


Article

Investigating the Situation for Children with Autism and Their Families in Cambodia

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Abstract: Following periods of conflict and instability during the oppressive regime of the Khmer Rouge (1975–1978) and the period of Vietnamese occupation (1978–1992), the Kingdom of Cambodia has adopted policies and initiatives that aim to ensure greater equity and stability across all services in the country as a signatory to international agreements for the promotion of universal primary education (United Nations 2015). The education of children with disabilities continues to present challenges to both policy makers and service providers in Cambodia, though government agencies have made a commitment and invested resources to improve facilities and increase awareness of the difficulties experienced by children and families. Previous studies of provision for children on the autism spectrum in Cambodia suggest that they are little understood and that many experience difficulties accessing appropriate services or support. However, these reports have often been based on localised small-scale studies and have not provided a broader national perspective of the situation. A national analysis of the situation for persons with autism was conducted to provide a more detailed picture of the experiences of children with autistic spectrum disorders and their families. Data were collated using focus groups and interviews with service users and providers from a purposive stratified sample across the country. The findings reveal that a limited awareness and understanding of autism amongst both professionals and the general public has limited opportunities for development. Education facilities and expertise are limited, and access to therapeutic and specialist medical provision is poor. The pervasive nature of poverty has been a major contributory factor in the slow development of and accessibility to services to this population. A number of recommendations have been made and are being used to shape future policies for children with autism and their families in Cambodia.

Keywords: autism; Cambodia; education; conflict; poverty

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1. Introduction

The Kingdom of Cambodia, situated on the Indochinese Peninsula of Southeast Asia, has made rapid socio-economic advances in the past 20 years, following periods of instability under the oppressive regime of the Khmer Rouge and the restoration of the monarchy in 1993 [1]. Cambodia faced perennial conflict since Angkorean times and during the French colonial rule; the country deteriorated and became the poorest in the region, a ‘victim of its geography and political underdevelopment’ [2]. The spillover of the conflict in Vietnam during the Cold War era led to the rise of Pol Pot regime that resulted in the collective trauma of the entire population. A million and a half died due to starvation and sickness, and an equal number of the population were eliminated in the name of the agrarian revolution, with a further two million people internally displaced between 1975 and 1978 [3]. Education systems were destroyed as the Khmer Rouge maintained control of the population, seeing this process as more easily achieved if they denied opportunities for

greater learning and understanding. The Paris Peace Agreement of 1991 led to UNTAC (United Nations Transitional Authority in Cambodia) [4] intervention that brought peace and stability, but the country continued to suffer from poor educational infrastructure as it was dismantled during the Khmer Rouge era [5]. The country is in the process of recovering from the trauma of war and conflict, but the lack of institutional structures, particularly education, remains a barrier to achieving the mandate of the UN Convention on the Rights of Persons with Disabilities (CRPD) [6], which was ratified by the Royal Government of Cambodia [7].

2. Disability, Education and Autism in Cambodia

The education of children in Cambodia is provided by both government and private sector schooling. Many students are able to receive 12 years of formal education through the school system, though those with disabilities have far fewer opportunities than their typically developing peers. In common with many Asian countries, the government of Cambodia has instituted a number of policies and initiatives in support of the Education for All (EFA) Goals [8]. Kalyanpur [9] has suggested that there may be difficulties in many economically disadvantaged countries in addressing the EFA goals, where these are incompatible with the current educational structures and beliefs within a country. Cambodia's efforts to adopt EFA and inclusive education for children with disabilities, she suggests, may be constrained in part because of a lack of information regarding the situation for this population and also through the limitations of a professional workforce ill-prepared to address their needs. Education in Cambodia, Kalyanpur claims, has been a prerogative of the elite and that whilst there has been a significant shift towards greater equity, it remains the case that many individuals and groups within the country continue to be marginalised. However, despite these misgivings, it is important to recognise that significant progress has been made along the road to the provision of education to a broader Cambodian population, as acknowledged by the World Bank [10]. As a share of GDP, government spending on education more than doubled from 0.9 percent to 2 percent between 1997 and 2002, allowing for the development of improved infrastructure and training of education professionals. A report from The Organisation for Economic Co-operation (OECD) in 2016 [11] indicated that Cambodia experienced significant increases in income and reductions in poverty during the period 2000 to 2015, when annual growth in Cambodia's GDP averaged 7.8%, raising GDP per capita to USD 1225, indicating a reduction in poverty rates from over 60% to 13.5% in 2014. Despite this progress, considerable disparities continue to impede progress towards education for all, with those living in rural areas and others who have disabilities or special educational needs remaining at a significant disadvantage. This point is reinforced in the studies by Palmer, Williams, and McPake [12] and Hackett, Hudson, West, and Brown [13], indicating that the link between poverty and disability in Cambodia is exacerbated by a failure of current systems to acknowledge the ways in which these two factors have inhibited opportunities for the promotion of educational opportunity and social advancement.

Nishio [14], in a review of developments in the education of children with disabilities in Cambodia, identifies a number of difficulties in providing accurate estimates of the number of children who may be described as disabled. A lack of a clear definition of disabling features coupled with an infrastructure that lacks the capacity to conduct accurate assessments has proven problematic. Nishio proposes that while some of the most obvious physical or sensory disabilities are often acknowledged, what he describes as "invisible disabilities", such as learning disability, intellectual disability, and emotional disturbance, are often overlooked. Within this category of invisible disabilities, we may include those children with autism. Mak and Nordtveit [15] concur with Nishio's assessment of the challenges of identification of specific disabilities and suggest that early intervention is invariably restricted by a situation in which understanding is limited. Furthermore, negative attitudes, exclusionary policies, inadequate teacher training, and poor resourcing further inhibit opportunities for development.

High levels of parental stress and anxiety have often been recorded in families with a child with autism [16–18]. In a systematic review of the literature that examined stress in parents of children with autism across seven Southeast Asian countries, Ilias et al. [19] identified a lack of information about autism as a factor leading to stigmatisation influenced by cultural beliefs that often resulted in self-blame in respect of a child's behaviours and other characteristics. The impact of stress has been recognised, and some initiatives have been implemented in an effort to provide additional support to parents. In a study conducted by researchers from Manchester University of 35 children with disabilities, of whom approximately a third had a diagnosis of autism, 94% of parents reported some alleviation of stress through participation in a programme provided by a Non-Governmental Organisation (NGO) initiated support to 2500 families who cared for a child with a disability [20]. An important finding of this research was that all of the families involved could identify positive changes resulting from interventions that considered their educational and social needs. Parents attributed a lowering of stress levels as being directly related to participation in a supportive programme, which also enabled parents to have more time to engage in other activities, including those that supported an increase in family income. While this small-scale study provided an interesting insight into what might be achieved through a well-planned and focused intervention programme, it would appear that such initiatives remain exceptional within Cambodia.

Education has been seen to play a critical role in reducing the stress of parents of children with autism, particularly where they feel well supported by the availability of effective schooling for their children and confident about the professionals with whom they engage [21,22] (Farmer and Reupert 2013; Milgramm et al., 2022). The need to ensure the provision of well-qualified and trained teachers who have a good understanding of approaches to address special educational needs is apparent [23,24]. Research conducted in Cambodia by Kartika and Kuroda [25] indicated that only 20.5% of teachers reported having received training related to special education and disability. These authors suggest that knowledge of disabilities and how to address specific needs at the classroom level is limited. Teachers, when interviewed, declared that they lacked the technical skills or the confidence required to teach students with disabilities. A reappraisal of teacher training programmes to ensure that future professionals are well equipped to face the challenges of a more diverse population is required. King [26] proposes that an accelerated pathway to greater understanding and skills development in Cambodia should also be achieved through the professional development of the existing workforce. At present, there has been little empirical study into this area in Cambodia, and the need for greater research is evident.

3. Research Aims

This research aimed to provide an understanding of the situation for children with autism and their families in Cambodia. This overall aim was addressed through the development of four specific questions, which were provided by the funder of the investigation:

1. What educational, health, and welfare provisions are made for children with autism and their families?
2. What policies exist for the support of children with autism and their families, and how are these applied?
3. What are the experiences of children with autism and their families in Cambodia?
4. What are the outcomes related to the current situation for children with autism and their families?

4. The Research Methods Deployed

An initial review of documentation, including Cambodian national policies and responses to international initiatives, provided an overview of government intentions and recent developments of provisions intended to support children with autism and their families. Much of this related to general special education and disability policy (Ministry of

Social Affairs, Veterans and Youth Rehabilitation [27,28]; Ministry of Education, Youth and Sport [29]) and had a minimal focus on children with autism. This was followed by a review of research-based literature utilising the framework developed by Rose, Shevlin, Winter, and O’Raw [30], which considered findings related to the four focus cells of Educational Policy, Provision, Experiences, and Learning Outcomes in a Cambodian context.

A purposive stratified sample was identified that considered the varied population within Cambodia and its distribution across both urban and rural environments. This enabled fieldwork to be conducted and data collected from service providers (education, social welfare and health professionals, representatives of Non-Governmental Organisations), service users (parents and carers), religious and community leaders, and policy makers. Semi-structured interviews and focus group instruments were developed, piloted, and amended, and members of the research team were provided with training in data collection and management to ensure consistency of approach. Most interviews and focus groups were conducted in the national Khmer language, though some, especially those with representatives of NGOs, were managed in English. It had originally been the intention of the research team to conduct interviews with young people in schools, including, where possible, some with autism. However, the onset of the global COVID-19 pandemic required a change of plan with a move made to conduct interviews online. It was deemed important to gain a holistic view of provision for children and their families. The relationship between disability, provision of health and social care and cultural factors is evident, each impacting the other. It was, therefore, agreed that a wide range of experiences and opinions was necessary in order to understand the current state of educational opportunities provided for children with autism and the potential opportunities for development in this area. Table 1 provides an overview of interview respondents, and Table 2 indicates focus group respondents.

Table 1. Interviews conducted. (Organisations represented N = 26) (individuals interviewed N = 28).

	Interviewee	Designation and Responsibility
1	Representative of Special Education Department, Ministry of Education, Youths and Sports, Phnom Penh	Government Department responsible for supporting effective teaching and learning, social and emotional development and curriculum standards for students with special educational needs and/or disabilities
2	Representative of National Institute of Special Education, Phnom Penh	Responsible for training teachers of students with disabilities and capacity building in special and inclusive education.
3	Representative of Ministry of Social Affairs and Veterans Youth Rehabilitation, Phnom Penh	Responsible for promoting the welfare of children, families, and persons with disabilities.
4	Representative of Mlop Tapang NGO, Sihanouk Ville province	NGO working with street children and youth, including those with disabilities, many of whom are currently out of school.
5	Representative of Karuna Battambang, Battambang province	NGO providing monthly clinical outreach services, including education, economic support and medical treatment to persons with disabilities, youth, women, and children.
6	Representative of Peace Village Centre (PVC), Takeo province	NGO Providing therapeutic interventions and education initiatives, including a daycare centre and home-based care support.
7	Representative of Epic Art, Kompot province	NGO that promotes the inclusion of people of all abilities and disabilities through the arts.
8	Representative of Disability Development Services Program (DDSP), Pursat province	NGO that works to promote the welfare of persons with disabilities through empowering and strengthening partnerships with relevant stakeholders across education, health, and social welfare to access a wide range of services

Table 1. Cont.

	Interviewee	Designation and Responsibility
9	Representative of National Special Olympics Cambodia, Phnom Penh	Organizes year-round sport activities for children with intellectual disability and autism.
10	Representatives (x3) of Growing Special Education School, Phnom Penh	Special schools addressing the needs of children with autism. Approximately 100 children on roll.
11	Representative of Rabbit School Organization, Phnom Penh, Kandal, Kompong Speu and Siem Reap province	Special schools addressing the needs of children with autism and intellectual disabilities.
12	Representative of Pour un Sourire d’Enfant’s School, Phnom Penh	A school that has a mission to help children, including those with disabilities, escape from destitution and lead them to decent, skilled, and well-paid jobs.
13	Representative of Government School HHC, Kandal province	An organization that promotes and protects the rights of children and youth with Intellectual Disabilities and Autism,
14	Representative of KPF Government school Phnom Penh and Kratie province	A school committed to the education of children and youth with moderate to severe disabilities, including some on the autism spectrum.
15	Representative of Organization to Improve Communication and Swallowing Therapy Services in Cambodia (OIC) Phnom Penh	An organisation committed to Improve Communication and make speech therapy accessible to all those who need it in Cambodia, including some with autism.
16	Representative of National Borey for Infants and Children (NBIC), Phnom Penh	An organisation that provides a home to those who are abandoned or orphaned HIV / AIDS-positive persons and others with disabilities.
17	Representative of Preash Sihanoukraj Buddhist University, Phnom Penh	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	Representative of Highest Council for Islamic Religious Affairs Cambodia, Phnom Penh	Council overseeing the welfare of the Muslim community in Cambodia, including oversight and support for those with disabilities, including children with autism.
19	Representative of Association for Aid and Relief, Japan (AAR Japan), Phnom Penh, Kandal province	NGO promoting Inclusive Education, cooperating with schools and communities in Kandal province to ensure that children, regardless of their disabilities, have access to school.
20	Representative of Children In Families (CIF), Phnom Penh, Svay Rieng province	NGO, dedicated to providing high-quality family-based care for orphans and vulnerable children in Cambodia, including those with disabilities.
21	Representative of National Paediatric Hospital (NPH), Phnom Penh	A government facility providing medical services, including assessment and therapeutic intervention for children and families with disabilities.
22	Representative of Founder Karuna Battambang	NGO providing care and home-based intervention in households and communities. Includes education, economic support and medical treatment to disabled persons, youths, women, and children, including those with autism.
23	Individual parents of children with autism	Mother of 15-year-old daughter with autism.
24	Medical Practitioner working for assessment and intervention with persons with disabilities, including autism	Government employed doctors involved in assessment and intervention programmes for children with disabilities, including those on the autism spectrum.
25	Representative of Damnok Toek—Goutte D’eau	Organisation working with rescued trafficked children, including many with disabilities.
26	Representative of Parents Association for Children with Intellectual Disabilities	Organisation supporting families and arranging activities for persons with a range of intellectual difficulties, including autism.

Table 2. Focus group parent respondents (all with a child with autism) (N = 49 in 9 groups).

	Group Composition	Location
1	2 fathers, 4 mothers	Phnom Penh
2	3 fathers, 2 mothers	Phnom Penh
3	1 father, 4 mothers	Phnom Penh
4	5 fathers, 1 mother	Phnom Penh
5	4 fathers, 3 mothers	Phnom Penh
6	0 fathers, 5 mothers	Kompong Cham
7	5 fathers, 2 mothers	Kompong Cham
8	1 father, 3 mothers	Battambang
9	1 father, 3 mothers	Battambang

Interviews were transcribed verbatim and, where necessary, translated into English prior to being subjected to thematic analysis. Multi-respondent triangulation was further strengthened by adopting a multi-analyst approach, with all data interrogated alongside the substantive literature and national documentation [31,32]. Written informed consent to use data was obtained from all respondents prior to commencing interviews and focus groups. Individual respondents were assured anonymity, though all organisations agreed that they should be identified as part of the reporting process (Appendix A).

5. Findings

Eight key findings emerged from the situational analysis. These were obtained through a process of discursive analysis [33], whereby codes were applied to the responses obtained from interviews and focus groups. The codes were derived from the original research questions, as supplied by the funding agency. These were subjected to a process of code reduction whereby overlapping codes were redefined and combined to provide the basis for further interrogation of the data, which enabled the identification of common themes related to the four focus cells developed by Rose et al. (2010), as described earlier in this paper. These recurring themes derived through interviews, focus groups, and documentation allowed for a high level of trustworthiness to be established. Coded statements were categorized as having either a high level of typicality (where evidence from across data sources was triangulated to provide assurance of the trustworthiness of statements) or a degree of exceptionality, where there was insufficient evidence to support a statement of confidence. In this way, it was possible to identify key issues arising from across the data sets. The interplay between these is apparent and indicates the necessity to adopt a holistic approach to development in this area if improved educational provision is to be achieved. The findings are tabulated below (Table 3) and are discussed with respect to the data from which these were derived before considering the implications of what has been learned.

Table 3. Substantive Findings.

1	The Government of Cambodia has made a commitment to ensuring appropriate access to education, health, and social welfare for all persons with disability and had made significant progress in the development of policies. While there is some evidence of the emergence of good practice in making provisions for persons with disabilities, including those with autism spectrum disorders, the gap between policy and practice remains considerable.
2	Awareness of autism spectrum disorders, both within the general population and among professionals, as well as leaders of faith-based organisations/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.

Table 3. *Cont.*

3	Educational provision for children on the autism spectrum is poor. A few specialist schools do exist, but educational facilities based on 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 the appropriate methods for teaching them is limited. The ability to provide an appropriate education is further impeded by a lack of appropriate resources, specialist teaching equipment, and a dearth of trained teachers.
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 a limited understanding of autism within the teaching profession, leading to reluctance to teach children or enrol them into schools.
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 NGOs which enables children and families to access resources.
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.
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 NGOs 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 coordination. The majority of interventions are currently provided by NGOs, and respondents expressed a need for greater government sector involvement.
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 NGOs are developing provisions in this area, but, at present, access is limited.

6. Discussion

While educational provision for children with autism and their parents is underdeveloped, it is important to acknowledge the significant efforts and commitment of the Cambodian Government and NGOs in their endeavours to improve this situation. Pockets of innovative practices have been developed, but these are inconsistent, available to only a small percentage of the population and lack coordination at the national level. Expertise in the education of children with autism does exist but is concentrated in a small number of specialist schools located in urban areas.

6.1. Socioeconomic Factors

Children who live in urban areas and those who come from well-educated and wealthier families are more likely to have access to services than those living in rural areas or from communities of socio-economic disadvantage. This finding from the investigation is similar to those highlighted by earlier studies [34,35] that suggest the need to provide financial and welfare support to families is essential if their life opportunities are to be improved. The importance of maintaining employment is critical to families, particularly those living in the poorer communities of Cambodia. The expense of providing daily care for a child with autism that would enable parents to work was seen as an inhibiting factor. The data obtained through interviews with professional organisations and official agencies indicate that there is a negative impact on the economy of families with a child with autism because of a lack of time for a person to earn income when spending time to look after the child. A lack of appropriate educational provision for children with autism exacerbates this situation, as daytime care is needed and prevents parents from working. The poverty of time, as well as lack of income, was a characteristic of families supporting children with autism observed throughout the research. This impacted significantly upon the ability of parents to access schools and other facilities, which required both taking time away from work and the expense of travelling to clinics or other facilities.

6.2. Services for Children with Autism

When parents are able to seek support from professionals, they demonstrate commitment to ensuring that their children with autism receive the best possible service. However, a lack of trained therapeutic professionals and those able to provide assessments has limited opportunities for families. Where clinicians are available to conduct assessments, they are often utilising tools that have been standardised in Western contexts and take inadequate account of cultural influences. While recommendations are often made that suggest the need for speech therapy or physiotherapy, the availability of professionals working in these disciplines is limited, and there are few opportunities for training within the country. In this, as in other areas, there is a high dependency on the services provided by NGOs. Professionals working in health services acknowledge the pressure placed upon parents by a lack of appropriate educational provisions for children with autism. Coordination across education and health services is seen by some professionals as key to ensuring improved access to both learning and therapeutic support for children with autism.

6.3. Education and Training Need

The availability of professionally confident and competent teachers with a good understanding of autism has been seen to be critical in ensuring appropriate education for this population [36,37]. The issue of training teachers highlighted in the data was equally significant with respect to ensuring an appropriate education for children with autism. Few opportunities exist for the development of pedagogical skills directly related to children with autism or others with disability at the initial teacher training level. This is equally true of professional development opportunities for serving teachers. The Education Strategic Plan 2019–2023 has acknowledged the need to prioritise and reform teacher training and professional development programmes in Cambodia, but as of yet, little progress has been made with respect to equipping the teaching profession to address special and inclusive education needs. Few teachers have had opportunities for professional development related to autism, and there are no requirements to address this topic within the current teacher training curriculum. The National Institution of Special Education has delivered some short courses in autism, as have some NGOs, but these have been accessed by only a small proportion of the teaching profession. There are a few centres of expertise in Cambodia where teachers have both experience and specific skills in teaching children with autism. These teachers are based within the specialist provision and address the educational needs of a small percentage of this population.

Closely allied to the lack of educational provision is the concern expressed by parents regarding adult life for their children with autism. Vocational training and employment opportunities are currently limited and are further inhibited because of the lack of basic education being provided to this population. Parents have major concerns regarding the future of their children. The provision of vocational and employment opportunities for persons with autism has been seen as a challenge in most parts of the world [38] and is closely allied to the development of appropriate schooling. Preparation of adult life requires a focus on those skills, knowledge, and abilities required to function independently in the workplace and community. In administrations where success for people with autism has been achieved in this area, the symbiosis between education, work-based training, and post compulsory education is apparent [39].

6.4. Awareness and Cultural Issues

The general lack of awareness of children with autism and their needs has, in some instances, led to the isolation of children and families. The strong religious influences within Cambodia and the concept of karma have, at times, inhibited the prioritisation of services in this area. Children with autism are often misunderstood and ostracised because of their behaviours and lack of communication skills. This situation exacerbates the stress felt in families and, in some instances, may result in them not seeking assistance for fear of being viewed negatively by other members of their community. The need to

educate religious and community leaders and to increase their awareness of autism and the importance of education is apparent.

7. Conclusions and Recommendations

Underpinning many of the obstacles to the development of provisions for persons with autism, including education, in Cambodia is a general lack of awareness of the condition. Traditional beliefs associated with karma have, in the past, proven to be a challenge in terms of addressing issues of disability in general [40,41]. In recent years, the Government of Cambodia, in collaboration with a number of NGOs and other agencies, has run campaigns to try and increase awareness of autism. It is not possible to judge the impact of these initiatives, but it seems likely that a more sustained approach to increasing awareness is necessary. However, awareness of autism is likely to increase both demands for services and expectations that provision, including appropriate schooling, is based upon a more knowledgeable and competent workforce. Awareness alone will not bring about change and will, therefore, need to be promoted alongside the development of opportunities for enhancing the educational and therapeutic expertise available in the country.

The expertise currently available in Cambodia is largely invested in NGOs that have worked effectively with government agencies. This collaboration affords a good foundation upon which further work could be developed to target specific areas that would likely have benefits. The development of schools with sufficient expertise in autism could provide centres of excellence through which greater skills, knowledge, and understanding could be developed and expanded. Such schools could provide an effective base not only for educational professionals but also for others who can support a holistic approach to improving the lives of children with autism. Studies of such provisions from across other Southeast Asian countries have indicated that the development of such provisions may provide a catalyst for further understanding and support for children with autism and their families [42]. Progress in support of children with autism and their families is most likely achieved only when attention has been given to providing a more skilled educational and therapeutic workforce. A focus on training both for professionals in initial training and through continuing professional development for existing therapists and teachers appears essential if the current deficits in the services available to children and families are to be addressed.

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Conflicts of Interest: The authors declare no conflict of interest.

Appendix A. Instrument

Situational Analysis of Persons with Autism in Cambodia [43]

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.

Interview Schedule—Parents of carers of Children/Young Adults on the Autism Spectrum

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)

Names of the parents/carers in the group:

Names of note takers

Section 1: Background Information

1. Tell me about your children/young adults—*allow the parents/carers to talk freely and encourage them to say whatever they feel they want to share.*
2. When did you first notice that your child/young adult was not developing like other children?
3. What was it that you first noticed as different?
4. Who was involved in assessing/diagnosing your child young adult?
5. Where did you have to go to receive this assessment?
6. What information were you given about your child young adult after this initial diagnosis?
7. Were you given advice about who might be able to help you and your child young adult?
8. Has your child young adult changed much since the original diagnosis/assessment?
IF YES: In what ways?

Section 2: Provision

9. Has your child young adult been seen by a psychologist? **IF YES:** Ask for details of when? Where? Why? and What was the outcome?
10. Has your 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?
11. Has your child young adult been seen by a physiotherapist? **IF YES:** Ask for details of when? Where? Why? and What was the outcome?
12. Has your child young adult been seen by medical specialists? **IF YES:** Ask for details of when? Where? Why? and What was the outcome?

13. Does your child young adult attend school/a work place/ a specialist centre? **IF YES:** Ask for details **IF NO:** Would you like your child young adult to attend such a facility?
14. 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?
15. Are you aware of such specialist organisations in your area? **IF YES:** Ask for details.
16. What are the greatest challenges that you face as the parent/carer for your child young adult?
17. What support do you receive from your family?

Section 3: Aspirations

18. What provision for your child young adult would you like to see in place in the future?
19. Who do you think should provide this?
20. 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?

Summing-up by note-takers (5 min)

Summarize the discussion (the salient points/aspects) and seek feedback (member-check)

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

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