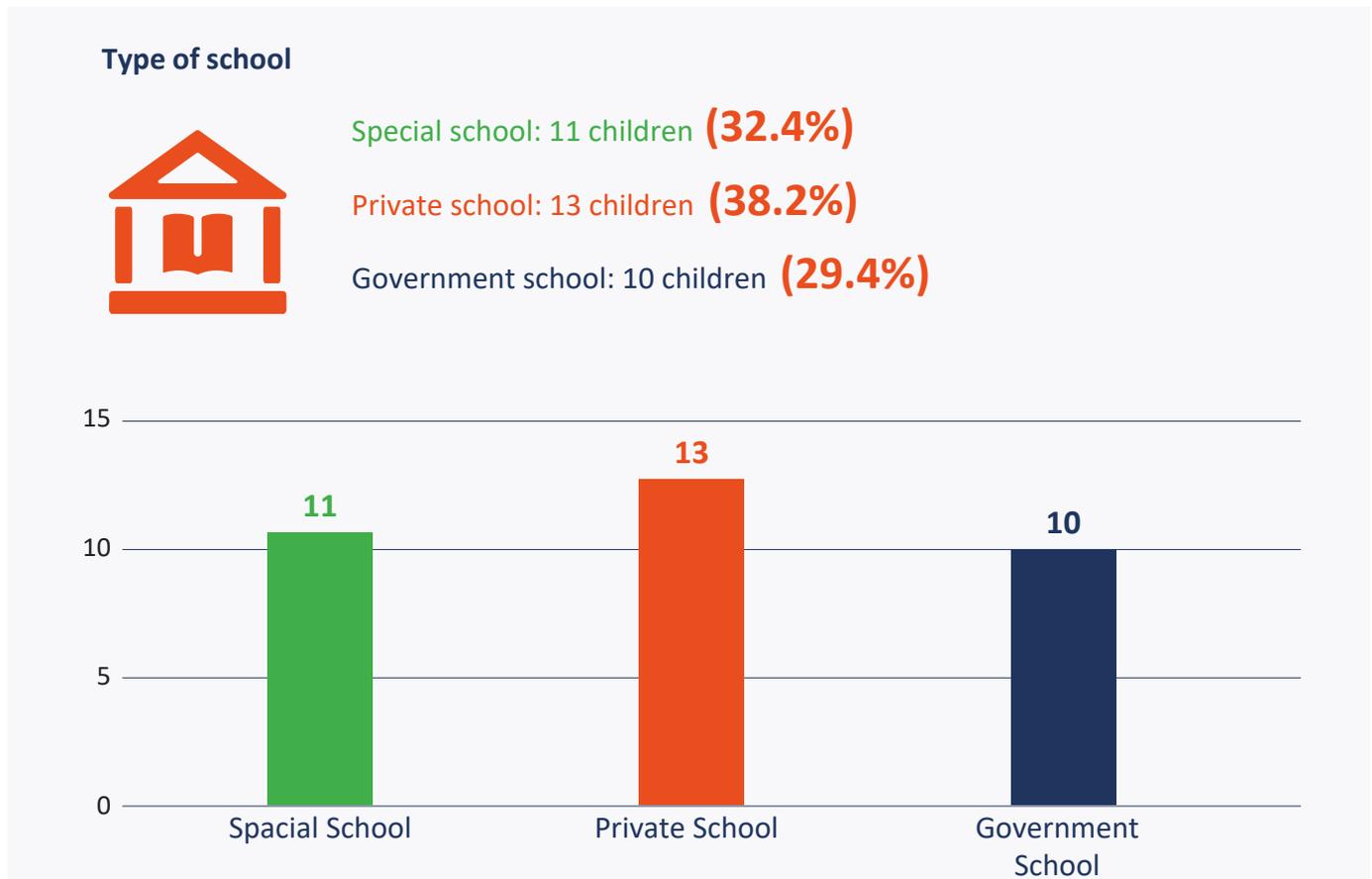
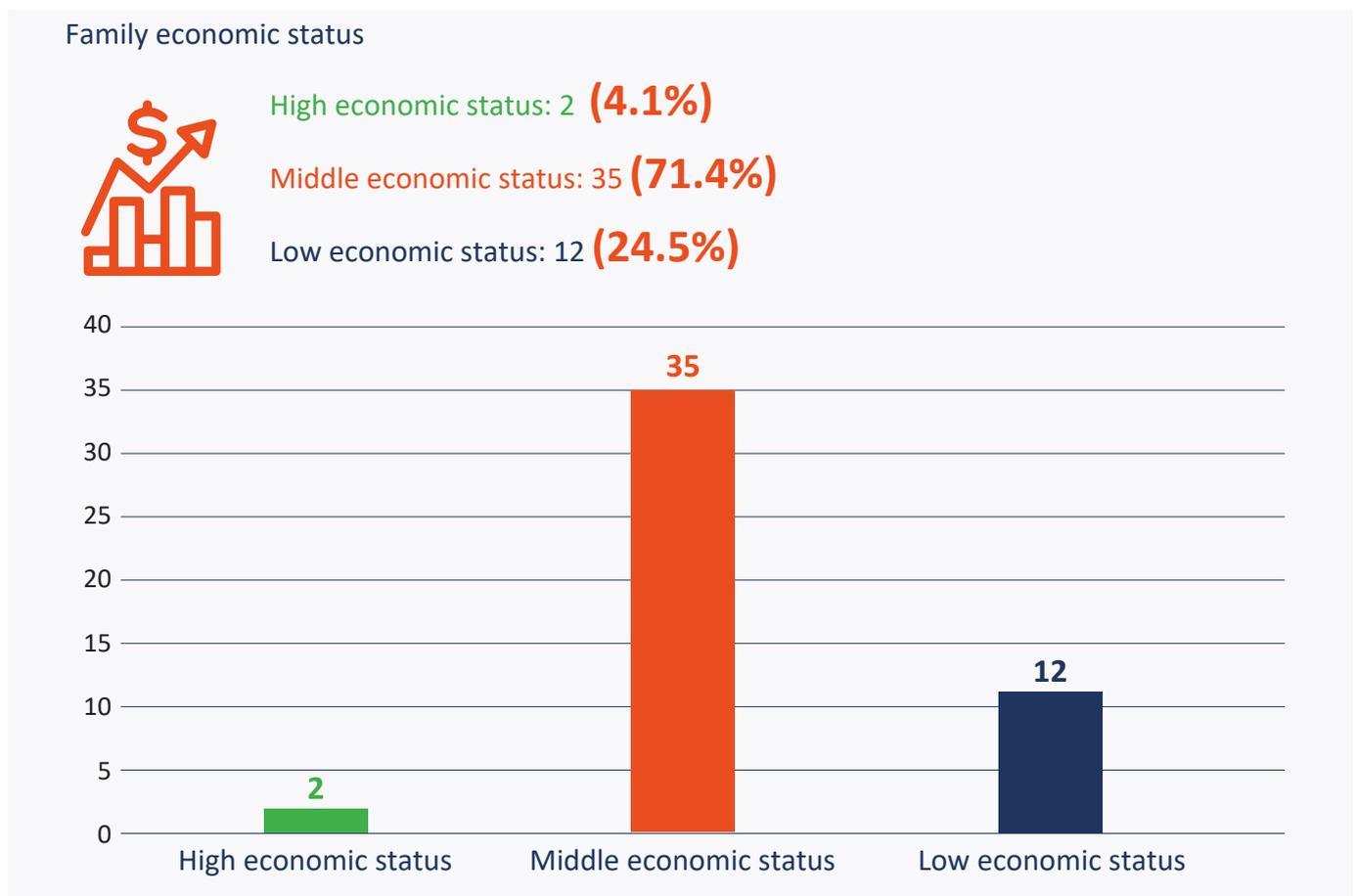


Figure 5. Family economic status:



**Data analysis:** Interviews and focus groups were audio recorded, transcribed and summarised. These were then subjected to thematic coding and a process of code reduction in order to obtain categories and identify key issues emerging from the data. Codes were derived from the initial research questions but were also influenced by the dynamic situation that emerged as data was collated. All codes were provided with a definition that was adhered to in order to verify the trustworthiness of interpretation (see table 2 below). A process of multiple respondent analysis of data provided a triangulated response to the data set.

**Table 2 Codes with Definitions**

CODE	DEFINITION
AR	AWARENESS RAISING: There is a need to raise awareness about autism and disability more generally
AS	ACCESS TO SCHOOL: There is a focus and need upon getting children with autism/disabilities into school
ASS	ASSESSMENT: Assessment is an important part of identifying need and providing support
ATS+	ACCESS TO THERAPEUTIC SERVICES: Access is provided to therapeutic services
ATS-	INADEQUATE ACCESS TO THERAPEUTIC SERVICES: Access to therapeutic services is limited
BE	BEHAVIOUR: Behaviour identified as an issue in the management or education of children with autism
CBR	COMMUNITY BASED REHABILITATION: CBR is available for families.
CI	COMMUNITY INVOLVEMENT: Encouraging the community to become involved in supporting people with autism/disability
COLLNGO	COLLABORATION BETWEEN NGOS: There is evidence of collaboration between NGOs working to support individuals with autism/disability
CPI	CHILD PROTECTION ISSUES: There are risks of physical and sexual abuse for children with disabilities/autism
DIS	DISTANCE AN OBSTACLE: Distance is an obstacle to gaining easy access to facilities and support
DISC	DISCRIMINATION: There is discrimination against people with autism/disabilities
EMP	EMPLOYMENT: There is a lack of employment opportunities for persons with autism/disability
FR	FACILITIES AND RESOURCES: Access to education and other services is dependent upon facilities and resources
GOV	GOVERNMENT INVOLVEMENT: Government/Ministry plays a direct role in provision for those with autism/disability
IE	INCLUSIVE EDUCATION: There is a focus or needs to be a focus upon developing education that is more inclusive

CODE	DEFINITION
IEP	INDIVIDUAL EDUCATION PLAN: an IEP is prepared for children with disabilities/autism
LEP	LACK OF EDUCATIONAL PROVISION: inadequate availability means that children are not accessing school
LS	LEGAL SUPPORT: Parents need legal support
PA	PROVISION OF ACCESS: Provision needs to ensure accessibility for all individuals including those with autism or disabilities
PKR	PARENTS PLAY A KEY ROLE: Evidence of direct parental involvement in support of individuals with autism/disability
POV	POVERTY: Poverty is a factor in families accessing services
PSEO	PARENTS SUPPORT EACH OTHER: Parents play a critical role in supporting each other
RUR/URB	RURAL/URBAN: There are distinct differences of provision in rural and urban parts of the country.
PL	PLACEMENT OF INDIVIDUALS: Efforts made to find placements for individuals with autism/disability
TN	Training from NGO: Some training has been provided to professionals through an NGO
TP	TRAINING FOR PARENTS: Training is provided for parents of children with disabilities
TT	TEACHER TRAINING: There is a need to provide training to teachers that includes promoting positive attitudes and an understanding of autism and disability

## Challenges experienced during the project and how these were addressed

The project was conducted during the time of a global pandemic. This inevitably constrained the ability of team members to travel in order to obtain data through personal contact with potential respondents. Field work was conducted in rural areas, but only at times when travel restrictions had been lifted. This necessitated the careful management of scheduling and also adherence to all necessary safe practices. The use of video platforms enabled individual interviews to be conducted by team members and was essential in ensuring that all

obligations to respondents were met. Focus groups were managed face to face but were limited to times when it was deemed safe to travel.

The gathering of data was managed in a way that ensured easy access to participants. Focus groups and some interviews were conducted by members of the project team in Khmer, others were conducted in English. This enabled all participants to make a choice about their preferred language and also enabled all members of the project team to be fully involved in the data collection process. Translations of transcripts from Khmer to English, managed by members of the team, ensured that the project leader had full access to all data.

## Findings

### Finding 1:

The Government of Cambodia has made a commitment to ensuring appropriate access to education, health and social welfare for all persons with disabilities and had made significant progress in the development of policies. While there is some evidence of the emergence of good practice in making provision for persons with disabilities, including those with autism spectrum disorders, the gap between policy and practice remains considerable.

The Law on the Protection and the Promotion of the Rights of Persons with Disabilities (2009) sets out the intention of the Government and in Article 2, asserted an intention to: -

- To implement policies aimed at ensuring the rights of persons with disabilities to be included in all those aspects of life expected by typically developing individuals have been established within Cambodia.
- To protect the rights and freedoms of persons with disabilities;
- To protect the interests of persons with disabilities;
- To prevent, reduce and eliminate discrimination against persons with disabilities;
- To rehabilitate physically, mentally and vocationally in order to ensure that persons with disabilities are able to participate fully and equally in activities within society.

Within this law the establishment of a Disability Action Council (DAC) was an important strategic move and has ensured an active body that has provided insights into developments in recent years. This body has overseen the generation of a National Disability Strategic Plan 2014-2018 (NDSP) and has maintained an overview of its implementation and published a review of achievements. The review led to the formulation of a new a National Disability Strategic Plan 2019-2023 (NDSP) which reiterates a commitment to improve the lives of all Cambodians living with disability.

In parallel with the National Disability Strategies,

the implementation by the Ministry of Education, Youth and Sport of an Education Strategic Plan 2019-2023 and a National Policy on Early Childhood Care and Development (2010) demonstrates a progressive approach to addressing the Education for All intentions of the Sustainable Education Goals to which Cambodia is a signatory.

While progress towards creating a more inclusive and equitable society for persons with disabilities is apparent in these important initiatives, a considerable gap remains between policy intentions and practice. These are highlighted in the findings below.

Documentation related to disability in Cambodia is often generalised with specific mention of diagnosed conditions such as autism being rarely cited. The language of much of the Cambodian documentation indicates a continuing medico-deficit model, though the desire to move to a social model of disability and inclusion is in evidence. The World Health Organization South East Asia Regional Strategy on Autism Spectrum Disorders (2017) acknowledges existing deficits in relation to the awareness of autism and structures currently available to provide necessary support. This is certainly the case in Cambodia. Where there is a focus upon autism spectrum disorder within Cambodia, this tends to be through the work of NGOs or those specialised facilities and institutions catering for a wider range of disabilities. However, there is an apparent willingness to challenge this situation within all levels of administration in Cambodia and to address shortcomings.

## Finnding 2:

**Awareness of autism spectrum disorders both within the general population and amongst professionals, as well as leaders of faith-based organizations/religious leaders in Cambodia is limited. With the exception of a few specialist organisations, the defining features of autism are not understood and opportunities for the development of professional knowledge in this area are few.**

Whilst there are some organisations and individuals in Cambodia who have experience and knowledge of autism, awareness of autism spectrum disorders amongst the general population is limited. Parents of children with autism report that their own knowledge and understanding of the condition was gained only after receiving a formal diagnosis of their child's needs. Following diagnosis many remain uncertain about the general characteristics of autism and especially about the potential for education and social development. Focus groups conducted with parents reveal that many continue to seek a cure for their child and some were unsure whether the condition may even be contagious. Other parents stated that they were confused about the nature of disability and whether their child with autism was similar to others categorised as disabled. For example, one mother reported that she confused autism with Down's syndrome. Another identified how she had used social media in order to understand her child's needs: *"One day, I saw a video on Facebook that talked about Autism. It said kids who have this condition are like that. They don't turn to you when you call them. I have never known Autism, so I watched the video to know better, to see why they don't react when called. After a few articles, I realized that oh! My child might have Autism."*

Lack of understanding in the general population has resulted in some children and families facing discrimination. Parents report that their children

are referred to as mad and dangerous and that others are discouraged from associating with them. The parents of children with autism are often accused of poor parenting and lack of management of their children's behaviour. Focus groups conducted with parents in Kampong Cham and Battambang suggest that exclusion and discrimination as a result of poor awareness is particularly prevalent in rural areas.

Awareness raising campaigns have been mounted in Cambodia with the support of Government and NGOs using a range of media, but it is apparent that the impact of these has been limited. Organisations including the National Institution of Special Education have organised workshops aimed at awareness raising and recognise the need to expand this type of activity. Many parents and professionals gain information about autism through a range of social media platforms. However, it was reported by many respondents to the research that these are particularly unreliable sources of trustworthy information, with some suggesting that social media sites often contain misinformation.

There are organisations within Cambodia that have a good understanding of autism. These include the Organization to Improve Communication and Swallowing Therapy Services in Cambodia (OIC) who provide therapeutic support for some children and young people with autism, Disability Development Services Program (DDSP) in Pursat,

Association for Aid and Relief Japan (AAR Japan) and special educators at Rabbit School. The Centre for Child and Adolescent Mental Health (CCAMH) in Phnom Penh have developed a level of expertise in relation to assessment and work closely with a number of NGOs in support of awareness raising.

Awareness of autism remains poor in schools and many health services. Parents report that they have difficulties obtaining a diagnosis with some medical practitioners themselves having limited knowledge and experience of autism. Expertise is available in a number of medical centres, but access to these is often expensive and not easily accessed by parents

living in provincial parts of the country. A medico-deficit model persists and is perpetuated because of the lack of understanding in respect of social models that have been shown internationally to be beneficial to individuals on the autism spectrum.

Community and religious leaders demonstrate empathy for the families of individuals with autism. However, the leaders of religious organisations admit to having limited knowledge about autism and recognise the need to increase their own awareness and that of the colleagues with whom they work.

### Finding 3:

**Educational provision for children on the autism spectrum is poor. A few specialist schools do exist, but educational facilities based upon a sound knowledge of autism is limited to these schools and is more likely to be found in urban areas. Within special schools providing for a range of disabilities, children on the autism spectrum have been identified, but understanding of their needs and of the appropriate methods for teaching them is limited. The ability to provide an appropriate education is further impeded by a lack of appropriate resource, specialist teaching equipment and a dearth of ained teachers.**

The Government of Cambodia is a signatory to the 2030 Agenda for Sustainable Development and has stated the intention to work towards achievement of the sustainable development goals. This includes a commitment to ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes. The intention to ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities has also been affirmed.

The Ministry of Education, Youth and Sport achieved the Education Strategic Plan 2019 – 2023 reiterates a commitment to inclusive education through an intention to, “ensure inclusive and equitable quality

education and promote lifelong learning opportunities for all.” The Strategic Plan identifies significant progress made in addressing educational development throughout the country. It also acknowledges the need to improve enrolment rates for school-aged children who are still not attending primary school, including children with disabilities and those living in rural and remote areas. The Government of Cambodia have set a target for all children and youths to have access to quality education at all levels, with equity and inclusivity, especially children from disadvantaged families and out-of-school youths. The Education Strategic Plan 2019–2023 indicates a significant level of awareness of the challenges faced in developing equitable and inclusive education for all and should provide the

impetus for strengthening of provision for all children with disabilities, including those with autism. The USAID Situational Analysis of the Education of Children with Disabilities in Cambodia (2018) identified 52% of children with disabilities as being not enrolled in schools. Those with severe and complex needs were seen to be least likely to receive a formal education, a situation that continues today.

Educational provision for children on the autism spectrum is poor. Discussions with parents reveal that the lack of appropriate schooling is a source of considerable frustration and stress to families. This situation not only inhibits opportunities for children with autism to learn, but also impacts upon family finances in situations where parents as primary caregivers are unable to work.

The perception of parents is that government schools and many private schools do not wish to enrol children with autism. This view was confirmed by a number of service providers, including school leaders and representatives from both government and non-governmental agencies, who indicate that schools are poorly equipped and ill-prepared to address the needs of such children. Parents believe that schools are worried about being able to manage their children with autism. In particular they are apprehensive about behaviour and the potential for disruption in classrooms. For example, a group of parents stated that *“when they saw our kids are hyperactive they said the class is full and tell us to come at the other day. It’s like they don’t want to accept our kids, but they couldn’t tell us straightforward.”* Another parent confirmed that, *“Some schools they frankly told me that the child like this will not be accepted according to the school policy. They said it’s difficult because if something happens, it’s hard for them to take responsibility.”* A private special school that does provide education to children on the autism spectrum confirmed that

access to other schools for such children is difficult and that as a specialist provider, they do not have the capacity to meet demand for places.

Where access to education is available this is most often provided in special schools or by NGOs. A special educator from Sihanoukville emphasised the necessity for schools to provide a curriculum that addresses more than just the academic needs of children. *“Because we have a school, we follow government curriculum in teaching especially the curriculum of kindergarten. It is not all children in the class who are having autism. We focus on activity for daily living. These children have difficulties in these areas, so we include some activities on toileting, bathing, and self-hygiene. Older kids learn to help to do house chore. We encourage the caregiver to involve them. We include some literacy and maths. Children with autism learn better this way.”* However, few schools have received the training necessary to modify the curriculum to address the needs of diverse learners. In those schools that have some expertise in the education of children with autism there is considerable enthusiasm and commitment in respect to maintaining and improving the services that they provide.

Private schools that do make some provision for children with autism invariably have to charge fees. In many instances these are prohibitive to all but the wealthiest families. A senior clinician from the National Paediatric Hospital stated that, *“The school fees for children with autism are very high compared to those without disabilities. The school fee can be \$1,000 (US) per year but for the child with autism the fee can be \$1,600 (US) per year. So, very few parents can afford that payment.”* This was confirmed by several parents, many of whom accept that a fee is necessary, but find it impossible to maintain the necessary levels of financing. This situation was confirmed by a Government doctor.

One parent indicated that *“If it is a private school, they are very happy when they see parents bring their children with Autism in. They would charge 30\$ per hour. Actually, this is very expensive, but for their children’s benefits, parents have to accept. For me, I could not afford it. If I could I would do the same.”* Another parent reiterated this point stating that, *“for the period of three months, she charged me 100\$. If we have an average social economic condition it is okay. But when the economic situation is down and during the pandemic of Covid-19, the ones who are poor this would be hard. It is not always that Autism occurs within the only rich families, even the waste collector’s family it also happens. I wish there is other school that has similar services.”*

There is a significant disparity between services available in urban and rural areas. Parents living in Phnom Penh are more likely to access therapeutic and educational services than those living in the provinces. The head of a special community providing for persons with disability identified this

problem as having been acknowledged at national level. *“The Ministry of education plan to collaborate with NGOs to develop more schools in provinces, however there is a lack of schools locate at districts and provinces.”* This was confirmed by a representative from the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY) who acknowledged that there was a need to improve school access in many of the provinces. Parents from the rural communities expressed frustration at the lack of educational facilities for their children which they believe will limit their opportunities for employment and independent living in later life.

A major obstacle to improving educational provision for children with autism is the lack of initial teacher training and professional development for serving teachers related to special educational needs. As a Government doctor stated, *“Many children cannot go to school because we do not yet have special educators.”* This is an important issue and one that is considered in finding number 4 below.

#### Finding 4:

**The need for specialist teacher training in order to provide increased knowledge, skills and understanding in the area of autism is evident. Respondents report limited understanding of autism within the teaching profession leading to reluctance to teach children or enrol them into schools.**

The Education Strategic Plan 2019-2023 has acknowledge the need to prioritise and reform teacher training and professional development programmes in Cambodia. This document reiterates an intention to *“modernize the standards of teacher training programmes to meet national needs,”* (section 4.4). This will be important as progress is made towards achieving the commitment stated, *“For the next five years (2019–2023) and towards*

*2030 and 2050, MoEYS is committed to achieving Sustainable Development Goal 4 on Education, based on the principles of inclusive, equitable and quality education and promoting lifelong learning opportunities for all,”* (Preface to The Education Strategic Plan 2019-2023).

The USAID Situational Analysis of the Education of Children with Disabilities in Cambodia (2018)

reported the development of new diploma courses for teachers working with children with sensory difficulties. Additionally, a manual promoting inclusive practice has been developed by Rabbit School. However, a lack of teachers trained in the area of autism spectrum disorders and for the promotion of inclusive education is a major obstacle to the provision of education for this population. Few teachers have had opportunities for professional development related to autism and there are no requirements to address this topic within the teacher training curriculum. While there is some evidence of efforts to address issues related to differentiated instruction, and to raise awareness of disability, as seen for example in the Cambodia Teacher Training Project [CTTP] based at the Kandal Primary Teacher Training College, there is no specific focus on autism. Representatives of both government and NGOs report this as being a major obstacle being faced by families of children on the autism spectrum. A senior professional at the National Paediatric Hospital suggested that, *“the schools can provide a service, but most don’t have proper training about autism or special needs. We need to work with primary school teachers and those in kindergarten.”* A representative from the Ministry of Education, Youths and Sports confirmed this belief when stating that *“In primary, and secondary level, autism has not yet been understood deeply due to the fact that teachers do not understand well and have not received any training or understanding yet. So, the service delivery is not yet good.”*

Within specialist provision providing education for children with disabilities, there are some teachers who have experience of working with children on the autism spectrum, a few of whom have had specialist training. In some instances, these professionals have worked in collaboration with The National Institution of Special Education on course development and delivery. The Organization

to Improve Communication and Swallowing Therapy Services in Cambodia (OIC) have worked in collaboration with the Ministry of Education to conduct basic speech therapy training to teachers at Phnom Penh and some provinces (Kandal, Kampot, Kampong Speu).

Some NGOs including the Association for Aid and Relief Japan (AAR Japan) have implemented short training courses in autumn for a limited number of professionals. Though these have been accessed by only a small number of teachers. The National Institution of Special Education has also implemented some short course of training in autism, but these have similarly been accessed by only a small proportion of the teaching profession. The Centre for Child and Adolescent Mental Health (CCAMH) located at Chey Chumneas Referral Hospital has also provided some training for teachers, health professionals and parents.

Parents of children with autism reported that a lack of trained teachers is often cited as a reason for schools refusing to enrol their children in school. During focus groups parents informed researchers that *“mostly schools reject (our children), do not accept them because they find difficulty in teaching or managing the child’s behaviour problems and the teachers lack skills in managing children with autism.”* This was a message that was given consistently across parent groups *“It seems that the teachers do not accept such kids. They don’t know how to teach so they can’t teach (children with autism) our kids.”*

A lack of training has severely impacted the confidence of parents in the ability of schools to provide an adequate education for their children and has similarly inhibited schools in respect of their ability to address the needs of a population of students with autism.

## Finding 5:

Access to medical and therapeutic support is variable and more likely to be available in urban settings. Even within urban settings, specialized services such as speech therapy and occupational therapy are not easily accessed. This situation is further inhibited as training in these fields is not currently available in the country. Some access is restricted because of the need to travel to specialist facilities. There are however, some good examples of transport provision made by some NGO which enables children and families to access resources.

Parents and professionals report difficulties in accessing therapeutic and health services for persons with autism. In some instances, where therapists are available they have a lack of sufficient understanding of the nature of autism spectrum disorders. Parents reported their difficulties in locating adequate support services stating that *“you search for the available services for your child and there is only CCAMH that can provide good services.”* Those living in rural areas reiterated the view that they were at a severe disadvantage and that services were only easily accessed in the larger cities. There are, however some examples of NGOs providing support with transport enabling families to access some services.

Access to physiotherapy is limited. While one special school provided examples of the way in which they had attempted to support parents in understanding the needs of their children and how this assistance could be provided, reporting that *“for children with cerebral palsy, we provide physiotherapy through asking parents demonstrate the activities they did with the child and if they couldn’t show us, we demonstrate the physiotherapy techniques to them.”* Similarly, a manager from Disability Development Services Programme (DDSP) in Pursat suggested that they were making strides in providing support to families. However, in other specialist provision it was suggested that the ability to obtain appropriate services and offer the necessary support was proving challenging. A Technical Advisor for Children in

Families (CIF), Phnom Penh, Svay Rieng province confirmed the difficulty in providing adequate services reporting that *“There are too few Cambodian physiotherapists or those who are Cambodia trained.”*

Speech therapy is similarly under developed, though a model for provision was evident in the work of the Organization to Improve Communication and Swallowing Therapy Services in Cambodia (OIC) whose Executive Director articulated a vision *“to focus on activities to develop speech therapy courses have students study this speech therapy to become speech therapists in Cambodia.”* This organisation has developed resources and in collaboration with nurses and physiotherapists, working at National Paediatric Hospital (NPH) have investigated the types of services needed. They have a plan to offer speech therapy services at Kompong Speu Physical Rehabilitation Center which could be a useful approach to capacity building. The positive impact of the work of this organisation was acknowledged by the Technical Advisor for Children in Families (CIF).

The issue of inadequate training for therapists was highlighted from several sources. A Programme Manager from Karuna Battambang informed us that staff had *“received some training from some partner NGOs, from CCAMH and volunteers from abroad”* but emphasised the need for a comprehensive training programme within the country. Programme manager from Karuna Battambang emphasised that

the limited therapeutic training that was available tended to be delivered by from so a few NGOs and sometimes from volunteers from abroad, a situation that was similarly identified in a study conducted by Salter and Yeoh in 2017.

Associated with the difficulties in accessing services, is the inadequate provision of appropriate assessment procedures. Where clinicians are using assessment tools to determine autism, these are generally those standardised in the USA or Europe and take no account of cultural influences. Assessments are often

informal and do not make use of verified assessment instruments. This was confirmed by a representative of the National Paediatric Hospital who stated, *“actually, we don’t have a formal assessment to do with the clients. Mostly we do the informal interview with the parents.”* Whilst the professionalism and commitment of such clinicians is not in doubt, their work could be greatly enhanced through access to appropriate screening instruments validated in Cambodian setting and training in appropriate use of tools for identification.

### Finding 6:

**Poverty is a major obstacle to progress in making adequate provision for persons with autism and their families. Services are more likely to be accessed by those with secure incomes.**

For families living in poverty there is often a major challenge in accessing services for persons with autism. A specific challenge relates to the limited opportunities that families of a child have to secure a regular income. The necessity to provide consistent child care makes a considerable demand upon family finances and was emphasised by both parent groups who typically reported that *“Families do not have time to look after their child and work and this results in a lack of income”*, and by professional organisations and official agencies including a representative of the National Institution of Special Education who suggested that *“there is an effect on the economy of the family because of a lack of time for a person to earn income when spending time to look after the child.”* Poverty of time, as well as lack of income was a characteristic of families supporting children with autism observed throughout this study. This situation was highlighted in previous research conducted by Cordier (2014) who perceived parents and particularly women

who were caring for a child with a disability in Cambodia to be more likely living in poverty.

The head of a centre providing specialist provision and support for families expressed a concern that some children with autism were at risk of neglect because of the economic pressures on families, *“There are some families received some services from our centre but they stopped coming here because they don’t have time. They said they have to spend time with other children or to earn money. They just abandoned the child. As I see when I visit them, they mainly faced financial issues. They have to pay back to the bank. Some poor families neglect their children, but some still pay a lot of attention to their children.”*

The cost of accessing education is seen to be prohibitive, particularly as this is most readily available through the private sector. One parent reported that the owner of a school who was

sympathetic because her own child had autism was charging 20\$ per hour for education. At another school in Siem Reap, some provision was available but the charge for two days a week over three months was 100\$, a cost that was beyond the budget of the family.

Families living in poverty are less likely to have access to important information about services and provision. Much of the information available to families is dependent upon internet access and broadcast media and for a significant number such facilities are not easily accessed.

Some organisations are providing material support to families, as an example, one school stated that *“We provide special education, inclusive education*

*services, food and snacks, rice to poor families, health care services and referral service to partner NGOs. We provide support to the whole families, provide school uniform, materials and accommodation.”* However, examples of such support were the exception rather than being common practice. Families living in rural communities had the greatest difficulty in accessing services, though there were some examples of organisations such as Epic Art in Kampot Province who were providing transport to ensure that families could participate. An organisation based in Battambang reported that *“we see people coming into the clinics with autism, but they are from the cities. We don’t see so many from the country areas. People there are poor. In the lives of the poor farmers, we don’t see them.”*

#### Finding 7:

**Where specialist support is available there is a high level of commitment to provide a professional service. A range of NGOs provide assessment, education and social support for children and families and in some instances, there is good communication and support across these services. In some cases, communication between NGO and Government Departments is good and has formed the basis for effective intervention. However, there is evidence that services are being developed and deployed in a piecemeal manner with the need for greater co-ordination. The majority of interventions are currently provided by NGOs and respondents expressed a need for greater government sector involvement.**

Non-Governmental Organisations (NGOs) provide a critical level of service in support of persons with autism and their families in Cambodia. These services range from initial assessment and identification of the needs of children, through provision of therapeutic and educational intervention and provision of support for families. It is suggested by some NGOs that identification of children with autism is inconsistent, and that while there are some procedures in place, there are many children who are not be identified through the current system. Organisations including

Association for Aid and Relief Japan (AAR Japan) have committed themselves to supporting families through assessment and identification but report that *“able children with autism may well not be identified by current assessment procedures. However, AAR have identified a boy as autistic having originally concluded that he had intellectual difficulties. It is evident that children are being missed because of the lack of assessment criteria to define them with autism.”*

Communication between NGOs and Government agencies is seen to be vital in enabling some individuals and families to receive support. A representative of the Special Education Department, Ministry of Education, Youths and Sports. Stated that *“we work with development partner NGOs, Ministry of Social Affairs, Veterans and Youth Rehabilitation, National Council for Children, Disability Action Council (DAC) and other NGOs working with disability. We work with AAR Japan at Ksach Kandal district, Save the Children, CRS and Aide et Action NGO.”* This interface between Government and NGOs is a major feature in ensuring that a significant number of individuals and families gain support, as confirmed by a Government Doctor who reported that *“we work closely with NGOs who can provide services if we can’t.”* There is some concern that there may be over-dependency on the services provided by NGO, the comment *“because I am working for NGO I am aware that Government is dependent upon NGO. Sometimes I think what we are doing may limit the actions of Government,”* was a sentiment shared by several respondents to the study.

NGOs with a focus upon disability and child welfare work in close collaboration and have formed good partnerships with many service providers. The director of one organisation reported that *“we work with Cambodia Autism Network NGOs members they have more than 10 NGOs and we work with 30 NGOs working in disability sector.”* The importance of this collaboration cannot be overstated a manager from The Peace Village Centre (PVC), Takeo province expressed a view that *“we have learned a lot from many NGOs in Cambodia, but our skill is still limited.”*

Access to NGO support is dependent upon geographical location with some areas better served than others. The chairman of an NGO based in Battambang felt that *“In the south there have been many NGOs working together very effectively, but less so in the north.”* However, he still believed that *“NGOs have been a driving factor in change and provision,”* and saw that the situation for many families living with disability, including autism had improved over the past ten years.

#### Finding 8:

**Opportunities for vocational training and employment are limited with concerns expressed about the provision available to adults with autism. This is closely related to the lack of education and training provision. Some NGO are developing provision in this area but at present access is limited.**

The National Disability Strategic Plan 2019-2023 identified the increased work and economic security for persons with disabilities as a priority (Strategic Objective 1). However, for persons with autism, a lack of vocational and employment opportunities limits both their life chances and those of their families.

Concerns were expressed by a range of professionals working with young people on the autism spectrum, that on reaching adulthood there were few opportunities for employment. The managers of specialist schools for children with disabilities expressed a view that on leaving education choices

for young people were limited. One suggested that *“There is a lack of providing skills for employment opportunities to children with autism,”* while another believed that without official support there was little likelihood of progress in this area, - *“we should have support from government to ensure children/youths with autism can have job to do in the future at all areas.”* The risk of falling further into poverty was emphasised by a third special school manager who stated that, *“there should be a place for these children to work either in agriculture or farm work for them to earn for a living when they grow up. Some work that people with autism can do to earn some money.”*

Parents endorsed these concerns and suggested that for young people with autism there were particular challenges that differed from those experienced by other persons with disabilities, *“They are not like other children. So, we have to prepare services for rehabilitation such as handicraft or things that depend on their talent. This should be the responsibility of the government, but there is not available yet, mostly for people physically disabilities. It is really difficult I think. And when she is 15 years old, what will she study? Because she is not like a child without disabilities, so we should initiate a business that suits her.”*

The need for specific vocational training was a topic raised by both professionals and parents and aligns closely to the intention to *“promote access to higher education with equity, inclusion and life-long learning”* as expressed in the Education Strategic Plan 2019-2023 (page 56). A representative of the Disability Development Services Program (DDSP) in Pursat, suggested the need to develop *“a job opportunity service and vocational skills training to persons with autism.”* Similar views were expressed by specialist from Epic Art Kampot Province and by leaders from specialist schools. A leader from the Peace Village Center (PVC), Takeo province asked *“How long should we continue to help them? After that, who will help them? We should provide a career training or*

*opportunities for them. They should be able to earn money. Should we help them for a life-long time or what to do?”* For all of these professionals the feeling was that once an individual with autism left education they were likely to remain at home and unemployed. This view was echoed by parents, one group stating that *“older children need to have vocational training especially those from poor families. After training here, some children just stay home, and the families are not happy. If we have such program, the families will be happy.”* Similar sentiments came from representatives of The Parents Association for Intellectual Disabilities who believed it may be appropriate to provide specific training such as *“To work as a waiter in a restaurant or to open a shop for them to participate.”* These respondents also felt that parents should take more responsibility for preparing their offspring for independent living and employment.

A common suggestion was that there should be a focus upon developing vocational colleges with courses suited to young people with autism. A representative of Disability Development Services Program (DDSP) in Pursat, felt that there should be *“vocational skills schools for persons with autism at national level.”* The need was seen to be so great that the head of a specialist school proposed that *“We should have one vocational skills training center in each province to give job opportunities for them.”* This need was acknowledged by a representative of the Disability Action Council (DAC), Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY), who believed that the country needed *“to have schools for vocational skills training to youths with autism, and also needs to have the specialists/ professionals to teach them in vocational skills training and find job for them.”* Further confirmation of this gap in provision came from a representative of the Special Education Department, Ministry of Education, Youths and Sports. However, this came with a caveat that *“this is beyond the capacity of education sector, it is related with the Ministry of Social Affairs and*

*Vocational Skills Training,*” a clear indication of the need for communication and effective collaboration across government departments.

A lack of vocational and employment opportunities inevitably leads to increased poverty and dependence upon local communities and the national state. Previous research conducted in Cambodia by Gartrell (2010) demonstrated how *“persons with disabilities are more likely than their counterparts without disabilities to be unemployed, in low status occupations, earn less or be out of the labour market altogether.”* These findings were from a study of a population with a range of disabilities. It is evident from this situational analysis that the vocational and employment opportunities for persons with disabilities remains challenging in Cambodia, but that the specific nature of autism requires consideration in respect of the type of provision to be made.

## Recommendations

### 1. Raising awareness

Awareness of autism should be raised through a series of seminar style events held around the country. These should be aimed at increasing the awareness of professionals working in the education, health, employment and social sectors and should be accompanied by the provision of leaflets and posters to be used around the country. Such an approach should fully involve individuals with autism and their families.

Future government documentation and that from NGOs which addresses issues of disability should make reference to autism and its unique characteristics in order to increase national awareness.

All government and NGO offices and

professionals should make available leaflets that explain the nature of autism. In addition, these should identify available services, providing contact details and explaining those services that are available to persons with autism and their families.

Consideration should be given to an awareness raising campaign using national broadcast and print media. This should include the presentation of role models in the form of individuals with autism who are making a positive contribution to their communities.

Social media has been widely used to gain information about autism and this can have benefits but needs to be carefully managed. Parents should be provided with details of secure and well-informed internet sources from where they may obtain reliable information. National organisations should review the manner in which they deploy social media in order to direct parents and professionals to reliable sources of information.

A package of training materials should be developed that would support many of the initiatives proposed in these recommendations. This should include presentation materials, information packages and details of appropriate and accessible web-based sites.

Religious organisations within Cambodia are highly influential. Consideration should be given to raising the awareness of autism within the leadership of religious bodies in order that they can become a source of increased support and information for families.

2nd April each year is World Autism Awareness Day. A few Cambodia based NGOs observe Autism Awareness Week/month with autistics and their families to raise awareness on this day/ during this week. Both the government and NGO sector should come together on 'World Autism Awareness Day/Week' to raise awareness and strengthen the parent movement.

## **2. Improving education provision**

The appropriate government departments, in partnership with NGOs who have experience of working with persons with autism, should develop a national strategic plan to improve access to education for children and young people with autism within an inclusive education agenda. This plan should be accompanied by a detailed timetable and should incorporate systems for monitoring both the delivery and impact of this plan.

A co-ordinated approach to increasing understanding of autistic spectrum disorders, along with exemplary materials demonstrating effective teaching methods, should be targeted at schools across the country. This should include opportunities to develop understanding and positive attitudes towards children with autism and their families and practical examples of teaching resources and methods that have proven beneficial for learners with autism in a range of settings. Such a programme should be applied nationally to ensure that professionals working in rural communities gain equal access to training opportunities to those offered in urban areas.

NGOs and other agencies, with support from appropriate ministries, should work with the

providers of vocational education to identify opportunities to amend existing course and develop new courses that are accessible for learners with autism. The awareness and skills of professionals working on vocational courses should be raised through a series of targeted workshops.

Support should be given to all providers of initial teacher training, to make essential developments to the teaching curriculum that will ensure that all new teachers enter the profession with an understanding of autism and have a range of teaching strategies appropriate to their needs. The Department of Special Education should consider working closely with the regional teacher training centres to develop specific curriculum documentation focused on teaching autistic children.

Institutions offering higher education should consider how they may develop course of professional development and in-service training for education and care professionals, with a focus on autism.

For all initiatives that aim to improved educational provision there should be a considered approach to monitoring change and impact. This should be accompanied by a national research strategy that aims to provide empirical evidence of the efficacy of teaching and learning for children and young adults with autism. An authoritative organisation such as the National Institute of Education may take the lead in research on what type of education/intervention works in a Cambodian context with the active collaboration of The Department of Special Education.

### **3. Improving health and rehabilitation support**

Government and NGOs should work together to provide a co-ordinated approach to increasing understanding of autistic spectrum disorders among all health, rehabilitation and social service professionals. This should include opportunities to develop understanding and positive attitudes towards persons with autism and their families. Such a programme should be applied nationally to ensure that professionals working in rural communities gain equal access to training opportunities to those offered in urban areas.

A review of the ways in which physiotherapy, occupational therapy and speech therapy along with family counselling are provided should be conducted as a priority. This should include an analysis of the availability of professionals working in these areas and the development of a plan to increase capacity within services. This will of necessity, require a review of current professional training courses and opportunities for developing professional skills within the country which might be taken-up the Technical School for Medical Care under the University of Health Sciences of Ministry of Health which oversees paraprofessional courses such as nursing and physiotherapy.

Existing training courses should be reviewed by the Ministry of Health to ensure that there is content that enables primary health professionals entering the care and therapeutic services to gain a good understanding of autism, its identification and the means of providing appropriate support. Such course should place an emphasis upon a social model of autism and

move away from existing medico-deficit emphasis. Some NGOs such as Caritas-CCAMH are already offering short-courses in autism for parents, nurses, physicians, paediatricians, and other mental health professionals which may be accredited and offered to a wider population of health professionals.

Early identification and psychoeducation at primary care level, advanced service provisions at district and provincial level for autistics, -a 'stepped-up care model', could be piloted in selected provinces before scaling-up. The Department of Mental Health and Substance Abuse (DMHSA), Ministry of Health should incorporate autism care/services in the strategy planning for the period 2021-2030.

### **4. Supporting opportunities for employment**

Lack of employment opportunity with individuals and their families. Such awareness could be provided through a programme of workshops to be implemented across the country.

Consideration should be given to the training of job coaches who will gain an appreciation of autism and the potential of individuals to contribute effectively to the workforce. Within the role of such professionals there would be a need to create work shadowing opportunities, mentoring and personal evaluations leading to skills development of the part of individuals with autism.

A representative group of employers should be established to work with the providers of vocational courses and a small group of persons with autism and their families to advise on the skills required by employers

that can be incorporated into training courses. The Ministry of Labour and Vocational training in collaboration with International Labour Organization (ILO) and Ministry of Social, Veteran and Youth Affairs (MoSVY) should review the current policy practice regarding employment of persons with disability, particularly those with autism to make recommendations. Sheltered workshops and job-coaching for individuals with autism should be developed in partnership with NGOs and private sectors before scaling-up.

#### **5. Policy and Strategy planning with a focus of persons with autism**

The new National Disability Strategic Plan 2019-2023 (NDSP) which reiterates a commitment to improve the lives of all Cambodians living with disability should be revisited by the key stakeholders such as Disability Action Council (DAC) and MoSVY in partnership with the respective line-ministries in the field of health (MoH), education (MoEYS), employment (MoLVT) and representative of Cambodian Disabled People's Organizations (CDPOs) with the aim of developing autism inclusive policy, and practices.

#### **6. Intersectoral collaboration and partnership across line-ministries to fulfil the rights of persons with autism**

People with autism have multiple needs and varied type of challenges across their lifespan from birth to adulthood as they traverse their growth trajectory and therefore multidisciplinary professionals across diverse sectors such as health, education,

employment, and social service sectors. It is mandatory that an inter-ministerial body constituted by the Royal Government of Cambodia coordinates various service providers across the line ministries and in private and non-government sectors to guide, oversee and monitor to ensure quality services to persons with autism.

#### **7. Involving private and corporate sectors to meet the needs of persons with autism**

Many countries in the region and in high income countries have successfully engaged with private & corporate sectors to develop autism specific services. In Cambodia, many private service providers in education and health sectors are active, which is an untapped potential. Successful entrepreneurs in private sector should be supported and evidence-based models/interventions should be scaled-up through public-private partnership.

#### **8. Parents as vanguards of movement to better the situation of persons with autism**

As with parents all over the world, the caregivers and parents in Cambodia are stressed and concerned about improving the situation of their sons and daughters and should play an active role in determining the policy, programmes, and services for persons with autism. The Cambodia Network for Autism (CAN), a broader coalition of parents, caregivers and service providers should be strengthened as well supported to join the regional network for autism coordinated by the Asia Pacific Centre for Disability (APCD), Bangkok.

## Appendices

### Appendix 1: Team Members

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<b>Professor Richard Rose</b> Principal Investigator	Overall leadership and management of the study, Liaison with DAC-SG focal person and representatives of ACCESS Generation of research instruments Data management and analysis
<b>Dr Bhoomikumar Jegannathan</b> Co-investigator 1	Co-ordination of in-country activity Regular liaison with Professor Rose Liaison with in-country professional groups and NGOs Management of study budget
<b>Dr Mong Dalin</b> Co-investigator 2	Undertaking field work Allocation of field work teams
<b>Mrs Sok Dearozet</b> Co-investigator 3	Undertaking field work Overseeing translation work
<b>Mr. Puthy Pat</b> Co-Investigator 4	Undertaking field work Initial cleaning and organisation of data

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## Appendix 2: Documents reviewed

Document	Document type
<i>National Disability Strategic Plan 2014-2018 (NDSP) and NDSP 2019-2023</i> Phnom Penh: DAC	National Policy Planning Document
Ministry of Education, Youth and Sport (2019) <i>Education Strategic Plan 2019-2023</i> . Phnom Penh: MoEYS	National Policy Planning Document
Ministry of Social Affairs, Veterans and Youth Rehabilitation (2008) <i>National Plan of Action for Persons with Disabilities, including Landmine/ERW Survivors</i> . Phnom Penh: (MoSVY)	National Policy Document
Ministry of Social Affairs, Veterans and Youth Rehabilitation (2009) <i>Law on the Protection and the Promotion of the Rights of Persons with Disabilities</i> . Phnom Penh: (MoSVY)	National Policy Document
Ministry of Education, Youth and Sport (2010) <i>National Policy on Early Childhood Care and Development</i> . Phnom Penh: MoEYS	National Policy Document
Salter, C, & Yeoh, W. (2017) Small steps towards a speech therapy profession in Cambodia: lessons learned so far. <i>Perspectives 2 (17)</i> , 104-113	Peer reviewed research paper
Mak, M, & Nordtveit, B.H. (2011) “Reasonable accommodations” or education for all? the case of children living with disabilities in Cambodia. <i>Journal of Disability Policy Studies 22 (1)</i> , 55-64	Peer reviewed research paper
Hackett, J.D., Hudson, R.F., West, E.A, & Brown, S.E. (2016) Cambodian Inclusive Education for Vulnerable Populations: Toward an Ecological Perspective Policy. <i>Journal of International Special Needs Education (2016) 19 (1)</i> , 3–14.	Peer reviewed research paper
Gartrell, A. (2010) ‘A frog in a well’: the exclusion of disabled people from work in Cambodia, <i>Disability and Society, 25 (3)</i> , 289-301	Peer reviewed research paper
Ravet, J, & Mtika, P. (2021): Educational inclusion in resource constrained contexts: a study of rural primary schools in Cambodia, <i>International Journal of Inclusive Education</i> . DOI: 10.1080/13603116.2021.1916104	Peer reviewed research paper
Burkhardt, J.A. (2015) Cambodia and Disability. <i>The McMaster Journal Fall</i> , 36 - 40	Report
Hayes, A, & Bulat, J. (2018) <i>Cambodia Situational Analysis of the Education of Children with Disabilities in Cambodia Report</i> . Washington D.C.: USAID	Commissioned research report

Bailey, S, & Nguon, S.K. (2014) <i>Situation analysis for disability-inclusive governance and community development</i> in Cambodia. Phnom Penh: UNICEF	Commissioned research report
Disability Action Council. (2001). <i>Country profile: Study on persons with disabilities (Cambodia)</i> . Phnom Penh: Disability Action Council Secretariat & JICA Cambodia.	Review report
Shoemaker, D., Chhim, S,, Dom, S,, Ngov, C,, Kennedy, R,, Peach, D, & Rowland, A. (2020) <i>Parents' Points of View: an Evaluation of the M'Lop Tapang Special Needs Programme, Cambodia</i> . Manchester: University of Salford	Review report
Kalyanpur, M. (2016) Inclusive education policies and practices in the context of international development. Lessons from Cambodia - <i>Zeitschrift für internationale Bildungsforschung und Entwicklungspädagogik</i> 39 ( 3), 16-21 - URN: urn:nbn:de:0111-pedocs-154526 - DOI: 10.25656/01:15452	Peer reviewed research paper
Ilias, K., Cornish, K., Kummar, K., Park, M.S, & Golden, K. (2018) Parenting Stress and Resilience in Parents of Children with Autism Spectrum Disorder (ASD) in Southeast Asia: A Systematic Review. <i>Frontiers in Psychology</i> . 9. doi.org/10.3389/fpsyg.2018.00280	Peer reviewed research paper
Palmer M., Williams, J, & McPake, B. (2019) Standard of Living and Disability in Cambodia, <i>The Journal of Development Studies</i> 55 (11), 2382-2402.	Peer reviewed research paper
Prigent, S. (2019) 'Education for All' in Cambodia: Democratic Educational and Children's Empowerment Global Values Facing State Patronage, <i>The Asia Pacific Journal of Anthropology</i> , 20: (1), 1-21	Peer reviewed research paper
Morgan, F. & Tan, B-K. (2011) Rehabilitation for children with cerebral palsy in rural Cambodia: parental perceptions of family-centred practices. <i>Child Care, Health and Development</i> . 37(2), 161-167.	Peer reviewed research paper
Zook, D.C. (2010) Disability and democracy in Cambodia: an integrative approach to community building and civic engagement, <i>Disability and Society</i> . 25 (2), 149-161	Peer reviewed research paper
Cordier, S. (2014) Caring for people with intellectual disabilities in poor rural communities in Cambodia: experience from ADD International, <i>Gender and Development</i> , 22 (3), 549-561	Peer reviewed research paper
World Health Organization (2017) <i>WHO South-East Asia Regional Strategy on Autism Spectrum Disorders</i> . New Delhi: WHO	Strategy Document

## Appendix 3: Code of Ethics and Informed Consent Form

**Situational Analysis:** Provision for Persons with Autistic Spectrum Disorders in Cambodia

### Ethical Code of Practice

THE SITUATIONAL ANALYSIS OF PROVISION FOR PERSONS WITH AUTISM IN CAMBODIA (hereafter referred to as the project), will be conducted with full compliance of research ethics norms. This study will adhere to the Revised Ethical Guidelines for Educational Research of the British Educational Research Association and The Ethical Standards for Research During Public Health Emergencies issued by the World Health Organisation. All researchers and others directly involved in the management of the project will sign a contract indicating their compliance with the code of ethics. The Principal Investigator will assume responsibility for all aspects of ethical management.

All project members will ensure that all participants have the purpose and the outcomes of the project explained to them in detail. A “project information sheet,” in non-technical language will be provided in Khmer and English for all participants. Where respondents have limited levels of literacy, the project will be explained orally prior to data collection. The information provided will include the contact details of the team. Participants will be advised of their right to retract information or withdraw at any point and will be informed about how anonymity and confidentiality will be assured.

Training will be provided to field workers, including a session on the ethical code jointly by the Principal Investigator. Field workers will be deployed only after they have completed training and signed an agreement of compliance to the code of ethics.

Participation in the research will be voluntary, and informed consent will be obtained in writing using forms in the language with which a respondent is comfortable. Verbal consent will be sought from children or those with limited cognitive abilities, with informed consent gained from a parent/

guardian.

All data will be coded, available only to members of the research team and will be secured at all stages, -data collection, storage, retrieval and use.

The Principal Investigator will issue a report on the ethical management of the project within the final substantive report provided to the funding body (ACCESS).

The research team will report accurately and with fair interpretation based upon rigorous application of research methods and analysis.

Agreement to abide by the Code of Ethics established for the Project: Situational Analysis: Provision for Persons with Autistic Spectrum Disorders in Cambodia.

Please note: All members of the project team have to sign this agreement, witnessed by a third party approved by the Principal Investigator

I(PRINTNAME)\_\_\_\_\_

Have read and understood the Code of Ethics prepared for this project and agree to comply with this code throughout the duration of the project.

I will not disclose information regarding and subjects of the research beyond the project team and will protect the rights and maintain the integrity of all participants.

I will immediately report to the Principal Investigator if I have concerns regarding the welfare of any person involved in the project, or any matter that may jeopardise the ethical rights of an individual.

Signed\_\_\_\_\_

Witnessed by \_\_\_\_\_

Date \_\_\_\_\_

## Appendix 4: Research Instruments for Service Providers and Users

### Situational Analysis of Persons with Autism in Cambodia

#### Interview Schedule –Provider of Services for Children/Young Adults on the Autism Spectrum

**BEFORE COMMENCING THE INTERVIEW PLEASE ENSURE THAT THE INTERVIEWEE UNDERSTANDS THE PURPOSE OF THE STUDY AND THE ETHICAL CODE THAT THE TEAM IS WORKING TO.**

**PLEASE ENSURE THAT YOU OBTAIN WRITTEN OR AUDIO RECORDED INFORMED CONSENT/ASSENT BEFORE COMMENCING THE INTERVIEW.**

#### **Pre-Interview Demographic Data to be collected and recorded prior to the interview**

Name of the interviewer:

Location of the interview: (e.g. Kampong Cham)

Name of the Individual being interviewed:

Name of the organisation represented by the interviewee:

Position of the interviewee within the organisation:

Please try to collect any documentation related to the organisation – e.g. brochures, policies, newsletters.

Please record details if the organisation has a website.

#### **Section 1: Background Information**

1. Please tell me something about yourself and your background (qualifications, experience)
2. How long have you been working for (INSERT NAME OF ORGANISATION)?
3. Describe what your work consists of (what does a typical week look like?)
4. How long has (INSERT NAME OF ORGANISATION) been operating in Cambodia?
5. Who are the people working for (INSERT NAME OF ORGANISATION), what are their roles?

#### **Section 2 Services Provided**

6. What services does (INSERT NAME OF ORGANISATION) provide to children/young people with autism?
7. What geographical area do you offer this service across?

8. How is your service funded?
9. How do families with a child/young person with autism get to hear about your services?
10. Who refers children/young people with autism to you?
11. What happens when you receive a referral? (find out about time lines and who is involved)
12. How many referrals do you receive each month?
13. Are there services you don't provide which you would like to provide?
14. Do you work closely with official departments/government agencies?
15. Do you work closely with other agencies similar to your own?  
 PROBE: Can you give examples?  
 What challenges do you face in addressing the needs of children/young people with autism?

### **Section 3 – Engagement with Families**

16. What do parents/families/carers hope to gain from your service?  
 PROBE: How do you know?
17. How familiar are the families you work with about the nature of autism?  
 PROBE: How do you know?
18. How do parents get to your service (transport question)?
19. Are you aware of families that would benefit from your services but who do not/cannot access these?  
 PROBE: If yes, why?

### **Section 4 – The wider Situation**

20. How good is provision for children/young people with autism in Cambodia?
21. What services do you think need to be provided that aren't currently available?
22. What are the greatest challenges faced by families with a child/young person with autism in Cambodia today?
23. What would be your priority for developing provision for families with a child/young person with autism in Cambodia at present?  
 PROBE: Who should provide this?
24. What are the greatest obstacles to improving the lives of persons with autism and their families in Cambodia?
25. Do you have suggestions for how the situation for children/young people and their families may be improved?

### **Section 5: Closing Observations**

Is there anything else you would like to tell us about your organisation or your experiences of working with persons with autism?

**Please be sure to thank the interviewee and provide them with contact details**

**Situational Analysis of Persons with Autism in Cambodia**  
**Interview Schedule – Parents of carers of Children/Young Adults on the Autism Spectrum**

**BEFORE COMMENCING THE INTERVIEW PLEASE ENSURE THAT THE INTERVIEWEE UNDERSTANDS THE PURPOSE OF THE STUDY AND THE ETHICAL CODE THAT THE TEAM IS WORKING TO.**

**PLEASE ENSURE THAT YOU OBTAIN WRITTEN OR AUDIO RECORDED INFORMED CONSENT/ASSENT BEFORE COMMENCING THE INTERVIEW.**

**Pre-Interview Demographic Data to be collected and recorded prior to the interview**

Name of the interviewer:

Location of the interview: (e.g. Kampong Cham)

Name of the parent/carer:

Is the parent/carer male or female:

Name of the child/young adult:

Is the child/young adult male or female:

Age of the child/young adult:

When was an official diagnosis of autism made?

Had the parent/carer previously heard of autism?

**Section 1: Background Information**

1. Tell me about (INSERT NAME OF CHILD YOUNG ADULT) – allow the parent/carer to talk freely and encourage them to say whatever they feel they want to share.
2. Does (USE NAME OF CHILD YOUNG ADULT) have brothers or sisters
3. When did you first notice that (USE NAME OF CHILD YOUNG ADULT) was not developing like other children?
4. What was it that you first noticed as different?
5. Who was involved in assessing/diagnosing (USE NAME OF CHILD YOUNG ADULT)?
6. Where did you have to go to receive this assessment?
7. What information were you given about (USE NAME OF CHILD YOUNG ADULT) after this initial diagnosis?
8. Were you given advice about who might be able to help you and (USE NAME OF CHILD YOUNG ADULT)?
9. Has (USE NAME OF CHILD YOUNG ADULT) changed much since the original diagnosis/assessment? IF YES: In what ways?

## Section 2: Provision

10. Has (USE NAME OF CHILD YOUNG ADULT) been seen by a psychologist?  
IF YES: Ask for details of when? Where? Why? and What was the outcome?
11. Has (USE NAME OF CHILD YOUNG ADULT) been seen by a speech and language therapist?  
IF YES: Ask for details of when? Where? Why? and What was the outcome?
12. Has (USE NAME OF CHILD YOUNG ADULT) been seen by a physiotherapist?  
IF YES: Ask for details of when? Where? Why? and What was the outcome?
13. Has (USE NAME OF CHILD YOUNG ADULT) been seen by medical specialists?  
IF YES: Ask for details of when? Where? Why? and What was the outcome?
14. Does (USE NAME OF CHILD YOUNG ADULT) attend school/a work place/ a specialist centre?  
IF YES: Ask for details  
IF NO: Would you like (USE NAME OF CHILD YOUNG ADULT) to attend such a facility?
15. Do you receive support from any specialist organisation with expertise in autism?  
IF YES: Ask for details (what support do they provide? Where? How Often?)  
IF NO: Would you like such support?
16. Are you aware of such specialist organisations in your area?  
IF YES: Ask for details
17. What are the greatest challenges that you face as the parent/carer for (USE NAME OF CHILD YOUNG ADULT)?
18. What support do you receive from your family?

## Section 3: Aspirations

19. What provision for (USE NAME OF CHILD YOUNG ADULT) would you like to see in place in the future?
20. Who do you think should provide this?
21. Who are the people who you feel can give greatest support to parents/carers of children or young people with autism?

## Section 4: Closing Observations

Is there anything else you would like to tell us about your experiences of being a parent/carer for a child/ young person with autism?

Please be sure to thank the parent/carer and provide them with contact details

## Appendix 5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), Definition of Autism Spectrum Disorder

To meet diagnostic criteria for Autism Spectrum Disorder (ASD) established within The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), a child must have persistent deficits in each of three areas of social communication and interaction (see A.1. to A.3. below) plus at least two of four types of restricted, repetitive behaviours (see B.1. to B.4. below).

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):
  1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

- B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):
  1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
  3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).





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