UNICEF Turkmenistan - a study to formulate recommendations for developing national policies with a view to preventing institutionalization of children aged 0-3 years of age – January 2014

Study Report - analysis of data following field work in December 2013

() Partnership for Every Child CEE/CIS Consultancy group for UNICEF Turkmenistan

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Glossary

The definitions given here are based on the UN Guidelines on Alternative Care for Children and the official handbook for implementing the UN Guidelines 'Moving Forward' (www.alternativecareguidelines.org) and references to articles (§) relate to the Guidelines.

Child with developmental difficulties- a young child who has not yet been diagnosed with a disability, but who has developmental delays or difficulties

Children with disabilities – in accordance with the UN Convention on People with Disabilities and its Russian translation.

Infant home – residential institution for children aged 3 years or under. There are four infant homes in Turkmenistan.

Institutional care – the term 'institutions' is used only once in the Guidelines – to describe 'large residential facilities' (§ 23). It is of course 'institutions', and not residential facilities as a whole, that are to be targeted through a 'de-institutionalisation strategy'.

Residential care - (§ 29.c.iv in the UN Guidelines on Alternative Care for Children) encompasses a wide range of settings, from emergency shelters and small group homes to the biggest residential facilities.

A. Executive summary

This report presents the findings from an extensive study of the situation in the four infant homes in Turkmenistan. The study gathered and analyzed secondary data at national, regional/infant home and individual levels and gathered primary data through interviews with 84 staff and 38 parents in maternity hospitals and infant homes.

There were 143 children living in four infant homes in December 2013. This represents about 37 infants per 100,000 children aged under 3 years of age which is a low rate compared to most other countries in the Central Asia region. Roughly a further 46 infants per 100,000 children aged under 3 years of age, are placed into guardianship each year. There are some discrepancies in data which make it difficult to pinpoint the overall trends in entry and exit of children from the infant homes, probably mainly related to the absence of data on children who have died while in the care of the infant homes, it seems likely that the overall trend is towards a slight decline, with some regional variations – Dashoguz is the only infant home showing a steady decline in numbers.

Just over 60% of all children who left the infant homes in 2012 left for adoption placements, with some regional variations. Most of the children leaving for adoption are from Ashgabat and Lebap infant homes. Around 1/3 of Mary children left for adoption and the remaining 2/3rds returned home to their families. Across the whole country in 2012 almost 90% of children either returned home or were adopted when they left the infant homes.

Of all 143 children who were in the care of the infant homes in December 2013, 71% entered at the age of 0-6 months. The average length of stay was 11.4 months for all children in all the infant homes with some regional variations – average length of stay for children in Lebap and Dashoguz infant homes in December 2013 was 19 months, in Ashgabat infant home was 16 months and in Mary infant home was 8.8 months. 36% of children had confirmed disability or pathologies, 64% were without pathologies or with some somatic diagnoses.

There is a high level of family contact with 50% of infants including many children with disabilities receiving visitors (even if infrequently) or telephone enquiries. 53% of those who have been completely refused by parents and family have a disability, but only 25% of newborns who were refused and were living in the infant homes in December 2013 had a disability.

Overall the main reasons for children to be in the care of the infant homes, based on the data for 143 infants resident in December 2013 were: refusal by parents (29% of all cases); temporary placement for social reasons including mothers serving sentences in the women's penal colony (27%); temporary placements because of the child's illness (20%); temporary placement because of parental illness (11%). There are significant regional variations with each infant home having a different main reason for placement.

The study identifies a typology of three groups of children who enter the care of the infant homes: 1) babies without disabilities; 2) babies and older infants with disabilities who enter mainly because of their disability or developmental difficulties; 3) babies and older infants who enter for mainly social reasons or parental illness.

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The main factors influencing decisions of parents to relinquish children or place them temporarily are: an understanding of disability based mainly on medical or health issues; lack of understanding of the needs of young children; a crisis in the family or other set of circumstances which challenge the ability of the family to care for their child; lack of any other alternatives; a recommendation from an official source or from a neighbor or friend to place the child. Professionals perceive the reasons to lie more with the psychological, social and personal circumstances of the mother of the child and lack of support from her parents or relatives.

Existing practice in maternity hospitals to prevent relinquishment are largely ad hoc, unstructured and rely mainly on the individual initiative of Head Doctors and individual staff members to give mothers advice and try to convince them to take their baby. In a few instances good practices in terms of encouraging breast-feeding in the maternity hospital were cited as an example of how to prevent relinquishment. The maternity hospital staff are not able to offer mothers much practical support or information about how they can address there problems when they leave the hospital with their newborn child. Some maternity hospitals inform local family doctors about the mothers' intentions to relinquish their infant, others don't.

The study summarises views of maternity hospital and infant home staff on how prevention of relinquishment can be strengthened. The study also summarises the experiences of a group of mothers of young children with disabilities at the birth of the baby and subsequently in terms of caring for their child in the community without recourse to the infant home.

The study identifies the strengths of the current system as: strong family traditions, an overall low level of usage of infant homes, a high level of adoption for some babies, a system of family doctors and home-visiting nurses that support families in the ante and post natal periods, a flexible system of visiting children at the infant homes and maintaining family contact, the opportunity to place children temporarily without losing parental rights, most children exit the infant homes for adoption or to return to their own families.

Challenges are: a high number of infants being relinquished in maternity hospitals each year (around 150 infant per year), a large number of children each year experiencing at least some period of time in the infant homes (492 children in 2012 for example), children with disabilities being over-represented in the infant home population (36% compared to around 1.5-5% in the general population), long periods of being cared for in the infant homes for some children, lack of alternative services, the need to support infants and families when the child returns home after their stay in the infant home.

Key recommendations to emerge from the study are: the need to expand and change the functions of the infant homes to reflect a more multi-faceted understanding (not only medical) of needs of children with disabilities in keeping with the ICF-CY; strengthening reproductive health services in order to prevent unwanted pregnancies; taking active and structured measures to prevent relinquishment in the maternity hospitals; strengthening links between Guardianship and Trusteeship organs, health, education and social services; creating new social services to support children and families in difficult life situations as an alternative to placement into infant homes; developing and implementing a Disability Policy; monitoring key indicators in prevention and alternatives to infant home care; training and re-training staff.

Key next steps are to develop an action plan for children aged under 3 that focuses on eventually reducing the numbers of children in infant home care to zero by creating alternatives and by strengthening prevention and support services for vulnerable families.

B. Introduction and overview of the study

The United Nations Guidelines for the Alternative Care of Children state that institutional care should not be used for children under the age of three and should be limited to cases where this setting is specifically appropriate, necessary, and constructive for the individual child concerned, and in his/her best interests.

Effective intervention to prevent or remedy child abandonment and relinquishment requires an understanding of the causes. However, specification of the causes of abandonment and relinquishment is hampered by the limited research on the topic and access to medical histories and overall data in Turkmenistan. This study was commissioned by UNICEF Turkmenistan, together with the Government of Turkmenistan in order to gain a better understanding of how many children are living in residential care in Turkmenistan and why they are being relinquished or abandoned by their parents.

Methodology and data collection

The researchers proposed a number of data collection instruments aiming to generate data that can help to inform the formulation of recommendations for the development of national policies to prevent the institutionalization of children aged 0-3 years. The instruments were tested at 1 maternity hospital and 1 infant home in Mary velayat before being finalized and tested by the data collection team in 1 maternity hospital and 1 infant home in Ashgabat city. The data entry system was based as much as possible on codes in order to ensure the minimum of errors in data entry while maintaining maximum quality of information gathered.

The specific research questions that the instruments were aiming to answer were:

- 1 How many children under 3 years of age are relinquished/ abandoned in Turkmenistan each year and how many relinquished or abandoned children under 3 years of age there are in Turkmenistan altogether?
- 2 How many children under 3 years of age are separated from their families and living in residential care or any other form of care?
- What are the main circumstances, motives and reasons associated with the relinquishment or abandonment of these children including factors relating to the role of family, social issues, community, disability or culture that are contributing to the relinquishment of infants under 3 years of age?
- 4 How are children taken into formal care? What assessments and decisions are undertaken?
- 5 What is being done/could be done more in maternity hospitals to prevent relinquishment or abandonment?
- 6 What social services are available to support the mother/family in order to prevent relinquishment or abandonment?
- 7 To what extent is reunification with birth family being explored as an option for children before adoption is considered? To what extent is adoption by extended family being encouraged?

The data was collected by a team of 16 Ministry of Health specialists visiting 4 infant homes and a sample of 12 maternity hospitals in rural and urban areas. The team of specialists received 2 day training on the methodology and use of instruments and tested the instruments in 1 maternity hospital and 1 infant home in Ashgabat city. The team seemed to perform the data entry process with relative ease and thanks to the system of coding built into the questionnaires this process was quite efficient. The instruments used, including data entry forms 1-4, are attached in Annex 1.

The secondary data collection and analysis included meta, mezzo and micro data.

Meta-data provided by the Ministry of Health and Medical Industry was entered it into form 1.

- 1. Number of live births per year per region disaggregated by gender
- Number of infants diagnosed in the maternity hospital with genetic developmental disorders or functional disorders resulting from birth complications – disaggregated by region and gender for 2010, 2011, 2012
- 3. Number of infants placed straight from the maternity hospital into the infant home by region and gender for 2010,2011, 2012
- 4. Number of infants placed into the infant homes by region, gender and age at which placed for 2010, 2011, 2012
- 5. The child population for each region broken down by gender and age for 2010, 2011, 2012
- 6. The number of children with disabilities registered with Ministry of Health bodies, with Ministry of Education bodies and with Ministry of Social Protection bodies.
- 7. Number of mother and child health centres in each region, number of infants aged 0-3 served each year at MCH centres.

Mezzo-data provided by the Ministry of Health and Medical Industry and their regional representatives regarding the four infant homes was entered into data entry form 2:

- 1. The number of children that enter each infant home for 2010, 2011, 2012 and 9 months of 2013, disaggregated by disability, gender, age at entry, region of origin and referring body maternity hospital, parent or relative (specify), Mother and Child Health centre, police, other (specify).
- 2. The number of children who leave each infant home disaggregated by disability, gender, age at disenrollment and region of origin and reasons for entry for 2010,2011, 2012 and 9 months of 2013.
- 3. The destination for each child upon leaving each infant home each year disaggregated by disability, gender, age at disenrollment and region of origin for 2010,2011, 2012 and 9 months of 2013.

Micro-data was to be collected by the research team from 100% of case files for infants in the care of all four infant homes at the time of the field work. The Head doctors, during interviews, stated that 143 children were in residence in all four infant homes and data was collected for all 143 children. The information was summarized in data entry form 3 and included:

1. Child – gender; date of birth; date of entry to infant home; where child entered from – maternity hospital, home, hospital, police, other (specify); disability status on entry; subsequent changes to disability status; ethnicity; siblings – gender and date of birth (if recorded); socio-

economic assessment at entry (if any); housing issues; reason for entry; services received before entry; legal status of the child; plan for child; other issues recorded (specify).

- 2. Mother and father or other main carer responsible for placing child, if not mother or father date of birth, education level, village/town of residence, social status, disability status (if any), ethnicity, employment, relatives, other issues recorded (specify).
- 3. Contact with family members how often do family members visit, who visits, how do they interact with the child? Does the child visit home? How often?

Primary data collection and analysis – key informant interviews

Primary data was collected through structured interviews with staff and service users at the following institutions and organisations: 4 infant homes, 12 Maternity Hospitals in urban and rural areas in the regions where there are infant homes. The sample used for key informant interviews: Maternity hospitals – Chief Doctor; 1 midwife; 1 paediatrician; 1 auxiliary staff; 1 statistician/lawyer; 3 parents. 4 Infant Homes – Chief Doctor; 1 paediatrician; 2 care staff; 2 auxiliary staff; 1 nurse working with children with disabilities; 3 parents/carers (or any visiting relatives present at the time of the survey visit by the data collection team).

Research Questions

The questionnaire for each of the proposed respondents along with the data entry matrixes were provided to the research team. The main areas for enquiry for each interviewee with some variations were as follows:

All maternity hospital staff: pregnancy registration; procedure for confirming identity; prevalence of infant relinquishment and abandonment; reasons – disability, social reasons, other (specify); factors that motivate mothers/fathers who relinquish; assessment of socioeconomic or housing situation of family; disability diagnosis in the infant home; process of handling relinquishment and abandonment; views on prevention; baby friendly maternity ward practices

Maternity hospital service users: pregnancy registration; procedure for confirming identity; prevalence of infant relinquishment and abandonment; reasons – disability, social reasons, other (specify); factors that motivate mothers/fathers who relinquish; assessment of socioeconomic or housing situation of family; disability diagnosis in the infant home; views on prevention; baby friendly maternity ward practices; other

Infant home chief doctor: number of children, girls/boys and ages of children; reasons for placement in the institution; status of parents (rights relinquished or not); at what age children were placed in the institution; how long they stay and how many children spent more than 6 months in the infant home; where the children are placed if they leave the institution; how many children were adopted; how long it takes to adopt a child and what the procedures are; staffing (e.g. number and roles of staff, qualifications of staff);family situation (e.g. the whereabouts of parents, extended family members, siblings); visitations (e.g. visiting times, number of visits that the children receive); views on prevention and support services; views on alternative care services.

Infant home other staff: qualifications; daily routine; reasons for placement of infants in the institution; family situation (e.g. the whereabouts of parents, extended family members, siblings); visiting times, number of visits that the children receive, who visits, how do they interact with the children, do children visit their homes, how often; views on prevention and support services; views on alternative care services.

Infant home visiting relatives: reasons for placement of infants in the institution; family situation (e.g. the whereabouts of parents, extended family members, siblings); visitations (e.g. visiting times, number of visits that the children receive); views on prevention and support services; views on alternative care services.

Data from questionnaires were entered into data entry form 4.

Data entry and analysis

Data was entered into the relevant data entry form and the analysis in this report was based on reviewing the qualitative and quantitative aspects of the data in the matrices. All data questionnaires and data entry forms are attached in Annex A.

Summary of data gathered

Region	Meta	Mezzo	Micro	Maternity hospital questionnaires	Infant home questionnaires
Ashgabat	Tables 1, 2, 4,	All	26 children	City: 5 staff,3 parents	8 staff
	5,		(100%)		2 parents
Ahal	Tables 1, 2, 3,	-	-	Etrap 1: 5 staff, 3 parents	-
	5, 6, 7, 8,9			Etrap 2: 2 staff	
Lebap	None	All	55 children	City: 5 staff, 3 parents	8 staff
			(100%)	Etrap 1: 5 staff, 3 parents	2 parents
Mary	All	All	42 children	City: 5 staff, 3 parents	8 staff
			(100%)	Etrap 1: 5 staff, 3 parents	3 parents
				Etrap 2: 5 staff, 3 parents	
Dashoguz	Tables 1, 2, 3,	All	20 children	City: 5 staff, 3 parents	8 staff
	4, 5, 6, 9		(100%)	Etrap 1: 5 staff, 3 parents	1 parent
				Etrap 2: 5 staff, 3 parents	
Total			143	52 staff; 30 parents	32 staff; 8
					parents

Source: UNICEF Turkmenistan

C. Findings

C1. Number of children under 3 years of age living in residential care in Turkmenistan

Stock data - number of children resident at a given time

Table 1 draws on the macro, mezzo and micro secondary data gathered by the study to summarise two versions of the number of children resident in the four infant homes at the end of 9 months of 2013 and shows that between 189 and 227 children were resident at that time.

Table 1 Number of children resident in four infant homes at the end of September and in December 2013

Infant Home	Calculated number of children resident	Given number of children resident	Number of children resident in December 2013 stated by head doctors
Ashgabat	39	32	26
Dashoguz	55	49	20
Mary	61	48	42
Lebap	72	60	55
TOTAL	227	189	143

Source: Mezzo, macro and micro secondary data provided by MoH teams; interviews with Infant home Head Doctors; author's calculations

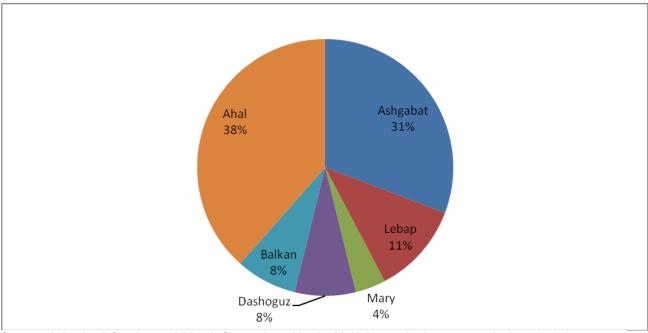
The 'calculated number of children resident' at the end of 9 months of 2013 is based on the data provided by the MoH teams from the four regions for the number of children resident at the end of 2011, the number who entered and left during 2012, and the number who entered and left during 9 months of 2013. The 'given number of children resident' is the number given by each of the MoH regional teams in the mezzo data recording sheets used during the study. The margin of difference between the calculated and given numbers of children is between 5-13 children or 10-20 % variation per children's home and 33 children or 17% variation overall. Table 1 also notes that infant home head doctors and staff confirm a figure of 143 infants in residence at the time of the data collection for this study in December 2013.

The contradiction between these numbers is symptomatic of the high turnover in the number of children entering and leaving the institutions during the course of any given period of time, a phenomenon which is explored in more detail in the flow data section below. It can be seen, for example, that the largest difference in the calculated, given and stated numbers is between the Dashoguz stated number of 20 children resident in December 2013 and the other two figures for Dashoguz infant home from the MoH data. The flow data below shows that it is unlikely that 29-35 children left the infant home between September and December 2013, however there was a state pardon programme which coincided with this period which affected women in the prison colony in Dashoguz and it could be that their children left the infant home *en masse* when their mothers were released from the colony as part of this amnesty

Where do the children living in the infant homes come from geographically?

The secondary micro data gathered for this study does not provide a detailed breakdown of the regions of origin of all the children who were resident in the infant homes, but it can be safely assumed from the 143 cases that were reviewed by the data gathering teams, that in all cases, apart from Dashoguz and Ashgabat, the infants have come from the towns and villages of the region where there infant home is located. The Dashoguz infant home cares for children from the Dashoguz region and for children from all over the country whose mothers are serving sentences in the women's prison. The Ashgabat infant home received children mainly from Ashgabat and Ahal velayat, but also from other parts of the country. Diagram 1 shows the breakdown of region of origin for the 26 infants who were resident in the Ashgabat infant home in December 2013 when the micro data was gathered for the study.

Diagram 1 Ashgabat infant home breakdown of region of origin for 26 infants resident in December 2013



Source: Ashgabat infant home children's files reviewed by the MoH data gathering team; author's calculations

It is not clear whether the children living in the Ashgabat infant home from Lebap, Mary and Dashoguz were recorded in this way because their mothers were from these regions originally, but they were born in Ashgabat, or whether they were sent to the Ashgabat infant home from their regions of origin for some administrative or other reasons. Either way it is clear that the majority - 18 infants or 69% - of children being cared for in the Ashgabat infant home are from Ahal velayat or from Ashgabat city. There is no infant home in Balkan, and 2 children (8%) from the Ashgabat sample of 26 infants in residence in December 2013 are recorded as being from Balkan. It seems likely that there are more children from the Balkan region living in the other infant homes as well, but the way that data was recorded did not permit analysis.

The micro data for 143 infants in all four infant homes shows that slightly more children (51%) come from rural areas than urban (38%), but given that no information was provided about geographic origin in 11% of cases, there are no significant conclusions that can be drawn from this information.

Proportion of children under 3 years of age resident at any given time in infant homes per 100,000 child population aged 0-3 years

Without full child population data is it not possible to calculate the rate of children per 100,000 child population to make international comparisons, but with the available data it is possible to look at some of the regional variations within Turkmenistan in the rates of children resident at any given time per 100,000 infants aged 0-3 in some regions as in Table 2.

Table 2.1 Proportion of children living in infant homes in September 2013 per 100,000 children aged 0-3 years

Region	Child population	Number of infants	Number of children
	aged 0-3 years of	given as being	in infant homes in
	age	resident in	September 2013
		September 2013 in	per 100,000 child
		each infant home	population aged 0-3
Ashgabat and Ahal velayat	108644	32	29

Dashoguz velayat	119703	49	41
Mary velayat	122408	48	39
Total	350755	155	37

Source: Meta and mezzo data provided by the MoH teams; author's calculations

Table 2.2 offers a comparison of how this rate compares with other countries in the Central Asian region as far as it is possible with the limited data available. Obviously the rate given for Turkmenistan in 2013 is based on the data presented in Table 2.1 and is in fact for three infant homes rather than for the whole country.

Table 2.2 Proportion of children living residential care in the Central Asia countries per 100,000 children aged 0-2

Country	2006	2011	2013
Kazakhstan	193,5	120	
Kyrgyzstan	60,2	38	
Tajikistan	23,4	27	
Turkmenistan	48,2		37
Uzbekistan	34,9		

Source: UNICEF Transmonee 2011 & 2013

The international comparison confirms the generally low rate of institutional care for infants in Turkmenistan compared to most of the countries in Central Asia, but it has to be treated with caution until fully comparative data is available.

Table 2.1 shows that the Dashoguz infant home has slightly a higher proportion of children per 100,000 children aged under three years than the average for three regions and the Ashgabat infant home has a much lower rate than the average. This would be even lower if adjusted for the residents in the Ashgabat infant home who are not from Ashgabat or Ahal velayat. It is interesting to note, however, that the Ashgabat infant home has the highest turnover of infants entering and leaving the infant home during any given period of time and the value of this rate as an indicator is limited on its own without examining the flow of children in and out of the institutions and other important aspects of the service information such as length of stay and age at entry into the infant home as well as reasons for placement.

Flow data – number of children entering and leaving the infant homes

The number of children resident at any given time is variable in all four infant homes as a part of the resident population of these institutions appears to be highly mobile, particularly in Lebap and Ashgabat where relatively large numbers of children enter and exit the institutions each year. In 2012, 285 babies and infants entered all four infant homes and in 9 months of 2013 259 children had already entered, so it is likely that there will be an increased total number of new children entering for the whole of 2013 once the year end data is finalised. Table 3 gives a detailed breakdown of how many children entered and left the infant homes each year together with the net movement for each year. It can be seen that the Dashoguz infant home population is gradually declining, the Ashgabat infant home population is fluctuating with a tendency towards declining and that more children enter than leave the Lebap and Mary infant homes each year for the period 2010-2013.

Table 3 Number of children entering and leaving the infant homes each year

Year		2010	2011			2012			2013			
	Number			Number			Number			Number		
	of	Number		of	Number		of	Number		of	Number	
	children	of		children	of		children	of		children	of	
	who	children		who	children		who	children		who	children	
	entered	who left	Net									
	during	during	move-	during	during	move-	during	during	move-	during 9	during 9	move-
Infant home	the year	the year	ment	the year	the year	ment	the year	the year	ment	months	months	ment
Ashgabat	164	164	0	145	154	-9	125	118	7	110	117	-7
Dashoguz	72	81	-9	52	53	-1	44	46	-2	34	38	-4
Lebap	116	104	12	96	78	18	62	58	4	65	51	14
Mary	70	55	15	70	64	6	54	44	10	50	47	3
TOTAL	422	404	18	363	349	14	285	266	19	259	253	6

Source: MoH data collection teams; author's calculations

For the purposes of planning alternative services, it is useful to note the rate of entry and exit from the infant homes. Table 4 further illustrates that across all four infant homes there has been a slowing down in the number of children entering each month, but that the rate for the first 9 months of 2013 indicates an increase and that on average there are roughly the same number of children entering and leaving Ashgabat and Mary infant homes each month, and average of 2 children more entering Lebap infant home each month than leaving and roughly one child more leaving Dashoguz infant home each month than entering.

Table 4 Average number of infants entering and exiting the infant homes each month and the monthly average for a 3 year and 9 month period for each infant home and across all infant homes

Rate of entry	2010	2011	2012	2013	Average
Ashgabat	14	12	10	12	12
Dashoguz	6	4	4	4	4
Lebap	10	8	5	7	8
Mary	6	6	5	6	5
Total	35	30	24	29	30
Rate of exit	2010	2011	2012	2013	Average
Ashgabat	14	13	10	13	12
Dashoguz	7	4	4	4	5
Lebap	9	7	5	6	6
Mary	5	5	4	5	5
Total	34	29	22	28	28
Net monthly difference - all infant homes	+1	+1	+2	+1	+2

Source: MoH data collection teams; author's calculations

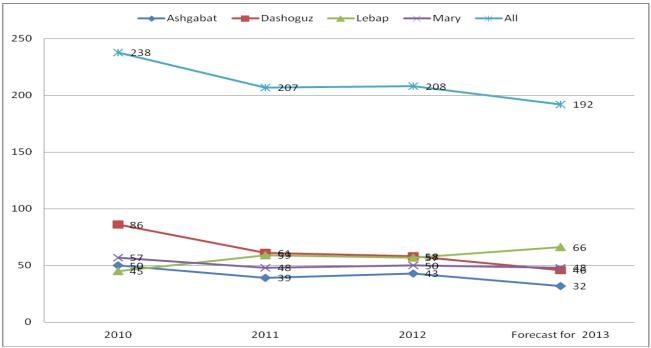
If the data provided to the study is accurate, and no action is taken to change the current patterns of entry and exit from the infant homes, then it is likely that there will continue to be a very slight growth in the number of infants resident in Lebap and possibly in Mary infant homes, a static number of children in the Ashgabat infant home and a gradually declining number in the Dashoguz infant home with an overall increase of 1 or 2 children per month resident across all four infant homes. More detailed analysis of historic trends, which can help in forecasting future trends, is provided in the next section of the report.

Trends in stock and flow over time - 2010-2013

The quantitative data gathered for this study as illustrated in Diagram 2 shows that overall the number of children resident in the infant homes at the end of each year fell in 2011 from the 2010 number and is likely to fall a bit further in 2013 across all infant homes. Mary has a relatively static number of children resident at the end of each year. The fluctuations in the other infant homes are greater, but generally quite slight. Lebap infant home numbers are increasing slightly, but only Dashoguz numbers are falling steadily in a similar pattern to the overall number. Diagram 2 has been plotted based on the numbers of children given as being

resident at the end of each year by the MoH teams and not on the calculated number or the number stated as resident in December 2012 by infant home directors.

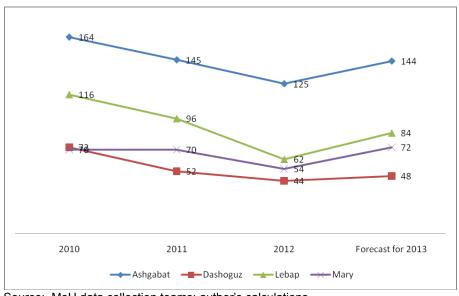
Diagram 2 Number of children resident in the infant homes at the end of each year 2010 – 2013 (forecast for 2013 estimated based on data provided for 9 months)



Source: MoH data collection teams; author's calculations

The number of children who enter the care of the infant homes during the course of the year has also fallen but an upward fluctuation seems likely in 2013 based on the data for 9 months so far, particularly for Ashgabat and Lebap infant homes as illustrated in Diagram 3.

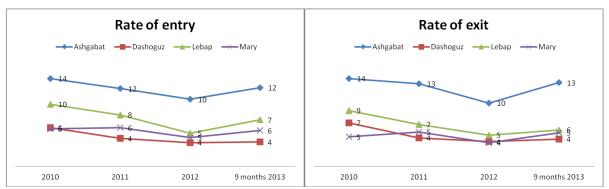
Diagram 3 Number of children entering the infant homes during the course of each year 2010-2013 (forecast for 2013 estimated based on data provided for 9 months)



Source: MoH data collection teams; author's calculations

Diagram 4 illustrates the gradual slowing of the rate of entry and exit across 3 years and the upward fluctuation that can be noted for the 9 months of 2013 for which data is available and summarized in Table 3.

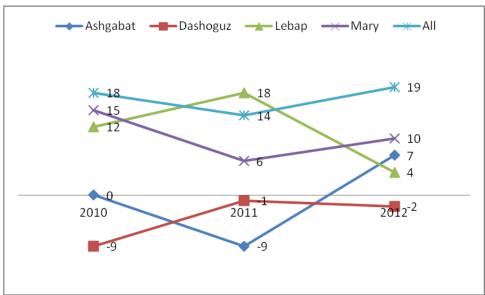
Diagram 4 Number of children who entered and exited the infant homes each month



Source: MoH data collection teams; author's calculations

Also based on the data in Table 3 above, Diagram 5 illustrates the net movement for each of the infant homes and for the whole system of residential care for children under three on a year by year basis.

Diagram 5 Net movement in numbers of children in the infant homes each year 2010-2012

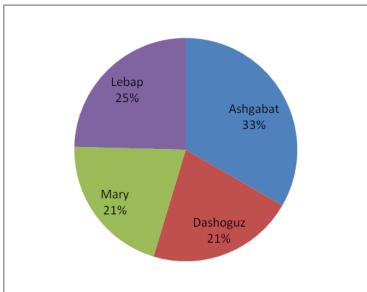


Source: MoH data collection teams; author's calculations

Diagram 5 illustrates again how Dashoguz infant home is the only institution steadily getting smaller, Ashgabat infant home has a fluctuating population and the annual increase in the Mary and Lebap infant homes also fluctuates.

If the number of children who enter the infant homes is added to the number which remain at the end of the previous year it is possible to understand how many children experience at least some period of time living in these institutions in the course of each year. In 2012 492 infants were either in residence at the beginning of the year or entered the infant homes during the course of the year. Of these, around 1/3 went through the Ashgabat infant home as illustrated in Diagram 6.

Diagram 6 Percentage of 492 infants who spent at least some time in each of the four infant homes in 2012



Source: MoH data collection teams; author's calculations

The number of children experiencing an episode in residential care in 2012 is considerably higher than the number left in residence at the end of the year. The rate of infants who remained in or entered residential care in Mary, Dashoguz and Ashgabat¹ in 2012 is 140 per 100,000 child population aged 0-3 years compared to the rate of 37 for infants in residence at the end of the year shown in tables 2.1 and 2.2.

Summary of number of children living in residential care

The main source for the above analysis of numbers of children living in, entering and exiting residential care was the numbers provided by the MoH data collection teams to the study. The interviews with infant home directors and the calculations on net movement reveal some contradictions in the data provided. It is probable that there is some data missing in relation to the number of children who exit the infant homes because of death. If, however, it is assumed that the data provided is the most accurate and up to date information available, then the numbers and trends relating to the care of children under 3 years of age in Turkmenistan can be summarized as follows:

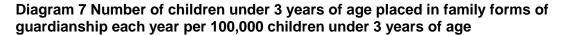
- There were 189 children resident in four infant homes in September 2013 and a projected 192 in residence at the end of 2013.
- 492 babies and infants had episodes of residential care of various lengths across all four infant homes during 2012

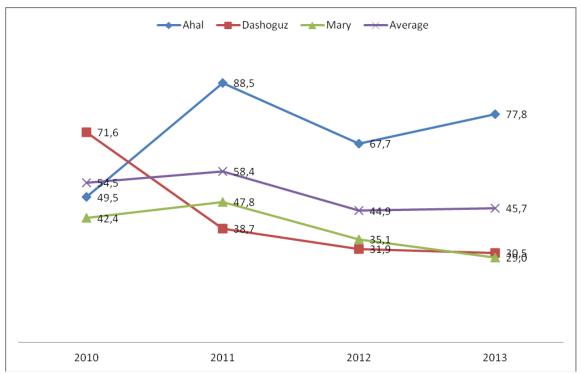
¹ Infant population data for Lebap and for the whole country was not provided so it is not possible to calculate rates for the whole group of infants in question across the country.

- Around 260 children entered and 260 children left the four infant homes in 2012 and nine months of 2013
- The rate of entry to the infant homes is on average about 30 children entering and 28 children leaving each month across the whole country. The rate of entry and exit in Ashgabat infant home is two to three times that of the other infant homes.
- It is probable that in fact there are more children leaving than entering but the data provided to the study is not complete.

C2. Number of children under 3 living in other forms of care

Data for children under 3 years of age being sent to other forms of care each year was available for Ahal, Dashoguz and Mary velayats and is summarized in a comparative form in Diagram 7.





Source: MoH data collection teams; author's calculations

Diagram 7 illustrates a high rate of placement of children into family forms of care in Ahal velayat compared to the other two velayats and an average of around 45-55 children per 100,000 children aged under 3 years for all three regions. It is possible that the higher placement into family care in Ahal is linked to the absence of a dedicated infant home in the towns and villages where the children are from, or it could be that the family care traditions are stronger. Finding local family solutions appears to be the first option for the municipal guardianship organs, rather than sending the infants to the Ashgabat infant home.

It is not clear from the data provided to the study whether the infants placed into family care are initially placed into residential care or not. Dashoguz and Mary velayats record 39 and 42 infants under 3 years of age respectfully who were placed into family type care in 2012. The Dashoguz and Mary infant homes provide the following information for infants under 3 years leaving the institutions in 2012:

	Number of infants under 3 years of age placed into adoption	Number of infants under 3 years of age placed into guardianship of relatives
Dashoguz	11	5
Mary	17	0

It is clear, therefore, that many children are placed straight into guardianship or other types of family care without first entering the infant homes – 23 children in the case of Dashoguz velayat and 25 children in Mary. It is not fully clear from the data what the data gatherers understood by 'placed into family forms of care', but it can probably be assumed that they meant placed into the guardianship of relatives. It is not clear whether they have also included children placed into adoption in the data for the velayats. Table 5 attempts to compare the proportion of children who entered infant homes in 2012 to the proportion who entered family placements. The rate of 67,7 for Ahal velayat does not include the children from Ashgabat who entered family type care in 2012 (as data was not provided for Ashgabat) and the rate of 115,1 is for the whole Ashgabat infant home and includes children from other regions and from Ashgabat as well as from Ahal so the rates are not comparable. It is notable that the Ahal data records only 7 children under 3 years of age being placed into the infant home in 2012, all of whom had already left the care of the infant home by the time of the data collection in December 2013. In the same year 44 infants under 3 years of age, more than 6 times more, were placed into family type care in Ahal velayat.

Table 5 Number of children under 3 years of per 100,000 child population aged under 3 years who entered infant homes and family based care in 2012

	Number of children under 3 years	Number of children under 3 years		
	per 100,000 child population aged	per 100,000 child population aged		
	0-3 years who entered infant homes	0-3 years who entered family type		
	in 2012	care in 2012		
Ashgabat & Ahal	115,1	67,7		
Dashoguz	36,8	31,9		
Mary	44,1	35,1		
Average (without				
Ashgabat and				
Ahal)	40,4	33,5		

Source: MoH data collection teams; author's calculations

It is interesting to note that the rate for residential placement in Dashoguz and Mary is slightly higher than the rate for family type placement. It is likely that the family placement rate probably includes some of the children who first were placed into residential care.

Gender variations

Data was only disaggregated for gender in 2013 and the data provided for boys and girls placed into family type care in 9 months of 2013 reveals an interesting anomaly in one region, but there is not enough data to know whether it is the rule or an exception. The rate of entry into family type care for boys and girls is roughly the same for all velayats that provided data, but in Ahal the rate for girls aged 0-3 being placed into family type care is more than twice the rate for boys per 100,000 girls and boys respectively. 34 girls aged under 3 years were placed into family type care in 9 months of 2013 in Ahal velayat compared to only 16 boys – this translates into a rate of 107 girls per 100,000 girls aged under 3 years and 47,7 boys per 100,000 boys aged under 3 years in Ahal. In the same period, 1 girl and 2 boys aged 0-12 months were placed into

the Ashgabat infant home. There was no discernible variation in gender for Mary velayat, the only other region to provide data disaggregated by gender for 2013.

Outcomes for children aged 0-3 years leaving residential care

This section examines in more detail the outcomes for children aged 0-3 in residential care, as return to the care of their own families is one of the main outcomes after placement into adoption and is not included in the data that has been reviewed thus far.

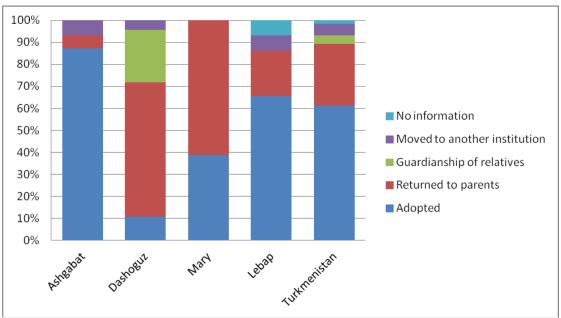
Table 6 Outcomes for children age under 3 years of age leaving all four infant homes in 2012

	Number of children who left the infant home during 2012	Of these, adopted	Returned home to parents	Placed into guardianship of relatives	Moved to another institution	Other (no information)
Ashgabat	118	103	7		8	
Dashoguz	46	5	28	11	2	
Mary	44	17	27			
Lebap	58	38	12		4	4
TOTAL	266	163	74	11	14	4
% of those who left		61%	28%	4%	5%	2%

Source: MoH data collection teams; author's calculations

Diagrams 8 and 9 further illustrate how different infant homes had very differing results in 2012 and how the overall outcomes for the country as a whole are made up. Of 266 children who are reported as having left the infant homes across the country in 2012, 163 or 61% were adopted, however this was the outcome for 87% of the children who left Ashgabat infant home in 2012 and for 66% of children who left the Lebap infant home.

Diagram 8 Care arrangements to which 266 children moved from each infant home in 2012 – % of children from each children's home into each type of care arrangement



Source: MoH data collection teams; author's calculations

The next most common next care placement nationwide following a stay in residential care for under 3 year olds in 2012 was a return to parents with 28% across the country returning to their parents, but with wide variations between regions. Only 6% of Ashgabat infant home children returned to parents while 61% of Mary and Dashoguz infants returned home and 21% of Lebap infants. The next most likely placement is into another form of residential care for 5% of all infants followed by placement into the guardianship care of relatives. In Mary however, in 2012 no children were moved into other types of residential care and in Dashoguz as many as 11 children out of 46 or 24% left the infant home to enter the care of their relatives. In the other infant homes there were no children who left for the care of their relatives in 2012. Diagram 9 shows how these outcomes are distributed by region with all regions sending children into adoption or back to their parents to a greater or lesser extent, 63% of all children who were adopted from infant homes in 2012 came from Ashgabat infant home, for example, and 74% of all children who returned to their parents came from Dashoguz or Mary infant home. Only 9% of those who returned to parents came from Ashqabat infant home and 16% from Lebap. Only Dashoguz sent children back to the care of their relatives and Mary did not sent any infant into other institutions in 2012 while 8 out of the 14 infants who went into other institutions from the infant homes in that year came from Ashgabat infant home.

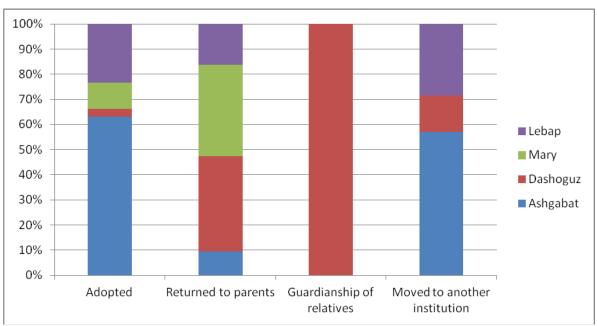


Diagram 9 % of children from all 266 children who moved into each type of care arrangement from each regional infant home

Source: MoH data collection teams; author's calculations

Summary of number of children living in other types of care

Overall there is not enough data available to this study be able to draw firm conclusions, but it is clear that in Ahal which has no local infant home and sends children to Ashgabat for placements, there is a much higher rate of placement into family type care for children under the age of 3 years than in Dashoguz and Mary which both have their own infant home facilities. In these two regions the rates of entry into residential type care are slightly higher than that of placement into family type care.

It is much more likely that children who have been in Mary and Dashoguz infant homes will return home to their parents and that infants who have been in Ashgabat and Lebap infant homes will go into adoptive families.

Guardianship by relatives is relatively uncommon after an episode of care in the infant home, except in Dashoguz where this is the outcome for about 24% of infants. This could be related to the link between Dashoguz infant home and the only women's prison in Turkmenistan, or it could be related to the practices in the infant home and the guardianship organs.

Either way, the outcomes for children are closely linked to the reasons for their entry into the care of the infant home in the first place and the next part of this report will explore these reasons in more detail.

C3. Number of children relinquished or abandoned in Turkmenistan

Meta and Mezzo data provided by the MoH teams relating to abandonment or relinquishment in the maternity hospital is summarized in Table 7, but it is incomplete and until data is collected systematically it will be difficult to determine accurately the number of infants under 3 years who are relinquished or abandoned. In 2012, for example, the data provided by the Ministry of Health teams at the Mezzo level records that, of 285 children who entered all four infant homes, 159 or 56% entered straight from the maternity hospital and 161 are recorded as having been

placed into the infant homes because of 'refusal by parents'. It is not clear whether the 161 were newborn babies or older infants and nor is it possible to reconcile the Mezzo data for 2012 with the numbers provided in the Meta data table which are summarized in Table 7.

Table 7 Number of babies relinquished at the maternity hospital 2010-2012 – data for Ashgabat, Dashoguz and Mary velayats

	Number of in	fants relinqu	ished in th	е				
	maternity hos	spitals			Per 10,000 live births			
				9				9
				months				months
	2010	2011	2012	2013	2010	2011	2012	2013
Ashgabat								
	39	44	22		36	37	18	
Dashoguz								
	72	44	39	28	24	13	11	11
Mary	28	30	28	39	8	8	8	11
Total	139	118	89	67	15	12	9	9

Source: MoH data collection teams; author's calculations

Until more systematic data can be collected, the micro data provides a greater insight into the extent of infant relinquishment or abandonment.

Secondary individual data was documented for all children resident in Ashgabat, Dashoguz, Mary and Lebap infant homes was provided at the time of the data collection field work which provides an important insight into the characteristics of the children who are resident in the infant homes at any given time. 33% of infants resident had a reason given as 'refusal of parents' – this contingent, however, only includes a few infants who are aged under 3 months and who are likely to be adopted quite quickly. On balance, the 2012 Mezzo data can probably be taken as the most reasonable indication of the extent of infant relinquishment of abandonment with around 56% of new entries into the infant homes each year coming from maternity hospitals following relinquishment at birth and this percentage can be applied to the numbers of children shown in Diagram 3 above for an indicative estimate. These infants cannot be seen in the micro data as they do not spend long in the infant homes, but move quite quickly into adoption as Table 6 above illustrates. The following sections explore in more detail the micro data and the reasons for relinquishment and abandonment of infants.

Summary of number of children relinquished or abandoned

Around 150 or 56% of all new entrants into the infant homes each year are probably babies who have been relinquished at birth in the maternity hospitals. This number is probably falling year on year, but with a recent, slight upturn in 2013.

C4 Analysis of data relating to 143 infants resident in the four infant homes in December 2013

This section notes the patterns in the population of children who were resident in the four infant homes at the time of the study and it must be emphasized that this sample captures data mainly for the longer term residents of the institutions and is not necessarily fully informative about the children who enter and leave after short stays. No significant gender differences were noted,

perhaps slightly more boys than girls were in residence at the time with 60 girls or 42% of the total population of children and 83 boys or 58%. The ethnicity of children also more or less reflects the ethnic make-up of the overall child population, although this should be checked with up to date census data to be certain – 123 children were Turkmen (86%); 6 were Uzbek; 7 were Russian, for two children ethnicity was not known and the remaining 5 were a mix of other ethnicities and nationalities such as Kazakh, Buludzh and Azerbaijani. The data relating to other social factors which probably have a very direct impact on the entry and exit of children into and out of the system of infant home care such as the level of education of parents, particularly the mother, the age of the mother, the number and age of siblings, employment and housing status and the civil status (married, unmarried, widowed, divorced) of parents was largely too incomplete to be conclusive. It can be noted, for example, that where education level was recorded only 2 out of 65 mothers had reached higher education and 63 had basic secondary education.

It is also interesting to note that where the marital status of the mother was recorded, there are more unmarried (63) and divorced (9) mothers of children resident in the infant homes in December 2013 than married mothers (35). Given that in 36 instances no information was given, however, it is difficult to draw conclusions. It is also interesting to note that among 40 refusals, 21 were by unmarried mothers and 19 of these were done when the child was aged 0-3 months and 9 were cases where the infant was refused at birth in the maternity hospital. Given the general absence of conclusive data, however, it is not possible to do more than just note these tendencies as generally supporting some of the other data in the study and at least not contradicting it.

It is not possible to draw any useful trends or patterns for nearly all the other parameters for which data was sought, given the general absence of information recorded. The most useful and significant data to emerge from the micro-data analysis relates to the age of children at entry, length of stay, disability status, visits by relatives, plans after exit and reasons for entry.

C4.1 Age at entry and age of 143 infants in the care of the infant homes in December 2013

59% of 143 children resident in December 2012 had entered the institutions at the age of 0-3 months and 71% at the age of 0-6 months.

All the other children entered at a range of ages one child at 7 months, one at 8 months, three at 9 months, one at 10 months and so on. One child entered at the age of 44 months or almost 4 years of age and four children at the age of 34 months or almost 3 years of age.

It is clear that children most likely to enter the care of the infant homes are babies and infants under 6 months old. However it is possible that infants enter at any age up to and exceeding the nominal 3 years of age up to which the infant homes are mandated to provide care and this applies not only to children with disabilities.

32 children over three years of age were in the care of the infant homes at the time of the study and of these, 14 entered the infant home in the first 6 months of life. All but one of these has a disability. Diagram 10 illustrates the extent to which the ages of children who were in the care of the infant homes in December 2013 are distributed fairly evenly from newborns all the way up to over 5 years of age.

49-65 months 4% 43-48 months 0-6 months 10% 20% 37-42 months 9% 31-36 months 7-12 months 13% 25-30 months 12% 13-18 months 19-24 14% months 9%

Diagram 10 Age of 143 infants in the care of the infant homes in December 2012

Source: MoH data collection teams; author's calculations

Babies and infants aged 12 months or under represent a larger proportion than other age groups. This is in keeping with data provided above showing a high number of entries into the infant home each month of babies straight from the maternity hospitals.

C4.2 Length of stay

The average length of stay in the infant home for the current population was 11.4 months in December 2013. There are some variations according to the reasons for entry and depending on the region.

For 55 Lebap children the average length of stay was 19 months, for 26 Ashgabat children 16 months, for 20 Dashoguz children 19 months and for 42 Mary children just 8.8 months.

For 67 children with disabilities and medical problems in Lebap, Dashoguz and Ashgabat – 18 months; for 93 children with disabilities and medical problems across all infant homes – 11 months.

For 10 children whose mothers are in prison – 19 months

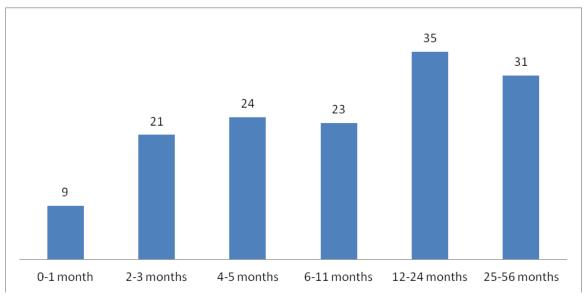
For 64 children in Lebap, Dashoguz and Ashgabat infant homes with reasons related to death of parents, refusal of parents and illness or disability of child the average length of stay in December 2013 was 17 months.

For 12 children with reasons related to illness of parents, the average length of stay was 15.5 months. For 26 children with reasons relating to social issues the average length of stay was 9 months – notably lower than for children who were in care for other types of reasons. For all 49

children in temporary placements including children placed for reasons of their disability, parent illness or social reasons the average length of stay was 16 months.

Shortest length of stay at the time of data collection was 0 months (just entered) and longest was 56 months. Diagram 11 illustrates that 66 children or 46 % had spent one or more years at the time of the survey (of these about half had spent 2 or more years) – and of these 66 children who have spent more than one year, 32 children were without disabilities, 32 were in 'temporary placements' for a range of reasons and for 25 children the plan is to return home.

Diagram 11. Length of stay to date - the number of children who had spent specific periods of time in the care of the infant homes by December 2013 (N=143 children)



Source: MoH data collection teams; author's calculations

It is reasonable to assume from interviews with infant home staff that babies who enter the infant home from the maternity hospitals and who are intended for adoption usually stay for periods of 1-3 months, sometimes up to 6 months, but by 6 months they have usually moved into their adoptive family. Other children, both with and without disabilities, end up staying for much longer periods and Diagram 11 helps to illustrate this pattern.

C4.3 Numbers of children with and without disabilities

50 children or 35% of 143 infants who were in the care of the infant homes in December 2013 did not have any health problems. 52 children or 36% had a confirmed disability (a genetic or developmental disorder) and 41 or 29% had some somatic health issues, but not a disability as illustrated in Diagram 12.

no pathology somatic pathology genetic pathology (ie. Down's Syndrome)

a developmental pathology (ie. Cerebral Palsy)

Diagram 12. Health status of 143 children resident in the infant homes in December 2013

Source: MoH data collection teams; author's calculations

The meta data provided by the MoH regional teams is incomplete, but the available data summarized in Table 8 shows that on average around 0.1% of live born children in three velayats were diagnosed with a pathology or genetic disorder in the maternity hospital every year from 2010 to 2012. There are significant variances, however, between the data from the three velayats so it is not clear how reliable this data is or the extent to which it can be generalized as an average across all three regions or the extrapolated as an average for the whole country.

Table 8 Prevalence of disability diagnosed at birth²

Number of infants born with developmental pathologies or genetic disorders diagnosed in the maternity hospital					per 100,000 live born children			
	2010	2011	2012	2013 (9 mths.)	2010	2011	2012	2013 (9 mths.)
Ahal velayat	37	43	50	52	203,3	220,2	258,8	337,1
Mary velayat	31	40	26	13	91,1	112,7	70,7	37,8
Dashoguz velayat	12	5	10	16	39,8	14,9	28,7	65,1
Average across three velayats	27	29	29	27	111	116	119	147

Source: MoH data collection teams; author's calculations

Table 9 shows that around 0.2% of infants aged 0-3 years in Ahal velayat and 0.02% in Mary velayat are registered with the Ministries of Health and/or Social Protection as having a

² It is not clear why the Ahal rate should be so much higher than the other two velayats. Either there is an error in the data or the way it was recorded in the Meta data sheets, or there is a different system for diagnosis and registering disability at birth in Ahal velayat.

disability, but again, there are discrepancies and variations in the data that mean it should be treated with caution.

Table 9 Prevalence of children with registered disability among infants aged 0-3 years³

Number of infants aged 0-3 years receiving disability benefits per 100,000 infants aged 0-3 years	2010	2011	2012	9 months 2013		
Ahal velayat	127,4	231,8	211,3	205,4		
Mary velayat	8,9	9,9	21,7	10,2		
Number of infants aged 0-3 registered with MoH as having disabilities per 100,000 children aged 0-3						
years						
Ahal velayat	147,2	204,4	272,4	148		
Mary velayat	8,9	9,9	21,7	10,2		

Source: MoH data collection teams; author's calculations

The only other data source that can help to determine the prevalence of disability among children available to the study is the 2005 report by the National Institute of the State Statistics and Information of Turkmenistan, the 'Situation Analysis Of Children Deprived Of Parental Care Or Reared In Families Which Lost Their Breadwinners'. This report documents the numbers of recipients of disability grants aged under 16 years in 2004 and Table 10 summarises this data and shows a calculation for a rate per 100,000 child population aged 0-14 provided to this study (in the absence of data for children aged under 16 years of age) in order to gauge a rough average rate across four regions of 0.73% or 728,7 children per 100,000 children aged 0-14 years.

Table 10 Very rough estimate of prevalence of disability among children aged 0-14 years based on available data

	Child population 0- 14 years in 2010	Number of disability benefits recipients under 16 years of age in 2004	Rate per 100,000 child population 0-14 years
Ashgabat	148060	893	603,1
Ahal velayat	149925	1346	897,8
Dashoguz velayat	340731	2255	661,8
Mary velayat	351002	2640	752,1
Average - 4 regions			728,7

Source: MoH data collection teams; author's calculations; NISSIT Situation Analysis, 2005

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³ It is not clear why the Ahal rate is so much higher than the Mary rate. Either there is an error in the data or the Ahal velayat authorities have a more systematic way of diagnosing and registering young infants with disabilities and therefore register more than in Mary. The Mary data for the MoH and MoSP register is the same.

Calculating prevalence of disability is notoriously complex (see for example Tossebro and Kittelsaa, 2004 and UNICEF on this question⁴) and even more complex to compare from country to country as it relies on disability assessments which can differ from country to country and system to system. Overall, however, it is likely that around 1.5-5% of children aged 0-17 years in any given country have disabilities so the rates calculated here seem very low. This is to be expected for very young children as disability diagnosis in early childhood is often not possible. Either way, however, the prevalence of disability in the infant home population of 143 infants in 2012 is at 36% over 100 times more than that for the highest estimated prevalence rate in the general population of a comparable age - 0.3% of newborns in Ahal velayat or 0.73% of children under 14 years of age - and indicates fairly conclusively that disability is a one of the key issues affecting the entry of infants and babies into the system of institutional care in Turkmenistan. The qualitative data from the interviews and the analysis of reasons for placement from the micro data given below also confirms this finding.

The micro data shows that there were 40 children in residence in the infant homes in December 2013 who had been relinquished or abandoned by their parents, of these 19 children or 48% have disabilities and 21 have no disabilities. A further 30 children were 'temporarily placed because of the child's illness' (including some children with somatic pathologies). Box 1 provides information on some of the characteristics of the situation for children with disabilities in the infant homes in December 2013:

BOX 1 Reasons for placement of 52 children with disabilities – age at entry, length of stay in the infant homes, plans for placement after the infant home

For all 52 children with disabilities who were in residence in the infant homes in December 2013, the following patterns summarizing their reasons for entry into the care of the institutions and other key characteristics can be summarized as follows:

19 children (37%) were refused by parents and 26 (50%) were temporarily placed because of child's illness and of these 45:

Age at entry: 28 children (62%) entered at age 0-6 months; 7 entered aged 7-23 months; 10 at more than 2 years of age

Points of entry: 6 entered the care of the infant homes straight from the maternity hospital, 19 from their family home, 19 from hospital, 1 from the police

Visits from relatives: 2 children have parents who phone to find out about how they are; 4 have parents who visit but rarely; for 4 children no information about visits was given in the micro data sheets; 13 children have parents or relatives who visit regularly; 22 are not visited although parents still have legal care and of these - 8 children have been in the infant home for less than a year and 14 had been in the infant home for more than a year at the time of the survey.

Plan for placement: for 12 children the plan is to return to parents, 1 child will go into the care of relatives and 32 will go into a social care institution after the infant home.

1 child was placed because of the death of a parent

3 children were placed temporarily for social reasons – these children are of a range of ages at entry into infant home care and a range of lengths of stay; two out of three are visited by relatives or parents -

⁴ Nordenmark Severinsson A., presentation at 4th UNICEF Central Asia Child Protection Forum, 2013 http://www.slideshare.net/unicefceecis/plenary-3-ans-eng

the plan is for these two to return home and for the third child the plan is placement in a social institution after the infant home

For 3 children with disabilities there is no information on reasons; they have lengths of stay from 5 to 23 months, a range of ages at entry from 6-36 months. None have visitors. For all three children the plan is to enter a social institution after the infant home.

Children without disabilities have a much more varied set of reasons for entry and pattern of visits, lengths of stay and plans than children with disabilities and these characteristics are summarized in Box 2.

BOX 2 Reasons for placement of 91 children without disabilities – age at entry, length of stay in the infant homes, plans for placement after the infant home

Death of a parent was the reason for placement for 6 children (7%) who entered at various ages including at birth. In 4 cases the children are visited by their fathers and the plan is to return home, three children have been in the infant homes since birth with placements of 13-15 months so far and 1 entered at 13 months and has been in the infant home for 26 months so far; in 1 case both parents are dead and the child is visited by the grandmother with a plan to return home, length of stay so far 9 months, age at entry 15 months. In the 5th case, the child entered at the age of 34 months, does not have visitors and the plan is to enter an education institution.

21 children were refused by parents mainly at birth, all entered at under 3 months of age except two from Lebap one who entered at age 5 months, brought in by police, whose mother is in prison and is now almost 5 years old (55 months) and another who entered at almost 3 years of age (31 months) about whom little else is known. Most of the children have been in the infant homes for six months or less, but 4 had stays of 10-50 months in December 2013. Two babies out of the six at Mary infant home are visited regularly and often by relatives-adopters, another Mary baby is visited as often by unrelated adopters and one is visited weekly by her grandmother. None of the other babies in the other infant homes have visitors. For 3 children from Ashgabat and 5 children from Mary, the plan is adoption and for one child from Mary the plan is return to grandparental care at the parental home. For all the rest from Lebap, the plan is stated as placement in a social protection institution even though six of them are aged 0-7 months and presumably would be eligible for adoption⁵.

4 children were in temporary placements because of illness of the child, all had some kind of somatic pathology, three in Ashgabat had entered at 1 month old from the hospital and are visited by parents, although rarely – two are from Lebap and one from Ahal. One in Lebap entered at 1 year old and is visited regularly by parents. The plan in all four cases is to return home. Length of stay in December 2013 was from 3-11 months.

16 children were in temporary placements because of illness of parent/s and had a range of ages at entry, a range of lengths of stay. All but two children are visited regularly by parents or grandparents. Three of the children have been in the infant homes in Lebap and Mary for 10 months and another

⁵ It could be that this is a misunderstanding about how to code the data as the plans for all Lebap children are given as either return to own family home or placement in a social institution, yet Lebap has a very high number of children leaving for adoption each year so it seems unlikely that so many would go on to a social protection institution.

three in Lebap for 2-2.5 years. All others had been in for 6 months or less in December 2013. In all cases the plan is to return the child home.

23 children are in temporary placements for social reasons and had a range of ages at placement, a range of lengths of stay from a few months up to almost two years. All except one child in Lebap are visited, in some cases in Mary several times a week. In some cases parents are working in Ashgabat and grandparents visit. In all cases the plan is to return the children home.

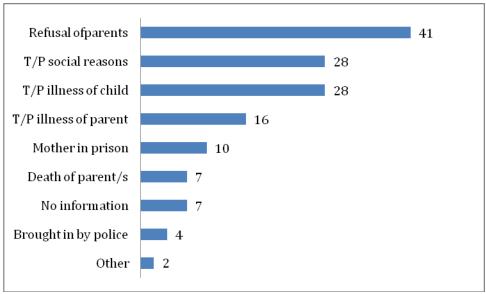
10 children have a mother in prison and had a range of ages of entry and a range of lengths of stay but 8 out of 10 entered straight from the maternity hospital. Range of lengths of stay – 3 children entered relatively recently and 7 entered before July 2012 and have been there for 18-34 months. In all but 2 cases the plan is enter an education institution. The other two will return to parents. All visit their mothers at the colony on a monthly basis.

4 children were brought in by police at a range of ages and with a range of stays to date. In the case of one child from Lebap the mother is in prison (but the reason given in the data form is that the police brought her in). The plan for the Lebap children is to place the children in a social protection institution, one 14-month old child from Mary who recently entered is to be placed for adoption and for the other, the plan is to return home. None have visitors

7 children had no information about reasons recorded - a range of ages at entry (from 0 to 34 months) and mainly longish stays (from 18 to 43 months so far), no visitors in all cases. The plan is a social protection institution in 6 cases and an education institution in 1 case. In one case the child's parents are officially declared missing and the child was brought to the Dashoguz infant home through the police by the child's grandfather. It is not clear why the grandfather could not continue caring for the child.

Diagram 13 illustrates how the reasons are distributed across all 143 children and it can be seen that temporary placements make up 72 or 50% of all placements, but given the information summarized above on 'length of stay' it can be seen that temporary placements are not necessarily the shortest placements. The biggest single reason is refusal of parents, mainly of babies, of which just over half are social reasons (single mothers relinquishing their babies in the maternity hospital) and just under half are linked to the child's disability. When taken together, the parental refusals because of disability and the temporary placements because of the child's disability represent about 32% of the reasons for the placements of the children in the infant homes in December 2013 and the origins of the 36% of children with disabilities in the population of the infant homes then becomes more clear, when combined with the generally longer stays of these children. Overall however, the children who are coming into the care of the infant homes, whether for short stays or for longer stays, are coming in mainly for social reasons which make up around 68% of all reasons.

Diagram 13. Breakdown of reasons for entry recorded in micro data sheets for 143 children in December 2013

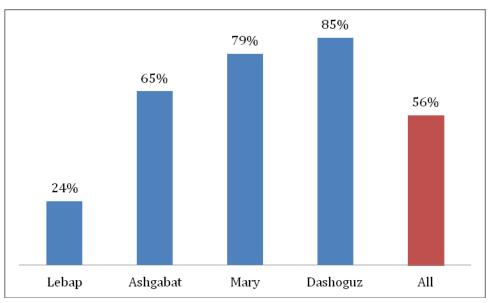


Source: MoH data collection teams; author's calculations

Visiting and levels of contact with families

The data on levels of visiting was recorded in different ways for different infant homes. Mary infant home provided detailed information about frequency, length of visit and where the child and visitors met, for example in a special visiting room. For other infant homes more general information was provided – 'often' 'not often'. Overall 56% of infants have some kind of contact with their parents, relatives or future adopters. In some cases, the visits are very frequent 'every other day, for 1-1.5 hours'. As illustrated in Diagram 14, there are distinct differences between infant homes regarding the level of visiting with only 24% of Lebap infants being visited and 79% of Mary infants maintaining contact with parents and family or being visited by prospective adopters.

Diagram 14. Percentage of 143 children in each infant home who maintain contact with parents, relatives or have visits from adopters



Source: MoH data collection teams; author's calculations

Although the children in Dashoguz appear to have the highest level of visiting, in most cases, these are monthly visits with infant home staff to the women's prison colony and can not be considered to be equivalent to, for example, the more frequent, flexible and more intimate visits that appear to be taking place in, for example, Mary infant home.

Summary of data for disabled and non-disabled children

Almost two-thirds (91 children or 64%) of the children living in the infant homes in December 2013 had no disabilities and were in the care of these institutions for a range of reasons that were to do with the social situation or other circumstances of their parents and wider family including refusal by parents in the maternity hospital, death of one parent, illness of parents or grandparents, mother in prison.

Just over one third (52 children or 36%) of the children in the infant homes in December 2013 had a disability – a genetic or developmental pathology. 45 children or 87% were in the care of the infant homes because their disability or illness had led to refusal by parents or temporary placement by parents and of these 62% entered in the first 6 months of life. In the remaining 7 cases (13%), there was either no information about reasons, the death of a parent or social reasons that led to the placement of the child rather than the disability being the main reason.

Temporary placements for reasons of the child's illness tend to be longer placements than temporary placements for social reasons or other types of temporary placements. The plan for nearly all children in temporary placements is return to parents and they tend to be visited by their parents or relatives on a regular basis, some of them quite often and others less frequently.

Among children without disabilities, the children of women who are serving prison sentences are among the longest resident infants in the infant homes. The plan for most infants with mothers in prison is to enter an education institution or in a few cases to return home – presumably the plan is linked to the length of the prison sentence and the age of the child. It is not clear why these children are not in the care of relatives while their mothers are serving their sentences.

A generally high level of visiting and contact is recorded in the micro data with 56% of infants receiving visitors (even if infrequently) or telephone inquiries and 44% not receiving visitors and the level of visiting is much higher in some infant homes than in others. Those who do not receive visitors tend to be children with disabilities more than children without disabilities, but many children with disabilities are also visited and maintain some family contact especially if they have been placed into temporary placements.

In 19 out of 40 (48%) refusals by parents, the child has a disability. This could be, however, because the infants without disabilities who were born at the same time and also refused are no longer living in the infant home, and in fact the percentage of refusals because of disability is actually much lower compared to all refusals each year. This data confirms that while disability is one significant factor in decisions about refusals by parents in the infant home, it is likely that that social or psychological reasons are the main trigger in the majority of cases.

C4.4 Infants aged 0-3 months in the care of the infant homes in December 2013

As noted elsewhere in this report, the children resident at any given time cannot reflect the characteristics of the contingent of children who are entering and leaving the care of the infant home after only short periods. It is likely that the infants who are in the care of the infant home and are aged under 3 months do reflect the characteristics of this more mobile population and a separate analysis is given in this section.

In December 2013 there were 13 infants living in all four infant homes who had been born in or after September 3013 and were therefore aged 0-3 months (ie under 4 months old) at the time of the data collection. Of these 13 infants, 8 are recorded as having somatic pathologies, 1 as having a genetic pathology and 4 have no pathologies. 6 of these infants were refused by parents, 4 were placed for social reasons and the other 3 were placed for a range of reasons as illustrated in Diagram 14.

t/p social refusal by parents; 6

t/p parent illness; 1

t/p child's illness; 1

Diagram 15. Reasons for entry to infant home recorded for 12 infants aged 0-3 months in December 2013

Source: MoH data collection teams; author's calculations

The plans for the infants are in 5 cases to return home to parents, in 2 cases to relatives, in 2 cases to move into adoptive families, in 1 case the plan is not recorded, in 2 cases to move into a social institution and in 1 case to move into an education institution.

In 6 cases the infants are being visited by relatives, in 4 cases the infants are not being visited, in the other cases no information is provided about visits. Six of these babies entered straight from the maternity hospital, five from the hospital and 2 from their families. This data is not conclusive enough to help clarify the main characteristics of the infants who are entering and then quickly leaving the infant homes for adoption, but it clarifies that the maternity hospital and the children's hospital where children go for post-natal treatment are key points of referral.

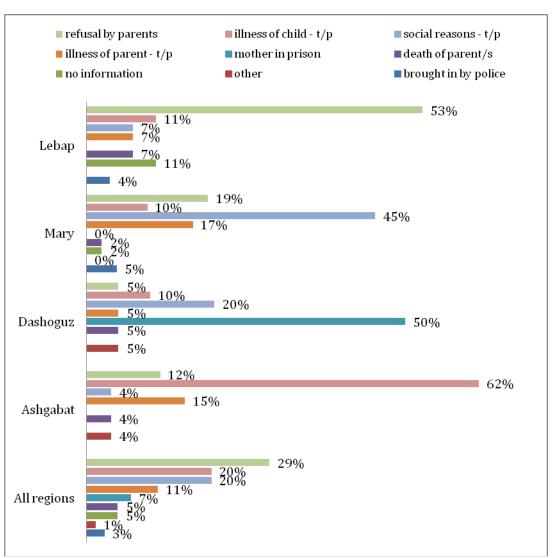
C4.5 Regional variations – reasons for placement recorded in the micro data

So far the micro data has been analysed without examining regional differences and this section will explore the variations in reasons for placement recorded in the micro data for 143 children resident in the infant homes in December 2013. Again, it is important to note that this analysis

relates to the children who happened to be in the care of the institutional system at the time of data collection and cannot necessarily be extrapolated to apply to all children entering the infant home care system.

Diagram 16 shows how the reasons for placement differ from region to region. 16 children or 62% of children in Ashgabat who were resident in December 2013 have been placed temporarily for reasons to do with the child's illness while in Mary, 19 children or 45% of children were placed temporarily for social reasons. In Lebap, 29 children or 53% of children in residence were there because parents had relinquished or abandoned them and 10 children or 50% of the Dashoguz infant home population were there because their mother were service prison sentences. It is notable, however, also that the placement for social reasons in Dashoguz represents a much higher proportion of reasons than, say, refusal of parents.

Diagram 16. Reasons for placement into infant homes – proportions of each infant home population and the country as a whole



Source: MoH data collection teams; author's calculations

In Mary, the large number of children recorded as entering temporary care for 'social reasons' or 'illness of parents' confirms the information for 2012 which was recorded for all infants in the Mary infant home and shows the large number who returned home as illustrated in diagrams 8 and 9 above.

Diagram 17 further illustrates how the main four reasons recorded in the micro-data are distributed across the population of the four regional infant homes. The most startling and significant variations are the extent to which Lebap infants make up the vast majority of 33 parental refusals and the Ashgabat infants make up the majority of 25 temporary placements for reasons to do with the child's illness.

14% 20% 44% 21% 68% 7% ■ Marv ■ Lebap 71% 25% ■ Dashoguz Ashgabat 57% 6% 14% 25% 14% 2% 7% 4% illness of parent - social reasons illness of child - refusal by parents t/p t/p t/p

Diagram 17. Distribution of placement reasons across Ashgabat, Dashoguz and Lebap infant homes

Source: MoH data collection teams; author's calculations

This section has focused mainly on the micro-data available within the context of some of the meta and mezzo data. This has provided insights into the characteristics of the children resident at any given time in the infant homes and some insights into why they are in infant home care, how they came to be there and how long they have been there. Three distinct groups of residents emerge of roughly equal size as described in Box 3:

BOX 3 Typology of children resident in the infant homes at any given time

Group 1: babies without disabilities who enter the infant homes straight from the maternity hospitals for short periods, probably 1-3 months, possibly up to 6 months, and then move into adoption placements. These babies are relinquished or abandoned by their parents and are typically not visited during placements except in some infant homes by prospective adopters who may also be relatives.

Group 2: babies and older infants with disabilities who enter the infant homes for longer periods, around 12-36 months (up to 4-5 years) depending on their age at entry, following temporary placement by parents or relinquishment because of their disability. They either return to their family homes or move

into institutional placements after the infant home. Around half are visited by their parents or relatives during placement.

Group 3: babies and older infants, both with and without disabilities, who enter the infant homes because of social problems including illness of parents for medium to long 'temporary placements' of around 6-36 months (depending on age at entry and nature of the problem). They tend to be visited regularly, if not always frequently, by their parents or extended family and tend to return to their family homes following placements in the infant homes. There is a sub-group of infants in this group who are the children of mothers serving prison sentences in the women's prison in Dashoguz velayat and who tend to move on to education institution placements or return to their family homes after long stays in the Dashoguz infant home. They visit their mothers every month in the prison accompanied by infant home staff.

The next section explores in more detail the perceptions of the professional health staff who work most closely with the children and their parents of the reasons why children are relinquished and abandoned.

C5. Main circumstances, motives and reasons for relinquishment or abandonment of children under 3 years of age

Questionnaires were completed following interviews with 76 staff members and managers and 35 parents in all four infant homes and in 11 maternity hospitals. Or these, only 8 parents or relatives were interviewed at the infant homes and this is the single group which can provide most insight into the reasons, motivations and circumstances for the relinquishment of infants under 3 years of age in Turkmenistan. Nevertheless, the sample was large and varied enough to gain some important insights that are summarized in this section of the report.

C5.1 Perceptions of parents and relatives of infants in infant homes

Interviews were conducted with 3 grandparents, 4 mothers and 1 father who were visiting their child or grandchild at the time when the Ministry of Health data collection teams happened to be at the infant homes. The parents and relatives of children already living in infant homes and who are visiting them can offer important insights into the reasons, motivations and circumstances which have led to them taking such a difficult decision. These parents and relatives, it must be remembered however, are not representative of all parents who have placed their child into temporary institutional care or who have abandoned their children, they are reasonably representative, however, of the parents who have temporarily placed their child and who continue to maintain contact with children from groups 2 and 3 in Box 3 above. This section explores their perceptions of how and why their child or grandchild has ended up in the care of the infant home and the next section will explore more the perceptions of mothers about to give birth and the circumstances surrounding relinquishment or abandonment of babies in the maternity hospital relating more to the children from groups 1 and 2 in Box 3 above.

The 8 parents and relatives had all placed their children temporarily for a range of reasons – in 5 cases the child's illness was the main motivating factor for the placement although in one case this was also complicated by parental illness. In the other three cases parental illness, two involving mothers in hospital, was the main factor, accompanied in these two cases problems in the extended family meaning that grandparents could not cope.

Table 11. Circumstances contributing to temporary placement of infants into the infant homes reported by parents and grandparents

Relative, age, education, place of residence – frequency of visits	Main reason presented / contributing factors	Circumstances of the temporary placement of the child/children into the infant home	What has to change in order to take the child home?
Father – aged 26-40, higher education, lives in the same town as the infant home – visits several times a week	child illness / parent illness	The child has Down's Syndrome and has been here since he was 6 months old, 1.5 years ago because there is qualified medical and pedagogical support here. My wife couldn't cope.	My wife's condition has to stabilize
Mother – aged 26-40, secondary education, lives in the same town as the infant home, - visits once a month	child illness	My child has cerebral palsy. I don't have a husband or mother, my father is ill, paralysed. I look after my ill father. My neighbor suggested that I bring my child to the infant home, she works there and she told me that they look after children well for one year. I am afraid that I won't be able to care for my child.	If my child's condition improves, if she can feed herself and walk. I have an ill father who cannot walk at home, it is very difficult for me to look after them both.
Grandmother – aged over 60 years, secondary education, lives in the same town as the infant home - visits once a month	parent illness/ social factors	I have a one year old granddaughter from my daughter, she has been here for 4 months, my daughter doesn't have a husband, the child's mother has been ill since childhood, she sometimes has fits, we will take our granddaughter back as soon as she grows up a bit and learns to talk and walk so that she can get away/run away when her mother has a fit so that she isn't crushed or dropped. I have high blood pressure and look after my daughter because she often has fits. There is nobody else who can help, my son's wife left him because of my daughter's illness.	The child has to at least grow up a bit and begin to walk.
Mother – aged 26-40, secondary education, lives about 100km away from the infant home – visits twice a month	child illness	My child is ill.	Psychological help and so that the polyclinics teach skills for looking after children with disabilities
Mother – aged 26-40, secondary education, lives in the same town as the infant home – visits from once to several times a week	child illness/ social reasons	My child is ill. Has been here for 2 months, temporarily	Material situation has to improve
Grandmother – aged over 60 years, secondary education, lives about 100km away - visits once a week plus daily telephone calls	parent illness	The mother and father of the child are deaf-mute disabled since childhood. The mother also has a psychiatric disorder and at the moment is in hospital. I am disabled – 2 nd group of disability. Twins were born. We plan to leave them in the infant home until they are 3 years old.	After improvement in the mother's condition and her return home.
Mother – aged up to 25 years, secondary education lives about 100km away - visits twice a month	child illness	My child has cerebral palsy. A second child has just been born which makes it difficult to care for the ill child. My child has been here for 2 months. I plan to take her back if her condition improves otherwise we will put her in a special institution.	Only if the child's health improves.
Grandparent – aged 41-60 years, secondary education, lives in the same town as the infant home – visits once a week	parent illness	The child's mother and father have tuberculosis, at the moment they are in hospital. The children have been here for 6 months. We plan to take them home when their mother's condition improves.	Only if the children's mother health improves.

Source: MoH data collection teams

The level of visiting and contact is high, even among parents and relatives who live around 100km away form the infant home. The least frequent visits are stated as being once a month and the most frequent several times a week, but nevertheless, all except one respondent wants to visit their child or grandchild more often, but can't either because of work commitments or because of providing care for younger children or other family members – the parent or grandparent of the child in the infant home. The parent who doesn't want to visit more frequently also has care-giving commitments at home and a job which limits her ability to visit, but mainly she says she doesn't want to visit because 'I get very upset when I see my child so ill'.

All parents and grandparents praise the arrangements for visits at all four infant homes and rate them very highly (10 out of 10). Their responses indicate that there are no limits to the time they can spend with the children they are visiting and that typically visits last for around half an hour to an hour/1.5 hours. One parent, who travels from further away, says her visits last for 4-5 hours. During visits, parents and grandparents report a variety of arrangements, most commonly the visits take place in a separate room in private and it is possible to use toys, creative materials and other items for joint activities with the child, some parents also report that it is possible for the parent or grandparent to spend long periods in the room where the child lives. Two parents report that staff in two infant homes help with facilitating contact with the child, two report that the visits sometimes take place outside in the grounds of the infant home. Overall there appears to be considerable flexibility and support for visits from the infant homes. Only two respondents suggested possible improvements – 'if it were permitted to sometimes take the child home'; and another respondent indicated that it would be helpful if staff helped to facilitate contact between the visiting parent and the child. All parents report that they are able to consult with staff at the infant homes about their child, both during visits and/or by telephone.

Generally, parents and grandparents found it difficult to answer questions about the kinds of support that are available near their homes for families in difficult situations. Typically they mentioned the maternity hospital and women's consultations. One respondent confirmed that the 'guardianship and trusteeship organ' and 'social protection institutions' can help, another mentioned the 'family doctor'. It was even more difficult for respondents to answer which services provide support in caring for children with disabilities near their homes. Four said there are no such services and three couldn't answer. One parent mentioned 'family doctor' as a service or organization near the home that can help with caring for children with disabilities.

On the whole, visiting parents and grandparents typically think that it is important to keep the child in the family except when there is a high risk of threat to the child's life and health in the family. Two respondents said that no matter the circumstances, the child should be kept in the family and two respondents said that sometimes the child can be better off in an institution than in the family.

In response to the question about what could make a difference to the situation so that the child could live at home the 8 parents and grandparents responded (in order of frequency of response):

- 1. The presence of a range of accessible local children's services with flexible working hours (kindergartens, nurseries)
- Social rehabilitation services delivered at home for children with disabilities and their families

- 3. Accessible psychological and social support, specialized services (crisis centres, social services)
 - Training for mothers (parents) in caring for children including for children with developmental disorders
 - Extended family, close social circle
- 4. Psychological support, information about child care and child development in women's consultations, maternity hospitals, other health services
- 5. Economic support from the state

One grandmother commented 'if there were a kindergarten nearby [the child could have stayed in our family], we applied to the 24 hour kindergarten but were refused a place'.

In all cases the respondents see the infant home as providing primarily a medical service even where the child who has been placed does not have a medical condition, disability or special medical needs: 'specialised medical support; pedagogical support'; 'good care, [the child] gets massage all the time, is well fed, under observation of doctors'; 'constant medical observation'; 'improving the health condition of the child'; 'they provide highly qualified care, upbringing, health protection'.

Summary of parent responses and conclusions

Parents and grandparents of children with disabilities have a medicalised view of disability seeing it as an 'illness' or a 'health' problem and therefore see the infant home as providing a 'specialised' service for the child which is not available in or near the family home.

Even where the child's disability is the main presenting factor that has motivated the decision to place the child into the infant home, there is often another factor or other factors that have compounded that decision – either the birth of a younger sibling or another person requiring the care and attention of the parent or main carer of the child with disabilities – an ill parent or grandparent for example. Illness of parents compounded by inability of grandparents to cope is a common narrative. Absence of one parent, usually the father, also features in the narratives of the visiting grandparents summarized in Table 11.

In the three cases where the child who has been placed into the care of the infant home does not have a disability, but has been placed because of the main carers' illness or incapacity, the narrative of the grandparents, apart from highlighting their own incapacity to provide care, also reveals a lack of understanding about the developmental needs of children – the grandparents assume that the child will receive better care in the infant home than in the family and don't understand the risks to the child's development from being cared for in an institutional setting. The grandparent placing a granddaughter into the institution until he or she can walk and feed herself clearly doesn't know that institutional care can cause developmental delays in young children.

The responses of parents and grandparents also, by the absence of mentions and the difficulty in naming services in the local community that can provide support, underline the lack of any other options open to these families apart from the infant home. One family tried to get a place in a 24 hour kindergarten because they were concerned about the danger to the young infant in the family from possible harm when her mother has epileptic fits. It is probable that the child was harmed in some way during a fit and their concerns are valid so some kind of constructive

intervention and support was needed. The only option open to them, as they saw it, when the kindergarten could not take the child, was to place the child into institutional care.

Behind all the presenting and compounding reasons mentioned by the parents and grandparents it is likely that an episode of crisis in the family situation has triggered the actual placement into the infant home – the nervous breakdown of a mother of a first, and currently only, child with Down's Syndrome who could not cope and who could not find any support or help in the community or among her friends and relatives; critical episodes of acute mental illness; hospitalization of a main carer for serious infectious or psychiatric illnesses; sudden illness of a grandparent or substitute carer – all these crises are present in the stories of the respondents.

Another strong strand to emerge in the circumstances surrounding the placement of a child into the institution is the lack of other options, the need for services that can in the first instance provide day to day services – nurseries, kindergartens or specialized rehabilitation for children with disabilities and in the second instance can provide crisis response services when a parent enters hospital or another crisis hits a family that is already struggling to cope. It is clear that the infant homes are organized as providers of medical services, yet are fulfilling a function as s social care service provider and these two functions are not fully reconciled.

Other key issues to emerge are the need for parents and other primary carers to access support in learning how to care for a young child, especially a child with special needs. Parents need help to not fear their child's disability and to help maximize their child's ability.

The predominance of a medical model of disability is clear in the responses of parents and grandparents and the next section of the report explores the responses of the staff and managers of the infant homes to questions about the role of the infant homes in caring for children, including for children with disabilities, about the reasons why children end up in the care of the infant home.

BOX 4 Case study of the motivation, reasons and circumstances for placing children under 3 years of age into residential care

Two siblings a girl aged 2 years and a boy aged 7 months placed temporarily in an infant home for a period of 6 months

At the time of the interview with the grandparents of the children, A. was 2 years old and N. was 7 months old and they had been living in the infant home for 6 months. A. and N. are the youngest of four children their older siblings are in the 1st and 4th classes at school. The children's parents both have tuberculosis and spend long periods in a sanatorium receiving treatment and in isolation from their family and the community in order to prevent contagion. The children's main caregiver is their grandmother who is over 60 years old and all four children live together with their grandmother and grandfather, who is also over 60 years old, and with their parents except when their parents are away receiving tuberculosis treatment.

A crisis occurred during the summer when A. and N.'s grandmother was hospitalized with a precoronary condition. The children's mother and father were in the tuberculosis sanatorium at the time and could not care for their children. Their grandfather tried to cope on his own with all four children while his wife was in hospital, but he was not able to manage both their care and his job at the local market. He asked for advice at the hospital where his wife was receiving treatment and the hospital staff suggested that the two youngest children could be cared for by the infant home in the local town. The grandfather went to the see the head doctor who agreed to take the two children for a temporary period – N. was one month old at the time and A. was 18 months old. Their grandmother came out of

hospital some weeks after they were placed into the infant home but her health continues to be poor and at the time of the interview, N. and A. had been resident for 6 months.

The grandmother and grandfather visit every week for 2-2.5 hours on the grandfather's day off from work. They take the children out for walks in the grounds of the infant home and sometimes they visit with them inside the building in a special visiting room. The grandmother and grandfather find the infant home staff helpful and the level of care good. At the time of the interview their daughter was temporarily at home, but was going to have to return to the tuberculosis sanatorium for further treatment. The grandmother and grandfather had consulted with the head doctor of the infant home and they had jointly agreed that they would leave the youngest two children in the infant home for the time being until the mother's treatment was complete and the situation at home stabilized.

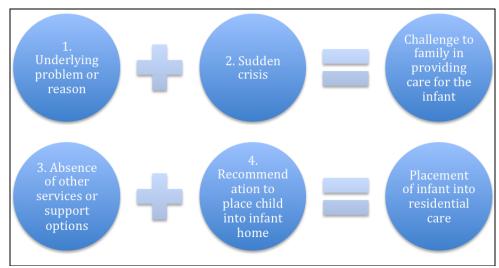
The main challenges facing the family at the time of the interview according to the grandparents were the ongoing poor health of the grandparents and the two older children were starting to act up, skipping school and displaying difficult behavior and the grandparents were finding it difficult to cope with them as well. They want to find out whether they can place the older children into an boarding school. They hope that eventually the younger children will return home.

This case study illustrates how acute underlying problems in the family – in this case the mother and father have tuberculosis and the grandparents are elderly and in poor health - combine with a sudden crisis - the hospitalization of the children's main caregiver - that challenges the ability of the family unit to provide care. In the apparent absence of other services and support options and with a recommendation from a state service provider – the hospital staff – the family sees no other alternative and the temporary placement of two young infants into residential care is triggered. The placement then slides into a medium to long term stay as the family is receiving no other support or help and is struggling to cope with ongoing ill-health and two older children who are now also at risk of entering state care. The removal of the younger siblings did not help the family to cope with caring for them, the family simply adapted to the absence of the infant and not having to care for them at all and, in the absence of any other services and support to address this situation, these infants are likely to remain in the infant home until they age out of the system. At this point it is not clear how the family will cope with their return to the household at the ages of 3 or 4 years as it seems unlikely that much will change between now and then. Another point worth noting is that in this case the infants require a social care service and the infant home is fulfilling this function, but by providing a health care service. The health needs of these two infants are the same as for any child of their age living in their own families in the community, but now that they are in the care of the infant home they are subject to a medicalised care regime which includes regular tests, analyses and other medical interventions which they did not necessarily need when they entered the infant home.

It would be interesting to examine a similar situation in a region where there is no local infant home to see how the extended family network, local community and local services might have coped to find an alternative solution – temporary care with neighbours or friends perhaps, or inhome support from neighbours and friends combined with nursery and kindergarten services.

In conclusion, from the perspective of parents and care givers, there are four elements that combine in Turkmenistan to influence the placement of a child aged under 3 years into institutional care as illustrated in figure 1a:

Figure 1a. Model of four factors influencing the placement of infants into residential care which emerge from responses of parents and relatives



Source: P4EC CEE/CIS consultancy group

There are a range of factors that can mitigate against the placement, including very strong family values and social or cultural norms, which partly explains the low level of use of residential care for infants in Turkmenistan compared to other countries with different family and social traditions and cultural norms, but without any interventions to change the situation in the family two phenomena can then combine to prevent the child from returning to the family even after the resolution of the crisis that may have been a catalyst for the placement:

Figure 1b. Two phenomena that retain infants in residential care



Source: P4EC CEE/CIS consultancy group

All six of these elements can be addressed to prevent or terminate placement, but a critical element is the absence of other services or support options without which addressing the other aspects will not change the process as a whole. Another factor is systemic institutional inertia – once a child is placed into an infant home, the staff and management are reluctant to release him or her back into a situation that they may perceive as unsatisfactory so the institution and the family collude in maintaining a situation which they perceive to be in the best interests of the child. The next section of this report explores the perceptions of staff and managers of infant homes in regard to this and other issues relating to the placement and retention of infants aged under 3 years in residential care.

C5.2. Role and functions – infant home staff responses

In total 32 personnel were interviewed in all four infant homes and their responses recorded in data matrices designed specially for the study. The respondents included 4 Head doctors; 4 paediatricians; 8 carers; 4 nurses from the special groups for children with disabilities; 4 nurses

from the non-disability groups; 8 support staff. As with the parent interviews, the questionnaires and data recording methods were simplified and coded as much as possible in order to streamline the data collection process and minimize possible inaccuracies or errors. The respondents were all women apart from 1 support staff member; the majority are aged 41-60 years and around a quarter are aged 26-40 years; the majority have a medical qualification and the those who don't either have a general secondary education or, in three cases, a pedagogical qualification. Nearly all staff members, of all types, have worked long-term at the infant homes as illustrated in Diagram 17.

15
11
11
1-5 years 6-15 years 16-30 years 31 or more years

Diagram 17. Length of service of 31 staff members in all four infant homes

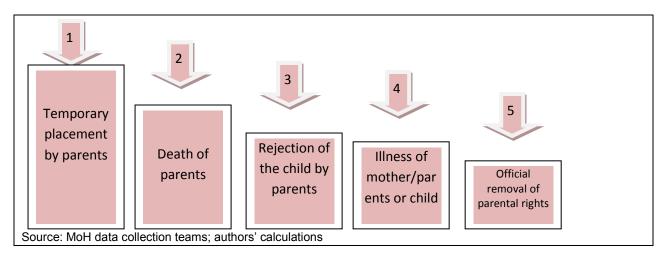
Source: MoH data collection teams; author's calculations

The responses of staff in relation to the numbers of children, length of stay and the care options to which infants go on leaving the infant home largely confirm the findings above from analysis of the available micro-, meta-, and mezzo- data. There are some discrepancies in perceptions of some staff in some infant homes about the numbers of children with disabilities currently resident and the typical age of entry and length of stay, but none that further expand or alter the above findings. This section, therefore, will focus mainly on perceptions of staff about the role and function of the infant homes, how and why children end up in their care and what can be done to help children return home or prevent their entry in the first place.

Perceptions of infant home staff of the most common reasons for placement of children into the infant homes

Infant home staff perceive temporary placements by parents as the most common reason for placement, followed by the death of parents as illustrated in Figure 2.

Figure 2 Perceptions of infant home staff of the most common reasons for placement of young children into the infant home (1 – most often, 5 – least often)



These perceptions are not entirely confirmed by the quantitative data above which shows that 'rejection of the child by parents' followed by 'temporary placement because of illness of the child' are the main two reason among children entering each year and living in the infant homes at any given time and 'death of parents' is among the less likely reasons for a child to enter, or be in, the infant homes. There are regional differences in reasons for entry evident in the quantitative data, and no real regional differences noted in the qualitative responses of staff.

Infant home staff also responded to a question about the factors that can influence the decision of parents to relinquish, abandon or temporarily place a child into the infant home and their responses will be examined below in conjunction with responses of maternity hospital staff.

General role and function of infant homes

All four Head doctors of the infant homes emphasise the health improvement and care functions of the infant homes, the aim to ensure that 'children are healthy – care is provided, illness prevented', 'improving the health of the children and bringing them up'. The Head doctors mention some aspects of care including play and rehabilitation and in all four infant homes they have a pedagogue on staff, in two they also have a speech therapist and in one infant home they also have a 'music worker'. Two Head doctors mention work with parents, one in the context of ensuring 'a quick return home' and the other 'health education work with parents'. One Head doctor mentions the function of the Infant home in referring children for adoption of into further institutional placements. Overall the Head doctors report that the infant homes are focused mainly on care and health services provision within the institution.

Prevention and reintegration functions

When asked, however, if work is undertaken by the Infant homes to prevent relinquishment and to try and return infants to their families, all Head doctors and most staff, confirm that nearly all staff members, with the exception of some support staff typically do engage in 'talking to parents' or 'explanatory work with relatives', one paediatrician responded that 'we tell them to talk to other parents, to their neighbours, talk to their husbands, go to the family doctor for advice, we give them advice ourselves' and a nurse from a special group for children with disabilities said 'we give advice, we tell them that a child is the most important thing for a Muslim, a child is the future support for parents and in any case the child should be kept'. The infant homes may not have a formally constituted mandate to carry out this work with parents and relatives, but it is clear both from the responses of staff and those of parents that this interaction between staff and visitors is happening to some extent or other in all of the infant homes with at least some parents and relatives and staff of nearly all types – the Head doctors, paediatricians, carers and nurses.

One Head doctor also mentions 'working with the Guardianship and Trusteeship organs' and another 'working with the Khyakimliik to solve problems' presumably to do with issues such as housing, benefits, documents or other issues within the competency of the Khyakimlik. When answering a question about which organizations and bodies are partners of the Infant home in preventing relinquishment of newborns, the Head doctors and staff mention first and foremost the Guardianship and Trusteeship organs and the Maternity Hospital and Women's consultations. In 8 instances respondents also mention NGOs, in 5 instances social protection organizations and in 3 instances religious organizations. Two Head doctors also refer to the Family Doctor, the Commission for Minors' Affairs and the Velayat health department as

partners in prevention. This confirmation of an extensive network of partners in the community tends to illustrate that the infant homes, as services located within particular communities can, and in some cases do, work alongside structures outside the infant homes themselves in order to solve problems for children within the infant home care.

As part of this work focused on the parents and relatives of the children in their care, the Head doctors and staff overall confirm the perception of parents and grandparents above that the visiting arrangements are largely satisfactory with most giving a mark of 10 out of 10 and around two thirds of respondents stating that there are no improvements that can be made. Almost a third of staff members from three Infant homes suggest that improvements can be made by making visiting times and durations more flexible. A few others from two Infant homes suggested that staff could do more to facilitate contact between children and parents and that there should be a private room where children and parents can spend the visit together.

Adoption functions

The Head doctors confirm that the infant homes do not carry out any work in seeking adoptive parents and clarify that this work is the responsibility of the local Guardianship and Trusteeship organs. One infant home Head doctor reported that she makes a contribution to assessing the suitability of the adopters by giving feedback to the Guardianship and Trusteeship organ specialist following visits by the adopters to see the child in the infant home. It is not clear to what extent this is a formalized part of the infant home functions. The role of the infant home in adoption procedures is to carry out medical tests to ascertain the health status of the infant and to identify whether there are any problems that the adopters should know about. The babies live at the infant home for the duration of these medical assessments.

The procedure for adoption is reported by two Head doctors as taking 1 month and by two others as taking up to 3 months. In Mary and Lebap the Head doctors report that adopters are often relatives of the child and in Ashgabat and Dashoguz that they are rarely relatives. This difference requires further study to understand why it should be the case. Did the Head doctors mean 'adoption' or did they take the question to be referring to 'guardianship' which is a different legal procedure? The mezzo data analysed above confirms adoption as one of the most common outcomes for infants leaving Lebap infant home. It would be useful to breakdown how many of those adoptions were into families related to the children and to confirm that they were indeed adoptions rather than guardianship placements.

One Head doctor indicated during an interview that in some cases adoptions by relatives of new born infants might be privately arranged between families. Two brothers, cousins or close friends may decide to adopt each others' child in order that a family with no boys and a family with no girls can, for example, achieve a gender balance. The families would then arrange the adoption through the Guardianship and Trusteeship organs and the infants in question would spend around 1 month in the infant home for all the necessary medical tests required by the adoption procedure to be completed. If this is a common and widespread cultural and social practice in some regions, then this could partly explain the high number of infants entering the infant homes in the first month or two of life and then leaving for adoption placements after a very short time that emerge in the meta and mezzo data above. It could also explain some of the discrepancies between the numbers of infants entering and leaving the infant homes and the numbers being relinquished in the maternity hospitals. It seems unlikely that this is a very widespread practice, but further investigation is required to clarify.

The role of the Guardianship and Trusteeship specialists and commissions in identifying, assessing and approving adopters needs to be separately assessed to understand the extent to which the adoption of some children, mainly healthy new born babies, seems to happen quickly and the adoption of other children, children with disabilities or older infants, doesn't seem to happen at all. It is also important to understand the demand side of the adoption equation – the supply of healthy babies relinquished at birth in the maternity hospitals seems to flow at a steady rate, are there adopters waiting for these babies? How do the Guardianship and Trusteeship organs find adopters and prepare them for adoption?

Staff capacity and skills for working with parents, relatives and adopters

It is clear from the respondents in the infant homes that there is a large number of staff, mainly with a higher medical or secondary specialized education who are interacting with parents, relatives and adopters without necessarily having been equipped with the knowledge and skills they need for this work. The study did not have a goal to assess the capacity and skills of infant home staff in detail, but responses to one question focused on the skills that might be required for interacting with parents, relatives and adopters shows that there is a demand among staff from all four infant homes of all ages and educational backgrounds for additional training and information. Only two staff members said they did not need any training or information, all the rest chose at least one topic, quite a few chose all the topics and several chose 2, 3 or 4 topics. The three topics in which staff showed most interest, in order of frequency are:

- Information about contemporary approaches to the rehabilitation and social integration of children with disabilities – 32% of staff chose this option
- Establishing trust with parents and relatives in order to stimulate attachment to the child
 22% of staff
- Training parents (during visits) in the skills needed to care for a child and creating an environment for positive communication with the child 20% of staff

The two other topics on informing parents sensitively about disability, prognosis, treatment and services and training on attachment and early childhood development were chosen less frequently, but nevertheless 15% and 12% of staff expressed interest in these topics respectively. The maternity hospital staff responded slightly differently with the three main topics of interest, in order of the percentage of respondents who expressed an interest as follows:

- Informing parents sensitively about disability, prognosis, treatment and services 23% of maternity hospital staff
- Establishing trust with parents and relatives in order to stimulate attachment to the child
 23% of maternity staff
- Information about contemporary approaches to the rehabilitation and social integration of children with disabilities 20%

The two other topics on parent skills training and attachment were chosen slightly less than the above three topics, but nevertheless were of interest to around 15% and 19% of maternity staff respondents. All maternity hospital staff chose at least one topic and many chose four or five topics. The differences and overlaps in areas of interest for maternity hospital and infant home staff are fairly self-explanatory and link closely to the situations in which they encounter mothers, father and relatives and interact with them about their infants and babies.

The next sections will look at the perceptions of all respondents about reasons for, and what can be done to prevent, abandonment, relinquishment or temporary placements into care of infants aged under 3 years in Turkmenistan.

C5.3. Reasons, motivations and circumstances for temporary placements, abandonment or relinquishment – perceptions of infant home and maternity hospital staff

Most infant home staff distinguish between the children with disabilities in the 'special needs' group, the other group of non-disabled infants who are temporarily placed for social reasons and the groups for young newborns and babies without disabilities who are moving into adoption. The maternity hospital staff, as a rule, mainly encounter the latter group, relinquished or abandoned infants with or without disabilities. They also encounter infants who are born with disabilities and their parents, where the parents do not intend to relinquish the child.

The responses of all infant home and maternity hospital staff to the question 'what factors can influence the decision of parents to place their child in the infant home' were slightly different at the beginning of the interviews when they were asked an open question and at the end when they were asked to choose reasons from a list of 20 possible options (attached in Annex 1 as part of the data collection instruments). As Figure 3 illustrates, the main difference is that in the answers at the end of the interviews, when the respondent has had some time to think about the issues and give a more considered response, the issue of 'unwanted pregnancy' emerges alongside the other main factors – fear of caring for a child with disabilities, emotional distress, immaturity of the mother.

Figure 3. The most common factors influencing the decision to place a child aged 0-3 in the infant homes – comparative analysis of the answers of respondents at the beginning and end of the interview N=85 staff 32 from infant homes and 52 from maternity hospitals

Responses at the start:

- Fear of not coping with caring for a child with disabilities; 60% of respondents chose this factor
- Emotional and mental distress of the mother; 52% of respondents
- Inability to take decision independently, to resolve difficult life situations; 45% of respondents
- Single mother; 39% of respondents
- Absence of support from parental family, close relatives, father of the child; 38% of respondents

Responses at the end:

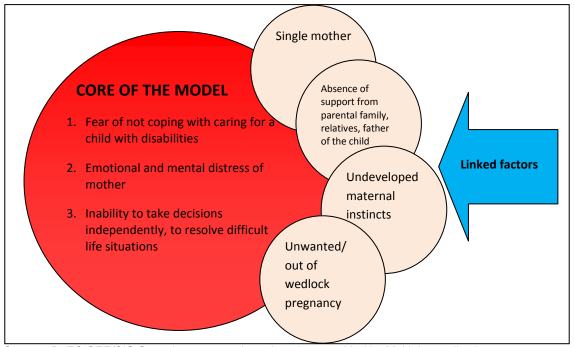
- Emotional and mental distress of the mother
- Inability to take decision independently, to resolve difficult life situations
- Fear of not coping with caring for a child with disabilities
- Undeveloped maternal instincts
- Unwanted/out of wedlock pregnancy (including as a result of sexual violence

Source: P4EC CEE/CIS Consultancy group based on data provided by MoH data collection teams

The responses of personnel from infant homes and maternity hospitals indicate that they have a perception of the reasons for relinquishment, abandonment and temporary placement that

focuses on the mother as the main agent for triggering the placement – her psychological condition, her immaturity, her fear, her inability to cope, her lack of feeling for the child - and on absence of support from family members as a significant contributing factor as illustrated in Figures 4 and 5.

Figure 4. Model of factors perceived as influencing the decision to place infants aged 0-3 years into infant home care – perceptions of 84 infant home and maternity hospital staff and managers



Source: P4EC CEE/CIS Consultancy group based on data provided by MoH data collection teams

Figure 5 presents all factors that were most often mentioned as being influential in decisions to place infants into infant homes, those that are mentioned with medium frequency and those which are mentioned with low frequency. Overall, the professionals see the mother and her immediate family as being the main locus of control on the decision making process, although the recommendations of professionals to place the child, absence of support services, low income, problems with housing and other social issues do emerge for a some respondents as one of the influencing factors.

Figure 5. Proportion of respondents selecting one or another factor as the most common – N=85

High frequency of mentions

- Fear of not coping with caring for a child with disabilities -60%
- Absence of support from parental family, close relatives, father of the child – 52%
- Inability to take decisions independently, to resolve difficult life situations - 45%
- Single mother 39%
- Emotional and mental distress of the mother – 38%
- Youth of mother (15-18 years) -35%
- Unwanted/out of wedlock pregnancy – 35%

Medium frequency of mentions

- Fear of not coping with caring for a child because of illness of mother or close relatives -28%
- Undeveloped maternal feelings–
 22%
- Risky sexual behaviour 22%
- Problem drinking or drug use by mother or close family – 20%
- Relationship problems between mother and her parents or partner – 20%
- Low income of mother's family12%
- Absence of housing 11%
- Absence of employment, unstable earnings 11%

Low frequency of mentions

- Absence of accessible support for women in difficult life situations – 10%
- Recommendation to place the child from the side of professionals (doctor, teacher, etc) – 7%
- Mother (other family members) is an institutional care leaver -
- Mother of multiple children 0%

Source: P4EC CEE/CIS Consultancy group based on data provided by MoH data collection teams

This set of factors and reasons and the model illustrated in Figure 4 differs to a large extent from the model that emerges from responses of visiting parents and relatives illustrated in Figure 1a above, where the absence of any alternatives emerges as a critical over-riding factor. The perceptions that emerge from staff responses relate to all types of placement into infant homes, with an emphasis on relinquishment or abandonment at birth, not only to the kind of temporary placements where parents or relatives continue to visit which relate to the Figure 1a model of reasons behind placements. Both models, however, place the locus of control externally to the systems and environments within which those responding exist. A combination of both models and sets of reasons and factors probably offers the most accurate overall picture.

Differences in perception between infant home and maternity hospital staff

There are no discernible differences between the way the Head doctors of infant homes or maternity hospitals answer compared to their staff members. All respondents in maternity hospitals and infant homes, however, have slightly differing views of the main reasons and circumstances for the placement of children into infant homes and relinquishment or abandonment of infants at birth. As Figure 6 shows, both groups of staff, with some variations in the weighting they give to each factor, give the most influential factors as fear of not coping with a child with disabilities, inability of the mother to take decisions independently and absence of support from parents of the mother, close relatives or husband. The differences that emerge between the two staff groups are largely linked to the parents whom they encounter. The maternity hospital staff see mothers who have just given birth and relinquished or abandoned their newborn child and they give factors such the youth of the mothers and unwanted pregnancy as important influencing factors. The infant home staff tend not to see these young mothers as their infants are quickly moved into adoption and are not visited by their mothers. The infant home staff members mainly encounter the parents and relatives who have placed their infants because of parental illness or illness of close relatives, circumstances that maternity

hospital staff may not ever encounter, so this emerges as an important factor among infant home staff

Figure 6. Differences in responses for 52 maternity hospital and 32 infant home staff on the most common reasons and influencing factors for placement of infants into infant homes

Infant home staff

- Fear of not coping with caring for a child with disabilities
- Absence of support from parental family, close relatives, father of the child
- Emotional and mental distress of the mother
- Fear of not coping with caring for a child because of illness of mother or close relatives
- Inability to take decisions independently, to resolve difficult life situations

Maternity hospital staff

- Fear of not coping with caring for a child with disabilities
- Youth of mother (15-18 years)
- Unwanted/out of wedlock pregnancy (including as a result of sexual violence)
- Absence of support from parental family, close relatives, father of the child
- Inability to take decisions independently, to resolve difficult life situations

Source: P4EC CEE/CIS Consultancy group based on data provided by MoH data collection teams

If an assumption is made that the maternity hospital staff are mainly thinking of the mothers and infants they encounter in the maternity hospital then the reasons and influencing factors they give relate mainly to the first group of babies and infants in the typology summarized in Box 3 above and part of group two, babies with disabilities who are abandoned or relinquished at birth. In this case, the youth of the mother and the pregnancy being unplanned and the infant unwanted, feature strongly alongside the absence of support from relatives and fear of not coping with a child with disabilities. The infant home staff responses can be taken as relating to the reasons and circumstances for all three groups of children, but because they tend not to meet or interact with the mothers and relatives of the groups of the infants that the maternity home staff encounter, they either are not referring to them at all or their choice of the 'emotional and mental distress of the mother' can be taken either as their impressions from second hand information or as direct experience of mothers who visit their babies in the infant home.

Apart from one exception, there were no major differences between the responses of staff across the regions or between urban and rural maternity hospitals. The only difference to emerge was in Mary where the issue of 'unwanted/out of wedlock pregnancy' and 'risky sexual behaviour' emerge as the most common factors influencing placement of infants into infant homes according to all Mary respondents. Another area where differences emerge is between medical staff, who were the majority of staff respondents, and non-medical staff from both the infant homes (pedagogues and support staff) and maternity hospitals (lawyers). The differences are similar to those between the maternity hospitals and the infant homes, but the medical staff recognize more than non-medical staff the 'emotional and mental distress' of the mothers and

their single parent status whereas non-medical staff tend to highlight their 'youth (15-18 years)' and 'problem drinking and drug use'.

Summary of reasons and influencing factors - perceptions of staff

Staff generally see the main reasons for relinquishment or abandonment as lying with the mother's inability to solve difficult life situations, fear of not being able to cope with a child with disabilities and absence of support from parents, close relatives or the father of the child. Other influencing factors vary according to the type of situation. For infants abandoned at birth the other key factors identified by staff are: unwanted pregnancy, single mothers, young (15-18 years) mothers. Emotional and mental distress of mothers is highlighted by infant home staff and by all medical staff. Infant home staff also see the illness of a parent of close relative as being an important influencing factor, presumably for temporary placements.

Other compounding factors also emerge from staff responses: problem use of alcohol and drugs, housing issues, low income and absence of support.

C5.4. Attitudes to abandonment and relinquishment

In response to the question 'should a child be kept in their family?', the less connection to or experience of the infant home, the more likely that the attitude of the respondent is categorically 'yes' as illustrated in Diagram 18.

■ Yes, no matter what 100% 90% 80% 70% ■ Yes, except when there is 60% a high risk in the family to the life and health of the 50% child 40% ■ Not necessarily, 30% sometimes the child 20% might be better off in the 10% infant home 0% ■ Don't know/ no answer 32 infant 52 8 infant 30 maternity home staff home maternity staff parents parents

Diagram 18. Distribution of responses from all 122 respondents to the question 'should a child be kept in their family?'

Source: MoH data collection teams; author's calculations

Perhaps understandably, there are more infant home staff and relatives of children in the infant homes who think that a child might be better off in the infant home than in the family, but even these respondents tend to prioritise family except when there is a high risk to the child in the family.

Interviews with 30 women in 10 maternity hospitals helped to establish an understanding of a) the attitudes to infant abandonment among the general population and b) the attitudes of

women who are in a position to potentially influence a mother who is intent on relinquishing her child immediately after birth. Eight respondents were in the hospital with their first pregnancies, eight with their 2nd, eight with their 3rd, four with their 4th and two with their 6th pregnancies.

While the women who responded were largely emphatic about the need to keep the child in the family under all circumstances, there were also largely sympathetic and non-judgmental in their responses to the question of how they would react if a mother in their ward in the maternity hospital were to announce her intention to relinquish her child:

I would tell her that there are no such things as irresolvable situations, all problems can be solved, I would help her. (Mother of 3 children, Ahal maternity hospital)

I would explain, giver her advice, but it is her life, she will decide. (Mother of 2 children, Mary maternity hospital)

Most respondents appeal to the hypothetical abandoning mothers' conscience and emotions 'don't abandon your child' 'how can you give up a child you have carried next to you heart for 9 months!'. Some emphasise that this might be the only child she ever has:

I would tell her not to give up her child, there are childless women and God gave you this child, you don't know if God will give you or not give you a child later. (Woman in Dashoguz maternity hospital with first pregnancy)

Only two mention practical issues such as the economic support that the government gives to the families of young children:

I would advise her not to give up her child, children are the future and support for their parents and in the end they should feed you. Now you have difficulties, but the government gives benefits, don't be afraid of difficulties, they will pass. (Mother of 4 children, Dashoguz maternity hospital)

When asked about the challenges that can face families with young children in Turkmenistan the women answered in four main ways:

- 1. There are no problems, 'everything is alright' 21 responses including four women who emphasized that there are no problems because of the support of relatives 'no difficulties, relatives teach how to look after a small child, there are no other problems'
- 2. Fear of not providing adequate care for the child 5 responses 'problems with the child's health, fear of not managing with care for the child', including concerns about lack of specific skills for one first-time mother 'difficulties with changing nappies, fear when the child cries'
- 3. Material problems, unemployment 5 responses '*material insufficiency, unemployed husband*'
- 4. Psychological or relationship problems in the family 4 responses *'lack of mutual understanding in the family'*

These responses confirm how important the role of the close family and relatives is in the upbringing of children and the ability of families to address problems or challenges when they arise. They also offer an indication of some of the issues that could be included in antenatal classes or training for new parents.

In spite of the importance of close family, the women who responded from the maternity hospitals think that it is mostly mothers alone who take the decision to relinquish their child (17 responses out of 30) 'Mama is the closest person to the child, a mother will never leave her own child because of someone else's opinion'. Some respondents could not conceive of a mother wanting to relinquish her child 'in my opinion it doesn't happen, it is not possible to abandon children'. Most of the others, 10 respondents, think that it is the father who decides as he is the head of the family. A few think that parents or friends of the mother can also influence her decision, but that the decision is hers alone in the end.

C6. Process of entry into formal care – assessment and decisionmaking

The responses of the four Head doctors of the infant home indicate the following procedures for placements:

Group 1 or 2 infants abandoned or relinquished at the maternity hospital – statement of the child's health condition and discharge papers from the maternity hospital, 'act of abandonment' from the police or 'basis for relinquishment' from the mother giving the reasons why she is leaving her child which is signed by the maternity hospital Head doctor.

Group 2 and 3 infants placed temporarily by parents – birth certificate of the child, 'basis for placement request' from the parents or legal guardian of the child with back up documents as appropriate for example 'death certificate or certificate of illness of a parent, certificate confirming single mother status, copy of the passport of the parent who is placing the child, medical assessment of the child and medical records.

In both cases, the referral is formally signed by a 'commission' in the case of Lebap or by the Chief Paediatrician of the Velayat Health Department. It is not clear whether there is an assessment by the Guardianship and Trusteeship body of the situation in the child's home as part of this procedure. It is reasonably clear that the basis for accepting a child into the infant homes can be the simple fact of a child being born out of wedlock, parental illness, child's disability, death of one parent and any number of other reasons which are considered valid by the health department.

C7. Existing approaches to prevention in maternity hospitals and in social services

Responses of the 52 maternity hospital staff suggest that most have experienced a situation where a mother wants to abandon her baby – 40 out of 53 answered that through conversations with the mothers who want to abandon, they can influence her decision. They characterize the mothers as 'quiet, closed in on themselves, troubled' 'alone, without visitors' 'frightened' 'disturbed, mentally ill' 'depressed'. 50 respondents say they have never suggested to a mother that they should place their child into the infant home, 3 say they have 'if the child is ill'. Some

maternity hospital staff say that they also talk to the relatives of the women, but do not indicate the extent to which they actually try to contact them in the case of young women already intending to relinquish her child at the point of entry to the maternity hospital and without any relatives evident before or after the birth.

More than half of the maternity hospital staff say that they either don't receive any information at the point of entry into the maternity hospital about the life situations of women or their intentions to relinquish their child or say that they don't know. Some say that they receive information informally, from the women's family doctor or gynecologist, others say that they find out from the other women in the ward and a few say that very rarely they find out from a friend of the woman. Otherwise, the maternity hospital staff find out about the women's intentions from their own observations or from the women themselves.

Nearly all maternity home staff say that work is carried out in their maternity hospitals to prevent abandonment and relinquishment. This mainly takes the form of 'explanatory conversations' by the hospital staff. The respondents confirm that there are no psychologists or social workers in the hospitals and no staff dedicated specifically to this task. The main non-medical staff members are lawyers. Three neonatologists and paediatricians from two Dashoguz rural maternity hospitals mention good practice in encouraging breastfeeding as a preventative measure 'we show the child to the mother. In the delivery room we put the child to the breast, skin to skin contact, and then it is harder for the mother to give up the child, we talk to the mother'.

When a mother who said she wanted to relinquish her child, but then doesn't, leaves the maternity hospital, there appears to be a range of different practices about whether the maternity hospital then informs other services at the mothers' home about the risk. Some respondents say that the health services are informed officially, others say they are told informally, yet others say they are informed through the medical notes in the mothers' file. Some respondents say that the maternity hospital does not inform any other services, some say that the police are also sometimes informed. It could be that there is no formal guidance in place and each maternity hospital and individual practitioner takes their own decision about whether to inform the health services or other bodies in the mother's community.

The mothers in the maternity hospitals who had already had babies before this pregnancy/birth confirm in their responses that there is an intensive programme of home-visiting in the first month of the baby's life and then at regular intervals up to at least one year, some report two years. This represents an important point of entry for offering support to mothers who may be struggling with the decision to place their child into the infant home.

There appear to be few other available services in the community, respondents found it difficult to answer questions about whether there are services available to support children and families. The mainstream health services, kindergartens and schools were the main named services both when asked about children and families generally or about children with disabilities specifically.

In one interview with a Guardianship and Trusteeship specialist, it became clear that this specialist is carrying out preventative work with the parents of infants who are at risk of placing their infants into the local infant home. The specialist's main role is to place children into adoption once they have lost parental care, but she also reports providing clothing and food from local sponsors for some families at risk, helping to ensure that available social support is

being claimed and helping to ensure that children can get places at kindergartens and schools. This kind of support appears to depend on the individual initiative of the specialist rather than to be a mandated function. This respondent also talked about providing support to children who are in the guardianship of relatives and to their guardians. Support includes making regular visits to families in their homes and assessing their needs. The Guardianship and Trusteeship specialist appears to have a strong link with the resources available in the wider Velayat structures – education, health, social support and can play a role in coordinating support to families.

Suggestions of maternity hospital staff and managers for improving prevention

The interviews with maternity hospital staff included more or less open questions about whether and what kind of measures need to be taken to decrease the number of relinquishments or abandonments and of placements of babies and infants into the infant homes. The responses to these questions are summarized in Table 12 and show that three main areas for improvement can be identified from the point of view of staff and managers in the maternity hospitals: 1) information campaigns among the general public and specific target groups; 2) interventions during pregnancy in the health centres and women's consultations both to advise women, provide psychological support and to prepare parents for child-rearing; 3) interventions both before and after birth focused on social and psychological support and parenting skills, including for children with disabilities.

Table 12. Proposals of maternity hospital staff and managers for reducing the level of relinquishments and abandonment of babies and infants in Turkmenistan

Are changes to procedures and regulations needed?	Is antenatal prevention work needed in Health Centres?	What needs to change at the national level?
32 respondents think introducing new rules are necessary	48 respondents think that antenatal prevention work is needed	45 respondents offered suggestions
10 respondents think that no changes are needed. In one case because 'enough is already being done' and in another because 'new rules will not help'	2 respondents think that no prevention work is needed including a rural Head doctor 'because the family is near, the mother-in-law, there is no need to carry out prophylactic work'	1 respondent said 'all conditions are in place'
10 had difficulty in answering the question or gave no response	2 had difficult in answering the question or gave no response	3 gave no response and 3 said 'I don't know'
Summary of responses	Summary of why 48 respondents	Summary of responses from 45
from 32 respondents	think antenatal prevention work is needed?	respondents
'More information about ill children. Training for mother in skills for caring for children with disabilities'	'especially during pregnancy, preparation for care, for brining up the future child'	'In secondary schools more health education work should be carried out. The reproductive health cabinets should work more on family planning'
'Counseling (beseda) during pregnancy'	'so that a healthy child is born. So that he or she is a wanted child'	'child care in the family, teaching the rule of family relations in schools, about the consequences of risky behaviour'
'for talking to women it would be good to have a	'In Health centres teach pregnant women how to take care of children	'additional social benefits for single women above the minimum, information

psychologist'	with disabilities. Prepare them psychologically'	campaign through the media about the risks of sexual activity'
'in schools teenagers have to be talked to' 'Conversations (beseda) among teenagers at polyclinics'	'so that an accessible and clear explanation is given' 'explain more about the future of such a child'	'if the social benefits were increased, the length of the benefit up to 5 years, employment were provided, if they were taught about how to prevent an unwanted pregnancy'
'radio ads, TV ads, booklets, advertisements' 'more television and radio programmes'	'develop maternal feelings and love for the future child'	'Registered marriage. Social support. Psychological centre for training'
'Early entry into antenatal programmes. Good quality antenatal care'	'family planning, information work among women, explain about contraception' 'the family planning cabinet should carry out information work'	'More information work with young people about responsible parenthood, so that they have knowledge about marriage, the family and take a responsible attitude to questions of family life. This should be done in schools, among the older classes and through the mass media.'
'provide material support' 'a social service for single mothers'	'if they restored the staff of midwives and pediatricians in the far out areas, then they would know better the situation in families and would carry out focused prevention work in such cases'	'solve issues of employment and housing for women'

Source: P4EC CEE/CIS Consultancy group based on data provided by MoH data collection teams

At the national level respondents see a need for policies that focus on informed choices among young people about family planning and contraception. They see a need for information to be provided in schools and health services targeting young men and women as well as wider public campaigns. Some respondents see a need for policies that focus on supporting women to work and to have social and housing support so that they can look after their children if they don't have husbands or the fathers of the children are absent. Some respondents highlight the need for policies that focus on positive family values and support young people to learn about family relationships, child-rearing and how to deal with problems should they arise. Some respondents highlight the need for more information to be more widely available about children with disabilities as well as more specifically targeting parents of children with disabilities to help them to look after their children at home.

At the level of services in the regions, respondents highlight a need for family planning services to be strengthened, for training and information to be available in Health centres and Women's consultations. Consultations with psychologists are also suggested by some respondents.

The suggestions of respondents about changes to regulations were more focused on general preventative strategies, although one nurse did say that no changes were needed to regulations, but that 'after the birth the child has to be put to the mother's breast' as this will help with bonding between the child and mother.

C8 Experiences of parents of young children with disabilities who have not placed their children into the infant home

The researchers conducted a focus group discussion with 8 mothers of young children with disabilities who continue to live with their families in the community. The purpose of the

discussion was to triangulate the data from interviews with maternity home and infant home parents and staff with the experiences reported by mothers of giving birth to and bringing up a child with disabilities in their own families. The mothers were all from Ashgabat and their children were aged from 2-12 years, both boys and girls with disabilities including Down's Syndrome, cerebral palsy and autism spectrum disorders. Key issues discussed included:

- Experiences in the maternity home of being told about their child's disability
- Providing day-to-day care for their child
- Existence and quality of support services in the community
- What can be improved to help families of young children with disabilities be able to care for their children

Maternity hospital experience

All mothers, who had the experience of being told about their child's disability in the maternity hospital, said they had been advised to relinquish their newborn baby by doctors in the maternity hospital:

"I didn't know yet then what Down's Syndrome was. The doctor at the Maternity hospital said 'So, your child is not normal in the head, leave the child here with us. It's better than torturing yourself with him. He'll die anyway. Or you'll put him in the children's home yourself.' Or else they tell us that a child who is born an invalid will die anyway."

"...most doctors in the maternity hospitals ask us to reject our children with disabilities, they say that they (the children) are not normal and it will be difficult for us in the future..."

The mothers focus on three main aspects of being told about their child's disability in the maternity hospital:

1) Where and how they were informed – insensitively, 'in the corridor... not in private... I started crying', without psychological preparation or support:

"when a disabled child is born to a woman, the doctors say 'that's the end'. The women start to be frightened. There is no support from the doctors. At that time we need psychological help."

The language that medical staff use to talk about the child's condition:

"a few hours after I gave birth they said 'Your child is abnormal, she is a Down. She is 100% Down and will die anyway'. I think that they should not talk to the mothers like that. When I started to protest and said that they should stop talking about my child like that, then they changed a bit and started to say 'they are such nice children. Little rays of sunshine, she will be a good helper for you'. But that was after I had hysterics. The doctors should not have these attitudes."

2) Negative messages given by the medical staff – an assumption that the child will 'die anyway', that the parent won't be able to cope:

"what can you expect if the paediatrician says 'Leave the child. He is ill. You're a young mother, you will have more children. Why do you need an ill child?' "

And an assumption that there is no emotional reward for the parents in caring for a child with disabilities:

- "...the paediatrician said that it was a genetic disorder. That my child is simply like a plant and I will look after him like a plant. The doctor said 'A piece of meat is lying around, and your child is just like that piece of meat. He will just lie around."
- 3) A lack of information about disability generally and their child's condition specifically which causes fear of not coping and anxiety about looking after their child:
 - "...it would be good if there were a psychologist as women become frightened when they are told that there child has been born abnormal, an invalid. If only there were a centre for parents like us where we could go for support and advice"
 - "Many mothers, when the doctor says their child has been born with disabilities, begin to think about what will happen next, what will people say, relatives, people around? What will be their attitude to the child?"

When asked about which of the staff at the maternity hospital had been helpful, one mother answered that 'the nurse helped me psychologically'.

Looking after a child with disabilities in the community

Mothers describe negative attitudes to children with disabilities among their neighbours and among the specialists whom they encounter in Health centres and among parents and staff in kindergartens:

"...children like ours aren't accepted in state kindergartens as they think they are ill. And in private kindergartens they say 'Mamasha, if you put your child into our kindergarten, the other parents will take their healthy children away. What if their child will be infected by yours.'

Another mother also described how her child was pushed out of a kindergarten because of the parents of other children, even though the kindergarten director and staff were supportive.

A couple of parents reported that their children are not accepted in the auxiliary school (special needs school) as their children are too healthy (they can sit, walk, eat, etc.) and they are not accepted in the mainstream school as their children are too ill. As a result none of the existent school establishment is good for their children (or their children cannot fit with any existing schools).

Nearly all parents report negative attitudes, a lack of understanding about disability in health centres and even among specialist staff such as speech therapists and special education teachers:

"I recently went through an assessment with my daughter and the doctor said that my child needs a speech therapist. I went to the local health centre and they said 'we will not take debil-children'. They advised me to find a private practitioner."

"In normal polyclinics they don't want to work with us."

Only one mother reported that she had confidence in her local health centre and that staff there did not have negative attitudes to her son with Down's Syndrome:

"...they always are happy to see us. The number of times I have gone to my local polyclinic and all of the staff know my child. They have good attitudes and whatever we need, treatment, medicines, they prescribe without any problems."

Some mothers report that some family doctors have good attitudes to children with disabilities, while others report negative and even hostile attitudes. Overall experiences vary widely from doctor to doctor with most parents deciding to use the two existing private service providers in the city.

The services provided by the NGO where the focus group took place were praised by the mothers with the main elements of support highlighted as:

- good attitudes towards the children and parents; expressing interest in their progress
- organizing a summer activity which helped the group of parents and children to bond as a group and where they felt they could relax in a safe, caring environment
- helping some parents to access specialist services that they otherwise can't access

The main challenge for the NGO is a lack of space to offer services and a lack of stable funding for specialists to provide services and for organizing activities for children and parents. All mothers stressed how important it has been for them to meet other mothers in a similar position and how supportive it is to feel that they are not alone with their problems.

Why do some parents place their child in the infant home and others don't?

The focus group respondents attribute the decision of some parents to relinquish children to three main factors:

- 1) Economic ability to access specialist support services 'we are ready to pay ourselves for good specialists, but not all families can pay'. Although they mentioned: "we are ready to pay, but there are no services, rehabilitation centres that we can use in our country. many of us go to Turkey, Germany for diagnosis and rehabilitation"
- 2) Support from other family members and close circle of friends and relatives lack of information about disability and general prejudice in wider society means that close relatives often put pressure on mothers and father to give up their children with disabilities, which can leave parents with no alternative. A couple of them reported that the extended families (mother-in-low) put pressure on the fathers to give up their children and wives.
- 3) Attitudes of specialist staff in the health and education services negative attitudes can create obstacles and challenges that have to be surmounted in order to care for a child day-to-day '...in the maternity hospital the doctors kill us mothers morally, telling us that the child has been born abnormal'; 'going here and there, it stresses your nerves rather than solving problems'

To some extent these views correspond with the views of parents who have placed their child because of the child's disability and who themselves had little access to information about their child's disability, about available services and who may not be getting they support and help they need from their relatives and friends. The main differing perspective to come from the focus group participants is that of the economic factor – those in a position to purchase private health and education services are possibly less likely to place their child into care than those who have no alternatives.

The respondents identify the following priorities for addressing the needs of children with disabilities going forward:

- Changing attitudes to children and adults with disabilities more information about disability
- Helping parents to have the strength and patience to overcome obstacles and rise to meet challenges
- Support from the government with accessing health, education and social services including psychological support

Box 5 summarises some of the key points relating to this study which emerged from the focus group discussion.

BOX 5 Experiences of parents of young children with disabilities who have not used the infant home (findings from focus group discussion with 8 mothers of children with disabilities aged 2-12 years)

The experience of being told their child's disability diagnosis in the Maternity hospital was shocking and difficult to overcome – they were made to feel that they and their child could have no future. They were offered no counseling or psychological support and were left to rely on their own personal and family inner resources. Mothers who had this experience all report that they were advised by the staff in the maternity hospital to relinquish their child.

Stigma and negative attitudes towards disability are prevalent not only among the general public, but also among their own family members and among specialists in the health and education services.

Parents report a lack of trained disability specialists in the health and education services. Even if some specialists – doctors, teachers – have positive attitudes towards children with disabilities and their parents, they do not necessarily have the training and skills to work with them to develop the child's abilities. There is a general lack of information available about disability of all kinds and this concerns health and education specialists as much as parents, relatives and the general public. Overall there is a lack of appropriate educational and medical services for children with disabilities.

Ability to purchase services privately could be making a difference between the decision to place a child into care or not.

Support from other parents facing similar problems is extremely important to ensuring that parents can continue to care for their children and continue to overcome the challenges they face in providing that care.

The only 'social' services that parents mention having used are those provided by an NGO that helps to organize activities, access to specialists and provides counseling and other kinds of psychosocial support.

D. Conclusions and implications for policy and practice focused on prevention

Who are the children entering and remaining in infant home care, how many are they, and why are they entering?

- 1) The biggest group of new entries each year are newborn babies who spend only a short 'pre-adoption' period of 1-3 months in infant homes while they undergo medical tests and examinations and the adoption procedures are being carried out by the velayat Guardianship and Trusteeship organ. For these infants almost no systematic work, apart from isolated cases, is being done to prevent the relinquishment in the maternity hospital or to bring about reintegration with their birth family including the extended family of the mother or father once the child is resident in the infant home. According to maternity home staff, these children are in most cases born to single mothers, often young (15-18 years) and the pregnancies were unplanned and the children unwanted. In some cases it is possible that there is a type of private arrangement between family members or friends where one family adopts another family's baby and these cases are handled through the infant home so that the baby in question can undergo all the necessary medical tests and adoption procedures and so that it is easier to keep the secret of the adoption.
- 2) The next biggest group to enter and to remain in the medium to longer term are infants of all ages with disabilities, including new born babies, who enter either straight from the maternity hospital, from their families or from the hospital where they live after the maternity hospital for a period of time for post-natal treatment. Some of these infants have been relinquished or abandoned by parents and family but many have been placed 'temporarily' - in most cases this means until they are 4 years old, in some cases even older. In some of these cases they then return to the care of their families in others they move into the disability institution for older children under the Ministry of Social Protection. Many of these infants are visited regularly by parents. The infant homes see their role as providing 'medical care and services' to these infants and parents also have a highly medicalised perception of what the infants are receiving in the infant home that they can't receive at home. 36% of the infants in the long-term population have disabilities - this is very high given that probably only around 1.5%-5% of children in the general population have disabilities. There are, nevertheless, many more infants with disabilities who are not in the care of the infant home and live with their own families. These families receive almost no support and services and are very much left to their own devices in caring for their children, sometimes children with very complex needs. They face high levels of stigma, many barriers to accessing health and education services and have to have considerable financial, emotional and psychological resources in order to be able to care for their child.
- 3) A smaller number and proportion of infants, including new born babies, but also older infants enter temporarily for 'social reasons' (some also have disabilities, but this is not the main reason for placement) this can include a mother in jail, family crisis, parental disability or illness, housing problems, death of the mother, other social problems. In these cases the children tend to live for quite long periods of time in the infant home, but not quite as long as the children with disabilities. Most of these children are visited regularly by family members and return to their own families when they leave the infant home. The role of the infant home is to deliver social care in these cases, but given the nature of the institutions this is a medicalised version of social

care - medical examinations, medical testing and treatments. In most cases, there is no other option of help and support available to these families.

In the case of the first two groups of infants, the maternity hospital staff play a role in 'facilitating' the placements into infant homes either by actively recommending relinquishment or by passively not intervening. In some maternity hospitals, the staff say that they try to talk the mothers out of relinquishing the newborn babies, but this is not done systematically or methodically and relies heavily on individual practice. The medical staff do not have any means of offering any practical support to the mother they are trying to 'talk out of' relinquishing her child. According to some mothers, medical staff in the maternity hospitals tend to actively advise mothers to relinquish their disabled child.

In regions where there is no infant home easily accessible in the local area, there is a significantly lower usage of this type of care, notably in Ahal, and a higher usage of family type care.

There are almost no other services available to support and help in the community apart from the mainstream universal services - polyclinics, kindergartens, schools – and some parents report considerable barriers in accessing these services for children with disabilities. Support from extended family is crucial for all three groups of children in the absence of formal services. There are some NGO services available for children with disabilities, but these are not available systematically to all children across the whole country.

Summary - strengths of the current system

- The role of the extended family, strong family values
- Overall a low level of use of institutions for children under 3 years of age 143 children in December 2013 and apparently continuing to fall
- Relatively high level of adoption of newborn infants
- The system of family doctors and nurses making visits to family in the home before and after the birth of a child
- Flexible system for visiting children in the infant homes, maintaining contact with the family of the child
- The possibility of placing a child temporarily without removal of parental rights
- Most children leave the infant homes to return home to their families or to other family based forms of care

Summary of challenges

- Around 150 infants each year lose parental care in the maternity hospital
- A high number of children entering the infant homes 492 children in 2012 entered the infant homes
- Disability (37% of children) and developing and understanding of a multi-faceted model
 of disability in keeping with the International Classification of Functioning (Children and
 Youth)
- Long stays in infant home care for some groups of children
- Strengthening prevention of relinquishments generally among at risk women and preventing refusals and abandonment in the maternity hospital itself
- Strengthening alternative services to the infant home

 Supporting children after they leave the infant home and return to their families (services for pre-school children)

Implications for policy and practice

If the intention is to bring use of infant homes down from the current low levels to zero in the coming few years, then the following policy and guidance is needed:

A vision of the policy goals for children under 3 years of age will have to be articulated as a cross-cutting priority across education, health and social policies – especially in relation to disability, reproductive health, early intervention, social protection and inclusive education policies. This may lead to revisions of policies relating to all vulnerable children and adults of all ages in the medium to long term.

Assessment of needs for preventative and alternative services in the four regions where the infant homes are being used most. This will require close attention to the main target groups identified in this study: 1) infants being abandoned in the maternity hospital for social reasons – single parenthood; lack of support from extended family; lack of use of reproductive health services; 2) infants with disabilities being relinquished in the maternity hospital or placed temporarily by families because of their disabilities; 3) infants placed temporarily by their families in the face of mainly social problems – includes a sub-group of infants placed while their mothers are serving sentences in the women's penal colony.

Planning and implementing the necessary services that can replace the infant homes as they are currently used. This may involve both adapting and strengthening existing services, possibly including the existing infant home facilities themselves, and establishing new services that currently do not exist. The low numbers across the country suggest that the creation of new services does not necessarily have to be resource intensive.

Staff training and development as part of developing existing services and introducing new services. This will include the need to develop an understanding of disability among a range of health, education and social policy decision-makers and practitioners, to develop a cadre of social workers who can deliver person-oriented services in a range of settings, to develop counseling and communication skills among medical personnel.

Ongoing monitoring of key indicators, both qualitative and quantitative, that can help to monitor implementation of policies and plans, but also ensure that plans are adjusted as necessary if new problems or vulnerable groups emerge.

The responses of maternity hospital staff summarized in Table 12 show that they are largely open to the idea of introducing new policies and practice that can help to change the current situation both within the maternity hospitals and outside in the provision of strengthened health, education and social services. The openness of participants to proposing ideas suggests that medical professionals will be largely open to the idea of training and development to address some of the challenges identified in this study. Similarly, both maternity hospital staff and infant home staff indicate that they would like to take part in and feel they would benefit from training on specific topics relating to infant relinquishment and abandonment prevention (as summarized on pages 47-48 above).

E. Recommendations

The following recommendations are intended to help decision-makers to move forward and develop an overall vision and a detailed plan of action that can lead to a reasonably fast, but carefully planned and measured, reduction in the numbers of infants being cared for in infant homes across Turkmenistan.

Further research:

- 1. Study the collaboration of the maternity hospitals with Guardianship Authorities for the prevention of infant abandonment and placement in infant homes, exploring how they are working with the first group of children in Ahal and Balkan regions why is there a much higher level of family placement in Ahal? Are there some good practices that can be shared with other regions? This could be done through focus group discussions with Guardianship organ specialists. More generally, the roles and accountability of Guardianship and Trusteeship bodies need to be reviewed, including regulations and staffing and interaction with health, education and social welfare sectors.
- 2. Study the reasons why the babies of women serving sentences in the women's colony in Dashoguz are not being cared for by extended family, but are being placed into the infant home for sometimes very long periods with only limited contact with their mothers.
- 3. A more detailed study needs to be done into the backgrounds of the mothers and fathers of the 150 or so infants who are relinquished each year in maternity hospitals; most of these are from Lebap and Ashgabat maternity hospitals. Some of the medical staff indicated that they are predominantly young women who have moved to the city for work or study from the rural areas. There is a need to explore where they are living and working, if their own families know about their pregnancies and births, if there is a way of targeting them with reproductive health information through the work place and/or the places they live, what policies should there be on family planning and reproductive health in schools and colleges.

Policy actions:

4a. Policy on the prevention of child relinquishment. Experience in other countries shows that in about 50% of cases it is possible to prevent relinquishment in maternity hospitals with only minimal supportive interventions. If the policy decision is to ensure that all measures are taken to prevent relinquishment, then abandonment prevention interventions need to be put in place in reproductive health services, maternity hospitals and linked to the Guardianship and Trusteeship organs. Preventive measures need to be put in place in maternity hospitals. Prevention of abandonment regulations, guidance, mechanisms for referrals and interventions need to be put in place in all maternity hospitals linking out to the Guardianship and Trusteeship organs, policlinics and other support services in the community. Consideration should be given to the employment of social and psychological workforce in maternity hospitals and policlinics to provide qualified support in ante-natal and post-natal periods. Medical staff (and social workforce) need to be trained in applying these protocols. In order to improve the quality of services offered in maternity hospitals, medical staff should be trained in communication, in developing tolerance and tackling discrimination towards women at risk of abandoning a child; as well as developing some work techniques that would contribute to the formation and consolidation of attachment between mother and her baby. Training is also needed for staff in

maternity hospitals and antenatal health services on talking to parents of children with disabilities. Consideration needs to be given to ante-natal parent training classes and to strong reproductive health services among the most vulnerable men and women.

Examples of preventative interventions in family planning and reproductive health services (many of these examples have already been mentioned by the participants in the study).

- **1. General public information campaigns** about family planning, reproductive health and early childhood development issues. It will be important to assess the purpose and expected impact of such broad public information campaigns, given that the topic may have some cultural and social sensitivity. There is some evidence from studies⁶ in the US that these types of campaigns can have an impact on between 3% to 6% of their target populations.
- **2.** Targeted information and education campaigns about family planning, reproductive health and infant care issues focused on the older classes in schools as well in further education institutions and health services. There are a range of options for training teachers to deliver information both in the classroom and/or together with parents. There is an extensive range of programs with strong evidence bases that can be reviewed and adapted for Turkmenistan from around the world⁷ and 'which evidence shows produced reductions of 15% or more in rates of sexual activity and increases of 25% percent or more in rates of contraceptive use⁸'.
- **3. Targeted outreach campaigns** about family planning, reproductive health and infant care focused on particularly vulnerable and at risk women and men. These kinds of campaigns can target particular population groups either geographically where high instances of unplanned pregnancies and births are documented, or by other characteristics women and men working in particular types of settings, women and men who have migrated for work and study and are living in particular locations, women and men of a particular age. A study such as that outlined in recommendation 3 can help to identify these particular groups and a review of evidence bases such as those mentioned in footnotes 6-8 can help to identify programs to trial among these groups.

Examples of abandonment prevention interventions in maternity hospitals

- 1. Response team with designated responsibilities in the maternity hospital trained to respond when a mother enters the maternity hospital. Responses can range from counseling and advice (as currently practiced in some maternity hospitals where this study interviewed staff) up to active interventions to seek relatives and arrange support for the mother and her child upon leaving the maternity hospital.
- **2.** Response team located outside the maternity hospital but mandated and trained to respond to a signal given by maternity hospital staff. The team can be located in a social

⁶ See for example: http://www.brookings.edu/research/reports/2012/03/unplanned-pregnancy-thomas

⁷ See for example: http://www.hhs.gov/ash/oah/oah-initiatives/teen-pregnancy/db/ and http://thenationalcampaign.org/featured-topics/sex-education-and-effective-programs

⁸ http://www.brookings.edu/research/reports/2012/03/unplanned-pregnancy-thomas

services department, in an NGO or with the Guardianship Organ. Maternity hospital staff also have to be trained to deal with the first communication from the mother, but responsibility for follow up is transferred to the response team ideally including a social worker and a psychologist. The response team is mandated to seek relatives and arrange support for the mother and her child upon leaving the maternity hospital.

This type of policy requires not only the development of abandonment prevention measures in maternity hospitals, but also the development of community based services that can support mothers and their babies upon leaving the maternity hospital.

4b. Policy on child and family support services /systems strengthening and development

The roles and accountability of Guardianship and Trusteeship bodies need to be reviewed, including regulations and staffing and interaction with health, education and social welfare sectors. The Guardianship and Trusteeship bodies may play an important role in the design of an effective gate-keeping system for all children and ensuring an inter-agency collaboration to prevent infant abandonment. Protocols for inter-agency collaboration may need to be developed in order to ensure better coordination of preventive measures undertaken by different sectors.

Social services that can offer psycho-social support need to be developed for work with mothers, fathers and the extended family. Early intervention services should be designed to provide effective interventions both earlier in the life of children and in the life of the family problem. Consideration needs to be given as well to the development of family support services to provide social work support to families where there is a risk of child separation in the communities.

Examples of child and family support services targeting mothers who reconsider their initial desire to relinquish their child in the maternity hospital

- 1. Community-based social workers these trained specialists can be attached to the Guardianship and Trusteeship bodies at the municipal level and mandated to deliver flexible packages of support mothers and babies where relinquishment was prevented in the maternity hospital. Alternatively, social workers can be attached to the social protection departments at the municipal level which are responsible for processing social benefits, but in this case the link with the Guardianship body has to be formalised and the roles and responsibilities of both specialists has to be clearly defined. Social workers can help mothers, father and extended families to solve practical problems such as housing issues, document registration, claiming social benefits, child care arrangements as well as provide individual psychological support, counselling and parent-skills training to mothers and fathers at risk. These teams of social workers can also work with other groups of vulnerable children and families being targeted by this programme of support to prevent use of institutional care. In the case of infant abandonment prevention, a programme of 6 months gradually tapered intensive support can help a family to reach a stable situation.
- **2. Visiting nurses** the existing nurse visiting programme can be strengthened to add a component of support, counselling, training and help with practical issues directed at vulnerable young mothers. The most effective approach would be to add a social worker to the visiting team where a mother has been identified as vulnerable.

Social work as a specialism can be developed both in practice and through the development of academic curricula and qualifications at graduate and post-graduate level.

Practice teaching and in-service training for experienced professionals with similar education, training and professional experience – social pedagogues, teachers, psychologists, nurses, NGO workers and other 'person-oriented' professions - can help to create an initial workforce to pilot and develop new services. In parallel academic curricula can be developed at university level – experience in the CEE/CIS countries shows that social work teaching tends to develop either departments of psychology or sociology or both. Social work curricula touch upon a theoretical foundation that touches upon aspects of sociology, philosophy, psychology, critical analysis, statistical analysis and social sciences.

Case management is a key tool used in social work where a single person is the lead responsible 'manager' of the work being carried out with a child or family. This could be the Guardianship specialist, or it could be a social worker. The case manager is responsible for coordinating all of the services that are being provided to a child or family whether they are health, education or social services. This helps to ensure not only that the services are achieving the goals set out in the plan of work with the child and family, but also that services are coordinated across different departmental and disciplinary boundaries.

5. Policy decision on adoption procedures and particularly how the route to adoption should be handled for all infants.

The authorities have to decide if there really has to be a period of 'hospitalisation' in the infant home pre-adoption, realizing that even a short period of separation of the infant from the family/family care could lead to long-lasting effects for the child development. The infant could be living in a temporary family arrangement while decisions are taken and social and health assessments are completed. Alternatively, the infant could be living with the potential adopters if the adopters can be approved in advance and be ready to take a child at any time after their approval. Also, the authorities should decide if stricter procedures have to be put in place, including the approval of adoption in court and not by the Guardianship Authority as it is currently.

If it is not possible to place children directly into adoptive families from the maternity hospital then options should be explored for developing alternative family-based care for infants without parental care. These can be developed as 'patronat' care where the family support centre or infant home employee is approved as a family-group carer and agrees to take care of a child in her own home. The family support centre or infant home retains responsibility of care for the child, but the child is attached to a particular staff member and lives with that staff member until the adoption is approved. This kind of arrangement is particularly suitable for short-term or emergency care provision, but can also be used for longer episodes of care when, for example, a child is expected to live in the institution until the age of 4 years.

Examples of alternative family-based care for infants without parental care or as a support service for children with disabilities living with their families

Emergency, short-term and long-term family placement services can provide alternative care to infants without parental care, including for mother-and-baby pairs to prevent relinquishment, specialized foster care for children with disabilities to avoid long-term placement in the infant

home and respite foster care for children with disabilities to avoid child-family separation and placement in alternative care. Pre-adoption placements straight into adoptive families or alternative family placements such as 'patronat' or 'family-care-groups' could be used instead of placing the child in the infant home. Family-based care can also be used for the babies and infants of women serving sentences in the penal colony if their own relatives are unable to take care of the child.

Family-care-groups – this model is used in the Russian Federation where Child and Family Support Centres recruit, assess and employ parents who look after children in their own homes. The parents are employees of the centres and the centre retains responsibility for the well-being of the child while in the family-care-group placement.

Patronat – this model from the Russian Federation also employs the patronat carers to look after infants in their own homes, but the employer tends to be the infant home or the children's home (for older children) so the child may move from a residential place in the infant home into the carers' own home. The infant home retains responsibility for the child's well-being. It is important with this model that the residential places in the infant home are gradually closed as the number of patronat carers increases.

Foster care – the local municipality has a team of social workers who recruit, train and support foster carers. The social workers can be located in the Guardianship body or in a social services centre. The responsibility for the child's well-being while in foster care remains with the municipality and the social workers support and monitor the foster carers as they care for the child.

Small group homes – this is like a small infant home with only a few children being cared for in a small unit – an apartment or small house. This model is only appropriate for very young babies and infants if the carers can be more or less constantly on 24 hour duty. Sometimes this model has 'house parents' who move into the residential unit and provide this 24 hour care. The house parents can be employed by a social services provider, the local municipality and/or an NGO. In this case, the model is fairly similar to the first three, only the housing is provided to the carers as well as a payment.

In all cases, the needs of children with disabilities who have no family should also be considered. It should be assumed that children with disabilities who have families can be largely supported in their own homes with a range of services.

All types of family-based care or small group homes require trained social workers to identify, assess, train, support and monitor carers and to support and monitor children during their placements. Family-based care is a service, like residential care, but in a family-based setting and requires the same level of management and regulation. The family carers are not left alone with the children without support and supervision and the level and type of support and supervision depend on the needs of the child.

6. Policy of family care and support for children with disabilities. This study has shown that there are surprisingly few infants with disabilities who are completely abandoned by their relatives; there are high levels of visiting compared to many other countries. This is a very positive base from which to build a strong policy of family care and support for children with disabilities, social inclusion and inclusive education. A range of services need to be developed

that can reach out to families in their homes that are based on a multi-faceted model of disability, not only on the medical needs of children. The International Classification of Functioning Child and Youth version offers an excellent basis for developing both policy and practice. The types of services that can help to ensure that families are able to care for their children with disabilities and will continue to do so and therefore not place them either temporarily or permanently in an infant home or any other type of institution include:

For children under 3 years of age: children and their families may require a combination of these services or only a single service and all provision of services should be based on a comprehensive assessment which is carried out together with the child's parents and family members by a qualified social work or disability specialist who is looking at all of the child's developmental needs and not only medical needs (for babies and infants this assessment can be carried out by early intervention services, for example).

Early intervention services⁹ – a multi disciplinary team including, for example, a pediatrician, social worker, speech therapist, psychologist, hearing and sight specialist, physiotherapist and ergotherapist work in partnership with parents to develop and implement a programme to support the maximum development of each individual child. The programme is regularly monitored and updated as the child's abilities grow and change. The child should graduate from early intervention services into inclusive kindergarten services at the age of three years or so. The programme can include parent/child groups and parent support groups to help parents come to terms with their child's disability and to find the emotional, psychological and technical support to be able to provide the care their child needs. This team can work in the child's own family home or the family can visit the team at an early intervention centre. An early intervention centre can be developed on the base of an NGO, a health centre, a nursery or kindergarten or in a social services setting. The inter-disciplinary nature of the team means that it can operate in any setting.

Assistive devices and technology library – as children grow and develop, their needs for devices to assist and enhance mobility, communication and self-care abilities change and develop. Assistive devices and technology can make an enormous difference to many children with disabilities and the creation of 'library' where such devices can be borrowed and used for short periods as children's needs change can make a huge difference to the growth and development of each individual child and to the ability of their family to care for them.

Parent groups – self-help groups for parents with children with disabilities can play an enormous role not only in helping parents to maintain their emotional resources and psychological equilibrium to care for their children, but also in ensuring that parents are informed about services, technology and latest advances that can help their children.

Inclusive parent groups – opening ordinary mother-toddler groups, nurseries or equivalent early childhood care services to children with disabilities can be an important resource for parents and enable them to cope.

⁹ See for example early intervention standards and normative guidance in Russian: http://www.raeci.ru/index.php/rv/kak-organizovat-sluzhbu http://www.raeci.ru/index.php/rv/standarty

Respite services – short, regular stays from a few hours to a few days at a time for children with multiple disabilities who require 24-hour care can play a huge role in ensuring that parents and other family members can continue to cope and have time for themselves. Respite foster care for young children with disabilities can often mean the difference between temporary placements into infant homes or not. The exposure to another home and family can help to build a child's socialisation and communication skills.

Individual plan and budget – in some countries the government gives parents of children with disabilities an individualized budget with which they can purchase the volume and type of services that they need. A social worker will assess the needs of the child and family together with the parents, health and early intervention specialists in order to define what type of services are needed to ensure the best possible environment for the developmental needs of the child to be met, including the stability of the family as a whole as the creators of the environment in which the child is being cared for. The services could be any combination of the above, but might also include personal assistance in the home, mobility and transport aids, family holidays. The plan is costed and the funds are given to the family to spend as needed. The social worker maintains regular contact with the family both to provide support and to monitor implementation of the plan. As the child grows and develops, the plan and the budget are adjusted according to the child's changing needs.

As children get older their needs change and any policy which is looking at the needs of children with disabilities under 3 years of age, will also have to consider the needs of these children as they approach school age and then as they enter young adulthood and enter further education and employment. A comprehensive disability policy is therefore of critical importance if children are prevented from entering infant homes only to then end up in residential schools or adult institutions. In the first instance, however, if the focus is in closing/re-profiling infant homes specifically, a policy focused on under-3s can be a good starting point for then developing further policies for the whole life-cycle of children and adults with disabilities. Strong disability policies can help to give parents a clearer understanding of what support they can expect and therefore what will be demanded of them in caring for their child with disabilities — this can also help at critical times such as just after birth, at the time of being told their child has a disability and when a child is entering and leaving various stages of education.

- 7. Understanding disability awareness campaign either as part of the disability policy or as a separate policy intervention, there is a need to raise awareness among health, education and social sector personnel about disability, to ensure that skills and knowledge are updated especially among health and education professionals. There is also a need to raise awareness among parents of children with disabilities about a less medicalised understanding of disability and among the general public about understanding disability, designed to reduce ignorance and stigma.
- 8. Strengthen policy and preventative child and family social services as an alternative for children entering infant homes for social reasons an efficient case management, gate-keeping and monitoring system can help to ensure that as soon as a family approaches the infant home or the local municipal authorities for help they are referred to a team of local social workers who have been trained to carry out multi-faceted assessments of the needs of the child and the whole family and develop a plan for meeting those needs. In the cases of some of the family situations documented above in this study, some very basic intervention consolidating partnership relationships between governmental services and services offered by non-governmental sector could have helped to prevent entry into the infant home and supported the

child in the family. These partnership relations could be improved by the development of unified protocols of intervention in the case of infant abandonment risk, involving existing specialists and community services.

Examples of alternatives that could have prevented entry for some of the cases from the study

Relative, age, education, place of residence – frequency of visits	Circumstances of the temporary placement of the child/children into the infant home	What services could be developed to support the family to care for the child instead of the infant home?
Grandparent – aged 41-60 years, secondary education, lives in the same town as the infant home – visits once a week – main reason for placement parent illness, grandparents not coping	The child's mother and father have tuberculosis, at the moment they are in hospital. The children have been here for 6 months – they came in when the grandmother had a stroke. We plan to take them home when their mother's condition improves	Temporary help in the home with cleaning and food preparation — especially when the grandmother was in hospital. Help with taking older children to and from school. After school homework clubs for the older children. Day-care and/or kindergarten places for the two younger children. Assessment and coordination of services by a social worker.
Grandmother – aged over 60 years, secondary education, lives in the same town as the infant home - visits once a month – main reason for placement parent illness/social factors	I have a one year old granddaughter from my daughter, she has been here for 4 months, my daughter doesn't have a husband, the child's mother has been ill since childhood, she sometimes has fits, we will take our granddaughter back as soon as she grows up a bit and learns to talk and walk so that she can get away/run away when her mother has a fit so that she isn't crushed or dropped. I have high blood pressure and look after my daughter because she often has fits. There is nobody else who can help, my son's wife left him because of my daughter's illness.	Early childhood development education for grandparents and parent. Assessment by social worker to support grandparents in creating a safe environment at home. Flexible day care provision. Work with health services to ensure medication of mother is as controlled as possible. Agreement with a neighbor or other close family friend that they will share care/ support the grandparent in providing care from time to time.

It is difficult to name the services that can be developed as the development of services depends on strong assessments that can explore the situation of children and families from every angle. The key is to introduce the trained social workers with a mandate to work through the case management cycle using a strong assessment framework and this can help families to use the available services and help the social workers and local authorities to identify the other types of services that need to be developed.

9. Policy and action plan on the transformation/closure of infant homes - into support services/day care centers, early intervention services or multiple purpose support services. As they transition into closure or becoming a new type of services, clear eligibility criteria are required for the infant homes to ensure short-term placement on the basis of a social work assessment, ensuring permanency for the child. Infant homes should consider employing social workers, psychologists to work with children and parents for family reunification – move from a medicalized model and introduce a social approach. Consideration should be given to the opportunity of the infant homes to be transformed into day care with some 24 hour groups and insist on children going home in the evening or at weekends – this is very close to the current situation. The change would be to have a shared care between the infant home and the family so that the family retains responsibility and the infant home helps to broker a more structured role of the family in caring for the child. Where a child has no family contacts and there is no possibility of resurrecting them, the options explored above for developing family-based or family-type care should be explored.

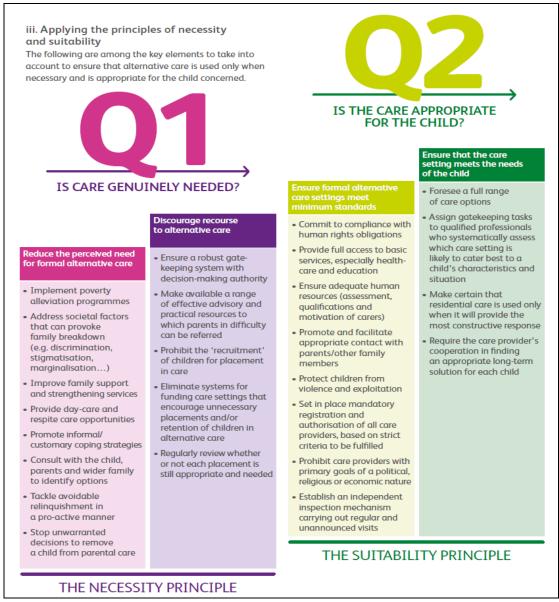
A communication campaign should also be considered to target groups of professionals (doctors, police, teachers) and general public about the effects of family separation and institutionalisation for babies which can both underpin and help to drive forward the planned reforms.

- **10. Data collection** and monitoring on infants and babies needs to be systematized to support the implementation of new policies on infant abandonment prevention and support for children with disabilities and their families. Review existing requirements in data collection in maternal hospitals and infants homes with regard to abandoned/relinquished/placed for temporary care children and propose improvements which are based on the new policy goals. In the short term the secondary data dimensions examined for this study can be used as a basis for a regular data collection exercise which can help to both inform new policy development and monitor implementation.
- **11. Possible immediate actions** develop and implement a policy and action plan for babies and infants which can include the following steps:
 - Expand and alter the functions of the infant homes in accordance with the International Classification of Functioning as it relates to babies and very young children.
 - Strengthen the existing health, education and Guardianship organ services; create new services to support children and families in difficult life situations while conserving the strengths of existing strong family values and informal care systems.
 - Take active measures to prevent infant abandonment and relinquishment in maternity
 hospitals by issuing guidance to staff and training staff in basic counseling and
 communication skills; general and targeted measures to prevent unplanned pregnancies
- **12. Consider extension of deinstitutionalization policies to all children** at risk of losing parental care or without parental care. Begin with an assessment of the needs and service provision of the existing system along the lines of this study into children under 3 years of age in order to inform the visioning for future child care policy development. This will allow for a planned and more cost-effective intervention to be designed and for internal and external resources to be mobilized in order to plan and undertake future reform actions.

Recommendations for key principles to guide policy development

The UN Guidelines for the Alternative Care of Children offer a strong basis for developing policies that can ensure the best interests of children are at the centre of policy-making on alternative care. Figure 7 summarises the key principles of necessity and suitability underlying the UN Guidelines which can help policy-makers to ensure they are creating a system that exhausts every possibility for supporting families and preventing entry into state care before ensuring that only suitable and appropriate care is offered to children that can meet their developmental needs.

Figure 7. Applying the necessity and suitability principles



Source: From Theory to Practice, Implementing the UN Alternative Care Guidelines, Cantwell et al., 2013

In the case of children aged under three years, the suitability principle clearly indicates that only family-based care, or in some exceptions family-type care, can be suitable for very young children if their development is not to be compromised in the first weeks, months and years of life when family care is of such critical importance.