

# **UNICEF Turkmenistan - a survey and situation analysis of the boys and girls with disabilities in Turkmenistan – June-December 2014**

## **Final Report – January 2015**

**( ) Partnership for Every Child CEE/CIS Consultancy group**

&



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## B Introduction and Overview of the survey

This survey was commissioned by UNICEF Turkmenistan as part of its agreement with the Government of Turkmenistan for 2014/2015. The purpose of the survey is to:

- To understand who are the children with disabilities
- To uncover the situation of children with disabilities in institutions (age, gender, geographic location)
- To understand the accessibility and availability of social services for children with disabilities

This report presents the findings from the survey which included:

- 301 interviews with parents or carers of children with disabilities – 151 children in residential care and 150 children in the care of their own families
- 11 interviews with directors of residential boarding schools for children with disabilities
- 3 focus group discussions with parents of children with disabilities in Ashgabat, Turkmenabat and Ahal (total number of participants – 25); 2 focus group discussions with parents of children without disabilities in Ashgabat and Ahal (8 participants) and one interview with mother of a child without disability in Turkmenabat
- Request for disaggregated administrative system and demographic data on children and young people with disabilities submitted to the Ministry of Labour and Social Protection, Ministry of Education, Ministry of Health and Medical Industry and the State Statistics Committee

An extensive desk review also informed the methodology for the survey and the findings in this report including:

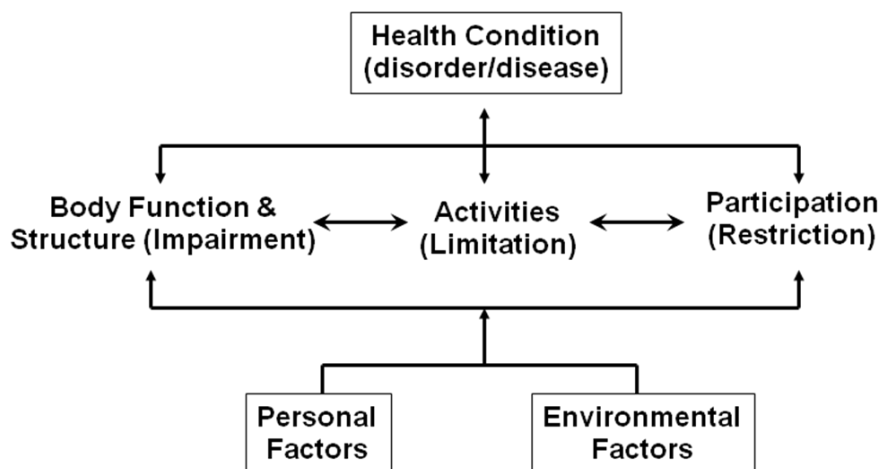
- Global practice on conducting surveys relating to disability and child disability (see notes in Annex 1)
- National legislation, policy and institutional arrangements for children with disabilities in Turkmenistan (full overview in Annex 2)
- Relevant studies and research reports from Turkmenistan (see Annex 2)

Upon completion of the field work and data analysis, a workshop was held on 18-19 December 2014 with key stakeholders from the Government of Turkmenistan, UNICEF and non-government organizations to discuss the findings and to draft an action plan on children with disabilities in Turkmenistan.

This report is structured to focus mainly on the findings of the survey and the conclusions and recommendations that follow from these findings, including the draft action plan generated in consultation with stakeholders after consideration of the findings from the survey. More detailed information relating to the methodology, the literature review and some of the data gathered as part of the survey is provided in Annexes.

### B1 Methodology for this survey

Following an extensive review of global best practice in disability surveys, a draft questionnaire was developed which was structured according to five of the six dimensions of the model of disability described in the WHO International Classification of Functioning – Children and Youth as shown in Figure 1.

**Figure 1 Dimensions of the ICF-CY model of disability**

Source: WHO, 2001

The ICF-CY was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21) as the international standard to describe and measure health and disability<sup>1</sup> and it sets out a social and human rights model of disability. Disability is understood as a construct which is created by a disorder or disease combining with environmental and personal factors to affect body function, ability to engage in activities and to participate in a range of life spheres such as education, employment, relationships, social interaction.

While adult disability surveys can be difficult to conduct with prevalence rates varying depending on the questions put, rather than on any 'given' definition of disability, child disability surveys are even more complex as a child's disability may not be obvious, especially at a younger age given that children develop at their own pace and while normative markers can be used to assess deviations from 'normal development' this is a complex field which cannot necessarily give a clear definitive answer to the question of whether a child has disabilities or not. This survey built on the ICF model and used questions focused on functions (seeing, hearing, speaking etc) and ability to carry out basic tasks (feeding, bathing, toilet) to assess severity of disability as well as the medical diagnosis reported by the respondent for each surveyed child.

This disability survey had limited resources to fully integrate an ICF-CY approach into the design of the survey and its instruments, but five of the six dimensions formed the basis of the instruments for data collection and the analysis – health condition, body function and structure, activities, participation and environmental factors. The structure of the main questionnaire is presented in Box 1.

<sup>1</sup> <http://www.who.int/classifications/icf/en/>

**Box 1 – Data collected about children in families and in residential schools or preschools**

**A Introduction** - ethical issues, informed consent

**B Basic data** – age, gender, family, housing, economic well-being, main carers, other carers, registered disability, medical diagnosis, level of functioning, type of care; level of contact with family

**C Activities and participation** – interpersonal with family, friends and peers; education and learning; leisure and play, preparation for independent living

**D Environmental factors** - health and rehabilitation; social services and support; needs

Focus group discussions were focused mainly on the main focus of inquiry being on how best to support families to care for their children in the community, how to work with communities to increase acceptance of children with disabilities and to reduce discrimination and stigma, to identify gaps in services and barriers to inclusion.

Interviews with Directors of 10 residential schools and 1 specialised day-school were intended to triangulate other sources of data and asked questions about the entry and exit of children from residential facilities, level of contact with family and outcomes for children and young people leaving residential institutions.

Statistical data requested from relevant line Ministries for 3 years (2012, 2013, 2014) included: child population disaggregated by Region, gender and age; number of children with disabilities registered with each Ministerial structure disaggregated by age, gender and diagnosis; number of children with severe disabilities; number of children with disabilities entering and exiting specialized residential institutions disaggregated by main types of pathology, referring organisation, reason for entry, region, age at entry and exit, age at time of survey and gender; outcomes for children leaving specialized residential institutions disaggregated by type of pathology, gender, age at exit and region of origin (before entry to the institution).

The full methodology and questionnaire can be found in Annex 3.

## **B2 Data limitations**

Overall there was a general lack of administrative statistical data provided to the survey, only the data provided by 10 Directors of residential facilities and 1 specialised day school give some limited information about the entry and exit of children into and out of a very limited sample of institutions. These interviews also provided some important data on the frequency of contact between children and families, but otherwise the uniformity of answers across all 11 interviews could suggest that their

responses had been pre-briefed or overly prompted and therefore to some extent have had to be discounted in the analysis.

For nearly all of the 151 children in surveyed in residential schools and preschools some sections of data are absent as whole groups of questions were not answered by the care staff or teachers who were responding – either because they do not know the answers to those particular questions or because of time constraints in answering questions and a tendency to skip questions which might require referencing a child's individual file.

For nearly all respondents, responses to some questions – especially more open or abstract questions – have very similar wording which suggests that they may have been overly prompted.

NGO beneficiaries are overly represented among children surveyed in families as they are nearly all clients of the NGO which was engaged in data collection for the survey. This means that they may not be as representative of 'typical' families as they could have been if they had been selected randomly. Similarly, data about children in residential schools are from a limited number and type of facility so cannot be considered to be representative of all children with disabilities across all types of facilities in the country as a whole.

It is important to qualify all findings from this survey as not necessarily being representative, although the size of the sample is enough to draw out some tendencies and trends and to highlight areas which could bear further study and investigation. If more administrative data could be made available it would be possible to assess the extent to which the overall sample and sub-groups within the sample, for example children with Down's Syndrome or cerebral palsy, are representative of the wider population of children with Down's Syndrome or cerebral palsy, and therefore findings could be more generalized.

## C Findings from survey

The findings are organized in five blocks based on the structure of the inquiry framework (see Annex 3) and the terms of reference for the survey:

- 1) Numbers and statistics – what do we know about the prevalence of child disability and different types of child disability in Turkmenistan?
- 2) Characteristics of the population of children with disabilities in Turkmenistan – description of the sample; what have we learned about types of disability, diagnosis and conferring of disability status, care, family structure, economic well-being, housing and employment of carers?
- 3) Participation and activities – what have we learned about the interpersonal interaction of children with disabilities with family, friends and peers, participation in education, play and leisure?
- 4) Environmental factors – what have we learned about barriers to inclusion in family and social life, education, play and leisure; how do health services and social support help to overcome these barriers?
- 5) Vision for children with disabilities in Turkmenistan – outline of action plan discussed with stakeholders based on initial findings

The main findings are highlighted in blue at the beginning of each thematic section or if there is more than one finding in a thematic section, then each blue highlight denotes a separate finding.

## C1 Number of girls and boys with disabilities in Turkmenistan

The sample of children for whom data was collected in this survey cannot be considered to be representative, so it is not possible to conclusively state how many children there are with disabilities in Turkmenistan, but it is possible to state that there are likely to be *many more* children with disabilities across the country than the 12,100 who receive disability benefits.

Given the almost complete absence of administrative data provided to the survey, it is not possible to give a definitive response to the question of how many girls and boys there are with disabilities in Turkmenistan. The only official data which can be used to at least begin to generate a rough estimate is the number of children aged 0-16 years of age (meaning all children who have not yet reached their 16<sup>th</sup> birthday e.g. children aged 0-15 years inclusive up to 15 years 11 months and 29/30 days) who receive disability benefits. According to the State Statistics Committee there were 12,100 children aged 0-16 years receiving this benefit in 2012. According to the child population data in the UNICEF TransMonee database for 2012, this represents 0,56% of the child population aged 0-17 years old (inclusive).

This seems very low given that the World Health Organization estimates 10% global child disability prevalence and that a disproportionate number of these children live in developing countries (UNICEF and University of Wisconsin, 2008). Attempts by UNICEF to measure child disability prevalence have had mixed success, but the 'Ten Questions' module<sup>2</sup> (TQ) from the multiple indicator cluster surveys (MICS) has been validated as a screen for child disability in 2-9 year olds (ibid.). The TQ has been proven to be a good predictor for disability or health problems, although few follow up assessments have been carried out to establish the full extent of its reliability. Where follow up assessments have been carried out after initial screening the Ten Questions, it can be noted that children assessed as having moderate to severe disabilities are around 20-30% of those who screen positive to the TQ and the majority of the rest may have either a mild disability or a health condition that requires treatment and that could lead to a disability if left untreated (UNICEF and University of Wisconsin, 2008). The latest MICS to generate data using the TQ took place in 2005-2008 with 205,674 children screened in twenty countries with those screening positive ranging from 14% to 35% in 15 of the participating countries and from 3% in Uzbekistan to 48% in Central African Republic. If the findings from the previous studies that then carried out follow-up clinical evaluations are applied in a rough way then these MICS3 positive screenings could be indicating a moderate to severe disability prevalence rate among 2-9 year old children of 1-4% prevalence for severe disabilities; 20% or so for mild disabilities or risk of disability. Table 1 summarises some of the literature and data from UNICEF on this issue:

**Table 1: Summary of studies using the Ten Questions (cited in UNICEF and University of Wisconsin, 2008)**

Country, sample size and study reference	% of children screening positive to one or more of the ten questions	% later assessed as having a severe disability or moderate impairment
Jamaica, 5,461 children surveyed (Thorburn et al, 1992; 15:115-127)	15.5%	3.5% were found to have a severe disability 7% to have some level of impairment

<sup>2</sup> Developed to be used in resource-poor settings, primary caregivers of children aged 2-9 years answer ten questions that screen for child impairment or inability in the realms of speech, cognition, hearing, vision, motor/physical and seizure disorders. If a parent or carer reports an impairment on at least one question, the child has screened positive.

South Africa (Christianson et al)	10.8%	3.6% estimated prevalence of child disability after clinical evaluations
Pakistan (Yaqoob et al)	20.3%	6.2% with disability after evaluation
Kenya, 10,000 children surveyed (Mung'ala-Odera et al)	9%	6% of children sampled have a moderate to severe disability based on follow up evaluation
MICS 3, 205,674 children surveyed in 20 countries 2005-2008	14%-35% in 15 countries 3% in Uzbekistan 48% in CAR	Conservative estimate based roughly on results of above studies: <i>From 1% in Uzbekistan to 4% in many other countries could have a moderate to severe disability (10-30% of those screening positive to TQ?)</i> <i>Around 20% could have a mild disability or a health condition that could be a risk of disability (roughly the average/median for 15 countries?)</i>

Source: UNICEF and University of Wisconsin, 2008; rough estimates in italics calculated by author

Even these very rough conservative estimates of 1-4% with moderate to severe disability suggest that the available Turkmenistan administrative data is giving a very low prevalence rate at 0.56%.

UNICEF reports (ibid.) note that household surveys such as those conducted for MICS do not capture data on children who are not in the household, who may be away at school or living in an institution or with relatives and that this could partially explain the very low positive screening rate in Uzbekistan from the MICS3.

For this study in Turkmenistan it is assumed that children in specialized residential boarding schools who are aged 0-16 are recipients of disability assistance and are therefore included in the official administrative data. No data was provided by carers about whether children surveyed have official disability status or receive disability benefits.

Among 148 children with disabilities in families surveyed and who gave a response, 21 children or 14% did not have official disability status and 24 children or 16% were not receiving disability assistance at the time of this survey. The reasons for not having disability status or not receiving disability assistance are discussed further below in this report. If, however, we know that this many children are not included in the official statistics as they are not receiving this payment then we can calculate<sup>3</sup> that it is likely that there are at least a further 2000 children with disabilities in Turkmenistan who are not included in the numbers of children with disability status and 2345 more children who are not disability assistance claimants - a total of 14,445 girls and boys with disabilities which is 0.67% of the child population aged 0-17 years (using 2012 child population data). This is still very low compared to prevalence data discussed above, but given that the official figure of 12,100 children does not include 16 and 17 year olds this number should be higher again.

The survey captured data from 108 children in Ahal velayat, 92 in Ashgabat and 101 in Lebap, but this is because of the way that the sample was designed – 50 children in families in each region and the way that the data collected ended up being gathered roughly 50 children in each region from residential schools or preschools. The administrative data was provided for the whole country and not disaggregated by region and conclusions on regional variances in disability prevalence cannot be drawn from the 301 children surveyed for this study, but it is worth noting that 3 out of 24 who were not receiving disability assistance at the time of the survey came from Ahal velayat, the others were evenly distributed in Lebap and Ashgabat.

<sup>3</sup>  $127/148 = 12100/x$  and  $12100/127=95$  so  $148*95=14,001=x$  or  $124/148=12100/x$  and  $12100/124=97.6$  so  $148*97.6=14,445 = x$



## C2 Characteristics of the population of children with disabilities

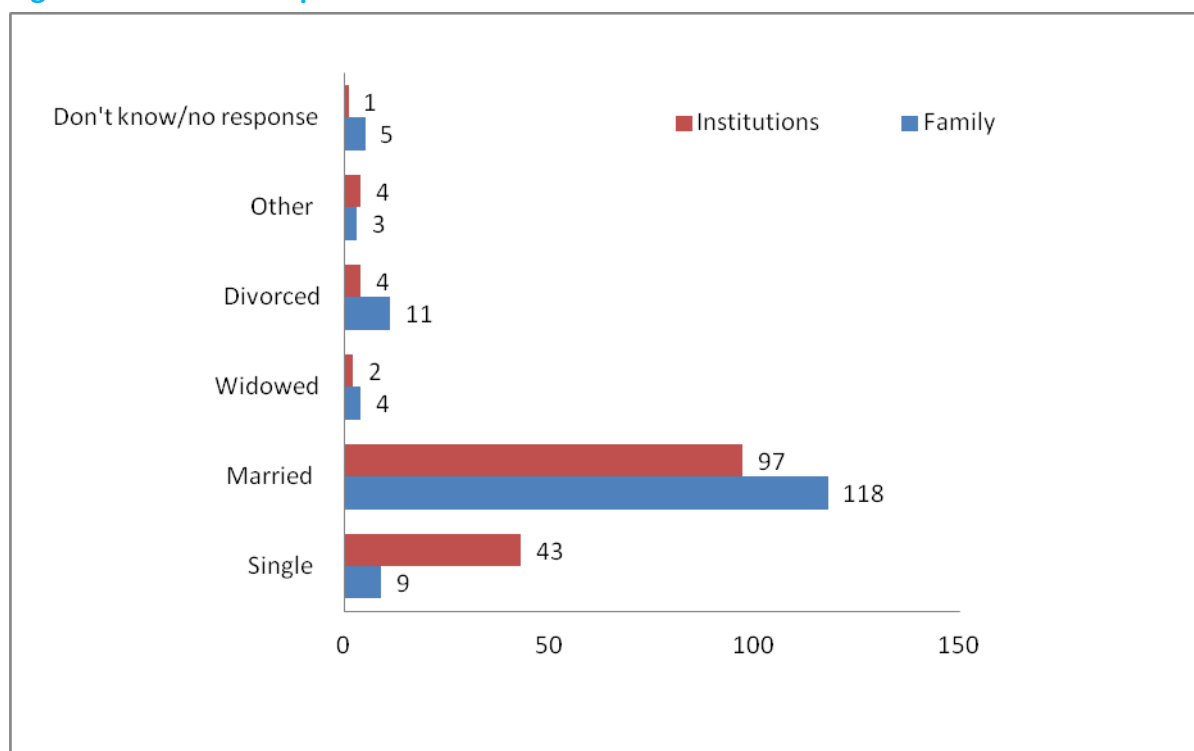
Some of the basic demographic data on the sample of 301 children surveyed for this study are set out in Annex 4 – age, gender, care setting. Children of almost all ages were included in the sample and there were roughly the same number of 143 girls and 158 boys. This section summarises some of the significant findings to emerge from the interviews with regard to the social profile of families with children with disabilities. Social profile of families with children with disabilities – urban/rural, economic situation, employment, housing, family structure

### C2.1 Family structure, housing, employment and economic situation

#### More single parents reported for children in residential institutions than in families

While bearing in mind that the sample cannot be considered to be representative, it is notable that significantly more children in residential facilities are reported to have a single parent than in family care as illustrated in Figure 2:

**Figure2 Civil status of parents of 301 children**



Source: survey respondents and authors' calculations

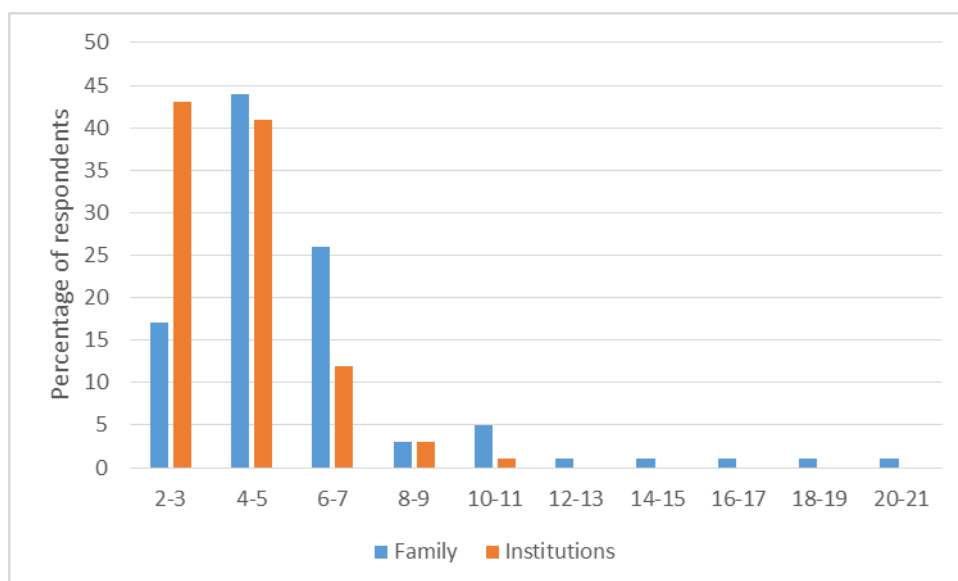
Figure 2 shows that there are over four times as many single parents whose children are in institutions compared to children that are in families. Of parents that were divorced, 11 were in the family and 4 were in institutions. Most parents are married, for both children in families and in institutions which probably reflects the trend nationally for all children.

#### In general, children who are in institutions come from smaller households than those in families

Figure 3 graphs the number of household members reported by respondents. Whilst only 68 respondents out of 151 for children in institutions answered this question, some tentative conclusions can be made, namely that children in institutions come from smaller families than children living in their families. For instance, 17 percent of children in families belong to 2-3 member households compared to

43 percent of children in institutions. Moreover, 39 percent of family-based children live in households that have 6 members or more compared to only 16 percent of institutional-based children.

**Figure 3 Number of household members (%) N= 149 for children in families and N= 68 for children in institutions**



Source: survey respondents and authors' calculations

Further in this report, the role of family members in helping to care for children with disabilities is discussed and this finding tends to underscore the importance of immediate and extended family support for children with disabilities and their parents. Questions about the presence of grandparents in the household were largely not answered by respondents for children in institutions. For children in families it can be noted that around half reported at least one grandparent living in the household which indicates the potential for support from this important familial resource.

### No conclusive findings relating to housing

In terms of housing type and tenure, the data (see Annex 4 Figures 9 & 10) tends to suggest that children in families are more likely to live in a house and children in institutions are more likely to live in an apartment, but this could be because the institutions sampled in the survey were located mainly in urban areas, or it could be for other reasons to do with bias in the sample. Either way, this information can be noted, but it is inconclusive and does not represent a meaningful finding.

### Slightly more unemployed or working mothers of children in institutions and stay at home mothers among children in families

Table 2 summarises the employment status of the respondent (or of the child's primary parental caregiver if the respondent was a teacher or institutional carer) and the employment status of the child's other parent, both expressed as percentages. Most respondents/main parent responsible for the child's welfare were either employed in paid work or were a housewife/ househusband. Most of the respondents for children in families were mothers and their responses confirm the traditional primary care-giving roles of women in Turkmenistan.

### Table 1 Employment status

Employment Status	of Respondent (or of the child's main caregiving parent) usually the mother)			of child's other parent		
	Family (%)	Institutions (%)	Total sample (%)	Family (%)	Institutions (%)	Total sample (%)
Employed	36	39	37	74	74	74
Housewife/husband	63	56	60	23	28	24
Unemployed	1	5	3	4	1	2
Retired	0	0	0	0	0	0

NB: Figures rounded to nearest percent so therefore total for each column may not equate to 100 percent. N= 286 for the employment status of the respondent (or the child's parent) and N= 277 for employment status of the child's other parent.

There were more unemployed main parental caregivers of children in institutions than in families had the highest percentages of who are unemployed; 5 percent compared to 1 percent. The employment status of the child's other parent (usually the father) is shown on the right hand side of the table. For children in institutions, there was slightly more working as housewives/househusbands whereas for children in families there is a higher percentage of unemployed. There were no respondents in the entire sample who answered that they are retired even though there were 22 grandparent respondents which is interesting if grandparents are considered to be an important additional resource for caring responsibilities. It could be, however, that these grandparent respondents (mainly grandmothers) have classified themselves as working in the home rather than as retired.

### Household economic situation varies, but almost no households are able to satisfy all their needs including for medical treatment, operations

A simple self assessment was administered to respondents and it provides some indication of how they perceive the economic wellbeing of the households that the children with disabilities surveyed are living in or come from. Respondents were asked to choose the statement that most closely reflects the economic situation of the child's family. It should be noted that the assessment for most of the children in institutions was given by staff and may not be reliable as they may not fully know the situation of the child's family or may contain a bias related to the staff members' subjective perceptions of economic wellbeing which may be skewing the data. Results are summarized in Table 3.

**Table 3 Economic situation of child's family N=300 (150 children in families, 151 children in institutions)**

Economic wellbeing Level	Description	Family (%)	Institution (%)
1	"We don't have enough for food"	19	8
2	"We have enough for food but buying clothes and buying basic medication is a problem"	22	51
3	"We have enough for food, clothes and minor household appliances but a washing machine, television or a fridge would be problematic"	33	34
4	"We have enough for large household appliances but a car, operations, rehabilitation and treatment abroad would be a problem"	19	9
5	"Our income allows us to buy everything except large purchases like	5	1

	property”		
6	“We have no financial difficulties”	1	0
8	Don’t know	1	0

Source: survey respondents and authors’ calculations

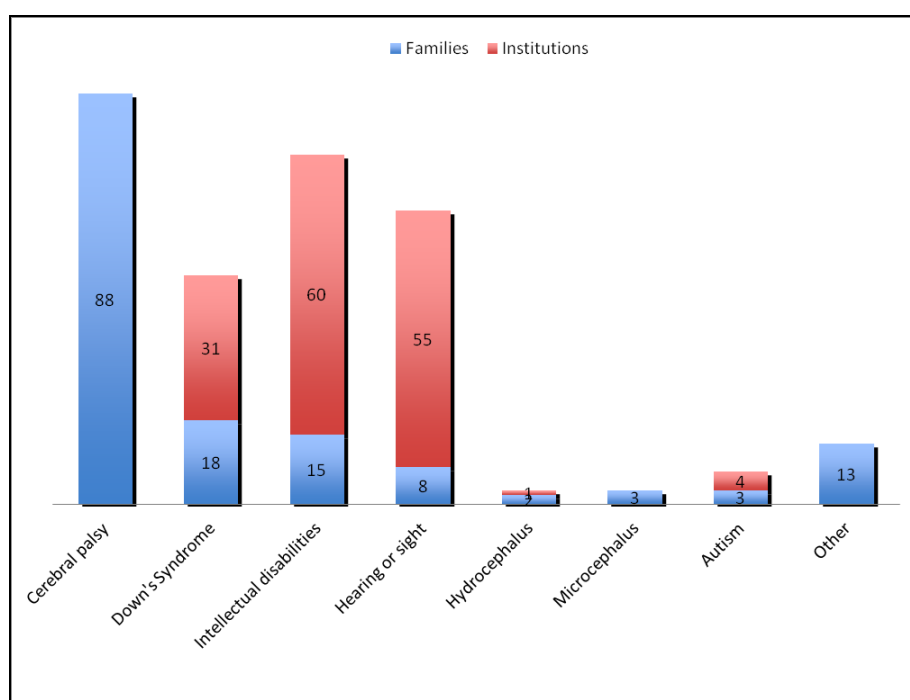
For nearly 60 percent of children in institutions, respondents perceive their families as not having enough money to buy clothes or basic medication, and 8 percent of these are reported as not having enough for food. Whilst in general, children in institutions are perceived as coming from poorer backgrounds, respondents for nearly a fifth of children in families report not having enough for food. At the other end of the scale, a fifth of children in families and a tenth of children in institutions state they have enough money for large household appliances, but view that buying a car or paying for operations and expensive medical treatment would be an issue for them.

It is also worth noting that of 24 respondents of children with disabilities in families who report not receiving disability assistance, 9 respondents assessed their economic situation as being in levels one or two brackets of this self-assessment. It could be that those who perceive their economic wellbeing to be higher are less motivated to apply for disability assistance. Reasons for non-receipt of disability assistance are discussed further below.

## C2.2 Type and severity of disability and care setting of sampled children

**The children in the sample mainly have cerebral palsy, Down’s syndrome, intellectual disabilities, hearing or sight impairments, but it is not clear how representative the sample is of the patterns of child disability in the country as a whole.**

As Figure 3 illustrates, children diagnosed with cerebral palsy dominate the sample of children in families and there were no children with cerebral palsy in the sample of children in institutions. It could be that the type of institutions where these children are educated were not included in the sample or there could be other reasons for the large numbers of children in families with cerebral palsy in the sample which are discussed later in this report. Without administrative data from the health and education system, it is not possible to determine how representative this sample of 88 children with cerebral palsy is compared to the whole population of children with cerebral palsy in the country and therefore how representative the experiences are that are reported by respondents. The same applies for children with Down’s syndrome and intellectual disabilities as it is possible that there are generally very few children with Down’s syndrome and intellectual disabilities as a whole in the child population and therefore the sample which ended up in this survey could be considered to be strongly representative.

**Figure 3 Medical diagnosis and care setting N=301 children**

Source: diagnoses reported by survey respondents, authors' calculations

Three of the institutions surveyed for this study were specialized boarding schools for children with sight and vision or hearing impairments, so these diagnoses are strongly represented among children in institutions and vice versa there are few children in families with these diagnoses – again, it is possible that this group of respondents is highly representative of children with these types of disabilities, but without administrative data to triangulate the findings from this sample it is difficult to know. It is also possible that the NGO gathering data for this survey has a client base more established among children with cerebral palsy, Down's syndrome and intellectual disabilities than among those with sight or hearing impairments. This could be because these families seek out this kind of support in the absence of other service providers, or because there are other NGOs or structure providing support to children with sight and hearing impairments. Either way, it is important to note this imbalance in the diagnoses and care settings as it has implications for some of the findings of this study as discussed further in this report.

### **Children assessed with more severe levels of disability are more likely to be living in family care**

Functional assessments can provide useful insights into the level of disability and during the interviews conducted for this survey, respondents were asked to assess the child's functional abilities across nine domains – seeing, hearing, speaking, walking, sitting, changing position, breathing, understanding speech or gestures, learning and comprehension – giving a level of functioning: 5=fully functioning, 4= mild dysfunction, 3=moderate dysfunction, 2=severe dysfunction and 1=can't function at all even with help. This subjective assessment was followed by questions about the ability of the child in taking part in four self-care activities: bathing, toilet, eating and dressing with the same ability levels as with functioning: 5=able to carry out, 4=needs some help, 3=needs regular help, 2=needs constant help and 1=unable to carry out even with help. This approach is based on the ICF-CY model of disability and best practice international in child disability surveys. While parent responses are subjective, they can often be more accurate than specialist assessments of ability and functioning as primary caregivers have

much greater knowledge from providing day to day care than specialists who may examine children in settings that are unfamiliar and intimidating for the child and therefore elicit atypical behavior. As UNICEF and the University of Wisconsin put it in their overview of MICS3 results *'parents often do very well at identifying whether their children have difficulty performing specific'* (UNICEF/UW, 2008:p9)

Table 4 summarises the results for four children with Down's syndrome and clearly demonstrates how children with the same diagnosis can have very differing levels of functioning.

**Table 4 One diagnosis – different abilities**

Gender/age	Sees	Hears	Speaks	Walks	Sits	Changes position	Breathing	Understands speech or gestures	Learns and comprehends	Bathing	Toilet	Eating	Dressing
Girl 10 years old	5	5	2	5	5	5	5	2	2	2	5	5	3
Boy 13 years old	5	5	4	5	5	5	5	3	3	3	3	4	4
Girl 8 years old	5	5	3	5	5	5	5	3	3	3	3	4	3
Girl 4 years old	5	5	1	1	1	3	4	3	3	1	1	1	1

Source: survey respondents

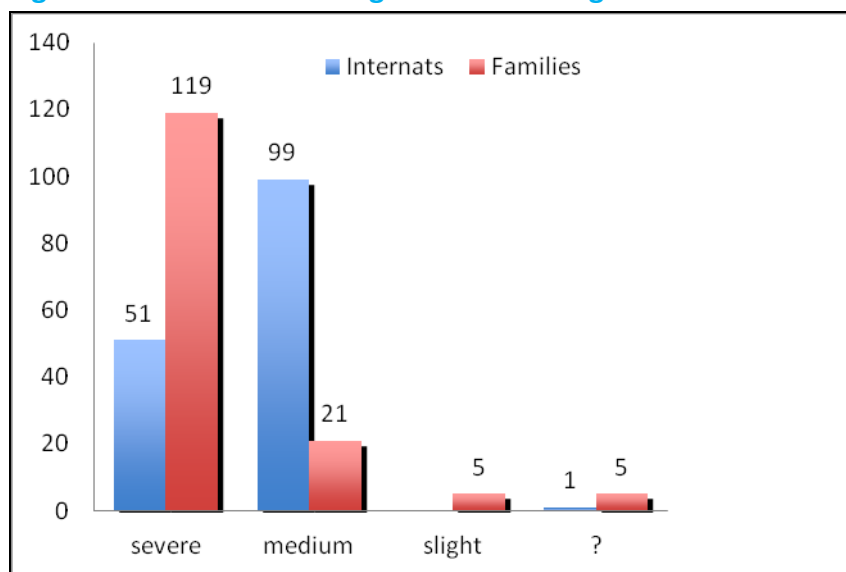
Figure 4 provides a summary of the results for all children in the sample with the classifications of severe, medium or slight having been determined by bringing together the assessments by respondents with the reported medical diagnosis as described here:

Level	Description
Severe	Scores 1 or 2 in at least one field of functioning or self-care activity
Medium	Scores 3,4 and 5 only and with a pathology such as cerebral palsy or Down's syndrome
Slight	Scores only 4 and 5 and with a medical condition, e.g. heart condition
?	Needs checking – scores given as only 4 and 5, but with a diagnosis which would indicate a probability of at least some limited functioning at the level of 1,2 or 3 in at least one domain (e.g. Down's syndrome, cerebral palsy)

Source: P4EC CEE/CIS Consultancy group/OPM

It is interesting that children in institutions were classified by staff consistently as mainly having medium levels of ability and largely able to carry out the main self care tasks and Figure 4 illustrates the extent to which children with medium levels of disability are more likely to be in the institutions which were sampled for this survey and that those with severe disabilities are more likely to be living in families than in institutional settings.

**Figure 4 Level of functioning and care setting N=301 children**



Source: P4EC CEE/CIS Consultancy group/ OPM based on levels of functioning reported by survey respondents, authors' calculations

This is counterintuitive as the expectation is that children with severe disabilities are more likely to be in the care of highly specialised institutions and it needs to be emphasised again that only a limited sample of institutions was included in this survey. This finding also underscores the findings from the U3 study (Rogers et al, UNICEF Turkmenistan, 2014) about the primary role of family in caring for children in Turkmenistan regardless of the severity of their disability. The relevance of severity of disability in relation to education is explored further in this report.

### **C2.3 Disability registration**

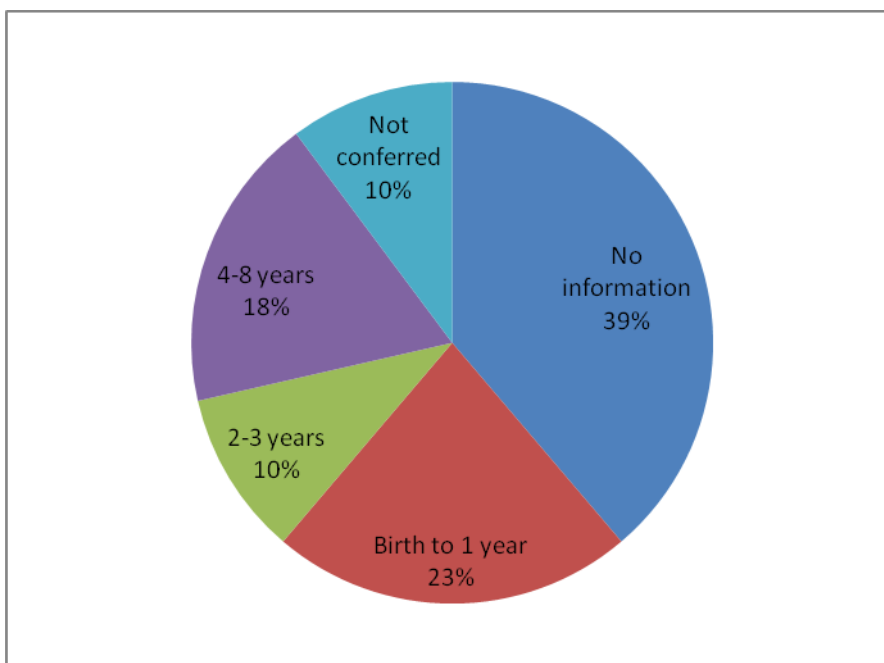
Annex 2 outlines the provisions in legislation and policy for determining whether a child has a disability or not and this section of the report provides an overview of the experiences of parents in applying for disability status or going through the medical pedagogical commission that directs children with disabilities into education services.

#### **Diagnosis is late for some children, parents report mixed experiences of applying for disability status and determination of disability in the case of children with Down's syndrome requires review**

The ages at which children surveyed for this study were medically diagnosed ranges from birth to 6 years of age. Some diagnoses are congenital (Down's syndrome) or are linked to birth trauma (infant cerebral palsy) and it can be expected that they will be diagnosed at birth or relatively soon after. It is important to note, therefore that among the children in the sample for whom information was provided, only 1/3 of children with Down's syndrome or cerebral palsy were diagnosed at birth, around 1/3 were diagnosed as late as two or even three years old. Reasons for late diagnosis, except for cases where disorders only become evident at a later age can include: parents/care-givers' unawareness or neglect, or by doctors' insufficient competence or their attitude towards patients.

Disability is determined by the Medico-Social Expert Commission (MSEC) which assesses 'the level of citizens' vital activity limitation, caused by physical or mental impairment' in accordance with the Code of Turkmenistan "On Social Benefits" of 17<sup>th</sup> March 2007. The findings of the study show that the age of determining disability status in children varies from 1 to 15 years. Most children were assessed as having a disability at the age of two (26%) or three (26%) years of age. Only 10% of children were conferred a degree of disability at the age of one. Patterns of disability status being registered for children with Down's syndrome among those for whom data was provided in this survey bears further examination as illustrated in Figure 5.

#### **Figure 5 Age in years at which disability status conferred for 49 children with Down's syndrome**



Source: survey respondents and authors' calculations

While most children with Down's syndrome are reported as having disability status confirmed since birth or before two years of age, some parents report that children with Down's syndrome are assessed for disability very late – almost 20% of children with Down's syndrome in the sample were conferred with disability status at the age of 4-8 years. In 5 cases (10% of the whole sample of those with Down's syndrome and 17% of those who provided data), disability status was not conferred:

*We applied to the Commission ... but they didn't certify disability. We spent 10 days in hospital and another 5 days gathering various documents (mother of 5 year old girl diagnosed with Down's syndrome at 1 year of age)*

It is not entirely clear why children with Down's syndrome are not being certified as having a disability. Discussions with experts and stakeholders during the action planning workshop indicate that the basis for assessing disability is a classification system that does not include Down's syndrome or autism and possibly other conditions which are widely recognized globally. Children with Down's syndrome in Turkmenistan are only conferred disability status if they have associated health conditions e.g. heart problems. There does not seem to be awareness that Down's syndrome is usually associated with at least some level of learning disabilities. While the approach of the MSEC could be considered to be particularly enlightened by regarding children with Down's syndrome as normally developing children, the lack of disability status means that families can experience difficulties in accessing social support, education and other necessary services.

Overall, in 24 cases (11% of children for whom information was provided or 8% of the whole sample) disability status was not conferred. In eight cases the disability status had not been conferred by the expert commission following applications by parents with various explanations being given to parents: *"the forms are filled out incorrectly", "the child is undergoing private treatment", "the child is not vaccinated (although the family doctor has stated that vaccines are contraindicated for the child)"* or simply rejected as in the Down's syndrome case cited above. In 10 cases, parents didn't apply for disability status. The explanations varied: *"we are embarrassed in front of other people", "I hear it's hard to get, that's why I didn't even go", "we didn't apply for disability certification, because we had a negative experience with the first child, who was not conferred disability" (the second child diagnosed*



*with microcephaly, encephalopathy, hearing disorder, the first diagnosis at the age of 6 months*). At the time of the study, several families were in the process of disability certification for their children.

According to the study, the time taken for conferment of a disability status varies from two weeks to 7-8 months, and even up to one year. Such a considerable variation in timing cannot be explained by the existing procedures. Most probably, it can be explained, on the one hand, by the possibilities and determination of parents, and on the other hand, by competence or barriers created by the healthcare staff itself.

Parents explain late conferment of a disability status or lack of its conferment altogether by the existence of different barriers emerging at various stages of the process: GP's unawareness about the procedures, referral obtaining, collection of necessary documents, attitude of physicians and the actual appearance before the Commission. *"There is no disability, because it is necessary to get the child registered at the psychiatry dispensary. The doctor said it was schizophrenia, so you choose. There's no moral support"* (mother of boy diagnosed with intellectual disabilities, autism at 2.5 years). Parents' opinions regarding the work of the disability certification commission vary – from good, positive, professional, to biased, and even extorting (100\$ - 200\$).

*They asked us at the hospital why we hadn't sought a disability status. I didn't know the child was sick. After that, I started the arrangements to certify disability. The Commission said the child was healthy, and the diagnosis was wrong. Then we went to the Ministry of Health and did everything very quickly.* (Mother of boy aged 4 years with infant cerebral palsy and intellectual disability; disability status conferred at the age of 2 years)

This process is most challenging for rural population:

*The GP recommended. It's difficult. The Commission members don't believe there are such children. There is a need for a lot of documents. There are queues, lots of children. It has taken me 7 months to collect the documents. Both adults and children are attend the same office.* (Mother of boy aged 4 with infant cerebral palsy from a rural area, disability conferred at the age of 2.5 years).

Parents' readiness to certify the degree of disability of their child also depends on the attitude of people around and social perceptions of children with disabilities. Parents feel embarrassed to apply for disability certification: *"We don't want people to talk, to point their finger"*, say parents showing emotions of resentment and shame.

#### **Parents with disabled children about the experience of disability certification**

*"When the child was 3 years old I noticed he was too hyperactive, there was no sign of speech, no reaction to anything, no attention to what we were saying, insomnia. I went to see a psychiatrist, on my own initiative. My employer requested a document certifying my child's disability. Having consulted the psychiatrist, we went to the Commission. We had no difficulties at all, we got disability certified at once";*

*"They diagnosed while certifying the disability; it had taken a while for the physicians to clarify the diagnosis. We got disability certified very quickly (5 minutes), because the child's condition is very serious";*

*"I asked the GP to refer us for disability certification, she said the child's health record was not*

complete (the mother had arranged for private treatment), that is why they wouldn't certify disability. The child hasn't been vaccinated, because the neuropathologist says they vaccines are contraindicated in her case";

"Delivery was very difficult. Convulsions started at 5 months, I went to the GP who gave a prescription, but didn't tell us anything. Until the child turned 2 we would always go to the local hospital (kolkhoz), but there was no result. When the child was 2 we went to an Ashgabat hospital, where the neuropathologist explained how to certify disability with status conferment. We had no difficulty with that";

"The doctor said everything was alright. But it was challenging. I had to literally grind out the disability status. The GP didn't know what to do with us. When I started threatening with the Ministry, things went easier. I had been running back and forth for 4 months. There were no problems at the Commission";

"First they diagnosed heart disease, then we went to an Ashgabat hospital, where they cancelled the heart disease diagnosis and said she was mentally retarded";

"The doctor recommended certifying a disability status. I was going to the Ministry, the GP didn't know. It took me six months to sort things out. They would keep sending me from one to another";

"Of course, we had difficulties. My ward mate advised me to get a vision disability status, as they pay better for that. The health center referred us to another hospital. They do not certify disability without the child present, and since it was difficult to carry him along we suspended the process. Disability is conferred for three years, that's why we'll be getting the vision disability status after this term expires";

"It was hard, I am a physician myself, and they wanted bribes" (Down syndrome);

"We did it quickly and got it at once, we didn't have to stay in hospital" (ICP)

"I learned about the diagnosis 3-4 months after giving birth. Before the child was 4, I didn't want to apply myself, hoped he would get better, I didn't want anyone to say the child was disabled. Then I realized things were getting worse, and decided to go for disability. I didn't want to accept the fact that the child was disabled, didn't want people to talk. It took us about 2-3 months, the process was difficult, to get the disability status. Mostly to get the child's documents processed".

"The doctor in the maternity hospital noticed, but it took us 2 months to pass all the tests. We were examined by the Commission at 6 months in order to get the disability pension – it wasn't difficult";

"Our relatives advised us to get the disability status, we had to appear before the Commission several times, it was difficult";

"We had no problems";

"It was noticed at birth. At 5 months they clarified the exact diagnosis. At 8 months we went to the commission and got a disability status conferred straight away";

"They advised us to get a disability status. They made us register at the psychiatry dispensary, and only after that they certified disability. Lots of documents".

Such contradictory opinions about the process of diagnosis and disability status conferment suggests a need to address standards of functioning in the mechanism of disability assessment, the attitudes of healthcare staff towards such children and families and to ensure that medical staff have access to up to date information about child development and disability and are using classification systems that are in keeping with the latest developments globally. The issue of the need for monitoring and evaluation of these structures within the health system also arises.

As for children from residential institutions, only in 60 cases (40%) the date of disability certification was indicated, and in the remaining cases it was not provided. All the children from this group were certified with disabilities before they entered the residential institution: at birth (7 children), before the age of 1 (2 children), at the age of 2 (8 children), at 3 (14 children), at 4 (14 children), at 5 (11 children), and at 6 (4 children). In some residential institutions this information was not provided either because it was missing from the children's personal files, or the respondents were not in a position to provide this information at the time of the survey. There is a need to ensure that there is a single national standard for maintaining individual case files with all information about children in residential institutions.

### **C3 Participation and activities – interpersonal interaction of children with disabilities in Turkmenistan with family, friends and peers; participation in education, play and leisure; preparation for independent living**

UNICEF CEE/CIS Regional office data suggests that 74% children with disabilities in Turkmenistan are in education provided in a residential setting, with the remaining 26% receiving education at home (UNICEF, 2013: slide 8) and that 87% of children in institutional care in Turkmenistan are children with disabilities (UNICEF, 2013: slide 12). These are the highest rates of institutionalized children in the central Asia region implying that children with disabilities in Turkmenistan are extremely likely (much more likely than their peers in other central Asian countries) to experience at least some period of time away from their families in residential care. This survey has not had access to data that can either confirm or otherwise this picture of children who are not able to participate in normal family life and benefit from the care of their own families. The responses of parents and carers in focus groups and interviews as part of this survey do however provide some alternative insights into the nature of the way in which children are educated and cared for in Turkmenistan and the interpersonal interaction of children with disabilities with their family members, friends and peers.

#### **C3.1 The family life of children with disabilities**

The findings of focus groups and interviews showed that the birth of a child with disabilities or the diagnosis of a health condition that affects a child's development and functioning radically changes the family's life. In common with families around the world facing similar news about their child, some families report that they go through a series of emotional states, similar to grieving, as a result of which they come to terms with the situation and develop a certain family lifestyle focused on the needs of the child with disabilities or adapted around them.

##### **Parents of children with disabilities about changes in their family's lifestyle after the birth of a child with health conditions that affect functioning**

"I used to work before my child was born. And then it so happened that I had to spend 24/7 with the child. You would think of taking a babysitter, but no stranger will take the same care as you do. I can't entrust my child to anybody. I cannot get a job, although arrangements have been made for the child already, but still we take him home earlier, I help him do his homework".

"Life has changed a lot - it has focused very much on the child. There are no more get-togethers with relatives or visits, meetings with friends, since all the time is dedicated to the child".

"It was difficult at the beginning, but then you get used to it, things settle. It used to be difficult financially".

Source: focus group discussions with parents of children with disabilities

Focus group participants talk about how sometimes families have to change their lifestyle and build it around the child with disabilities, restricting their own needs, wishes, opportunities to pursue their career and the lifestyle they have developed: *"I had to quit my job. My husband refused to take a babysitter, and I had to stay at home. It's hard to stay at home all the time. It's hard to get him up and down the floor. He is growing, he's already 11 years old"*. Some families, however, manage to preserve stability of life scenarios based on understanding and coming to terms with what has happened: *"I don't have a possibility to work, because I give all my time to the child. Of course, one would want a healthy child, but I can't say I have suffered in any way"*.

Families with disabled children may become more isolated either in order to hide their problems *'you try not to go out, in order not to bother people'* or as their lifestyle changes and social circles reduce. Some families don't bear the test of these challenges and break down: *"My husband left me straight away. Because who needs such a child? But I didn't leave him. There are parents who do. He might call once or twice a year and ask: "Does he talk, walk?" That's the first question,"* (focus group participants).

Many parents report having feelings of guilt related to the birth of a child with disability and that this is often nurtured by the attitude of relatives (most often the mother-in-law is mentioned by the women who took part in focus groups): *"They look and they think, well, the mother is normal, and the child has been born like this. But it's not our fault, is it?"*; *"It was hard for the first three years, while he was small. My husband left me straight away, he said: "There's no such disease in my family, it's all from you""*. Guilt for the birth of a child with disabilities is a very strong and heavy feeling that destructively influences the mother's self-esteem, her attitude towards her own child, her ability to overcome difficulties and to find a way out of the existing situation.

A few families, on the contrary, find the strength to all their efforts to survive looking for ways out of the situation, which seems like a dead-end at the first glance:

*"My child gave me an impulse to live. I got scared at the beginning of diagnosed with cerebral palsy, but then I started my own business, a café, the child is always with me"*

*"It was very hard for the first 5 years. And then it got better. Thanks to the child. I found a job, I found everything";*

*"My daughter is my greatest happiness. I really feel grateful"* (Focus group participants)

The crisis that a family with a disabled child faces brings with it a series of problems and peculiarities of socio-psychological functioning that are specific for such families and parents in Turkmenistan are no exception. There are some tendencies among survey respondents and focus group participants in Turkmenistan that can be noted, however. Parents tend to focus on child health issues and to have a very medical view of. They don't always think about the child's development, education, building their independence, they are prone to overestimating their child's capabilities. At the same time, they worry about the child's future, how he/she will live without them, being aware of the state's limited possibilities to provide for people with disabilities.

They tend to deny the existence of state aid, not recognizing that receiving a disability allowance is in fact a form of social support from the state. So, when asked about support from the government, many

respondents said they didn't receive any, apart from NGOs. It could be that this type of support, the child disability allowance, can only address some small part of the challenges that come with the birth of a child with disabilities, and the support that this allowance can give becomes devalued in the eyes of the respondents.

To some extent, many of the issues raised by families of children with disabilities can be linked in a general sense to the family perception of their economic situation – families who have lower economic wellbeing are more concerned with financial issues, the money they need to get treatments for their child and those who perceive themselves to be better-off are more focused on services, their child's development, quality in health care and education and rehabilitation.

Certain families do not even display the need for aid – they don't see the use of it, do not understand the importance of building the child's autonomy and ability to eventually lead an independent life. They have come to terms with the fact that they will have to take care of their child all their lives.

Thus, difficult life situations faced by families with disabled children determine development and manifestation of various life scenarios focused on survival and overcoming of dead-end experiences. In this context it is very important to study the survival strategies of families with disabled children, in order to develop a system of assistance measures, including moral support for such families.

### High levels of interaction with siblings, parents and other family members for children in families, but apparently also for children in institutions

One of the major findings from this survey is that there appears to be high frequency of contact between children with disabilities and their siblings and parents both in families and, importantly, for children in institutions. The interviews with institution directors tend to confirm that frequency of contact is high. These findings are summarized in Box 2.

#### Box 2 Level and frequency of contact with family for children in institutions

##### Survey respondents report for 151 children in residential institutions that:

30% have daily contact with families

87% have daily contact or see their families at weekends

12% of children from two internats see their families only during the holidays

Depending on the institution and where it is located - different patterns of contact 5% to 67% have daily contact and 20% to 90% have weekend contact

##### Institution directors from 10 residential schools state that<sup>4</sup>:

29% of children in one boarding school and 18% in another have daily contact

61% of children in 9 urban boarding schools and 33% in one rural boarding school have weekly contact

80% of children in 10 boarding schools see their families either weekly or 2-3 times per month

##### Survey respondents report that:

Of 47 children for whom information was provided 72% spend 'some' 'a lot' or 'all' of the time with their siblings compared to 74% of children in families who were sampled

Source: survey respondents, key informant interviews and author's calculations

<sup>4</sup> See Annex 4, Table 2 for detailed breakdown of responses from Directors

Overall these seem to be quite high levels of participation in family life for children living in institutions and tend to confirm how important the family is in Turkmenistan society and culture. This could also partially explain why the UNICEF CEE/CIS Regional office data seems to be out of step with Turkmenistan's neighbours – if 74% of children with disabilities are being educated in residential institutions, around 20-30% of these children could actually be attending on a daily basis and live at home and around 80-85 % have weekly or more frequent contact with their families so are not 'institutionalised' in the way that children are who live long term in residential care with little or no family contact.

Turkmenistan has an extensive network of specialized schools for children with disabilities which are both residential and non-residential, but this survey tends to suggest that even in residential schools, many children are essentially either day pupils or weekly boarders; that for most children family contact is maintained and that because of the extensive nature of the network, it is possible that for many children, certainly in urban areas, a specialized school is likely to be located somewhere nearby simply because there are so many of them. The director interviews indicate that in most cases children in residential schools live within 50km of their family homes:

Percentage of children in 11 specialised schools living more than 50km from their families	
Urban helping internat school A	15%
Urban helping internat school B	48%
Urban helping internat school C	2%
Urban boarding school for children with intellectual disabilities	10%
Urban boarding school for children with hearing impairments	6%
Urban boarding school for children with sight impairments	5%
Rural specialised boarding school	7%
Urban helping day school	6%
Urban specialised boarding school	20%
Urban specialised boarding school	36%
Urban specialised boarding school	18%
Average for 11 specialised schools	16%

Source: key informant interviews and author calculations

If the status of the internat or boarding schools could be changed to day schools with only very small dormitories, this would respond to the needs of children for close family contact and at the same time better meet the demands of parents who, on the whole, do not want to send their children away as these comments from parents who took part in piloting of the questionnaire demonstrate:

*'Put my child in the internat? – no, what are you saying? Well she left her child for a week at the kindergarten and I already hate her for this. I don't think a mother can do this.'*

*'Day services are needed (centres to leave the child for a day or for 3-4 hours), not to get rid of the child, but so that the child can develop'*

*'We would pay for this ourselves, as long as there were people who would work with the children'*

And this mother who participated in the focus group discussions:

*"I dream of him going not to a residential, but a mainstream school. I would take him to school and back home myself, would stay there during classes. Why do children abroad attend regular schools, they just take a wheelchair with remote control. My daughter has left, now I'll stay home with him, like in a deep forest, because I can't go out with him";*



The issue of specialized or mainstream education, residential or day provision is discussed further in this report. The data discussed in this section relates more to the care provision that is associated with providing education and specifically to whether residential care provision limits the opportunities for children to participate in family life. While these results should be treated with caution because of the data limitations already discussed, the issue of frequency of contact should be examined more closely with a view to helping parents to bring children to school on a daily basis – investing in transport, not beds and overnight staff – and which help them with services in the community to provide care for their child at home.

**Children with disabilities in families tend to have frequent of interaction with siblings and in around 50% of cases constant contact with parents; around 36% of parents say they need help to communicate with their child with disabilities**

The information collected from parents/care-givers about the frequency of their disabled child's communication with siblings shows that, out of 151 children, 22 (14.6%) do not have siblings, 34 children (22.5%) spend time with their siblings, 39 children (25.8%) spend much time, and 29 children (19.2%) spend some time with their siblings. 11 children (7.3%) spend little time and 3 spend no time at all with their siblings. Among the reasons for poor communication with siblings, there were: *"the child doesn't understand, beats the younger one, doesn't approach"*, *"she is all in herself, watches TV"*, *"the child is bad tempered"*, *"when children come from school"*, *"the brother is eager to fight"*.

104 teachers/educators (68%) in institutions where disabled children are placed did not provide any information about communication with siblings. The boarding school staff report that 10 children (6.7%) do not have siblings, 8 children (5.3%) spend all the time with their siblings, who are probably placed in the same institution. The information shows that 17 children (11.3%) spend a lot of time with their siblings and that must be children who go home every night. 8 children (5.3%) spend some time, 1 child spends little time, and 1 child does not spend any time with their siblings.

The information collected within the study from parents/care-givers of children with disabilities living in families suggests that they spend a lot of time with their children. Data shows that 75 parents (49.7%) spend all their time with the child (24/7), because *"the child requires constant care"*, *"I'm afraid to leave, there is a need for supervision"*, *"there is a need for constant care, he cannot feed himself"*, etc. 54 parents (35.7%) indicated that they spent a lot of time with the child. In order to reduce the subjectivity of perception, parents were asked to indicate how many hours that implied. The range of timeframes estimated as 'a lot of time' varied from 4-5 to 20 hours a day. 14 parents (9.3%) spend some time with their children quantified as 4-6 hours a day. 8 people (5.3%) spend little time with their children, which means for them from 4 to 8 hours a day. No parent said they spent no time with their child. The main reason for little time spent with the child was work of the parent/parents (one mother said she worked in three places).

Parents of disabled children were asked whether they or their family members needed support in order to improve the process of their communication with the child. 54 respondents (35.8%) said they needed such help. Most of them mentioned the need for assistance of a speech therapist, some that of a disability correction specialist. They also mentioned the need for assistance *"to teach the child to speak"*, *"to teach the child to communicate, she is very withdrawn"*, *"there is no possibility to communicate with peers"*. 16 parents (10.6%) responded they did not know whether they needed assistance in communication. 81 parents/care-givers (53.6%) responded they did not need such assistance.

In the group of institutionalized children, only 8 answers (5.3%) were received stating the need of staff for assistance in improving their communication with the child. All the other answers, almost to the same extent, mentioned they did not need such assistance or knew nothing about such a need, or there was no answer to this question.

Within the study a question was asked about the need to provide assistance to the child in interpersonal communication. In 48 cases (31.8%) parents mentioned that children required help of speech therapists and disability correction specialists to learn understanding speech, gestures in order to communicate with people. 16 parents/care-givers (10.6%) did not know how to answer this question, and 87 respondents (57.6%) answered negatively (they did not need help) or did not give any answer.

For institutionalized children, in 36 cases (24%) they mentioned a need to help the child in interpersonal interaction, in 30 cases (20%) this need was denied, while in the other cases no answer was given to this question.

**On the whole, family members help to provide child care for children living in families, but 12% of respondents say that nobody helps them and 21% of respondents say older siblings help**

The issue of child care in families with disabled children is a substantive and delicate issue. The study was interested in finding out how parents/care-givers were dealing with child care. The received data shows that the main care-giver for the child is their mother. In 151 families with disabled children, the main care-giver of the child in 132 cases (88%) is their mother although many mothers also work as discussed above.

In the group of institutionalized children, the main care-giver in 102 cases (68%) is a member of staff, in 40 cases (26.7%) - mother, and in 5 cases (3.3%) - grandmother. This data confirms the findings from the 'frequency of contact data above' that although children may be in residential care, they keep in touch with their family, and their mother is perceived as carrying the main responsibility for child care. Again, the higher number of single mothers with children in residential institutions noted above is significant.

Given that around 1/3 of primary caregivers also work, the study was able to determine who else, apart from the main care-giver, was helping with child care in the family. For 49 children in families (33%) it is the grandmother and for 16 families (11%) it is the grandfather who helps with child care; followed by fathers in 44 cases (29%) and siblings in 31 cases (21%). The implications of siblings taking such a large share of the care burden needs to be taken into careful consideration as caring for siblings with disabilities can disrupt education, peer relations and play or leisure activities for many children if this practice is as widespread as it is in the sample. While the important role played by the family and extended family in Turkmenistan society and culture is clearly demonstrated here, it is significant that 18 families (12%) of the children in the sample who report that 'nobody helps' with child care.

Within the study, parents and main care-givers of the child were asked: "When you have to go out and cannot take the child with you, who stays with him/her?" as a question cross referenced to the question about who else helps with care responsibilities. 22 mothers (15%) said nobody helped them to take care of the child, when they had to go out which is slightly higher than the 12% who said they have nobody else to help provide care. They also specified that they *"tie up the child to the bed"*, *"we always go together"*, *"I don't go anywhere without the child"*.

In response to other questions, 20% of respondents say that they need a lot of support with everyday care – toilet, bathing, dressing and feeding. While relying on extended family support for child care and



every day care is an important founding stone of the Turkmenistan social assistance system, it is clear from this survey that there may be a need for additional support for the parents of children with disabilities who do not have access to extended family, who work at the same time as being primary caregivers and who may have a child who had high levels of need for support in carrying out day to day activities related to everyday care.

### **Data on the differences between family and institution children in interaction with friends and peers are inconclusive – in both cases around 40-50% of children with disabilities are reported as having friends**

The study aimed at collecting information about whether disabled children had friends, as well as how often and where they meet. Out of 151 parents/care-givers, around half of respondents (59 people (39%) mentioned their children had friends. 20 (13%) of them meet their friends every day, 27 children (18%) meet their friends around once a week, and 3 children (2%) once a month. 12 children (8%) from this group meet their friends in their home, 9 children (6%) outside, and 5 children (3%) in educational institutions.

Children in institutions, according to educators and parents, in 71 cases (47%) have friends, and in 14 cases they have friends outside of the institution whom they meet in most cases once a week at art club. It is not entirely clear to what extent this assessment of friendships by residential institution staff can be considered to be reliable, but if it is, then it tends to suggest that children in residential education settings are slightly more likely to have friends than children at home. All institution directors interviewed agreed that children acquire 'an education and friends' at their institutions.

### **C3.2 Participation in education, leisure and play**

The extensive network of specialized education institutions both residential and non-residential for children with disabilities in Turkmenistan has already been noted. UNICEF and the Government of Turkmenistan are in the process of developing a road map for inclusive education which aims over time to transform the current largely non-inclusive education system into an inclusive system which implies children with disabilities will be integrated into the community and accessing education close to home so they do not have to leave their families to access education. The new Law on Education passed in 2013 specifies '*inclusion of children with special educational needs into mainstream schools and the development of state standards to improve the quality of education*'. This section of the report will present some of the key findings of this survey about education which may help to inform some of the steps towards inclusive education outlined in the road map, especially the baseline survey, and to highlight some important priorities going forward. The main questions explored in this section are:

- Why some children are educated in boarding schools and others are educated at home
- Are there children outside of education? Why?
- Is the education system helping children to learn? Do they like going to school?
- Quality of education
- Inclusion

According to the existing procedures and to the Regulations of the Commission, children with disabilities can be referred to educational institutions (residential or mainstream) only upon the qualification by a medico-educational Commission. Thus, lack of the Commission's qualification becomes an obstacle to a disabled child's integration into the education system.

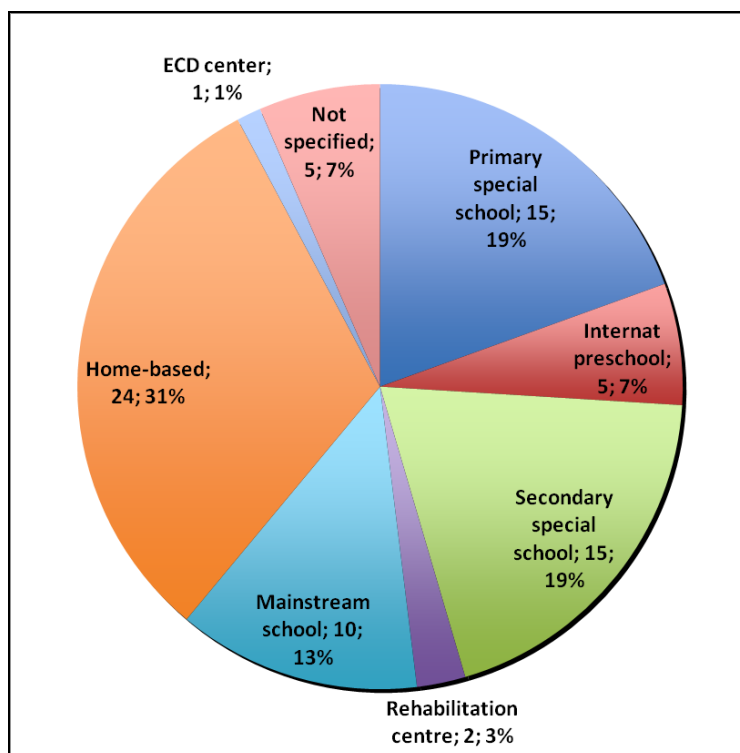
Data on children from residential institutions and the interviews with directors confirm that all children have passed the medico-educational Commission before enrolling into the institution. It is fair to say that presence of the Commission's referral is one of the compulsory conditions for inclusion of a child into this type of educational institution.

Comprised of healthcare and special education specialists (children's psychiatrist, speech therapist, disability correction specialist, hearing-impairment and visual-impairment specialists), one of the Commission's tasks is to give appropriate recommendations to teachers with special skills who work with specialized groups and in specialized children's institutions, as well as to the child's parents based on their expert conclusion. At the same time, this regulation does not require taking into consideration the parents' desire to place a child into the recommended institution, nor does it indicate the term of placement.

**Of 77 children in families (just over 50%) are accessing education, 31% are in home-based education and 13% are in mainstream schools. The majority are in specialised education settings. Parents report positive and negative experiences of education for their children with disabilities.**

All children in institutions surveyed are accessing education in residential schools and preschools. Just over 50% of children in families are accessing some kind of education and Figure 6 illustrates how, with the majority in some form of specialized disability education, almost a third in home-based education (including one child whose parent takes him to school every day) and 13% are in mainstream education services:

**Figure 6 Education settings of 77 children in families who are in education**



Source: survey respondents and authors' calculations

UNICEF Turkmenistan reports<sup>5</sup> 830 children with disabilities in home-based education in 2012 which is 7% of the 12,100 children who are registered as receiving disability allowance by the State Statistics Committee, so there are a significantly higher than average (almost 5 times higher) number of children with disabilities in home-based education in the sample for this survey. As discussed earlier in this report, this could be because families who are not accessing education or other services may be more active in seeking support from other sources such as the NGO which was responsible for identifying

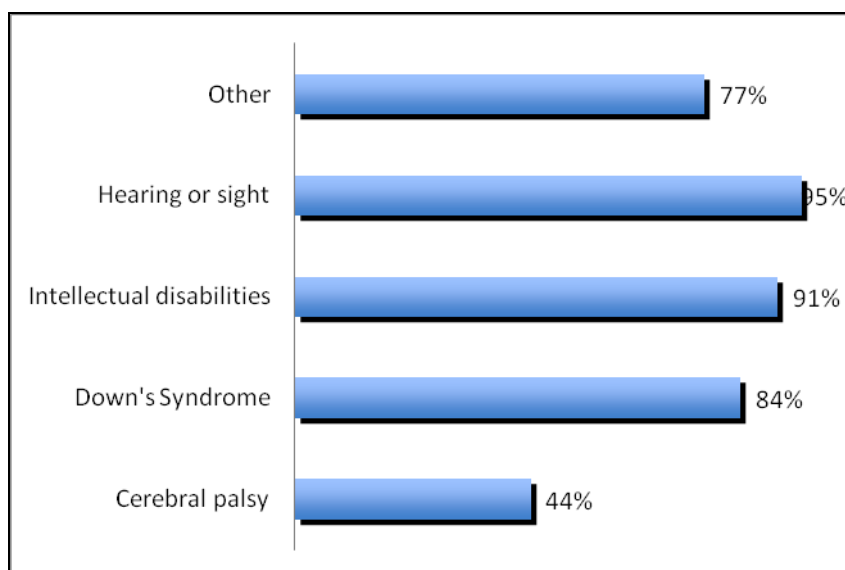
<sup>5</sup> Discussion with UNICEF Turkmenistan staff referring to official GoT data, December 2014

families for this survey or because the NGO has a specialism in supporting children with the types of diagnosis that mean they are more likely to be excluded from school-based education.

The finding from this survey tends to support the data from UNICEF CEE/CIS Regional Office presented at the beginning of this section of the report that 26% of children with disabilities are in home-based education and 74% are in residential forms of specialized education. It is important to note, however that 13% of children in families are reported to be attending mainstream education settings. And to recall that children in families are reported as attending residential schools and preschools on a daily basis and that many children reported as being children in residential education settings could actually be going home on a daily or weekly basis as discussed above in the section on frequency of contact with family (while continuing to bear in mind that data limitations mean this finding has to be qualified and cannot be considered as conclusive).

When this data is examined through the lens of medical diagnoses, it can be seen that a high proportion of children who were sampled and who have intellectual disabilities, sight and hearing disabilities or Down's Syndrome are in education, but a high proportion of these are in residential boarding schools. Only 44% of children with cerebral palsy among all children with cerebral palsy who were surveyed are in education as illustrated in Figure 7:

**Figure 7 Percentage of children with motor disabilities in education is lower than for other types of disabilities among 301 children surveyed**



Source: survey respondents and author's calculations

Of these 39 children with cerebral palsy who are in education, 15 or just over 1/3 are being educated at home which represents almost 2/3 of all the children in families who are reported as being educated at home. While it has to be treated with caution because of the data limitations discussed above (no children attending specialized schools for children with motor disabilities were included in the sample of children in residential settings), this finding is of major significance as it indicates that there is probably a need to review school-based education services for children with motor disabilities as a priority and ensure that they are being provided at a sufficient level to meet demand. Certainly the experience of parents discussed in focus groups, in the review of the early childhood development centers and during interviews for this survey all tends to indicate that there is a lack of specialized school places for children with cerebral palsy and a lack of specialists and teachers able to work with them. Some parents, though do note positive education experience for their child with cerebral palsy:

*We are going to a new school (residential), where there are 9 children in a class, lots of different sections for different categories of children. They have special equipment in the gym for children with cerebral palsy. Their teacher works with children individually for 20 minutes per day after classes. (Mother of boy with cerebral palsy and hearing impairments, focus group discussion)*

If the responses of the participants in focus groups and interviews for this survey are generalized, they tend to show that parents want their child with disabilities to have a high quality education in a friendly/respectful environment together with other children. Experiences reported by parents of the education system as a whole are mixed with around 1/3 of parents reporting that they consider their child to be receiving quality education: *'he is receiving a good education, is learning languages'*; some of these parents express ways in which they would want to improve the education their child is receiving *'preferably increase the length of lessons and the number of teachers for different subjects'* (referring to a child in home-based education). Other parents report having faced various problems related to discrimination on the part of teachers, other children and their parents. As a result of such attitudes, some parents withdrew their children from educational institutions, some hired private teachers, and others sought home schooling programs.

**Parents of children with disabilities about their experience of integration in educational institutions**

"Children at school paint his shirt, pour soup into his trousers. I don't say anything. The deputy head told me today that he disturbed other children, shouted. I said he must have been hurt, annoyed, he can't speak and that's why he shouts. She's mentioned three kids now: a girl is crying, another boy cannot sit down, keeps walking back and forth, and our child. They told us maybe we should think of transferring our children to another school. Another school has been recently opened on Kotovsky. I told her we would think about it. Our child understands Russian speech, but that school is in Turkmen. I warned the teacher in the very beginning that he wouldn't understand her, let him stay, I brought him for socialization. As for education, we do that at home";

"We used to attend a regular kindergarten, but they asked us to leave. They said 'your child is in diapers'. Now we are going to a residential kindergarten. What about afterwards? Not all the speech therapists are keen, even for money";

"Also teachers at school yell, shout, put psychological pressure. Our child fainted twice";

"I see my child lying on the floor in the classroom, and the English teacher doesn't even come up";

"We used to go to a private kindergarten, where educators were very loving. Until one mother said: 'I will close you down, if you don't get rid of this child'. I was taking him to a kindergarten where he communicated with healthy children for two months, and he advanced like in a whole year. He changed visibly";

"It's hard to get there, you have to give bribes. I gave 100 dollars for my child to be enrolled in the school";

"The teachers refused this year. The local education authority said we had to go to a special kindergarten (school). It affected her (our daughter) very much, she doesn't want to get up in the morning, she is very upset".

"Some say that our children don't let their children study. But if their children have such skills, they will know things anyway. But they just need a pretext, they say the child disturbs others, he threw his pen down. But he won't be throwing the pen down for two hours in a row. We studied at school, there were such children in the class too, but we learned things anyway. And now either parents have become mean or society is evil";

"I couldn't find a form of care, and the child stayed at home until the age of 7. The problem is that the child has two diagnoses: cerebral palsy and deafness, that's why we could get neither into the kindergarten for deaf children, nor in the one for children with motor disorders. Now we have

enrolled into a school for deaf and mute. We are happy the child is socializing. We are going to a new school (residential), where there are 9 children in a class, lots of different sections for different categories of children. They have special equipment in the gym for children with cerebral palsy. Their teacher works with children individually for 20 minutes per day after classes."

Source: focus group participants

Some parents report a lack of specialized staff in educational institutions that considerably limits children's rehabilitation and development opportunities:

*"My son attends speech therapy school X. But we don't see any response from the school. Just like all parents, we want them to work with our children, for money, but they are not doing that. They have also reduced speech therapy hours, 30 minutes per week".*

According to some parents educational institutions need to adapt better to the needs and possibilities of disabled children:

*"She went to the kindergarten for children with motor disabilities. She doesn't go to school, because she cannot sit up (although she reads, counts). There is no furniture in the new residential school for such children so far, when they get it, probably, they will start admitting such children".*

Many families appear to lack information or are misinformed about available educational opportunities for children with disabilities. This makes parents feel uncertain and not seek opportunities for their child's education, parents can lose hope and strength to go on advocating and fighting for their child in the system.

#### **Parents of children with disabilities about the experience of their child's educational integration**

"The child studies at home. But we have a problem now – a residential school has opened, but they say we shouldn't go to the boarding school. I don't know (whether to transfer). Some people say that the residential school is good, and others say it's better to study at home. At school they ask them to wear diapers, but he tells us when he wants to the toilet, I don't want diapers... I wanted to take the child to school on the 1st of September, bought a shirt for him, but the teacher said I shouldn't";

"She attends residential school No. X. I would like her to go to a mainstream school. But they wouldn't take her - they say there is a special school for such children. She just has one sick leg – a club-foot. She is a twin. One goes to school, and the other doesn't. She has such sad eyes, she tells me: "Mom, let's go with her"";

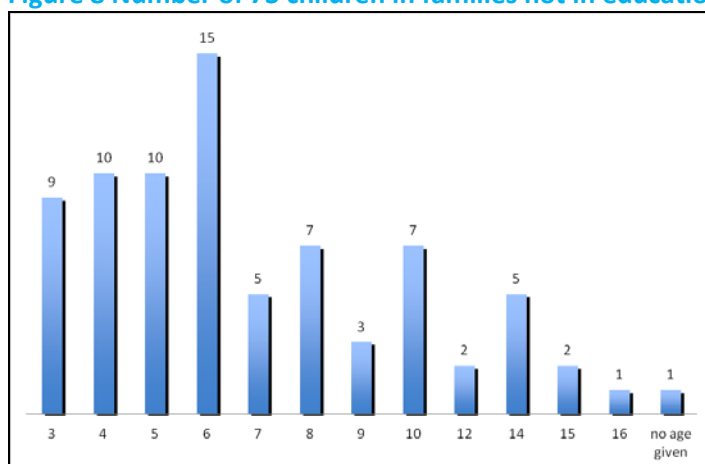
"the education has to correspond to his level of intellectual development since his intellect is intact, but a regular school wouldn't take him" (survey respondent, about a child in residential special school)

"It's every parent's dream for their child to go to school".

Source: focus group participants unless otherwise indicated

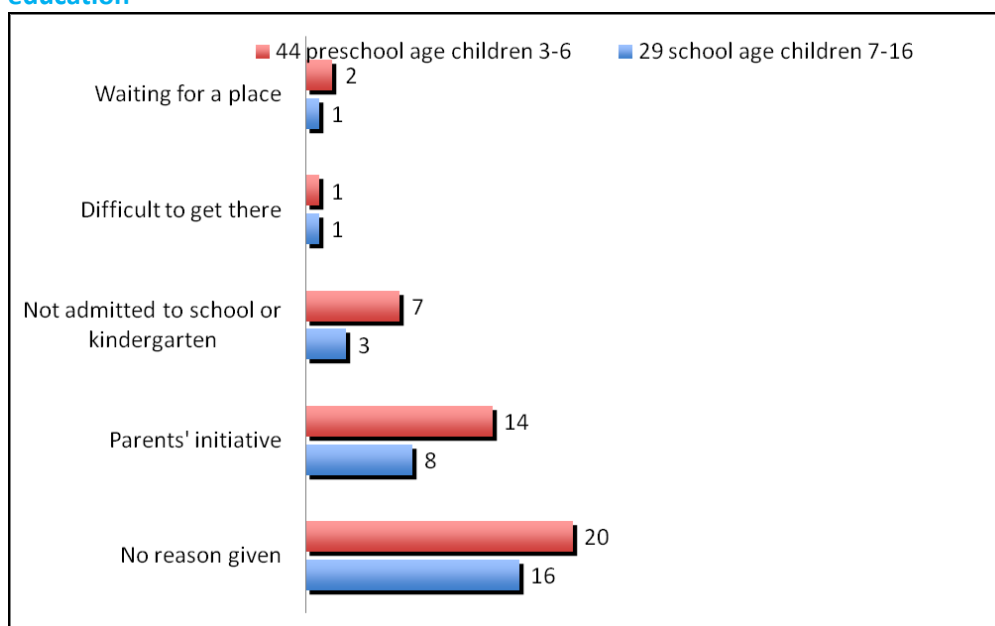
#### **Almost 50% of children with disabilities in families in the sample are not in education**

The age of the child is one reason for non-inclusion in education among the children sampled, as 44 (60%) of these children are aged 6 years or under and are not required to be in education as illustrated in Figure 8:

**Figure 8 Number of 73 children in families not in education by age in years**

Source: survey respondents and author's calculations

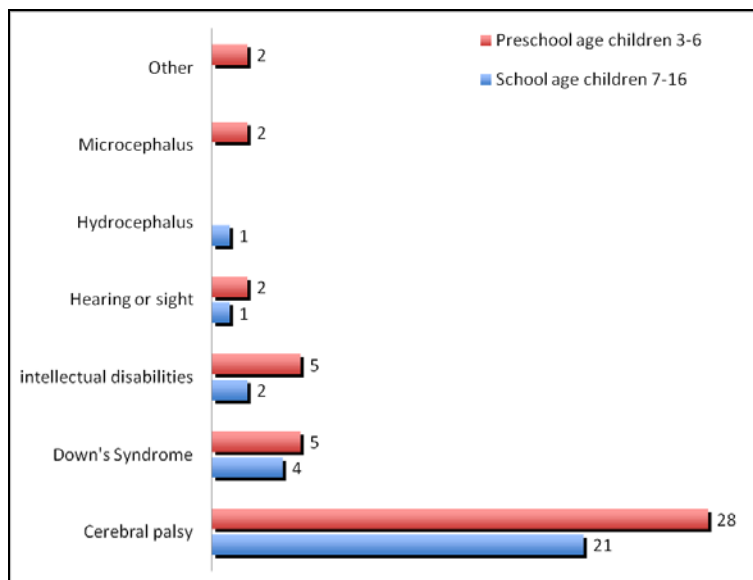
It is important to note, however, that access to pre-school education is as much a right of children with disabilities as access to primary and secondary or tertiary education. It is important not to be complacent about young children with disabilities not accessing education services. As illustrated in Figure 9 most parents did not give a reason why their child is not in education. Some parents don't want their child with disabilities to go to school or pre-school either because they are afraid and *"have renounced the idea"* or they perceive their child as being unable to participate *"the child is not capable"*. Some parents report applying to put their child into school or pre-school, but cannot get a place as the school or kindergarten says the child is too severely disabled and cannot manage self care tasks. This seems to be confirmed by the higher number of children assessed as 'severe' in families than in residential institutions discussed above. Another reason is distance from the school and problems with transport although in this sample this reason was not prominent with only 2 respondents mentioning it. Perhaps in a sample with more children from rural areas the balance of reasons might be different. Or, as discussed earlier in the report, there seems to be such an extensive network of institutions that distance from education establishments is not such a prominent reason for non attendance. The data is not conclusive, but these reasons are worth noting when planning for inclusive education reforms.

**Figure 9 Reasons for not attending school or pre-school given by parents of 73 children not in education**

Source: survey respondents and authors' calculations

Possibly the most significant factor affecting access to education from this survey, however, is that children with cerebral palsy represent 67% of children not in school or pre-school. And 72% of children of school age out of school. Figure 10 illustrates further how the education system appears to lack places for children with motor disabilities like cerebral palsy:

**Figure 10 Medical diagnoses and age of 73 children not accessing education**



Source: survey respondents and authors' calculations

There are some cases when parents are well-informed about the current national legislation and try to overcome the barriers to exercise the rights their children are entitled to:

*"Children with disabilities should be around ordinary children, because children imitate each other, they can repeat the other's defects. The child gains a lot from this, and other children learn the lesson of kindness. The society is diverse, and locking children up in special institutions is not right. Our legislation stipulates inclusive education. We went to ordinary school with home schooling, but had a conflict with the headmaster right from the start, simply rejection, and they expelled us. We had all the health certificates confirming that we could attend a mainstream school. The headmaster just wouldn't enroll, wouldn't teach. They sent us to the commission for cases of minors because my son didn't attend, although I told them we were on home schooling. We tried to attend. The headmaster collected complaints of teachers, parents, that he (the child) was disturbing. And the Commission made a decision to expel. Now we are at home. I communicate with law-enforcement agencies to make sure the law is enforced. There is a new law adopted in 2013 stipulating that all children are entitled to inclusive education, and that primary education is compulsory, whether the headmaster/mistress wants it or not."*

Based on the data from survey respondents, such cases seem to be very rare and they need the support of state agencies and civil society organizations and associations.

**Just over half of parents of children who are in school report that their children like going to school or preschool; getting to school can be problematic for some children, especially with motor disabilities**

Out of 77 children who attend educational institutions, 53% (41 children) like the school/kindergarten because they play there, they like the educator, communication, food, they feel at home there, like

choir classes, humanities, have TV, like doing sports, drawing, education, atmosphere, the teacher, have school friends, like the school environment (findings from questionnaires).

Among the children attending educational institutions, 5 children are reported as not liking it, because they prefer to stay with their mother, like being alone, there are no results, they get tired at the lessons or have to walk to the second floor. In three cases the answer was uncertain – 'I don't know'.

The majority of integrated children attend educational institutions on a daily basis, apart from one child who goes to school 2-3 times a week and another one who goes to school every other day (due to health problems).

Getting to school/kindergarten is a serious challenge for many children and parents, both in terms of distance and the need to have a personal transport means or hire one. According to the interview findings, some children get to the educational facility by public transport, and it takes them: 1 hour (5 children), 30-40 minutes (7 children). A part of children get to school in their parents' car or by taxi, and it takes them: 1.5 hours (1 child), 1 hour (2 children), 30 minutes (4 children), and 15-20 minutes (6 children). The rest go to school by foot, and it takes them: 30 minutes (2 children), 10-15 minutes (5 children), and even 5 minutes (4 children). These findings show that the distance from home to school is a serious barrier for some families with disabled children, especially with motor disabilities.

Quality of home schooling varies according to respondents and given that there is a single provision in legislation and education standards, this is a notable finding. The frequency of teachers' home visits to children and the duration of classes as reported by parents vary within the following limits: from 5 to 1 visit per week; classes last from 1 hour to 25 minutes. All parents in this group noted that their children enjoyed those visits and lessons.

As for the quality of education, out of 77 parents whose children are included into the educational process, 39% are satisfied with its quality. 17% of the interviewed parents expressed their dissatisfaction with the quality of the education provided to the child. They pointed out that *"there is a need for qualified specialists", "they don't teach anything at school, he doesn't know anything, they don't teach writing", "a special Russian-speaking school should be opened", "it's hard to study in Turkmen, there are many Russian-speaking children, but there is no class for them", "the teachers are good, but they don't know how to work with them", "there should be special education centers", "they should work more with the child"*.

At the same time, 61% of parents whose children attend educational institutions mentioned their child as having made certain achievements in education: *"learns to write, distinguish between colors", "does well at school, gets grades 4 and 5", "she started to talk better", "he became more communicative", "he is developing generally, has learned to pronounce several words", "knows the sign language", "does well in Mathematics, Russian", "he talks more, expresses himself", "he is trying hard, but it's always an effort", "in one month the child started writing, reading"*. 14% of parents consider that their children are not making progress in education, while 8% of parents do not provide information about their children's educational achievements.

In terms of inclusion of disabled children in residential institutions, the study findings showed that 40 children (27%) had come to boarding schools from other institutions and the remaining 110 children (73%) from families. In relation to the first group of children, one may assume that a child once integrated in the residential care system continues to pass through all its levels. As for the grounds for enrolment into the institution, only in 9 cases (6%) the indicated reason for the child's enrollment in the boarding school was poverty of the family. In one case, a mother could not cope with child care. In 105 cases (75%) the reason for the child's enrollment into the institution was their diagnosis. 35 answers



(23%) did not provide information for the child's enrollment into the institution. The higher proportion of single mothers among the sampled children in institutions discussed above tends to confirm that although the main purpose of placing children into residential schools is to access education, for a small minority there may be other factors of equal importance driving the decision to place a child into residential care – social reasons (lack of other family members helping), economic reasons (the need to work) or psychological reasons (difficulty in coping alone).

As for the achievements made by children in institutions in the process of study, the respondents mentioned that 85 children (57%) had made progress at school: *"he can read very well, knows history, and is good at mathematics", "reading and writing"*. 62 children (41%) from institutions, in the opinion of institution staff, do not show dynamics in their learning outcomes.

**Community based leisure and play activities are very difficult for children with disabilities to access – most such activities (intended for children with disabilities) are based in residential institutions so children in residential institutions have better access than children in families.**

As discussed already, children both in institutions and in families seem to have high levels of interaction with siblings and peers. Most children in institutions are reported by staff also as having high levels of access to additional leisure and play activities with 89 children reported as attending activities or clubs: 38 children (25%) take part in sports; 28 children (19%) attend arts and crafts; 24 children (16%) attend music; and 23 children (15%) attend drama and dance. 61 children from institutions (41%) are not reported as attending activities or clubs at the boarding schools or preschools.

In 2 cases, children from residential institutions attend clubs and activities outside the boarding school, according to the information provided by respondents: *"Goes to the Youth Arts Palace once a week. But it was a whole lot of a deal to be admitted. There is a condition that somebody has to accompany"*. In 25 cases (17%) children do not attend clubs and activities outside the boarding school, and there is no information in this regard for 123 children (82%).

23 (15%) children in families are reported as taking part in additional activities with swimming, sport, chess, music all being mentioned. In several cases the additional activities are *'at home, for money'* so not necessarily ensuring that children are integrated into activities with other children outside the home. One parent mentioned crafts classes run by the NGO Yenme. Parents of 116 other children (77%) say their child does not take part in any additional activities, with 37 of these parents giving reasons which can be grouped into four main types:

1. No information about such activities – *'there are no such activities' 'I don't know where to find such activities'*
2. Applied to take part but the child was rejected because of their disability – *'don't take him'*
3. The parent perceives the child as too severely disabled to take part and so has not tried to find such activities - *'not able' 'too heavy' 'can't move, can't see'*.
4. Logistical reasons - not enough time, difficult to go, or cost – *'all free time is used up by homework' 'we used to go to art class in the City, but I couldn't get off work in time' 'we live on the 4<sup>th</sup> floor, it is difficult to go out'*

It is clear from the parents' responses that the first two types of reasons are inter-linked as most parents seem to assume that their child with disabilities cannot take part in such activities for normally developing children and so they don't try, but they lack information about such activities for children with disabilities.

These findings could be seen to indicate that children with disabilities in boarding schools or preschools are able to access after school activities and clubs and that children in families are not accessing their right to play and leisure to the same extent. The findings can also be interpreted in a different way – resources such as play and leisure activities for children with disabilities are concentrated in residential or segregated school settings which means children in families are not able to access them as easily and access to community based play and leisure activities is extremely limited for all children with disabilities as they are not inclusive and tend to put barriers up against participation by children with disabilities.

**Attention to preparation for independent living and employment for young people with disabilities are not being sufficiently addressed on the whole either by parents or residential schools, especially for children with more severe disabilities**

Several questions about learning self-care skills and preparation for independent living were put to parents and carers with the intention of assessing the extent to which this issue is being given active consideration. For example a questions was put on the availability of employment services for older children at the local level and out of (31) parents with children aged 12 years or older, only 2 have mentioned such services. 29 parents mentioned they had used such services and care staff did not mention that any children from residential institutions in the respondent group had been using youth employment services.

A summary of the results is provided in Annex 4, but they require further analysis linked to severity of disability, age of child and inclusion in education in order to ensure that useful conclusions can be drawn for the purposes of supporting parents in this task and developing services in the future that can help young people with disabilities prepare for independent or supported independent living and entry into further education or employment. The main conclusions that can be drawn from the analysis conducted at this point is that overall neither residential schools nor families give sufficient attention to preparation for independent life and acquiring self-care skills that can help children with disabilities to be more integrated into society and lead fulfilled, independent lives.

**C4 Environmental factors – barriers to inclusion, health services and assistive technology and devices; social support and services**

Access to quality health and social services including access to the latest technology and understanding of disability is a right of people with disabilities under the UN Convention on the Rights of People with Disabilities. Health and social services cannot cure a disability, but they can help to remove some of the barriers to functioning and participation and increase the range of activities in which people with disabilities can take part. The following two points from Article 4 of the CRPD direct State parties:

- h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
- i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

**C4.1 Health services and assistive devices**

**A medical model of disability dominates in Turkmenistan and this affects all aspects of the provision health and social services with parents seeking treatments in private health clinics or abroad if they feel they are not accessing adequate treatment in Turkmenistan and not really having any information about social services.**

The needs of disabled children and their families are complex and require connection to healthcare, social, and educational services and institutions. Because the absolute majority of parents and caregivers who took part in the survey perceive disability as a health problem, they first of all focus on access and quality of healthcare services. In this regard, they mention generally that healthcare services covered by health insurance are of poor quality, and many medications that are supposed to be free of charge are not on sale. Many say they are forced to buy these medicines "*in private pharmacies*" at a "*very high price*" and for some this is compounded by the need for constant medication or periodic long-term treatment which they often pay for in private health care services. Some report positive changes in their child's condition and functioning after treatment, others see no difference, some are positive about their experiences in the health system whether private or State provided others not:

**Parents experiences of medical treatment of their child with disabilities**

Лечение не помогает. Не доверяю своему врачу невропатологу. (Parent of child with Down's syndrome)

Мне кажется, что после лечения ничего не меняется, на время прекращаются судороги (Parent of child with cerebral palsy)

Из-за финансовых трудностей не могу постоянно проходить лечение, улучшений не вижу. (Parent of child with cerebral palsy)

Сама делаю массаж дома (Parent of child with cerebral palsy)

Нет в аптеках лекарств, не знаю где брать. После лечения изменений не вижу (Parent of child with cerebral palsy)

Ходили на ипподром помог очень, массаж помогает голову поворачивать, массаж на дому, expensive (Parent of child with cerebral palsy)

Массаж, лечение проходит каждые 3 месяца it helps with walking, sitting and changing position (Parent of child with cerebral palsy)

Есть бесплатный массаж для инвалидов - бесплатная услуга некачественная. Хороший массаж платно. Остальное мед. обслуживание для детей до 12 лет бесплатно. (Parent of child with cerebral palsy)

Source: survey respondents

So medical is their understanding of disability that some parents see speech therapy as a medical 'treatment' rather than an educational intervention:

Благодаря лечению с логопедом мой ребенок говорит лучше. (Parent of child with Down's syndrome)

Several parents talk about treatment abroad that is not available in Turkmenistan. Some turn to alternative therapy - one parent mentioned acupuncture treatment in China. Several others mention treatment in Samara for their child with intellectual disabilities which is expensive (USD4000-5000 per course of treatment) and it is not clear what the treatment is for or is likely to achieve.

*Раньше лечились в Ашхабаде, но толку не было. Сейчас сами ездим в Самару на лечение, прошли два курса, есть небольшие изменения, она стала активнее, любопытнее.*  
(Parent of child with intellectual disabilities)

*Лечим самостоятельно, ездим 2 раза в год в Самару, есть результат, но небольшой.*  
(Parent of child with intellectual disabilities)

The purpose of some of the treatment described by parents seems doubtful:

*Лечит психиатр, медикаментозно, принимает массаж, но изменений никаких нет.*  
(Parent of child with intellectual disabilities)

Overall, the perceptions of some parents seem to be that with enough money for treatments, they may be able to 'cure' their child. Others seem to have a good understanding of how treatment can help to improve functioning. Either way, parents seem to be left very much to their own devices in terms of the treatments they choose for their children or to be very dependent on what is available in the state system, depending partly on their economic situation.

**Few assistive devices for children are available in Turkmenistan – parents report that more than 50% of children who need even such basic mobility devices as wheelchairs, do not have them; there appears to be very little knowledge about other types of devices to assist with communication, posture, mobility, especially for children with motor disabilities**

A big problem for children with disabilities is lack of specialized equipment available in Turkmenistan. The Ministry of Health and Medical Industries has plant that manufactures orthopedic devices, but it does not produce children's wheelchairs, for example, only adult-size wheelchairs. Some parents report currently available orthopedic devices as of poor quality, many cannot be used. Some parents have to think of and construct such devices themselves (wheelchairs, buggies, chairs, verticalizers, etc.). Other parents/care-givers try to buy them abroad, but they are expensive and not many can afford them.

For 150 children in families, 90 parents report their child needs assistive devices (wheelchairs, orthopedic shoes, hearing aids) and of these 38 parents have managed to provide or partially provide their child with what they need – 19 parents purchased the equipment themselves; 8 parents report that an NGO such as the Red Crescent or Yenme provided the equipment, 4 parents report making the equipment themselves 'Grandfather knocked it up', 4 didn't explain where it came from and 3 parents said the State orthopedic factory provided shoes. Among this group of parents, some say they have partially provided the equipment the child needs, usually this mean they still need a wheelchair. One parent reports that friends abroad purchased a high quality wheelchair, but the customs officials wouldn't let it into the country so it is currently in Uzbekistan. The remaining 52 parents say their child does not have the equipment he or she needs and the reasons mirror what the parents who have equipment have said as the main reason given in most cases is lack of financial means followed by not being able to find the necessary equipment itself. In two cases, parents say they don't want their child to use a mobility device like a wheelchair as this will make their disability visible and they feel shame or stigma.

#### **C4.2 Social services and social support provision and needs**

As a social services assessment which took place in parallel to this survey showed, there are overall very few formal social services in Turkmenistan. There are strong family traditions and many community based forms of support for vulnerable children and families, but no system of providing services to address specific issues such as disability. This section provided the responses of parents and carers about their understanding of the social services and other forms of social support that do exist and which they are able to access. Issues that affect access to services are also considered – mainly information and transport issues. Respondents were also asked to identify and prioritise their needs for support which is always a difficult exercise as they are being asked about what support they need when they have little knowledge about what support could be provided.

**Overall there is a lack of understanding about what is meant by social services and social support among parents and caregivers in institutions. Most families are receiving disability allowances which many don't see as social support and some families are accessing some other support and services in their communities from the Khyakimlik, public organizations and NGOs**

68% of parents with disabled children in families mention that they have been benefiting from some sort of social services. 33% of them are beneficiaries of social and other services and help provided by NGOs (most often, Yenme, sometimes Red Crescent, trade unions) – this quite clearly could be a sample bias and should not be taken as too conclusive in terms of the numbers, but the fact that NGOs are mentioned by parents at all is important. Among these services, the following types of services were mentioned: hippotherapy (therapeutic horseback riding), activities for children and parents, help with getting a voucher to a health resort, arrangement of a trip abroad for treatment, help in getting housing, invitations to festivities, provision of diapers, cash aid, food packages, provision of a wheelchair, attendance of a computer club, etc. Some of these types of services had also been mentioned as health services, for example hippotherapy and treatments abroad.

34% of respondent families mentioned they were receiving state aid in the form of disability allowance.

28 % of families mentioned they had not benefited from any social services and had not received any external aid.

In response to a direct question about the receipt of social benefits, 83% families mentioned they were receiving child disability benefit amounting to around 75 USD. This amount is enough to get a monthly supply of diapers and some other minor items. 14% of families do not receive this benefit because disability has not been conferred as discussed earlier in this report. It is interesting to note that not all respondents mentioned this form of support when they were asked about the state aid which they receive in a previous question.

Residential institution staff were asked whether they were informed about whether the child or his/her family benefited from some social assistance. The answers mentioned 2 families that were receiving food packages from the Khyakimlik, 10 families receiving benefits, and there was no information on the remaining families. To the question what organizations families were receiving assistance from, they mentioned only the child disability benefit, because the state was supposed to provide it (45 answers - 30%).

The study raised the question whether the child/family had access to services located in the city/etrap/village of the family's place of residence, i.e. at the level of local community. 24% of parents answered "yes", 69% answered "no", and 7% answered "I don't know". When asked to list services provided at the community level, parents mentioned services provided by NGOs/CBOs as mentioned above. Among the services provided by the state, only disability benefit was mentioned.

Considering the possibilities and the process of social integration of children with disabilities and their families, there was a question about existing possibilities for children to attend youth activities in the community. Around 25% of respondents said they were taking part in town/village activities, including those that take place once a year, e.g. the New Year parties, they also mentioned rehabilitation activities at Yenme, activities held in parks, circus, theater, swimming pool, holidays - New Year and 1 June.

Most other parents answered they did not participate or did not know. To the request to explain why their children were not taking part in town/village events, they said that *"there are no such events"*, *"they point their finger"*, *"there's no transport"*, and *"nobody invited us"*.

**Apart from pilot early childhood development centers in two locations and residential kindergarten services, there is almost no day care provision for children with disabilities**

Parents of 44 children aged 0-5 years and living in families took part in the survey. Of these, 12 mentioned early intervention services almost exclusively in relation to health services – Health House,

polyclinic, neurologist, children's hospital, but also include speech therapist in this list. Parents who attend two new pilot early childhood development centers and who took part in focus group discussions as part of a UNICEF monitoring exercise particularly mentioned that they appreciate the 'respite' that taking their child to the center gives them to manage their own affairs and not just to 'get rid of the child' but so that they are actively developing while there.

Parents of 15 young children mention day care services mainly in terms of kindergarten. One or two mentioned a rehabilitation center or an NGO and one called the child's grandmother 'a day care service'. This tends to confirm the findings set out earlier in this report concerning the extent to which informal services provided by extended family are the main foundation of child care support in Turkmenistan for families with children with disabilities.

The study tried to correlate the frequency of using day care with its physical accessibility - distance to the service. Some respondents assessed the distance to the place of service rendering as follows: *"20 minutes to the horse-course, 1 hour to the special kindergarten"; "it's not far away, it takes about 20 minutes to get there by foot"; "not far away, I'm taking my car"; "far away, 20 minutes by car"; "far away, 30 minutes by car or bus"*. Excluding subjectivity of perception, it is fair to say that the distance and availability or accessibility of transport is a problem for parents with disabled children in using existing day care forms.

**Provision of information about social services needs to be more extensive and parents think that national television and health services including family doctors and visiting nurses are the best places to disseminate information.**

The study was interested in finding out whether families with disabled children were informed about the existing social services. Out of 151 interviewed parents, only 15% (23 respondents) knew something about social services for children with disabilities. 66% (100 respondents) of parents declared they did not know about this kind of services. The explanations of unawareness were very limited: *"they don't inform", "I'm not going places they inform about this stuff"*. Other sample representatives could not answer this question.

In the case of institutionalized children, the majority of staff considers that families do not know about social services for children, since *"they rarely go out, outside their narrow circle of communication"*.

In the process of study, the most efficient ways of informing about social services for both categories of respondents were identified and both institution staff and parents named national television and health care institutions as the best way to disseminate information. A detailed breakdown of responses regarding information channels can be found in Annex 4.

Overall, the feedback from survey respondents gives evidence that healthcare institutions/staff, as well as media are the most important sources of information for the general public related to disability issues. State institutions (social welfare office, khyakimlik) are also trusted by the population. Given that social services in totality have to be developed at the local level, physicians, staff of social welfare offices and khyakimlik, as well as local media could be used as primary sources of information about social services for families with disabled children.

This information is interesting in the context of development of social services and corresponding awareness raising activities among the population. In order to focus targeted information and cover the greatest number of beneficiaries possible, it is necessary to use the ways of information transmission that are most favored and most suitable for this category of population, as well as most trusted by families.



## Needs of children with disabilities and their families

In order to assess the perceptions of parents and carers about the support needs of the child with disabilities and of the support needs of the child's family, respondents were asked to select any number of answers from a list of statements about needs which was developed based on pilot interviews, previous studies including the U3 study (UNICEF, 2014 Rogers et al) and the desk review carried out for this survey. The full results are presented in tables in Annex 4 along with the responses of survey participants to an open question about what and a summary of the most commonly named needs is given here in Table 5 along with an assessment, based on the information gathered for the survey, of how these needs are currently being met.

**Table 5 – Analysis of needs of children with disabilities and how they are being met now**

Needs	How they are being met now
Care provision – support with providing day to day care in the home	Extended family where available; NGO
Support with providing day to day care outside the home	ECD centers; residential schools and kindergartens; rehabilitation centers
Improved and strengthened parenting and care skills including: alternative communication where needed, lifting and carrying, child development – what to expect, understanding of disability	Not being met
Information about services – play, leisure and after school activities; health, education, community services; social services; assistive technology and devices	Not being met
Appropriate diagnostics and medical treatments	Family doctor and visiting nurse – needs strengthening with specialised knowledge and skills (developmental paediatrics)  House of Health neurologist and paediatrician – needs modernising and specialisation  Treatment abroad by specialists not available in Turkmenistan – physiotherapy, ergotherapy, cognitive behavioural psychology, speech therapy and alternative communication, child neurology and psychiatry
Inclusive community and education services, play and leisure	Not being met

Preparing for independent living	Not being met
Information about disability legislation and support in claiming benefits and accessing services	Not being met

Source: P4EC CEE/CIS Consultancy group/OPM based on responses of survey respondents and focus group participants

### C4.3 Barriers to inclusion

#### CASE STUDY - experience of one mother of a nine year old girl with Down's syndrome

I don't believe we can get through to our government. Everybody has to pay for disability. For the medico-educational commission - 100 USD. They ask money for disability. "Your children are retarded". Speech therapist: "We don't work with the retarded". As for this NGO, I am grateful that people have such hearts. MoH says that medicines are free of charge, and the medical assistant - I don't know, hiding. Where does it all go? I went to the Khyakimlik - please help us to arrange a children's playground - nothing for 2 years. They pay no attention. We haven't been asking for much, are always trying to cope on our own, but there has to be a children's playground. "Get away from the child!" as if she were a leper. The Golden Age, but they cannot get the message through that this is just a chromosome, it's not contagious. They point their finger at this child. Children are mocking, as if my child were an alien - not like them. We haven't been going out for the past year, although we used to. I cannot bear it morally. As if God himself had sent me to find this NGO. I was tired of trying to get through, to find out something. 5% of the state's attention is directed towards these children.

Source: survey respondent

#### Attitudes to children with disabilities vary but overall parents report children with disabilities being stigmatized not only by the general public, but by some professionals in the health, education and social support systems.

Public attitude towards children with disabilities and to the eventuality of their placement into residential institutions is conditioned by Turkmenistan's socio-cultural aspects. The key peculiarities in this sense refer to family values, strong relations within the extended family, strong social reliability of the population on the opinions and appreciation of people around. Strong relations within the extended family on the one hand can stimulate mutual support and help being provided by family members. On the other hand, this social phenomenon contributes to development of interdependence and a tendency to keep the problems of a child with disabilities within the extended family, as well as unwillingness, sometimes even fear of asking for state support, that is, of taking the problem beyond the family. Some parents prefer to keep their children at home, with them and around them and are unwilling to send their child to a residential facility because of social embarrassment or for religious reasons, although they are aware that they have neither possibilities, nor conditions for their child's development at home and communication with other children.

Overall, the interviewed parents signal negative attitude of the society towards children with disabilities *"they like to gossip", "people look strangely, stare"*:

#### Parents of children with disabilities about public attitude

"When my son was born, they told me right away that such children were not appreciated here. In France, there are special communities, they can work. I thought back then: Good Lord, do I have to



go to France for my son to be accepted, to be able to work, study? Our people (about 80%) are very cruel. A parent of another child would say: "Stay away from him", as if he were contagious";

"Our neighbors don't like it. They look surprised that the child has a defect, as if we had been asking God for it";

"Some children mock at the child, I have told their parents, but they don't seem to care. There are shallow people who behave like that. The headmistress had a very negative attitude towards me".

Source: focus group participants

Some parents of children with disabilities report how professionals including speech therapists, educational establishments or medical personnel can exclude them from services because of their child's disability or the severity of the disability: *"They tried to persuade me to abandon the child "she is a monster, why do you need a monster. They need such children in America" "(Down syndrome at birth, disability at the age of 8)*

Parents describe how often children with disabilities face aggression, teasing or cruelty on the part of other children: *"There are cruel children, who mock at them", "children tease them", "point their finger at them".*

Unawareness and lack of knowledge about children with disabilities causes groundless phobias, stigma and ostracism in the society, which leads to marginalization and further social exclusion of such families. *"We also have such problems. They are afraid. We were taking gymnastics classes along with healthy children, and then parents (of other children) refused, started attending separately" (focus group participant).*

At the same time, sometimes there are also cases when extended family members can feel ashamed, guilty for the birth of a child with disability and try to hide the problem in the family: *"My mother-in-law would never sit at the same table with the child"; "All our relatives are, of course, good people, but they feel embarrassed to invite me with the child, and I won't go alone. Or, one family said he was disturbing. So you try to stay home and not to disturb people" (focus group participants).*

Parents often face stigmatization of their children, an attitude that pushes them to adopt a certain lifestyle and social circumstances forcing them to embrace certain predetermined forms of behavior. *"I just grabbed my child. The woman made the sign of the cross. I told her: "Did you see devil in my child, or what?" This is wrong. My child reacts to this (the gazes). He asks me: why do they look at me as if they saw something?"; "People look strangely, examine" (focus group participants).*

Parents in such situations are forced to resort to self-protection mechanisms that often contribute neither to improvement of the condition of a disabled child, nor to better family relations and awareness of the full value of life: *"You needn't pay attention to the way they look at the child. Forget that your child is different, for you he/she is normal" (focus group participant); "Relatives didn't want anybody to call him disabled; they thought it would pass by itself" (parent of boy with cerebral palsy).* While the extended family can be a source of support, it can be seen that in some cases members of the extended family can also be a source of additional stress, pushing parents into even greater isolation even within the family.

*"Everyone feels sorry. They love. They see, they know. There's no negative attitude. They ask: "How do you manage with them?" Our society isn't used to these children. In fact, my daughter is healthy, she just cannot walk. The majority treat her squeamishly, because she isn't quite ordinary. Our neighbor passed away recently, and it was only then that we learned he was there actually. It appeared he had lived there all his life, we never saw him. How is the society going to accept such children, if they are just*

*invisible?"* (focus group participants). Social marginalization and even isolation are one of the mechanisms justifying inaction, lack of attention to problems of families with disabled children, and actual acknowledgment of the problem: there are no/we don't see children with disabilities - we don't have problems. This leads to a situation when people around, adults and children, do not know about the problems of families with disabled children, have no experience in communicating with them, not to mention having no idea and not being able to interact with them. Such attitude to children with disabilities is transmitted from parents to their children and so on: *"Everything comes from adults. The child copies"; "Everything depends on education. In fact, children do not even notice that someone is different"*. So, there is a vicious circle where nobody sees anything or does anything, which can be broken only when the attitudes and perceptions of children with disabilities and their families are changed.

At the same time, parents also talk about benevolence and expressions of understanding and sympathy by people: *"He can start singing in public transport, some may pay attention, but usually they don't"; "Everyone loves my child. Children come up and say: "Can I buy you an ice-cream?"; "There is no negative attitude. Only when we go for a walk in the park, people stare, and I say: "Don't look". They feel pity, but I don't want them to"; "The neighbors are very kind, supportive"; "Attitudes are individual, you cannot generalize. Probably, the attitude is positive, since they have a mother and a father who take them (to the theatre)"* (focus group participants).

Some families identify strategies to change other children's attitudes themselves as described by these focus group participants:

*Where we live, everyone adores him, kisses him. Neighbors give presents. There are children who love him, who laugh at him. In another place everyone treats him nicely as well, but children haven't accepted. The ones he grew up with got used to him. But we've moved, and it's different there. There's a boy in our block, his name is R-. Before, all the boys would tease A-, but R- talked to them. Now they all show respect for the child. Once I heard him telling them: "What are you doing? You cannot say such things". And they started coming to me, asking whether they can go for a walk with A-, they take him and play with him outside.*

*When I stay at home with him, I can't say he is different in any way, but when I go out, I can see the deviations. People would come up (give advice), and it was a psychological trauma for me, because they hadn't seen what my child used to be like before, and how he had been progressing. I even locked myself up in the house for some time, refused to go out, and didn't want to show him to anyone. But then gradually we started going out, and kids started coming to visit us. Now he is good at reacting to contacts, and kids are kind with him. He wears a hearing aid, and children come up at the bus station and ask what that is, I tell them it helps him hear well.*

In real life, families with disabled children say that they face mixed attitudes of people around: understanding, pity or rejection, denial: *"Kids treat her nicely, friends come, and children come up in the street. People pay attention, but nothing horrible has ever happened. We try not to mention to her that she's different from the others. Sometimes people say: "We understand you", I feel like telling them: "You don't understand us at all". There are people that say we are simply making use of disability"*. Such varying emotional reactions lead to highly unpredictable social situations for families with disabled children, resulting in people feeling strained, permanently uncertain about possible attitudes and in a state of advanced readiness to protect themselves.

In analyzing the responses of parents to questions about health and education services, it can be seen that these attitudes among the general public appear to be mirrored among the professionals in the health and education services – some are kind and knowledgeable and other refuse to work with a child *‘even for money’* because of their disability. While it may take many years and a major investment in communications campaigns to achieve significant changes to public attitudes to disability, it should be possible to achieve much faster results among state employees of the health, education and social systems which could have a major impact on the quality of life of children with disabilities and their families.

## D Conclusions and recommendations

The survey has provided a comprehensive picture of the situation for over 300 girls and boys with disabilities in Turkmenistan. Given that the sample cannot be considered to be representative, the findings have to be treated with some caution. The findings summarized and discussed in this section are drawn from the report above and were discussed at the outset of a two day action planning workshop with key stakeholders from the Government of Turkmenistan including representatives of: national structures such as the Parliament, Ministry of Health and Medical Industry, Ministry of Education, Ministry of Labor and Social Protection, Ministry of Culture, Ministry of the Interior, State Statistics Committee; regional structures such as a Guardianship and Trusteeship Organ of Ashgabat City; and NGOs such as Yenme and the Red Crescent as well as UNICEF representatives. The conclusions and recommendations are therefore rooted in the outcomes from that discussion and are presented in the form of an Action Plan for Children with Disabilities which was the result of the meeting.

### D1 Conclusions

The main findings of the report are highlighted throughout in blue and the conclusions discussed here are based on these main findings, but take into consideration some of the nuance that needs to be taken into account because of the limited sample size and possible sample bias. These conclusions are structured to cascade from general issues that affect all aspects of the situation for children with disabilities in Turkmenistan through to specific issues that need to be prioritized as plans are taken forward to work towards improving the situation.

1. Given global prevalence rates it seems likely that there are many more children with disabilities in Turkmenistan than those who are receiving disability benefits. If full administrative data were available for 16-17 year olds receiving disability allowances, the number of children of different ages attending education institutions of all types and the medical diagnosis data from the medico-social expert committee or from the health system, then it would be possible to more accurately state the number of children and to look at regional differences within the country. A fuller understanding of the numbers of children with different levels of functioning across different domains in each region is essential for the purposes of planning education reforms, the development of supportive social services and the provision of effective health services.
2. A medical model of disability dominates public and private discourse about disability in Turkmenistan with the child's condition being seen mainly as an illness that needs treatment so that the child can be more 'normal' and with some parents even seeking a 'cure'. Having said this, there appear to be significant constraints on knowledge and understanding of disability among medical professionals for example parents report that Down's syndrome is not considered to be a disability and autism spectrum

disorders is not known or diagnosed. Stigmatising attitudes towards disability among some medical professionals appear to reflect general public attitudes. Some parents of children with disabilities report they undergo a range of medical procedures that may or may not be helping their child. The mixed picture of treatments and their benefits or effectiveness reported by parents for this survey suggest that there is a need to strengthen the skills and knowledge of the medical profession in relation to disability as a whole and based on latest evidence globally especially in relation to children with motor disabilities like cerebral palsy, autism spectrum disorders and intellectual disabilities.

3. The extended family together with the State disability allowance is the main foundation of social support for children with disabilities in Turkmenistan.

This survey indicates that there are many children and families who are not receiving the disability allowance for various reasons including late diagnosis; barriers in the application process such as lack of information, non-recognition of documents from private health services, or lengthy administrative procedures in some places; non-conferral of disability status even with a relevant diagnosis such as Down's syndrome; attitudes to disability among families and professionals which create prevent families from applying for disability status or allowances.

The survey confirms the important role played by extended family especially in helping primary caregivers to provide every day care for children with disabilities, but also highlights that this support cannot always be relied on either because of attitudes to disability within the extended family or because of the absence of key extended family members such as grandparents. 12% of parents surveyed said they had no help with providing care for their child. The survey also indicates that siblings play a role in the provision of care that needs to be noted as this could have implications for their own wellbeing and outcomes in education and other spheres. It should also be noted that single mothers in particular may need additional support from the community or from formal services as they may be at greater risk of having no extended family support. In the survey sample, for example, there are more single mothers reported for children in residential institutions than in families and in general, children who are in institutions come from smaller households than children in families and there are slightly more unemployed or working mothers among children in residential institutions.

4. The children in the sample mainly have cerebral palsy, Down's syndrome, intellectual disabilities, hearing or sight impairments, but it is not clear how representative the sample is of the patterns of child disability in the country as a whole. With this caveat in mind there are important, but qualified conclusions to be drawn from the findings about children assessed with more severe levels of disabilities, especially combined with a cerebral palsy diagnosis, being more likely to be living in a family and less likely to be in pre-school, primary or secondary education. Without knowing the full extent of the provision of pre-school, primary and secondary education for children with cerebral palsy available in the country and the number of children with this diagnosis requiring education, it is possible to say that the knowledge and skills of staff working with children with disabilities in specialized education settings need to be strengthened so that they are able to work with children with motor disabilities like cerebral palsy. The equipment available to schools and families to help children to communicate and be mobile so that they can take part in education activities needs to be improved and to take advantage of the latest advances in technology and assistive devices.

5. There appears to be a general lack of access to basic mobility devices such as wheelchairs for children and a complete absence of knowledge about, let alone access to, more advanced computer based communication devices or better technology for mobility devices. Only orthopedic footwear seems to be available and its quality is not always satisfactory in the view of some parents. If Turkmenistan is to

move towards meeting its obligations under the UNCPD, then an urgent priority is to provide wheelchairs for children in a sustainable way, for example through modernizing existing production facilities under the Ministry of Health and Medical Industry and taking advantage of advances in technology and assistive devices to ensure that children in Turkmenistan can be enabled to reduce the barriers to functioning which they may have.

6. The special education system appears to be highly dependent on residential boarding schools and preschools, but findings from this study tend to suggest that most of the children who attend these boarding schools are attending on a daily or weekly basis and that the network of schools is extensive so that distances to schools tend not to be too considerable making this level of contact feasible for many families. This finding has to be treated with caution as a full sample of different types of residential schools especially in rural areas were not included in the survey, but as assessments are taken forward as a first step in implementing the road map for inclusive education, consideration should be given to the question of family contact and distance from the education facilities. It could be that residential facilities could be turned fairly easily with minimal resources into mainly day-schools with resources being re-directed towards transport to bring children to and from school. This could be a quick, early win in moving towards more integrated and inclusive education in the medium to long term and in meeting the desire of parents to be able to keep their children in the family while ensuring they receive a high quality education adapted to the child's needs and abilities. Parents who took part in the survey report both positive and negative experiences about their child's education as well as uneven application of education standards. On the whole home-based services seem to function at a minimum standard level with children linked to schools and teachers from the schools carrying out visits – the quality of the teaching, length of visits and curricula appear to vary widely. Just over half of parents of children who are in education report that their children like going to school or preschool; getting to school, preschool or day care can be problematic for some children, especially with motor disabilities.

7. Apparently high levels of interaction with siblings and close contact with primary caregivers for children with disabilities in families tends to suggest that many children are integrated into the life of their family, but parents in over a third of instances say they need help to communicate with their child with disabilities. This suggests that parent training and better assistive devices are needed to help improve participation in family life of the child with disabilities and to ensure that better care is being provided within the family. Bearing in mind that a large number of children in families in the sample have cerebral palsy this links to the findings in 4 and 5 above about the need to strengthen the responses of medical and education professions to this type of disability, but also the to ensure that parents are partners in this process so they can continue at home the work of specialists provided in health or education settings.

8. Attitudes to children with disabilities vary but parents overall report children with disabilities being stigmatized not only by the general public, but by some professionals in the health and education systems. This is compounded by the invisibility of children with disabilities in mainstream settings and manifests itself in:

- a largely segregated education sector with around 1/3 of the children with disabilities in the sample who are in education being educated at home and just over half in specialized education settings, both residential and day schools and preschools; almost half of the children in the sample who are living in families are not in any kind of education

- a largely segregated leisure and play system where children with disabilities living in families are almost unable to access extra-curricular activities for normally developing children or for children with disabilities as they are mainly located within specialized school settings
- 40-50% of children with disabilities reported as having friends and in many cases these are other children with disabilities in segregated educational settings
- a general lack of access to youth services including preparation for employment, higher education and supported independent living for children with disabilities

9. Apart from pilot early childhood development centers in two locations which have a limited catchment area and some specialised kindergartens, mainly residential, there is almost no day care provision for young children with disabilities especially for children with motor disabilities.

10. Attention to preparation for independent living and employment for young people with disabilities are not being sufficiently addressed on the whole either by parents or residential schools, especially for children with more severe disabilities. Parents appear to accept they will have full caring responsibilities for their child with disabilities into adulthood and the extended family and siblings are expected to share this duty. Data was not available, however, on the entry of young people with disabilities into institutions for adults, into the workforce or into further education. Full data is required in order to understand the current outcomes for children with disabilities from the provision of education and the ongoing burden on the adult social care system.

11. Provision of information about social services needs to be more extensive and parents think that national television and health services including family doctors and visiting nurses are the best places to disseminate information. Overall there is a lack of understanding about what is meant by social services and social support among parents and caregivers in institutions. Most families are receiving disability allowances which many don't see as social support and some families are accessing some other support and services in their communities from the Khyakimlik, public organizations and NGOs

In conclusion, children with disabilities in Turkmenistan appear to be largely in the care of their parents and extended families where they can be said to take part in family life and to lead, to some extent, a 'normal' life, playing with neighbouring children in the courtyard, their siblings and relatives. On the other hand there appears to be a tension created by a largely stigmatizing attitude to disabilities which means that some parents and families may isolate their child in the family either through fear or through a lack of information about the educational and other opportunities that are available in the community and more widely in society for their children.

An extensive, specialized and largely segregated education system appears to be providing education to most children, although it is possible that many children with cerebral palsy are not in education and there is an urgent need to strengthen the knowledge and skills of education and health professionals as well as to properly equip them to work with children with motor disabilities. A significant part of the education system, both pre-school and school, is provided in residential settings, but there is some evidence to suggest that these are not institutional settings, but many students are able to attend on a daily or weekly basis in some types of schools.

The Turkmenistan system of social support is founded on two pillars – State disability allowances and the support of strong extended families. In some cases, especially families where single and working mothers have primary carer responsibilities for children with disabilities, it could be that extended family are not available as a resource and these children are more likely than others to be placed into some kind of residential setting. If their disability is too severe or if they have motor impairments and are not able to carry out self-care tasks, they are more likely to be rejected from any educational setting.

Medical services are of mixed quality with a general need to modernize in terms of understanding disability and responses to disability from the medical perspective. There is a chronic lack of knowledge and provision of assistive devices for mobility, posture and communication in the medical and education systems. Travelling abroad for medical treatment of sometimes questionable value appears to be common for families who are more economically well-off. The system of conferring disability, which is the main way for families to access the social support, health and education systems, appears to need revision as the length of time and procedures appear to vary from commission to commission. The conditions which are considered to confer disability need revision to include Down's syndrome and autistic spectrum disorders.

## E Action plan and vision for children with disabilities in Turkmenistan

### E1 Discussion of findings and problem analysis

The summary of the current situation and problem analysis presented below in Table 6 was the result of consultations on the findings of the disability survey and the social services assessment undertaken in parallel by UNICEF with a range of Government stakeholders.

**Table 6 Summary of the current situation and analysis of strengths, weaknesses and opportunities**

Strengths	Weaknesses/Opportunities
<p><b>Strong family traditions and culture</b></p> <p>Extended families available to many children and parents on a day to day basis (Grandparent/s in half the families interviewed for the survey)</p>	<p>First line of informal support for children with disabilities and their parents – day care, help with day-to-day care tasks and child rearing</p> <p>Additional/alternative support needed for single parents or those without extended family support readily available</p>
<p><b>Special schools and institutions for children with disabilities</b></p>	<p>The majority of children with disabilities are in some form of education.</p> <p>Most of the provision of specialized education is organized in boarding school settings and all provision is segregated in special helping schools, internats or preschools. There is evidence from the disability survey that significant proportion of this type of education is actually provided on a daily or weekly boarding basis. It seems likely that family contact is maintained in many if not most cases, that most children are in this form of education primarily for education purposes and that this type of facility cannot be classified as providing 'institutional care'.</p> <p>There is evidence from the disability survey that a significant</p>

	<p>proportion of children with motor disabilities may not be accessing any primary or secondary education.</p> <p>Very few children with disabilities attend mainstream schools and those who do have high levels of functioning.</p> <p>It is not clear the extent to which specialized schools are teaching children based on a contemporary understanding of special needs education, alternative communication approaches or individualized approaches to learning.</p> <p>There is no data on children with disabilities attending higher education institutions or technical colleges. Anecdotal evidence is that barriers to entering higher education are high.</p> <p>Parents are not always informed about the choices available to them or about the rights of their children to quality specialized education.</p>
<p><b>Family doctors and visiting nurses</b> offer mainly medical services, but also provide advice, information and counseling to parents on behavior, child development and other child focused issues.</p> <p>Developmental pediatrics are being developed for early screening.</p>	<p>Services are highly rated by nearly all parents and represent a strong potential entry point for offering social services and community based rehabilitation services to children with disabilities and their families in the community.</p>
<p><b>Public and non-governmental organisations are providing some types of social services</b> and support to some children and families in some parts of most Velayats and Ashgabat.</p>	<p>There are very few NGOs and their coverage across the country is uneven. The main focus of NGO services for children with disabilities is on material support, advice and information, events and parties. Some NGOs provide crisis intervention services, legal consultations and support with claiming benefits, addressing housing issues or accessing assistive devices, sanatorium treatment or medical treatment abroad. Only one NGO provides day care services and even so only rarely.</p>
<p><b>Informal social services</b> and support is well-rooted at community level with neighbours, friends, local community members providing</p>	<p>Parents also report negative and even hostile attitudes towards children with disabilities from community members and sometimes even from friends and extended family members.</p> <p>Not all children with disabilities and their families can always rely on receiving informal social services and support of the right</p>



support and help to families in many cases.	kind when it is needed.
<p><b>Formal social services</b> for children without parental care are provided by statutory officials such as the specialists of the Commissions of Guardianship and Trusteeship.</p> <p>State social services are also provided at Centers for Social Protection in each velayat and ECD Centers in two Velayats</p> <p>Parents' centers in etrap kindergartens provide parent training and consultations for children not in preschool.</p>	<p>Centers for Social Protection provide center and home-based services only to the elderly and to adults with disabilities. They could represent a resource for developing home care or day care services for children and young people with disabilities.</p> <p>ECD Centers are being piloted in two Velayats and early monitoring has shown that they provide a valuable <i>social</i> service to local community residents – children with disabilities and their parents as well as providing pedagogical and early development services specifically to children. These Centers also act as resource centers for training staff from Parents' Centers in early childhood development programs.</p> <p>Formal state social services for children with disabilities and their families are currently available only to relatively few children and families.</p> <p>Parents are not always informed about available services – for example Parent's centers.</p>
<p><b>Prosthetics factory</b> producing wheelchairs for adults and other equipment operates under the Ministry of Health.</p> <p>Children who need orthopedic footwear are entitled to receive them free of charge every year.</p>	<p>The factory only produces wheelchairs and equipment for adults. There is no specialized equipment apart from orthopedic footwear produced in Turkmenistan or provided to children.</p> <p>Parents have to resolve these issues themselves and those who can afford it go abroad, to China, Turkey, Russia or even to Europe to access specialists, equipment and up to date therapies and rehabilitation.</p> <p>There is a general lack of equipment, communicative assistive technology and devices available for children with motor disabilities, cerebral palsy and autism which are based on latest developments globally.</p> <p>Parents lack information about assistive technology and latest developments in disability services, treatments, rehabilitation and abilitation approaches.</p>
<p><b>Social assistance</b> is available to children with disabilities and families: cash benefits include birth allowance, child benefits up to 2 years of</p>	<p>Provision of social assistance to children with disabilities is triggered through a disability assessment carried out by a medical expertise commission 'MSEC' which is possibly based on the Soviet classification of disability system (possibly modified according to ICD-5 – International Classification of Diseases and Related Health Problems – 5<sup>th</sup> edition). Some parents of</p>

<p>age inclusive, child disability benefit at a flat rate up to 15 years of age inclusive, disability pension for 16-17 year olds differentiated according to three groups of severity of disability and a further 20% paid to the main carer if a child requires continuous care (group 1 disability)</p> <p>In-kind benefits include: reduced charges for utilities; preference in receiving public housing as it becomes available</p>	<p>children with disabilities report negative and even hostile attitudes from social assistance department staff at Khyakimlik offices when applying for utility bill discounts or housing privileges.</p> <p>Ministry of Social Protection and NGO specialists report that some parents do not want their child to be labeled as 'disabled' as they perceive this status to carry a stigma and therefore don't apply for this status.</p> <p>Parents of children with Down's Syndrome report that in order to apply for disability status their child undergoes extensive medical assessments. If a medical condition such as heart disorders, bowel abnormalities or other health conditions are identified then they may be given disability status. Some parents report that their child is not confirmed as having a disability if they have Down's Syndrome, but no associated health condition. The MTEK disability classification system appears not to recognize that some level of learning disability is common to all people with Down's Syndrome regardless of their levels of functioning in other areas.</p> <p>Parents generally lack information about all the benefits and support to which they are entitled and the process for applying for these benefits.</p>
<p><b>Free medical services and health care for children</b></p> <p>Annual referral to a health sanatorium for all children and adults with disabilities</p>	<p>Some parents report that they are asked to pay for some of the treatments and medical services to which their children with disabilities are entitled for free.</p> <p>The quality of some types of medical services for children with disabilities provided by the primary health care system is questioned by parents. Parents also report specialists such as speech therapists and massage specialists in the mainstream primary health care system refusing to work with their children because of their disability. For these reasons, some parents end up paying for services in the private sector which should be free in the primary health system.</p> <p>Some types of health care specialisms which are important for some children with disabilities don't exist in the primary health care system – child neurology, child psychiatry, ergo therapy (occupational therapy), physiotherapy – and other types of specialisms may need to be modernized and strengthened – audiology, ophthalmology, pediatrics, neurology and orthopedics.</p> <p>Parents travel to seek access to specialists and treatments abroad that don't exist in Turkmenistan, but have limited access</p>

	<p>to information about the quality and effectiveness of treatments and services.</p> <p>Parents generally lack information about treatments, rehabilitation services, contemporary approaches to orthopedics and assistive technology, mobility devices and other important aspects of health care services for their children.</p>
<b>Legislation provides for employment quotas for people with disabilities</b>	<p>In practice this law is not always enforced or implemented and there is a general lack of support for young people with disabilities wanting to train for professions and enter employment. Reliable data about young people with disabilities in further education or entering employment is not available.</p>
<b>Data</b> is gathered by each Ministry which is relevant to children and young people with disabilities.	<p>Full data is not available on children and young people with disabilities and data that is gathered is not sufficiently disaggregated by type of disability, age, gender, region and other key parameters to enable effective planning of programs and policies. Existing administrative data is not collated into a full data set which can present a whole picture.</p> <p>The State Statistics Committee is able to request data sets from each Ministry, but there is a need to determine which key pieces of data should be collected on a systematic basis and collated by the SSC.</p>
<p>There is support for the Paralympic movement in Turkmenistan and for promoting the rights of people with disabilities.</p> <p>Turkmenistan was the first country in Central Asia region to ratify the Convention on the Rights of People with Disabilities</p>	<p>Public attitudes and behavior towards children with disabilities continues to be largely negative. Some people believe that ‘if you look at a child with disabilities you may have a child with disabilities.’ Others believe that a child’s disability – cerebral palsy or Down’s Syndrome – is catching and their child can be ‘infected’ by a child with disabilities.</p> <p>Public information and national communications campaigns can address these attitudes and behaviors and help reduce social barriers to inclusion in schools, employment and other settings where children with disabilities are currently excluded. Support for such campaigns from the highest levels can help to ensure their effectiveness in reducing discrimination and stigma. Training in understanding of disability for personnel in state services – health, education and social assistance services – and among public officials can also contribute to changing social attitudes and reducing barriers to inclusion.</p>
Some public buildings have been adapted to increase physical accessibility	<p>Public transport is not accessible for many children with disabilities and their families and the prohibitive expense of taking taxis or owning and running a car can compromise the accessibility of education, health and leisure services for many</p>

	children with disabilities and their families.
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## E2 Draft Vision and Action Plan for Children with Disabilities in Turkmenistan 2020

The working meeting brainstormed a draft vision statement and defined goals for a possible five year strategy for children with disabilities in Turkmenistan.

**Vision:** Equal rights and opportunities are realized for all children in Turkmenistan, including children with disabilities, where all children participate together in activities and events and where no child feels they are disadvantaged in any way.

### Goals for 2020:

1. Social services are supporting children with disabilities and their families.
2. Children with disabilities have access to schools, kindergartens and inclusive education.
3. Society has an understanding attitude towards children and adults with disabilities, they are active and visible participants in society.
4. Medical, social and pedagogical specialists are trained and educated to work with children with disabilities and their families using contemporary methods, skills and knowledge based on the ICF-CY.
5. Latest innovations in technical aids, assistive technology and devices, mobility and communication devices are available to children with disabilities in Turkmenistan.
6. Children with disabilities and their families have access to information and transport.
7. More young people and adults with disabilities in employment.
8. Complete statistics and data on children and adults with disabilities
9. Universal services function as they should for children with disabilities and their families – health, education, cash benefits and other social protection measures, accessible housing

### Priority activities

These activities were set out in order of priority while participants acknowledged that there is a need to carry out several activities in parallel.

#### 1. Development of social services

- 1.1 Needs assessment in the etraps to determine and study the demand for social services – what type are needed, to what scale and how close does each type need to be to the child and family
- 1.2 Choose existing structures/organizations where it is possible to attach new specialists, functions and services e.g. policlinics, family doctors and visiting nurses, kindergartens, schools, social welfare offices
- 1.3 Select, train and supervise in practice a cohort of new specialists – social workers specializing in child disability and (for example) community based rehabilitation; occupational therapists and physiotherapists; special education teachers. Update the skills and knowledge of existing specialists – neurologists, family doctors and nurses, speech therapists
- 1.4 Develop statute and normative framework for social services
- 1.5 Pilot new services
- 1.6 Monitor, evaluate effectiveness of new services

**2. Strengthen access to better assistive technology and devices**

- 2.1 Assess the need for each type device (prioritize children's wheelchairs); study the market for assistive technology and devices including for example Tajikistan where mobility and posture devices are being manufactured locally by people with disabilities following training from Japanese specialists.
- 2.2 Train staff – including orthopedic doctors and nurses – in the latest assistive technologies and devices
- 2.3 Strengthen and improve existing manufacturing
- 2.4 Create a resource for children – a 'technoteka' to be fitted for devices which they borrow and the return
- 2.5 Define government policy on the provision of assistive devices – free, co-funding with parents, means-tested provision and other options.

**3. Training and education of staff – modernize existing curricula and introduce new specialisms in the higher and secondary technical education system**

- 3.1 Medical college and Universities– ergotherapy and physiotherapy specialisms; child neurology and psychiatry; audiology, ophthalmology, pediatrics, neurology and orthopedics
- 3.2 Pedagogical college and Universities – social pedagogues, special teachers, psychologists (ABA, CBT), speech therapists
- 3.3 Social work – college and university level. A first group of specialists could be established at the Ministry of Labour and Social Protection as a methodological unit.

**4. People with disabilities are active in public life and visible in society**

- 4.1 Communication campaign to address prejudice and stigma and promote inclusion – advertising clips on television; information events in schools and kindergartens; build on opportunities presented by the paraolympic movement and Disability Day on 3<sup>rd</sup> December of Child Rights Day on 1<sup>st</sup> June. Show the successes of Turkmen children with disabilities abroad on the main news channels (for example a recent concert where children performed).
- 4.2 Encourage and facilitate communication and interaction between children with disabilities and those without disabilities – e.g. volunteering schemes such as the 'Timurovtsev'.
- 4.3 Information events for parents at schools and kindergartens

**5. Ensure statistics and relevant data are available and can be used in planning, implementing and monitoring.**

- 5.1 Create an inter-ministerial data protocol for gathering relevant administrative data from the Ministry of Health and Medical Industry, Ministry of Education and Ministry of Labour and Social Protection
- 5.2 Formulate the list of indicators and data which needs to be gathered on a regular basis

**6. Create options for accessible transport**

- 6.1 Social taxi; public transport to be made more accessible

**7. Preparation for independent living for young people with disabilities**

- 7.1 Introduce employment and careers advice programmes for young people with disabilities
- 7.2 Housing and support for independent or semi-independent living

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## Annex 1 Disability surveys globally – notes from desk review

### Disability Surveys in developing countries

- In developing countries, surveys are often conducted as stand-alone researches (Mitra et. al. 2011).
- Data on disability in low-income countries suffers from poor quality, lack of comparability, limited applicability and is out-of-date. It is mostly impairment based (Eide and Loeb 2005).
- Better to have involvement of individuals with disabilities at all stages of the research process as it improves the quality of the research, the sense of ownership among Disabled People's Organisations and to its application at different levels.
- Rural people/children, females and those from ethnic groups more likely to be disabled.

### Disability statistics

- In addition to disability prevalence rates, a rate of severe/significant disability should be reported.
- Two different strategies for developing disability statistics:
  1. Impairment or activity based statistics with the purpose of categorising individuals into disabled or non-disabled, studying the disabled sub-population and comparing with the non-disabled, &
  2. Activity and participation based statistics aiming at studying the distribution of limitations and restrictions in a population, comparing between groups in the population, and to analyse the relationships between individual, social and environmental factors and activity limitations/restrictions in social participation.

Both approaches are meaningful but there is a need to distinguish between the two and to be explicit about the basis for collecting disability statistics both with respect to analytical and “end-point” requirements (Eide and Loeb 2005).

- There is a lack of qualitative data (UNICEF 2005).

### Disability Definitions

- There is no agreed international definition of disability nor a standard to measure it. Definitions of disability in different surveys and within the same country are non-comparable.
- Purely medical definitions used in the past are giving way to definitions that incorporate continuous measures of the activities that people can undertake, the extent of participation in society and social and civic life, as well as the role of adaptive technologies (Filmer 2005). Efforts to develop measures of disability have accordingly focused on measures that capture activity limitations and participation restrictions (Mont 2007, Mitra et. al. 2011).
- Most use the International Classification of Functioning, Disability and Health (ICF) definition of disability, developed by the WHO in 2001. There are three disability measures from ICF:
  - Impairment: presence of impairment intrinsic to the individual.
  - Functional: limitations experienced with particular bodily functions such as seeing, walking etc, irrespective of whether the individual has an impairment or not.
  - Activity: limitations in activities of daily living such as bathing or dressing.

### Questions to ask and not to ask in a disability survey

- “Do you have a disability?”: (1) people may feel stigma at identifying themselves as disabled (especially for mental/psychological disabilities); (2) “disability” often implies a very significant condition and may leave out people who feel their disability is less severe; and (3) disability is interpreted as relative to the ‘norm’. E.g. an elderly person has difficulty in performing basic activities but feels she does not have a disability as they are performing as well as a person of that age is expected to perform (Mont 2007).

- “Do you have (X diagnosable condition)”: (1) people may not know their diagnosis; (2) knowledge about diagnosis correlated with variables such as education, socio-economic status, access to health services etc.; and (3) functional effects of a particular condition can vary widely (Mont 2007).
- Questions that focus on basic activities or major body functions serve as better screens e.g. do you have difficulty walking? Do you have difficulty holding a conversation with others?
- Functioning should be recorded without the use of assistive devices, except for glasses and hearing aids (Mont 2007).
- Contextual factors e.g. transportation, accessible schools and health care, culturally-based beliefs and attitudes about people with disabilities, the social stigma associated with disability, and the inconsistency in terms used to describe the experience and cause of impairments all must be considered in designing surveys to measure disability (UNICEF and University of Wisconsin 2008).

#### Limitations and Issues with disability surveys

- Interviewers may not be adequately trained to survey persons with disabilities or the perceived use of the survey by interviewees might affect the overall estimated rates (Filmer 2005, Mitra et. al. 2011).
- ‘Mild’ or ‘moderate’ responses categories to certain measures of disability have not performed well in cognitive testing (Miller 2003).
- Census questions, which are generally limited in number and specificity, are inappropriate when the purpose of the disability survey is to provide services. For this you need detailed information on peoples’ functioning levels, that supports that people have available to them within their family and within their community, and environmental characteristics (Mont 2007).

#### Children

- Child disability: limitations in mental, social and/or physical function relative to age-specific norms. Children with disabilities are often affected in multiple domains due to the nature of the underlying impairment, or due to increased susceptibility to other causes of disability among children with a single disability (UNICEF and University of Wisconsin 2008).
- Disability measurement often takes place through the filter of a parent or another adult (Washington Group on Disability website). Parents do well at identifying whether their children have difficulty performing specific tasks (UNICEF and University of Wisconsin 2008).
- Child functioning and disability module measures difficulties in functioning. It includes the reference “compared with children of the same age...” but respondents do not always make this comparison and for activities that children do without other children (isolated or internal activities) it is hard to compare e.g. self-care, emotions, attention.
- Population reference age should be 2-17—it’s hard to capture disabilities for children under 2 due to the nature of the development process (Washington Group on Disability website).



## Annex 2 Disability policy and social protection systems in Turkmenistan

### I. Disability policy and legal base of the rights of children with disabilities

Turkmenistan is making considerable efforts in the implementation of stipulations of international agreements and conventions on the rights and freedoms of children with disabilities and on creating conditions for their development and achievement. Since 1991 a series of legislative acts on the protection of the rights and freedoms of persons with disabilities, including children with disabilities (over 25 normative acts) have been approved in Turkmenistan to ensure detailed regulation in this area.

#### **Rights and freedoms of children with disability**

A series of articles of the Fundamental Law – the Constitution of Turkmenistan (of 18 May 1992, with amendments of 27 December 1995, 27 December 1999, 15 August 2003, 25 October 2005, and 26 September 2008) provide state protection of the rights of children with disabilities. Namely, Art. 23 of the Constitution stipulates that “a person cannot be limited in their rights or deprived of the rights to which they are entitled...”. Art. 37 of the Fundamental Law foresees that citizens are entitled to social benefits, based on age, in case of disease, disability, loss of work capacity, loss of bread-winner, employment. Or, every citizen has the right to health protection (Art. 35), the right to education (Art. 38), etc.

The Law of Turkmenistan “On the securing of rights of children” of 5<sup>th</sup> July 2002 determines the child’s legal status as an independent subject, guarantees the child’s rights and legal interests, and secures the child’s physical and spiritual development, shaping of his civic consciousness, based on the national and universal human values. The law secures equal rights and freedoms to all children who live on the territory of Turkmenistan, regardless of any varying circumstances, including health conditions.

The rights and freedoms of the child are secured by the state policy that provides: legislative coverage of rights and legal interests of the child, non-acceptance, on this base, of discrimination, restoration of rights in the case of their violation; development and implementation of state’s targeted programs securing the rights and legal interests of the child, support of motherhood and childhood; determination of state social standards of children’s life level; contribution to physical, intellectual, spiritual, and moral education and development of the child, support of and collaboration with public and other organizations that ensure the activity in the child’s best interest; fulfilment of international obligations of Turkmenistan, with regard to the rights and legal interests of the child (art. 4). The law proclaims the right of children with disabilities to worthy and full-fledged participation in the life of the society. For the purpose of social support and social integration of children with disability, the state supports educational, health-care, and rehabilitation institutions to ensure children’s education, accessible professional training and up-bringing that corresponds to the children’s health condition. Employment of children with limited professional opportunities due to their health condition is ensured by the state employment service. Parents (legal representatives) of the child who raise children with disabilities are provided allowances stipulated by the legislation of Turkmenistan.

#### **Securing rights to social protection for children with disabilities**

The main legislative act that is meant to secure direct protection of rights, freedoms, and legal interests of persons with disabilities, including children, their material wellbeing and social protection, is the Code of Turkmenistan “On Social Benefits” of 17<sup>th</sup> March 2007 (with amendments and completions introduced by the Laws of Turkmenistan: No 234-III of 23.10.2008 and No. 23-IV of 06.03.2009). Social Benefits is a state system of material allowances and social assistance of citizens who are incapable of

work, persons with disabilities, families with children, and other persons, provided through payments in the form of pensions, state allocations, and affordance of social benefits.

The Code provides a definition of the notion of “person with disability”, that is, a person with limited vital activity resulting of physical or mental impairment. Limited vital activity of a person is manifested in full or partial loss of the person’s capacity or possibility to perform work activity, self-service, independent movement, orientation, communication, control of own behaviour (Art. 81). Besides, the Code identifies categories of persons with disabilities, including children with disabilities under 16 (Art. 82).

The disability category is determined by the Medico-Social expert commission (MSEC), depending on the level of citizens’ vital activity limitation, caused by physical or mental impairment. There are three categories of disability, according to Art. 84. The Code provides a system of actions aimed to ensure social support to citizens in case of disability. First of all, this is the determination of the state allowance for disabled persons (Art. 54 – 55).

Social protection of persons with disabilities proclaims fullness of social-economic, political, personal rights and freedoms, stipulated in legislative acts of Turkmenistan. Discrimination of persons with disabilities is forbidden and persecuted by the law (Art. 146).

Social assistance includes a series of social services provided to persons with disabilities at home or in social assistance institutions: 1) social assistance at home, including social-medical assistance; 2) half-residential social assistance in day-care social assistance facilities; 3) residential social assistance in full-time social assistance facilities.

Rehabilitation of persons with disabilities represents a complex of medical, professional, and social actions, focused on the restoration of disorders or lost functions of the body, self-service capacity, and various types of professional activity. Rehabilitation of persons with disabilities is provided in rehabilitation centres, sections of restoration treatment, special teaching and educational, specialized health-resort institutions and facilities providing social and personal services to persons with disabilities (Art. 151). Health-care, professional, and social rehabilitation of persons with disabilities is provided, in line with individual rehabilitation program, developed by health-care facilities. Central and local public authorities, local governments, enterprises, organizations, and institutions, provide support in the implementation of the individual rehabilitation program of a person with disabilities (Art. 152). Education and professional training of persons with disabilities (Art. 153-154) proclaims their right to work in enterprises, organizations, and institutions with ordinary work conditions, specialized enterprises, workshops and sections that use the work of persons with disabilities, and to perform entrepreneurial activity that is not forbidden by the legislation of Turkmenistan.

Social support is provided to persons with disabilities in the form of cash benefits and exempts, medicines, wheelchairs, prostheses, and other prosthetic and orthopaedic items, printed editions with special fonts, special sound and signalling equipment, and in the form of services of medical, social, and professional rehabilitation and every-day activity personal services.

Medicines and health-care is provided for free, covered by the State Budget of Turkmenistan in a preferential manner, determined by the Cabinet of Ministers of Turkmenistan: for children with disabilities, for persons disabled since childhood, for disabled persons of I and II categories – providing wheelchairs, prostheses and other prosthetic and orthopaedic items; disabled persons of III category – providing prostheses and other prosthetic and orthopaedic items (art. 169).

According to the individual rehabilitation program, persons with disabilities are provided facilities in choosing accommodation, taking into consideration the type of building, number of storeys, relevant equipment, and other conditions necessary for living.

Children with disabilities placed in residential facilities, who are orphans or without parental care, upon entering adult age, are entitled to accommodation and material support for its equipment, on preferential basis (without staying in waiting list), if their individual rehabilitation program stipulates that they are capable of self-service and independent life (Art. 174).

According to the Code, benefits are provided not only to children with disabilities directly, but also to women who gave birth to and raised children with disabilities. Namely, women are entitled to retire three years earlier than ordinary retiring age, if they gave birth to and raised a child with disability till the age of 8. The work record includes the term of care provided to a person with category I of disability or raising a child with disability till the age of 16, but this work record shall not exceed overall 10-year term (Art. 24).

### **Securing rights to education for children with disabilities**

The state secures rights to citizens with health-related limited possibilities, namely the right to education, correction of disorders related to their development and social adaptation, based on special pedagogical approaches and special state educational standards (The Law of Turkmenistan “On Education” of 15<sup>th</sup> August 2009, Art. 9, section 4).

Education authorities and other state structures create necessary conditions for the access of after-school education of children with disabilities (Art. 159). Education authorities organize educational activities of children with disabilities placed into residential, health rehabilitation or illness treatment-and-prevention institutions (Code of Turkmenistan of 17<sup>th</sup> March 2007, with amendments and completions introduced by Laws of Turkmenistan No. 234-III of 23.10.2008 and No. 23-IV, art. 160, of 06.03.2009).

The Law of Turkmenistan “On Education” of 15<sup>th</sup> August 2009 provides benefits to persons with health-related limited possibilities. Children with disabilities of categories I and II, who, according to the resolution of the medico-pedagogical commission, are not recommended other type of education than in mainstream institutions, are enlisted into secondary mainstream and higher professional education institutions, with the condition of successful enrolment examination outside competition (Art. 14). Children who need long-term treatment and those with impaired physical or mental development are provided placement into special educational institutions (Art. 24). Children with limited health-related possibilities are provided, by education authorities, special (correction) educational institutions (classes, groups) that ensure their treatment, education, and training, social adaptation, and social integration. Children who require long-term treatment are provided placement into health-resort educational institutions, including sanatorium-type institutions. For such children, education can be provided, by educational institutions, at home or within medical institutions (Art. 34).

The educational system at the level of Etrap and Town Education Department includes Medico-Pedagogical Commissions that have the duty to select children with speech disorders, physical (motor, visual, and hearing) impairments, intellectual disorders (mental delay, late mental development), and report them to competent specialized institutions/groups for children, in order to provide them with health rehabilitation/treatment facilities. These Education Departments also examine issues related to the transfer of children from one specialized child institution to another, or discharges children from these specialized institutions/groups, and writes necessary recommendations for teachers of specialized institutions/groups and for the child’s parents. The Commissions include mainly specialists in health-

care and special teachers (child psychiatrist, speech therapist, defectologists, surdopedagogue, typhlopedagogue). The Commission decides whether it is necessary or not to place a child into specialized institution/group for children, and while making this decision, the opinion of the child's parents is not consulted or taken into account.

School and after-school load of specialized institutions/groups, classes schedule of schoolchildren are determined by the relevant state authority responsible for education, and by the statute of the educational institution, taking into account the recommendations of health-care authorities.

### **Securing rights to health care for children with disabilities**

The state proclaimed the right to medical and social support to children with disabilities and to persons disabled since childhood. This includes all types of rehabilitation, provision of subsidized medicines and medical items, as well as professional training and retraining, in line with normative and legal acts of Turkmenistan (Law of Turkmenistan "On the protection of health of citizens" No. XM-84 of 25<sup>th</sup> October 2005, amended and completed by Law No. 32-IV of 18<sup>th</sup> April 2009).

Children with problems of physical or intellectual development, and those attributed disability status due to health conditions, are entitled to health-care and social support in specialized child institutions. The list of medical contraindications for the placement of such children into specialized institutions and mainstream educational institutions is approved by the Ministry of Health and medical industry of Turkmenistan.

Upon the request of parents (legal representatives), children with impaired physical and psychic development can be placed into specialized institutions, supported by local budgets, charity and other funds, and by funds of parents (legal representatives) (Art. 17).

Disabled children under 16, persons disabled since childhood, persons with category I, II, III of disability, are provided with free medicines of certain type, based on the recipe of the treating doctor. This category of persons with disabilities are provided free medical care and free medical items of certain types (Decision of the President of Turkmenistan "On free and subsidized provision of certain groups of citizens of Turkmenistan with medicines, medical assistance, and medical inventory" No 10683 of 30<sup>th</sup> October 2009).

### **Securing rights to access to social and physical environment for children with disabilities**

The Legislation of Turkmenistan proclaims access of persons with disabilities to social infrastructure, and stipulates an extended set of actions and obligations related to their access to social infrastructure. Specifically, the central and local public authorities and local governments, enterprises, organizations, and institutions, regardless of their form of property, are obliged to create conditions for persons with disabilities, ensuring their access to residential, public, and production buildings, constructions, and rooms, use of public transport, means of communication, and information (Code of Turkmenistan on "Social assistance" of 17<sup>th</sup> March 2007 (with amendments and completions introduced by the Laws of Turkmenistan No. 234-III of 23.10.2008 and No. 23-IV of 06.03.2009), art. 162).

Planning, projecting, and construction of residential areas, creation of residential districts, making projection decisions, construction and reconstruction of buildings, objects, social infrastructure, means of communication and information, are performed, taking into consideration accessibility for the use of persons with disabilities (art. 163). Living spaces, provided to persons with disabilities and their families, and settled by them, should be equipped with special items, devices, and telephone connection. Equipment of the mentioned residential spares is ensured by the local public and local executive authorities, enterprises, organizations, and institutions in charge with the given residential facilities.

Equipment of individual homes where persons with disabilities live is provided by enterprises, organizations, and institutions that are guilty for the disability, and in certain cases – by relevant state authorities, with the participation of public societies of persons with disabilities (Art. 164). The local executive and local public authorities must create necessary conditions for persons with disabilities, securing their access and use of cultural institutions (like cinemas, theatres) and sport facilities, participation in sport activities and sporting events, as well as provide special sport inventory (Art. 165). Persons with disabilities of categories I and II, and children under 16 with disabilities use these services free of charge, while persons with disability of category III are exempt 50% of payment for the provided services. Enterprises and organizations producing prosthetic and orthopaedic items and special transport units for persons with disabilities, organizations providing rehabilitation to persons with disabilities, and those providing care and rehabilitation services to persons with disabilities, are offered benefices according to the existing legislation of Turkmenistan (p. 168).

The state proclaimed a series of rights of the youth, including right to youth employment, protection of children from economical exploitation through the use of violence, and non-acceptance of situations that may prejudice their health or constitute obstacles to their education, or affect their health, physical, mental, and spiritual development, hinder the pursuit of freedom of consciousness (The Law of Turkmenistan “On securing the rights of youth to employment” of 01 February 2005).

The rights related to sport activities were proclaimed for children with disabilities and orphans, by means of creation and allowance of a system of benefits and incentives, for the purpose of their social integration and physical rehabilitation. The Law provides for the creation of special sport and resort facilities and creates conditions for physical and sport activities of persons with disabilities within public facilities (Art. 18). The state recognizes and supports the training and participation of Turkmenistan sports persons in Para-Olympic Games (The Law of Turkmenistan “On Physical Culture and Sport” of 07 July 2001, art. 19).

The state also pointed out the right of children with disabilities to access to cultural facilities (Art. 33, section 1) that should be taken into consideration while projecting and using cultural facilities (The Law of Turkmenistan “On Culture” of 17<sup>th</sup> May 2010); the right of children with disabilities (in wheelchairs) to residential areas, adapted by surface of the area, availability of storerooms, with adapted elevators, staircases, ramps, etc. (CHT 2.08.0106 “Residential buildings” No. MB-99).

The State proclaimed at the Legislative level the access to justice for persons with disabilities. Certain norms on the rights and interests of persons with disabilities are reflected in Turkmenistan’s Criminal Code. Namely, if during a criminal process a deaf or mute person is interrogated as victim, suspect, or accused, then this process should involve a person who understands their signs and is able to communicate with them using sign language. If the interrogated person has psychic or other severe disorder, their interrogation is only possible upon resolution of a doctor and in the doctor’s presence (Criminal Code of Turkmenistan (YPKT) of 18<sup>th</sup> April 2009, art. 252).

The Criminal Code stipulates responsibility for cruel treatment of a person that is in a dependent position or in helpless situation, caused by disease, disability, old age, and provides punishment with correction work up to one year or imprisonment for up to two years (Criminal Code of Turkmenistan (YKT) of 10 May 2010, art. 114).

## **II. Institutional framework of the child social care system**

The existing legislation of Turkmenistan appoints state authorities and institutions at the central and local level that are responsible for a given segment of work with persons with disabilities, including children with disability. At the national level this is, first of all, the Cabinet of Ministers of Turkmenistan,

Ministry of Education of Turkmenistan, Ministry of Health and Medical Industry of Turkmenistan, Ministry of Labour and Social Protection of the Population of Turkmenistan. Locally this responsibility is attributed to executive authorities (hakimlik of all levels) and local public authorities (gengesh).

The Cabinet of Ministers of Turkmenistan, as executive and governing authority, performs general governing of all branches and areas of state administration, including the activity of state administrative authorities in charge of health condition, educational conditions, and social assistance (protection) of persons with disabilities, including children with disabilities.

The tasks of the Ministry of Labour and Social Protection of the Population of Turkmenistan includes the implementation of state policy in the area of labour, social assistance, and social protection of the population (p. 4). The main functions of the Ministry include: to create commissions for the examination of documents for the provision of pensions, within social assistance departments of etraps (towns) and welayats, and to institute special commission within the Ministry, for the provision and recalculation of pensions, in line with the existing legislation; to submit data for the allocation of state benefits, to be examined at the central inter-departmental commission; to determine the budget amount necessary for the financial coverage of pensions and state allocations, in line with the existing legislation, in order to ensure timely submission of the relevant documents to bank institutions; to organize and coordinate the provision of social assistance to lonely and elderly citizens and persons with disabilities (Regulation of the Ministry of Labour and Social Protection of the Population of Turkmenistan, approved by the Decree of the President of Turkmenistan No. 11593 of 8<sup>th</sup> April 2011).

The state governance in the area of health protection of citizens is performed by the Ministry of Health and Medical Industry of Turkmenistan, and by relevant local executive authorities and local public authorities. The Ministry implements the state policy in the area of health protection of citizens; ensures the rights of citizens to guaranteed state package of free health care services; performs activities for the development and consolidation of the primary network of healthcare and improvement of the preventive healthcare system; performs other activities that ensure the quality of the health care provided to the population (The Law of Turkmenistan "On Health Protection" of 25<sup>th</sup> October 2005, art. 8).

According to the Regulation of the Ministry of Healthcare and Medical Industry of Turkmenistan, the main tasks of the Ministry are: to perform the medico-social expertise and determine the category of disability; to organize healthcare services and assistance of persons with disability and the elderly, within medico-social institutions, including the provision of material support for everyday activities; to provide prosthetic and orthopaedic assistance, according to the existing standards, and to ensure rehabilitation of persons with disabilities (Regulation of the Ministry of Healthcare and Medical Industry of Turkmenistan, approved by Decree of the President of Turkmenistan No. 3608 of 27<sup>th</sup> February, p. 8). The Ministry is in charge with the following organizations and institutions: Centre (including residential care) for prosthesis and rehabilitation of persons with disabilities, 5 institutions for adult persons with disabilities and 1 for children – Psycho-neurological Residential Institution for Children in Yoloten Etrap of Mary velayat.

The functions of the local executive authorities and local public authorities, in terms of health protection of citizens, include: implementation of state policy in the area of health protection of citizens; creation of necessary conditions for health improvement of citizens, preventive care and sanitary and epidemiologic well-being on the subordinated territory; making sure that state and regional programs are implemented; exerting control of compliance with the existing standards of quality of healthcare; coordination of activity of enterprises, institutions, and organizations, regardless of their form of

property, in terms of health protection of the population; provision of benefits and social support to certain categories of citizens, in line with the Legislation of Turkmenistan, etc. (art. 9).

The Ministry of Education of Turkmenistan, within its competences, performs the implementation of state policies in education; develops perspectives and directions of development of education, requirements for the support, level and volume of education; develops state educational standards, develops normative and instructive documents for the organization of the training, educational, methodological, scientific work of all types of educational institutions; performs quality control of the training of graduates; develops conditions for the enrolment into educational institutions; produces standard instructions on educational institutions, rules of their attestation and accreditation; regulates issues related to equivalent documents of other states referring to the Education in Turkmenistan; writes the rules of attestation and improvement of qualification of education staff, etc. (Law of Turkmenistan "On Education" of 15<sup>th</sup> August 2009, art. 27).

The range of functions and competences of the Ministry of Education includes: record of children entitled to compulsory education based on primary and secondary mainstream education curricula; development of a network of school and mainstream educational institutions; social protection of educational staff, children, studying youth, and creation of conditions for their work, education, and training, in line with the norms of material, technical, and financial coverage; organization of nutrition of pupils and preschool children; provision of regular transportation to educational institutions for pupils from rural areas, covered by local budgets, organization of educational and methodological supply of mainstream educational institutions, improvement of the professional level of the teaching staff, improvement of their qualification; identification of the needs and making requests for additional educational staff, signing agreements for the training of the educational staff; control of the execution of state requirements for the level of preschool and mainstream secondary education, etc. (Regulation of the Ministry of Education, approved by the Decree of the President of Turkmenistan No 3824 of 11<sup>th</sup> August 1998, art. 27).

According to the Decree of the President of Turkmenistan "On actions for the improvement of work of special educational institutions for children and adolescents with impaired physical or mental development" (No. 431 of 08 October 1991), and for the purpose of further improvement of the activity of special educational institutions, the Ministry was assigned the coordination responsibility of organizational, methodological, and educational activity in special educational institutions, regardless of their departmental subordination and profile of illness prevention, treatment, and rehabilitation of children and adolescents placed in these institutions.

The organizations and institutions related to children and adults with disabilities include the Ministry of Finance of Turkmenistan that ensures financial coverage of areas dealing with disabled persons; the Ministry of Economy and Development of Turkmenistan that has the role to produce state programs of social and economic development, including those related to persons with disabilities; National Institute of Democracy and Human Rights of Turkmenistan, under the patronage of the President of Turkmenistan, that, among other functions, provides funds for activities related to the functioning of institutions for children with disabilities (Regulation of Turkmenistan's National Institute of Democracy of Human Rights under the patronage of the President of Turkmenistan of 23<sup>rd</sup> October 1996, p. 2).

Important role in the protection of rights and freedoms of persons with disabilities, including children, is performed by public associations of persons with disabilities, created for the purpose of social protection, social, work, and health rehabilitation of persons with disabilities, and their involvement into activities of public utility. Among public organizations created and functioning in Turkmenistan are The Society of Disabled Persons of Turkmenistan (Regulation of 24<sup>th</sup> June 1994, with amendments approved

on 2<sup>nd</sup> April 2004), the Society of the Blind and Deaf of Turkmenistan, and other public societies of persons with disabilities. They have their subdivisions in weyalaty centres.

**Conclusions:**

The Legislation of Turkmenistan regulates a large variety of issues related to children with disabilities (under 16). The benefits and privileges are reflected in the legislation in the area of social assistance, education, healthcare, and labour.

The national legislation quite comprehensively regulates the right of children with disabilities to education, although it is made dependent on the degree of children's health.

The legislation on persons with disabilities does not sufficiently reflect the need and specific norms of awareness-raising campaigns, dissemination of information, development of public acceptance and respectful attitude to the rights of persons with disabilities, and the responsibility of the directors of the relevant institutions to perform such work among the population.

The legislation proclaims the access of persons with disabilities, including children, to the social infrastructure (transport, connection, information, buildings, areas, etc.), but, in fact, it does not contain any regulations related to relevant standards of accessibility (opportunities for the use) for persons with disabilities.

The system of social protection of children with disabilities is represented by state structures and institutions at the national and local levels, and by other support-providing structures. At the same time, a number of ministries simultaneously perform responsibilities related to the social protection of children with disabilities: the Ministry of Education of Turkmenistan, the Ministry of Healthcare and Medical Industry of Turkmenistan, and the Ministry of Labour and Social Protection of the Population of Turkmenistan, there is no single coordination structure. The situation at the local level (executive authorities –hakimliks of all levels – and local public authorities – gengesh) presents the same fragmentation in approaches to children with disabilities.



## Annex 3 Methodology and overview of field work

### A Final Research Methodology and Instruments

#### 1. Introduction

##### Purpose of the Survey

In accordance with the UNICEF Turkmenistan terms of reference for this survey, the specific objectives of this survey are:

- To understand who are the children with disabilities
- To uncover the situation of children with disabilities in institutions (age, gender, geographic location)
- To understand the accessibility and availability of social services for children with disabilities

In addition, the terms of reference articulates the need to ‘develop a common vision and prepare an action plan’. The implication is that the survey not only constitutes a situation analysis, but also incorporates the first steps towards addressing any gaps in the accessibility and availability of social services for children with disabilities and their families that are identified during the survey.

In order to achieve these objectives, this methodology proposes to interpret the first objective ‘to understand who are the children with disabilities’ as an open inquiry into a broad range of social, economic and family circumstances that can help policy-makers and practitioners to understand any underlying factors that may need addressing when developing services. A similar approach will be taken with the second objective ‘to uncover the situation of children with disabilities in institutions’ with the added element of the potential for a comparative analysis of factors that have led to some children being cared for in institutions and others not, depending on the final sample of children and parents who are included in the survey. This approach will help to ensure that the third objective can be achieved and that the action plan that emerges as a result of the survey is based as far as possible on the realities of the situation for girls and boys with disabilities in Turkmenistan and their families.

This survey will link to and draw upon several other pieces of research which have been commissioned by UNICEF on child protection and social policy in 2012-2014 including:

- Study into the institutionalization of children aged under 3 years in Turkmenistan – a study which examined the reasons why children aged under 3 years are in institutional care in Turkmenistan and offers recommendations on the development of alternative services which could lead to the eventual deinstitutionalization of services for young children – 2013-2014
- Social Services Assessment – a study which is mapping the existing networks of social services for children and families including for children with disabilities and assessing the potential for further development of social services<sup>6</sup> 2014
- The Impact of Cash and Non-Cash Benefits, 2014

It will also try to take into account key pieces of research related to health and education including:

- Mapping of Developmental Pediatrics/ early intervention services in Turkmenistan as a part of Regional survey in 2012
- Report on Home visiting assessment , 2012;
- Report on PHC MCH assessment, 2012;
- National strategy on Maternal, New born, Child, Adolescent Health , 2014
- Inclusive education Road Map development, 2014

- Early Childhood Development monitoring, 2014

This survey uses the definition of disability set out in the CRPD Article 1 *‘those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’*.

### Survey protocol

The methodology for this survey is based on the following key elements of disability surveys outlined in the terms of reference:

*Human rights based approach* – the efforts of Turkmenistan to implementing the rights of all children in keeping with the CRC and the CRPD will be part of the inquiry framework for this survey

*Equity* – the survey will consider equality of access to quality education, health services, social services, protection, mobility, housing and accessible environment for children with disabilities in Turkmenistan; consideration will also be given to equitable access to play and leisure activities and to eventual employment and independent living

*Social Model of Disability* – the survey instruments are structured around the ICF-CY dimensions of functionality and barriers to functionality and the analytical framework used in the survey will be underpinned by the ICF-CY. The final report will therefore be structured in keeping with the ICF-CY, but will be accessible to a wide audience even if they are unfamiliar with the ICF-CY

*Inclusive Development Approach* – the survey will gather both quantitative and qualitative data from a range of participants who are key to ensuring a full understanding the central objectives of this survey – children, parents, carers, decision-makers, educators, health professionals and will ensure as far as possible that rural and urban inhabitants, men and women will take part in the survey.

*Disability Community as Key Stakeholders* – a disability NGO Yenme will involve its members - adults with disabilities, parents of children with disabilities and children /young people with disabilities – at all stages of the survey. The consultants will work with Yenme to ensure that the disability community is consulted at the following four key stages of the survey: methodology and instrument design; as direct respondents during the survey; at the stage of analysis and finalizing the report; at the stage of developing a common vision and an action plan

*Lifecycle approach* – the survey is focused on children with disabilities, but will consider the full lifecycle with a specific focus on the transition from childhood into young adulthood, further education and employment. Consideration will also be given to issues relating to supported independent living for young adults with disabilities.

*Strengthen data and qualitative analysis* – the survey explicitly aims to generate new knowledge and data and to use qualitative analysis to ensure that any policy or practice developments that are based on the survey will be informed by valid data and a clear exposition of the current situation that has been triangulated by the perceptions and experiences of people with disabilities, parents of children with disabilities, professionals and decision-makers.

In addition, the survey will secure informed verbal consent from families and other respondents who take part in the survey and the OPM ethical review committee will review the methodology and instruments to help ensure that all ethical considerations have been taken into account at the outset of the survey.

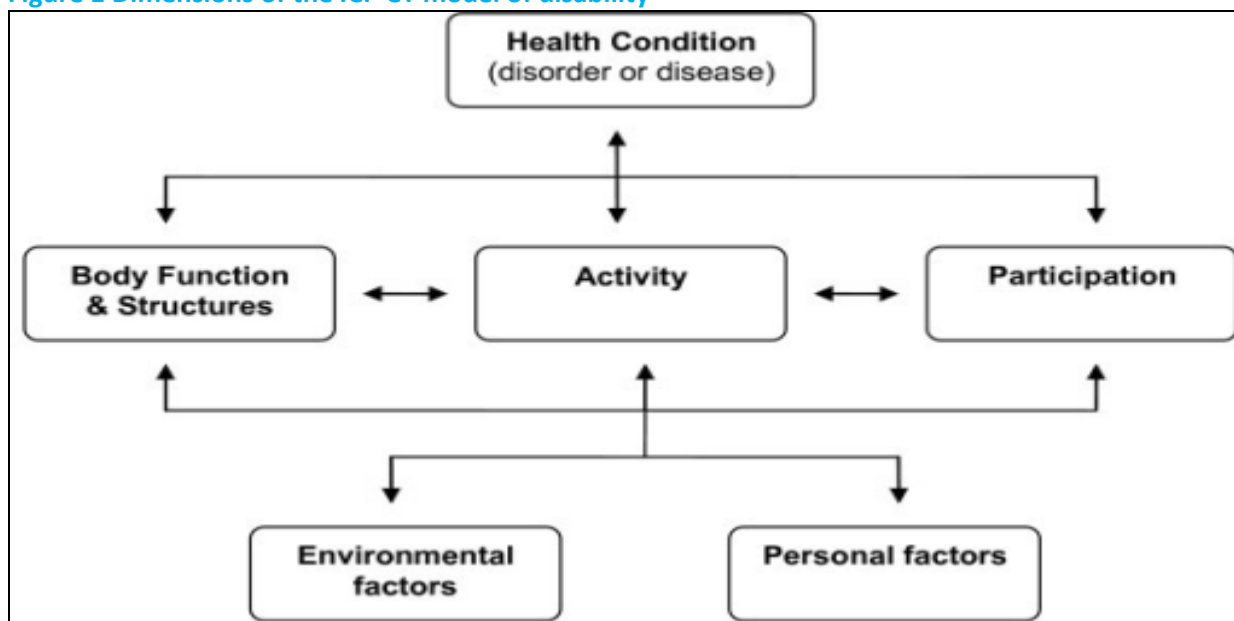
### International Classification of Functioning, Disability and Health – Children and Youth version (ICF-CY)

The ICF-CY was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21) as the international standard to describe and measure health and disability<sup>6</sup> and it sets out a social and human rights model of disability. Disability is understood as a construct which is created by a disorder or disease combining with environmental and

<sup>6</sup> <http://www.who.int/classifications/icf/en/>

personal factors to affect body function, ability to engage in activities and to participate in a range of life spheres such as education, employment, relationships, social interaction (see figure 1).

**Figure 1 Dimensions of the ICF-CY model of disability**



Source: Judith Hollenweger, Fourth Central Asian Forum on Child Protection, Dushanbe, 2013

This disability survey has limited resources to fully integrate an ICF-CY approach into the design of the survey and its instruments, but the six dimensions of the ICF-CY will guide the structure of the survey, the instruments for data collection and the analysis. This will help to ensure that UNICEF and the Government of Turkmenistan are well-positioned to base policy decisions relating to implementation of the CRPD on information that corresponds to the social and human rights model of disability that underpins the CRPD and is actualized in the ICF-CY.

## 2. Proposed research questions

The methodology and instruments for the survey which are described in this document will help to gather sufficient information to analyse the situation for girls and boys with disabilities in Turkmenistan and to inform policy and practice development in relation to child and family support and social inclusion. The instruments for data collection which form part of this methodology are focused on the following research questions:

- 1) How many children with disabilities are there in Turkmenistan, with an approximate breakdown by type of disability and level of functioning, district of origin, gender and age?
- 2) What are the characteristics of the population of children with disabilities according to age, gender, age at which disability was diagnosed, type of care (eg. family, relatives, institutional, other), social services to which children and families are connected and to which they have access?
- 3) What is the social profile of families with children with disabilities – urban/rural, economic situation, employment, housing, family structure, social assistance being received; what are their needs for social support?
- 4) What needs do children with disabilities and their families have that are not being met by social services or other forms of support including support from the extended family and social networks? What family support services are needed to help families look after their children at home?
- 5) How do children with disabilities end up in formal care or in residential institutions? What assessments are made and how are decisions taken? To what extent do children with disabilities being cared for in residential institutions have contact with their parents and relatives? How far does the family live from the institution?

- 6) What are the outcomes for children with disabilities after leaving residential care or school; what are the differences in outcomes for children being cared for in residential institutions and children being cared for in their families in terms of – education, physical development and habilitation, preparation for independent living, emotional and personal development, friendships and socialization?
- 7) Which services exist and which services are lacking that can help to facilitate the social inclusion of children with disabilities?

A related question which is not central to the survey, but which is relevant to the whole issue of developing appropriate social services and which will also be explored in the survey is:

- 8) Are there children using residential services for children with disabilities who do not have disabilities; are residential services being used as social care services in the absence of alternative community-based services?

### Inquiry framework

The inquiry framework for the survey summarized in Table 1 is based on the research questions and the six dimensions of the ICF-CY and will inform the underlying structure of the data collection instruments for this survey with the main focus of enquiry being the inter-relation between environmental factors, especially the availability of social services that can help to enable activity and participation.

**Table 1 Inquiry framework**

ICF-CY dimension	Main questions concerning the child	Main questions concerning the family
1. Basic data and health condition	Age, gender, district of origin, age at which disability was diagnosed  Level of body function: seeing, hearing, speaking, walking, sitting, changing position, breathing, understanding  Level of ability self-care: bathing, toilet, eating, dressing  Medical diagnosis	Socio-economic data: urban/ rural, economic situation, employment, housing, family structure
2. Activity – interpersonal interactions	Type of care – family, residential, extended family, other?  Interpersonal interactions with parents, siblings, extended family  Social relationships: friends and peers	Who is the main carer of child?  What support is there from other members of the family for the main carer?  What are the differences in relating to emotional and personal development, friendships and socialization between children living in families and those who live in residential care?
3. Activities and level of participation	Home activities: helping around the house, playing with other children in the home  Leisure activities and play: outside the home  Education: pre-school, primary, secondary, higher or vocational; where? Quality? Outcomes and progress?	What support does the family need to increase the level of participation of their child in these activities?  Why have some families placed their child in residential care and others haven't?  What support do families need to look after their children at home?  How do outcomes and level of participation differ for children living at

	Preparation for independent living: using money, using transport, self-care, going to the store	home and children living in residential care across these activities?  Are levels of participation affected by socio-economic factors in the family? By degree of functioning? Any other factors that might be affecting the family and the child?
4. Environmental factors	Access to assistive technology and rehabilitation services  Access to social services  Access to other services – which?  Access to informal support – from whom?	Which services exist and which are lacking that can help to facilitate social inclusion of children with disabilities and their families?  What needs do children with disabilities and their families have that are not being met by social services?  What barriers to inclusion for children with disabilities and their families exist in the local communities?

Personal factors such as individual characteristics of children, their personal interests and how these interact with the other dimensions of the ICF-CY framework cannot be included in this survey as resources are lacking and the main focus of enquiry is into the interaction between environmental factors and diagnosis, functioning, activities, participation.

### 3. Data collection

Data will be collected by a team of researchers comprising staff of a disability NGO Yenme, delegated staff members of the State Statistics Committee and the Ministry of Labour and Social Protection and UNICEF. The team will be trained by and operate under the supervision of the international consultants.

#### 3.1 Quantitative data

Quantitative data about children with disabilities will be collected from statistical and administrative sources across all velayats of Turkmenistan and the country as a whole. The main statistical data which will be collected are:

- **State Statistics Committee** – the number of the child population aged 0-17 years in each velayat at the time of the survey disaggregated by age and gender; number of children with disabilities in each velayat disaggregated by age and gender if available; if possible the child population data will also be disaggregated by the numbers of children in urban or rural areas.
- **Ministry of Labour and Social Protection** – number of children aged 0-16 receiving child disability pensions disaggregated by age and velayat (and gender if possible); number of children aged 17 receiving disability pensions disaggregated by disability group; data on other social benefits for children with disabilities and their families; data on employment of young people with disabilities. Number of children entering and leaving the Psychoneurological internat each year for 2011, 2012, 2013 and 9 months of 2014; number of young people with disabilities entering the adult disability internats each year for 2011, 2012, 2013 and 9 months of 2014.
- **Ministry of Health and Medical Industry** – number of children passing the medico-pedagogical commission each year, disaggregated by age and region for 2011, 2012, 2013 and 9 months of 2014; number of children with disabilities receiving medical rehabilitation and other health

services disaggregated by age and region for 2011, 2012 and 2013; number and type of rehabilitation programmes disaggregated by target client groups, region and outcomes.

- **Ministry of Education** – number of children with disabilities attending: mainstream schools and kindergartens; residential schools; specialised day or residential schools and kindergartens; home schooling - all disaggregated by velayat and where possible by gender and age; total number of children in residential schools and pre-schools (including 24 hour kindergartens) – disaggregated by parental care status, region and disability. Data from the medico-pedagogical commissions in each velayat for 2011, 2012, 2013 and 9 months of 2014. Data on entry of young people with disabilities to further education institutions and colleges for 2011, 2012, 2013 and 2014 disaggregated by disability, age, gender and region.

All data will be entered into form 1 and collection of data can begin as soon as UNICEF is ready to finalise the plan for the survey with the Ministry of Labour and Social Protection and other government counterparts. The UNICEF team will lead on gathering this national level data together with GoT counterparts and partners.

Other potential areas for gathering administrative data include information gathered for a range of other purposes including:

- Data from NGOs supporting children with disabilities and their families: number of clients each year disaggregated by age, disability, gender, region;
- Data from Khyakimlik authorities and other local velayat structures gathered to provide support for children with disabilities – number of children with disabilities and their families benefitting from material support, humanitarian aid, housing provision and other types of support

This type of local data will be gathered through interviews in Ashgabat, Ahal velayat and Lebap velayat.

The quantitative data from all sources will be subject to a comparative analysis to identify the extent to which children with disabilities may not be included in one or all part of the system of provision of health, education and social support services. All data will be entered into excel sheets and organized in the following blocks:

1. National system data

Data from the State Statistics Committee, MLSP, MoE and MoH will be entered into form 1:

- 1.1 Number of children with disabilities aged 0-17 years registered with MLSP, MoE and MoH disaggregated by main types of pathology, region, age and gender in 2011, 2012, 2013 and 9 months of 2014; number of these children who are severely disabled.
- 1.2 Total number of children aged 0-17 years disaggregated by region, age and gender in 2011, 2012, 2013 and 9 months of 2014;
- 1.3 Number of children who were newly designated disabled in 2011, 2012, 2013 and 9 months of 2014 disaggregated by region, age and gender;
- 1.4 Number of children with disabilities entering and exiting specialized residential institutions disaggregated by main types of pathology, referring organisation, reason for entry, region, age at entry and exit, age at time of survey and gender in 2011, 2012, 2013 and 9 months of 2014;
- 1.5 Outcomes for children leaving specialized residential institutions disaggregated by type of pathology, gender, age at exit and region of origin (before entry to the institution) in 2011, 2012, 2013 and 9 months of 2014:
  - i) Return to live with birth family
  - ii) Return to live with extended family with adoption or legal guardianship being established

- iii) Transfer to another type of residential institution
- iv) To continue education in an educational facility with a professional profile;
- v) Move to independent living
- vi) Other \_\_\_\_\_

If the necessary disaggregation does not exist at national level especially for points 1.4 and 1.5, then this data will be gathered for the three main regions being targeted by the survey through interviews and gathering of data in residential institutions.

## 2. Individual data on children in residential care<sup>7</sup>

Data will be gathered on **individual children in residential care in three regions** that can form the basis for quantitative analysis. If possible, this data should be gathered **for ALL children resident in the participating institutions** at the time of the survey. All data will be anonymised and entered in to data entry form 2.

- 2.1 Child – gender; date of birth; date of entry into residential institution; region of origin; diagnosis; parental care status (orphan, parental rights removed, in parental care, in guardianship care); where was child referred from into residential institution (from family, infant home, hospital, other); any changes in diagnosis since entry; ethnicity; brothers or sisters (gender and date of birth if known); reason for entry (education, social care, rehabilitation, other); services received before entry; care plan; education programme (mainstream school, specialized school in the institution, modified curriculum, mainstream curriculum, other); how far do family members live from the institution; frequency and type (phone, in person visits) of contact with parents and family; frequency of visits home.
- 2.2 Parents – for both mother and father if known – date of birth, where do they live, education, disability status, civic status (married, divorced, single, widowed), employment
- 2.3 Other carer/guardian - date of birth, where do they live, education, disability status, civic status (married, divorced, single, widowed), employment
- 2.4 Holidays and weekends – does the child spend holidays in the residential institution? Weekends?

## 3.2 Qualitative data collection and analysis – structured interviews and focus group discussions

The Terms of Reference does not give an indication of how many children with disabilities are estimated to be living in residential institutions in Turkmenistan, although it notes from 9,959 to 14,487 children with disabilities in total in the country according to various sources. A 2004 report by the National Institute of Statistics of Turkmenistan<sup>8</sup> provides tables that indicate there is one 'boarding school' for children with disabilities in Yoloten which had around 240 residents at the end of 2003 and 14 'auxiliary boarding schools' which are for children with special educational needs, but may also be used for children with social needs and there were 2500 children resident in them at the beginning of the 2003/2004 academic year. The report also notes 8 'specialised pre-school' institutions 'with beds' at the end of 2003 with 665 children aged 3 years or more who had special education needs. There are therefore potentially around 3000 children in residential institutions that probably have disabilities of some kind or other and should be targeted by the survey. While it is likely that these numbers have dropped since 2004, given the drop in the numbers of children overall, it is still likely that the desk review will need to incorporate up to date information from the relevant Ministries in order to be able to correctly define the potential number of children who should be targeted by the survey. Infant

<sup>7</sup> It is not clear whether this will be permitted by the Ministry of Education and the Ministry of Labour and Social Protection. If not, then it is proposed that interviews will be carried out with carers or parents of 150 children with disabilities in residential care and this type of data gathered for at least these 150 children if it is not possible to gather data for all children in residence in the institutions.

<sup>8</sup> 'Situation Analysis Of Children Deprived Of Parental Care Or Reared In Families Which Lost Their Breadwinners', 2004



Homes for children aged under 3 years of age will not be included in this survey as a recent study was completed by UNICEF which provides data on these children.

### SAMPLE AND DATA COLLECTION STRATEGY – 300 interviews and 6 focus groups

Primary data about children and their families will be collected through structured interviews with parents of 150 children with disabilities who live at home, with staff caring for 150 children with disabilities in institutions (or where possible their parents) – overall 300 interviews concerning 300 children with disabilities will be conducted or 10% of the estimated number of children with disabilities in residential institutions of one kind or another. The main focus of the inquiry will be on establishing the existing current situation and the sample size is intended to be large enough to extrapolate some quantitative findings as well as record more qualitative data – perceptions of parents and carers and their experiences in relation to the 300 children who are the subject of the inquiry. Three focus group discussions with parents of children with disabilities and three focus group discussions with parents of children who do not have disabilities will enrich and deepen the findings from the survey with the main focus of inquiry being on how best to support families to care for their children in the community, how to work with communities to increase acceptance of children with disabilities and to reduce discrimination and stigma, to identify gaps in services and barriers to inclusion.

### Proposed sample for 300 structured interviews and 6 focus group discussions

#### Sample for household interviews 150 families of children with disabilities – 50 in each region

- Age – the survey will cover girls and boys aged 3-17<sup>9</sup> years living at home and receiving disability benefits<sup>10</sup>; interviews will be conducted with parents or main carers of the child
- Place of residence – urban (Ashgabat and 50% of Lebap sample) and small-town or rural (Ahal and 50% of Lebap sample)
- Type of pathology – roughly 20% with intellectual disabilities; 20% with motor disabilities; 10% with low sensory functioning; 10% with speech dysfunction; 40% combined

#### Sample for interviews with institution staff (or where possible parents) about 150 children who are resident in the institution<sup>11</sup> – 50 in each region

- Age – the survey will cover girls and boys aged 7-17 years living in residential institutions at the time of the survey; interviews will be conducted with a carer who knows the child well and if appropriate and possible with the child him or herself present at the time of the interview. The carer will have the child's personal file available during the interview in order to access the maximum amount of information about each child. If the child has parents and it is possible to interview them, then the interview should be conducted with the parents.
- Place of residence – a range of types of institutions will be sampled in both urban and rural settings in the three regions. The final sample will be agreed with the Ministry of Education, MLSP and UNICEF at the outset of the survey.
- Type of pathology – roughly 20% with intellectual disabilities; 20% with motor disabilities; 10% with low sensory functioning; 10% with speech dysfunction; 40% combined

<sup>9</sup> It will be important to try to include families of at least 5 children in each region who are aged 4-6 years of age as these children are currently too old for the infant home, but too young for special schools

<sup>10</sup> If possible to identify, this sample will also include households with children with disabilities who are not receiving any disability pensions – aim for 10-20% ie 5-10 in each region

<sup>11</sup> It is possible that some children do not have disabilities although the institutions are for children with disabilities – screening questions will be included to try and determine level of functioning.

Sample for focus group discussions with parents – 2 in each region

Parents of children with a disability – 8-10 parents or carers of children who are receiving disability benefits

Parents of children without a disability – 8-10 parents or carers of children from the same communities as the other focus group participants

#### 4. Questionnaires and guides

Questionnaires and focus group discussion guides for each of the proposed groups of respondents are attached – all based on option 1 outlined above. If it is decided to implement option 2, then the questionnaires, guides and matrices will be adapted accordingly. The focus group guides will be further refined following the initial testing of the questionnaires. The main groups of questions for each questionnaire are based on the inquiry framework in Table 1 above and are summarized here along with the introductory statement and consent request which is the same for all instruments.

##### 4.1 Questionnaire A – for 300 parents or carers

This questionnaire will be administered by the international consultants, national NGO and/or the data collection team seconded by the Ministry of Labour and Social Protection /State Statistics Committee. The data collection team will be trained by the international consultants to administer the questionnaire with maximum level of objectivity and accurate recording of responses by parents and carers (and children if children should also end up contributing answers). The questions will be read out to the respondents and in most cases responses will be checked off against a set of pre-tested options. Where an open questions have been asked, the data collection team will be trained to record as faithfully as possible the direct speech of respondents. The coded responses will be entered into a data matrix along with the qualitative data from direct speech and subject to both quantitative and qualitative analysis.

The household respondents will be identified by the NGO Yenme and from lists of registered disabled children provided by the Velayat authorities in three regions and as far as possible will follow the stratification proposed in the 'sample methodology' above.

The respondents relating to children in residential care will be identified prior to the visit of the data collection team to the institution in question. The residential institutions will be asked to identify children who fit the required criteria in terms of age, disability, gender etc. If their parents live nearby, then the residential institution will arrange for the interview to take place with the parents of the child identified in the sample. If the parents live too far away or if the child does not have parents, then the institution will nominate a staff member who knows the child best and who will be the respondent for the interview concerning the child. In all cases the family or the institution will be informed that the child does not have to be present for the interview, but if the child is interested, able and willing, then it is encouraged for the child to be present during the interview and to take part as appropriate.

#### A Introduction

To be read out by interviewer to respondent:

I am a staff member from the NGO Yenme (the State Statistics Committee... the Ministry of Labour and Social Protection...) which has been asked by UNICEF Turkmenistan and the Government of Turkmenistan to carry out this interview as part of a survey on children with disabilities in Turkmenistan that UNICEF is carrying out together with the Government of Turkmenistan. Yenme is an NGO working with children with disabilities and their families and with adults with disabilities (the State Statistics Committee is...the Ministry of Labour and Social Protection...). The research is being supervised and supported by a team of international experts who will also review all the information gathered as part of the survey and produce a report. The report will help to inform the policy and programmes of the

Government of Turkmenistan regarding children with disabilities and especially to support the development of social services for children with disabilities and their families. Social services are services that the Khyakimlik or an NGO can provide to families that help them to take care of their child. Over 300 people caring for children with disabilities in three velayats will take part in the survey. All information that you provide will be completely anonymised and summarized into the final report along with the information given by other parents and carers. There will be no benefit or harm to you or your family from taking part in this survey. It is a chance for you to share your experiences of caring for a child with disabilities and to contribute to the development of recommendations for improving services for children with disabilities and their families. There are no right or wrong answers to the questions that we are going to ask, please ask if anything doesn't make sense, please answer honestly and to best of your ability. Please ask if anything doesn't make sense or you don't understand the question, we can stop asking questions at anytime and if there are questions you don't want to answer, we can skip them. The questionnaire will take approximately 30-40 minutes. Do I have your consent to ask questions and record your responses in this form? Do you have any questions for me about this survey before we start? Please can you confirm that you are (respondent's name) mother/father/carer of (child's name) – I need to confirm this before we can begin, but I remind you that the interview will be completely anonymous. Thank you.

If the child with disabilities is present at the time of the interview, an additional statement should be read after this first statement if the child seems interested and able to take part in the interview:

May I talk to your child/to (name)? Have you heard what I have just said, does it make sense? These questions that I am going to ask your carer/parent are about you and your family, friends, education, health, activities – about your life. You can also answer if you want to, but you don't have to. You can correct anything your parent/carer says and add your own information. I am asking your carer/parent because he/she is your legal guardian and UNICEF and the Government of Turkmenistan wants to talk to adults rather than children this time as they think that adults can help to give a clearer picture of the situation for children with disabilities and their families. But we know that children can also give important information and insights and I want you to feel comfortable to contribute if you want to. Please don't hesitate to stop me if there is anything you don't understand and want repeated or if you want to skip any of the questions. Is that ok? Thank you.

#### B Basic Data

1. Name of child with disabilities who is the subject of this interview \_\_\_\_\_ Gender ☐ M ☐ F
2. Where do you/name's family live? \_\_\_\_\_ town/village  
\_\_\_\_\_ etrap \_\_\_\_\_ Velayat/City
3. Name's month and date of birth \_\_\_\_\_
4. Your relationship to (name)  
☐ Mother ☐ Father ☐ Grandmother ☐ Grandfather ☐ Institution care staff ☐ Institution teacher  
☐ Other (please describe) \_\_\_\_\_
5. Your education level:  
☐ Primary ☐ Incomplete secondary ☐ Secondary ☐ Secondary technical ☐ Higher
- 6 a). Your employment /employment of (name's) parents if known: ☐ Employed ☐  
Housewife/husband ☐ Unemployed ☐ Retired ☐ Other \_\_\_\_\_

6 b) Employment status of other parent/carer or other adults in the household (if different):

☐ Employed ☐ Housewife/husband ☐ Unemployed ☐ Retired ☐ Other \_\_\_\_\_

7. Your civil status/ civil status of (name's) parents: ☐ Single ☐ Married ☐ Widowed  
☐ Divorced ☐ Other \_\_\_\_\_

8. Your children/name's brothers/sisters:

No.	Year of birth	Gender	Does this child attend kindergarten or school? Yes/no

9. (For parents only) Does anyone help you to look after your child/ren?

	All the time	Sometimes	Never
1. Relatives who live with you	1	2	3
2. Relatives who don't live with you	1	2	3
3. Volunteers from NGOs	1	2	3
4. Friends and neighbours	1	2	3
5. The child's other parent who is not living with you	1	2	3
6. Staff from state services	1	2	3
7. Others _____			

10. Total number of people who live in your household/name's family household: \_\_\_\_\_

Who are the household members? \_\_\_\_\_

\_\_\_\_\_

11. Housing:

In which kind of housing do you and your family live/name's family live?

☐ apartment ☐ house

This housing is: ☐ Rented ☐ Privately owned by us/by name's family ☐ Privately owned by other family members ☐ Provided rent free by state ☐ Other (please describe)

\_\_\_\_\_

12. How would you describe the economic situation of your family/name's family? (*read out and ask the respondent to choose the most appropriate statement or give a print-out to the respondent so they can read and choose*)

1.	We /they don't have enough money for food	
2.	We/they have enough money for food, but buying clothes is a problem for us	
3.	We/they have enough money for food, clothes and small electronic and household items, but it would be difficult to buy a television, refrigerator or washing machine	
4.	We/they have enough money for buying large household items, but we can't buy a new car	
5.	Our /their earnings are enough for everything except for large purchases such as an apartment, an allotment or a dacha	
6.	We/they have no financial difficulties	
7.	I refuse to answer	
8.	I don't know	
9.	Other _____	

13. Level of name's body function:

Function	0	1	2	3	4
Seeing					
Hearing					
Speaking					
Walking					
Sitting					
Changing position					
Breathing					
Understanding speech or gestures					
Learning/comprehending					

0 = fully functioning 1 = mild dysfunction 2 = moderate dysfunction 3 = severe 4 = unable to function at all even with help

14. Level of name's ability in self-care activities:

Activity	0	1	2	3	4
Bathing					
Toilet					

Eating					
Dressing					

0=able to carry out 1 = needs some help 2 = needs regular help 3 = needs constant help 4= unable to carry out even with help

15. Medical diagnosis/-ses or health conditions (if any) \_\_\_\_\_  
 \_\_\_\_\_ and age at which disability was diagnosed

Certification of disability status \_\_\_\_\_ Age at which disability was certified

*(In the words of parents or main carers)*

At whose initiative did you apply for disability of the child to be certified and where did you apply?  
 \_\_\_\_\_

How did the process of establishing the child's disability status go? Where there any difficulties?

Tell me about your experience of passing the Commission that confers disability status.

#### 16. Type of care

a) Who is (name)'s main carer? ☐ Father ☐ Mother ☐ Grandmother ☐ Grandfather ☐ Older sibling ☐ Care staff in residential institution ☐ Other \_\_\_\_\_

b) Who else helps you (the main carer) in looking after (name)? ☐ Nobody else ☐ Father, Mother ☐ Grandmother ☐ Grandfather ☐ Older sibling ☐ Other relative ☐ Neighbour ☐ Friend ☐ Care staff in residential institution ☐ Social services staff (who/where?) \_\_\_\_\_ ☐ Teacher (who/where?) \_\_\_\_\_ ☐ Health staff (who/where?) \_\_\_\_\_ ☐ Other \_\_\_\_\_

c) Does (name) live mostly at home with his/her family? Yes/No

If not, where does (name) spend time when not at home?

1. Residential school 2. Sanatorium 3. Other medical institution 4. Residential pre-school or 24 hour kindergarten 5. In the home of relatives (who) \_\_\_\_\_  
 6. Other \_\_\_\_\_

d) *(for parents or main carers)* When you have to go out and can't take (name) with you, who looks after him/her? ☐ Nobody (she/he stays alone until I get back) ☐ Father ☐ Mother ☐ Grandmother ☐ Grandfather ☐ Older sibling/s ☐ Younger sibling/s ☐ Other relative ☐ Neighbour ☐ Friend ☐ Care staff in residential institution ☐ Social services staff

(who/where ☐ \_\_\_\_\_ ☐ Teacher (who/where?) \_\_\_\_\_ ☐ Health staff (who/where?) \_\_\_\_\_ ☐ Other \_\_\_\_\_

## C Activities and participation

### 17. Interpersonal interactions

#### *Family*

a) How much time does (name) spend with his/her brothers and sisters?

☐ He/she has no siblings ☐ All the time ☐ A lot ☐ Some time ☐ Very little ☐ None

If very little or none, why not? \_\_\_\_\_

b) *(for parents or main carers)* How much time do you spend with (name)?

☐ All the time ☐ A lot ☐ Some time ☐ Very little ☐ None

How much time is this each day in hours \_\_\_\_\_

If very little or none, why not? \_\_\_\_\_ *(prompts: other demands on time include other children, household tasks, work/job, other household members requiring care,)*

*If all the time, why?* \_\_\_\_\_ *(prompts: requires*

c) Do you or other family members need help to communicate with (name)? Yes/No/I don't know What kind of help do you think you need?

\_\_\_\_\_ *(prompts: learn sign language, learn alternative means of communication, learn to understand sounds/speech/gestures/behaviours)*

d) Does (name) need help to establish relationships? Yes/No/I don't know What kind of help do you think he/she needs? \_\_\_\_\_

#### *Friends and peers*

e) Does (name) have friends? How often does he/she see them? Where?

f) Does (name) go out and play with other children? Where?

g) Does (name) have friends at school? Does he/she see them outside of school?

### 18. Education and learning

a) Does (name) go to school/pre-school/college or receive home schooling? Yes/No If no, why not \_\_\_\_\_? *(prompts: I tried, but was refused; I haven't tried; I want my child to be at home with me)*

b) If school, which school:

Level: ☐ pre-school ☐ primary ☐ secondary ☐ higher or vocational

Type: ☐ residential ☐ day school ☐ weekly boarding ☐ special school ☐ mainstream ☐ home school ☐ Other \_\_\_\_\_

Attends every day? Yes/No If not, why not? \_\_\_\_\_

Does (name) enjoy going to school? Yes/No

If yes what does he/she like about it? If no, why not? \_\_\_\_\_

c) If school, how long does it take to get to school each day? \_\_\_\_\_ How does (name) go to school? \_\_\_\_\_

d) If home schooling, how often does the teacher come? \_\_\_\_\_ How long does the teacher spend? \_\_\_\_\_ What is the curriculum like in your view? \_\_\_\_\_ Does (name) enjoy the lessons? \_\_\_\_\_

e) In your view is (name) receiving a good quality education? Yes/no How can it be improved (if at all)? \_\_\_\_\_

f) Is (name) making good progress in education? What results have you noted so far in his/her education? \_\_\_\_\_

19. Leisure and play (*a-e for older children; f for all children*)

a) Does (name) take part in any activities or clubs? Yes/No

b) If no, why not? \_\_\_\_\_

c) If yes, which ones? ☐ sport ☐ arts and crafts ☐ music ☐ drama/dance ☐ others \_\_\_\_\_ Where \_\_\_\_\_

d) Are there any activities that (name) would like to take part in but doesn't? ☐ sport ☐ arts and crafts ☐ music ☐ drama/dance ☐ others \_\_\_\_\_

e) How often does (name) play with other children? \_\_\_\_\_ Where? \_\_\_\_\_

f) (*For children of all ages*) Are there any other play activities that (name) takes part in? Yes/No If yes, which ones \_\_\_\_\_ Where and how often? \_\_\_\_\_

20. Preparation for independent living (*for older children aged over 12 years*)

a) Self-care – does (name) know how to care for him/her self? Is he/she learning these skills?

Activity	Can already do this independently	Yes, is learning	Who is teaching him/her?	No, is not learning	Why not?
Bathing					
Toilet					
Eating					
Dressing					



b) Managing a household and daily tasks – does (name) know how to use money, transport or go to the store? To cook, clean and look after the home? Is he/she learning these skills?

Activity	Can already do this independently	Yes, is learning	Who is teaching him/her?	No, is not learning	Why not?
Using money					
Using transport					
Going to the store					
Cooking					
Cleaning					
Looking after the home					

c) Preparing for employment (from 12 years) – does (name) know what he/she wants to do in future? Is he/she receiving an education that can help him/her to do this type of work? Who is helping him/her with these tasks and activities?

Activity	Can already do this independently	Yes, is learning	Who is teaching him/her?	No, is not learning	Why not?
Careers advice					
Seeking employment					
Learning a trade					
Acquiring relevant qualifications					

## D Environmental factors

### 21. Health and rehabilitation

- Does (name) need any assistive devices to support mobility, communication, standing, sitting, seeing, hearing, other \_\_\_\_\_
- Does (name) have these devices? Who provided them and fitted them?
- If not, why not?
- Do the health services help to increase functioning in:

Function	Y	N
Seeing		
Hearing		
Speaking		

Walking		
Sitting		
Changing position		
Breathing		
Understanding speech or gestures		
Learning/comprehending		

How? Please describe your experiences of health and rehabilitation services for (name) \_\_\_\_\_

How far away are they? \_\_\_\_\_ How long does it take to get there? \_\_\_\_\_

How do you get there with (name) \_\_\_\_\_ How much do these services cost?

\_\_\_\_\_

## 22. Social Services and Social Support

- a) Do you or (name) receive or use any social services? NGO, religious organization, local Women's Committee, Khyakimlik? What kind of services \_\_\_\_\_?
- b) Do you (does name) receive social benefits? Yes/No What kind? \_\_\_\_\_

Why/why not? \_\_\_\_\_

- c) Does (name) have access to community services? Y/N Please describe \_\_\_\_\_  
(for older children) Does (name) have access to community based youth activities? Y/N  
Please describe \_\_\_\_\_

Does (name) have access to employment services? Y/N Please describe  
\_\_\_\_\_

(for younger children) Does (name) have access to Early intervention services? Y/N Please describe \_\_\_\_\_

Day care/ child care? Y/N Please describe \_\_\_\_\_ (prompt  
– can be formal or informal ie provided by relatives or community members)

How far away are they? \_\_\_\_\_ How long does it take to get there? \_\_\_\_\_

How do you get there with (name) \_\_\_\_\_ How much do these services cost?

\_\_\_\_\_

23. If you don't know about any such 'social' services – why don't you know about them do you think?
24. Where would it be convenient for you to find out about social services? What is the best way to inform you about them? (prompts: radio, local television, national television, word of mouth from neighbours and friends, education organization, health organization, religious organization, community notice board, social benefits office, Khyakimlik, local newspaper, national newspaper, sms message on your mobile phone, internet (email or social networking sites), other \_\_\_\_\_)

## 25. Needs (for children living at home)

- a) Do you need help in providing day to day care for (name) – toilet, feeding, dressing, bathing? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- b) Do you and other family members need help in learning how to communicate with (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- c) Does (name) need help in learning how to communicate with you and other family members? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- d) Do you need help in developing your relationship with (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- e) Do you need help in improving your parenting skills and managing the behaviour of (name) and your other children (if any)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- f) Do you need help in reducing stress in the family or improving relationships between family members? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- g) Do you need help to find out about activities for (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- h) Do you need help in supporting (name) to make friends with other children at school, at home in the neighbourhood? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- i) Do you need help in supporting (name) to learn self-care skills? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- j) Do you need help in supporting (name) to learn independent living skills? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- k) Do you need help in getting (name) to school and to other activities? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- l) Do you need help in accessing assistive technology and qualified medical specialists for (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- m) Does (name) need assistance in order to go to mainstream school or preschool or to do better at school? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- n) Do you need help to claim benefits or find material support for (name) and your family? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- o) Do you or any family member need help with alcohol, drug or other addictions? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- p) Do you or any family member need help with mental health problems such as depression? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- q) What other help to you need (if any) \_\_\_\_\_
- r) What other help does (name ) need (if any) \_\_\_\_\_

## 26. Needs (for children living in residential institutions)

- a) Does (name) need help with toilet, feeding, dressing, bathing? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- b) Does (name) need help in learning how to communicate with you and other carers/ other children? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- c) Do you need help in learning how to communicate with (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer

- d) Do you need help in developing your relationship with (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- e) Do you need help in improving your care skills and managing the behaviour of (name) and other children (if any)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- f) Do you think (name's) family needs help in reducing stress in the family or improving relationships between family members? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- g) Do you need help to find out about activities for (name)? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- h) Do you need help in supporting (name) to make friends with other children at school, at home in the neighbourhood? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- i) Do you need help in supporting (name) to learn self-care skills? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- j) Do you need help in supporting (name) to learn independent living skills? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- k) Does (name's) family need help in getting (name) to school and to other activities? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- l) Does (name) need help in accessing assistive technology and qualified medical specialists? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- m) Does (name) need assistance in order to go to mainstream school or preschool or to do better at school? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- n) Does (name) and his/her family need help to claim benefits or find material? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- o) Do any of (name's) family members need help with alcohol, drug or other addictions? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- p) Do any of (name's) family members need help with mental health problems such as depression? 1. No 2. Yes some help 3. Yes, a lot of help 4. I don't know 5. I don't want to answer
- q) What help do you think (name's) family needs in order for him/her to live with them?  
\_\_\_\_\_
- r) What help to you need (if any) to better help/education/care for (name)?  
\_\_\_\_\_
- s) What other help does (name ) need (if any) \_\_\_\_\_

27. Thank you for taking the time to answer these questions. Is there anything else you want to say about how services for children with disabilities should develop in Turkmenistan?

#### 4.2 Focus group guide for parents

The focus group guide for parents of children with disabilities and for parents of children without disabilities aims to explore in more depth cultural and attitudinal issues and questions, the barriers to inclusion and participation and the potential for overcoming these barriers. Ideally these focus groups will be conducted after an initial round of household and institution interviews have already taken place so that this guide can be adjusted to explore any issues that may arise. The outline below is therefore a first draft only and will be adjusted ahead of the focus groups being conducted on the basis of initial testing of the main questionnaire. All focus group participants will be asked to complete a 'basic data questionnaire' (Questionnaire B – below) in order to support analysis of the qualitative data.

**1. Introduction** – overview of the survey, anonymity, consent to participation, consent to recording the discussion and if not given, then consent to notes being taken. Handing out 'Questionnaire B' to record basic information about each participant based on the basic information section in the main questionnaire.

**2. Attitudes to children with disabilities in the community?** How are these attitudes expressed? Why? Is there stigma attached to child disability? Are parents perceived as being at fault?

**3. Barriers to inclusion:** in the community, at pre-school, school, college/university? Where else do you think children with disabilities face barriers and obstacles to inclusion?

For parents of non-disabled children: how would you feel about children with disabilities going to your child's school/pre-school/university? Why? How would you feel about CWD being in your child's class? How would you talk to your child about this if it were to happen? What information would you need to feel ready to accept a child with disabilities in your child's class, what information would you need to help your child feel ready to accept a child with disabilities in their class?

For parents of disabled children: how would you feel about your child with disabilities going to a mainstream school/pre-school/university? Why? How would you feel about your CWD being in a class with children without disabilities? How would you talk to your child about this if it were to happen? What information would you need to feel ready to place your child into mainstream education settings? What information would you need to help your child feel ready to accept a child with disabilities in their class? Would your children need assistance in a mainstream setting? What kind of assistance is most important and useful in your view?

**4. Needs and services:** what are the needs for support of families and children with disabilities themselves, how can these needs be met? By whom?

For parents of disabled children - needs and services to meet needs of children and families: what are your greatest needs in looking after your children? How can the Khyakimlik and the local community help to meet these needs? How can children with disabilities participate more in the life of the city/local community? What do families of non-disabled children have to do to help inclusion? What do children themselves have to do? How can adults help them to do this?

For parents of children without disabilities – what do you think, what help to families of children with disabilities most need? How can these needs be met? What is your role in meeting these needs (if any)? How can children with disabilities participate more in the life of the city/local community? What do families of non-disabled children have to do to help inclusion? What do children themselves have to do? How can adults help them to do this?

**5. What do you think needs to happen in national/Velayat policy for children with disabilities to participate more in normal life? What do you think needs to happen in communities, in the etraps?**

(prompts for all questions to include: family life, play and leisure, education, health, participation in society/community events and activities, transport, physical environment, assistive technology and equipment)

#### Questionnaire B – Focus Group Participants Basic Data – Parents

Where do you live? \_\_\_\_\_ town/village

\_\_\_\_\_ etrap \_\_\_\_\_ Velayat/City

**Gender:** ☐ M ☐ F

**Age:** \_\_\_\_\_ years

**Education:** ☐ Primary ☐ Incomplete secondary ☐ Secondary ☐ Secondary technical ☐ Higher

**Employment:** ☐ Employed ☐ Unemployed

**Civil status:**    ☐ Single        ☐ Married        ☐ Widowed    ☐ Divorced

**Children:**

No.	Year of birth	Gender	Does you child attend kindergarten or school?

If one or more of your children has disabilities, please note here what they are:

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**Does anyone help you to look after your child?**

	All the time	Sometimes	Never
1. Relatives who live with you	1	2	3
2. Relatives who don't live with you	1	2	3
3. Volunteers from NGOs	1	2	3
4. Friends and neighbours	1	2	3
5. The child's other parent who is not living with you	1	2	3
6. Staff from state services	1	2	3
7. Others _____			

**Housing:**

In which kind of housing do you and your family live?        ☐ apartment    ☐ house

This housing is: ☐ Rented    ☐ Privately owned by us ☐ Privately owned by other family members

☐ Provided rent free by state    ☐ Other (please describe)

**Who lives in your household?** \_\_\_\_\_

**How would you describe the material situation of your family?**

1.	We don't have enough money for food	
2.	We have enough money for food, but buying clothes is a problem for us	
3.	We have enough money for food, clothes and small electronic and household items, but it would be difficult to buy a television, refrigerator or washing machine	
4.	We have enough money for buying large household items, but we can't buy a new car	
5.	Our earnings are enough for everything except for large purchases such as an apartment, an allotment or a dacha	
6.	We have no financial difficulties	
7.	I refuse to answer	

## B Overview of Field work

### Ethical considerations

The methodology, sample and tools were reviewed by the OPM Ethical Review Committee (ERC) who provided the following comments:

*“The ERC recommends obtaining written verbal informed consent from the parents of the disabled children and for record review. Verbal consent is sufficient for the focus group discussions and key informant interviews.”*

*“Please clarify the role of the local NGO and their involvement in the implementation of the project and the potential conflict of interests would be mitigated if the NGO is engaged in the implementation.”*

With regards to the first point, P4EC/OPM responded that we would ask for written consent from the parents, but if they did not agree, then the interviewer would sign to say they have received verbal consent. On the second point, P4EC/OPM stated that the NGO is used because it can facilitate access to disabled parents and to ensure that ‘nothing about us without us’ principle is upheld. In addition, Yenme is not an activist disability NGO, rather it provides services to adults and children living with disabilities and the NGO has no particular agenda to promote other than wanting things to be generally better for them. P4EC/OPM ensured that there were as many closed questions as possible, for international consultants to conduct the research with Yenme at the start, and for as much quality control and supervision to occur as possible. The full response to the Ethical Review Committee is available on request.

Ten government staff and NGO workers from Yenme were trained at the UNICEF Office on 30 September 2014. The day started with training on defining disability, and why certain questions are not asked in disability surveys. Trainees were reminded about the outline and aims of the study, as well as a specific work plan for the initial week and a tentative plan for the rest of the project. The methodology was explained as well as the sample that the project was aiming for. The capacity of trainees was raised in the importance of being objective, friendly, knowing the questionnaire thoroughly, speaking slowly and accurately recording answers. Ways in which verbal and non-verbal feedback can be given were described and suitable techniques for probing were discussed. Trainees also learned about how quality control will be integrated into the data collection.

The majority of the day was spent examining the preliminary questionnaires for children in families and children in institutions.<sup>12</sup> Svetlana Rijicova, as the lead trainer, went through the question by question making sure that trainees knew what the question was asking, and about the possible answers. Opinions from the group were elicited on wording and phrasing, and on the set of answers. Changes were made to some questions, which were projected onto the wall for all the group to see and agree on before moving on. Where open questions were asked, trainees were trained to record as faithfully as possible the direct speech of respondents. In the last session, the Government and NGO representatives were asked to review the matrix to make sure that they were comfortable with how data would later be entered.

Piloting was held on the next day, 1<sup>st</sup> October, at the Yenme office as the location was known to many families in the area. Some parents/carers attended in the morning and some attended in the afternoon. Most of the parents/carers signed the informed consent form, but where they felt uncomfortable the interviewer signed that the respondent was happy to be questioned. No parents refused to be interviewed. After the piloting, the questionnaire was fully translated into Turkmen by the UNICEF National Survey Coordination Consultant for use during the data collection.

Survey data collection took place from 1 October to 20 November by Yenme staff, in the areas of Ashgabat, Lebap and Ahal. In total, 150 parents/caregivers who live in the family were interviewed, and the questionnaire was also administered to 151 children who are in institutions.<sup>13</sup> The sample was evenly distributed across the three regions (some are more urban than others) and the aim was to achieve a range of disabilities, ages and genders.<sup>14</sup> Household respondents were identified by Yenme and from lists of registered disabled children provided by Velayat authorities. The pre-defined questions were read out to respondents and in most cases the responses were checked off against a set of pre-tested options. Visiting each individual household, especially outside of Ashgabat, proved to be cumbersome and timely. Therefore an approach was taken to invite families to one home and interview them all together. Small gifts were given as an appreciation of the respondents' time and a leaflet was handed out by Yenme which gave information what the services they can provide support on. Some respondents were asked questions in Russian and others in Turkmen depending on their preference. Where the child was able and willing, he/she participated in the interviews but in most cases this did not happen.

The government provided permission for Yenme staff to collect data from institutions. Respondents from institutions were identified prior to the visit of the data collection team, with a request for children that fit the required criteria in terms of age, disability, gender and so on. The NGO workers first asked to speak with the parents, and if they were available then the residential institution would facilitate the meet-up. If the child did not have parents or they live too far away then they requested to speak with the caregiver who knows the child best, using data from the child's file if necessary. Coded responses were regularly entered into the data matrix along with the qualitative data from direct speech. Data collection was monitored by the international consultants on a regular basis, and the matrix was subject to qualitative and quantitative analysis.

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<sup>12</sup> The differences between the two questionnaires were minimal.

<sup>13</sup> A sample of 151 children in institutions is approximately a 10% sample of all children with disabilities in institutions in Turkmenistan.

<sup>14</sup> An aim was to have a sample that included 20 percent intellectual disabilities, 20 percent motor disabilities, 10 percent low sensory functioning, 10 percent speech dysfunction and 40 percent combined.



Three focus groups with parents of children with disabilities (total number of participants—25) and three focus group discussions with parents of children who do not have disabilities (8 participants) took place across the three regions. Focus groups with parents of disabled and non-disabled children occurred in the same community for comparisons to be made at the analysis stage. One interview was conducted with a mother of a child without a disability in Turkmenabat. The qualitative data enriched and deepened the findings from the survey, providing information on how best to support families to care for their children in the community, how to work with communities to increase acceptance of children with disabilities and to reduce discrimination and stigma. It identified gaps in services and barriers to inclusion.

## Annex 4 Characteristics of the sample of children about whom data was gathered

Figure 1: Institution/Family setting

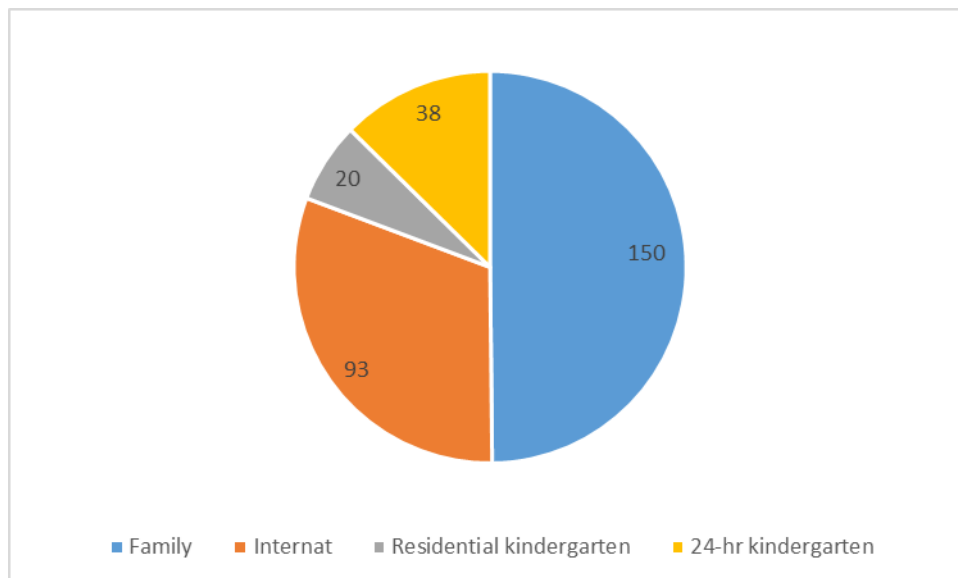


Figure 1 above shows that approximately half of children live in family settings, nearly a third are in internats and the rest are in residential kindergartens and 24-hour kindergartens. This mirrors the intention of the study which was to gain results from children in family settings and from children in a range of institutions in a 50:50 ratio.

Figure 2: Gender of Child

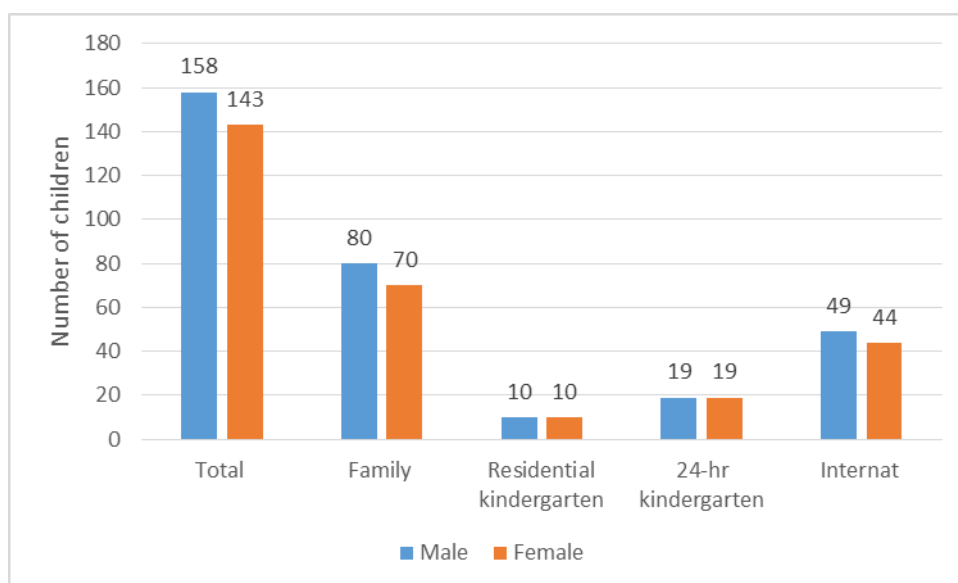


Figure 2 shows there were 15 more boys than girls in the sample. There were an even number of females and males in the residential kindergartens and the 24-hour kindergartens, while males were slightly overrepresented in the family and in the internat (ten and five more males respectively).

Figure 3: Age of Sampled Children

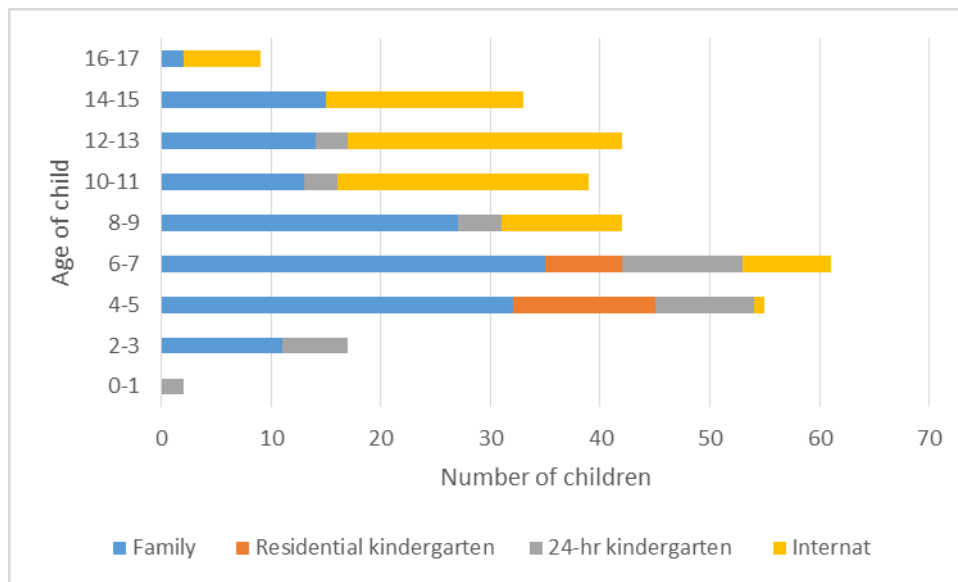


Figure 3 shows the age distribution of the sampled children. As can be seen, most children in the sample belonged to the 4-15 age category. There were only children aged 4-7 years old in the residential kindergarten and there were no older children sampled in the 24-hour kindergarten and only 1 child that was less than 7 years old in the Internat. Most children based in a family setting were in the 4-7 age group.

**Table 2: Averages and Range for Children's Age**

	Family	Residential kindergarten	24-hour kindergarten	Internat	Total
Mean (to nearest year)	8	5	6	12	<b>9</b>
Median	8	5	6	10	<b>8</b>
Mode	6	5	6	13	<b>6</b>
Range	14	3	13	12	<b>17</b>

Table 1 shows some summary statistics for age. In general, it shows that the average age was higher in the Internat, followed by children in family settings and then those in the 24-hour kindergarten. Children in the residential kindergarten were, on average, the youngest children to be sampled in the survey.

**Figure 4: Respondent**

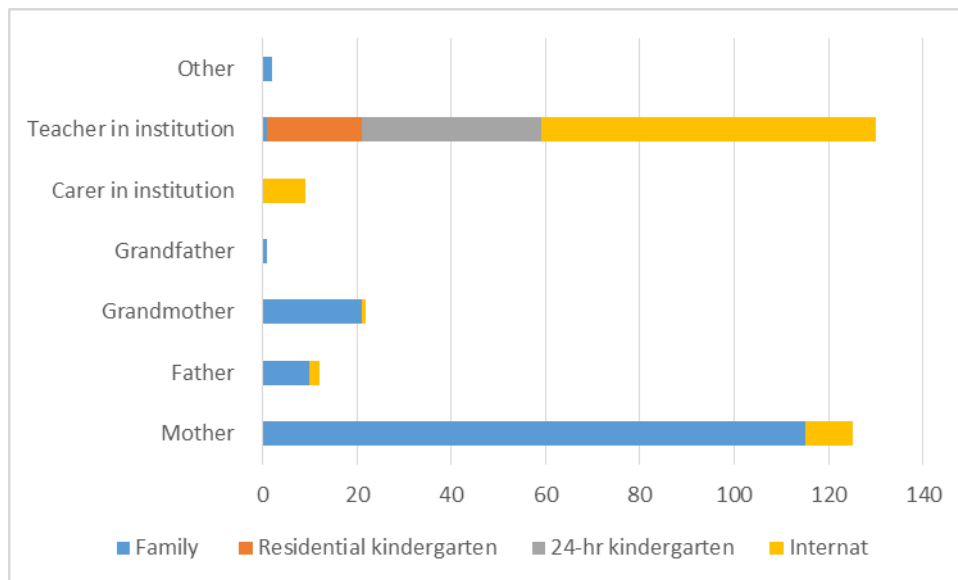


Figure 4 depicts the respondent who answered the survey questions. For children based in the family, 77 percent of respondents were mothers and 14 percent were grandmothers, suggesting that it is women in the family who spend most time with the children and are deemed most responsible for their welfare. For children in institutions it is teachers who usually answered the survey questions (85 percent).

**Figure 5: Education of Respondents**

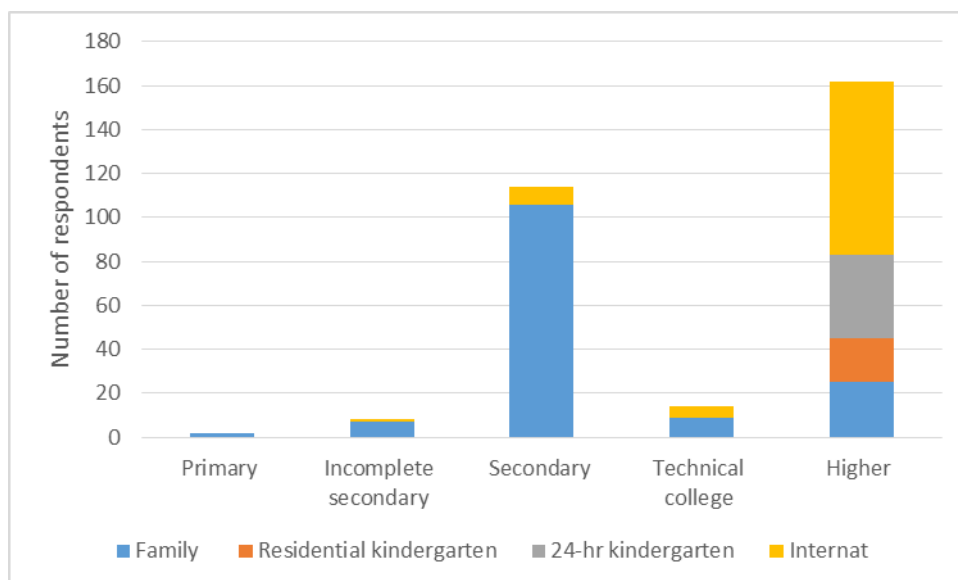
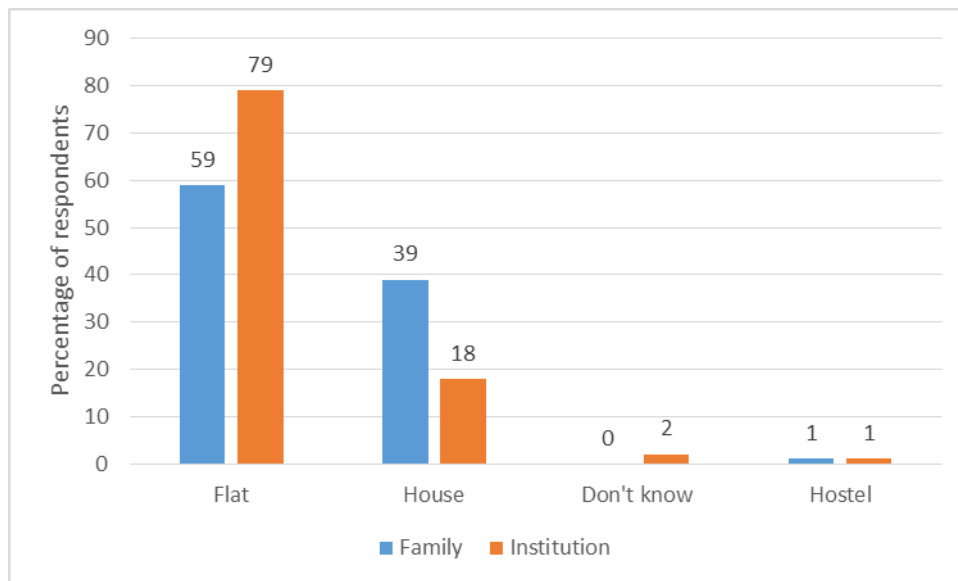
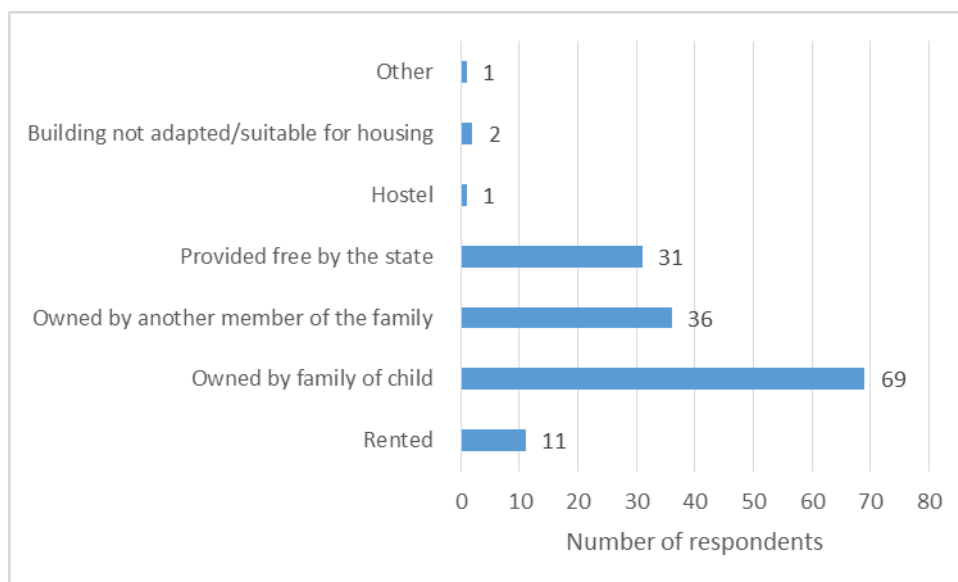


Figure 5 shows that respondents that have children in the family have a lower education level than respondents whose children are in institutions. For example, 91% of respondents in institutions reported that they have a higher education qualification compared to only 17% of respondents that have children in the family setting. This is presumably because respondents from institutions are usually teachers (see Figure 4), and therefore require a university degree for their job. Most respondents whose children are in family settings only have a secondary education.

**Figure 6: Accommodation type**

N= 243 (147 from children in families and 96 from children in institutions)

Figure 9 provides evidence that children living in institutions are more likely to have a household that lives in a flat than a house, whereas vice versa is true for children living in families.

**Figure 7 Housing tenure**

As Figure 10 presents, most children (69 out of 151) live in a house that is owned by their family. Less children are from rented accommodation. The vast majority of respondents who answered this question were answering on behalf of children who were living in families.

**Table 2 Frequency of contact reported by directors for children with disabilities in residential boarding schools of different types**

% of children with daily/weekly/monthly contact with family	Urban helping internat school A	Urban helping internat school B	Urban helping internat school C	Urban boarding school for children with intellectual disabilities	Urban boarding school for children with hearing impairments	Urban boarding school for children with sight impairments	Rural specialised boarding school	Urban specialised boarding school	Urban specialised boarding school	Urban specialised boarding school	Average for 10 residential schools
daily contact	18%	29%	1%	10%							6%
weekly contact	67%		88%	60%	69%	61%	33%	74%	55%	75%	58%
2-3 times per month	9%		2%	30%	31%	34%	67%	20%	9%	18%	22%
monthly	6%	14%				5%	0%	6%	36%	7%	7%
not specified		57%	10%								7%

There is a difference between the rural specialized boarding school and the other boarding schools which are all based in urban settings and which have very similar patterns of contact with over 60% of children having weekly contact and most of the remainder having contact 2-3 times per month. Some directors report quite high levels - 29% or 18% - of children in their residential schools going home at night (ie in daily contact with family).

### Preparation for independent living

The study examined whether disabled children had developed the basic skills showing their readiness for independent life. This group of skills include: self-care skills (bathing, toilet, eating and dressing), daily tasks (using money, transport, shopping, cooking, cleaning, and housekeeping), and readiness for employment.

Parents of children with disabilities assessed development of self-care skills in their children as follows: bathing - 24 children (15.9%), toilet - 37 children (24.5%), 46 children (30.5%) can feed themselves, and 33 children (21.9%) can dress themselves. Another group of parents/care-givers teach their children self-care skills. Most often, the role of adults teaching children self-care skills is played by mothers. Only in 2 cases, the role of teachers was played by fathers, in 2 cases by both parents, and in 3 cases by grandmothers. The number of families teaching their children self-care skills is greater than the group of children with developed self-care skills. According to study findings, 47 parents (31.1%) teach their children to bathe themselves, 46 parents (30.5%) teach their children to use toilet, 44 parents (29.3%) teach their children to feed themselves, and 53 parents (35.1%) teach their children to dress themselves.

The group of parents/care-givers who do not teach self-care skills to their children is even more numerous. 64 parents/care-givers (42.4%) do not teach their children to bathe independently, 51 parents (33.8%) do not teach their children to use toilet, 43 parents (28.5%) do not teach their children to feed themselves, and 48 parents (31.8%) do not teach their children to dress themselves. To specify, parents gave the following arguments: "doesn't understand, serious diagnosis", "small, not adapted" (6 years old, ICP), "doesn't learn, it's too early" (6 years old), "won't learn it", "won't be able to", "won't learn it, is mentally retarded", and "doesn't manage". All these explanations show underestimation of the possibilities and capacities of the child, unwillingness to think about the child's future and the need to lead an independent/relatively independent lifestyle. "Doesn't learn (to feed themselves), poor appetite, it's easier to do it myself" (6 years old), "doesn't learn, won't manage alone" (12 years old, mental retardation).

39.3% of institutionalized children have developed such self-care skills as using toilet, feeding, and dressing. The ability to bathe independently has developed in a less number of children (29.3%). 29.3% children need assistance of an adult in order to bathe and are in the process of learning this skill. 22.7% children need help in order to learn using toilet, feeding and dressing. Most often, the adult helping and teaching self-care skills to the child is a teacher at the boarding school (13.3%) or the child's mother (4.7%).

Among daily and routine actions considered in the process of study, the focus was placed on the ability to use money and transport, to go shopping, to cook, to clean and to do housekeeping. The collected information shows that institutionalized children have different levels of ability to perform daily tasks: 8 children (5.3%) can use money, 8 children (5.3%) can go shopping, 13 children (8.7%) can clean, and 12

children (8%) can do housekeeping. At the same time, none of the children can independently use transport or cook. Nevertheless, children learn to manage with the daily tasks with the help of their mothers, fathers, grandmothers and educators: 26.7% learn using money, 30.7% using transport, 30% cooking, 28% cleaning, and 28.7% housekeeping. According to the data, 11 children (7.3%) do not have and do not learn skills to perform daily tasks.

As for development of abilities to perform daily tasks in children from families, parents/care-givers assessed independence of children in everyday life as follows: 13 children (8.6%) can use money, 6 children (4%) can use transport, 12 children (7.9%) can do shopping, 8 children (5.3%) can cook, 16 children (10.6%) can clean the house, and 22 children (14.6%) can do housekeeping. Parents teach their children to do the following: use money - 21 parents (13.9%), use transport - 21 parents (13.9%), go shopping - 22 parents (14.6%), cook - 24 parents (15.9%), clean the house - 29 parents (19.2%), and do housekeeping - 27 parents (17.9%).

Most of parents/care-givers do not develop abilities to perform daily tasks in their children. Thus, 71 parents (47%) do not teach their children to use money, 77 parents (51%) do not teach their children to use transport, 72 parents (47.7%) do not teach their children to do shopping, 71 parents (47%) do not teach their children to cook, 59 parents (39.1%) do not teach their children to clean the house, and 56 parents (37.1%) do not teach their children housekeeping. The motivation behind can be explained by parents' distrust, underestimation of their child's abilities: "doesn't learn anything, because doesn't understand, it's too difficult for her", "he won't be able to do it on his own", "we don't teach going shopping, because it's unnecessary", "doesn't learn, she's too little, there's no need", "in a wheelchair". Some explanations reflect lack of an adapted environment: "doesn't learn to use transport, won't manage, it's dangerous, if there had been a special transport than would have used it". The role of people who help children acquire skills to perform daily tasks is played by the same people who help them acquire self-care skills: most often, these are mothers, in some cases – the child's father, grandmother, sister.

Lack of understanding, distrust in children creates barriers to learning skills of independent everyday life organization and satisfaction of daily needs. This attitude and applied educational strategies do not contribute to development of children's independence; on the contrary, make them more dependent on the care-givers.

Parents/care-givers were asked whether they knew what their children would like to do in the future. Only 12 parents (7.9%) know/have talked to their children about it. Among the mentioned professions: "IT", "would like to become an imam (clergy)", "a singer". 43 parents (28.5%) answered negatively, and 23 (15.2%) said they did not know. Arguments supporting unawareness: "I have been thinking about it, but most probably he won't be able to" (a child in a wheelchair), "doesn't know what would like to do", "will she be able to do it?", "nobody is going to give a job anyway", "where can he go with his diagnosis?", "there's no need, the child's got a mother", "cannot decide, doesn't understand". The received answers show parents' unawareness about the capabilities of their child, especially in prospect, as well as about total unawareness about the possibilities of professional integration of children with various health conditions.

The study was interested in preparation of children with disabilities for employment and their career orientation. Parents/care-givers told about the preparation of children for employment and assistance they were receiving in this process. Only 3 parents said they were teaching their child occupational skills: "career orientation, learns, grandmother", "learns, mother". 17 parents (11.3%) said they did not teach children and 5 (3.3%) said they knew nothing about this aspect: "Learning a trade - no, doesn't learn, there's no possibility, we haven't thought about it". The rest (83.4%) did not answer this question.

As for the future employment of institutionalized disabled children, no answer was received with regard to the desired future for the children. All the received information consisted of negative answers and no answers. The received answers showed total unawareness of educators and teachers about their pupils' plans for the future. Moreover, children in institutions do not receive any help in preparation for future

employment: help in career orientation, job search, according to the received data, they do not learn the basics of a trade. Such findings could be conditioned by the young age of children or lack of the corresponding components in the syllabus of special residential institutions.

### Information channels trusted by parents

The responses of parents/care-givers themselves is covered in the first column and the opinion of residential staff about where the parents of children in residential care could find information are recorded in the second two columns:

For parents of disabled children	No. of	For parents of institutionalized	No. of
Healthcare institutions	64	National TV	91
National TV	41	Healthcare institutions	57
Social Welfare Office	38	Local TV	55
Neighbors	31	Local newspaper	52
Local newspaper	29	Educational institutions	46
Friends	28	Social Welfare Office	7
Local TV	26	Khyakimlik	7
SMS to mobile telephone	21	Neighbors	5
Khyakimlik	14	Radio	5
National newspaper	13	Friends	3
Public information board		Public information board	3
Internet (e-mail or social media)		SMS message to mobile phone	3
Educational institutions	10	National newspaper	3
Radio	9	Internet	1
Billboards	6	Billboards	0
Religious organizations or mosque	0	Religious organizations or mosque	0

Among other information communication channels acceptable for parents of children with disabilities, they mentioned: "community-based non-governmental organization" (referred to in 11 cases), "calling on the home telephone", "gathering people in a place and telling them, maybe at NGO", "putting up information at banks, kindergartens".

According to the opinion of residential institution staff, the most adequate ways of transmitting information on social services are national and local media, healthcare and educational institutions. High level of trust by residential institution staff in educational institutions as the source of information about social services is conditioned by high appreciation of institutions in the system they belong to.

The received data shows that the most suitable way to inform parents with disabled children is through healthcare institutions - by GP or medical specialists. Because of the health condition of children, physicians are perceived by parents as competent, most frequently visited specialists who can provide all kinds of information related to child care and treatment. Mass media (national and local) are also part of the most trusted sources. Information transmission by word of mouth from other parents with disabled children and neighbors is also significant. A non-governmental community-based organization as a source of information for parents was indicated only in 11 cases.

### Needs of children and families – survey respondents perceptions

	Children in families – parent responses	1	2	3	4	5
	Needs	No	Yes, some help	Yes, a lot of help	I don't know	I don't want to answer
a)	In daily child care: toilet, feeding, dressing, bathing	74	40	28	-	-
b)	To learn to communicate and develop a good relationship with the child	97	26	15	1	-
c)	To improve your parenting skills and to manage the	83	15	20	2	-



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	behavior of your child and other children (if any)					
d)	To reduce stress in the family or to improve relationships between family members	89	21	24	2	-
e)	To learn more about activities or clubs for the child	23	47	66	1	-
f)	To help the child make friends at school, at home, in the neighborhood	70	36	15	-	-
g)	To help the child learn self-care skills	39	47	48	1	-
h)	To help the child get ready for independent life	28	46	56	1	1
i)	To help the child in getting to school, kindergarten and other places of activities	78	27	21	2	-
j)	To help the child do better at school	75	35	20	-	-
k)	To get access to assistive technologies for the child	40	31	62	-	-
l)	To get access to the services of qualified healthcare staff for the child	15	26	93	-	-
m)	To claim benefits or material aid for the child or the family	37	34	62	-	-
n)	To you or other family members to solve problems of alcohol, drug or other type of addiction	127	-	5	-	-
o)	To you or other family members to manage such issues of mental health as depression	98	18	16	1	-
p)	To help the child better communicate with you and other family members	87	21	19	1	2

The data from the table shows that families with disabled children need most help in terms of getting access to services of qualified healthcare staff, to activities and clubs for the child, to assistive technologies for the child, as well as to material aid to cover the child treatment-related needs.

Additionally, the study gathered information about help and support required by families with disabled children. The received data shows that material aid for medicine procurements and child treatment is most needed by families (66 people - 44%), only one family said they did not have any financial problems. 19 respondents (12.7%) need help in solving a housing issue: getting housing, expanding the living space, exchange of housing for the ground floor ("we live on the third floor"). Also, under the types of help needed by families, they mentioned: psychological counseling and moral support (8 respondents), information and literature for parents (5 respondents), food packages (9 respondents), and help in getting disability certification (4).

Additional information about the help needed for the child included: quality and free-of-charge treatment, including abroad (28); qualified specialists (36), such as physicians, speech therapists, disability correction specialists, teachers; free-of-charge medicines - "the expensive ones" (16); support technologies, such as wheelchairs (12), walking aid (2), orthopedic footwear (2), hearing aids (2), toilet bowl (1). Families indicated the need for specialized and support services for children: specialized centers (3); free-of-charge massage (4); child development places/programs (15), communication with children and time-spending/activities (13); health resort therapy (4); taxi/transport adapted to the disabled (2); training programs for independent living (2); diapers (5). Also, some parents mentioned the need for help to pass the medico-educational commission, to get the child employed, to enroll them in school.

The knowledge of residential institution staff about the needs of children with disabilities and their families (150 respondents) is presented in the following answers.

	Children in residential institutions – staff responses	1	2	3	4	5
	Needs	No	Yes, some help	Yes, a lot of help	I don't know	I don't want to answer
Help for the child						

a)	In using toilet, feeding, dressing, bathing	17	44	-	-	-
b)	To learn communicating with you and other staff/children	17	43	1	-	-
c)	To improve school performance	2	57	2	-	-
<b>Help for the child's family</b>						
d)	To reduce the level of stress in the family or to improve relationships between family members	4	42	1	14	-
e)	To help the child get to the boarding school or other places of activities	-	46	-	14	-
f)	To have access to assistive technologies for the child	1	12	14	-	-
g)	To have access to services of qualified healthcare staff for the child	-	45	15	-	-
h)	To receive benefits or material aid	15	12	-	-	-
i)	For family members to solve a problem of alcohol, drug or other addiction	1	13	-	14	-
j)	For family members to manage problems of mental health, such as depression	34	11	-	14	-
<b>Help for staff</b>						
k)	To learn communicating and to develop a good relationship with the child	15	45	-	-	-
l)	To improve your child care skills and to manage the behavior of the child and other children	17	10	-	-	-
m)	To find out more about the activities for children in the town/village (beyond the boarding school)	3	23	1	-	-
n)	To help the child make friends with other children at the boarding school	18	10	-	-	-
o)	To help the child learn self-care skills	16	11	-	-	-
p)	To help the child get ready for independent living	2	25	-	-	-

Additionally, residential institution staff indicated the needs of families for the following types of help and support: financial aid (3), assistive technologies (2), housing conditions (2), as well as free-of-charge treatment for children, "taxi for disabled". At the same time, 2 respondents mentioned that those families did not need help, "everything is alright".

### **General wishes of parents/care-givers (according to respondents)**

#### **The need in quality services and qualified specialists:**

##### Healthcare and rehabilitation services

- Good treatment;
- Qualified physicians for children to feel the same as the healthy ones;
- ICP rehabilitation centers - massage, herbal treatment, invitation of foreign experts to exchange experience, prescribe treatment;
- Experienced physicians, Experienced physicians, Experienced physicians;
- Physicians' integrity, awareness, moral support, regardless of the financial situation of parents;
- More attention on the part of the Health Center, no need to wait in line to see the doctor, respect for such children. Help in getting hospital admission, inpatient treatment - free of charge and other facilities. Sanatoriums and health resorts are not covered by health insurance - it has to be dealt with;
- There is no social assistance in velayats. To build rehabilitation centers in velayats, specialized schools;
- To examine parents before child birth for less children with disabilities to be born.

##### Educational and developmental services

- "There is a need for qualified teachers, speech therapists, disability correction specialists, music teachers. To open specialized centers or clubs to spend time, communicate and develop. There is a need for learning guides";
- Specialized teachers, specialized speech therapy kindergartens;
- There is a need to open more specialized centers, more specialists, since nobody knows we have such children. There is a need to open rehabilitation centers with qualified specialists, as well as a possibility to invite ICP specialists from other countries.
- Preparation of children for school, education, preparation for independent living;
- There is a need for special kindergartens and schools; clubs and activities for such children; specialists: speech therapists, psychologists.
- To create groups for children with mental retardation by specific issues. To divide groups by diagnosis. To invite specialists from other countries, maybe on a contract basis (China?), very beneficial for children;
- Special centers, inclusive schools. Centers to bring the child for a day, for 3-4 hours. Information on child care, development, how to develop him/her; specialists; specialized centers for various categories of children located in the city;
- Schools for such children, for them to want to stay there, good food, to be possible to leave them there for the whole day. If it were possible to leave him for a while without worrying. For these children to learn and be literate.

#### Social integration and employment

- More communication is needed;
- More clubs, to take them to entertainment places, concerts, theaters;
- Trips to the seaside (Yenme organizes);
- To open afterschool centers for children while their parents are at work; specialized teachers in those centers;
- Creation of places, where it would be possible to leave the child for a while, to have rest;
- Flexible working hours of specialized staff;
- To open a center for ICP children with qualified staff (swimming pool, massage, exercise equipment, gymnastics, warm swimming pool) all specific conditions in one place;
- There are not enough specialists in the country to work with such children; there is a need for specialists to have special training and their activities with children to be effective;
- Provision of transport for school activities (boarding schools to have their own transport);
- There is a need for more organizations to teach and employ people with disabilities;
- There is a need for professional fulfillment possibilities for disabled children.

#### Attention and help on the part of the state:

- For the adopted laws to be implemented. For the state to hear us and understand;
- There is a need for attention on the part of the state;
- The state has to provide for trips to the seaside, for treatment abroad;
- More attention to families, to help them;
- Examination is costly - it has to be free of charge;
- More attention to children;
- The state has to take care of children, more charity organizations.

#### Living conditions and accommodated environment

- Housing. Provision of housing on the ground floor, expansion of the living space;
- Work;
- Adapted living conditions;
- Pavements and crossings for children with disabilities;
- Adapted transport;

- Inclusive schools;
- To improve material and technical endowment of special institutions for children with disabilities;
- To have special tables, chairs, furniture;
- Access to assistive technologies.

Attitude to disabled children and their families

- For our society to accept children with disabilities, benevolent attitude towards them in healthcare institutions, healthcare staff to visit and treat them at home more often;
- For the employer to understand and help. For people to be informed about persons with disabilities, about their problems. For people to know about their rights;
- Equal chances for these children in the society;
- Accommodation in the society, communication with healthy children, to look at healthy children, where they would not bully him;
- The state has to help children with disabilities more, to give diapers, medicines free of charge;
- More community-based organizations;
- For the child to have a future related to their adult life in the society, not being embarrassed in front of other people, not to be pointed and laughed at.

**General wishes of residential institution staff (according to respondents)**

Among general wishes, there were: change of people's attitude towards children with disabilities; "possibilities for professional fulfilment of children with disabilities are needed in the country"; a need for care on the part of the state; a need for specialized physicians, speech therapists, nutritionists; a need for rehabilitation centers, free-of-charge sanatoriums, specialized kindergartens and schools; autism has to be recognized as a diagnosis. A number of residential institution staff mentioned: for the child to have a future related to their adult life in the society, not being embarrassed in front of other people, not to be pointed and laughed at.

## Annex 5 Full, final questionnaire for Children in Families

# Интервью о ребенке-инвалиде в семье

<b>Контакты</b>	
Велаят	
Этрап/город	
Село	
Имя респондента	
Адрес респондента (улица, номер дома)	
Домашний / Мобильный телефон	

	Дата			Начало		Конец	
	День	Месяц	Год	Час	Минута	Час	Минута
Дата и время визита							
Второй визит (при необходимости)							

<b>Результат интервью</b>	1 = Завершен 2 = Не завершен 3 = Не было интервью → <b>Напишите комментарий</b>
Если не было интервью, объясните почему, и какие меры были предприняты что бы провести интервью	

Команда	Имя	Дата		Подпись
		День	Месяц	
Интервьюер				
Проверил: супервайзер				

Я \_\_\_\_\_ согласен/на на проведение интервью про своего ребенка \_\_\_\_\_

\_\_\_\_\_ (подпись респондента и дата)

Респондент дал устное согласие на проведение интервью про своего ребенка \_\_\_\_\_

\_\_\_\_\_ (подпись интервьюера и дата)

Я сотрудник неправительственной организации Yenme (Государственный Комитет Статистики... Министерство Труда и Социальной Защиты...), которую ЮНИСЕФ Туркменистан и Правительство Туркменистана попросили провести данное интервью, в рамках исследования ситуации детей с инвалидностью в Туркменистане, проводимого ЮНИСЕФом совместно с Правительством Туркменистана. Yenme является общественной организацией, которая работает с детьми с инвалидностью и их семьями, а также со взрослыми людьми с инвалидностью (Государственный Комитет Статистики является ... Министерства Труда и Социальной Защиты...). Исследование проходит под эгидой и при поддержке группы международных экспертов, которые также рассмотрят всю информацию, собранную в рамках исследования, и составят об этом отчет. Отчет будет способствовать информированию политики и программ Правительства Туркменистана в отношении детей с инвалидностью, в особенности, развитию социальных услуг для этих детей и их семей. Социальные услуги это те услуги, которые Хякимлык или неправительственная организация могут предоставлять семьям, которые помогают им ухаживать за детьми. Около 300 людей, осуществляющих уход за детьми с инвалидностью в трех велаятах примут участие в исследовании. Все сведения, которые вы предоставите, будут полностью анонимными, и включены в финальный отчет, наряду с информацией, предоставленной другими родителями, опекунами или/и воспитателями. Участие в данном исследовании не принесет вам или вашей семье ни выгоды, ни вреда. Это ваш шанс поделиться опытом воспитания ребенка с инвалидностью и содействовать разработке рекомендаций по улучшению услуг для детей с инвалидностью, и их семей. Не существует правильных или неправильных ответов на вопросы, которые мы планируем задавать. Пожалуйста, переспросите, если вопрос не понятен, и, просим вас, давать правдивые и искренние ответы. В случае, если вы не хотите отвечать, мы в любой момент можем прекратить задавать вам вопросы, мы можем перейти к другим вопросам. Опросник займет приблизительно 30-40 минут. Вы позволяете мне задавать вам вопросы и записывать ответы в данном вопроснике? Пожалуйста, подтвердите ваше согласие здесь *(попросить пописать, если не хочет, то подпишите сами, что устное согласие получено)*. Перед тем, как мы начнем, у вас есть ко мне вопросы, относительно исследования? Пожалуйста, подтвердите, что вы (имя респондента) являетесь матерью/отцом/опекуном/воспитателем ребенка (имя ребенка) – мне нужно удостовериться в этом, прежде чем мы начнем, но я вам напоминаю, что интервью будет полностью анонимным. Спасибо.

Если ребенок с инвалидностью присутствует во время интервью, и если ребенок проявляет интерес и способен участвовать в собеседовании, то необходимо зачитать дополнительное обращение, по мимо того, что было приведено выше:

Могу ли я поговорить с вашим ребенком (имя)? Ты слышал(а) о чем мы говорили? Это понятно? Вопросы, которые я хочу задать твоей маме (папе, опекуну, воспитателю) – о тебе и твоей семье, твоих друзьях, образовании, здоровье, занятиях – о твоей жизни. Если хочешь отвечать, пожалуйста, отвечай, но ты не обязан(а) это делать. Можешь поправить любой ответ, который дают твои родители (опекун, воспитатель), и добавить твой собственный ответ. Я спрашиваю маму (папу, опекуна, воспитателя) потому что они за тебя в ответе перед законом, и потому что ЮНИСЕФ и Правительство Туркменистана в этот раз хотят говорить больше с родителями, чем с детьми, потому что они думают, что взрослые могут помочь более правильно описать ситуацию детей с инвалидностью, и их семей. Но мы знаем, что дети тоже могут дать важную информацию и высказать ценные мнения, и я хочу чтобы ты себя чувствовал(а) комфортно и поделился(лась) с нами, если ты этого желаешь. Прошу тебя, не стесняйся прервать меня, если ты что-то не понимаешь и хочешь чтобы я повторил(а), или не хочешь отвечать на какие-либо вопросы. Хорошо? Спасибо.

#### А Основные сведения

1. Имя<sup>15</sup> ребенка с инвалидностью, являющегося предметом данного интервью \_\_\_\_\_

Пол 1 ☐ М 2 ☐ Ж

2. Где вы проживаете/семья ребенка проживает? \_\_\_\_\_ город/село  
\_\_\_\_\_ этрап \_\_\_\_\_ Велаят/Город

3. Дата рождения ребенка \_\_\_\_\_ месяц \_\_\_\_\_ год

4. Кем вы приходитесь ребенку (имя)

1 ☐ Мать 2 ☐ Отец 3 ☐ Бабушка 4 ☐ Дедушка 5 ☐ Воспитатель учреждения 6 ☐ Преподаватель учреждения 7 ☐ Иное (пожалуйста, укажите) \_\_\_\_\_

5. Ваше образование:

1 ☐ Начальное 2 ☐ Незаконченное среднее 3 ☐ Среднее 4 ☐ Среднее техническое 5 ☐ Высшее

6. Ваша/ родителя ребенка занятость и трудоустройство

а). Ваша (родителя ребенка) занятость: 1 ☐ Трудоустроен 2 ☐ Домохозяйка (работник по дому) 3 ☐ Безработный(ая) 4 ☐ На пенсии 5 ☐ Иное \_\_\_\_\_ 6 ☐ Не знаю

б) Статус трудоустройства второго родителя/опекуна или другого взрослого в семье (если таковой имеется): 1 ☐ Трудоустроен (на) 2 ☐ Домохозяйка/работник по дому 3 ☐ Безработный (ая) 4 ☐ На пенсии 5 ☐ Иное \_\_\_\_\_ 6 ☐ Не знаю

7. Ваш гражданский статус / гражданский статус родителей ребенка: 1 ☐ Не женат (не замужем) 2 ☐ Женат (замужем) 3 ☐ Вдовец (вдова) 4 ☐ Разведенный (ая) 5 ☐ Иное (указать) \_\_\_\_\_ 6 ☐ Не знаю

8. Ваши дети / (братья/сестры ребенка):

№.	Год Рождения	Пол	Ребенок посещает детский сад или школу?		
			Да	Нет	Не знаю

9. (Только для родителей) Кто-нибудь помогает вам ухаживать за ребенком/детьми? (Можно выбрать любое количество ответов)

<sup>15</sup> Заметка интервьюеру – в дальнейшем используете имя ребенка в вопросах вместо слова «ребенка»



	Всегда	Иногда	Никогда
1. Родственники, которые проживают с вами	1	2	3
2. Родственники, которые не проживают с вами	1	2	3
3. Волонтеры из НПО	1	2	3
4. Друзья и соседи	1	2	3
5. Второй родитель ребенка, который не проживает с вами	1	2	3
6. Сотрудники государственных служб	1	2	3
7. Прочие _____			

**10. Общее количество людей, проживающих совместно с вами /в семье ребенка:** \_\_\_\_\_

Назовите членов семьи: 1 ☐ Мама 2 ☐ Отец 3 ☐ Ребенок 4 ☐ Бабушка 5 ☐ Дедушка  
6 ☐ Брат 7 ☐ Сестра 8 ☐ Другие (укажите) \_\_\_\_\_ 9 ☐ Не знаю

**11. Жилищные условия:**

В каких жилищных условиях вы и ваша семья проживаете /семья ребенка проживает?

1 ☐ квартира 2 ☐ дом 3 ☐ Не знаю

Это жилье: 1 ☐ Снимаем 2 ☐ Является нашей (семьи ребенка) собственностью 3 ☐ Является собственностью других членов семьи 4 ☐ Предоставлено государством для бесплатного найма  
5 ☐ Иное (укажите) \_\_\_\_\_ 6 ☐ Не знаю

**12. Как вы можете описать экономическую ситуацию вашей семьи /семьи ребенка? (Прочтите и задайте вопросы собеседнику, чтобы он мог выбрать только **один** подходящий ответ или дайте ему распечатанный вопросник, чтобы он мог прочитать и выбрать ответ)**

1.	У нас (них) нет достаточно денег на еду	
2.	У нас (них) достаточно денег на еду, но покупка одежды проблематична	
3.	У нас (них) достаточно денег на еду, одежду, и мелкие электрические и бытовые приборы, но было бы трудно купить телевизор, холодильник, или стиральную машину	
4.	У нас (них) достаточно денег на покупки крупных бытовых предметов, но недостаточно для покупки машины	
5.	Наши (их) доходы позволяют купить все, за исключением крупных покупок, таких как квартира, участок, или дача	
6.	У нас (них) нет финансовых трудностей	
7.	Я не хочу отвечать	
8.	Я не знаю	
9.	Иное	

**13. Степень<sup>16</sup> функционирования организма ребенка (имя):**

Как хорошо ваш ребенок (имя):

Функция	1	2	3	4	5
Видит					
Слышит					
Говорит					
Ходит					
Сидит					
Меняет положение					
Дышит (дыхание)					
Понимает речь или жесты					
Усваивает содержание / понимает					

5 = ребенок полностью функционален 4 = слабая дисфункция 3 = средняя дисфункция 2 = тяжелая, может функционировать только при посторонней помощи 1 = неспособен функционировать, даже при посторонней помощи

**15. Уровень сформированности у ребенка (имя) навыков по самообслуживанию:**

Сколько помощи необходимо оказать вашему ребенку для того, чтобы он:

Действие	1	2	3	4	5
принял ванну					
сходил в туалет					
поел					
оделся					

5=может выполнить самостоятельно 4 = нуждается в некоторой помощи 3 = часто нуждается в помощи 2 = нуждается в постоянной помощи 5= неспособен выполнять, даже при посторонней помощи

**16. Медицинский диагноз (диагнозы) или проблемы здоровья (если имеются) у ребенка (имя), \_\_\_\_\_ и возраст, когда был поставлен диагноз \_\_\_\_\_**

Присвоение статуса инвалидности \_\_\_\_\_ Возраст, когда была присвоен статус инвалидности \_\_\_\_\_

*(Рассказы родителей или основного человека осуществляющего уход за ребенком)*

По чьей инициативе Вы обратились за присвоение статуса инвалидности ребенка и куда?  
\_\_\_\_\_

Как прошел процесс присвоения статуса инвалидности? Какие трудности сопровождали этот процесс?  
\_\_\_\_\_

<sup>16</sup> (\*Если 5-балловая система оценки не будет работать, поменять на 3-х уровневую).

Расскажите про ваш опыт прохождения Комиссии по присвоению статуса инвалидности.

### 17. Уход за ребенком

**а) Кто является основным человеком осуществляющим уход за ребенком (имя)?**

1 ☐ Отец 2 ☐ Мать 3 ☐ Бабушка 4 ☐ Дедушка 5 ☐ брат/сестра 6 ☐ Персонал учреждения-интерната 7 ☐ Другое лицо (указать) \_\_\_\_\_

**б) Кто еще помогает основному человеку осуществляющему уход за ребенком (имя)?**

1 ☐ Никто 2 ☐ Отец 3 ☐ Мать 4 ☐ Бабушка 5 ☐ Дедушка 6 ☐ братья/сестры 7 ☐ Другие родственники 8 ☐ Соседи 9 ☐ Друзья 10 ☐ Работники интерната 11 ☐ Сотрудники социальных услуг/служб (Кто, где?) \_\_\_\_\_ 12 ☐ Учителя/воспитатели (кто, где?) \_\_\_\_\_ 13 ☐ Медицинский персонал (кто, где?) \_\_\_\_\_ 14 ☐ Другое лицо (указать) \_\_\_\_\_ 15 ☐ не знаю

**с) Ребенок (имя) живет по большей части дома, с семьей?** 1 ☐ Да 2 ☐ Нет

**Если нет, то где ребенок (имя) проводит время, когда он не находится дома?**

3 ☐ в интернате 4 ☐ в санатории 5 ☐ в другом медицинском учреждении 6 ☐ в круглосуточном садике 7 ☐ в интернатном детском саду 8 ☐ в доме у родственников (степень родства) \_\_\_\_\_ 9 ☐ иное (указать) \_\_\_\_\_

**д) (только для ребенка в учреждении) В каком возрасте ребенок попал в учреждение впервые?** \_\_\_\_\_ В какое? \_\_\_\_\_

В каком возрасте ребенок попал в это учреждение? \_\_\_\_\_

Откуда? \_\_\_\_\_ Почему? \_\_\_\_\_

**е) (Только для родителей или основного человека осуществляющего уход за ребенком) Когда вам нужно выйти куда-нибудь, и вы не можете взять с собой ребенка (имя), кто присматривает за ним/ней?**

1 ☐ Никто (ребенок остается один, пока я не вернусь) 2 ☐ Отец 3 ☐ Мать 4 ☐ Бабушка 5 ☐ Дедушка 6 ☐ Старший брат/сестра 7 ☐ Младший брат/сестра 8 ☐ Другой родственник 9 ☐ Сосед 10 ☐ Друг 11 ☐ Работники интерната 12 ☐ Сотрудники социальных услуг/служб (Кто, где?) \_\_\_\_\_ 13 ☐ Учитель/Воспитатель (Кто, где?) \_\_\_\_\_ 14 ☐ Медицинский персонал (Кто, где?) \_\_\_\_\_ 15 ☐ Другое лицо \_\_\_\_\_

### Б Участие в социальной жизни и мероприятиях

### 18. Взаимодействие с окружающими

*Семья*

h) Сколько времени проводит ребенок (имя) с братьями/сестрами?

1 ☐ У него/нее нет братьев/сестер 2 ☐ Все время 3 ☐ Много времени 4 ☐ Некоторое время  
5 ☐ Мало времени 6 ☐ Совсем не проводит 7 ☐ не знаю

Если мало времени или совсем не проводит время, то почему? *(Объясните)*

—

i) *(для родителей или основного человека осуществляющего уход за ребенком)* Сколько времени вы проводите с ребенком (имя)?

1 ☐ Все время 2 ☐ Много 3 ☐ Некоторое время 4 ☐ Мало времени 5 ☐ Совсем не провожу

Это примерно сколько часов в день? \_\_\_\_\_

Если мало или совсем не проводят время с ребенком (имя), то почему?  
\_\_\_\_\_ *(подсказка: время уходит и на других детей, хозяйственные заботы, работу, заботу о других членах семьи, нуждающихся в уходе)*

Если все время, то почему? \_\_\_\_\_  
*(подсказка: ребенок требует постоянного ухода/надзора, неумение совмещать разные виды деятельности, много помогают по хозяйству члены семьи, др.)*

j) Вы или другие члены семьи нуждаетесь в помощи для общения с ребенком (имя)?

1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю Какая помощь вам нужна, как вы думаете?  
\_\_\_\_\_ *(подсказки: выучить язык знаков, выучить альтернативные способы коммуникации, научиться понимать звуки/речь/жесты/поведение ребенка)*

k) Ребенок (имя) нуждается в помощи для установления взаимоотношений? 1 ☐ Да 2 ☐ Нет  
3 ☐ Не знаю. Какая помощь ему (ей) нужна, как вы думаете?

\_\_\_\_\_

*Друзья и ровесники*

l) У ребенка (имя) есть друзья? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю

Если да, то как часто он (она) с ними встречается? 1 ☐ Каждый день 2 ☐ раз в неделю 3 ☐ раз в месяц 4 ☐ Другое \_\_\_\_\_ 5 ☐ Не знаю

Где? 1 ☐ Дома 2 ☐ Во дворе 3 ☐ В интернате 4 ☐ Другое место \_\_\_\_\_ 5 ☐ Не знаю

m) Ребенок (имя) выходит играть с другими детьми? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Где они играют?

1 ☐ Дома 2 ☐ Во дворе 3 ☐ В интернате 4 ☐ Другое место \_\_\_\_\_ 5 ☐ Не знаю

- n) (для детей, посещающих школу) Ребенок (имя) имеет друзей в школе? Они видятся за пределами школы? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю Где?  
1 ☐ Дома 2 ☐ Во дворе 3 ☐ В интернате 4 ☐ Другое место \_\_\_\_\_ 5 ☐ Не знаю

### 19. Образование и учеба

- g) Ребенок (имя) ходит в школу (садик, колледж, ВУЗ) или получает обучение на дому? 1 ☐ Да 2 ☐ Нет. Если нет, то почему? \_\_\_\_\_
- h) Проходил ли ребенок Медико- Педагогическую Комиссию? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю.
- i) Если посещает, то какое учреждение посещает ребенок (имя)?:  
1 ☐ дошкольное учреждение 2 ☐ начальная школа 3 ☐ средняя школа 4 ☐ среднее специальное 5 ☐ высшее образование 6 ☐ Иное \_\_\_\_\_

Тип образовательного учреждения: 1 ☐ интернат 2 ☐ пятидневный интернат 3 ☐ спец школа 4 ☐ общеобразовательная школа 5 ☐ обучение на дому 6 ☐ Иное \_\_\_\_\_

*(Для детей на домашней учебе переходите на вопрос 18e)*

Ребенок (имя) посещает учреждение в каждый день? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Если нет, то почему? \_\_\_\_\_

Ребенку (имя) нравится ходить в школу? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю

Если да, то что именно ему (ей) нравится там? Если нет, почему? \_\_\_\_\_

j) Если ходит в школу, как много времени уходит на дорогу до школы каждый день? \_\_\_\_\_ Как ребенок (имя) добираться до школы?  
\_\_\_\_\_

k) Если пользуется обучением на дому, как часто приходит учитель? \_\_\_\_\_ Сколько времени проводит с ним (ней) учитель? \_\_\_\_\_ Как вы относитесь к учебной программе для ребенка? \_\_\_\_\_ Ребенку (имя) нравятся занятия? \_\_\_\_\_ Почему нравятся? \_\_\_\_\_ Почему не нравятся? \_\_\_\_\_

l) Как вам кажется, ребенок (имя) получает качественное образование? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Каким образом оно может быть улучшено (если это возможно)?  
\_\_\_\_\_

m) Ребенок (имя) достигает какие-либо результаты в обучении? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю  
Какие результаты/успехи вы заметили в его/ее обучении? (чтение, письмо, др.)  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### 20. Игра и досуг (пункты a-d для старших детей, e для всех детей)

g) Ребенок (имя) участвует в каких-либо занятиях, кружках? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю Если нет, то почему? \_\_\_\_\_

- h) Если да, то в каких? 1 ☐ спорт 2 ☐ ИЗО 3 ☐ музыка 4 ☐ театр/танцы 5 ☐ другое \_\_\_\_\_  
Где? \_\_\_\_\_
- i) Есть ли какие-либо кружки, в которых ребенок (имя) хотел бы участвовать, но не может?  
1 ☐ спорт 2 ☐ искусство, мастерство 3 ☐ музыка 4 ☐ театр/танцы 5 ☐ другое \_\_\_\_\_
- j) Как часто ребенок (имя) играет с другими детьми? \_\_\_\_\_ Где? \_\_\_\_\_
- к) (Для детей всех возрастов) Участвует ли ребенок (имя) также и в других игровых, развлекательных мероприятиях? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Если да, в каких \_\_\_\_\_  
Где \_\_\_\_\_ и как часто? \_\_\_\_\_

## 21. Подготовка к самостоятельной жизни (для детей старше 12 лет)

- а) Самообслуживание – умеет ли ребенок (имя) самостоятельно ухаживать за собой? Учится ли он (она) этим навыкам?

Действие	Уже может делать это самостоятельно	Да, учится	Кто учит его (ее) <sup>17</sup> ?	Нет, не учится	Почему?
Принятие ванны					
Туалет					
Прием пищи					
Одевание					

- б) Занятие хозяйством и бытовыми рутинными – умеет ли ребенок (имя) пользоваться деньгами, транспортом, делать покупки? Готовить, убирать, следить за порядком в доме? Учится ли он (она) этим навыкам?

Действие	Уже может делать это самостоятельно	Да, учится	Кто учит его (ее)?	Нет, не учится	Почему?
Пользоваться деньгами					
Пользоваться транспортом					
Ходить в магазин					
Готовить					
Убирать					
Следить за порядком в доме					

- д) Подготовка к трудоустройству – знает ли ребенок (имя), кем он (она) хочет стать в будущем?

1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю

Получает ли он (она) образование, чтобы научиться выполнять такую работу?

<sup>17</sup> Например: Мама, папа, бабушка, брат или сестра, основной человек осуществляющий уход, воспитатель, педагог, терапевт или врач, психолог, социальный педагог и т.д.

1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю

Кто ему (ей) помогает в этой подготовке? (выберите подходящие ответы)

Действие	Уже может делать это самостоятельно	Да, учится	Кто учит его (ее)?	Нет, не учится	Почему?
Профориентация					
Поиск работы					
Изучает профессию					
Получает необходимую квалификацию (диплом)					

**С. Внешние факторы****22. Здоровье и реабилитация**

е) Ребенок (имя) нуждается в каких-либо технических устройствах для поддержки собственной мобильности, общения, способности стоять, сидеть, видеть, слышать, выполнения иных потребностей 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю

ф) Есть ли у него (нее) эти устройства? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю Кто их предоставил и настроил?

g) Если нет, почему нет? \_\_\_\_\_

h) Получаемые медицинские услуги помогают ребенку для улучшения:

Функция	Да	Нет	Не знаю	Нужен ли помощь с этой функцией? (да, нет, не знаю)
Зрения				
Слуха				
Речи				
Ходьбы				
Способности сидеть				
Способности менять положение				
Дыхания				
Понимания речи и жестов				
Усваивания содержание /понимания				

(Рассказы родителей и воспитателей)

Каким образом эти услуги помогают? Пожалуйста, опишите ваш опыт медицинских и реабилитационных услуг для ребенка (имя) \_\_\_\_\_

Как далеко находятся эти услуги? \_\_\_\_\_ Сколько времени необходимо, чтобы до них добраться? \_\_\_\_\_ Как вы добираетесь туда с ребенком (имя) \_\_\_\_\_ Сколько стоят эти услуги? \_\_\_\_\_

### 23. Социальные услуги и социальная поддержка

- d) Вы или ребенок (имя) пользуетесь какими-либо социальными услугами? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю

Какие организации предоставляют эти услуги? 1 ☐ Хякимлик 2 ☐ другая государственная организация 3 ☐ НПО 4 ☐ религиозная организация 5 ☐ Женский совет 6 ☐ другая (какая?) \_\_\_\_? Какой вид услуг \_\_\_\_\_?

- e) Вы или ребенок (имя) получаете социальное пособие? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю Какое? \_\_\_\_\_ Почему/почему нет? \_\_\_\_\_

- f) Имеет ли ребенок (имя) доступ к услугам, находящимся в вашем городе/этрапе/селе на уровне местного сообщества? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Пожалуйста, опишите \_\_\_\_\_

(Для старших детей) Имеет ли ребенок (имя) возможность посещать мероприятия для молодежи в вашем городе/этрапе/селе: 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Пожалуйста, опишите \_\_\_\_\_

Имеет ли ребенок (имя) доступ к услугам в вашем городе/этрапе/селе по трудоустройству? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Пожалуйста, опишите \_\_\_\_\_

(Для младших детей) Имеет ли ребенок (имя) доступ к услугам раннего вмешательства и раннего развития? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Пожалуйста, опишите \_\_\_\_\_

Дневное пребывание/Дневной уход за ребенком? 1 ☐ Да 2 ☐ Нет 3 ☐ Не знаю. Пожалуйста, опишите \_\_\_\_\_ (подсказка – услуга может быть официальной, то есть, предоставляться учреждениями или организациями, или неофициальной, то есть, предоставляться в виде поддержки со стороны родственников или соседей (членов местного сообщества))

- d) Как далеко они расположены<sup>18</sup>? \_\_\_\_\_ Как долго к ним добираться? \_\_\_\_\_ Каким образом вы добираетесь туда с ребенком (имя) \_\_\_\_\_ Сколько стоят эти услуги? \_\_\_\_\_

### 24. Знание/Информированность о социальных услугах

- a) Знаете ли вы что-либо о таких социальных услугах для детей с инвалидностью? 1 ☐ Да 2 ☐ Нет .

<sup>18</sup> Эта группа вопросов относится к всем видам вышеуказанных социальных услуг, которые упоминает респондент



в) Если вы не знаете о таких услугах – почему вы о них не знаете, как вы думаете?

с) Где вам было бы удобно узнать о социальных услугах? Какой для вас наилучший путь информирования об услугах (выберите 3 самые удобные варианты ответов)?

- |   |   |
|---|---|
| 1 <input type="checkbox"/> радио                              | 9 <input type="checkbox"/> общественная информационная доска        |
| 2 <input type="checkbox"/> местное ТВ                         | 10 <input type="checkbox"/> собес                                   |
| 3 <input type="checkbox"/> национальное ТВ                    | 11 <input type="checkbox"/> хякимлик                                |
| 4 <input type="checkbox"/> от соседей                         | 12 <input type="checkbox"/> смс сообщение на мобильном телефоне     |
| 5 <input type="checkbox"/> друзей                             | 13 <input type="checkbox"/> интернет (емайл или в социальных сетях) |
| 6 <input type="checkbox"/> учреждений образования             | 14 <input type="checkbox"/> местная газета                          |
| 7 <input type="checkbox"/> медицинских учреждений             | 15 <input type="checkbox"/> национальная газета                     |
| 8 <input type="checkbox"/> религиозной организации или мечеть | 16 <input type="checkbox"/> рекламные щиты                          |
| 17 <input type="checkbox"/> иное _____ (укажите)              |   |

## 25. Потребности (для детей, проживающих дома)<sup>19</sup>

(Пройдите через весь список потребностей и оцените необходимую вам, вашей семье и/или ребенку (имя) помощь)

В какой помощи нуждаетесь вы, ваша семья и ваш ребенок? Помощь:

		1	2	3	4	5
	Потребности	Не т	Да, некоторая помощь нужна	Да, очень нужна поддержка	Не знаю	Не хочу отвечать
a)	Для ежедневного ухода за ребенком (имя): пользования туалетом, кормления, одевания, принятия ванны					
b)	Чтобы научиться общаться с ребенком (имя) и установить хорошие взаимоотношения с ним					
c)	Чтобы улучшить ваши родительские способности и справиться с поведением вашего ребенка (имя) и других детей (если есть)					
d)	Для уменьшения уровня стресса в вашей семье или для улучшения взаимоотношений между членами семьи					
e)	Чтобы узнать больше о занятиях или кружках для ребенка (имя)					
f)	Чтобы помочь ребенку (имя) подружиться с другими детьми в школе, дома, по соседству					
g)	Чтобы помочь ребенку (имя) усвоить навыки самообслуживания					
h)	Чтобы помочь ребенку (имя) подготовиться к самостоятельной жизни					

<sup>19</sup> Для тестирования: опция 1 – ответ на все потребности; опция 2 – выбрать 5 приоритетных потребностей

i)	Чтобы помочь ребенку (имя) добираться до школы, детского сада или других мест для занятий					
j)	Чтобы улучшить школьную успеваемость ребенка (имя)					
k)	Для получения доступа к вспомогательным техническим средствам для ребенка (имя)					
l)	Для получения доступа к услугам квалифицированных медицинских работников для ребенка (имя)					
m)	Чтобы получить пособия или материальную помощь для ребенка (имя) или семьи					
n)	Вам или другим членам семьи, чтобы решить проблему алкогольной, наркотической, или другой какой-либо зависимости					
o)	Вам или другим членам семьи, для того, чтобы справиться с проблемами психического здоровья, как например, депрессии					
p)	Чтобы ребенок научился лучше общаться с вами и другими членами семьи					

q) Нужна ли вам еще какая-либо помощь/поддержка? Какая? \_\_\_\_\_

r) Нужна ли ребенку (имя) еще какая-либо помощь/поддержка? Какая? \_\_\_\_\_

26. **(ДЛЯ ВСЕХ)** Спасибо вам за то, что выделили время, чтобы ответить на эти вопросы. Есть ли что-то еще, что вы хотели бы сказать о том, как должны развиваться услуги для детей с инвалидностью в Туркменистане?