LUND UNIVERSITY

European Master's Degree in Human Rights and Democratisation
A.Y. 2016/2017

De-institutionalising India's Orphanages

Localising Child Rights in an Institution for HIV-infected/affected Children in Rajasthan

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Abstract

The fact that children growing up in institutional settings are at risk of harmful development is recognised in both psychological studies and international law on children's rights. Still, orphanages persist in many parts of the world. In India, 'care homes' or 'hostels' are common alternative care solutions for children from impoverished families. Through a legal and, primarily, an anthropological lens, this thesis asks to what extent the clear impetus towards de-institutionalisation in international human rights law has potential to change such practices. The study contributes to a body of scholarship on 'localising children's rights' by conducting an ethnographic case study of an institution for HIV-infected/affected children in Rajasthan. The study finds a complex picture with numerous causation factors of institutionalisation, including a widespread stigma of HIV/AIDS, poverty, a positive perception of institutions, and lack of functional alternatives. The institution in question also played a range of social functions other than child care, such as education, a means for parents to 'rescue' their children from extreme poverty, and a supportive environment for the community of people living with HIV/AIDS. These factors point to the need for a more contextualised approach to children's rights, specifically that local causation factors and social functions of existing institutions should be taken into account when developing rights-based de-institutionalisation strategies.

Abbreviations

AIDS = acquired immune deficiency syndrome

ART = antiretroviral therapy

CCI = child care institution

CRC = Convention on the Rights of the Child

CSC = Care and Support Centre

CWC = Child Welfare Committee

DCR = Department of Child Rights

GA = General Assembly

GC = General Comment

HIV = human immunodeficiency virus

ICESCR = International Covenant on Economic, Social and Cultural Rights

IQ = intelligence quotient

JJ Act = Juvenile Justice (Care and Protection) Act 2015

NACO = National AIDS Control Organisation

NGO = non-governmental organisation

OHCHR = Office of the High Commissioner for Human Rights

UN = United Nations

UNHRC = United Nations Human Rights Council

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1 Introduction

There is a global trend of moving away from institutional care and towards family-based care of children deprived of their biological family environment. Such standards are supported both by international human rights law, especially the Convention on the Rights of the Child (CRC), and by innumerable studies demonstrating the detrimental psycho-social effects on children growing up in institutions. In line with this trend, the state of India is currently moving towards de-institutionalising child protection and care. This is especially evident in the updated Juvenile Justice (Care and Protection of Children) Act 2015,[1] which translates many of the CRC's norms into the national legal system. But how will these national legal changes affect the long-time practice of orphanages run by non-governmental organisations (NGOs)? To what extent can they change the behaviour of families who struggle with poverty and health problems, who typically choose to place their children in such homes for better education and care? What are the social obstacles for de-institutionalisation in India, and what are the potentials of new forms of care, such as foster care, which are written in the new laws but not yet widely practiced? Through a case study of a care home for children infected with or affected by human immunodeficiency virus (HIV) in Rajasthan, this thesis will explore the perceptions and practices of institutionalisation among local stakeholders, compare these with the international human rights norms on the topic, and discuss strategies for minimising the gap between the two.

This first chapter will clarify terms, present the study's theoretical framework, and provide a literature review of previous studies on (de-)institutionalisation and its relation to human rights. Chapter 2 will show which international human rights norms are relevant to de-institutionalisation. Chapter 3 will briefly set the stage in India, contextualising the main issues to be studied. Chapter 4 will detail the case study, and analyse local practices and perceptions of institutionalisation. Lastly, Chapter 5 will compare the international human rights norms identified in Chapter 2 with the local perceptions and practices identified in Chapter 4, and demonstrate a significant gap between the two. The gap will be discussed from an 'implementation gap approach' and a 'localisation approach' to children's rights studies.

[1] See 3.3 below.

1.1 Terminology

'Alternative care' is understood as the type of care that a state provides to children who are deprived of parental care, or at risk of becoming so.[2] It can be 'family-based' (e.g. foster care) or 'institutional' (e.g. orphanages). 'Family-based care' refers to care in a 'family environment', implying a parental, as opposed to professional, relationship between children and carers.[3] 'Institutional care' (sometimes also called 'residential care') refers to care in 'a group living arrangement for children in which care is provided by remunerated adults who would not be regarded as traditional carers within the wider society'.[4] The terms 'orphanage', '(child care) institution', 'care home' and 'hostel' will be used synonymously to denote such an arrangement. The process when a state transitions its alternative care system from one of primarily institutional care to one of primarily family-based care, is termed 'de-institutionalisation'.

The term 'HIV-infected/affected children' is used to include both those children who themselves are infected with HIV, and those who are affected by the disease by being children of infected parents, or orphans of parents who died from HIV/AIDS.

1.2 Theoretical framework

By linking human rights and de-institutionalisation, I inevitably limit myself to specific aspects of both topics, which could very well be studied independently of each other. Human rights studies can be approached from a range of disciplines (law, ethics, political science, history etc.), while institutionalisation of children is usually studied through a psychological lens. In order to link international law with local perceptions, I have limited myself to a legal and, primarily, an anthropological framework.

[2] UNGA Res 64/142 (24 February 2010) UN Doc A/Res/64/142 para 1. Cantwell calls this 'formal alternative care', as opposed to 'informal alternative care' provided by relatives outside the state's formal system (Nigel Cantwell, 'The human rights of children in the context of formal alternative care' in Wouter Vandenhole and others, *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015)). As the present study is not concerned with informal alternative care, I am simply using 'alternative care' to denote formal alternative care provided by the state.

[3] Kevin Browne, *The Risk of Harm to Young Children in Institutional Care* (Save the Children, London 2009) 1.

[4] Andrew Dunn, Elizabeth Jareg and Douglas Webb, *A Last Resort. The growing concern about children in residential care* (International Save the Children Alliance, London 2003) 1.

The legal approach is necessary to analyse international conventions that touch upon the topic of institutionalisation of children. It is notoriously difficult to codify international law on children, because it relates to a social phenomenon that differs immensely across the globe, namely family.[5] The classic legal approach to children's rights is often referred to as the 'implementation gap approach', in which international legal standards are taken as unquestionable, and the main problem is implementation.[6] Vandenhole challenges this approach, arguing that the norms themselves should be questioned by applying a 'children's rights from below'-approach.[7] Similarly, Liebel argues that children's rights should not only be 'implemented', but 'reflected according to their cultural, political and structural coherence'.[8] In Liebel's view, the CRC should be a 'convenient benchmark', but not the final word on children's rights.[9] In order for this to be effective, the legal approach should be complemented with other disciplines, such as anthropology.

Anthropology contributes to human rights studies with its 'ethnographic'[10] or 'empirical'[11] approach. Most anthropologists today do not study unchangeable 'cultures', but changeable local realities.[12] In the case of children's rights, this means to study how children and their families experience rights, and how their daily lives influence discourses and practices of rights.[13] This is significant because the gap between what is formalised in children's rights law and children's real lives can be so wide that the former in fact has no relevance for the latter.[14]

[5] Ellen Desmet and others, 'Conclusions: Towards a field of critical children's rights studies' in Wouter Vandenhole and others (eds), *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 416-17.
[6] Wouter Vandenhole, 'Children's rights from a legal perspective. Children's rights law' in Wouter Vandenhole and others (eds), *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 38-39.
[7] ibid.
[8] Manfred Liebel, *Children's Rights from Below: Cross-Cultural Perspectives* (Palgrave Macmillian, Hampshire 2012) 2.
[9] ibid 15.
[10] Ulf Johansson Dahre, 'Searching for a middle ground: anthropologists and the debate on the universalism and the cultural relativism on human rights' (2017) 21 The International Journal of Human Rights 611.
[11] Mark Goodale, 'Introduction to Anthropology and Human Rights in a New Key' (2006) 108(1) American Anthropologist 1.
[12] Akhil Gupta and James Ferguson (eds), *Culture, Power, Place: Explorations in Critical Anthropology* (Duke University Press, London 1997) 2.
[13] Geraldine André, 'Anthropologists, ethnographers and children's rights: Critiques, resistance and powers' in Wouter Vandenhole and others (eds), *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 119.
[14] GA Snodgrass, 'Our right is the right to be killed: Making rights real on the streets of Guatemala City' (1999) 6(4) Childhood 423.

1.2.1 Localising human rights

A combination of the legal and the anthropological approach to human rights studies is particularly valuable when studying the global/local dichotomy, which will be a common thread throughout this thesis. I have taken inspiration from what Oré Aguilar calls the 'localising human rights case study methodology', which combines the ethnographic case study with human rights methodologies such as impact assessments, indicators, evaluation and monitoring.[15] While the present study is not directly applying these human rights methodologies, it is more than simply an ethnographic case study, as I, just as Oré Aguilar, focus on the question of how the human rights framework[16] is relevant to resolve the needs and problems of local people.[17] Furthermore, the objective of methodologies such as human rights impact assessments is to measure e.g. 'how great the gap is between human rights norms and reality'.[18] Where my study differs from Oré Aguilar's methodology, however, is that hers is specifically catered to local communities that 'decide to appeal to human rights to achieve their goals'.[19] This is based on an understanding of 'localisation studies' as studies of grassroots organisations that appropriate their struggles to human rights terms to make them globally relevant. In the present study, 'localisation' is instead understood as an exercise of zooming in on a context that would be affected by human rights laws (such as reforms of the child care system in India), and asking to what extent such laws would improve the situation of the affected people in that specific context. Vandenhole has made a similar distinction of different 'localisations' in relation to children's rights, namely between 'strategic local mobilization of children's rights in order to further the cause of children' and 'cultural acceptance of the *idea* of children's rights'.[20] My focus will be on the latter.

Vandenhole and others advocate for 'critical children's rights studies' which should 'conduct research on the interplay – and possible tension – between universal and particular understandings of children's rights and on how these understandings are moving between the global and the local'.[21] In this view, children's rights should be an object of 'constant analysis' and be studied 'in a contextualised way'.[22] This is not far from Merry's theories of how human rights law is only

[15] Gaby Oré Aguilar, 'The local relevance of human rights: a methodological approach' in Koen De Feyter and others (eds), *The Local Relevance of Human Rights* (Cambridge University Press, Cambridge 2011) 123-124.
[16] Defined as the norms, principles, ideas, values, discourses and arguments contained in the Universal Declaration of Human Rights along with subsequent United Nations (UN) human rights treaties (ibid 114-115).
[17] ibid 115.
[18] ibid 129.
[19] ibid 118.
[20] Wouter Vandenhole, 'Localizing the Human Rights of Children' in Manfred Liebel, *Children's Rights from Below: Cross-Cultural Perspectives* (Palgrave Macmillian, Hampshire 2012) 80.
[21] Desmet and others (n 5) 427.
[22] ibid.

effective if it is 'translated down' into local systems, and if local actors' experiences are conversely 'translated up'.[23] In the views of these scholars, it is important to keep the specific local context in mind. In my case, it means to constantly and critically translate between international norms on de-institutionalisation, and how local people are experiencing and understanding the child protection system.

1.3 Literature review

Numerous studies over the last 50 years or more show that children growing up in institutions will detrimentally not develop in the same way as those who grow up in a family environment,[24] while only very few studies put a case forward for the opposite.[25] For so-called 'developing' countries, however, the trend of orphanages has been increasing in the last few decades, and donor countries who long ago abolished orphanages at home, have kept supporting orphanages in these countries.[26] This mismatch has begun to be acknowledged in the literature, and a number of organisations supporting family-based care have recently emerged with studies on and concrete guides to de-institutionalisation, such as UNICEF,[27] Save the Children International,[28] Better Care Network,[29] Terres des hommes Foundation,[30] Hope for Himalayan Kids,[31] and more. This section is to a large extent a review of such studies.

[23] Sally Engle Merry, *Human Rights and Gender Violence: Translating International Law into Local Justice* (University of Chicago Press, Chicago 2006).

[24] E.g. Deborah McArthur, *10 Steps Forward to Deinstitutionalisation* (Terre des hommes Foundation and Hope for Himalayan Kids, Nepal 2011) 5; Aaron Greenberg and John Williamson, 'Families, Not Orphanages' (2010) Better Care Network Working Paper <https://www.thinkchildsafe.org/thinkbeforevisiting/resources/Families_Not_Orphanages_J_Williamson.pdf> accessed 22 June 2017; Aaron Greenberg, 'Child Protection and Children Affected by AIDS: A Companion Paper to the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS' (The United Nations Children's Fund, New York 2007) 18; Erick Otieno Nyambedha, Simiyu Wandibba, and Jens Aagaard-Hansen, 'Changing Patterns of Orphan Care due to the HIV Epidemic in Western Kenya' (2003) 57 Social Science & Medicine 301, 310; Dunn, Jareg and Webb (n 4) 9; David Tolfree, *Roofs and Roots. The Care of Separated Children in the Developing World* (Save the Children Fund, UK 1995); Gillian Doherty, *The Long-Term Effects of Non-Parental Child Care* (University of Toronto, Toronto 1996).

[25] See e.g. Kathryn Whetten and others, 'A Comparison of the Wellbeing of Orphans and Abandoned Children Ages 6-12 in Institutional and Community-Based Care Settings in 5 Less Wealthy Nations' (2009) 4(12) PLoS ONE.

[26] Greenberg and Williamson (n 24) 3.

[27] Greenberg (n 24).

[28] Dunn, Jareg and Webb (n 4).

[29] Greenberg and Williamson (n 24); Gillian Mann, 'Family Matters: the Care and Protection of Children Affected by HIV/AIDS in Malawi' (Better Care Network, New York 2002) <http://www.crin.org/docs/Care%20and%20Protection%20of%20Children%20Affected%20by%20H.A%20in%20Malawi.doc> accessed 22 June 2017.

[30] McArthur (n 24).

[31] ibid.

A study for Save the Children identifies two categories of causation factors for institutionalisation: the socio-economic environment (e.g. globalisation, urbanisation, the HIV/AIDS epidemic, or armed conflict) and factors operating at family level (e.g. abuse, divorce etc.).[32] Greenberg and Williamson highlight 'AIDS and other diseases, armed conflict, natural disasters, forced displacement and extreme poverty'.[33] Poverty is pointed out by most studies as a main reason.[34] According to Greenberg and Williamson, it is a common dynamic across regions that in communities under severe economic stress, the number of children in institutions increases because children are 'being pushed out of poor households to fill these places'.[35] The consequence is that institutions end up as 'expensive and inefficient' ways to deal with poverty.[36] Similarly, Bilson and Cox have approached the topic of institutionalisation from the point of departure that for many parents, sending their children to institutions seem like the preferable option to being brought up in poverty.[37]

Several authors have demonstrated concern for the fact that the combination of poverty and HIV/AIDS is increasingly a common causation factor for institutionalisation.[38] There have been many studies on institutionalised HIV-infected/affected children, but most have focused on Sub-Saharan Africa, because of the high number of orphaned children in the region.[39] However, India's HIV/AIDS prevalence is getting close to that of Sub-Saharan Africa,[40] and Asia is beginning to face similar issues as Sub-Saharan Africa in terms of children orphaned due to HIV/AIDS.[41] The present study is thus contributing to a regionally needed body of scholarship on the social consequences of HIV/AIDS, a disease that may carry different types of stigma in different cultural contexts.

Most of the reviewed studies on institutional care begin with an acknowledgement of the already

[32] Dunn, Jareg and Webb (n 4) 13.
[33] Greenberg and Williamson (n 24) 3.
[34] ibid 7; McArthur (n 24) 46; Greenberg (n 24) 18; UNICEF, 'Child Protection Information Sheet: Children Without Parental Care' (UNICEF, New York 2006) <https://www.unicef.org/chinese/protection/files/Parental_Care.pdf> accessed 22 June 2017; Dunn, Jareg and Webb (n 4) 1; Nigel Cantwell and others, *Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children'* (Centre for Excellence for Looked After Children in Scotland, UK 2012) 3; Andy Bilson and Pat Cox, 'Caring about Poverty: Alternatives to Institutional Care for Children in Poverty' (2007) 13(1) Journal of Children and Poverty 37.
[35] Greenberg and Williamson (n 24) 8.
[36] ibid.
[37] Bilson and Cox (n 34) 37.
[38] Greenberg and Williamson (n 24) 8; Bilson and Cox (n 34) 38; Dunn, Jareg and Webb (n 4) 1; Browne (n 3) 5.
[39] Amongst numerous studies, see e.g. Nyambedha, Wandibba and Aagaard-Hansen (n 24); James Ntozi, 'Effects of AIDS on children: The problem of orphans in Uganda' (1997) 7 (suppl.) Health Transition Review 23; Mann (n 29); Dunn, Jareg and Webb (n 4) 5.
[40] Pam O'Connor and Jaya Earnest, *Voices of Resilience: Stigma, Discrimination and Marginalisation of Indian Women Living with HIV/AIDS* (Sense Publishers, Rotterdam, 2011) xxi.
[41] Dunn, Jareg and Webb (n 4) 1.

large number of global studies demonstrating developmental harms to institutionalised children.[42] Browne has conducted a review of existing studies in this area, demonstrating some of the detrimental effects on children in institutions compared to those in families, such as physical under-development, motor skill delays, missed developmental milestones, limited opportunities to form selective attachments, lack of consistent care, and learning disabilities.[43] Similarly, Greenberg and Williamson argue that the problem with institutional care is that children receive only physical care, and do not get the 'love, attention and attachment figure from whom they develop a secure base on which all other relationships are built'.[44] Dunn, Jareg and Webb argue that the administrative procedures and routines associated with living in an institution are significantly different from 'normal patterns of upbringing' which leads to a marked difference in social development and makes it problematic for the adolescent to integrate into society upon leaving the institution.[45] Other studies show later language acquisition and lower intelligence quotient (IQ) of children growing up in institutions, factors which improve with foster care, and even more if children grow up in their own families.[46] According to Browne, 'a socially rich family environment' will promote brain growth, while 'an impoverished environment through (…) institutional care' will suppress development of the brain.[47]

Even apparently 'good quality' institutions can be lead to difficulties for children in forming relationships throughout their life, because the lack of a continuous relationship with a caregiver can 'produce children who are desperate for adult attention and affection'.[48] Browne emphasises that 'regardless of the quality of institutional care, "normal" child development requires the opportunity for frequent and consistent one-to-one interaction with a parent or foster parent'.[49] Greenberg and Williamson agree with this finding, arguing that even if every family is not ideal, 'it is often far better than the alternative in terms of what the evidence shows is in the best interests of

[42] E.g. Greenberg and Williamson (n 24) 5; Georgette Mulheir and others, 'Report of the Ad Hoc Expert Group on the transition from institutional to community-based care' (European Commission. Directorate-General for Employment, Social Affairs and Equal Opportunities & European Commission 2008) 12; M Freeman, 'Article 3: The best interests of the child' in A Alen and others (eds) *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007); Cantwell and others (n 34) 3; Bilson and Cox (n 34) 38.
[43] Browne (n 3) 10.
[44] Greenberg and Williamson (n 24) 5.
[45] Dunn, Jareg and Webb (n 4) 9.
[46] Browne (n 3) 13-14; Greenberg and Williamson (n 24) 6.
[47] Browne (n 3) 14.
[48] ibid 13.
[49] ibid 18.

the child'.[50] In other words, while there can be shortcomings to every type of care – also by foster or biological parents –

> 'It is clear (…) that the available literature on child development indicates that families have better potential to enable children to establish the attachments and other opportunities for individual development and social connectedness than does any form of group residential care. Well-implemented family-based care is preferable to well-implemented residential care'.[51]

The reason for all these detrimental effects is, according to Giese and Dawes, 'the culture of institutional practice' which is 'primarily concerned with the physical care of children and the establishment of routines, with less emphasis on play, social interaction and individual care'.[52] A European Commission study similarly defines 'institutional culture' as one of depersonalisation, rigidity of routine, block treatment and social distance between staff and residents.[53]

These types of findings are not new. In 1926, paediatrician Chapin published an influential study arguing for family-based foster care rather than orphanages.[54] In the 1940s and 1950s, Bowlby presented work on negative long-term effects of institutional care on children, later published by the World Health Organisation, which influenced policy changes on institutionalisation in the United States and Europe.[55] So why do orphanages persist in many countries? One reason for the lack of political will towards de-institutionalisation could be the cost; however, there is not agreement on the cost-benefit analysis of institutional versus family-based care.[56] Greenberg and Williamson argue that a main reason for orphanages' persistence is that they seemingly take care of a number of immediate problems, and donors can see that 'something is being done'.[57] The long-term adverse developmental effects, however, are only evident after several years and perhaps not as obvious.[58] Some studies argue that 'over-investment in current institutional arrangements', e.g. in new buildings, is a common response to poor quality institutions, but that it in fact makes it more

[50] Greenberg and Williamson (n 24) 4.
[51] ibid 20.
[52] S Giese and A Dawes, 'Child care, developmental delay and institutional practice' (1999) 29 South African Journal of Psychology 17.
[53] Mulheir and others (n 42) 9.
[54] Henry Dwight Chapin, 'Family vs. institution' (1926) 55 Survey 485.
[55] Greenberg and Williamson (n 24) n ii; Jan Williamson, 'A Family Is for a Lifetime: Part I. A discussion of the need for family care for children impacted by HIV/AIDS' (The Synergy Project 2004) <http://www.crin.org/docs/AFamilyForALifetimeVersion_1March04.pdf> (accessed 22 June 2017) ix.
[56] See e.g. differing views in Richard Carter, *Family Matters: A study of institutional childcare in Central and Eastern Europe and the Former Soviet Union* (Everychild, London 2005); Greenberg and Williamson (n 24) 7; Mulheir and others (n 42) 13; Dunn, Jareg and Webb (n 4) 6.
[57] Greenberg and Williamson (n 24) 12.
[58] ibid.

difficult to close institutions in the medium term.[59] In this way, resources are too often consumed by such expansion instead of being used to reform the care system.[60] Still, there is a global move towards de-institutionalisation. Many countries have already 'transitioned', e.g. a number of post-Soviet countries,[61] and in most Western European countries, family-based care is much more common as a form of alternative care than institutions.[62]

The studies described so far take a psychological approach and do not necessarily link the detrimental effects of institutional care with a child's 'rights'. The field that connects de-institutionalisation directly with human rights is considerably smaller, but is increasingly applied by a number of organisations. For example, Save the Children underlines the fact that that residential care 'has largely been ignored as a rights issue' and that 'many features of residential care are an abuse of children's rights'.[63] They promote that 'children in residential and foster care and children living independently deserve to be shown the same interest and commitment by international and UN Bodies as child soldiers, working children and sexually exploited children'.[64] Therefore, Save the Children's report goes through a number of rights, arguing why they are often violated within institutional care, e.g. highlighting the developing capacities of the child – which is undermined by institutionalisation – as a key feature of Article 6 of the CRC.[65] Terres des hommes and Hope for Himalayan Kids also apply a 'rights-based approach' in their work towards de-institutionalisation by referring to CRC as the norm to be followed.[66] Similarly, the European Commission argues that 'the characteristics of institutional care are bound to make it extremely difficult to (…) ensure enjoyment of human rights'.[67] Human Rights Watch has also dealt with the topic of institutionalisation in a study where they approach abuses against HIV/AIDS-infected/affected children from the human rights-lens of discrimination..[68]

Not only organisations, but also scholarly literature has connected human rights and de-institutionalisation. Like most children's rights issues, alternative care has evolved from being

[59] Mulheir and others (n 42) 15.
[60] Greenberg and Williamson (n 24) 12, 21.
[61] ibid 11.
[62] Mulheir and others (n 42) 10.
[63] Dunn, Jareg and Webb (n 4) 1.
[64] ibid 4.
[65] ibid 12.
[66] McArthur (n 24) 3.
[67] Mulheir and others (n 42) 11.
[68] Human Rights Watch, *Future Forsaken. Abuses Against Children Affected by HIV/AIDS in India* (Human Rights Watch, New York 2004) 12.

approached as a topic of 'protection' to one of 'rights'.[69] Cantwell has examined children's rights in relation to alternative care, and identifies rights issues both in the provision of such care, and in the acknowledgement that institutions should always be a last resort.[70] In contrast to many NGOs, however, Cantwell warns against an inflation of the rights language and argues against an unqualified 'right to a family' which in his views is 'unwarrantedly extrapolated from what is no more than an agreed policy objective'.[71]

The above literature review has demonstrated that the causes and effects of institutionalisation are well studied by numerous experts who argue for de-institutionalisation because of detrimental psychological effects of institutionalisation on children. In addition, many newer studies have added to the growing field by linking de-institutionalisation to human rights. The present study will contribute to this field by pointing out a number of causation factors and obstacles to de-institutionalisation on the ground, in the specific case of HIV-infected/affected children in Rajasthan. The study will highlight the lack of dialogue between rights-based expert arguments for de-institutionalisation (primarily from UN soft law and treaties), and realities on the ground where de-institutionalisation is barely recognised as an objective. Hopefully, the study can be useful for existing institutions, NGOs and others working towards de-institutionalisation, and for further academic work focusing on the challenges of HIV for children, and/or (de-)institutionalisation in the context of India. The study also hopes to address a gap identified by Cantwell, namely that while de-institutionalisation should be favoured, the 'deeply rooted ideology behind the institution model'[72] is too rarely taken into account. Alternative care of children is an intimate family-related subject that always depends on local practices, history, religion and more.[73] But in international human rights law, it is dealt with as if similar solutions could be applied to different contexts. Similar to Cantwell, Save the Children has also called for a deeper understanding of the issues confronting children in institutional care, arguing that there is a need for 'comprehensive analysis of all the factors that surround the care and protection of children in a particular cultural and social context'.[74] This study will thus seek to address and explore the ideology around the institution model, and the culturally and socially contextualised factors of institutionalisation in the case of Rajasthan, India. In order to examine these factors and understand how human rights potentially can

[69] Cantwell (n 2) 258.
[70] ibid.
[71] ibid 273.
[72] ibid 258.
[73] ibid.
[74] Dunn, Jareg and Webb (n 4) 7.

be a tool for de-institutionalisation, it is necessary to first review in detail some of the relevant international human rights treaties that India is bound by.

2 De-institutionalisation in human rights law

The purpose of this chapter is to demonstrate that international human rights treaties ratified by India uncontestably recognise that remaining in a family environment, in the vast majority of cases, is in the best interest of the child, and that institutionalisation should be a last resort and non-permanent. I will highlight provisions related to institutionalisation of children from the Convention on the Rights of the Child (CRC) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).[75] I will supplement with soft law material such as the work of treaty bodies and resolutions of the General Assembly (GA). Even though these are not directly binding on states, they are relevant for translating treaty provisions into detailed and concrete recommendations for state action.

2.1 Convention on the Rights of the Child

This convention from 1989 was ratified by India in 1992.[76] Already in the preamble it is recognised that 'the child, for the full and harmonious development of his or her personality, should grow up in a family environment'.[77] In 2009, the GA adopted the resolution 'Guidelines for the Alternative Care of Children' to 'enhance the implementation' of the CRC.[78] These guidelines seek to 'support efforts to keep children in, or return them to, the care of their family or, failing this, to find another appropriate and permanent solution'.[79] The Guidelines will be used throughout this section to elaborate on the articles of the CRC that touch upon deprivation of a family environment. The most relevant of these, for our purposes, is Article 20.

[75] There are arguably other treaties that indirectly affect institutionalisation of children, but due to limited space, I have focused on the ones that are most directly applicable.
[76] UN OHCHR, 'Ratification Status for CRC – Convention on the Rights of the Child' (OHCHR 2017) <http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Treaty.aspx?Treaty=CRC&Lang=en> accessed 22 June 2017.
[77] Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 United Nations Treaty Series 3 (CRC) preamble.
[78] UNGA Res 64/142 (24 February 2010) UN Doc A/Res/64/142 para 1.
[79] ibid, para 2.

2.1.1 Article 20

Children who are not living in a family environment are considered a particularly vulnerable group, protected by Article 20 of the CRC.[80] The Article states,

'1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.
2. States Parties shall in accordance with their national laws ensure alternative care for such a child.
3. Such care could include, *inter alia*, foster placement, *kafalah* of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background'.[81]

In terms of application, this article is intended for situations in which the state and parents already have failed to ensure a family environment,[82] namely to children without overnight care of at least one of their parents for 'whatever reason',[83] including, *inter alia*, death of parents, abandonment by parents, permanent or temporary incapacity of parents (such as illness), and voluntary placement by parents.[84] According to Cantwell & Holzscheiter's commentary on the article, the wording 'family environment' is not exclusively aimed at biological parents, but family in a broader sense.[85] The article does thus not pose any obligation on the State to ensure alternative care for a child who is being looked after informally by the extended family.[86]

Article 20 requires States Parties to 'ensure alternative care for the child' and lists options for such care in 20(3). According to the article, 'alternative care' ranges from kinship care, foster care and other forms of family-like care placements, to non-family-based care, such as residential institutions. In the drafting process of the CRC in 1982, it was the delegation from India that introduced a list of alternative care options to Article 20, proposing to include in this list 'placement in community and State child care institutions'.[87] The Indian delegation did not differentiate between family-based and other forms of alternative care, but in the final wording of Article 20,

[80] Nigel Cantwell and Anna Holzscheiter, 'Article 20: Children deprived of their family environment' in A Alen and others (eds) *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007) 10-11.
[81] CRC (n 77) art 20.
[82] Cantwell and Holzscheiter (n 80) 9.
[83] UNGA Res 64/142 (n 78) para 29.
[84] Cantwell and Holzscheiter (n 80) 38-39.
[85] ibid 11.
[86] ibid 37.
[87] ibid 30.

there is arguably an implicit ranking of what is most beneficial for the child.[88] The drafters of the CRC chose to place institutions at the end of the list, and this provides us with an impetus to de-institutionalisation in international human rights law. However, accepting that institutions should be a last resort of alternative care still implies the inevitability of their existence. The existing institutions therefore need to be 'suitable'. This refers to the fact that they have to live up to some general criteria, and be suited to the individual child's needs.[89]

Commentaries on Article 20 highlight HIV-infected/affected children as particularly vulnerable to deprivation of a family environment. Cantwell & Holzscheiter recognise that the ideal of remaining within a family structure 'may not be available due to the impact HIV/AIDS has on the extended family. In that case, States parties should provide, as far as possible, for family-type alternative care (e.g. foster care)'.[90] Similarly, the CRC Committee has recognised that although 'institutionalized care may have detrimental effects on child development, States parties may, nonetheless, determine that it has an interim role to play in caring for children orphaned by HIV/AIDS when family-based care within their own communities is not a possibility'.[91] They do, however, underline that institutionalised care should be a 'measure of last resort', and that 'programmes must be developed to support any children who stay in these institutions, whether infected or affected by HIV/AIDS, to successfully reintegrate them into their communities'.[92]

2.1.2 Other articles linked to alternative care

Article 3(3) states that, 'States parties shall ensure that the institutions, services and facilities responsible for the care and protection of children shall conform with the standards established by competent authorities'.[93] In the case of residential institutions for children, the 'Guidelines for the Alternative Care of Children' provide examples of what such ideal standards might be: there should be plans for the individual child, including the goals of the placement, developed with participation of the child;[94] there should be a review of all the children preferably at least every three months;[95]

[88] ibid 13.
[89] Nigel Cantwell, 'The human rights of children in the context of formal alternative care' in Wouter Vandenhole and others (eds), *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 260-262.
[90] Cantwell and Holzscheiter (n 80) 42.
[91] UN Committee on the Rights of the Child, 'General Comment No. 3' (17 March 2003) UN Doc CRC/GC/2003/3 para 35.
[92] ibid.
[93] CRC (n 77) art 3(3).
[94] UNGA Res 64/142 (n 78) paras 62-4.
[95] ibid, para 67.

there should be paid special attention to children whose parent(s) are imprisoned or hospitalised and contact should remain between parent(s) and child;[96] adequate and nutritious food should be ensured;[97] play and leisure should be ensured within and outside the care facility;[98] children should have access to a person of trust they may confide in;[99] siblings should not be separated in order to keep the most family-like environment for the children;[100] alternative care facilities should not exist to further the economic or religious goals of the providers;[101] care of children under three years old should always be given in family-based settings;[102] there should be staff trained in child protection, and a staff code of conduct;[103] specific attention should be given to children with disabilities or HIV/AIDS;[104] the authorities should establish rigorous screening procedures for admissions;[105] the institutions should be accountable to a specific public authority;[106] and there should be plans and support for when the children leave the institution, for integration into the community, such as skills and vocational training.[107] Additionally, even where residential institutions still exist, an overall de-institutionalisation strategy should be developed, because the goal of institutions should be their progressive elimination.[108] A part of this could be promotion of family reintegration: a child's situation should regularly be assessed to determine whether it would be in his/her best interests to be reintegrated with the family. Such a strategy would include continuous contact between family and child while the child is in the institution.[109]

Article 12 relates to the right of the child to express his/her views freely and to be heard 'in any judicial and administrative proceedings affecting the child'.[110] The CRC Committee has emphasised the importance of this article in relation to alternative care, where children should be able to express their views, which should 'be given due weight in matters of their placement, the regulations of care in foster families or homes and their daily lives'.[111]

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[96] ibid, para 82.
[97] ibid, para 83.
[98] ibid, para 86.
[99] ibid, para 98.
[100] ibid, para 17.
[101] ibid, para 20.
[102] ibid, para 22.
[103] ibid, para 105.
[104] ibid, para 117.
[105] ibid, para 125.
[106] ibid, para 128.
[107] ibid, paras 131-136.
[108] ibid, para 23.
[109] ibid, paras 49-52.
[110] CRC (n 77) art 12.
[111] UN Committee on the Rights of the Child, 'General Comment No. 12. The right of the child to be heard' (20 July 2009) UN Doc CRC/C/GC/12 para 97.

Article 18(2) relates to the obligation to provide assistance in child-rearing: 'States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children'.[112] This is important in relation to prevention of institutionalisation, as it is addressing root causes of child abandonment. The state could under this article support parents in their parental responsibilities to ensure that the family is capable to take care of the child,[113] through e.g. counselling, day care or financial assistance.[114] The state could also acknowledge the vulnerability of certain categories of children (such as HIV-infected/affected) by e.g. 'tackling discrimination on the basis of any status of the child or parents'.[115] Thus, if the State fulfils its obligations under Article 18(2), the need for residential care institutions would be considerably smaller.

2.1.3 General principles of the Convention

Apart from specific articles, some of the general principles of the CRC are also relevant for our case. These, also known as 'basic principles' or 'umbrella provisions', are to be taken into account in the application of all other rights in the CRC.[116] One of these principles is the 'best interest of the child'.[117] It means that when a decision is made about a child, his or her best interests should be a primary concern.[118] It is repeated explicitly in some articles of the CRC, including Article 20, which demonstrates that this principle is particularly important in relation to alternative care. The CRC Committee 'recalls that it is indispensable to carry out the assessment and determination of the child's best interests in the context of potential separation of a child from his or her parents'.[119] In the GC on the best interests of the child, it is repeated that the family is 'the fundamental unit of society and the natural environment for the growth and well-being of its members, particularly children'.[120] As a consequence, separation of children and parents 'should only occur as a last resort measure, as when the child is in danger of experiencing imminent harm or when otherwise

[112] CRC (n 77) art 18(2).
[113] UN Committee on the Rights of the Child, 'General Comment No. 14' (29 May 2013) UN Doc CRC/C/GC/14 para 61.
[114] UNGA Res 64/142 (n 78) paras 32-38.
[115] ibid, para 9.
[116] Nevena Vuckovic Sahovic, Jaap E Doek and Jean Zermatten, *The Rights of the Child in International Law* (Stämpfli Publishers Ltd, Bern 2012) 91.
[117] CRC (n 77) art 3(1).
[118] Vuckovic Sahovic, Doek and Zermatten (n 116) 92.
[119] UN Committee on the Rights of the Child (n 113) para 58.
[120] ibid, para 59.

necessary'.[121]

The best interests of the child is one of the most contentious principles in the CRC. It has been critiqued for being 'inherently subjective',[122] because Article 3, which introduces the principle, contains 'no checklist (…) just an unadorned normative statement'[123] and different cultures will 'inevitably operate with different concepts of what is in a child's best interests'.[124] Liebel argues that in practice it often depends on the authority in a specific case.[125] One point of controversy can be between a child's 'current interests' (e.g. immediate needs such as nutritious food) and 'future interests' (e.g. psychological and developmental considerations). Thereby, while the intention of Article 3 was to mediate conflicts between rights,[126] conflict often arises between Article 3 itself and other rights. The CRC Committee's GC14 has attempted to solve this problem by explaining the principle of the child's best interests as a balancing exercise. In the case of separation from parents, elements to balance are for example preservation of the family environment against the risk of abuse. This exercise has to be done on a case-by-case basis, but under the general guidelines of GC14.[127]

Another general principle of the CRC is non-discrimination. Article 2 states that,

'States Parties shall respect and ensure the rights set forth in the present Convention (…) without discrimination of any kind, irrespective of the child's *or his or her parent's or legal guardian's* race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status'.[128]

The CRC Committee has interpreted that the status of being HIV-positive falls under 'other status'.[129] HIV/AIDS does not only affect infected children, but also non-infected orphans of positive parents, who also suffer trauma and stigmatisation. In this case, it is important that States 'support and strengthen the capacity of families and communities of children orphaned by AIDS to provide them with a standard of living adequate for their physical, mental, spiritual, moral,

[121] ibid, para 61.
[122] M Freeman, 'Article 3: The best interests of the child' in A Alen and others (eds) *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007) 26.
[123] ibid 31.
[124] ibid 2.
[125] Manfred Liebel, *Children's Rights from Below: Cross-Cultural Perspectives* (Palgrave Macmillian, Hampshire 2012) 15.
[126] Freeman (n 122) 32.
[127] UN Committee on the Rights of the Child (n 113) paras 80-84.
[128] CRC (n 77) art 2 (emphasis added).
[129] UN Committee on the Rights of the Child (n 91) para 9.

economic and social development, including access to psychosocial care, as needed'.[130] Discrimination against HIV-infected children can result in 'abandonment by their family, community and/or society'.[131] Discrimination can also occur when separating HIV-infected children from their peers and placing them in institutional care:

'… these children see themselves confronted with widespread discrimination in terms of access to education, health and other social services. As a consequence, their life opportunities are considerably reduced compared to those of children growing in their family environment'.[132]

To sum up, the CRC can guide us a long way in identifying international human rights norms relating to institutional care. However, to consider root causes of institutionalisation and more structural problems, we should also look to economic and social rights more generally.

2.2 International Covenant on Economic, Social and Cultural Rights

The ICESCR from 1966 was ratified by India in 1979.[133] It is relevant for institutionalisation of children, because it addresses some of the root causes of the phenomenon, such as poverty. Human rights can be useful to address poverty by not only focusing on income, but on issues such as empowerment, voice, and access to health and education.[134] The Committee on Economic, Social and Cultural Rights has defined poverty as,

'a human condition characterised by sustained or chronic deprivation of the resources, capabilities, choices, security and power necessary for the enjoyment of an adequate standard of living and other civil, cultural, economic, political and social rights'.[135]

Economic and social rights are protected specifically for children under the CRC's article 27. Children 'have a reduced capacity to meet their socio-economic needs' and a limited ability to

[130] ibid, para 33.
[131] ibid, para 7.
[132] Cantwell and Holzscheiter (n 80) 6.
[133] UN OHCHR, 'Status of Ratification' (OHCHR 2017) <http://indicators.ohchr.org> accessed 22 June 2017.
[134] Francine Mestrum, 'Child poverty in the context of global social development' in Wouter Vandenhole and others (eds) *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 362.
[135] UN Committee on Economic, Social and Cultural Rights, 'Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights: Poverty and the International Covenant on Economic, Social and Cultural Rights' (10 May 2001) UN Doc E/C.12/2001/10 para 8.

negotiate their rights.[136] They are affected differently by poverty than the rest of the population,[137] e.g. by experiencing greater impact of violations of economic and social rights.[138] However, it can be argued that it is dangerous to focus solely on 'child poverty', as it is part of larger economic and social conditions.[139] Not taking care of one's children may be seen as negligence, but it is often marginalisation and struggles for survival that force parents to do this.[140] But ideally, economic reasons should not be a justification for separation of children and parents.[141] In the 'Guidelines for the Alternative Care of Children' it is stated that,

'Financial and material poverty, or conditions directly and uniquely imputable to such poverty, should never be the only justification for the removal of a child from parental care, for receiving a child into alternative care, or for preventing his/her reintegration, but should be seen as a signal for the need to provide appropriate support to the family'.[142]

Since children are still being institutionalised for reasons attributable to poverty,[143] we need to not only look at rights directly related to institutionalisation such as Article 20 of CRC, but also economic and social rights that provide social security for adults and children alike. So which rights are relevant for poverty reduction? Van Bueren argues that poverty does not subdivide neatly into rights, but that international human rights law more generally needs to be included in strategies to eradicate poverty.[144] Other authors, such as Hunt, Nowak and Osmani,[145] do specify which rights are most related to poverty reduction: the right to food (Article 11 ICESCR), to an adequate standard of health (Article 12 ICESCR), to education (Article 13 ICESCR), decent work (Articles 6, 7 ICESCR), adequate housing (Article 11 ICESCR), to personal security (Article 9 ICESCR, but it is also a civil and political right), the right to appear in public without shame (mainly related to non-discrimination), the right of equal justice (again a civil and political right), and political rights and freedoms. Mestrum also argues that extreme poverty could be violating the civil right to life.[146]

[136] Aoife Nolan, 'Economic and Social Rights, Budgets and the Convention on the Rights of the Child' (2013) 21 International Journal of Children's Rights 248, 251.
[137] Mestrum (n 134) 362.
[138] Nolan (n 136) 251.
[139] Mestrum (n 134) 367.
[140] Geraldine Van Bueren, 'Combating Child Poverty – Human Rights Approaches' (1999) 21 Human Rights Quarterly 680, 686.
[141] UN Committee on the Rights of the Child (n 113) para 61.
[142] UNGA Res 64/142 (n 78) para 61.
[142] ibid, para 15.
[143] UN Committee on the Rights of the Child, 'Day of General Discussion. Children Without Parental Care' (17 March 2006) UN Doc CRC/C/153 para 658.
[144] Van Bueren (n 140) 683.
[145] Paul Hunt, Manfred Nowak and Siddiq Osmani, 'Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies' UN Doc HR/PUB/06/12 (UN OHCHR, Geneva 2012) ch III.
[146] Mestrum (n 134) 366.

Apart from addressing poverty, ICESCR also recognises that '[t]he widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children'.[147] The same article provides for special protection for mothers, and lastly, for children, recognising their need for special measures of protection and assistance.[148]

2.3 State obligations

The CRC states that the duty to take care of a child is first of all on the parents or legal guardian(s).[149] However, UN treaties pose positive obligations on states, not parents. By ratifying the CRC and the ICESCR, India has obliged itself to ensure that they are respected by third parties – not only parents, but also non-state service providers, such as NGO-run orphanages. NGOs are in this way indirectly bound by the Convention, because if the state delegates care of children to a non-state entity, 'the State must make certain that such care is then effectively provided and that, in all cases, it meets the standards laid down for the public and private sectors alike'.[150] The CRC Committee asks states to ensure that authorities inspect non-state institutions to make sure they are in compliance with the Convention.[151] In relation to prevention of institutionalisation, India is obliged to progressively realise the anti-poverty rights in ICESCR,[152] to ensure that children do not need alternative care in the first place. The primary obligation is thus on the state even when they are not directly involved: to ensure that families are fit for child-rearing, and to ensure minimum standards in non-state care-providing entities.

This chapter has demonstrated that the primacy of a family environment as the most desirable, and the vulnerability of children living outside such environment, are uncontested principles in international law.[153] Based on the binding treaties and soft law dealt with in this chapter, we can identify an 'ideal path' in accordance with UN norms, for a child who is at risk of being deprived of

[147] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 United Nations Treaty Series 3 (ICESCR) art 10(1).
[148] ibid, art 10(3).
[149] CRC (n 77) art 18(1).
[150] Cantwell and Holzscheiter (n 80) 51.
[151] UN Committee on the Rights of the Child, 'General Comment No. 5' (27 November 2003) UN Doc CRC/GC/2003/5 para 44.
[152] ICESCR (n 147) art 2(1).
[153] Cantwell and Holzscheiter (n 80) 28.

his/her family environment: first, the state should ensure that there are preventative services or families, such as counselling and social and financial support, to encourage parents to keep their children in their care; if this fails, a professional assessment should be undertaken to determine whether there are other family members who could take permanently care of the child; if this also fails, a permanent family placement outside the child's family should be found. Placing the child in a residential institution should only be a last resort, and a temporary measure while other solutions are found. During the entire process, the best interests of the child and the views of the child should be taken into account. Before we turn to the case study of how these norms match or not with a local situation, let us contextualise HIV, residential care institutions, and child protection legislation in India.

3 HIV and residential care in India

Scholars have argued that any de-institutionalisation strategy should take account of the history of institutions and which role they play in a given society.[154] Accordingly, the purpose of this chapter is to provide a brief background for the case study by introducing the extent and social consequences of HIV in India; the social role institutions currently play; and the legal framework for child protection.

3.1 HIV in India

India is one of the countries in the world with the highest number of people living with HIV/AIDS.[155] National adult (15-49 years) HIV prevalence was estimated at 0.26% in 2015.[156] While statistics indicate that HIV prevalence is declining,[157] many believe that official numbers are underestimated.[158] HIV only transmits through certain bodily fluids. The most common mode of transmission is through sexual intercourse, but mother-to-child transmission during pregnancy or childbirth is also significant, and this is the way that the vast majority of HIV-infected children become infected.[159] Many women may not know that they are infected or that they infect their children upon birth.[160] Of the total number of people living with HIV/AIDS in India, it is estimated that around 7% are children of under 15 years of age.[161] Deaths of children with HIV amounted to 7% of AIDS-related deaths in India in 2011.[162] In order to decrease the prevalence of mother-to-child transmission, the National AIDS Control Organisation (NACO) provides free counselling for

[154] E.g. Nigel Cantwell, 'The human rights of children in the context of formal alternative care' in Wouter Vandenhole and others, *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 269; Andrew Dunn, Elizabeth Jareg and Douglas Webb, *A Last Resort. The growing concern about children in residential care* (International Save the Children Alliance, London 2003) 6.
[155] Human Rights Watch, *Future Forsaken. Abuses Against Children Affected by HIV/AIDS in India* (Human Rights Watch, New York 2004) 17-18.
[156] Government of India, 'Annual Report NACO 2015-16' (Department of Health & Family Welfare 2016) <http://naco.gov.in/sites/default/files/Annual%20Report%202015-16.pdf> accessed 22 June 2017, 336.
[157] Government of India, 'Narrative country progress report of India: Global AIDS Response Progress Reporting 2015', GOI/NACO/SIM/GR-RPT/200415 (Ministry of Health & Family Welfare, 2015) <http://www.unaids.org/sites/default/files/country/documents/IND_narrative_report_2015.pdf> accessed 22 June 2017, 2, 4.
[158] Human Rights Watch (n 155) 16-17.
[159] ibid 17.
[160] UN Committee on the Rights of the Child, 'General Comment No. 3' (17 March 2003) UN Doc CRC/GC/2003/3 para 2.
[161] Government of India (n 157) 4.
[162] ibid 5.

pregnant women.[163] NACO has also since 2004 set up 475 free Antiretroviral Therapy (ART) Centres where patients can receive ART drugs free of cost.[164] However, there is a significant challenge in linking people living with HIV/AIDS to the ART Centres, raising awareness about their existence and getting people to continuously show up and collect their medicine. To lessen this gap, NGOs such as the India-wide Positive Women Network, have set up Care and Support Centres (CSCs) to be the link between the government-provided services and people living with HIV/AIDS.[165]

It is widely recognised that stigma and discrimination is a major factor in the spread of HIV/AIDS,[166] as the fear of discrimination discourages people to get tested or seek treatment,[167] and inhibits knowledge about the disease to take root in society.[168] Human Rights Watch has conducted a study on children with HIV/AIDS in India, which demonstrates that discrimination against these children is widespread and contributes to the number of infections.[169] Children living with HIV may be exposed to 'double vulnerability' by being children as well as being HIV-positive – and most often also by being poor – factors that all influence each other.[170] Human Rights Watch argues that the main causes of the relatively high HIV/AIDS prevalence in India is 'stigma and discrimination, the low use of condoms and safe sex, migrant and highly mobile populations and the low status of women'.[171] HIV/AIDS has devastating effects on families, as parents become sick, lose their income, health expenses increase, and 'misinformation about how HIV is transmitted and fear of discrimination by the community causes some families to reject children who are HIV positive, or who are perceived to be because their parents died of AIDS'.[172] In sum, HIV/AIDS poses serious challenges on Indian society in areas including health, poverty and discrimination. Facing these challenges, families struggling with HIV/AIDS may feel obliged to place their children in one of the country's many child care institutions.

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[163] ibid 12.
[164] ibid 13.
[165] Positive Women Network, 'About Us' (Positive Women Network 2015) <www.pwnplus.in/about> accessed 22 June 2017.
[166] Pam O'Connor and Jaya Earnest, *Voices of Resilience: Stigma, Discrimination and Marginalisation of Indian Women Living with HIV/AIDS* (Sense Publishers, Rotterdam, 2011) xxi; UN Committee on Economic, Social and Cultural Rights, 'Consideration of reports submitted by States Parties under Articles 16 and 17 of the Covenant. Concluding Observations of the Committee on Economic, Social and Cultural rights. India' (8 August 2008) UN Doc E/C.12/IND/CO/5 para 13.
[167] Human Rights Watch (n 155) 37.
[168] O'Connor and Earnest (n 166) 2.
[169] Human Rights Watch (n 155) 36.
[170] UN Committee on the Rights of the Child (n 160) para 7.
[171] Human Rights Watch (n 155) 1-2.
[172] ibid 126.

3.2 The role of child care institutions in India

When the extended family is not willing or able to take care of a child, institutional care is the predominant system of care in India.[173] Just as worldwide, it is difficult to determine how many children are currently living in institutional care in India,[174] but the CRC Committee is 'concerned that institutionalization is still dominant in the State party, instead of family-based care'.[175] According to Bajpai, institutions have in practice become hostels, 'where children are being placed for food, clothing, shelter, and education due to inability of their parents to look after them'.[176]

There is a regrettable lack of comprehensive sources on the historical role of child care institutions in India. But if we look to studies of institutionalisation in postcolonial societies in general, it is argued that institutional care is an 'outdated export' of colonial powers.[177] In the early twentieth century, missionaries or colonial governments introduced residential care institutions, 'replicating what was then common in their own countries'.[178] Institutions were used to impart 'religious or secular education to poor orphaned children'.[179] But while institutional care quickly became 'judged to be developmentally inappropriate and phased out of developed countries', these same countries 'continue to support this care in poorer countries'.[180] Cantwell points out the irony in the fact that orphanages are often funded by foreign charities from countries in which institutional care has been highly criticised and largely eliminated.[181]

While institutional care is the predominant model of child care by non-relatives, other forms of

[173] Foster Care India, 'National Consultation on: Promoting Non-Institutional Alternative Care (NIAC) for Children in Rajasthan: A Report' (Foster Care India, Udaipur 2014) <http://fostercareindia.org/wp-content/uploads/2014/11/Foster-Care-India-Consultation-Report.pdf> accessed 22 June 2017, 6; Asha Bajpai, *Child Rights in India. Law, Policy, and Practice* (Oxford University Press, New Delhi 2003) 453-454.
[174] Foster Care India (n 173) 9; UN Committee on the Rights of the Child, 'Concluding observations on the combined third and fourth periodic reports of India' (7 July 2014) UN Doc CRC/C/IND/CO/3-4 para 55; Nigel Cantwell and Anna Holzscheiter, 'Article 20: Children deprived of their family environment' in A Alen and others (eds) *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007) 3.
[175] UN Committee on the Rights of the Child (n 174).
[176] Bajpai (n 173).
[177] Aaron Greenberg and John Williamson, 'Families, Not Orphanages' (2010) Better Care Network Working Paper <https://www.thinkchildsafe.org/thinkbeforevisiting/resources/Families_Not_Orphanages_J_Williamson.pdf> accessed 22 June 2017, 8.
[178] ibid.
[179] Dunn, Jareg and Webb (n 154) 15.
[180] Greenberg and Williamson (n 177) 8.
[181] Cantwell (n 154) 271.

alternative care are not absent in India. For example, sponsorship models also have a 'long tradition' in the subcontinent.[182] Sponsorship programmes consist of financial assistance to needy children who are often 'sponsored' by foreign donors.[183] Tolfree observes that even though this model can effectively prevent institutional care, it is often not used for this purpose in India, as many organisations provide both orphanage care and sponsorship programmes, not utilising the latter as a prevention tool for the former.[184] He regards this lack of linkage surprising in the Indian context where 'large numbers of children continue to be admitted into institutions largely because of poverty'.[185] Another alternative care model is foster care, which is often said to be a new concept in India.[186] Tolfree, however, points out that foster care – not as the legal, western concept, but as a practice – has a 'long tradition in India', e.g. through the practice of Gurukul, where students live with their *guru*, or teacher.[187] Gurukul has now largely been replaced by sending children to relatives for study purposes, or to boarding schools, another legacy of British colonialism not far from institutional care.[188]

In sum, India predominantly falls in the category that Cantwell calls the 'alternative care system in private hands with foreign support'.[189] It can be very difficult to transform foreign-funded orphanages into family strengthening programmes or foster care organisations, but this seems nonetheless to be the long-term goal of India's recently amended national child protection laws.

3.3 The Indian legal framework for child protection

There are over 250 Indian laws, commissions and frameworks relating to children.[190] Many are relevant for my case, e.g. the Integrated Child Protection Scheme (ICPS)[191] and the National Commission for Protection of Child Rights.[192] However, I have chosen to focus on the Juvenile Justice (Care and Protection of Children) Act ('JJ Act') passed in 2000, because it is the primary

[182] David Tolfree, *Roofs and Roots. The Care of Separated Children in the Developing World* (Save the Children Fund, UK 1995) 180.
[183] ibid.
[184] ibid 181-182.
[185] ibid 182.
[186] E.g. Foster Care India (n 173) 1.
[187] Tolfree (n 182) 258.
[188] ibid.
[189] Cantwell (n 154) 269-70.
[190] Bajpai (n 173) 473.
[191] UNHRC, 'National report submitted in accordance with paragraph 5 of the annex to Human Rights Council Resolution 16/21. India' (8 March 2012) UN Doc A/HRC/WG.6/13/IND/1 para 71.
[192] ibid, paras 67-70.

national legal framework for child protection;[193] because it systematically introduces non-institutional alternative care forms into Indian law; and because it is the law that was drafted specifically for the purpose of conforming the existing child protection and juvenile justice legal framework to the CRC, after India had ratified the Convention in 1992. In 2015, the JJ Act was amended, introducing foster care in India, as well as making adoption easier, thus recognising in the law the primacy of a family environment, and institutions as a last resort.[194] The purpose of this section is to briefly go through the Act, explaining how child care institutions in India are legally governed, and highlighting the Act's striking similarities with the CRC in terms of non-institutional care.

The JJ Act's main beneficiaries are 'children in conflict with the law' and 'children in need of care and protection'.[195] For the purpose of this thesis, focus will exclusively be on the latter, which consists of twelve subcategories. Relevant for my case are primarily the categories of children 'suffering from terminal or incurable disease, having no one to support or look after or having parents or guardians unfit to take care',[196] 'who [have] a parent or guardian and such parent or guardian is found to be unfit or incapacitated, by the Committee or the Board, to care for and protect the safety and well-being of the child',[197] and 'who [do] not have parents and no one is willing to take care of, or whose parents have abandoned or surrendered him'.[198]

In terms of the discourse around institutional care, the JJ Act is very much in line with the terminology found in the UN documents,[199] and refers explicitly to the CRC in its preamble. Among many other examples, the JJ Act uses the terms 'best interest of the child',[200] a child's

[193] Bajpai (n 173) 4.
[194] While the JJ Act is progressive in terms of non-institutional care, it has been argued to be very regressive in terms of juvenile offenders (see e.g. Jhuma Sen, 'Regressive Step' (Frontline, 2016) <http://www.frontline.in/cover-story/regressive-step/article8068317.ece> accessed 22 June 2017). This aspect has given the amended Act most of its public attention, as the amendments took place in the wake of the 2012 Delhi rape case (see e.g. Sunil Prabhu, '16-Year-Olds to be Tried as Adults in Extreme Crimes, Says Lok Sabha' (NDTV 2015) <http://www.ndtv.com/india-news/changes-to-juvenile-justice-act-spurred-by-gang-rape-outrage-passed-in-lok-sabha-761221> accessed 22 June 2017; or Express Web Desk, 'Rajya Sabha passes Juvenile Justice Bill, Jyoti's parents welcomes new law' (Indian Express 2015) <http://indianexpress.com/article/india/india-news-india/live-rajya-sabha-adjourned-after-uproar-over-ddca-issue> accessed 22 June 2017). This part of the Act is, however, outside the scope of this thesis.
[195] Government of India 'The Juvenile Justice (Care and Protection of Children) Act, 2015' (The Gazette of India No. 2 of 2016, Ministry of Law and Justice, New Delhi 2016) ('JJ Act') preamble.
[196] ibid, art 1(14)(iv).
[197] ibid, art 1(14)(v).
[198] ibid, art 1(14)(vi).
[199] See Chapter 2 above.
[200] Government of India, JJ Act (n 195) art 1(9).

'basic rights',[201] 'participation',[202] 'family responsibility' (emphasising that 'the primary responsibility of care, nurture and protection of the child shall be that of the biological family or adoptive or foster parents'),[203] 'equality and non-discrimination',[204] and most importantly, the principle of 'institutionalisation as a measure of last resort'.[205]

The types of non-institutional alternative care provided for in the JJ Act are foster care,[206] after care,[207] adoption,[208] and sponsorship.[209] Foster care is 'the placement of a child (…) in the domestic environment of a family, other than the child's biological family, that has been selected, qualified, approved and supervised for providing such care'.[210] Rajasthan was one of the first states make a state ruling on foster care in 2014.[211] Sponsorship is a financial aid for special cases, such as if the mother of the child is a widow or abandoned by the family, if orphans are living with the extended family, or if parents are victims of a life threatening disease.[212] Adoption means 'the process through which the adopted child is permanently separated from his biological parents and becomes the lawful child of his adoptive parents'.[213] Aftercare is understood as the financial or other support to persons between 18 and 21 years who have left institutions, to 'join the mainstream of the society'.[214]

The JJ Act created Child Welfare Committees (CWCs), which are quasi-judicial, district level bodies composed by experts. Their functions include dealing with cases about children in need of care and protection.[215] When a child is produced before the CWC, the Committee has the task to identify or not the produced child as 'in need of care and protection',[216] in other words, whether it belongs to one of the twelve categories mentioned above. If the child is deemed so, the CWC has the power to order them to foster care, sponsorships, institutions, declare the child legally free for

[201] ibid, art 1(9).
[202] ibid, art 3(iii).
[203] ibid, art 3(v).
[204] ibid, art 3(x).
[205] ibid, art 3(xii).
[206] ibid, art 44.
[207] ibid, art 46.
[208] ibid, Chapter VIII.
[209] ibid, 45.
[210] ibid, art 2(29).
[211] Foster Care India (n 173) 1.
[212] Government of India, JJ Act (n 195) art 45(2).
[213] ibid, art 2(2).
[214] ibid, art 2(5).
[215] ibid, art 29(1).
[216] ibid, art 37(1)(a).

adoption and more (such as refer them to counselling or psychiatric services).[217] If they opt for an institution, it is also the CWC who selects the institution based on the child's age, gender, disability, needs and available capacity of the institution.[218] The CWC furthermore has the responsibility to conduct inspection visits to child care institutions (CCIs) in order to ensure their compliance with the JJ Act.[219] The JJ Act specifies which services shall be provided by institutions, namely basic requirements (food, shelter, clothing, medication), equipment for children with special needs, appropriate education, skill development, occupational therapy, mental health interventions, recreational activities, legal aid where required, case management, birth registration, assistance for obtaining proof of identity, and referral services for, *inter alia,* education and treatment.[220] If the institution does not fulfil the prescribed criteria for registration, their registration will be cancelled.[221]

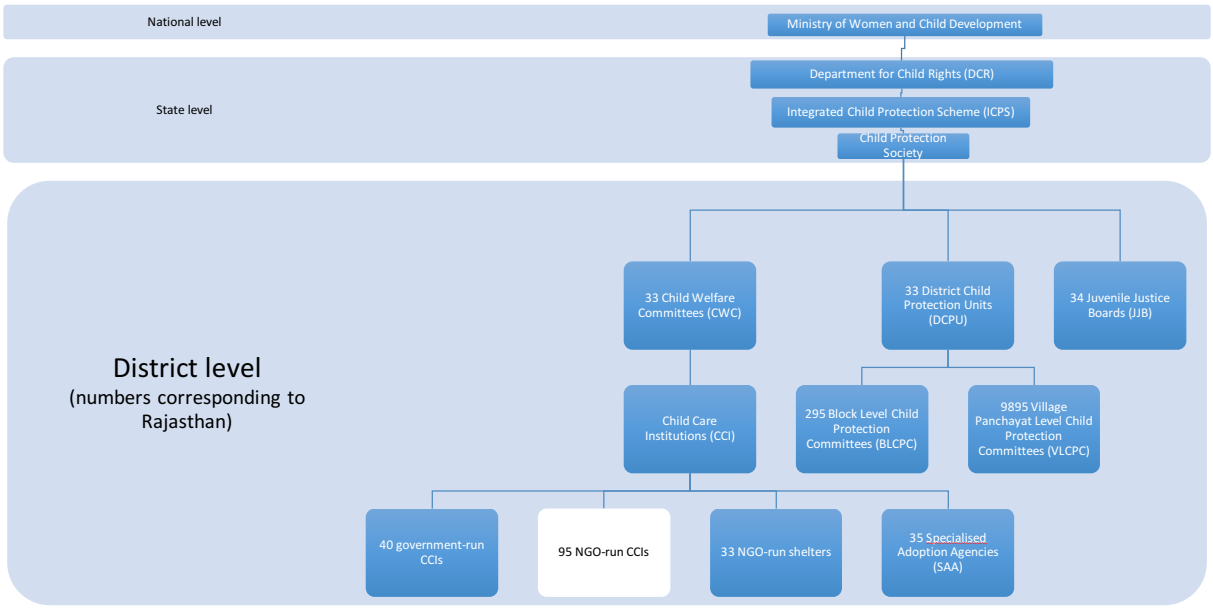
Once a child is placed in an institution, the JJ Act, again in line with the 'Guidelines for the Alternative Care of Children',[222] provides for measures for rehabilitation and social re-integration. This should preferably happen 'through family based care such as by restoration to family or guardian with or without supervision or sponsorship, or adoption or foster care'.[223] The JJ Act states that 'the restoration and protection of a child' to parents, adoptive parents, foster parents, guardians or fit persons 'shall be the prime objective of any Children's Home'.[224]

A last comment on the JJ Act concerns implementation. The Act underlines the principle of 'positive measures', requiring that 'all resources are to be mobilised including those of family and community' to ultimately reduce 'the need for intervention under this Act'.[225] 'District Child Protection Units' bear the primary responsibility for implementation of the Act in each district.[226] The National Commission for Protection of Child Rights is responsible for monitoring the implementation.[227] An important part of implementation is public awareness. The JJ Act provides that the Central and State governments 'shall take necessary measures to ensure that (…) the provisions of this Act are given wide publicity through media including television, radio and print

[217] ibid, art 37(1)(c-g).
[218] ibid, art 30(vii).
[219] ibid, art 30(viii).
[220] ibid, art 53.
[221] ibid, art 41(3).
[222] UNGA Res 64/142 (24 February 2010) UN Doc A/Res/64/142.
[223] Government of India, JJ Act (n 195) art 39(1).
[224] ibid, art 40(1).
[225] ibid, art 3(vii).
[226] ibid, art 1(26).
[227] ibid, 109.

media at regular intervals so as to make the general public, children and their parents or guardians aware of such provisions'.[228]

To sum up this section, I have visualised relevant parts of the child protection system in India set up by the JJ Act:[229]



This is by no means an exhaustive chart of India's child protection system, but it places non-governmental CCIs in the larger legal system and provides overview for the purpose of my case study. The white '95 NGO-run CCIs' box is where my case study is located. It is thus one of many CCIs in Rajasthan, monitored by the CWC of Jaipur, under the Department for Child Rights at the state level.

[228] ibid, art 108.
[229] This chart was made with the help of Husn Ara, Programme Manager, Department of Child Rights, Rajasthan during my interview with her 9 March 2017 (see Interview 41, Appendix 1).

4 Case Study: Aashray Care Home

This chapter wants to explore experiences, perceptions and practices around institutionalisation, HIV/AIDS and human rights at a local level through a case study. Before turning to the analysis, I will present the study's setting and methodology.

4.1 Setting

A desert state located in India's north-west, Rajasthan is the country's largest state by size. Its population is of approximately 68,5 million people, of which 51,5 million live in rural areas.[230] The state's capital, Jaipur, is part of the larger Jaipur District with approximately 6,6 million people.[231] Aashray Care Home ('Aashray') is located in an urban, residential part of Jaipur. Aashray is part of the NGO Positive Women's Network of Rajasthan Society, the Rajasthani branch of an Indian-wide organisation that supports HIV/AIDS-infected women in accessing treatment, government schemes, and care homes. Aashray itself has existed since 2005 and is a residential care home for children infected with or affected by HIV/AIDS. It is funded primarily by donations from private individuals and funds (both local and foreign). The home receives children through the Child Welfare Committee (CWC) of Jaipur District, and is currently the home of 37 children (25 boys and 12 girls). Due to a state regulation, Aashray is divided in two separate houses, a 'Boys' Home' and a 'Girls' Home', the latter being both for girls and small children of both sexes. The Boys' Home is also where the organisation's office is placed. Children live in rooms with 6-8 beds. They go to school in the area, and spend the rest of their day eating meals, doing homework, playing, doing yoga, watching TV, cleaning, and going on the occasional outing financed most often by individual donors. The staff consists of the founding married couple (officially titled 'founder and director' and 'consultant'), a warden (also the founder's sister) who lives permanently at the Boys' Home with her own children, a care taker living permanently at the Girls' Home, as well as two full-time care takers, a full-time educator and a cook who all come daily. Apart from this core staff group, many people are involved in the organisation to various degrees, such as local donors and

[230] Government of India, 'Rajasthan Profile' (Census of India 2011) <http://censusindia.gov.in/2011census/censusinfodashboard/stock/profiles/en/IND008_Rajasthan.pdf> accessed 22 June 2017.
[231] Government of India, 'Jaipur' (Census of India 2011). <httphttp://www.censusindia.gov.in/pca/SearchDetails.aspx?Id=90414> accessed 22 June 2017.

neighbours, volunteers and donors from abroad, a yoga and English teacher, a nurse, relatives of the staff and many more. The fixed staff roles are therefore not immediately visible during everyday life at the care home, which rather gives the impression of the collaboration of a group of people – including the older children – in running the place.

4.2 Methodology

The selected research method was a qualitative case study consisting of interviews and participant observation. Qualitative research is said to be 'especially effective in obtaining culturally specific information about the values, opinions, behaviours, and social contexts of particular populations'.[232] As my objective was to understand the perspectives of the participants and the meanings they gave to certain concepts (institutionalisation, HIV/AIDS, and child rights), to learn about the process from when a child is identified as in need of alternative care, to that child becomes institutionalised, and to identify experienced barriers to receive family-based care in Rajasthan, a qualitative approach was appropriate.[233] This study may contribute to understanding specific challenges facing children in Rajasthan by studying the experiences of rights-holders and attitudes of duty bearers, and as such it is a piece in a larger puzzle to understand why so many children grow up in institutions in India despite international and national efforts for de-institutionalisation. However, in order to get a comprehensive picture, one would need several more case studies for comparison, as well as quantitative data on the extent of institutionalisation in India, over time and geographical space, as well as on the global trends of (de-)institutionalisation.

Flyvbjerg has pointed out that case studies often have been criticised for being subjective, not generalisable, and generally not useful compared to other types of qualitative research.[234] In this view, knowledge is only valuable if it can be generalised to all contexts. Agreeing with Flyvbjerg, I would instead argue that case studies are valuable in contributing to the *contextual* development of knowledge,[235] as learning can be maximised if researchers place themselves in the context they

[232] Natasha Mack and others, *Qualitative Research Methods: A data collector's field guide* (Family Health International, North Carolina 2005) 1.
[233] Nouria Brikci and Judith Green, 'A Guide to Using Qualitative Research Methodology' (Medicins Sans Frontieres 2007 <http://fieldresearch.msf.org/msf/bitstream/10144/84230/1/Qualitative+research+methodology.pdf> accessed 22 June 2017, 7.
[234] Bent Flyvbjerg, 'Fem misforståelser om casestudiet' in Svend Brinkmann and Lene Tanggaard (eds), *Kvalitative metoder* (Hans Reitzels Forlag, Copenhagen 2010).
[235] ibid 466.

study.[236] Case studies demonstrate real life's complexities and contradictions,[237] providing depth rather than width.[238] In Flyvbjerg's words, 'the power of the example' has been undervalued in social science.[239] Some argue that individual case studies often lead to the verification of the researcher's preconceived ideas.[240] However, according to many scholars who have conducted case studies, this critique is false, as the case study usually forces researchers to revise their hypothesis,[241] a statement I can recognise from the present study. As Geertz puts it, the field is 'too insisting'.[242]

I am not using the case study, as it is often used in social science, to test or develop a theory.[243] Instead, in line with legal anthropologists such as Merry, I use it in the ethnographic sense of exploring people's perceptions of a globalised international law phenomenon.[244] This type of focus is on how law meets everyday life. Even though I did not conduct the 'deterritorialised ethnography'[245] championed by Merry, my concern with the local and global meeting is similar to hers when she argues that international legal language is a place where the two intersect: it is created 'globally', but ultimately for local situations.[246] This type of case study is specifically focused on the local relevance and perceptions of human rights, which can be said to be a sub-genre of human rights studies.[247] I find an ethnographic case study valuable to explore how the obstacles to global norms – which are created to improve the lives of people who inevitably are living in a certain locality – are materialising at the local level.

The specific care home, Aashray, was chosen because it is a specialised home, in the sense that it caters to children with specific needs, namely those infected with or affected by HIV. The findings

[236] ibid 480-81.
[237] ibid 481.
[238] ibid 486.
[239] ibid 473.
[240] E.g. Jared Diamond, 'The Roots of Radicalism' (1996) 43(18) The New York Review of Books 6.
[241] E.g. Donald T Campbell, 'Degrees of Freedom and the Case Study' (1975) 8(1) Comparative Political Studies 178; Charles C Ragin, '"Casing" and the Process of Social Inquiry' in Charles C Ragin and Howard S Becker (eds), *What is a Case? Exploring the Foundations of Social Inquiry* (Cambridge University Press, Cambridge 1992); Clifford Geertz, *After the Fact: Two Countries, Four Decades, One Anthropologist* (Harvard University Press, Cambridge, MA 1995); Michel Wievorka, 'Case Studies: History or Sociology?' in Charles C Ragin and Howard S Becker (eds), *What is a Case? Exploring the Foundations of Social Inquiry* (Cambridge University Press, Cambridge 1992).
[242] Geertz (n 241) 119.
[243] Flyvbjerg (n 234) 473.
[244] Sally Engle Merry, 'Crossing Boundaries: Ethnography in the Twenty-First Century' (2000) 23 Political and Legal Anthropology Review 127, 127.
[245] ibid 129.
[246] ibid.
[247] Gaby Oré Aguilar, 'The local relevance of human rights: a methodological approach' in Koen De Feyter and others (eds), *The Local Relevance of Human Rights* (Cambridge University Press, Cambridge 2011) 121.

will have value as an 'extreme case',[248] based on the assumption (confirmed by my data) that HIV-infected children are more difficult to de-institutionalise than non-infected children, because of their special care needs (allegedly requiring an institution) and the social stigma around the disease (preventing alternative family-based care). In addition to poverty, they also suffer from discrimination. Therefore, if I can argue that de-institutionalisation is possible even for these children, it should also be possible for children who are not in need of specialised care.

I have thus far argued for the value of the case study and its appropriateness for my objectives. However, it is important to also point out certain limitations arising from how the study was conducted. The study was short, as I was only present in the field for two weeks. However, I had spent one month living at the orphanage in 2016, where I got a solid understanding of the daily routines and became familiar with the people, thus minimising the need for 'entering the field' for the present short study. Still, if I had had the possibility to return a third time, if the study had been longer and I had had more respondents, I would have been able to provide more nuanced results. It is also necessary to be aware of the nature of the data collected. Being a foreigner could influence the respondents' trust and behaviour in different ways: as I was a relatively unknown outsider to many, it may have limited the amount of personal information they were willing to share. I believe this was particularly evident with the children I interviewed. For the staff in the NGO-run care homes, I could have been seen as a potential donor or advocate for their cause, thus leading them to want to give me 'pleasing' answers, a risk that is transferable to most interviews. But my foreignness could also have had positive outcomes, as I from a different cultural context would be unlikely to share what they said with their community. This I believe was evident especially when HIV-infected adults talked openly about their disease with me. They assumed that I did not carry prejudice or stigma, as I was not from their local environment. The fact that I was able to speak with respondents in their native language also enhanced their trust and possibility to express themselves without an intermediate.

Having now generally presented the case study methodology and its limitations, I will proceed to detail how the interviews and observations were conducted. I was present in the field for a total of two weeks, of which I stayed nine full days at the care home, and otherwise travelled within Jaipur and to Delhi to conduct interviews with stakeholders from outside the care home. The empirical

[248] Flyvbjerg (n 234) 475.

data I collected consists of interviews and field notes from observations.

4.2.1 Interviews

I conducted 46 interviews, of which 41 were semi-structured individual interviews, two were semi-structured group interviews, one an unstructured individual interview and two were unstructured group interviews.[249] Semi-structured interviews allow for letting the field data shape the research, which is crucial when the purpose is to let people express their own interpretation of social phenomena. It consists of having an interview guide with planned questions and prompts, but leaves scope for flexibility for the interview to vary with each individual and pick up on sensitivities or unexpected topics.[250] Two of the semi-structured interviews were group interviews, both cases of families. Unstructured interviews were only used in the respondent group of HIV professionals, as the purpose was to obtain knowledge about an unknown issue to the researcher, namely how the stigma around HIV/AIDS plays out in urban and rural Rajasthan.

I used purposive sampling to identify respondents, meaning that I grouped them according to criteria decided beforehand.[251] As I wanted to explore the perceptions and implementation of primarily Article 20 of CRC, it was important to include the groups that it applies to, which, according to UNICEF, are 'the social work or welfare departments of government and (…) social workers, foster caregivers and adoptive parents'.[252] As I was specifically concerned with institutionalisation, I chose to leave out adoptive and foster parents, and to focus on children, families, care home staff, authorities, experts and HIV professionals. This small sample will not be able to claim which views are most prevalent in Rajasthan, but the interviews of all the groups combined serve to get an overview of how institutionalisation works in Rajasthan through a broad range of experiences. All interviews except three were recorded, due to the preference of the respondents. All participants consented to being part of the research, the children both themselves and through the care home staff as their guardians. Children, families and care home staff remain anonymous in the thesis. The interviews in Hindi were translated by myself with assistance from two native speakers.

[249] Appendix 1 contains a full list of interviews (including details of length, place and language), and Appendix 2 the guides for the semi-structured interviews.
[250] Jess Prior, 'The Use of Semi-Structured Interviews with Young Children' in Jo Van Herwegen and Jess Prior (eds) *Practical Research with Children* (Routledge, New York 2016) 109, 111.
[251] Mack and others (n 232) 5.
[252] Rachel Hodgkin and Peter Newell (eds), *Implementation Handbook for the Convention on the Rights of the Child* (UNICEF, Geneva 2007) 277.

The first respondent group was children. It is by now commonplace in qualitative research to interview children rather than adults about issues concerning children, because parents' or care takers' answers will reflect their own concerns rather than the children's.[253] The can be many reasons to include children as informants. For my purposes, it was mainly to hear first-hand experiences of institutionalisation, and to give the rights-holders a voice (as per the CRC's Article 12[254]). They took place at the care home where the children were in familiar surroundings. Due to the young age of the respondents, the interviews were kept short. To get a representation of the children living in the care home, I included boys and girls, children from the city and villages, children infected with as well as affected by HIV, and ages from 6 to 18, and one interview with a 23-year-old who grew up in the care home and now lived separately. I did not interview very young children, as it is common practice (though still debated) to exclude this age-group from formal interviews.[255] The thematic focus of the interviews with children was on where they had lived over the course of their lives, where they preferred to live and why, especially about preferences of family or care home. The interviews also touched upon children's daily lives and future dreams. A limitation in interviewing children is that they are socialised, through schools and general upbringing, to give the 'correct' answer, assuming that adults are looking for a particular response in their questions.[256] Many of them did exactly this, by answering 'yes' to contradicting questions or choosing not to answer if the question was ambiguous or complicated.

Just as the children, the respondent group of families (parents and relatives of institutionalised children) provides personal experience with institutionalisation. These interviews focused on the question of why there was a need for their child to live at the care home. As most of the parents came from outside Jaipur, these interviews were also used to shed light on how care homes and HIV/AIDS were perceived in village communities.

The respondent group of care home staff was chosen to get views from the providers of care working professionally on the ground with institutionalisation. I included respondents from different job positions, from day-to-day care takers to manager level. Six of the respondents in this group were from Aashray Care Home, while two were from a different care home, Rays. The purpose of including respondents from a care home outside the primary case study, was to confirm

[253] Prior (n 250) 109.
[254] Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 United Nations Treaty Series 3 (CRC) art 12.
[255] Prior (n 250) 110.
[256] ibid 113.

whether Aashray generally was a representative or a deviant case study within the category of care homes for HIV-infected/affected children in Rajasthan. As will be evident from the analysis, Rays' responses to a large extent confirmed Aashray's, and I have included them in the analysis as strengthening the views expressed by Aashray staff. The thematic focus varied as per the job level of the staff members. With the care taker staff, focus was on daily life at the care home and their views on the care home versus family-based care; I asked similar questions to the warden, but due to her experience with the legal side of institutionalisation, I also asked about the process and causes of institutionalisation; with the manager level staff, I asked more detailed questions about causation factors, governmental inspections, long-term goals of the home, alternative care options and HIV/AIDS stigma.

The fourth respondent group was representatives of the authorities, who are the duty bearers in relation to the children as rights holders, and are therefore an important respondent group. It is furthermore important to hear the official understanding of institutionalisation and child rights. I interviewed one representing the district level, and one the state level. These interviews focused on which laws and frameworks govern institutionalisation in Rajasthan, how the government inspects institutions, as well as their views on institutional versus family-based care, their policies on prevention of HIV/AIDS, their views on NGOs being service providers, and their perceptions of international human rights. If I had had the time to conduct a longer study, it would have been useful to hear the views of more government representatives, perhaps also at the national level. As a student researcher and due to the lengthy and official process of getting an appointment with the government in Rajasthan, my access to government representatives was limited. The two interviews I did conduct, happened through my contacts at Aashray, and could not take place at the respondents' offices. Since both respondents were engaged in social work outside their official work, there is a risk that they are not representative of the prevalent view in the government.

I conducted two interviews with experts, both working for NGOs related to child protection, namely Antakshari Foundation that works with, *inter alia,* child health and rural development, and Foster Care India,[257] that promotes foster care and de-institutionalisation. This respondent group did not need to be large, because the purpose was not representativity, but rather insight through their specialisation. The expert interviews, both conducted at the end of the fieldtrip, also served as verifications of other findings from the study. They were thematically catered to the individual

[257] Foster Care India, an NGO that operated in Rajasthan, no longer exists. The interview for this thesis was focused on the previous work of the organisation, and on the general theme of de-institutionalisation.

respondent, but general themes were child protection in Rajasthan, de-institutionalisation, and foster care.

Lastly, I included the respondent group of HIV professionals. Hereunder, I conducted one individual interview with the consultant nurse at Aashray, one expert group interview with nurses and pharmacists working with HIV, and one group interview with fourteen field officers who counsel HIV/AIDS patients. These respondents were linked to the Vihaan Care and Support Centre (CSC) in Jaipur.

While I do believe that these six respondent groups provide a useful overview of the situation and perceptions in the case of Aashray, if I had had more time, I would also have liked to include government child care institutions, providers of 'group foster care', and more representatives from the government. If these actors had been included, the image of institutionalisation in Rajasthan would have been more comprehensive.

4.2.2 Participant observation

Secondary to the interviews, participant observation was used to collect additional data. This method was chosen to understand the daily life at the care home and get insights into parts of the children's lives that they would not express in a formal interview. The type of participation could be characterised somewhere between what Spradley calls 'moderate' and 'active' participation.[258] I took active part in certain daily routines at Aashray, such as preparation and consumption of meals, homework with the children, laundry, and playing games, while observing and afterwards noting down my observations. In these field notes, I noted down e.g. what was being said, who were present in different situations, in what ways people were expressing themselves, the atmosphere of the places, and personal reflections on my own preconceptions about issues that came up (e.g. about what good child care is). The advantage of this ethnographic approach is that it allows for 'richer and more varied material' than what could be achieved through only interviews.[259] Just as with the interviews, a limitation in my use of this method is that I was not able to return to the field after an initial analysis of my field notes, which would have made the analysis more rigorous.

[258] James Spradley, *Participant Observation* (Holt, Rinehart and Winston, USA 1980) 60-61.
[259] Eva Gulløv and Lisbeth Skreland, 'Ethnographic Studies of Young Children' in Jo Van Herwegen and Jess Prior (eds) *Practical Research with Children* (Routledge, New York 2016) 127; 142.

4.2.3 Data analysis

After having transcribed and translated the interviews into English, I followed the process of qualitative data analysis recommended by Brikci and Green, namely to read and annotate transcripts; identify themes and summarise texts; develop a coding scheme; and code the data into thematic patterns.[260] I looked for patterns within each respondent group, as well as larger thematic patterns across groups. The interview situation as an exchange where adults may want to 'please' the foreigner who had travelled to India to 'get results', and where children may want to give the 'correct' answer, was taken into account when analysing and interpreting the data. The analysis process did thus not simply focus on what the respondents said, but also on why they may have said it.

There is inevitably a strong subjective touch to the ethnographic approach, but that is exactly the point of this type of study. It should be clear that these are my observations and my interpretations, but as I have laid out the method choices in detail, the reader will hopefully be able to transparently follow the discussion of results.[261]

4.3 Findings and analysis: local experiences and perceptions of institutional care of HIV-infected/affected children

The main findings of the study concern, firstly, the identification of a number of causation factors for institutionalisation in Rajasthan; secondly, that respondents continuously proposed 'awareness' as a way to address social problems; and thirdly, the social functions other than child care played by Aashray in the community. Before detailing these findings, I will explain a typical path for a child who cannot live with his/her parents, until he/she ends up in an institution, based on information obtained in the interviews.

4.3.1 Experienced processes of institutionalisation

In Chapter 2, I identified an 'ideal path' for children at risk of deprivation of family environment, according to UN treaties and soft law. This path went from preventative services at the family level, to consideration of possible care by relatives, to family-based alternative care options, and lastly, to

[260] Brikci and Green (n 233) 22-28.
[261] Gulløv and Skreland (n 259) 142.

institutional care only in absolutely necessary circumstances. Let us now look at a typical process of institutionalisation of a HIV-infected/affected child in Rajasthan according to the respondents.[262]

The vast majority of the children were living in a village before they came to Aashray. Their path to institutionalisation began when one of their parents got infected with HIV. A typical cause of infection was when a father from a rural family worked as a trucker or other work that required long periods away from home, or had been sexually active before marriage and then brought the disease to the wife and (future) children.[263] Often the family did not learn about their disease until opportunistic infections kicked in and a family member went to a government hospital, where there is compulsory HIV-testing. Usually they would not disclose their positive status to relatives or community due to fear of stigmatisation. However, if one of the parents died, the other was often compelled to disclose the status. If the mother was left alone with children, she was facing a multitude of difficulties: stigma by relatives, physical weakness due to disease, gender discrimination (the woman was most often blamed with bringing HIV to the family even if it was not true),[264] poverty due to the husband's – the breadwinner's – death, and much more. Such dire circumstances could lead the surviving parent to go to the village council for help, who could refer the child to the district's Child Welfare Committee (CWC).[265] She could also desperately leave her children on the street. If lucky, the child would be found by police or bypassers who contact the ChildLine, who would then refer the child either directly to the CWC, or to a hospital who after treatment would refer the child to the CWC.[266] If both parents had passed away from disease, very few relatives would take HIV-infected children in, because they were afraid that the virus would spread to their own children.[267] Some kept them for a short time until they or the village council referred the child to the CWC. In the case of Aashray's children, two out of the 26 interviewed children had both parents alive. The majority had one living parent, while six had none.

When a child was referred to the CWC, the Committee would provide the child with a temporary shelter home until a decision was made about the child, and make a profile of the circumstances

[262] The following analysis is only based on stories relating to children who lived in or had been living in an institution. It should be kept in mind, however, as was pointed out to me during the fieldwork, that the majority of HIV-infected/affected children in Rajasthan did not know about alternative care options or the Child Welfare Committee. I am here only concerned with the children who 'made it' to the formal alternative care system.
[263] E.g. Interviews 27; 28; 31. For details of the interviews, see Appendix 1.
[264] Interview 34.
[265] Interviews 27; 29.
[266] Interview 37.
[267] Interview 34.

based on what the child sayd, age verification, medical tests etc. If the family of the child was located and they wanted to take the child back, the child could be sent back. If the child was deemed 'in need of special care and protection' as per the JJ Act, [268] the CWC would decide, 'does the child need institutional care or does the child need family?'[269] An ex-CWC member said that the CWC would try to place the child in sponsorship, foster care or adoption, but when talking to children and parents who had experienced the system, no one mentioned non-institutional alternative care options. Care home staff and experts agreed that in reality it was 'institutions or nothing for the CWC'.[270] The child was thus almost immediately sent to a child care institution (CCI). The vast majority of CCIs in Jaipur are run by NGOs.[271] If a child was HIV-infected, he/she was always sent to one of the three NGO-run 'special homes' for children infected with or affected by HIV.[272] However, if the child was very young, he/she was sent to 'Shishu Graha', the government home for infants. Some of the children at Aashray had lived at the Shishu Graha until they were old enough to be moved to another institution, and as such they were examples of an entire upbringing in institutional settings.

Once the child was living in the institution, the government was continuously checking up on the care homes.[273] According to the ex-CWC member, they check 'how the child is kept, what condition the child is in, food is there and the education is there, recreation is there', basically whether any norms of the JJ Act were not implemented.[274] The care home created a file for each child, detailing the child's and family's HIV status, family background etc. so they could counsel and coordinate how to help the child, and 'lessen the gap between the family and the child, so that the acceptance of that child slowly increases'.[275] According to the ex-CWC member, the CWC continuously looked at the case profiles of each child for the 'next decision'.[276] However, at Aashray, less than a handful of children had actually been replaced in a family environment after being ordered to the institution.[277] According to the representative of the Department of Child Rights (DCR), there was no specific focus on rehabilitation in families in the authorities' monitoring of institutions, which instead focused on the standard of facilities in the institutions.[278]

[268] ibid.
[269] Interview 40.
[270] Interview 43.
[271] Interview 40.
[272] Interview 33.
[273] Field notes 3 March 2017.
[274] Interview 40.
[275] Interview 34.
[276] Interview 40.
[277] Interview 34.
[278] Interview 41.

During their stay in the institution, the vast majority of children had some relatives to visit in the holidays, and parents or relatives also sometimes came to visit the children at Aashray. Only one child respondent did not have any contact with relatives.[279] Everyone else were able to produce a long list of people when asked who were in their families. They were sent back to their families twice a year, but according to Aashray's consultant, the relatives would not be willing to take them in full time.[280]

How did the children themselves experience their lives in the institution? In the formal interview settings, nearly all expressed that they liked living at Aashray. However, they also liked to go back to their villages. When asked where they would prefer to live, the majority said that they preferred the care home. A 23-year old who grew up at Aashray said that he preferred 'living with the children the most, because I have lived with children from the beginning. I have lived very little in a family'.[281] This is an illustration of the effect of institutional care on people, when it becomes their norm: how could he prefer a family environment without remembering living in one? This resonates with the statement of a 17-year-old boy who had lived in Aashray for ten years. His mother was a care taker at Aashray, and he had two siblings there. He was so connected to the place that when asked what he would like to become when grew up, he said 'staff at Aashray'.[282] Another boy's immediate response to the question of where he preferred to live, was that he preferred the village, but when I asked 'With whom?' he changed his mind, perhaps realising that he did not have family who accepted him anymore. 'No, I would like to live here', he said.[283] A 6-year-old boy who was interviewed with a few other kids present, was silent at the question. One of the older boys tried to get him to say 'here' as he may have had the feeling that this would be the 'correct' answer. In the end, the 6-year-old said 'here'.[284] Only few expressed directly that they preferred to live in their village. These gave reasons such as 'Mum lives there'[285] or 'I go there sometimes, therefore I like it, because I miss it'.[286] One boy said, 'It's nicer in the village. Here it's 50/50, in the village it's 100%. I don't feel so happy and at place here, more in the village, like… I like it there'.[287]

[279] Interview 5.
[280] Interview 34.
[281] Interview 2.
[282] Interview 22.
[283] Interview 5.
[284] Interview 14.
[285] Interview 6.
[286] Interview 21.
[287] Interview 7.

4.3.2 Causation factors of institutionalisation

The four main causation factors for institutionalisation in this case may be identified as: the social stigma of HIV/AIDS; poverty and the rural-urban divide; a positive perception of care homes; and lack of functional alternatives to institutions.

Before I turn to each of these, however, it will be interesting to see what the children themselves said when asked why they lived in the care home. Many answered that they came to the care home because of their studies,[288] for example that 'in the village I cannot study'[289] or 'for my school fees'.[290] One boy said that the reason he could not live with his family was that, 'through studying here (…), I want to make my father, my grandfather, my family, whoever is there, also Aashray, to make them proud. And thank them too'.[291] Some of the older children simply said that it was because their parents had passed away.[292] Others emphasised the medical facilities in Jaipur that did not exist in the villages,[293] or gave the reason that 'I take medicine'.[294] Some children emphasised financial aspects, such as 'In the village there is no one to earn money'[295] or 'Mum thought that here [the village], there is a shortage of money, so let's go to Jaipur'.[296] Others talked of the bad health of their parents as the main reason.[297] One boy said that he came for disciplinary issues ('I couldn't go to school, couldn't wake up in the morning, therefore they sent me to a hostel').[298] Only one, an older boy, mentioned HIV-discrimination and that his family had 'separated' them.[299] The children's perceptions give us insight into what types of justifications they are given about living at Aashray. All of them of course have some truth to them, but the overall picture is more complicated.

[288] Interviews 6; 13; 17; 18.
[289] Interview 13.
[290] Interview 11.
[291] Interview 9.
[292] Interviews 1; 3; 16.
[293] Interview 3.
[294] Interview 21.
[295] Interview 11.
[296] Interview 19.
[297] Interviews 11; 16.
[298] Interview 23.
[299] Interview 22.

4.3.2.1 Social stigma of HIV/AIDS

The stigma around HIV/AIDS was evident across all respondent groups, whether described by experts or experienced by families or care home staff. The stigma leads to direct discrimination, which is also one of the root causes of institutionalisation of children with HIV.

A mother of three children at the care home said that in the village, 'everyone throws you out, untouchable disease'.[300] Another mother expressed that her daughter could not play with other children because they would not touch her, and that this was the main reason that her daughter lived at the care home. If the daughter lived at home, 'then all the other children would say: Disease, stay away! So she would begin to cry, here she is happy, so I am also happy'.[301] A care taker at Aashray who herself was HIV-positive said that when she made food in her village, people would not eat it, but throw it away.[302] A HIV-positive patient at the CSC said that he was not allowed to drink from the village well, and had to walk extremely far just to get water.[303] If people disclosed their disease, it was typical that the family would give them separate kitchen equipment and blankets. Such discrimination was widespread according to the outreach workers at the CSC.[304]

There was a general consensus that the stigma was worse in the villages, because people there knew their community and neighbours better than in the cities.[305] Therefore the HIV/AIDS-status was often kept secret in villages. An uncle and aunt of a boy at the care home said that the boy's parents had hidden the disease for 15 years until they were in the last stage.[306] 'If you tell, then (…) people will not talk to you, will not go to your house, will not eat from your hand', said the warden at Aashray.[307] The HIV professionals said that the infected people get 'socially boycotted' and 'isolated'.[308] This is often described as the reason why relatives of HIV-infected children do not take the children in their own care. 'The child's relatives can keep the child if they want. But the problem is that they are scared that it will also spread to their children. Therefore they don't want to keep the child', said the consultant at Aashray.[309] His estimate was that only 5-10% of relatives accepted HIV-infected children into their care.[310] Aashray's nurse said that if the relatives chose to

[300] Interview 27.
[301] Interview 28.
[302] Interview 39.
[303] Interview 46.
[304] Interview 46.
[305] Interviews 27; 29; 31; 33; 37; 44; 45; 46.
[306] Interview 30.
[307] Interview 33.
[308] Interview 45.
[309] Interview 34.
[310] Interview 34.

keep the child, 'discrimination will happen to this child' and he would be treated

'like a servant in the house and they will use him. So this thing will leave a big imprint in the child's mind. And they will keep their own children well, so the child will also (…) think: why are they giving cold water to me or old torn clothes to me, or always hitting me?'[311]

The uncle and aunt of a boy at Aashray are examples of such relatives who let the child visit them in holidays, but cannot keep him permanently. Even though they underlined that they did not mind his disease and that he was in the care home exclusively for medical reasons, they also made an effort to make sure I understood that they were not infected themselves. When I wanted to ask about discrimination in the village, I had only said 'in your village, is there a lot…' when the uncle said, 'No one has such a thing'. 'Does he experience discrimination?' I finished. 'In our family, we all did a check-up, no one has anything. Only one, [child's name]'. Determined to ask about discrimination, I asked again, 'And do other relatives, towards the child…', but again I was interrupted by 'No. No one has it'.[312] Even though he did not himself have misconceptions about how HIV/AIDS spreads, the uncle here demonstrated a defensiveness toward HIV-infection that he probably had practiced in the village when met with stigma towards the nephew. Aashray's consultant underlined that because there were a lot of places where people 'really, really discriminated (…) socially and economically', the care home was in fact a last resort for these children.[313] In his view, discrimination was the 'major reason' for institutionalisation of these children.[314] The outreach workers at the CSC agreed, expressing that HIV-infected children in villages were both sick and socially outcast, isolated in their own house and village, ultimately needing a care home.[315]

According to care home staff, the stigma was also present at the government level in the separation of 'HIV homes' from other homes. The fact that homes for HIV-infected/affected children are considered a 'special home' is often explained by the medical demands of these children.[316] However, the founder of Aashray said that by separating, the government implied that they thought that HIV would spread through eating utensils or walls.[317] In fact, the reason that both Aashray and Rays began their work, was that they realised the impossibility of finding a care home placement

[311] Interview 44.
[312] Interview 30.
[313] Interview 34.
[314] ibid.
[315] Interview 46.
[316] Interviews 32; 41.
[317] Interview 32.

for a HIV-infected child.[318] When they began their work, it was very difficult for both Aashray and Rays to rent a building for the care home due to misconceptions about how HIV transmits.[319] Discrimination was also felt by the care home staff when they had to enroll the children at Aashray in schools. Three schools refused enrolment because of HIV. But when the staff found one that accepted, they kept looking for more, and now they have children enrolled in a number of different schools in order to decrease discrimination in the local community.[320] However, a boy of 18 said that not everyone at school knew about the HIV, only close friends and teachers.[321]

Even in the medical system there was discrimination. One of the medical professionals said that, '… in the beginning we were also afraid. When we as medical professionals can be afraid, the rest of the people who don't know, they will also be afraid'.[322] A nurse told about a family friend who had gotten infected, and once he told his family doctor, the doctor not only refused to provide him treatment, but also deleted the patient's number from his phone and cut contact.[323]

4.3.2.2 Poverty and the rural-urban divide

There are also economic and practical reasons that children get institutionalised. As we have seen through the children's own explanations of why they live at Aashray, it often had to do with a perception of villages as a backward place where there were no opportunities for education, medical facilities, or even 'care'. Poverty was often mentioned as a root cause, although some highlighted discrimination as worse.[324] As Aashray's consultant expressed it, 'most of the community of HIV-positive people, poor, so economically poor, socially poor, and so, discarded by society'.[325] The ex-CWC member said that the majority of cases before the CWC were related to poor families,[326] and the founder of Foster Care India said that poverty was one of the main root causes for institutionalisation.[327] A HIV nurse said that 90% of HIV-infections happened in 'labour class or middle class people'.[328] The founder of Aashray explained that the people most likely to send their

[318] Interviews 32; 37.
[319] Interview 37.
[320] Interview 34.
[321] Interview 1.
[322] Interview 45.
[323] ibid.
[324] E.g. Interviews 28; 34.
[325] Interview 34.
[326] Interview 40.
[327] Interview 43.
[328] Interview 45.

children to the care home were wives of truckers or construction workers without knowledge of contraceptives, from poor families.[329]

The warden of Aashray said that not only the parents were poor, but the entire extended family, thus making it difficult for them to take in another child even if the stigma around HIV/AIDS had not existed.[330] A Rays staff member underlined that poverty was also a problem because of medication: When 'children are staying in villages and if they are staying with a mother who doesn't have a husband, there is no bread-earner in the family, then medication gets a problem'.[331] Aashray's nurse said, 'there are problems at home that their income is low, and the child's father, he can't earn much, so who can the child depend on?'[332] In the group interview with medical experts, their opinion that care homes were a solution to the poverty problem was clear: 'If there is a patient who cannot afford it (…), then he can send his child to the care home (…) so he can get good treatment and a good education', or 'the rich patient can afford good care (…), but the poor patient who doesn't have basic knowledge, he will need the care home'.[333] There simply was a need for the care home because 'their bills have to be paid'.[334] Therefore the medical professionals would readily suggest the care home to patients during counselling if the patients could not afford living with HIV.[335]

In addition to poverty within an individual or extended family, the lack of medical facilities in rural areas in general was highlighted by many respondents. Both Aashray and Rays staff said that HIV-infected people usually came to Jaipur because there was no treatment in the villages. They had to leave the children permanently in Jaipur because they could not afford to take the trip every month.[336] Jaipur has better facilities not only than villages, but also than other towns in the state.[337] Aashray's nurse said that the main problem he saw in his work as a counsellor to people living with HIV/AIDS was that 'they are living in the villages, so no facilities there (…), sometimes there is no medication'.[338] A father of two boys in the care home had to go to Jaipur himself twice a month to get his medicine.[339] An uncle of a boy in the care home said that the authorities had told them that

[329] Interview 32.
[330] Interview 33.
[331] Interview 37.
[332] Interview 44.
[333] Interview 45.
[334] ibid.
[335] ibid.
[336] Interviews 32; 34.
[337] Interview 46.
[338] Interview 44.
[339] Interview 29.

'treatment and all that, you cannot give on time, not care for him in a proper manner' because there was no good hospital in their area.[340] His wife complemented that 'we cannot give medicine properly, therefore we left him here'.[341] When asked what the best environment for a child to grow up in would be, the uncle said that 'if children get more facilities in a place like this, treatment on time', it would be better to leave them at a care home.[342] The lack of available medicine in their town had also been the reason that the boy's parents had not received proper treatment and eventually died.[343]

Furthermore, a larger urbanisation tendency contributed to a perception of the city as full of opportunities and the village as backward. Urbanisation was pointed out by the Antakshari Foundation expert as one of the root causes of institutionalisation.[344] A care taker and mother of three children in Aashray said that their relatives in the village had more or less accepted them now, but what would her son 'do in the village now? If he will do a job, it will be here (…). All the facilities are not there, if we want to make food, there is no gas (…) and there are no water facilities'.[345] The Project Director at the CSC similarly said that the villages lacked proper facilities 'like drinking water, like toiletry'.[346] The medical experts underlined that the availability of better treatment in Jaipur was coupled with the fact that people could also get 'better quality education and better facilities in the care home'.[347]

The sheer extent of illness that parents experienced also contributed to them feeling compelled to place their children in care homes.[348] The families of children at Aashray clearly demonstrated a vast disease suffering in their families: 'My husband passed away. I don't have my parents either', said a mother of three, and later added, 'In childhood I was with Mum and Dad, Mum left us. Dad had asthma, he died. My 17-year old brother, poor thing, died. (…) He had pneumonia'.[349] Furthermore, one of her children was disabled and required special care. A HIV-positive staff member explained how her late husband had been HIV-positive as well, but her children were

[340] Interview 30.
[341] ibid.
[342] ibid.
[343] ibid.
[344] Interview 42.
[345] Interview 39.
[346] Interview 46.
[347] Interview 45.
[348] Interview 38.
[349] Interview 27.

negative. However, she had had to deal with a range of other diseases, including a serious brain problem in her oldest son, requiring two operations.[350]

These types of difficulties, from illness to lack of facilities in rural areas, may lead parents to think themselves not in a position to take care of their children. As one mother said, 'I can't keep the children because I can't give as good care as there is here'.[351] The interview with a mother and grandmother who had decided to keep the children at home in spite of HIV,[352] highlighted the difficulties faced by many. They complained about school fees, and a general lack of support from the government. The reasons they were able to keep the children at home were that both parents were alive and well enough to work; they had disclosed their status to the close family, so they could get support from the grandmother; and they lived in Jaipur, so they had access to a large hospital with proper treatment and facilities. 'I want that as long as I am here, the children will live with me', said the mother. The slightly higher socio-economic status she enjoyed, compared to the parents who had decided to place their children in the care home, was crucial for her to be able to afford such a statement.

When arguing for de-institutionalisation, it is thus important to keep in mind that many families face immediate problems that make them feel compelled to place their children in a care home. How can we expect parents to consider 'detrimental socio-psychological effects of institutions' when the alternative is for the child to live on the streets or risk dying from disease?[353]

4.3.2.3 A positive perception of care homes

So far I have discussed two causation factors of institutionalisation that virtually all respondents agreed should be combated: HIV/AIDS stigma and poverty. The third factor is more ambiguous, namely the widespread positive perceptions of institutions as places where children get the 'best care'. The views ranged from an exclusively positive perception of care homes by HIV-affected parents, relatives and children themselves, the majority of care home staff, and HIV professionals; over a realistic acceptance of care homes while still recognising the primacy of family care, expressed mainly by higher-educated care home staff and the district level government representative; to complete agreement with CRC norms of institutions as a last resort, expressed by the state government representative, and the child protection experts. The more educated the

[350] Interview 39.
[351] Interview 27.
[352] Interview 31.
[353] Interview 45.

respondent was, the more critical he/she was to institutions. On the other hand, the closer the respondent was to personally experiencing the care home system, the more positively he/she saw it – and after all, they are the ones who are affected by institutionalisation.

As mentioned above, the children diverged in their answers on whether they preferred to live in the care home or in the villages with their families. However, the day before a major holiday, some families came to pick up their children and it was clear that this was a joyous day for those children. They had talked with excitement about seeing their families several days in advance.[354] But this emotional response did not correspond with the families' more pragmatic considerations. In fact, the family members of children at Aashray had an unquestionable positive perception of the home. When asked where the best place would be for their children to live, the overwhelming response was the care home.[355] One mother said that she placed the kids at the care home because there is good *parvarish* (rearing or support), 'they will be able to stand on their own feet', the staff are 'paying much attention to my children', and 'my kids are studying well'.[356] Another mother said that she thought everything at the care home was good, and that 'the children are well taken care of, they give them affection, they serve good food'.[357] A father said that he put his children in the care home because, 'I only want that they study and their life gets better'.[358]

The staff also had a generally positive perception of care homes. The founder of Aashray said that the reason more HIV-infected children did not live in the care home was that the capacity of homes was limited, and there were 'so many children living with the families still'.[359] This statement implies an ambition to, at some point, let all HIV-infected children live at care homes. The same line of thought came through in the interview with the Vice President of Rays, who said that the children in the care home were 'the lucky bunches', and that 'the rest of them are staying at home because we don't have vacancies'.[360] She said that, 'the biggest threat for these children, it is if you're not behaving well, we'll send you back', because 'the amount of care and love and affection that is taken care of' was much higher in the care home than in the village.[361] According to her, the children 'are taken (…) care of so well, and they're able to live a normal life' instead of 'living with

[354] Field notes, 10 March 2017.
[355] Interviews 27; 28; 29; 30.
[356] Interview 27.
[357] Interview 28.
[358] Interview 29.
[359] Interview 32.
[360] Interview 37.
[361] ibid.

the stigma'.[362] In this view, the village would be full of detrimental psycho-social effects, while the care home would lead them to a 'normal life'.

According to the founder of Aashray, the parents liked care homes because 'in care homes, [children] obey' while in families, 'children not taking timely medicine'.[363] One care taker said, 'In my opinion, the care home is just as good as families. Here they get everything, they get good food, here are good programs, they can enjoy. And in the holidays they go back to their families'.[364] The educator at Aashray repeated throughout her interview that 'there are no problems here' and that the children got everything they needed.[365] The founder of Rays demonstrated a strong positive perception of care homes, when I asked what she thought could have been done to avoid that the children came there in the first place:

'Why avoid? Meaning, they are getting good care, they are getting good education, they are getting whatever (…) a child should get, so why avoid? If they can come here and get good care and good placement and jobs or something, then why not?'[366]

Similar to other care home staff, she also thought that the parents who send their children to care homes 'are the ones who want their children to be better off'.[367] The founder of Foster Care India argued that such perception that the children were happy there, was mainly due to the specialised nature of care homes for HIV-infected/affected children. It was different from other care homes, because in specialised settings, 'they know the care and protection they get'.[368] In his estimation, 80% of children in non-specialised institutions would prefer to live with their families.

However, some of the care home staff did express views of the primacy of a family environment. The consultant of Aashray underlined that they did try to replace the children back with families if possible. In his view, it was 'the best' when 'the child's development (…) happens in the family'. He acknowledged that, 'Actually (…) we think that this kind of institution should not be here. The major fundamental institute is the family'.[369] He gave one example of a mother who was reluctant to place her child in the home, but necessities demanded it. However, when she got a job through a

[362] ibid.
[363] Interview 32.
[364] Interview 33.
[365] Interview 35.
[366] Interview 38.
[367] ibid.
[368] Interview 43.
[369] Interview 34.

government scheme, the child went back to live with her.[370] So the consultant did consider Aashray a 'last resort', but a necessary and inevitable one for many children. The founder of Rays agreed that in the future, 'more children should live with their families' but it would be inevitable that some children would always need institutions.[371] One care taker at Aashray agreed that 'family is the best' because the child would know his/her relatives and would be able to inherit property.[372] But even if they did acknowledge the primacy of a family environment, all except one of the interviewed care home staff had never heard the word 'de-institutionalisation', demonstrating a gap between the international discourse and local knowledge. The one who had heard the word before had a slightly different understanding of it than what the international norms prescribe, namely that, 'it means that after leaving the institution (…) children need to be placed in society',[373] thus seeing it more as what in the JJ Act is called 'aftercare'.

From the viewpoint of nurses, pharmacists and consultants working directly with HIV patients, the positive perception of a care home for HIV-infected/affected children was perhaps the most explicit. Aashray's consultant nurse said that the child would get a future at the care home:

'If he or she stays at home and the father cannot give full support, cannot give them study, cannot give them proper nutrition, for these reasons, what happens, the child's future, it becomes damaged, then they go or will do labour work, and in the care home they get full support, they get a place to live'.[374]

Similarly, in the group interview with nurses and pharmacists, the notions of 'proper treatment', 'proper facilities' and 'proper education' continuously came up when talking about the care home. 'All the facilities that a child needs, they are well provided for in the care home', said one.[375] They named the institutional care as the 'best care' associated with status symbols (even though not always true) such as 'good food from the hotel (…), they put the children in good English-medium schools' and general well-being, such as 'the parents (…) can also work in the NGO' and that the children 'all are happy'.[376] A nurse rhetorically asked, 'What would better care be?'[377] Similar to the care home staff, a pharmacist said,

[370] ibid.
[371] Interview 38.
[372] Interview 39.
[373] Interview 34.
[374] Interview 44.
[375] Interview 45.
[376] ibid.
[377] ibid.

'they get better education, they get better medication, they get a better environment, they will become self-dependent. They will get the job by their education after 18 years. But if they spend their life in villages, then no facilities will be there to survive in their life. So this is the best decision (…) for them'.[378]

When asked about the fact that the children did not grow up with their own families, the HIV professionals did not see a problem. In fact, one nurse said,

'it is good for saving the children from this disease, not to see their parents for a long time. There is nothing bad in a gap in seeing your parents, but if they lived with them continuously, then the health of the parents is deteriorating, so no one would be able to take care of the children, and the immunity of the child would decrease, the child would get the infection from the parents, that would be more dangerous, so it is right that they are living in a safe environment'.[379]

In his view, the care home would also provide education to the children who would then be part of a generation more aware about HIV.[380]

When the parents expressed exclusively positive statements about the care home, it was most likely due to their dire circumstances at home, over which the care home was to be preferred; and perhaps because they saw me, the interviewer, as someone they needed to convince of the good conditions at the care home. The care home staff also had their own interests in expressing positive views on the institution, as it was not only their livelihood, but, at least for some, their life project. Regarding the HIV professionals, however, it is more difficult to point to reasons for endorsing the care home, other than a genuine perception that children would get better care there. Working as professional nurses, pharmacists and counsellors, they had seen how discrimination played out in society, and that this did not happen in the care home. Regardless of the reasons behind, the fact is that this positive perception was undeniably prevalent and likely to reinforce itself as these stakeholders interacted.

On the other hand, from the viewpoint of the authorities, the primacy of a family environment was highlighted. The ex-member of the CWC said, 'definitely the child needs to be de-institutionalised. He needs to be restored in his family', and further, 'if [the child] has a family, then the child should be established in the family. Because there is no better institution than the family'.[381] However, she

[378] ibid.
[379] ibid.
[380] ibid.
[381] Interview 40.

also said that there were some situations where institutional care would be needed.[382] Similarly, the representative from DCR said that the best environment to grow up in for a child was the family, and that institutions only should be the last resort, referring to the JJ Act.[383]

The child protection experts also argued unambiguously for de-institutionalisation. 'I am totally in favour of de-institutionalisation' said the representative of Antakshari Foundation, 'people think that children get luxurious care in institutions (…), but from a child rights perspective, it is very necessary to have a family'.[384] He added that 'of course institutions can give love, affection and care, but they cannot replace the family (…). There cannot be a comparison of family and institutions. Both have significant role and importance, but of course every human being is required a family'.[385] Similarly, the founder of Foster Care India said, 'I truly believe that children's best place is as close to their cultural origin as possible, and as close to their biological mother-father, and then after that kin, and in a family setting'.[386]

One issue demonstrated particularly well the positive perceptions of care homes as an obstacle to de-institutionalisation, namely the wish of care homes to expand. This was evident with both Aashray and Rays. Aashray is currently in the process of building a new care home that would house 100-200 children instead of the current 37. Ironically, part of the reason for expanding, the consultant explained, was the government's requirements of minimum standards, and as the CWC sent more and more children to Aashray, they had to expand. Furthermore, the current rented building was non-permanent and expensive.[387] But another important reason for expanding was also simply the well-meant goal of helping more children. Aashray's consultant said that they made the new home 'so that we can give the children more and more facilities and live a long life'.[388] The idea of expansion, however, goes against what several care home staff said about being 'like a Mum' to the children,[389] which logistically would be impossible for 200 children. The warden at Aashray said that there would be many more care takers at the new home, and that they would not be able to manage the daily chores, such as cleaning and laundry, in an informal way where everyone helps each other, as they did now.[390] Rays did not have concrete plans, but certainly

[382] ibid.
[383] Interviews 40; 41.
[384] Interview 42.
[385] ibid.
[386] Interview 43.
[387] Interview 34.
[388] ibid.
[389] E.g. Interviews 32; 35; 36; 39.
[390] Interview 33.

dreamed to expand. The founder said that 'we would really want to support 200, 300, 400 children, if we have the financial support'.[391] Not only the care home staff, but also the HIV professionals saw the need for expansion, as they thought that care homes were the 'best care' for HIV-infected/affected children. One medical professional said that 'there needs to be more. I think there should be five care homes attached to each Antiretroviral Therapy (ART) Centre in each district',[392] thus directly linking the provision of medicine with care homes.

The idea of expansion would go directly against the UN recommendations of having small, family-sized living units[393] and that 'establishment of new residential facilities structured to provide simultaneous care for large groups of children on a permanent or long-term basis' should be prohibited.[394] However, the dream of and actual plans to scale up were happening on the ground, not only because NGOs waned to help more children, but also because they saw no alternatives, considering the stigmatisation and immediate needs of children. As one expert said, the care home staff were 'not bad, because a lot of time they're thinking about serving more children, and that's not a bad thing'.[395] According to him, 'that type of thinking can only be changed by exposing them to the benefits of (…) family-based alternative care'.[396]

4.3.2.4 Lack of functional alternatives

As we have seen in Chapter 3, the formal non-institutional alternative care options in the Indian laws are adoption, sponsorship, aftercare and foster care. On the ground, however, there was 'a gap between institution and non-institutional care services'.[397] I will here go through three of the four official family-based alternative care options and their limitations in Rajasthan,[398] from the viewpoint of the respondents.

Adoption is the only form of family-based alternative care that was described as actually functioning in India.[399] The limitation with adoption, however, is that it applies only to children whose parents are either both deceased (which is only the case for a small part of children in most

[391] Interview 38.
[392] Interview 44.
[393] UNGA Res 64/142 (24 February 2010) UN Doc A/Res/64/142 para 23.
[394] ibid, para 154(d).
[395] Interview 43.
[396] ibid.
[397] Interview 42.
[398] Since aftercare is the provision of care upon leaving institutions, and thus not an alternative to them, I have left it out of the analysis.
[399] Interview 41.

'orphanages') or willing to give them up permanently (which also rarely is the case when children live in institutions for financial and medical reasons). The institutions that adoptions take place from are not 'Child Care Institutions' like Aashray, but 'Specialised Adoption Agencies', a different category of institutions that the CWC can send children to. Therefore, the adoption system functions more or less as intended by law, but it does not apply to the case of Aahsray.

Sponsorship is a solution which allows the child to remain with his biological (often extended) family, while receiving financial support. There are different sponsorship schemes in different Indian states, and in Rajasthan the scheme is called Palanhar Yojna.[400] Both the Antakshari Foundation expert and the DCR representative identified Palanhar Yojna as the main scheme to promote family-based rather than institutional care.[401] It provides that if a child is in one of the categories of children in need of care and protection (one of which is HIV/AIDS-infected/affected children), his/her caretakers can receive between 1000 and 3000 rupees per month, some of it earmarked for school materials and clothing.[402] This scheme was described by the authorities as very successful.[403] Aashray's founder said that some relatives had indeed chosen to make use of this scheme instead of sending their children to the care home.[404] The Antakshari Foundation expert said that the scheme was doing well compared to other schemes, but that it only reached a small percentage of potential beneficiaries.[405] There are thus some significant obstacles for Palanhar Yojna to function properly. As expressed by Aashray's consultant, 'Government schemes are very good. Implementation is very bad'.[406] Several respondents emphasized the high level of corruption at various level in the government, and that the schemes rarely reached the intended beneficiaries.[407] A concrete example of the doubtful implementation came out in the interview with the mother and grandmother who had chosen to keep their children at home. They had applied for the Palanhar Yojna so they could financially support their children, but had had problems with the online application, and never heard anything from the government even though they had tried to contact them repeatedly.[408] They expressed their frustration with the government in phrases such as 'my son

[400] Foster Care India, 'National Consultation on: Promoting Non-Institutional Alternative Care (NIAC) for Children in Rajasthan: A Report' (Foster Care India, Udaipur 2014) <http://fostercareindia.org/wp-content/uploads/2014/11/Foster-Care-India-Consultation-Report.pdf> accessed 22 June 2017, 9.
[401] Interview 42; 41.
[402] Interviews 42; 41; 40.
[403] Interviews 40; 41.
[404] Interview 32.
[405] Interview 42.
[406] Interview 34.
[407] E.g. Interviews 34; 40.
[408] Interview 31.

has [HIV], my daughter-in-law has it, the child has it, but they are not getting any facilities'.[409] The representative from the DCR said that one of the big challenges for the department was how to reach out to all the children in need of care and protection, and that they were currently working on surveys to track children. Lack of data was another problem regarding the Palanhar Yojna. The expert from Antakshari Foundation complained that, 'We don't have number of total of orphan in Rajasthan, there is no data, there is no survey, so how will you project (…) how many orphan children you require to reach?'[410] He also pointed out that Palanhar Yojna was only financial help, and that there was a need to monitor and evaluate the scheme better.[411] The DCR representative said that they had not yet measured its effect in terms of decreasing the number of children in institutions.[412]

Foster care is an interesting case in India and Rajasthan because it was introduced into the law very recently. According to Aashray's consultant, foster care was not yet 'spread in society and offices and NGOs', there was only 'that ruling and directorate and some literature, but not spread, not practically successful'.[413] The Vice President of Rays said that, 'to have foster parents (…) is so common in other countries, but in India, the child is given to the other family only if the child is legally adopted'.[414] Similarly, the DCR representative said that since foster care was so new in Rajasthan, there was lack of monitoring and will from parents, and it was a sensitive thing to convince parents to take unknown children non-permanently into their care.[415] The expert from Antakshari Foundation said,

'… all the new non-institutional care is a new concept in the (…) perspective of Indian culture. It's not a very old system, no? So people are not understanding, people don't understand difference between adoption and foster care, and they also don't understand that what is impact of non-institutional care on children'.[416]

A common problem with all of the above options, specifically in the context of HIV-infected/affected children, is again the stigma around the disease. Respondents repeatedly underlined that even if Palanhar Yojna or foster care worked properly, relatives or foster families

[409] ibid.
[410] Interview 42.
[411] ibid.
[412] Interview 31.
[413] Interview 34.
[414] Interview 37.
[415] Interview 41.
[416] Interview 42.

would be reluctant to take a child with HIV in their care.[417] As Aashray's consultant said, '… there are a lot of other non-institutional care options. The child's relatives can keep the child if they want. But the problem is that they are scared that it will also spread to their children'.[418] Another common problem, in the view of the DCR representative, was that any type of alternative care – including institutions – had the potential to be very good or very harmful for the child, as it would depend on the individual family or institution.[419]

We have seen that the majority of respondents, especially those closer to the personal experience of institutionalisation, have other priorities than 'family or institution'. Instead, they focus on whether the child gets the best physical care and escapes poverty, disease and backwards rural areas. We have also seen that even though the JJ Act provides a range of family-based alternative care options, there are many difficulties in implementing them. So what needs to be done? According to many respondents, 'awareness' was the answer.

4.3.3 The call for awareness

The theme of awareness was striking across respondent groups, even though the topic to raise awareness about varied: HIV/AIDS and sex, foster care, or the harmful developmental effects of institutional care.

In relation to HIV/AIDS, respondents called for awareness about how the disease spreads, because that was what often lead to discrimination. People coming from villages to the CSC in Jaipur had heard the term 'HIV' before they found out about their status, but did not know what it was.[420] 'Due to lack of knowledge, (...) the disease spreads more easily', a pharmacist said.[421] He also said that most people in 'labour class (…) don't know what the disease is, how it spreads, how to protect the wife, if the wife has it, how to stop it from spreading to the children, so there is deficiency of awareness'.[422] The outreach workers at the CSC agreed that counselling and making people aware would be the best way to reunite stigmatised children with their relatives.[423] As a HIV nurse expressed it, 'The society's mentality has to change'.[424] 'When we started Aashray', the care

[417] E.g. Interview 32.
[418] Interview 34.
[419] Interview 41.
[420] Interview 44.
[421] Interview 45.
[422] ibid.
[423] Interview 46.
[424] Interview 45.

home's consultant said, 'then the challenge in front of us that we faced was the major level of discrimination in society'.[425] He said that if people knew that HIV does not spread from 'sitting, eating, drinking, sleeping together' then society would accept them.[426] The Rays staff also complained that people did not understand that HIV was not 'something which will come through the air' or 'while talking to the child, or while sharing a meal'.[427] Aashray's consultant nurse agreed that people needed to become more aware about how the disease spread.[428] Especially within extended families in rural areas, he said, awareness would be the best solution.[429] According to the nurses and pharmacists, there was also a need for awareness about testing and counselling services. Even though there were health centres for this in 'every state and every city' and anyone could go there for free, 'people are not going by self-choice. They are recommended by doctors (…). Otherwise they are not aware to go there'.[430]

Sex in general was also something people needed to be more aware about, according to the nurses and pharmacists. Aashray's nurse said that the reason people had so little knowledge about HIV/AIDS was its immediate connection to (extramarital) sex.[431] Another nurse said that the fact that people did not talk about sex in public was 'the main reason' for lack of awareness about HIV.[432] A Rays staff member said,

'in first world countries, people openly talk about sex, but in India, that's not so. And knowing that this is the disease that is transmitted through sexual intercourse, which is not acceptable in India, so (…) nobody respects you for that if you have HIV, because it has come through a wrong reason'.[433]

A nurse argued that sexual education should be mandatory in schools in order to create awareness. Nowadays, he said, if a child asked a parent or teacher about HIV/AIDS,

'they connect it with sex. So they think the child is going in the wrong direction, so there is a need to make them medically aware (…) If a child (…) asks about condoms, then his parents will (…) forbid him, saying that this is wrong (…). They should tell him what a condom is, why it is used, how it is used (…). And because of this, he will not tell

[425] Interview 34.
[426] ibid.
[427] Interview 37.
[428] Interview 44.
[429] ibid.
[430] Interview 45.
[431] Interview 44.
[432] Interview 45.
[433] Interviews 37; 38.

anyone else in the future that he is infected'.[434]

Aashray has done awareness work themselves, by running programs that give knowledge to children, empower women to raise awareness in their communities, or simply by door-knocking, collecting small donations and explaining about the disease.[435] Many pointed out that being raised in the care home in itself was a form of awareness raising for the next generation. A Rays staff member said, 'all this learning will not come through (…) upbringing in villages, because (…) they don't talk about such things'.[436] This was also evident by the fact that, while virtually all adult respondents pointed out the lack of awareness in the larger society, they were aware themselves, because they had been directly or indirectly exposed to HIV/AIDS. As one nurse put it: 'It's stigma for the people in the society, but *we* don't see it that way (…). Because we think they are equal, they can live together, they can play together'.[437]

The authorities and experts were the only ones who called for awareness about the benefits of foster care and family-based care in general. The DCR representative said that there was a need for awareness about the new foster care system.[438] Similarly, the Antakshari Foundation expert said that there was very little awareness about the scheme.[439] He further called for awareness about the detrimental effects of institutional care.[440] He said that, 'we need to build a perspective on what is de-institutionalisation and how it will impact (…) each child's life'.[441] In his view, it was necessary to make the individual institution aware, to build their understanding so they would begin working towards de-institutionalisation.[442] Similarly, the Foster Care India expert argued that it was necessary to spread awareness at all levels, also in the government and the CWC about de-institutionalisation.[443] He further argued that awareness should be built on social change theory on how ideas diffuse in society, looking at the benchmarks of political will, resource allocation, opinion leaders, capacity of on-the-ground workers, and public dialogue.[444] So in his view, in order to de-stigmatise HIV/AIDS, or de-institutionalisation, in a community, one would need to look across all these pillars. Concrete ideas, in his view, could be SMS campaigns, newspaper ads,

[434] Interview 45.
[435] Interviews 33; 34.
[436] Interview 37.
[437] Interview 45.
[438] Interview 41.
[439] Interview 42.
[440] ibid.
[441] ibid.
[442] ibid.
[443] Interview 43.
[444] ibid.

billboards, and through these means, people would talk to each other about the issues, and that would be how awareness really spread.[445] He also suggested training sessions for institution directors on alternative care, which should be non-aggressive and address e.g. how the brain develops differently in institutions and family, and explain how an institution might transition without losing their funds. Then they might choose to become a different type of NGO instead of expanding their institutional services.[446]

In sum, experts and authorities were aware of the psychological effects of institutionalisation and called for this to be spread in the community to argue for a right to family-based care. At the same time, most care home staff and all families did not see any problems with institutionalisation, but called instead for awareness about HIV/AIDS. The HIV/AIDS experts agreed, but further argued for more awareness about sex, a point not mentioned by anyone else, unless brought up by me. This case is therefore far from an example of a local network of actors fighting for social change, as many other 'localising human rights case studies'.[447] Rather, it is an example of a clear difference in priorities across levels (government, experts, institution, family) as well as lack of dialogue between these levels, in the same locality.

4.3.4 The institution's social functions

An important finding from the study was that not only did the respondents 'perceive' care homes in a positive way, the care home also played a range of functions in society. One of these was education. Some families, and also children, saw the main reason living at the care home as a way to get a proper education.[448] Many of the parents themselves were illiterate, while their children were studying in high grades and speaking and writing both Hindi and English, often in addition to speaking a local dialect. In a way, the significant difference between parents and children in terms of education was an illustration of an impressive social mobility over just one generation. The care home furthermore helped the older children to become independent by providing skills courses, and helping them renting rooms during their studies or while they looked for a job.[449]

Another social function fulfilled by the institution was how it had become a means for parents to 'rescue' their children from the extreme poverty that the family otherwise lived in. Institutions were

[445] ibid.
[446] ibid.
[447] Gaby Oré Aguilar, 'The local relevance of human rights: a methodological approach' in Koen De Feyter and others (eds), *The Local Relevance of Human Rights* (Cambridge University Press, Cambridge 2011) 115.
[448] E.g. Interviews 29; 5; 11; 13; 17; 18.
[449] Interviews 1; 32.

in this way to some seen as 'boarding schools' where they could send their children during the school year. This was clear from the fact that many children used the term 'hostel' when they talked about institutions.[450] 'Hostel' implies education and non-permanency, and even 'care home' – the commonly used words among respondents – has a much more positive ring to it than 'institution'. As Aashray's consultant nurse said, often the children from poor families who did not go to care homes would end up doing labour work or 'get associated with crime'.[451] This finding was confirmed by the founder of Foster Care India' who said that, 'child care institutions (…) are thought of as babysitting places, as places where children can go to get a proper meal and education'.[452]

Furthermore, the institution played the function of uniting the otherwise stigmatised community of people living with HIV/AIDS. Many of the care home staff themselves were infected, and they had found in the care home the 'family environment' they had been deprived of at home.[453] For example, one care taker had had a daughter who passed away from HIV/AIDS.[454] Ousted from her own family, and now childless, the care home was a way for her to live in a comfortable environment at the same time as earning a living. There were some families whose entire world evolved around institutions. A mother of three children in the care home had herself been brought up at an orphanage,[455] and many children had siblings in other institutions.

While the care home was a symptom of stigma and discrimination, it was also in itself a type of prevention of stigma. The children growing up in the institution did not experience daily discrimination as they would in the villages. Instead, they became aware of their disease, how it spreads and does not spread, and how it gets treated. In the interviews with the Rays staff, they proudly explained how two young HIV-infected couples from their care home had gotten married and conceived HIV-negative children, because of access to treatment and prevention of mother-to-child transmission through the care home and hospital.[456] If the children had remained in the villages with their families, they would have been much more likely to give birth to HIV-positive children. Several respondents argued that it was in the best interests of the child to be placed in an

[450] Interviews 1; 6; 8; 19; 23.
[451] Interview 44.
[452] Interview 43.
[453] Interviews 35; 36; 37.
[454] Interview 36.
[455] Interview 27.
[456] Interview 38; 39.

institution because otherwise they would live with the stigma daily.[457]

These social functions represent further obstacles to de-institutionalisation: not only do 'people's minds need to be changed', but there is a need to look for alternatives to what can fulfil these functions. Foster care was described as 'new', and it was underlined that it was not easy to send your child to a different family.[458] However, as we have seen, it was very easy to send your child to a 'hostel', indicating that it is not so much the act of sending your child away, but the fact that it has to be to a socially accepted place. We can thus see that there is a need for social acceptance of alternative care options, which currently exist primarily in the JJ Act, and not on the ground.

This chapter has presented a complex picture of causation factors for institutionalisation of HIV-infected/affected children in Rajasthan, as well as significantly diverging views on institutional care across respondent groups. These findings point to the fact that de-institutionalisation is not a straight forward process, especially since Aashray fulfils a number of functions apart from simply child care, that would need to be taken into account in a de-institutionalisation strategy.

[457] E.g. Interviews 27; 37; 44.
[458] Interview 37.

5 The global and the local of child care institutions

A comparison of the UN treaties and soft law norms on de-institutionalisation with the case of Aashray shows significant divergences. The purpose of this chapter is to discuss these gaps in two ways, both engaging with the local/global dichotomy. Section 5.1 will apply an 'implementation gap approach' and evaluate to what extent India is fulfilling its human rights obligations in relation to de-institutionalisation. Section 5.2 will apply a localisation approach and ask to what extent international human rights are relevant for this context, and how local experiences could expand their relevance.

5.1 The implementation gap approach

As Vandenhole explains, the implementation gap approach implies to identify mismatches between law and practice, and on that basis argue for better implementation.[459] Implementation gaps in human rights law do not always mean that a state is breaching its obligations, especially when it comes to the treaties dealt with in this thesis, in which the state has obliged itself only to 'take steps (…) to the maximum of its available resources, with a view to achieving progressively the full realization of the rights'[460] in the case of the ICESCR, and to 'undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention' in the case of the CRC.[461] Arguably, India is 'progressively realising' the rights in the these treaties through legislative measures such as the first JJ Act in 2000, and the amended JJ Act in 2015. However, this does not mean that we cannot identify gaps between the rights in the CRC (and the provisions of the JJ Act) and realities on the ground. This section will provide (non-exhaustive) examples of where implementation could be improved.

The most important of the relevant rights is Article 20, establishing that institutions should be

[459] Wouter Vandenhole, 'Children's rights from a legal perspective. Children's rights law' in Wouter Vandenhole and others (eds), *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 38-39.

[460] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 United Nations Treaty Series 3 (ICESCR) art 2(1).

[461] Convention on the Rights of the Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 United Nations Treaty Series 3 (CRC) art 4.

necessary, non-permanent, and a last resort. According to the CRC, children should only be placed in institutions in absolutely necessary and thus very few circumstances. However, the reality in Rajasthan is that so many children live under dire circumstances that institutions are 'absolutely necessary' for a large number of children. While a child should ideally not be placed in an institution due to poverty or discrimination, these are realities that many families in Rajasthan live in. In addition to the necessity principle, non-permanency is a central international human rights norm when it comes to institutionalisation. Ideally, institutions should, if necessary at all, only play an interim role.[462] This is not the reality in Rajasthan, where Aashray was considered by virtually all stakeholders as a permanent place. In fact, the ex-CWC member distinguished between 'child care institutions' (like Aashray) and 'temporary shelter homes' where children were placed while waiting for a decision by the CWC,[463] thus implying that child care institutions were not temporary. Lastly, from the CRC's Article 20, institutions should be a 'last resort' in a 'continuum of care' of foster placement, adoption and if necessary suitable institutions. It was clear from across respondent groups that this continuum of care is not the practice in Rajasthan. Foster care and other forms of non-institutional alternative care are new and non-consolidated practices in Rajasthan. Even though some respondents (including the authorities) agreed that institutions should be a last resort, this did not result in few children being institutionalised.

The CRC's Article 18(2) on the state's obligation to provide assistance in child rearing was only fulfilled in a scattered and non-comprehensive manner. In the 'Guidelines for the Alternative Care of Children' it is argued that financial and material poverty should 'never be the only justification for the removal of a child from parental care'.[464] This is far from the reality in Rajasthan, where poverty is a main reason for institutionalisation. The Palanhar Yojna that is supposed to fulfil Article 18(2) in Rajasthan is facing severe obstacles in implementation. According to Foster Care India, more than 100.000 children have benefited from this scheme, but 'there are no mechanisms to monitor and track the beneficiaries, to identify additional potential beneficiaries'.[465] Similarly, the CRC Committee has expressed concern about India's 'lack of a national strategy and programmes to support parents and families in fulfilling their child-rearing obligations'.[466] There are some

[462] E.g. UN Committee on the Rights of the Child, 'General Comment No. 3' (17 March 2003) UN Doc CRC/GC/2003/3 para 35.
[463] Interview 40.
[464] UNGA Res 64/142 (24 February 2010) UN Doc A/Res/64/142 para 23.
[465] Foster Care India, 'National Consultation on: Promoting Non-Institutional Alternative Care (NIAC) for Children in Rajasthan: A Report' (Foster Care India, Udaipur 2014) <http://fostercareindia.org/wp-content/uploads/2014/11/Foster-Care-India-Consultation-Report.pdf> accessed 22 June 2017, 9.
[466] UN Committee on the Rights of the Child, 'Concluding observations on the combined third and fourth periodic reports of India' (7 July 2014) UN Doc CRC/C/IND/CO/3-4 para 55.

employment schemes and self-help groups for women that are meant to empower people in rural areas and reduce poverty so they are capable of taking care of their children.[467] It was not the object of this study to evaluate the effect of these schemes, and it is doubtless that they do reach some, perhaps many, beneficiaries. The fact is, however, that they are far from working comprehensively. Many children are still living in institutions due to poverty and HIV/AIDS-infection, which would not be the case if the schemes worked as they should. Respondents complained about implementation problems with government schemes, as well as lack of data to reach all potential beneficiaries. Apart from state measures, the CRC Committee has also suggested that preventative measures could extend to the community, to 'seek alternative measures within the community for the institutionalization of children'.[468] In Rajasthan, Foster Care India was an example of this, but the amount of NGOs advocating de-institutionalisation are very few compared to those providing institutional care. Related to these measures to prevent institutionalisation, is prevention of its root causes. The obligations that ICESCR pose on India suggest that especially poverty needs to be addressed more comprehensively, e.g. through the right to food, to an adequate standard of health, education and more.[469]

CRC's Article 3(3) states that States parties should ensure that institutions conform with the standards established by competent authorities, closely linked to the 'suitability' criteria of Article 20. To a large extent, these criteria were fulfilled by the authorities and Aashray, except for the requirements of professional staff trained in child protection, family re-integration programmes, and an overall de-institutionalisation strategy with the goal of progressive elimination of institutions.[470] The CRC Committee consistently encourages states to phase out institutional care in its Concluding Observations,[471] but Aashray and Rays were dreaming and planning to expand their facilities rather than phasing them out.

The 'Guidelines for the Alternative Care of Children' asks states to tackle discrimination on the basis of any status of the child or parents, including HIV/AIDS.[472] HIV/AIDS stigma and

[467] Interview 24.
[468] UN Committee on the Rights of the Child, 'Day of General Discussion. Children Without Parental Care' (17 March 2006) UN Doc CRC/C/153 para 674.
[469] Cf. Paul Hunt, Manfred Nowak and Siddiq Osmani, 'Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies' UN Doc HR/PUB/06/12 (UN OHCHR, Geneva 2012) ch III.
[470] UNGA Res 64/142 (n 464) para 15.
[471] Nigel Cantwell, 'The human rights of children in the context of formal alternative care' in Wouter Vandenhole and others (eds), *Routledge International Handbook of Children's Rights Studies* (Routledge, London; New York 2015) 268.
[472] UNGA Res 64/142 (n 464) para 9.

discrimination turned out to be a major causation factor of institutionalisation, as it occurred when separating HIV-infected children from their peers and placing them in institutional care. In their commentary on Article 20, Cantwell and Holzscheiter argue that when family is not available, the state should provide as far as possible for family-type alternatives for HIV-affected children.[473] This was largely not available in Rajasthan, as experienced by respondents. Instead, there are some government schemes under the National Aids Control Organisation (NACO), such as the Vihaan Care and Support Centre (CSC), but their existence is clearly not preventing discrimination to the point that institutionalisation of children is not necessary, partly because of the positive perception of institutions with the CSC staff, who often recommends care homes to HIV/AIDS-positive parents.

The implementation of the 'best interests of the child' principle is more problematic to evaluate due to its definitional difficulties. The critique of it being inherently subjective was indeed evident from the present case study, in which different respondent groups had different views on what would be in the best interest of the child. For example, some considered a family environment to be in a child's best interests, while others emphasised education and physical care. In his commentary on Article 3 of the CRC, Freeman concludes that 'the rights of the child precede the 'best interests' standard',[474] which in this case would mean that the right not to be deprived of a family environment (Article 20) would precede the best interests of the child. But who should define the best interests? All adult respondents seemingly had the children's best interests at heart. However, the authorities and experts largely agreed that only in very few circumstances could institutional care be in the best interest of the child,[475] while the parents were of the opinion that institutions would provide the 'best care' and thus be in the child's best interest. The Foster Care India founder gave an interesting example that illustrates the difficulty of this principle:

'our first foster family that we licensed, they asked to have a 2-4 year-old girl that associated with Hinduism if she associated with a religion. We found a girl, we matched them up. Her skin was dark, and so they said they wouldn't take her. And that made me very angry. But what they explained, and these are two professors, and they said, in our home it would have not been a big deal at all. But the second we went to our extended family, the second we walk into our community, she would have been so horribly stigmatized and traumatized that it wasn't in her best interest for us to

[473] Nigel Cantwell and Anna Holzscheiter, 'Article 20: Children deprived of their family environment' in A Alen and others (eds) *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007) 42.
[474] M Freeman, 'Article 3: The best interests of the child' in A Alen and others (eds) *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007) 9.
[475] Interviews 40; 42; 43.

take her'.[476]

The example of the dark-skinned girl can be an analogy to children with HIV/AIDS. It has to be acknowledged that it may not be in the child's best interests to be placed in a foster family as long as the stigma around the disease remains. Therefore, in many responses, living in the care home was deemed in the best interest of these particular children. Aashray's consultant and the HIV professionals expressed these views,[477] and the parents who chose to place their children in the care home were accepting the placement in their child's best interest.[478] The difficulty of determining what is in a child's best interest, differing between experts and parents, is similar to the common conflict between 'current interests' (needs) and 'future interests' (development).[479] The 'current' needs can be understood as material needs resulting from e.g. poverty or homelessness, which 'is clearly not in a child's best interests',[480] and it is difficult for parents and NGO workers to put these needs aside for future, developmental interests.

The difficulty of evaluating the implementation of the 'best interest' principle demonstrates the shortcomings of the implementation gap approach. While it is useful to point out gaps between law and realities, this approach sees only a one-way-street from treaties, through implementation, to practice. The localisation approach, on the other hand, questions the law itself based on local realities.

5.2 The localisation approach

The localisation approach highlights the importance of context. The context in this case includes the HIV stigma and poverty, which means that the child's immediate needs become a priority. It is a context in which NGO-run institutions fill the gap of providing for HIV-infected/affected children, that the state is largely neglecting. Furthermore, the context demonstrated diverging views of the respondents: the authorities and experts prioritised differently than care home staff and parents when it came to institutionalisation; the former based themselves in Article 20 and detrimental psycho-social effects of institutionalisation, while the latter saw the immediate needs of discriminated and poor children as the problematic issue. The case is thus an example of something

[476] Interview 43.
[477] Interview 45; Field notes 4 March 2017.
[478] Interviews 27-30.
[479] Freeman (n 474) 3.
[480] ibid 27.

different than the numerous 'localising human rights case studies' on how civil society organisations appropriate rights discourses strategically in their work.[481] It shows instead how something that is perceived as a human rights issue at the international level (de-institutionalisation), is barely considered a problematic issue at the community level. Its root causes (such as poverty and discrimination based on misconceptions about how HIV/AIDS spreads) are framed as problems both locally and globally, but while the institutions themselves are seen as harmful at the global level, they are considered positive solutions on the ground. In this way, the case is an example of 'localisation' in the sense of whether to accept the idea of children's rights locally, rather than adopting a rights discourse in local struggles.[482]

It is important to underline that this study is by no means questioning the long-term objective of de-institutionalisation. The localisation approach can indeed include the recognition that child rights, hereunder de-institutionalisation, are ultimately a goal to be pursued. However, what the localisation approach adds, is an acknowledgement that different local contexts require different strategies. There is a tendency in much rights-based de-institutionalisation literature to condemn institutions for the work they are doing, but I would argue that this risks a harmful, non-contextualised de-institutionalisation. Cantwell questions the '…unhelpful and unwarranted amalgam between residential care and institutional placements, where anything other than a family-based care setting tends to be unjustifiably decried, not to say demonized'.[483] I would agree, because many of the existing institutions are simply trying to address social problems in their society, such as poverty. Bilson and Cox argue that just as with institutionalisation, there is vast scientific evidence of the detrimental psycho-social effects of being brought up in poverty.[484] In their view, the positive perception of institutions relates to a 'rescue mentality' which 'is a key factor in maintaining the practice of using institutional care'.[485] To illustrate this, let us take an example from the case study.

[481] E.g. Koen De Feyter and others (eds), *The Local Relevance of Human Rights* (Cambridge University Press, Cambridge 2011); Gaby Oré Aguilar, 'The local relevance of human rights: a methodological approach' in Koen De Feyter and others (eds), *The Local Relevance of Human Rights* (Cambridge University Press, Cambridge 2011); Carolyn Heitmeyer and Maya Unnithan, 'Challenges in "Translating" Human Rights: Perceptions and Practices of Civil Society Actors in Western India' (2014) 45(6) Development and Change 1361; Wouter Vandenhole, 'Localizing the Human Rights of Children' in Manfred Liebel, *Children's Rights from Below: Cross-Cultural Perspectives* (Palgrave Macmillian, Hampshire 2012) 80.

[482] Wouter Vandenhole (n 481). Cf. also 1.2 above.

[483] Cantwell (n 471) 268.

[484] Andy Bilson and Pat Cox, 'Caring about Poverty: Alternatives to Institutional Care for Children in Poverty' (2007) 13(1) Journal of Children and Poverty 37.

[485] ibid 48.

When Aashray's consultant explained my research topic to the HIV professionals, he said that he found it interesting how we learnt in our human rights course about the international norms on how growing up in a family environment is always better; because in his view, the people who wrote this did not know India. How could they assume that these specific children would not get the necessary emotional, mental and physical development in institutions, which they would have gotten in a family environment? In the case of HIV-infected children in rural Rajasthan, he argued, it was the exact opposite: once the children had been diagnosed with HIV, they were marginalised within the extended family with separate room, bed, eating utensils etc. They were made to do more work, they were not getting to play with the other kids, all things that harms their development. However, if they grew up in an institution like Aashray, they would be surrounded by people who knew that HIV does not transmit in children's everyday activities, and they would be treated as any other children.[486] The HIV professionals agreed, arguing that cares homes like Aashray were places where children could get the care they would not get at home, such as good education, treatment and care. They did not consider a 'gap in seeing your parents' as harmful for a child.[487] This view also came through in interviews with some care home staff, who underlined that the village would be the place with detrimental psycho-social effects, while the care home was a 'normal life'.[488]

The localisation approach in this case has also helped to shed light on the social functions that Aashray was fulfilling other than just child care: education, a means of parents to 'rescue' their children from extreme poverty, and a supportive environment for the community of people living with HIV/AIDS. One ethnographic case study cannot say what these functions might be in other contexts, but it does suggest that acknowledging the social functions of institutions in any context is important. As an example, the social function of uniting the community of people living with HIV/AIDS could be seen as an asset to de-institutionalisation, as the founder of Foster Care India explained: one could create a network of foster families who had experienced HIV/AIDS, and they would be more willing to take infected children in their care.[489]

This study has demonstrated significant gaps between, on the one hand, international human rights law on the rights of the child, psychological studies on institutions, and the views of local authorities and experts; and on the other, practice on the ground and the views of care home staff,

[486] Field notes, 4 March 2017.
[487] Interview 45.
[488] Interview 37.
[489] Interview 43.

parents and HIV professionals. Changing long-time practice on the ground is difficult: when parents see how their children can be 'rescued' from the circle of poverty they live in themselves, and donors are willing to pay, the supply and demand for orphanages reinforces itself. However, the gaps between law and reality could be addressed by, firstly, preventative measures, or fighting root causes of institutionalisation; secondly, creating awareness about the detrimental effects of institutionalisation, rather than demonising it, especially to target groups such as at-risk parents, existing institutions, and importantly, donor countries; and providing alternatives that take the social functions of existing institutions into account.

6 Conclusion

For decades, it has been widely agreed by scholars that institutional care has negative developmental consequences for children. While orphanages have been phased out in a number of western countries, these same countries have continued to support institutional care in 'developing' countries. This contradiction is being addressed by many NGOs who are working towards de-institutionalising child care, often appealing to arguments of a child's rights related to growing up in a family environment, such as Article 20 of the CRC. Still, a large number of institutions are functioning and even expanding on the ground. This study has focused on the institutionalisation of HIV-infected/affected children in India, who are part of a globally widespread poverty-led institutionalisation. Through a case study of a care home in Rajasthan, the thesis has contributed to the emerging field of connecting human rights with de-institutionalisation, and specifically to theories of 'localising child rights', following scholars such as Merry, Vandenhole, Oré Aguilar and Cantwell. However, contrary to many other 'localising human rights' studies, this case dealt with an issue (institutionalising children) that was not considered a 'rights' issue, or even a problematic issue, by the affected community of parents and institution staff – in fact, it was considered a solution to other problems. These problems, or causation factors of institutionalisation, were identified as a widespread HIV/AIDS stigma, poverty and the rural/urban divide, and lack of functional alternatives to institutionalisation. Furthermore, the thesis has demonstrated that the institution in case played certain functions in society apart from child care. With these conclusions, the thesis has argued that the classic 'implementation gap approach' to children's rights studies needs to be complemented by a 'localisation approach' that emphasises contextualisation in order for human rights to be relevant in diverse contexts. While a 'global call' to end a practice such as institutionalisation is admirable, it is unrealistic to expect a global solution. Children's rights as enshrined in the CRC are useful as overall guidelines; for example, Article 20's acknowledgment that children living outside a family environment are vulnerable, can be a point of departure at both local and global levels. However, de-institutionalisation will not be effective by recourse to a global recipe. Instead, local causation factors and social functions played by institutions should be central parts of de-institutionalisation strategies.

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Appendix 1: Lists of interviews

Children								
Interview no.	**Type of interview**	**Gender**	**Age**	**Date**	**Place**	**Length**	**Language (main/secondary)**	**Notes**
1	Semi-structured individual interview	Male	18	1 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	English	
2	Semi-structured individual interview	Male	23	1 March 2017	Medical Room, Aashray (Boys' Home)	6 min.	English/Hindi	
3	Semi-structured individual interview	Male	18	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	English/Hindi	
4	Semi-structured individual interview	Male	10	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	Hindi	
5	Semi-structured individual interview	Male	12	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	Hindi	
6	Semi-structured individual interview	Male	12	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	Hindi	
7	Semi-structured individual interview	Male	10	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	Hindi	
8	Semi-structured individual interview	Male	9	1 March 2017	Medical Room, Aashray (Boys' Home)	5 min.	Hindi	
9	Semi-structured individual interview	Male	10	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	Hindi	
10	Semi-structured individual interview	Male	10	1 March 2017	Medical Room, Aashray (Boys' Home)	4 min.	English/Hindi	
11	Semi-structured individual interview	Male	12	1 March 2017	Courtyard, Aashray (Boys' Home)	3 min.	Hindi	
12	Semi-structured individual interview	Male	15	1 March 2017	Courtyard, Aashray (Boys' Home)	3 min.	Hindi	

13	Semi-structured individual interview	Male	12	1 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	Hindi	
14	Semi-structured individual interview	Male	6	1 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	Hindi	
15	Semi-structured individual interview	Male	10	1 March 2017	Courtyard, Aashray (Boys' Home)	3 min.	Hindi/English	
16	Semi-structured individual interview	Female	16	2 March 2017	Common room, Aashray (Girls' Home)	3 min.	Hindi	
17	Semi-structured individual interview	Female	13	2 March 2017	Dorm, Aashray (Girls' Home)	3 min.	Hindi	
18	Semi-structured individual interview	Female	16	2 March 2017	Common room, Aashray (Girls' Home)	3 min.	Hindi	Not recorded
19	Semi-structured individual interview	Male	11	4 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	Hindi	
20	Semi-structured individual interview	Male	13	4 March 2017	Medical Room, Aashray (Boys' Home)	2 min,	Hindi	
21	Semi-structured individual interview	Male	15	4 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	Hindi	
22	Semi-structured individual interview	Male	17	4 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	Hindi/English	
23	Semi-structured individual interview	Male	13	4 March 2017	Medical Room, Aashray (Boys' Home)	3 min.	Hindi	
24	Semi-structured individual interview	Female	8	6 March 2017	Dorm, Aashray (Girls' Home)	3 min.	Hindi	
25	Semi-structured individual interview	Male	7	6 March 2017	Dorm, Aashray (Girls' Home)	2 min.	Hindi	

26	Semi-structured individual interview	Male	7	6 March 2017	Dorm, Aashray (Girls' Home)	2 min.	Hindi	

Families						
Interview no.	**Type of interview**	**Characteristics**	**Date**	**Place**	**Length**	**Language**
27	Semi-structured individual interview	Mother of three children living in Aashray	8 March 2017	Medical room, Aashray (Boys' Home)	5 min.	Hindi
28	Semi-structured individual interview	Mother of one child living in Aashray	10 March 2017	Dorm, Aashray (Boys' Home)	4 min.	Hindi
29	Semi-structured individual interview	Father of two children living in Aashray	10 March 2017	Dorm, Aashray (Boys' Home)	4 min.	Hindi
30	Semi-structured group interview (2 respondents)	Uncle and aunt of one child living in Aashray	10 March 2017	Dorm, Aashray (Boys' Home)	5 min.	Hindi
31	Semi-structured group interview (2 respondents)	Mother and grandmother in HIV-affected family living at home with her children	10 March 2017	Respondent's home	7 min.	Hindi

Care home staff							
Interview no.	**Type of interview**	**Job title**	**Date**	**Place**	**Length**	**Language (main/secondary)**	**Notes**
32	Semi-structured individual interview	Founder and Director, Aashray	1 March 2017	Medical room, Aashray (Boys' Home)	45 min.	English/Hindi	
33	Semi-structured individual interview	Warden, Aashray	2 March 2017	Medical room, Aashray (Boys' Home)	8 min.	Hindi	
34	Semi-structured individual interview	Consultant, Aashray	3 March 2017	Medical room, Aashray (Boys' Home)	40 min.	English/Hindi	

35	Semi-structured individual interview	Educator, Aashray	4 March 2017	Medical room, Aashray (Boys' Home)	6 min.	Hindi	
36	Semi-structured individual interview	Care taker, Aashray	6 March 2017	Dorm, Aashray (Boys' Home)	10 min.	Hindi	Not recorded
37	Semi-structured individual interview	Vice President, Rays	7 March 2017	Dorm, RAYS (Boys' Home)	29 min.	English	
38	Semi-structured individual interview	Secretary and Founder, Rays	7 March 2017	Dorm, RAYS (Boys' Home)	12 min.	English	
39	Semi-structured individual interview	Care taker, Aashray	8 March 2017	Medical room, Aashray (Boys' Home)	12 min.	Hindi	

Authorities							
Interview no.	**Type of interview**	**Job title**	**Date**	**Place**	**Length**	**Language (main/secondary)**	**Notes**
40	Semi-structured individual interview	Ex-member of Child Welfare Committee, Jaipur District	5 March 2017	Respondent's home	47 min.	English/Hindi	
41	Semi-structured individual interview	Programme Manager, Child Rights Department, Rajasthan	9 March 2017	Hotel	45 min.	English	Not recorded

Experts						
Interview no.	**Type of interview**	**Job title**	**Date**	**Place**	**Length**	**Language**
42	Semi-structured individual interview	Project Director, Antakshari Foundation	10 March 2017	Respondent's office	26 min.	English
43	Semi-structured individual interview	Founder, Foster Care India	11 March 2017	Respondent's home	28 min.	English

HIV professionals						
Interview no.	**Type of interview**	**Job title**	**Date**	**Place**	**Length**	**Language (main/secondary)**
44	Unstructured individual interview	Consultant nurse specialised in HIV/AIDS	4 March 2017	Medical Room, Aashray (Boys' Home)	27 min.	English/Hindi
45	Unstructured group interview (4 respondents)	Pharmacist, nurse, nurse, data manager	4 March 2017	Vihaan Care and Support Centre	42 min.	Hindi/English
46	Unstructured group interview (14 respondents)	14 staff members, primarily outreach workers of Vihaan Care and Support Centre for people living with HIV/AIDS	4 March 2017	Vihaan Care and Support Centre	19 min.	Hindi/local Hindi dialect with translator

Appendix 2: Guides for semi-structured interviews

1. **Interview guide – children**
    - **a.** What is your name?
    - **b.** How old are you?
    - **c.** Can you tell me about when you arrived here at the care home?
    - **d.** For how long have you been living here?
    - **e.** Do you like to live here?
    - **f.** What do you like about the care home?
    - **g.** What don't you like?
    - **h.** What do you do during the day here?
    - **i.** Who is in your family?
    - **j.** Where do they live?
    - **k.** Do you sometimes visit them? Do they visit you?
    - **l.** Do you like to be in your village/home?
    - **m.** What do you like to do there?
    - **n.** Where would you like to live?
    - **o.** How is your school?
    - **p.** What would you like to become when you grow up, and where would you like to live?

2. **Interview guide – relatives of children living in the care home**
    - **a.** What is your name?
    - **b.** How many of your children/nephews/nieces are living at the care home?
    - **c.** How long have they been living here?
    - d. Where do you live?
    - e. Is the child often coming home to visit?
    - f. Why is the child living in the care home?
    - g. How was it decided that the child should live here?
    - h. What do you think about the care home?
    - i. In your opinion, where is the best place for a child to live?
    - j. If you would like to share it, since when have you had HIV?
    - k. Are you disclosing your HIV-status to relatives, neighbours, society?
    - l. What do people think about HIV in your village/town?
    - m. How did your and the children's lives change after getting HIV?

3. **Interview guide – family affected by HIV not using the care home**
    - **a.** What is your name?
    - **b.** How many children do you have?
    - **c.** Do your children have HIV?
    - d. If you would like to share it, since when have you had HIV?
    - e. Are you disclosing your HIV-status to relatives, neighbours, society?
    - f. What do people think about HIV in your village/town?
    - g. How did your and your children's lives change after getting HIV?
    - h. Do your relatives help you in taking care of your children?
    - i. Does the government help you in any way?
    - j. Why have you chosen not to send your children to a care home?

k. In your opinion, where is the best place to live for your child?
l. How does a normal day in your and your children's life proceed?

4. Interview guide – manager level care home staff

a. What is your name and title?
b. Could you tell me a typical story of how some of the children ended up here, using a few examples of children you know well?
c. Why were other options than institutionalisation not considered/chosen for these children?
d. How is the care home working with the families of the children in the process of institutionalisation?
e. HIV seems like the main reason that the children live in the care home. Do you think poverty is also a reason?
f. Do you think anything could have been done to avoid that the children ended up here? If yes, what?
g. Have there been any cases where the children have been placed here against the parents' will?
h. How is the government involved in the care home? How do they check that you comply with their standards? Do you think the level of government involvement is good?
i. Do all the children have birth certificates? If no, what are the obstacles for those who don't?
j. What kind of child care training do your staff members have?
k. In your experience, are these the bulk of children with HIV in Rajasthan, or are most of them living at home while these are the exception?
l. What do you think about the segregation of HIV-infected/affected children from other children in institutions?
m. Do you think the children are experiencing much discrimination in their villages? Here?
n. Are there specific challenges for a girl child with HIV? If yes, which?
o. Do you have specific plans for each child? What do these contain? Are there plans to reintegrate the children into their communities?
p. Is this a permanent institution for the children?
q. What is the long-term goal of the kind of social work you do?
r. What do you think is the best environment for a child to grow up in?
s. Do you know the word de-institutionalisation? If yes, do you think it is important? If no, could you imagine being a centre with various activities helping families rather than a residential place? Do you think you would lose donors in such a process?
t. What do you think about foster care as an alternative to institutions?
u. What do you think about the future of this care home? What are the goals of the building of a new care home?
v. Most of the children said in their interviews with me that they were very happy here. Where do you think such a statement comes from?

5. Interview guide – warden at care home

a. What is your name and title?
b. For how long have you been working here?
c. What are your daily tasks here?
d. Have any new children arrived in that time? If yes, what is your experience of where the children come from, and what the process is of the children coming here?

e. How is the collaboration between the government and the care home?
f. Do you think the children experienced a lot of discrimination in their villages compared to here?
g. Why can't the children live with their relatives?
h. Do you think poverty has a role to play in why the children are here?
i. In your opinion, is there a need for more care takers?
j. What do you think about the plans for a new care home?
k. In your opinion, what is the best environment for a child to grow up in?

6. Interview guide – care taker staff

a. What is your name and title?
b. What are your daily tasks here?
c. For how long have you been working here?
d. What do you think is functioning well here? Less well?
e. Is it difficult to take care of so many children?
f. Do you have a personal relationship with the children?
g. Most of the children said in their interviews with me that they were very happy here. Do you think that is right?
h. What do you think is the best environment for a child to grow up in?

7. Interview guide – authorities

a. What is your name and job title?
b. Which laws/frameworks govern institutionalisation of children in Rajasthan?
c. What is the typical process, from a child is deemed not being able to live with his/her parents, to being sent to an institution?
d. Do you keep a record of which residential institutions exist in Rajasthan? How do you make sure that they comply with your standards?
e. Whose primary responsibility do you think it is to provide for children who cannot live with their families?
f. What do you think is the best environment for a child to grow up in?
g. How does the Rajasthani authorities support families in child-rearing, to avoid institutionalisation?
h. How do your prevent further spreading of HIV/AIDS, and what types of awareness programs do you have against stigma and discrimination?
i. What is the department's approach to children with HIV?
j. What is your view on placing children with HIV in separate institutions from other children in need of care and protection?
k. Is your department working within the international norms on child rights, such as the Convention on the Rights of the Child? If yes, how?
l. What is the relation between the central government and the state government in relation to institutionalisation and implementation of international norms?
m. What is your view on the fact that NGOs, not the government, is running most child care institutions in Rajasthan? Who do you think ideally should do this work?

8. Interview guide – Antakshari Foundation child protection expert

a. What is your name and job title?
b. Can you tell me a bit about your organisation?
c. What is the process of institutionalisation of children in Rajasthan?
d. What is your opinion on institutionalised versus family-based care? On de-institutionalisation?

e. What do you think about foster care, and its potential in India and Rajasthan?
f. What do you think about the relation between NGOs and government as providers of institutional care?
g. What do you think are the root causes of institutionalisation?

9. Interview guide – founder of Foster Care India

a. What is your name and job title?
b. Can you tell me a bit about your organisation?
c. What is your opinion about children growing up in institutions, specifically in Rajasthan?
d. Do you think the Child Welfare Committee too often places children in institutions instead of considering other options? If yes, why do you think they do this?
e. What do you think are the root causes of institutionalisation that need to be fought?
f. Do you think institutions are necessary or inevitable as a last resort?
g. Do you think there can be any "good" institutions? If the child gets enough carers, small-sized units, good food, good education, freedom etc.?
h. In Rajasthan there is a widespread and deep stigma of HIV/AIDS, and often children and/or parents are ostracised from their larger families and communities if they disclose the disease. It is therefore arguably in their best interest to grow up in an institution where they are not stigmatised, but treated as normal children and getting regular medicine, than with discriminating relatives. Do you agree? Or do you see any alternatives for HIV/AIDS-infected children in Rajasthan?
i. Are your organisation's goals based in international norms and conventions, e.g. CRC? Do you see any gap between these norms and the realities in Rajasthan?
j. What do you think the obstacles for an effective foster care system in Rajasthan is?
k. Are there any downsides of foster care? Aren't institutions and foster care both potentially good or bad, depending on the institution/the foster family?
l. What do you think about the relation between NGOs and the government in Rajasthan? Is it functioning as it should?
m. 80% of the kids whom I talked to said they preferred living in the care home. Isn't that also something we should take into account?