FROM INSTITUTIONS TO THE COMMUNITY:

The Fundamor experience of transforming care for HIV-positive children and young people in Colombia

LUMOS

Protecting Children. Providing Solutions.

ABOUT LUMOS

Lumos, an international non-profit organisation founded by J.K. Rowling, is dedicated to ending the institutionalisation of children by 2050 – a practice that decades of research have shown is harmful to child development. We work with governments, UN agencies, civil society, community, families and children to ensure the right of every child to family life and transform the lives of estimated eight million children currently living in institutions and orphanages. We help countries transform education, health and social care systems for children and their families, and help move children from institutions to family and community-based care. By advocating at all levels, collaborating widely and running evidence-based demonstration programmes that prove reform can work, we are able to achieve maximum impact from our funding to benefit some of the most vulnerable children in the world.

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Executive summary

Colombia has made significant advances in recent years, yet the country still struggles with conflict-related violence and poverty, especially in rural areas. There is also insufficient access to services and support in the community, and over 11,000 children are currently living in residential institutions.

More than 80 years of research and evidence demonstrates that institutionalisation causes serious harm to children's health, development and future life chances. Family-based care results in much better outcomes for children and is less expensive than institutional care.

A global movement is growing that is raising awareness of the harm caused by institutions and influencing governments, civil society and communities to end the reliance on institutional care and develop family and community-based services instead. This is also true of Colombia. State authorities and civil society have discussed the need to transform systems of care and move away from institutions for several years, but achieving this in practice is challenging.

Fundamor, a renowned NGO that specialised in providing services for HIV-positive children, decided to try to close its institution and move children to family-based care. The institution had been established at a time when state support for HIV-positive people was in its infancy. Insufficient access to adequate health care, coupled with poverty, led parents of HIV-positive children to bring them to the Fundamor institution. Over time, the leadership of Fundamor noticed that whilst children received good health care, nutrition and education, they were not developing as they would in a family environment. Fundamor became concerned about the children's independence and ability to cope in the community once they left the institution.

Fundamor sought out a range of partners and, with training, guidance and funding from Lumos, it embarked on a process of transforming care. Since 2015, Fundamor has worked in partnership with Lumos to ensure the care transformation process is carried out thoughtfully, striving at all times to ensure each child's best interests were met.

This report documents that process, drawing out successes and challenges.

Fundamor discussed its plans with the Colombian Family Welfare Institute (ICBF), the government department responsible for children in care, who did not yet have resources to lead care transformation across the country. ICBF did, however, endorse Fundamor's care transformation programme, and supported the process in whatever way it could.

Fundamor and ICBF should be congratulated for this pioneering care transformation, particularly since it addressed the needs of a group of children with complex needs, who suffer considerable stigma in society.

Overall, the care transformation was a success, with most children placed in sustainable family environments that met their needs and improved their quality of life and inclusion in society. However, the process of transforming care is not without risk. To ensure all children are safe and their rights are respected, every decision must focus on the child's best interest. Each element of the process must be carefully planned and costed, and resources found, to ensure good outcomes for children and long-term sustainability of any new services established. Placing children from Fundamor into families also required ensuring they would continue to access the health care they needed to survive and thrive.

The key challenges in this care transformation included:

- **Unrealistic timescales.** Initially, Fundamor planned to complete the process for 52 children within a year. However, the recruitment of sufficient and appropriate foster families for those children who could not be reunited with their families proved challenging. Fundamor sought financial support from Lumos to extend the process by a further year. At the end of the process, families had still not been found for a small number of children. Fundamor would receive no more funding from ICBF for its residential programme, as its licence as an institution service provider had come to an end. At this point, the family advocates saw no other option but to place the remaining children in other institutions.
- **Regulatory restrictions.** Since Fundamor was not a foster care provider, it had no right to follow up children in foster families unless the family advocates and foster families agreed. Where it was possible to carry out the follow-up, it was a vital component in the process, due to Fundamor's specialist expertise in the treatment and support of HIV-positive children. Moreover, the personnel knew the children best and so their follow-up eased the distress of transition for the children.
- **Insufficient or inconsistent cooperation from ICBF's regional office and family advocates.** Although ICBF at national level was supportive of care transformation, some regional representatives were less enthusiastic. In particular, some expressed the belief that HIV-positive children are better cared for in institutions and did not believe any families would want to foster these children. Some family advocates were supportive and engaged constructively with Fundamor personnel. Others refused Fundamor permission to follow up children.
- **Insufficient resources to fund the transition from institutional to family-based care.** As children gradually moved from Fundamor, ICBF's funding reduced, since it is provided on a 'per child' basis. Without a grant from Lumos, Fundamor would have been unable to continue providing high-quality care, whilst preparing children to move into families and following up those who had already moved.
- **Stigma and discrimination.** Fears around HIV and a lack of knowledge of how to manage this health condition led to challenges in recruiting enough foster families, as well as prejudiced attitudes and approaches on the part of some practitioners.

Despite these challenges, Fundamor was able to carry out the care transformation with overall success. Highlights of the process include:

- careful and thorough assessment of children and families
- full participation of children and young people in the care transformation process and in decisions that affected them
- careful training and selection of high-quality foster families
- awareness raising and training of relevant stakeholders to reduce stigma around HIV and increase knowledge of how to handle the health condition
- thorough follow-up of those children for whom it was legally possible.

In addition, Fundamor continues to advocate for the children who were moved to other institutions. The team still aims to find family care for these children.

The reform process undertaken by Fundamor demonstrated not only that transforming care for children and young people in Colombia is possible, but also that institutions can lead the process. The learnings from their experience can support other institutions and authorities in implementing change, and accelerate transformation across the country, away from institutions towards family and community-based care.

The results

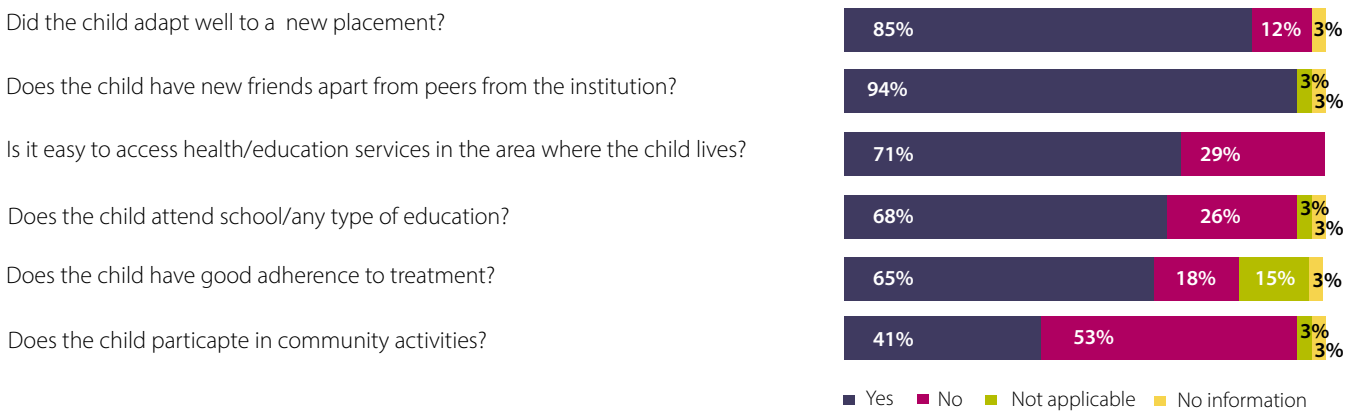
Children and young people do not need to grow up in institutions. Care can be provided successfully in families and services in the community. This includes children and young people who are HIV positive. However, children and families still face barriers to accessing universal services including education and health care, as well as targeted support services. This is particularly the case for those living in rural areas affected by the armed conflict. The care transformation process should pay special attention to these factors when planning alternative services.

At the outset, there were concerns that children's health would deteriorate, and that their quality of life would decrease when they moved from the institution to the community. However, this has not been the case. Data from Fundamor demonstrates:

- 85% of children were reported to have adapted well to their new placements
- 94% of them were reported to have made new friends
- 71% of children were reported to have 'easy access' to health and education services in their community – despite the existing barriers to accessing services
- 68% are attending school or another form of education.

Results show that children and families living in rural areas affected by armed conflict are the most likely to struggle to access services.

Adaptation and access to services (2018)

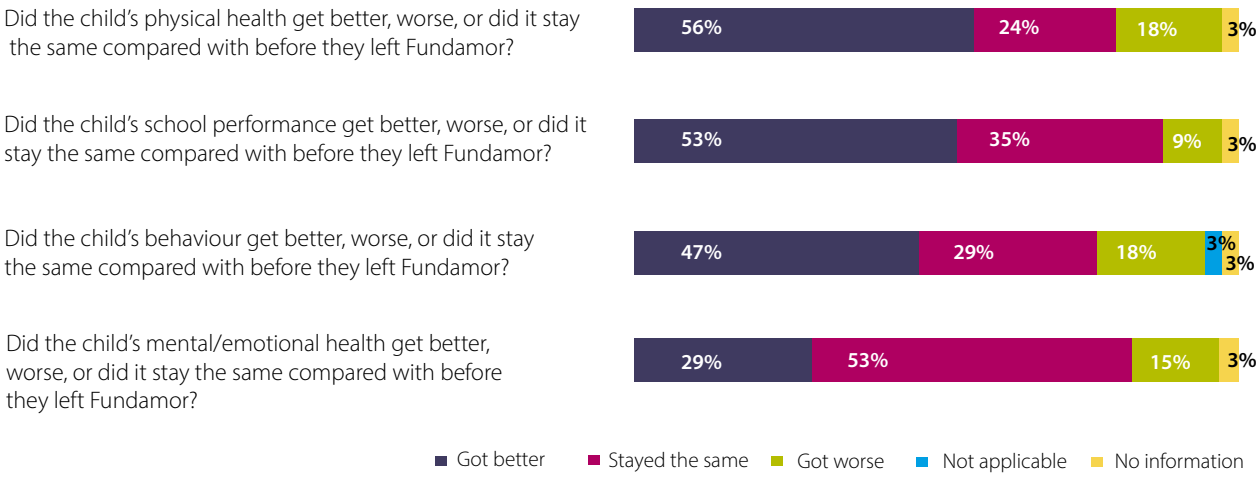


Base: All children in family or community care. (34)

Furthermore, follow-up data from Fundamor showed:

- 80% of children's physical health stayed the same or improved since leaving
- 65% were reported to adhere well to their HIV-related treatment – this is a particularly important finding, as ensuring good physical health in the community for HIV-positive children and young people was a major concern for many actors in the transformation process
- 82% of children's mental/emotional health improved or stayed the same, and challenging behaviours had improved for 47% of children.

Changes compared with when the children left Fundamor



Financial considerations of the transformation process

To implement a major reform such as care transformation, professional capacity and resources are needed. Naturally, this is major concern to governments and decision makers, who must identify resources both to carry out reform and to sustain newly developed services in the future. However, there are already significant resources in the current system which should be ring-fenced, or protected, and reinvested into the new higher-quality services.

Care transformation processes throughout the world have demonstrated that:

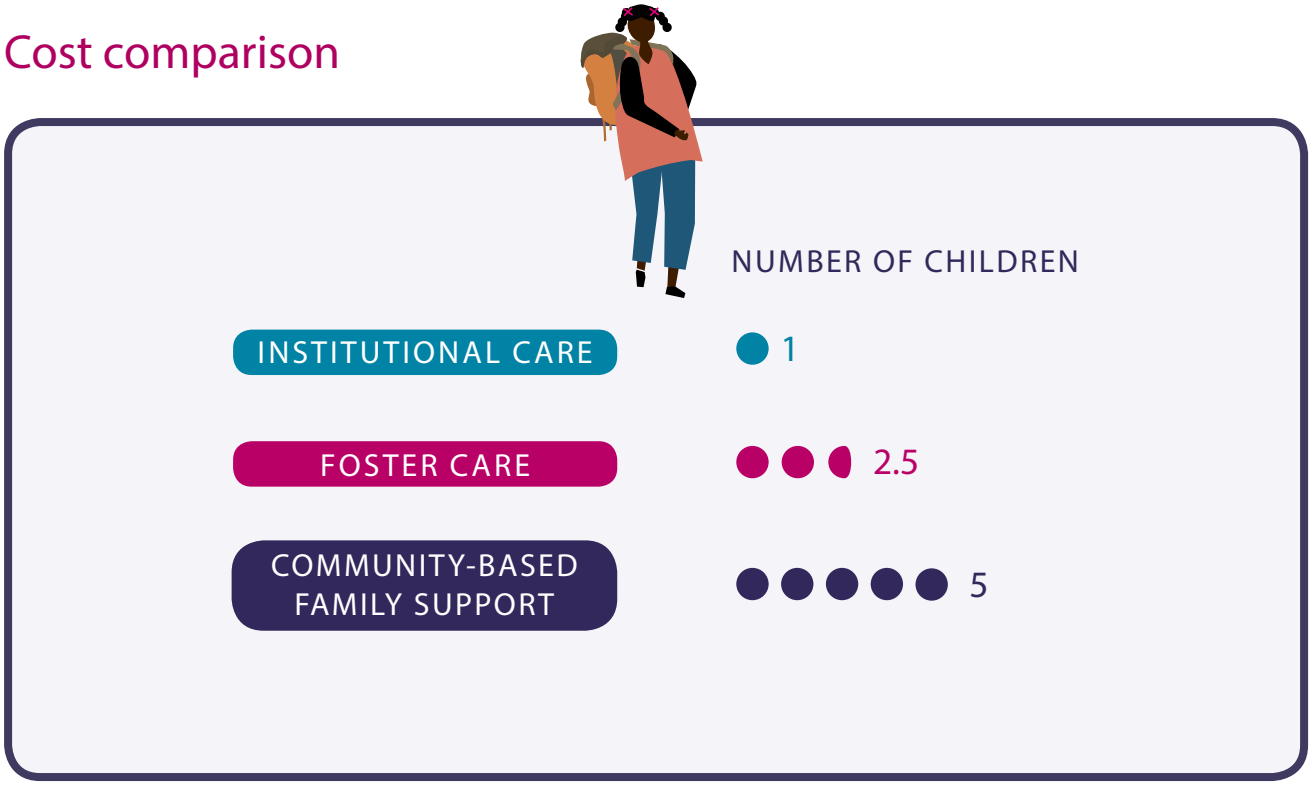
- Supporting children to live in their families, or in foster families, and providing services in the community is less expensive than caring for them in institutions.
- Since institutions are expensive and outcomes for children are poor, this represents poor value for money.
- If State authorities develop regulations to ring-fence, or protect, funds in institutions and transfer them across to family and community-based services, the State can help many more children live in better-quality family care and significantly reduce reliance on institutions.

Therefore, supporting children to live in families is less expensive and better outcomes for children also make it the most cost-effective option.

The Fundamor process demonstrated this is also true in Colombia. The following table compares the costs for one child to be cared for in an institution with costs in foster care, or in the birth or extended family (including staff to support the process of reunification and material support to the family).

Type of placement/support	Total annual cost (COP)	Total annual cost (USD)
Fundamor institution	27,600,000	8,835
Foster family care	10,711,998	3,429
Family support	5,376,000	1,721

The cost of one year of institutional care in Fundamor for one child is equivalent to the cost of supporting 5 children to live with their family in the community. The cost of one year of institutional care in Fundamor for one child could alternatively fund 2.5 foster family placements.



Clearly there are significant resources in the institutional system, which could be used to facilitate care transformation. According to ICBF data, the **annual cost to the State per child of institutional care is $6,189.** This is **equivalent to Colombia's Gross Domestic Product (GDP) per capita, which is $6,301.** Institutions generally commit at least a further $3,000 per child in order to meet the true cost of care for a child.

This makes institutional care in Colombia extremely expensive.

If these figures are extrapolated to the entire institutional system under ICBF in Colombia, which looks after over 11,000 children, the combined public and private annual budget for children's institutions would be: **US$110,000,000.**

However, at present, legislation does not allow for ring-fencing and redirection of budgets from institutions to community-based services. Therefore, as children gradually moved out of Fundamor, the State budget for the institution reduced. Without access to additional external funding to cover the period of transition, Fundamor would not have been able to implement such a careful and high-quality care transformation process.

Therefore, when planning care transformation across the country, it is recommended that ICBF put in place regulations to ring-fence and redirect resources from institutions to the newly established community-based services. External funding should be sought to cover the transitional costs of transforming care.

The transformation led by Fundamor demonstrates that:

- **It is possible for children and young people to live in families and communities, including those with special health care needs such as HIV.**
- **Children's lives can be considerably improved when they moved from institutions to families and communities.**
- **Family-based care is also cost-efficient.**

It is hoped that the learning from this experience provides evidence and insight to inform the development of a comprehensive national action plan for transforming care in Colombia. This would eventually guarantee the right of every child – including the most marginalised – to access all their rights to health care, education and protection, as well as their right to grow up and thrive in a family, fully included in the life of their community.

Summary recommendations:

Summary recommendations for key stakeholders, full recommendations are covered in chapter 5.

National ICBF:

- Lead the development of a national action plan for transforming care, working closely with Ministries of Education and Health and civil society organisations.
- Develop a clear regulatory framework to support initiatives to transform care, removing barriers to effective care and ensuring the best interests of the children are the central focus.
- Ensure the resources currently in the system are ring-fenced so that funds cannot be diverted away from the children and families during the care transformation process.
- Ensure collaboration and consistency of approach between ICBF at the national and regional levels.
- Empower children and young people to take a lead role in care transformation.

Regional ICBF:

- Support local care transformation processes and ensure effective coordination.
- Follow regulations, policies and standard operating procedures provided by ICBF national office.
- Undertake training and awareness raising with all key stakeholders locally to support care transformation.

Family advocates:

- Ensure regular ongoing monitoring and support for carers or a child's family to meet their needs.
- As new children require support, refer them to family and community-based services rather than institutions going through care transformation.
- Give children and young people opportunities to express their wishes and take their wishes into account when planning care placements.

Governments involved in transforming care for children who are HIV positive:

- Ensure that families and children have access to a comprehensive set of universal and specialist services.
- Ensure benefits, such as transport allowances, are available in advance to families, so they can access medical care and medicines on time. Ensure that families and young adults have comprehensive support after a new placement.
- Develop a strategy to address stigma and discrimination, particularly involving government departments responsible for health, education and child protection.

NGOs and institutions interested in completing a care transformation process:

- Seek official support from national and local government before embarking on a care transformation process.
- Empower children and young people to participate fully in the transformation process.
- Document learning and share this with other institutions and NGOs.

Donors:

- Prohibit investment in institutions and divert funds to care transformation.
- Prioritise investment in care transformation and in family and community-based services, such as inclusive education, community health care, family support services and alterative family care.

Purpose

The process of transforming care is complex. Transitioning to new forms of care and ensuring that all children's needs are met in the community can be a challenging prospect. This is particularly true when caring for children and young people with special health care needs such as HIV. There are fears that family and community-based services may not be able to meet children's needs effectively and that it will be a more expensive form of care and therefore unsustainable in the long term. Unfortunately, governments in many countries still believe that providing care and protection to children through institutions is the easiest and most cost-effective option. This report aims to dismantle these beliefs and demonstrate that although complex, the transition from institutions and towards family and community-based services is in fact financially sustainable and results in better outcomes for children, families and communities, including those with special health care needs such as HIV.

In particular, the purpose of this report is to:

- Document the first process of transforming care in Colombia, providing an analysis of the legal, regulatory, cultural and financial considerations, while highlighting barriers to reform and identifying practical solutions that have been successfully applied.
- Recount the process of closing an institution for children who are HIV positive, to demonstrate to countries in similar contexts that HIV-positive children do not need to be institutionalised and care can effectively be provided in the community.
- Demonstrate the significant resources within the current system of care for vulnerable children and the cost-efficiency of transforming the care system from institutions to family and community-based services.

It is hoped this report will be of use to:

- the Colombian Government, in particular the Colombian Family Welfare Institute (ICBF)
- Colombian service providers, including institutions considering reform
- other stakeholders across the globe who are interested in learning from the process of transforming care for children with special health care needs, including those with HIV.

Methodology and limitations

Lumos used a mixed methodology approach to collect data and information for this report, both from primary and secondary sources. The research was based on both quantitative and qualitative approaches to enable a comprehensive analysis of the issue. The quantitative approach focused on the financial analysis, cost comparison and the results of the children's experience of the reform. The qualitative approach focused on the experience of Fundamor, children and families. Two types of strategies were used: documentary analysis (Fundamor and Lumos documents) and narratives (collective and individual conversational techniques used in a reflective workshop, focus groups and individual key informant interviews). Every ethical aspect was considered, and informed consent was given by all the participants, including the legal authorisation of family advocates to approach children and foster families under their legal guardianship.

The limitations include the lack of comprehensive publicly available, up-to-date and consistent data on the current system, including on numbers of children and the detailed costs of services. Due to these limitations, the financial analysis should be treated as an estimate based on available sources of data. Follow-up measures on children's wellbeing compared with when they left the institution are based on the professional assessments of Fundamor staff and not on independent standardised measures.

Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ECLAC	The Economic Commission for Latin America and the Caribbean
ICBF	Instituto Colombiano de Bienestar Familiar (Colombian Family Welfare Institute)
IDP	Internally Displaced Person
LAC	Latin America and the Caribbean
MPI	Multidimensional Poverty Index
NGO	Non-Governmental Organisation
PAI	Proyecto de Atención Institucional (guidelines for institutional care)
PARD	Administrative Process for the Reestablishment of Rights
SGH	Small Group Home
SNBF	Sistema Nacional de Bienestar Familiar (National System of Family Welfare)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund

1. Introduction

COLOMBIA

IS CONSIDERED AN UPPER-MIDDLE INCOME COUNTRY[1]

It has a multidimensional poverty index (MPI) of **0.021**[2] and a GDP per capita of **$6,302**[3]

The country's neighbours **BRAZIL ECUADOR AND PERU** have MPIs of 0.016, 0.018 and 0.052,[5] and GDPs per capita of **$9,821, $6,273,** and **$6,572** [6] respectively.

In terms of MPI, Colombia ranks **11th** out of 20 developing Latin American and Caribbean countries listed in UNDP's Global MPI for 2018.[4]

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4. UNDP & OPHI. op. cit.
5. Ibid.

Background and context

Colombia has made significant advances in recent years, yet it still struggles with poverty, conflict-related violence, and – in many parts of the country – a lack of access to universal services, such as health and education. This precarious situation increases the risk of marginalisation of already vulnerable children and families. A report by UNICEF in 2015 found that one in every three children in Colombia lived in poverty, and children and young people in rural areas were between 2.4 and 2.8 times more likely to live in multidimensional poverty than those living in urban areas.[7]

An aspect of Colombia's history which has had a profound effect is the 52-year war between the government and various illegal armed groups. This war has left more than 220,000 people dead, 81.5% of whom were civilians.[8] More than 2,237,049 children and young people have been direct victims of the conflict.[9] In 2016, Colombia was the country with the highest number of internally displaced people (IDPs) in the world (7.4 million IDPs).[10] At least 63% of households that are considered displaced live in poverty, with one third living in extreme poverty.[11] The armed conflict affected rural areas in particular, where poverty is also prevalent.[12] In addition, people in rural areas generally struggle to access high-quality services, such as health care, particularly in regions with a large proportion of indigenous and Afro communities.[13]

A lack of access to services coupled with a high level of poverty can increase the risk of institutionalisation for vulnerable children. Access to health care is particularly important for those with special health care needs, such as HIV and AIDS. However, there can be numerous barriers to accessing services and support in Colombia, not only for children who are HIV positive, but also other vulnerable groups of children from rural and poor communities, or those affected by the conflict. This can result in institutions being viewed as the only viable option to care for these children.[14] However, institutionalisation is harmful to children's health and development, exposes them to a high risk of abuse and neglect, and denies children the right to be cared for by their family and supported in their community. Institutions are also more expensive than family-based care.[15]

Fortunately, many of the key building blocks for transforming care systems are already in place. Colombia has made progress in reducing reliance on institutions and has introduced a range of programmes aimed at preventing family separation. There are now various types of family and community-based care and support options available, which can be strengthened and built upon. There are also significant resources already in the institutional system which could be redirected to support more children to live in families, included in the community. As this report will demonstrate, it is essential that reform programmes are thoughtfully coordinated and implemented, and that they are implemented for all children, including those who are HIV positive.

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Fundamor

Fundación dar Amor (Fundamor) is an NGO focused on providing care and meeting the needs of children living with HIV/AIDS. Located in Colombia's third largest city, Cali, Fundamor was originally established in 1992 to support HIV-positive adults at a time when no other official forms of support existed in the country. After years of providing targeted programmes, Fundamor became well-known and respected for its support to HIV-positive people. Concerns around HIV-related stigma and discrimination, coupled with the lack of financial resources and access to services and support in the community, resulted in HIV-positive parents starting to bring their babies and children to Fundamor.
This is how Fundamor, with support of ICBF, started to provide institutional care for HIV-positive children. Over time, Fundamor became regarded as a pioneer of best practice in caring for HIV-positive children.

As the children grew older, the leadership and personnel at Fundamor began to realise that while they did everything they could to provide good care, the children were isolated from the community and were not developing as they would in a family environment. Fundamor became concerned about the children's inclusion in society and their need to live independently in the near future. The organisation took the brave decision to transform its care service if it were to guarantee that children and young people have all their needs met and rights fulfilled, including the right to family life.

Fundamor began searching for information about care transformation around the world and read about Lumos. Since 2015, the two organisations have worked in partnership, striving to ensure the care transformation process is successful and each element is carried out in the best interests of each child. Lumos has provided technical assistance, training and financial support. The ICBF national office also supported and endorsed Fundamor's initiative to transform care.

As yet, a national plan for transforming care has not been developed. However, the government, through ICBF and the strong legal child protection framework, recognises that children receive the best care in a family environment.

The Fundamor experience provides an opportunity to demonstrate how a transformation process should be implemented in practice. It is hoped the lessons learned from the successes and challenges during Fundamor's care transformation will assist ICBF and the government to move towards the development and implementation of a national action plan.

This experience also demonstrates that is possible and beneficial for children – including those with special health care needs such as HIV/AIDS – to be safely transferred from institutions and to family and community -based settings. The findings in this report support those of the growing body of evidence that transforming care results in better outcomes for children, families and communities, while also being cost-effective and financially sustainable.

Caring for children with HIV/AIDS in Colombia

HIV stands for human immunodeficiency virus. This virus can lead to acquired immunodeficiency syndrome, or AIDS, if left untreated. Unlike some other viruses, the human body is not able to get rid of HIV completely, even with treatment. Therefore, once a person contracts HIV, they will have it for life.[16] Over time and without access to effective treatment, HIV compromises the immune system, making the body more likely to get other infections or infection-related cancers. These opportunistic infections or cancers take advantage of the weak immune system, causing the person to enter the last stage of the HIV infection which is AIDS.[17] No effective cure currently exists, but with appropriate medical care, HIV can be controlled. When taken properly, medication can dramatically prolong the lives of people infected with HIV, keep them healthy, and greatly lower the risk of infecting others.[18]

According to UNAIDS, approximately 150,000 people live with HIV in Colombia,[19] of whom 1,800 are children aged 0 to 14.[20] Throughout Latin America and the Caribbean (LAC) region, an estimated 1.5 million adults and children are living with HIV.[21] LAC only represent 2.3% of the total worldwide HIV/AIDS prevalence, placed fourth after Sub-Saharan Africa, South Asia, and East Asia and the Pacific.[22] However, the spread of HIV is not consistent across the region, and the Caribbean region has the second highest HIV prevalence in the world.[23]

SEVEN

Caribbean countries reported a HIV prevalence of over 1% (Bahamas, Belize, Guyana, Haiti, Jamaica, Suriname, Trinidad and Tobago).

NINE

Latin American countries had a prevalence of over 0.5% (Brazil, Colombia, Ecuador, El Salvador, Guatemala, Honduras, Panama, Uruguay and Venezuela).[24]

COLOMBIA

represents 7.6% of the population of the LAC region,[25] the above estimates indicate that 10% of LAC's HIV-positive population live in Colombia.

One of the main causes of children becoming orphans in the LAC region is HIV/AIDS.[26] In Colombia, orphaned or abandoned children, including those who are HIV positive, are cared for by the Colombian Family Welfare Institute (ICBF) or specialised institutions, with the health system being responsible for ensuring access to health care and medication. Historically, NGOs have been the principal actors caring for or responding to the needs of HIV-positive children.[27]

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21. García, P. J., Bayer, A., & Cárcamo, C. P. (2014). The changing face of HIV in Latin America and the Caribbean. Current HIV/AIDS Reports, 11(2), 146-157.
22. World Bank(2018). Time to be efficient: HIV/AIDS in the Latin America and the Caribbean Region. http://blogs.worldbank.org/latinamerica/time-be-efficient-hivaids-latin-america-and-caribbean-region [Accessed 13 January 2018].
23. UNAIDS (2013). Global Report. UNAIDS report on the global AIDS Epidemic 2013. http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Global_Report_2013_en_1.pdf [Accessed 15 January 2018]. http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Global_Report_2013_en_1.pdf(annex epidemiology)
24. García, P. J., Bayer, A., & Cárcamo, C. P. (2014). op. cit.
25. United Nations Population Division (2017). World Population Prospects [electronic database]. https://population.un.org/wpp/DataQuery/ [accessed 28 February 2019].
26. RELAF (2010). Niños, niñas y adolescentes sin cuidados parentales en América latina. Documento de Divulgación Lationamericano. https://www.relaf.org/Documento.pdf p 11 [accessed 8 January 2018].
27. Barrios Acosta, M. E., Díaz Amaya, J. G., & Koller, S. H. (2013). Una respuesta institucional colombiana a niños/as que viven con VIH/SIDA. Ciência & Saúde Coletiva, 18, 507-516.

However, since the outbreak of HIV/AIDS in the LAC region in the 1990s, Colombia has made significant advances in providing for and meeting the needs of children more consistently.[28] In addition to a strong regulatory framework, Colombia's Ministry of Health, together with the United Nations Population Fund (UNFPA), developed evidence-based Clinical Practice Guidelines (CPG) on care for HIV-positive children under the age of 13. The CPG procedures facilitate a consistent approach to diagnosis and clinical management of the infection throughout the country.[29]

The Ministry of Health is one of the key ministries and is part of the National Family Welfare System (SNBF). The ministry guarantees all children access to health care, including specialised treatment and rehabilitation, and guidance and support to the family or carers.[30] The health system has two types of regimes: a contributory one for those in formal employment (or with ability to pay); and a subsidised regime, for the poorest population.[31] Across the country, work has been carried out to ensure adequate care is provided for people with HIV/AIDS. In theory, the poorest population are guaranteed access to treatment in public health services, with access to specialists and the necessary medication to manage the diagnosis.[32]

However, people encounter numerous obstacles to accessing these services, which mean they are not always available in practice. Obstacles include:

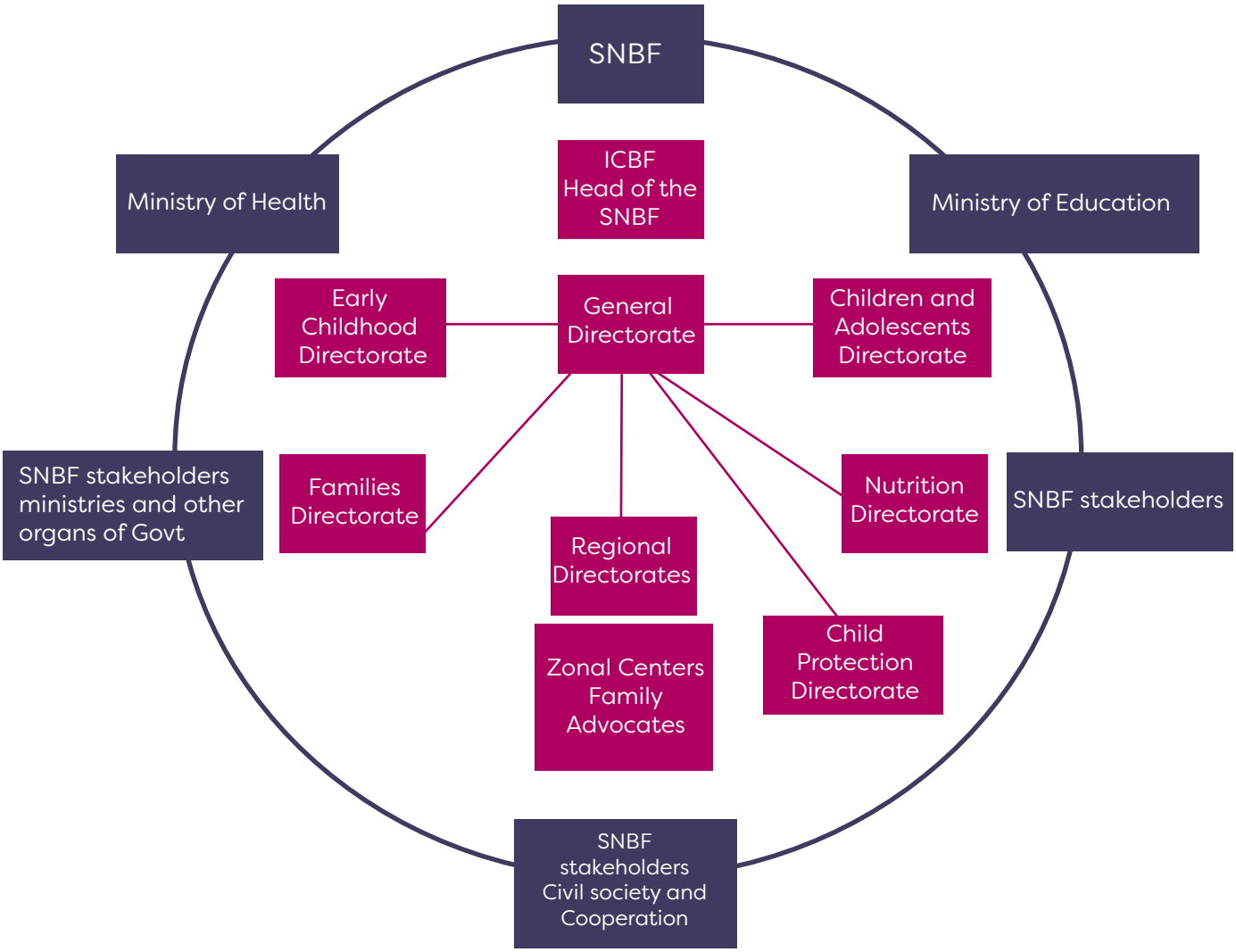
- few clinics and treatment centres in rural areas – rural populations must travel a significant distance to access medical care
- shortages of medication and lack of consistent access
- lack of adequate nutrition, affecting the effectiveness of the medication
- insufficient training, not just for families, but also for carers and health care professionals providing HIV services for children
- low levels of awareness of the diagnosis in the community, and how to support it
- HIV-related stigma and discrimination
- insufficient HIV medicines made specifically for children – for example, the bitter taste of the medicine can be difficult for children.[33]

Therefore, many people, especially children, find it difficult to follow the rigid treatment schedule vital to ensuring a prolonged and healthy life. Skipping medicines makes the HIV multiply, which increases the risk of the virus mutating and producing drug-resistant strains of HIV.[34] These obstacles and associated risks increase the likelihood of institutionalisation for affected children, as parents and professionals may view this as the only option to care adequately for the children. This is especially true for those children living in deprived areas, with even fewer options and support services.[35]

28. See annex III for an outline of relevant laws and policies.
29. Ministerio de Salud Colombia https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/VS/PP/GPC-corta-VIH-pediatrica-final.pdf p20
30. Ibid
31. Panamerican Health Organization http://www.paho.org/col/index.php?option=com_content&view=article&id=1241:perfil-de-los-sistemas-de-salud-colombia&Itemid=0
32. Alcaldia Cali(2015). Situación del vih/sida en el municipio de cali. http://calisaludable.cali.gov.co/saludPublica/2014_Publicaciones/BOLETIN%20EPIDEMIOLOGICO%20VIH.pdf
33. ibid
34. ibid & Trejos Herrera, A. M., Tuesca Molina, R. D. J., & Mosquera Vásquez, M. (2011). Niñez afectada con VIH/SIDA: Uso y acceso a Servicios de Salud en cinco ciudades colombianas. Salud Uninorte, 27(2).
35. Pezeshki, A., Mamalis, C., & Disabato, A. (2012). Op. cit.

The child protection system in Colombia

Colombia has a set of comprehensive laws and policies that guarantee the rights of all children and young people.[36] The State has the overall responsibility for the child protection system and oversees both public and non-State protection organisations and institutions. The National Family Welfare System (Sistema Nacional de Bienestar Familiar) or SNBF, includes a wide range of ministries and agencies responsible for ensuring comprehensive protection of children and young people, and the support and strengthening of families.[37] The SNBF is led by the Colombian Family Welfare Institute (Instituto Colombiano de Bienestar Familiar) or ICBF. ICBF is a centralised system where the office in Bogotá controls all legislation and sets standards, which are then passed down to regional ICBF offices. The government, in particular ICBF, has primary responsibility for providing and supervising care services.



36. For example, Law 1098 (Code of Children and Adolescence) from 2006 is a key piece legislation, which outlines policies, plans, programmes and actions at the national, departmental, district and municipal level; and allocates financial, physical and human resources towards implementation https://www.procuraduria.gov.co/portal/media/file/Visión%20Mundial_Codigo%20de%20Infancia%202011(1).pdf p20

37. ICBF Sistema Nacional de Bienestar Familiar. https://www.icbf.gov.co/bienestar/sistema-nacional-bienestar-familiar

When a child is at risk, ICBF intervenes and an Administrative Process for the Reestablishment of Rights (PARD) can be opened by the administrative authority.[38] This involves an evaluation of the child's caregivers and their ability to provide appropriate care to the child. If the authority decides that the child should be removed from the family or caregivers immediately, the child can be placed in alternative family-based care or an institution while the PARD process is being completed. However, a PARD does not necessarily mean that the child is placed in care, they may also remain in their families. Once the PARD assessment process is completed, the evaluator's decision may lead to the loss of parental care meaning the child is declared "adoptable"; or alternatively, the family situation is deemed safe and the child is reintegrated into their family and their rights restored.[39] Each child is assigned a family advocate (defensor de familia) who is responsible for making all decisions in relation to the child's case.[40] These decisions include: the type of care placement (such as foster family, institution or group home); how often the case is reviewed; and whether the child should be moved to another placement. The family advocate is supported by a professional interdisciplinary team, which should consist of a psychologist, a social worker and a nutritionist, who will assess the situation throughout the process and generate reports to support decision making.[41]

ICBF use the following five categories when classifying the reasons for children and young people entering the system through PARD (data from 2016):

1. Child maltreatment: 10,917
2. Sexual violence: 10,752
3. Use of psychoactive substances: 5,068
4. Child labour: 1,307
5. Malnutrition: 1,234[42]

In practice, children also enter the care system for many other reasons, such as poverty and a lack of access to services, which in cases related to HIV could be life-threatening. However, this is not always documented by ICBF as their guidelines do not include these as standalone reasons for entering the system. ICBF does refer to HIV/AIDS as afectación familiar which means 'family impact' as it can affect many areas of their life, and is frequently associated with either the child becoming an orphan, or the diagnosis of the disease in parents and other family members.[43] Even though HIV/AIDS should not be a driver for institutionalisation, as support should be available in the community, the related high costs of care can generate a significant decrease in the capacity of households to cover other basic needs. In some instances, children must help care for other family members who are also diagnosed.[44] All of these associated issues affect the vulnerability of the family and can increase the risk of children being taken into care.

Forms of care

ICBF is responsible for providing and supervising three different forms of care: family strengthening and support; initial (transitional) placement; and care outside the birth family, which includes both residential (institutions and group homes) and family-based (foster care). This is delivered through non-State service providers, which are overseen by regional ICBF offices that make monthly inspections based on guidelines for care and supervision.[45]

38. ICBF (2017). Sistema Nacional de Bienestar Familiar. http://www.icbf.gov.co/portal/page/portal/PortalICBF/bienestar/proteccion/especializados/Modalidades
39. Law 1098 establishes that children and adolescents are adoptable, it includes the absence of the father or the mother because of death, a mental illness or serious psychic anomaly, certified by the National Institute of Forensic Medicine and Forensic Sciences.
40. For further information see ICBF website at http://www.icbf.gov.co/cargues/avance/docs/concepto_icbf_0000026_2013.htm
41. ICBF (2017). Reestablecimiento de derechos http://www.icbf.gov.co/portal/page/portal/PortalICBF/procesos/misionales/proteccion/restablecimiento-derechos/LM3.P%20Lineamiento%20T%C3%A9cnico%20Ruta%20Actuaciones%20para%20el%20Restablecimiento%20de%20Derechos%20NNA%20v1.pdf p21
42. ICBF(2016) Observatorio. http://www.icbf.gov/co/portal/page/portal/Observatario1/datos/tablero3 [Accessed 12 October 2017].
43. ICBF (2006) Caracterización de la niñez y la Adolescencia afectada por el vih – Sida Atendidos por el icbf en el proyecto de Protección especial: 2004 – 2005. http://www.cls.org.co/uploaded_user/pdf2006/44.pdf. [Accessed February 16th 2019].
44. Aldeas Infantiles SOS Colombia. (2010). Situación de los derechos de la infancia de los niños y niñas que han perdido el cuidado de sus padres o están en peligro de perderlo. http://www.aldeasinfantiles.org.co/Conozcanos/abogacia/Documents/situacion-de-derechos-ni%C3%B1os-as-sin-cuidado-de-sus-padres-o-en-riesgo-de-hacerlo.pdf [Accessed January 10th 2018].
45. ICBF(2017).Protección. at http://www.icbf.gov.co/portal/page/portal/PortalICBF/procesos/misionales/proteccion/restablecimiento-derechos/3C15FEA84482232CE053528511ACF6B5 [Accessed 10 November 2017].

Family strengthening and support: In some cases, the administrative authority determines through the PARD that, although the child's rights have been threatened or violated, they can remain with their family or their close network. There are three types of family strengthening and support services available: support interventions (intervención de apoyo) such as psychosocial support; external daytime services (externado) to address various forms of vulnerability; and management homes (hogar gestor) often for children and young people with disabilities or victims of the armed conflict, who may need financial or psychosocial support to ensure a protective family environment. The administrative authority aims to use these forms of support to address the identified crisis and enable families appropriately to care for and protect their own children.

Initial (transitional) placement: During the PARD, if it is in the child's best interest, they are initially placed into either Homes of Passage (Hogar de Paso), where either families or group homes (Casa Hogar) receive children on a subsidised, voluntary basis for a maximum of eight working days; or Emergency Centres (Centro de Emergencia), where children between six and 18 years of age are referred on an emergency basis for a maximum of eight days, if their current living situation has been deemed unsuitable.

Care outside the birth family or close family network: When the administrative authority deems it necessary to separate the child from their birth family, the child is either placed in an institution, a group home of up to 12 children or foster care.

Institutional placements are provided on a full-time, residential basis for children up to the age of 18. Children who enter the care system for protection, as well as children who have been declared adoptable, may be placed in institutions.

Group homes have no more than 12 residents who stay for a maximum of six months, unless otherwise determined by the authority. Children, young people and pregnant or breastfeeding women whose rights have been violated or threatened live here and are given access to professional support.

Foster care has existed in Colombia since the 1970s to prevent the harmful effects of institutionalisation.[46]
There are three types of foster care:

- foster homes for children whose rights have been violated (each home accepts up to three children)
- foster homes for children with disabilities or special needs (each home accepts only one child unless the child has siblings)
- foster homes for children recruited by armed groups (each home accepts only one child unless the child has siblings).

ICBF also provides specialised programmes for family support and strengthening in environments outside of the birth family or close network, for example for street-connected children or children with substance abuse problems.[47]

46. ICBF (2009). Evaluación del medio familiar hogares sustitutos y amigos. Colaboracion Save The Children. p 14 https://colaboracion.dnp.gov.co/CDT/Sinergia/Documentos/267_Evaluacion_del_medio_familiar_Hogares_Sustitutos_y_Amigos_del_ICBF_DOC.pdf [Accessed February 16th 2019].
47. ICBF(2017) Prtoección, Modalidades ICBF at http://www.icbf.gov.co/portal/page/portal/PortalICBF/bienestar/proteccion/especializados/Modalidades [Accessed 10 November 2017].

Numbers of children in care

Figures from ICBF's information system (Sistema de Información Misional) showed that as of 30 September 2018, there were 21,768 children and young people listed by ICBF as receiving services outside their family. The placements were as follows:

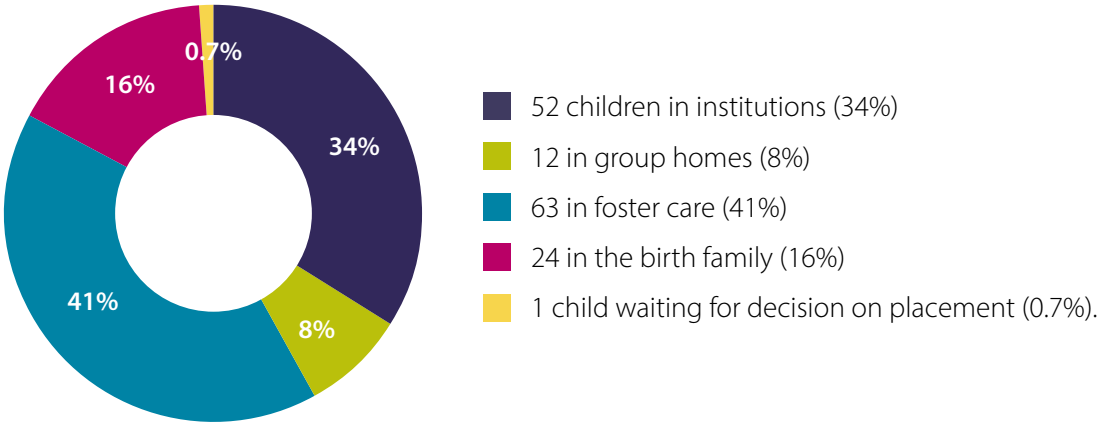
11,201
children in institutions (51%)

255
children in group homes (Casa Hogar) (1%)

10,312
children in foster families (1%)

At the same time, 10,525 children were being supported by ICBF in their family. This means that out of all children supported by ICBF (32,292) at that time, 33% were supported in their birth family, 32% in foster families and the rest in residential care (institutions and group homes). ICBF should be congratulated that a clear majority were being cared for in family and community-based care. This provides a good basis for transforming the care system and gradually ceasing reliance on institutional care.

The most recent publicly available information specifically for children with HIV/AIDS in the care system is from ICBF's 2005 census. The census found that a total of 152 HIV-positive children (79 boys and 73 girls) between 0 and 18 years old were in the child protection system, dispersed across almost all the regions of the country.[49] The placements were as follows:



This demonstrates a longstanding commitment from ICBF to support children in families. Of the children placed in institutions, the majority (75%) were living in Fundamor.[50] There is no publicly available data on where the 1,800 children with HIV/AIDS from the 2018 estimate[51] are being supported, as this diagnosis is only registered within ICBF records if it is a reason for admission to care.

48. Information based on request for information by Lumos to ICBF.
49. ICBF (2017). Reestablecimiento de derechos Op. cit.
50. ibid
51. UNIADS (2017). Data Colombia. http://www.unaids.org/es/regionscountries/countries/colombia.[Accessed February 11th 2019].

The harm of institutionalisation

An estimated eight million children worldwide live in residential institutions, including so-called orphanages, that deny them their human rights and fail to meet their needs.[52] An estimated 80% of children in institutions are not orphans and have at least one living parent. Most children could, with support, live with their birth or extended families.[53] Children are often placed in institutional care because their parents face extreme poverty; because the children have physical or intellectual disabilities; or because they are from socially excluded groups.[54] Over 80 years of research from across the world has generated a vast body of evidence on the harms caused by institutionalisation to children, who are deprived of loving parental care and suffer life-long physical and psychological harm.[55] Babies in particular fail to develop as they should without one-to-one parental interaction, and research demonstrates the severe impact of institutionalisation on early brain development. According to numerous studies, children who remain in institutions after the age of six months often face severe developmental impairment, including intellectual and physical delays.[56]

The negative impact of institutionalisation has also been found in research focused on children with HIV/AIDS. A systematic literature review of the institutionalisation of children living with HIV in the LAC region conducted in 2012 highlighted the complexity of the phenomenon. The review found that the physical needs of children living with HIV in institutions are met effectively. The strictly scheduled routines of institutions allow for regular medical care, routine medical examinations and timely administration of medications, which are crucial components for the treatment's success.[57] However, vital emotional needs are not met in an institutional setting and the review found that institutions are inadequate in stimulating genuine family relationships.

Research states that children living with HIV in institutions risk falling into a pattern of complex grieving, which is often manifested in depressive symptoms, anxiety, guilt, anger, hostility and loneliness.[58] Furthermore, HIV-positive children who have lived in institutions from a young age can also struggle to develop emotionally.[59] [60] This could be explained by the lack of close and meaningful interaction, attention and affection provided by carers at institutions. AVERT, an international HIV/AIDS organisation, states that the most important support and protection for children with HIV comes from family, friends and community, and their research supports the idea that removing children from their families should only be a last resort.[61]

Transforming the care system

Transforming the care for vulnerable children from a system that relies on institutions to family and community-based services is a complex process. It involves:

52. The number of residential institutions and the number of children living in them is unknown. Estimates range from more than 2.7 million ('tip of the iceberg') in Petrowski, N., Cappa, C. & Gross, P. (2017). Estimating the number of children in formal alternative care: Challenges and Results. Child Abuse and Neglect, 40, 388-398. https://doi.org/10.1016/j.chiabu.2016.11.026 [accessed 27 April 2018]. to 8 million (Cited in: Pinheiro, P. (2006). World Report on Violence against Children, UNICEF, New York). These figures are often reported as underestimates, due to lack of data from many countries and the large proportion of unregistered institutions.
53. Csáky, C. (2009) Keeping Children Out of Harmful Institutions: Why we should be investing in family-based care London, UK: Save the Children. p7. Better Care Network. (2009). Global facts about orphanages.
54. Faith to Action Initiative. (2014). Children, Orphanages, and Families: A summary of research to guide faith-based action. pp6-7.
55. Berens, A. & Nelson, C. (2015) Op. cit.
56. Michael Rutter (1998), Development catch-up, and Deficit, Following Adoption after Severe Global Early Privation, Journal of Child Psychology and Psychiatry, 39 (4).
57. Pezeshki, A., Mamalis, C., & Disabato, A. (2012). A systematic literature review of the institutionalization of children living with HIV. Horiz. enferm, 23(1), 75-79.
58. Li, X., Naar-King, S., Barnett, D., Stanton, B., Fang, X., & Thurston, C. (2008). A developmental psychopathology framework of the psychosocial needs of children orphaned by HIV. Journal of the Association of Nurses in AIDS Care, 19(2), 147-157.
59. Doring, M., Junior, I. F., & Stella, I. M. (2005). Factors associated with institutionalization of children orphaned by AIDS in a population-based survey in Porto Alegre, Brazil. Aids, 19, S59-S63.
60. Sgombich, X. M., Navarro, S. G., Mola, G., & Hernandez, H. (2005). Situación de la infancia afectada por el VIH. SIDA en Chile Informe Final de Resultados Gobierno de Chile: Ministerio de Salud.
61. Pezeshki, A., Mamalis, C., & Disabato, A. (2012). Op. cit

- Developing community-based services and approaches that prevent admissions of children to institutions, and that give children and families support within their communities to allow them to stay together.
- Transferring all children currently in institutions to families or family and community-based care placements that respect their rights and meet their individual needs. No child should be left behind.
- Ring-fencing and protecting the resources (financial, human and material) from institutions and transferring them to the newly developed community-based services, providing long-term sustainability. Crucially, the purpose of reform is not to cut costs, but to take funds which would be spent on institutions and reinvest them in family and community-based services, to support more children and produce better outcomes.
- Developing and deploying sufficient professional capacity and expertise to manage this complex process of change.
- Changing attitudes, policies and practices.
- Empowering children and families to take a lead role in the process of change.

When an adequate system of family and community-based services is available and accessible to everyone, most cases of family separation and institutionalisation can be prevented, as children and their families can access the support they need within their own communities. This means most children living in institutions could be successfully reunited with their birth families, and most children will not need to be removed from their families in the first place.

To implement and achieve care transformation, a full range of family and community-based services must be available, including both universal and targeted services. Where they do not already exist, these services must be developed. Universal services are those which should be available and accessible to everyone, regardless of race, gender, disability, sexual orientation, religion, ethnicity or nationality. They include education and health services. Targeted services are aimed at the children and families that have additional needs and require extra support. This can be provided through targeted health, education and social services based within the community.

These services include:

Services for families:

- social services with supervision, monitoring and ongoing training for the personnel
- family support services offering a range of practical and material support for families, including specialised support for children with disabilities and their families
- services based in hospitals to support new parents
- community health professionals to support new parents at home and ensure early identification of vulnerable families and children with additional needs
- classes to help parents develop skills to better care for their children
- early childhood services such as day care centres and children's centres
- inclusive education for all children, specially adapted for children with disabilities
- support services to prevent all forms of child maltreatment, including services to address domestic violence and substance abuse in the home, and support for parents struggling with mental illness or trauma
- financial assistance to prevent or address poverty.

Emergency intervention services:

- specialised services to address cases of child abuse and neglect
- emergency housing and support for adults and children fleeing domestic violence
- crisis intervention services to support children and their families to address difficult situations which affect their wellbeing
- emergency foster families for children who must be removed from families.

Support services for vulnerable children and those with specific needs:

- early diagnosis and intervention services for children with disabilities
- housing adaptations, technical aids and assistive technologies for children with disabilities
- short breaks (respite care) to give children with disabilities or complex needs and their families a break from their usual routines and caring roles
- after-school and holiday clubs for vulnerable children
- emotional and behavioural support in schools
- therapy and rehabilitation services such as physiotherapy, occupational therapy and speech and language therapy
- child and adolescent mental health services (CAMHS) for young people with mental health support needs.

Substitute family care:

- a range of different types of foster care
- adoption.

Specialised residential care:

- small group homes for a minority of children with multiple, complex needs – these homes look after small groups of children (ideally no more than six) and have highly qualified and trained personnel.

Care leavers' services:

- support to care leavers and those preparing to leave care, to become financially independent, develop independent living skills and build up support networks in the community
- access to suitable housing.

2. The Fundamor care transformation process

Fundamor has been a pioneer in the care transformation process in Colombia since 2000. There have been three main phases of the process:

- considering a more inclusive care model
- planning and preparation
- transition and follow-up.

An overview of theses phases is given below to provide context and learning for the analysis for a wider care transformation in Colombia and for developing family and community-based care for children who are HIV positive.

1. Considering a more inclusive care model (2000–2015)

Fundamor opened in 1992 to treat and care for adults with HIV/AIDS. Due to poverty, lack of support in the community and barriers to accessing services – amplified by stigma and discrimination – HIV-positive babies and children were also brought to Fundamor to receive services.

In 1996, with support of ICBF, Fundamor officially changed its services from supporting adults to supporting HIV-positive children, which included institutional care. However, as the children grew older, Fundamor's personnel and executives started to question their model and discuss issues around inclusion and future independent living for the children.

The first phase of Fundamor's care transformation process took the longest – over 15 years. During this time, there was a gradual realisation of the need to consider family and community-based care, as personnel became more aware of the harms of institutionalisation. The focus during this phase was gaining knowledge and exploring how best to ensure that the children's needs were met through non-institutional services. One of the first projects was established to address the effects of stigma and discrimination on the children's education and inclusion in the community.

As schools sometimes refused to accept children who were HIV positive, in 2000 Fundamor developed a pre-school setting on its own premises where children from outside the institution could also attend. This was called inclusion inversa (inverted inclusion) because the personnel brought the outside community inside Fundamor. Although the solution was not ideal, it allowed the children living in the institution to access high-quality education alongside their peers from the community.

Not all initiatives had immediately positive results. Around the same time, Fundamor also developed the option of part-time institutional living, where children could go home to their families over the weekend. However, sometimes families did not have appropriate resources to provide nutritious food or follow the strict medication schedules, which meant that in some cases the children's health started to be compromised. This reinforced the general belief amongst Fundamor's personnel that full institutional care was the best alternative to guarantee the children's physical care, as there was insufficient support available in the community. However, Fundamor's leadership remained committed to the idea that children should ideally be cared for in families. Working with Children of the Andes (now Children Change Colombia), Fundamor was able to adjust its guidelines for institutional care (Proyecto de Atención Institucional – PAI)[62] and develop several vocational programmes. These programmes have served as inspiration for public policies to prepare young people for independent living. The success of the programmes raised further doubts about institutionalisation, and the young people themselves also started to question why they could not have a family or an independent life like other young people.

Inspired by peers from Africa at the HIV World Congress in Mexico in 2008, Fundamor reaffirmed its commitment to care in the community for HIV-positive children and for children's voices to be heard. It formed an alliance with UNICEF Colombia to provide children with a platform to express their views. Together, they organised the first HIV National Forum where children could express their feelings and opinions. It was here that children took the opportunity to raise their concerns about stigma and discrimination and the importance of a family. The Diagnosis Disclosure Tool was also developed, which was the first tool of its kind, created to support a sensitive disclosure of the HIV diagnosis. This tool is now used nationally, as well as internationally in Mexico and El Salvador, in different contexts, such as in health care settings.

During this time, Fundamor continued to gain recognition for its work and even won awards in the region. These awards came from prominent actors, including national and international organisations such as the Colombian Ministry of Education, the Interamerican Development Bank, the Economic Commission for Latin America and the Caribbean (ECLAC) among others. Despite praise for their work, Fundamor did not waiver from the conviction that its care model needed to change.

In 2015, the Executive Board took the decision to move away from institutional care completely and start a thoughtful process of care transformation.

There were several reasons for the decision to transform the care model, but the overriding consideration was to guarantee the rights and guiding principles set out in the UN Convention on the Rights of the Child. Improving the lives of children and their emotional needs, while guaranteeing their rights to health, education, no discrimination ***and*** their right to family life were the drivers that led Fundamor to transform the care model:

62. PAI: is a document that must be developed and implement by all care providers. It outlines the relevant processes to address children and young people having their rights unobserved, threatened and violated. It is reviewed and updated based on latest practice, knowledge and experiences, to allow a strengthening of the care process.

2. Planning and preparation (2015–2016)

Following the decision in early 2015 of Fundamor's Executive Board to transform the model of care, Fundamor expanded its search for organisations working in the field. Through colleagues at Children of the Andes, Fundamor heard about the work Lumos was doing on transforming care systems for children. In April 2015, Fundamor's Director contacted Lumos, seeking advice on how to move forward with the transformation plans. Lumos initially provided guidance documents and research about the transformation process to help their thinking, and invited Fundamor's Director to London to participate in Lumos' training programme on Transforming Care.

Subsequently, Fundamor developed an advocacy strategy to influence ICBF and connect with allies, such as UNICEF and other residential institutions who wanted to transform the way they care for children. The thinking around the need for care transformation was initially discussed at a meeting with the ICBF Child Protection Director in Bogotá.

The idea had a mixed response and there was some anxiety, as ICBF stated it was not yet fully prepared for a complete transformation of the country's entire care system. Nonetheless, Fundamor took the courageous decision to continue with its plans and sent an official letter to ICBF communicating the decision to end the residential aspect of its care. The letter outlined the importance of inclusion, independence skills and family care for the wellbeing of the children. ICBF understood and applauded their intention. However, ICBF was firm in their opinion that the wider system was not ready.

The readiness of the system was a significant issue for Fundamor when closing the institutional care unit, as the personnel did not know whether it was possible to secure good foster families for the children and young people, or whether they would be placed in another institution. The emotional impact that care transformation could have on the children and young people in their care was also a major concern.

During this phase, ICBF's National Child Protection Director proposed that Fundamor become a foster care service provider which could select, manage and supervise the foster care families in which the children could be placed. Fundamor was open to the idea, but the regional authority did not consider there was a need for another foster care service provider in the region. The regional authority also stated that even if it granted Fundamor a licence, Fundamor would have to search for the minimum required 25 foster care families on its own to become a provider.

This is a very complex process and entails a great financial risk, because ICBF funds according to the final number of families found, not the search process. Considering this risk, and the reservations from the regional office, Fundamor decided not to pursue this option. It did however open a non-residential day care programme which is still in operation today.

The somewhat rigid and bureaucratic approach of the regional ICBF office restricted Fundamor's ability to implement all aspects of transforming care at the desired level of quality. With hindsight, it became apparent that there was a strongly held opinion amongst the regional authorities that children are better cared for in institutions, particularly if they have a medical condition such as HIV. While the national ICBF office supported Fundamor's initiative to transform their care service, insufficient support from the regional office hindered progress. Nevertheless, the process officially started in December 2015.

3. Transition and follow-up (2016–2018)

When the process started, Fundamor and the regional ICBF office agreed on a strict deadline of one year, with a completion date of December 2016. Together, they drafted a care transformation plan which anticipated that all children would be placed in family-based care at the same time. The main reason for this strict plan was that Fundamor did not want to extend the one-year service provider contract that it had with ICBF. However, there were several obstacles in the care transformation process, which made this deadline impossible. The most difficult one was the lack of foster carers. The family advocate who made the final decision regarding children's placements was insufficiently supportive of the process and no children were placed with foster families that year. In addition, fear, stigma and discrimination related to HIV meant that the foster care service providers were reluctant to place HIV-positive children in families.

At the end of 2016, the process of transforming care was still not complete, which meant that Fundamor was running a non-residential care programme, the pre-school (centre for childhood development), and its traditional institutional care as children were still being referred to them. At this point, Fundamor realised that a more gradual approach was needed, in which children would be placed when family-based care settings became available and with sufficient time allocated to preparing the children for this life-changing move. This approach was a clear financial risk for Fundamor as funding from ICBF is calculated according to the number of children resident and reduced each time a child moved out. However, it was the right decision for the children. To support this approach, Lumos provided financial support to Fundamor during 2017 and 2018. This enabled Fundamor to prepare children well, transfer them to their new placements in a phased manner and follow them up after they had moved. This additional financing allowed Fundamor to maintain their current services and support the children who remained in their care, while also building and executing a thorough follow-up plan for the children who had moved. Lumos also supported them with foster care recruitment plans and with technical input to support the transition process and ensure best practice was followed, within regulatory constraints.

Finding foster carers

As the legal responsibility to find families is with the foster care service provider, Fundamor worked closely with them to build and implement the recruitment plan and to raise awareness. In mid-2017, Fundamor designed three large workshops about HIV, two of which were for 150 already established foster families. The workshops were successful and immediately afterwards, 46 already established foster families expressed interest in fostering HIV positive children. However, when Fundamor contacted the ICBF regional office asking them to pursue the process with these families, the official response was that no family was willing to care for children with HIV. From the workshop for new potential foster care families, 50 were put forward, but only three passed ICBF's criteria to be accepted as foster care families. During this time, children were still being referred to Fundamor. However, as Fundamor was not admitting any more children, the children were referred on to the foster care service provider who did not have any expertise around HIV and therefore contacted Fundamor for advice. With support provided by Fundamor, a total of seven foster families (three new and four already established) were selected by the service provider, with a capacity to care for 12 children. These 12 children would be under the legal authority of two different family advocates. As Fundamor did not have a licence for this type of care, under the current regulations the personnel did not have the legal right to follow up the children.

One of the family advocates was supportive of Fundamor's care transformation process and recognised that it was in best interest of children for them to continue monitoring their new placements. However, the other was more reluctant, which prevented Fundamor from effectively following up and monitoring all children.

Previously, at the suggestion of ICBF National Bureau, Fundamor also presented a proposal for a holistic follow-up plan for children and families who had left its institutional care. This plan was tailored to the needs of families and children and based on the knowledge and expertise in supporting HIV-positive children Fundamor had gained over the previous 20 years. This plan covered: support to guarantee access to appropriate health services; legal advice if needed to access services; psychosocial support; and home visits. The plan was accepted by ICBF's national office, but not approved by ICBF's regional office as Fundamor was not a foster care service provider, so it would not have the legal right to follow up the children remaining under ICBF's care.

Involving the children and young people

Fundamor thought it was essential to involve the young people in the process and have open discussions with them. The team started to have conversations with the children and young people about care transformation once the key strategic administrative issues for their placements had been resolved, and then continued to consult them throughout. However, it was not always possible to follow the children's wishes. For example, many of the children wanted to go to foster care, but there were not enough foster families. In addition, the decision making and approval process for foster carers took a long time, making the children anxious. The ICBF regional office then changed the initial plan and provided alternative placements instead, such as the programme for independent living. These placements happened at very short notice, which meant that the appropriate transition procedure, including adequate preparation, was not possible for all children. For example, pre-meetings between foster families and children are crucial for a successful transition, but it was only possible to do this with one foster family because of the sudden changes and demands of the child protection system.

The importance of this meeting was acknowledged by one of the foster parents:

"I had the opportunity to meet them [the children] in Fundamor. It is such a great idea to go and meet them before they are placed. It is better than when they arrive and we feel like strangers. At least we already know each other and they already know who is going to be their foster mother."

- Foster mother

When talking about their experience of moving to new placements and relationships with the family advocate, the children and families expressed that sometimes they did not feel listened to:

> ***"They said [the family advocate] that I could no longer go to a foster family because I was already an adult and I was going to start studying... but I don't understand because what we really wanted was the love of a family, being part of a family."***
>
> *- Young woman during a focus group*

The lack of clarity about the process, the sudden change of plans and decisions by authorities, and the relationships with family advocates were sources of stress and mistrust among a number of those involved. However, it is important to note that these experiences were not necessarily widespread and there were family advocates who fully cooperated with the care transformation process. They worked together with Fundamor to facilitate the monitoring and follow-up, had good relationships with the children and young people and granted permission to do this research:

> ***"My family advocate has known me since I was little, and she values me."***
>
> *- Young man during a focus group*

To start to address these concerns, Fundamor advocated for the children's participation in the official process, asking the child protection system to listen to them, even using legal procedures to guarantee their right to be heard.

Transition process

Every child and young person expressed having mixed feelings about the process. On the one hand, they were leaving a place where most of them had lived for their whole lives, a place where they had established strong bonds with friends, carers and the Fundamor personnel. But on the other, they were curious to experience family life and eager to become more independent. They expressed feelings of fear that the process of transforming care would not work, but they also felt excited about the change.

> ***"Where I am now there are problems, but I think it is important to have problems and to face them. I didn't want to stay in a foundation [institution] for my whole life where everything was done for me. It is really difficult now that I have to deal with my medical appointments and organise my medicine but someday, I would have had to do it."***
>
> *- Young woman during a focus group*

Despite the difficulties of the transfer and new placements, and the sadness of missing their friends, the young people were clear that they would never go back to an institution:

> ***"I'll stay here because it is the first time that I have lived in a house with a family... I can go out and play, she [the foster mother] takes us to the park and I like being with her."***
>
> *- Young adult who lives with a foster family*

As children were leaving Fundamor one at a time, Lumos' financial support allowed Fundamor to maintain the complete team until the end of November 2017 to support the follow-up and to help with the transition. There were several activities that supported the children and young people in preparing for the new placements. Fundamor, with advice from Lumos, started activities such as writing life story books,[63] preparing memory boxes,[64] and preparing and packing their suitcases.[65] These activities helped the children with emotional aspects of the move, saying goodbye to their friends and carers and building relationships with their new families.

The new placements

A total of 52 children and young people were part of the transformation process: 15 in 2016 and 37 in 2017. Following assessments and by the end of 2017, out of the 52 children and young people

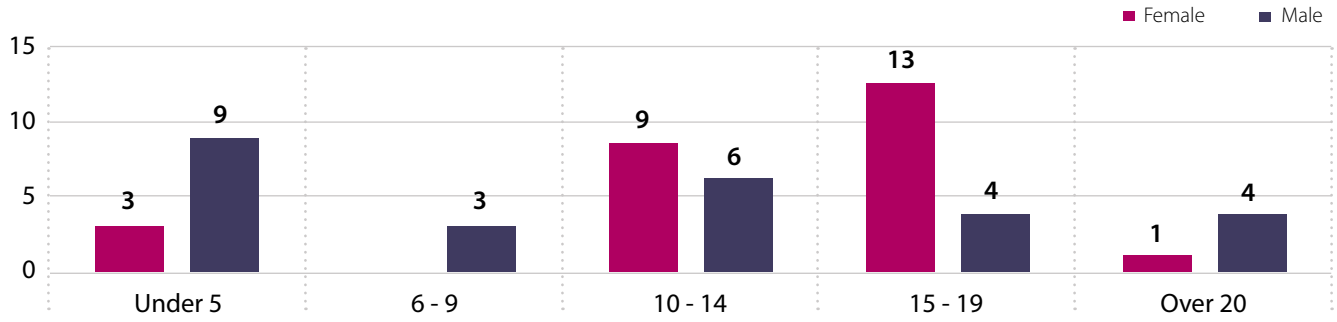
- 11 were able to return to their birth families with the right support,
- 9 were adopted,
- 12 were placed in foster families,
- 8 were placed in the programme for independent living, and
- 3 were able to live independently.

However, despite Fundamor's best efforts to place all children and young people in family and community-based care, 9 children and young people were moved to other institutions, as family and community-based alternatives had not been found in time and Fundamor's institutional license was expiring. However, over the course of 2018, there were further changes in the types of placements. Some children in foster families were reunited with their birth families and others were relocated to the programme for independent living.

Type Year	Foster care	Birth family	Institution	Adoption	Programme for independent living	Independent	Transit home	Total
2016	0	4	2	7	0	2		15
2017	12	11	9	9	8	3		52
2018	8	14	9	9	6	5	1	52
	52 children were placed							

63. A life story book is a clear account of the child's life told through words, pictures, photos and documents which the child is fully involved in making if old enough. Lumos will provide more information on life story work on request.
64. Memory box: The message given during the moving process is that the child has permission to form new attachments. This can be done by giving the child the opportunity to collect and keep good memories, by taking photos and collecting details of friends and colleagues in the institution. These can be taken along with other special items in a memory box to the new placement.
65. Prepare a Suitcase: Children are encouraged to pack their personal belongings along with the life story book and the memory box in their suitcase. This helps to prepare them for the transition.

Number of children by gender and age when they left Fundamor



Base: all 52 children part of the Fundamor transformation process.

Foster care

As foster families were not available for all children and young people, a programme for independent living was introduced. This programme was also thought to be more suitable for young adults than a foster family. It is not uncommon for parents to be reluctant to provide foster care for teenagers because of fears about safety and expectations about challenging behaviour.[66] This was also mentioned in some of the cases Fundamor dealt with. However, these challenges can be addressed with training and support to the family before the young person arrives and support is provided throughout the placement, such as how to deal with challenging behaviour.

Programme for independent living

The programme for independent living is a group home. It is still a residential service where the young people are supervised by carers, but with a higher degree of responsibility for their own care, such as cooking, attending medical appointments or looking after their own money. This is particularly important for young people raised in institutions, who may not have acquired all the relevant social skills or developed their own support networks in the community.

It was highlighted by those involved in the Fundamor care transformation process, that the programme for independent living did not provide emotional support and that young adults wanted to have a close relationship with a person that they trust. However, what caused the most tension and distress was that the programme for independent living was not the initial plan, nor what the young people had desired. This change of placement and uncertainty was repeatedly acknowledged by the small number of young people who expressed their disappointment and anguish during the process:

66. Geiger, J. M., Hayes, M. J., & Lietz, C. A. (2014). Providing foster care for adolescents: Barriers and opportunities. Child & Youth Services, 35(3), pp237-254.

"I don't have any idea of what a family is, what it is to love a mother and when they said that you are going to a family... then you start to prepare yourself for that... but then they changed their mind and then what?"

- Young man during a focus group

However, the programme for independent living brought valuable lessons and experiences to the young people. They are now facing important challenges that put them outside of their comfort zone, making them aware of the benefits and responsibilities that come with adulthood, and giving them some independence.

They are excited to start doing simple things that they could not do inside the institution,[67] such as cooking and managing their own medical appointments:

> ***"I would have liked that during my time in the institution that they wouldn't have been so overprotective with us and that they would have let us do more things like cooking. We couldn't go into the kitchen because we could burn ourselves... and I understand that was intended for our own good but I feel that this was doing us harm."***
>
> *- Young woman during a focus group*

In the programme for independent living, the young people have more freedom than in the institution to learn about how to live in society as adults. This has been acknowledged not only by the young adults but also by the Fundamor Care Transformation Coordinator:

> ***"They are starting to learn to prioritise, to handle money, to know where to buy their own clothes, how to bargain, you know? Things that you do in a normal life. To decide whether they are going to use all the money or if they are going to save some."***
>
> *- Fundamor Care Transformation Coordinator*

67. Not because of Fundamor's rules but because the general child protection guidelines for care.

The young adults in the focus group agreed that even though the process or the placement was not what they had expected and that it is sometimes difficult, they are now happy with the change as it has given them more independence.

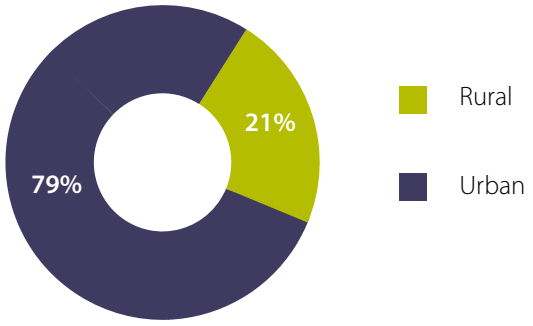
Results from the follow-up of the children

Fundamor faced a number of unexpected barriers when it came to follow up of the 52 children and young people that were part of the transformation process. There were several reasons, including legal barriers that prevented Fundamor from carrying out follow up activities. In the cases where children returned to their birth families, Fundamor was able to carry out follow-up activities, as the families granted authorisation. However, for the children who moved to foster families or the programme for independent living, Fundamor had to rely on the openness of the family advocates who decided if they would allow Fundamor to follow up. Fundamor was not able to carry out any follow-up activities for the children that were adopted as it is not legally allowed.

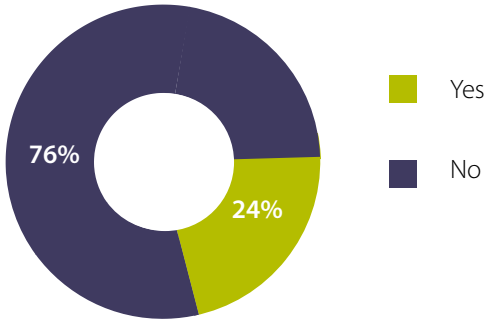
Based on the follow-up Fundamor was allowed to undertake, the psychosocial team provided information about how the children were doing at the end of 2018. The charts below are based on the 34 children reintegrated into family and community-based care.[68]

79% of the children placed in family or community settings are in urban zones and 24% of the children live in areas where there are reported problems with armed conflict. Further analysis of data show that children and families living in rural areas where there is armed conflict are the most likely to struggle to access services.

Urban or rural placement?



Presence of amed conflict in the location of the child's placement?

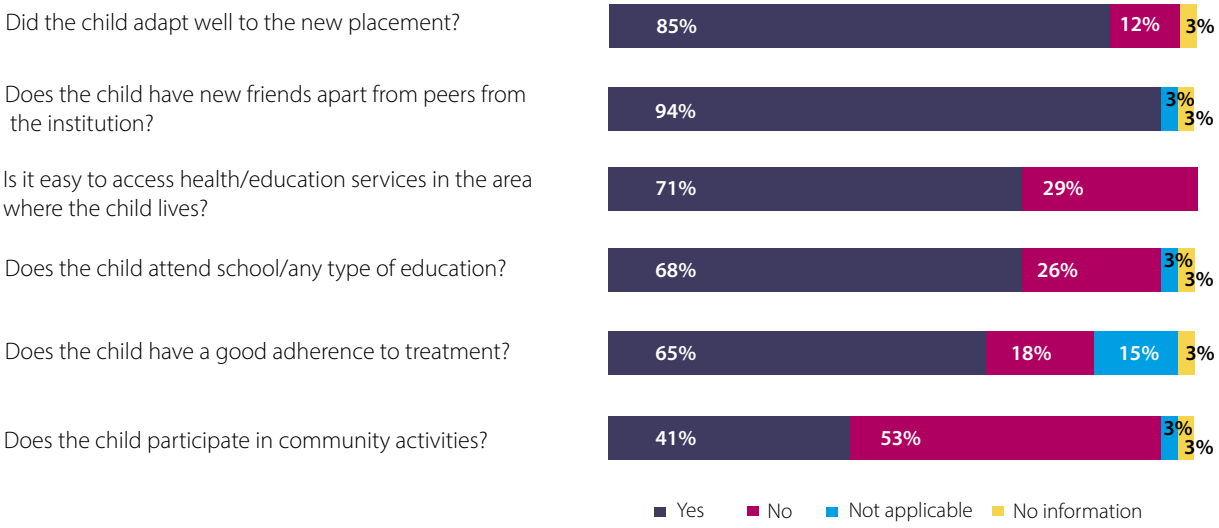


At the outset of the process, there were concerns that the children's health might deteriorate, and their quality of life would decrease when they moved from the institution to the community. However, this has not been the case. Data from Fundamor shows that:

- 85% of children were reported to have adapted well to their new placements
- 94% were reported to have made new friends
- 71% of children were reported to have 'easy access' to health or education services in the area where they lived
- 68% were attending to school or another type of education.

68. Whilst this data covers all children who were integrated into family and community care, it should be borne in mind that the numbers are relatively small.

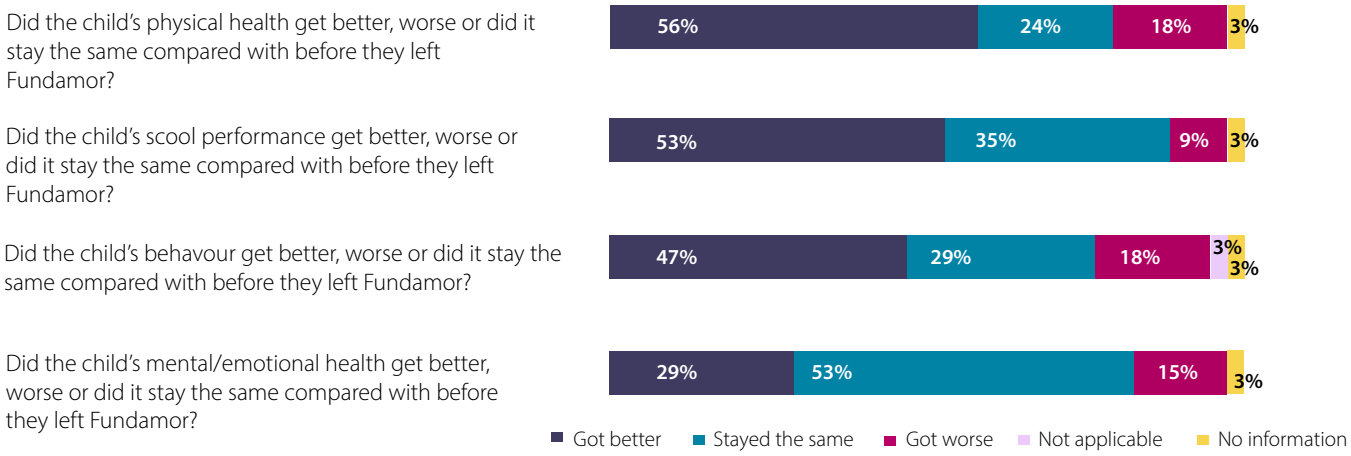
Adaptation and access to service (2018)



Base: All children in family or community care (34)

In relation to physical health, it is striking that in 80% of cases, children's physical health stayed same or improved compared with when they left Fundamor; and 65% were reported to have good adherence to the treatment. This is important, as ensuring good physical health in the community for HIV-positive children and young people was a major concern for many actors in the transformation process. Moreover, it was reported that mental or emotional health improved or stayed the same for 82% of the children. Improved behaviour, compared with when they left Fundamor, was reported for 47% of the children. And in more than half of the cases (53%), children's school performance was reported to have improved since leaving Fundamor.

Changes compared with when the children left Fundamor (2018)



Positive changes were also acknowledged by foster carers and Fundamor's team during interviews:

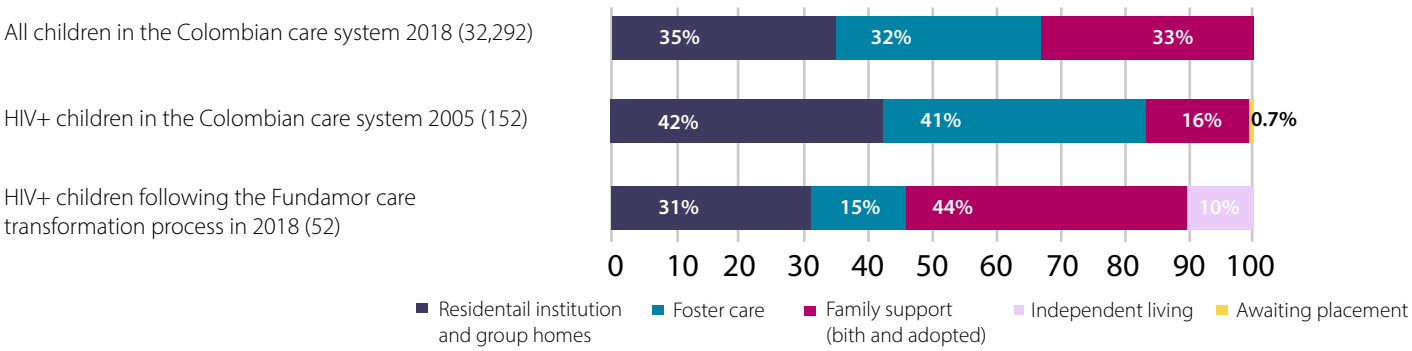
> ***"The Fundamor team were surprised, they say that he [child with cognitive disabilities] talks much more now and his skin is better. I think he has changed, and he seems really happy here... I think it is a positive change."***
>
> *- Foster care mother*

It should be noted that it is of concern that physical and mental health deteriorated for some children and young people after they left the institution. Fundamor continues to follow up in an attempt to ensure improvements in the health of these children.

Reduced reliance on residential care

Children and young people who are HIV-positive are one of the most vulnerable groups of children, who tend to be left until last in the care transformation process in many countries. In Colombia this group was prioritised, and ICBF and Fundamor have led the way to shift the reliance on residential care and to increase family-based care. In 2018, out of all children in the care system, 35% were in residential care, 32% in foster care and 33% were supported in their families. In 2005, 42% of HIV-positive children and young people in the care system were supported in residential care, 41% in foster care and 16% supported in their family. In 2018, out of the children and young people who had been part of the Fundamor transformation process, 31% were supported in residential care, 15% in foster care and 44% in birth or adoptive families.

Reliance on residential care



Actions taken and tools used in the care transformation process

Actions taken and tools used in the care transformation process		
Phase	**Actions taken/approach**	**Methods/tools**
Considering a more inclusive care model – inception	1. Reverse inclusion. 2. Adapt the institutional action plan to children's needs. 3. Creation of new programmes of care (the programme for independent living). 4. Strengthening youth participation and shared experiences. 5. Strengthening services for HIV-positive children and their families.	1. Awareness workshops for the educational community. Creation of a pre-school and workshops to tackle stigma and discrimination. 2. Periodical strategic planning meetings and discussions including revising national guidelines for care from ICBF. 3. Researching national and international care models. 4. Vocational courses for children according to their age to prepare them for an independent adult life. 5. Discussions with children about autonomy, inclusion and their future. Develop the first national forum for children with HIV. 6. Tool to support the diagnosis disclosure for children.
Planning and preparation	1. Building alliances. 2. Transformation preparation process. 3. Informing ICBF about the decision to transform the care.	1. Find national and international partners to support the care transformation process (Lumos, The Global Fund). 2. Read Lumos guidance about care reform, researching for previous experiences. Modelling cost and budget implication of transformation. Training on DI. Establishing new programmes of non-residential services. Writing a care transformation plan. 3. National and regional meetings about the reforms. Reform advocacy and agreements with ICBF.
Transition and follow-up	1. Raising awareness about care reform. 2. Finding new foster care families. 3. Tackling fear, stigma and discrimination to find families. 4. Follow-up plan.	1. Workshops and conversations for Fundamor personnel, directors and children about care transformation Plan. 2. Use social medias networks. 3. Workshops with ICBF providers and foster care families. 4. Creation of holistic plan to support families in collaboration with ICBF.

3. Key considerations in care reform

Colombia has a comprehensive child protection system in place with skilled professionals supporting vulnerable children and their families across the whole country. However, the lack of services, or the difficulty in accessing them, in certain areas and for certain groups, means that many children are still routinely placed in institutions, against their best interests. This is not only potentially harmful for the children but is also very expensive. Family and community-based services are more cost effective and result in better outcomes for children than institutions. However, there are challenges to transforming care, as demonstrated by Fundamor's experience. The main challenges identified are outlined and analysed below, together with lessons learned and recommendations on how to address these issues.

Planning and coordinating the reform

Transforming care must be a thoughtful process where the best interests of each child is central to every decision taken. Each element of the process must be carefully planned and costed, and resources identified, in order to ensure high-quality implementation and sustainability. Without proper planning and management, there is a risk care transformation will not be successful and sustainable, which may result in harm to children.

To implement plans effectively, it is essential that the institution coordinates and agrees the whole reform process with the regional ICBF office. A detailed written agreement should be agreed between all relevant parties, as without the full support of ICBF, implementing care transformation will be impossible. Insufficient awareness on the part of the authorities of the key components of high quality care transformation, may result in decisions that negatively affect children. Unfortunately this happened with a small number of children in the Fundamor process.

Fundamor had strong support from the national ICBF office for the transformation, while the regional office did not give full endorsement. Consequently, progress at every stage depended on the will and acceptance of each authority, rather than having a firm basis in an agreement. This lack of consistency brought confusion and tension. Children were still being admitted to Fundamor's residential services, at the same time as it was working hard to change its model of care, and attempting to ensure family and community-based alternatives for the current residents.

The main problem was not individual people, but that the child protection system and its different actors did not always effectively collaborate and coordinate their work, and there was no consensus about the transformation process itself. This allowed for a subjective decision-making process that hindered coordinated action. This resulted in direct, negative impact on some children, including: insufficient family-based alternatives being made available; insufficient time allocated to find alternative placements, or to prepare for new placements; insufficiently meaningful child participation; barriers to adequate follow up of some children in their new placements.

It should be noted that at the outset of the process, ICBF at the national level expressed their view that it was not yet ready for care transformation. Although the national ICBF office was supportive of Fundamor's pioneering programme of reform, it is clear there was a need for a longer period of awareness raising, training and preparation for ICBF's regional team and children's advocates in particular.

Arbitrary targets

The national ICBF office and Fundamor initially set a deadline of December 2016, which was effectively only a year to complete the whole process, including finding placements, preparing the children and ensuring they transitioned safely to their new placements. It became evident this timescale was unrealistically short. Setting arbitrary targets and timetables for moving children without taking account of the services available and the preparation needed, is not conducive to a high-quality process and may even be harmful for children. It is essential that the transformation process is based around the needs of the children and any changes carefully communicated to them to avoid raising expectations that cannot be met. In one case a young woman became particularly distressed as she was not able to move back to her family at the time she was originally told it would happen:

> ***"The process was so stressful that my daughter had a crisis and suffered a facial paralysis. She was so stressed when she found out that she could not get out of Fundamor after the two months that they had originally told us."***
>
> *- Birth mother*

The strict deadline also meant that Fundamor's licence expired before stable family and community-based placements had been found for all the children. As a result, nine children were transferred to other institutions. Fundamor did not want to sign another full-year licence and ICBF did not allow them to extend it on a month-by-month basis.

It is essential that transformation plans and agreements are flexible and prepare for relevant contingencies to ensure that no child is harmed in the process. It is likely that new regulations are required specifically for the care transformation process, that would make it possible for institutions like Fundamor to be given a more flexible approach to licensing, financing and follow up of children.

Preparation

When planning care transformation, adequate time must be allocated to prepare children to move. Moves for children can be highly traumatic, especially if the changes in their lives seem to happen with no explanation. The right preparation can greatly reduce negative impact on the child and help them settle into their new placements. If the reasons for change are understood – and particularly if it can be demonstrated that the change is an improvement to their current situation – it is more easily accepted. If the children feel confident and happy about the change, the new placements are more likely to be successful. However, if children are scared or resistant to the move, the chances of placement breakdown are much higher. Preparation programmes help children build a relationship with their new carers and say goodbye to friends and carers in the previous placement. They enable a child's wishes and feelings to be included in the planning of the move.

The insufficient support from the ICBF regional office and inconsistent coordination between the national and regional ICBF offices, resulted in abrupt placements for some children in the Fundamor process, without enough time and consideration being given to preparation and careful communication with the children.

> ***"There are family advocates who change placements without even asking. It is something that happens from night to day without any explanation."***
>
> *- Young person during a focus group*

The financial support from Lumos enabled Fundamor to retain its psychosocial team who could also spend some of their time on supporting the transformation processes, including preparing the children as well as following up children who had recently moved. Retaining sufficient personnel to be able to continue provide high-quality care for the children, as well as support all aspects of the transformation process, must form part of the agreement between the institution, national IBCF and regional ICBF. Furthermore, to implement care transformation nationwide, resources should ideally be made available by ICBF. The transformation process cannot be financed exclusively by donors and institutions cannot be expected to absorb all additional costs.[69] Therefore, a national action plan for care transformation should include resources allocated to cover the transitional costs of the process.

Follow-up

Leaving an institution can be a very difficult time for children and young people, as they may never have lived anywhere else, making the move unsettling. Following up on their wellbeing is therefore crucial to ensure that they are adjusting to the change. Once the child has moved into the new placement, there should be regular ongoing monitoring to see how the child is settling in and to make sure that there is appropriate contact with the child's family, as well as friends from the institution. Follow-up is also important to ensure that the new placement remains appropriate to their development, or if their needs have changed. For example, a child who was initially placed in foster care may now be ready to be reunited with their birth family.[70]

Currently, the follow-up is the responsibility of the family advocate and their team. The large caseloads of family advocates (often hundreds), mean that they have insufficient capacity to follow up adequately with each child. They may also not have the required knowledge to follow up children with special health care needs such as HIV. This could put the children at risk and may lead to them re-entering institutions. There is an element of arbitrariness in the current system, as institutions like Fundamor are not able to follow up with the children and young people reunited with families or in foster care, unless the family advocate specifically agrees to this, or the family themselves consent.

Fundamor's experienced and committed multidisciplinary team led the care transformation process. The team included experts on HIV and health, and social workers, some of whom had over 20 years of experience in this area, as well as former carers who knew the children well. This team was involved in preparation and assessment for family reunification and had a deep understanding of the children's specific health needs, and the support families need to look after HIV-positive children and young people. The value and importance of this team was expressed by every child and young person during the home visits for this research. However, the team was not legally allowed to follow up all the children.

Fundamor's experience shows that monitoring needs to be responsive and some families need more support than others. It was not uncommon for families to call several times about the same problem, for example how to access medical care or how to fill out the paperwork for the medication. This is not only a matter of one specific training session or workshop, but it is a process that needs to be established over time. Ensuring a comprehensive plan of monitoring and follow-up, regulated and allowed by authorities, is crucial to guarantee a good quality of life and positive outcomes for children. In the case of some HIV- positive children, it is also a question of survival.

To ensure care transformation is effective and is achieving what was intended, monitoring must be built into the process from the outset and continue until the child is fully settled in the new placement and the case can be closed. Children and families must feel confident they can reach out for support, especially when requiring specific services and consistent access to medicines and health care. Allowing monitoring and follow-up going forward will require changes in legislation or the introduction of new regulations for transforming care that allow institutions to follow up children and families. This could be designed as a comprehensive joint programme between family advocates and the institution undertaking care transformation.

69. For further information of the financial implications, see the Financial analysis section.
70. Mulheir & Brown (2007). Op. Cit.

Child participation

Another important aspect of an effective care transformation process is child participation. Under both the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD), children have the right to be included in planning and decisions which affect them. Practitioners should develop appropriate mechanisms to ensure genuine child participation when transforming care. Involving children in decision making usually results in a better service design as children have a different perspective on their situation and needs.[71]

> ***"Transforming care is an important process that must be improved through us, the children and young people. Take into account what we have to say."***
>
> *- Young man in a focus group*

When planning care reform, it is important to empower children and families to take a lead role in designing and implementing the process of change.

Being aware of what is happening and actively participating in the process can also help reduce anxiety. Fundamor put a significant effort into strengthening its child participation and involved the children in decision making and planning. The personnel had open communication with the children, and discussed independence, inclusion and their futures. Fundamor also held the first national forum of children with HIV in Bogotá, with the support of UNICEF. At the forum, children expressed their opinions, and had the opportunity to raise their concerns about stigma, discrimination and their feelings about the importance of family. Fundamor also arranged workshops and meetings where all children who were part of the care transformation process were able to see their friends from the institution and share experiences. These opportunities to get together were highly valued and appreciated by the children.

Providing and developing family and community-based alternatives

Well-planned and well-delivered universal services, that are designed to be accessible to vulnerable children, can provide most of the support that families need. However, to develop to their full potential, children with more complex needs may require targeted social, health and education services to prevent family separation. When transforming care, a full range of family and community-based services must be available and where they do not already exist, these services must be developed. As mentioned in previous chapters, there are already a range of support services available for vulnerable children and families in Colombia. However, these must be strengthened to ensure that they are accessible for all children, including those from rural and poor communities, those with disabilities and those who are HIV positive.

Access to support services

Families and children can face multiple barriers to accessing health care and other support. This may include: services being concentrated in urban areas; effects of various forms of discrimination; or the presence of armed conflict. For children who are HIV positive, timely access to appropriate medical care and medicines is crucial in the process of transforming care, as the lack of access to services to respond to their medical needs is often the main reason they were institutionalised in the first place.[72] While HIV-positive people in Colombia are entitled to free access to health treatment, research indicates that the way the health system is organised does not always encourage people to use it. In addition, foster families in Colombia receive their transport allocation monthly in arrears, so families have to spend their own money to access medical care and medicines in a timely manner.[73]

71. Ibid p25.
72. Pezeshki, A., Mamalis, C., & Disabato, A. (2012). Op. cit.
73. As a result of Fundamor's follow-up, agreements have been made with the health system to deliver the medicines to the family's home.

> ***"There are many more barriers than facilitators to accessing medical care, and this is one of the biggest risks for children returning to an institution. When we follow-up about the reasons why carers are not giving the children the medication or going to medical appointments, they said that when they went to the appointment, they were also asked to go to another office to start the paperwork for authorising the medicine and that they didn't have enough money left to also go there, only the money for food."***
>
> *- Fundamor Care Transformation Coordinator*

The decentralised and bureaucratic health care system poses a significant challenge to successful care transformation in Colombia. The extensive paperwork, long queues, non-inclusive access and insufficiency of services in rural areas undermine access to health care:

> ***"The problem of paperwork is very widespread, their services are not centralised nor organised. It is not that families do not want to take care of the children's health, it is more that they can't afford to. Of course, there are cases of negligence but in most of the cases it is because of a lack of resources."***
>
> *- Fundamor Care Transformation Coordinator*

This is even more difficult for families who live in rural areas that are affected by conflict. In Fundamor's experience, in 2018, most of the children (32) were placed in urban settings and six out of the 11 children living in rural areas also live in areas where there is armed conflict. The team reported that for five out of those six children, accessing services is challenging. Care transformation needs to take this issue into account as access to services is a crucial component for the success of the reform. Children need to be protected from any form of violence, but they also have the right to grow up in their family and access services without being at risk.

Appropriate and timely access to medical care and medication is one of the most important aspects for managing HIV effectively and guaranteeing survival. Comprehensive access to health care with trained, multidisciplinary medical personnel and medicines should be guaranteed for every family and child. Additional support may be needed during the care transformation process as it is a sensitive time when families can feel overwhelmed by the situation. If things go wrong, there is a real risk that children may be re-institutionalised.

Availability of alternative placements

Foster care is a vital alternative form or care for children of all ages.[74] Identifying new foster families available to care for the children can be a significant challenge for the care transformation process. It is important to have a strict and rigorous process, but it can be lengthy, and this must be planned for.

In addition, when dealing with children with a special health care condition such as HIV there is a risk that the stigma and discrimination surrounding this diagnosis make it more challenging to recruit foster carers. Fundamor found that families were reluctant to care for HIV-positive children due to the potential implications for health and the additional responsibilities related to managing the treatment. However, Fundamor found ways to address and change these beliefs and perceptions.
Together with ICBF, they held workshops with care providers and potential foster care families to raise awareness of HIV. Fundamor involved children and young people in these workshops so they could have a voice in the process but also

74. Geiger, J. M., Hayes, M. J., & Lietz, C. A. (2014). Op. Cit.

to share their stories with the families. They also invited current foster care families to share their experiences, according to the principle that 'there are no better foster care recruiters than foster carers themselves'.

Once new foster carers have been identified, it is important that they are also prepared to receive the child, including visits to build relationships. If this is to an adoptive or foster family, it is essential that an appropriate matching process has taken place, selecting families who are most suited to children's needs, wishes and personalities. Training and preparation programmes must be carried out in advance and the new families should ideally have several visits with the child and have begun to form a relationship.[75]

When transforming care, it is important that the agreement with ICBF includes conditions to encourage the placement of children in foster care. The planning process must allow sufficient time to complete recruitment and preparation of foster carers. It is also important that respite care is developed to provide children with complex needs and their families a break from their regular routines. Where possible the institution undergoing transformation should apply to become a foster care service provider. Having this second licence could mean that foster care placements would be more readily available for the children of the institution undergoing the transformation process. This also means that follow up by the institution would be possible in many cases, as their foster care licence would give them the right to undertake follow up.

If children are placed in another form of residential care, it is essential that the care is not institutional but based around the needs of the children and young people. Institutional care is any residential care where institutional culture prevails. The size of the institution matters, but is not the only defining feature. 'Institutional culture' means that children are isolated from the broader community and are compelled to live with other non-related children. These children, and their families, have insufficient control over their lives and over decisions which affect them. Crucially, the requirements of the organisation itself tend to take precedence over the children's individual needs. This makes it difficult for children to develop a secure attachment and to receive sufficient stimulation and attention to develop normally.[76]

There are many ways of providing effective support in non-residential settings, including for children and young people. For example, to address the issue of support in the community, Fundamor opened a non-residential day care service (externado). This service provides support and monitoring for 6–12 months to vulnerable children who had been referred to the child protection system but have not been separated from their families.

Leaving care services

Institutions can leave children unprepared for independence and being part of society, as they may not have acquired all the relevant life skills or developed their own support networks.

> ***"We were used to having everything done for us, even the bed. And now no one makes our bed for us, and if you use some dishes you have to clean it yourself."***
>
> *- Young woman during a focus group*

A range of services should be provided for young people when they leave care and support available. This includes services assisting those preparing to leave care and live independently, with personnel who help young people make the transition to independent living. They provide advice and guidance in finding employment, training or continuing education.

The service may also include suitable housing and supported independent living for young people with disabilities or other additional needs.

75. Mulheir & Brown (2007). De-institutionalising and Transforming children's services. A guide to good practice.
76. Mulheir, G & Gyllensten, L (2017) Institutionalisation and the commodification of children. How to ensure children regain their right to family life. In Dolan, P & Frost, N (eds.) The Routledge Handbook of Global Child Welfare, Routledge.

Contextual considerations

In addition to the challenges around policies, regulations and services there are also other, less tangible, but equally important issues to consider. These include stigma and discrimination, as well as challenges related to adolescence. Learning from others' experience and raising awareness around these issues is also essential for the care transformation process.

Stigma and discrimination

Stigma and discrimination related to HIV can be significant barriers to accessing care and living a regular life, because of the fear of social consequences, in the family, in education, or in the health care system.[77] This may affect the wellbeing and mental health of HIV-positive children and young people and can also affect their adherence to the HIV medical treatment.[78] Stigma around HIV is also present in Colombian society, which can affect the family advocates' and ICBF's ability to seek alternative care options which do not involve institutionalisation. In theory, HIV should not result in institutionalisation. However, there is anecdotal evidence that children have had to remain in the institution because families have such a difficult time accessing universal services, such as health care and education for their children.

> ***"I've seen that when they [the school] see their clinical history, they started to block the process. When I went to the school, they started to enrol the child but when they found out about the HIV they stopped the process."***
>
> *- Foster care mother*

Since its establishment, Fundamor's work has included tackling stigma and discrimination, and is one of the main parts of the follow up with families and children. When the family raises concerns during home visits, the team provides practical advice and helps them access support through the service network. To raise awareness, Fundamor has carried out workshops at schools, in the community and in the child protection system.

To ensure all children's rights and needs are met, it is important that training and information is made available and implemented in the child protection system, as well as in other parts of society. The focus should be to debunk the myths around HIV and address the stigma and discrimination faced by HIV-positive children and young people.

Adolescence

Age is a crucial factor to consider when ensuring that children's and young people's needs are met. When care transformation was undertaken, most of the children in Fundamor were between 11 and 20 years old and living through the rapid biological and behavioural changes that comes with that age.[79] Adolescence can also be a challenging time for any family, and it is important that support is available as part of the care transformation process.

Fundamor's Transforming Care Coordinator stated that the number of calls asking for support was higher in families who were caring for young people between the ages 14 and 16 than any other group.

The main reason was that the families did not know how to deal with, or were nervous to talk about, dating and romantic relationships that were naturally starting at that age, so they turned to Fundamor for support.

77. Ministerio de Salud y Protección Social. Plan nacional de respuesta ante las its-vih/sida. Colombia 2014-2017. http://www.nationalplanningcycles.org/sites/default/files/planning_cycle_repository/colombia/plan-nacional-respuesta-its-2014-2017.pdf p3
78. Willis, N.(n,d) Adolescents with HIV speak out against stigma and discrimination. UNICEF INNOCENTI. https://www.unicef-irc.org/article/988-adolescents-with-hiv-speak-out-against-stigma-and-discrimination.html. [Accessed February 11th 2019].
79. World Health Organization (2018). Adolescent development. http://www.who.int/maternal_child_adolescent/topics/adolescence/development/en/ [accessed 9 January 2018].

Colombia is a relatively conservative Catholic country and sex education is often avoided, not only in families but also in the educational system. In fact, one of the young adults mentioned this as a key issue:

> ***"It would be very important that this [sexual transmission and protection] was taught at schools because when you ask them to talk about sexuality they get worked up."***
>
> *- Young adult who left the care system*

Another challenge is around setting boundaries and standards of acceptable behaviour at this age. Families can struggle with challenging behaviour and sometimes do not know how to deal with it. That is why it is important to provide training for families about understanding: attachment, separation, trauma and loss; the impact of institutionalisation on children; and why teenagers may engage in risk-taking behaviours. Training about setting house rules in consultation with the child are also important to help families and carers deal with adolescent challenging behaviour. Connecting with the child or young person through empathic listening, rather than shaming and disciplinary sanctions unrelated to the behaviour and using limit setting with clear choices that have logical consequences, are key to building predictable, coherent and affectionate relationships.

Awareness raising and building support

To ensure transformation of the care system, requires not only new policies and services, but also a shift in attitude among authorities, professionals, care service providers, donors, families, as well as the wider community. It is important to raise awareness on the harmful effects of institutionalisation and the better alternatives that exist. Institutions embarking on care transformation should, at a minimum coordinate, plan and implement their programme together with regional child protection system and the local community, and, where possible, with national level actors. They should seek alliances and partnerships to amplify the messages.

By organising national and regional meetings about care transformation together with ICBF, Fundamor helped raise awareness of the importance of transforming care and emphasised the advantages and benefits of family and community-based services. This also provided an opportunity to the best way to achieve a transformed system of care for children in the country. Through building alliances with key partners such as UNICEF, Lumos and The Global Fund, Fundamor accessed technical advice, guidance and financial support to help them in the transformation process.

Fundamor strove to ensure their care transformation process was based on best practice. As there were few relevant documents available for Colombia specifically, they reviewed a wide range of international materials to learn from experiences in other countries and sought out relevant training opportunities. Seeking support is also important to ensure that knowledge and learning is transferred. Sharing experience and study exchange opportunities are vital to accelerating care transformation across the country. Service providers and policy makers should develop a joint vision of what is possible and have the courage to champion innovative practices in their own communities.

Capacity and resources for care transformation

To implement a major reform such as care transformation, which is a complex process of change management, adequate professional capacity and finances are essential. Sufficient professional capacity to address the complex needs of vulnerable children and their families is also a vital ingredient. Naturally, this is of great concern to governments and decision makers, who should consider what resources will be necessary to both implement and sustain the reform, and where these resources will come from. There is a tendency to underestimate the resources required to manage care transformation. However, there are already significant resources in the current system which should be ring-fenced and reinvested into new higher quality services.

Workforce

The workforce is the greatest asset of any child protection system. However, it is not uncommon for personnel to be blamed for inadequate practices in institutions and poor outcomes for children. Yet, it is often the case that the numbers of direct care workers are insufficient to provide a holistic and individually tailored service to children. Limited support, supervision and training is provided. Where it does exist, it is sporadic rather than systematic, and caseloads are often too large to be managed effectively.

The workload of the family advocates and their teams was identified as a key challenge in the Fundamor transformation process. Family advocates do not always have the necessary skills and knowledge in relation to social work or child development to make fully informed and considered decisions. Therefore, there could be a wide range of interpretation of a child's best interest. This could result in some family advocates prioritising institutional placements rather than providing support for vulnerable families to ensure they can care for their own children. Or, as in Fundamor's case, assuming that children who are HIV positive require institutional care. Increasing the capacity of family advocates and their psychosocial teams should be a priority for the government. This should include raising awareness about: HIV; the harms of institutionalisation: and the better outcomes for children in family and community-based care.

It is important to ensure that the workforce is included in planning and that practitioners are given the opportunity to develop skills and knowledge around care transformation. These are often skilled and experienced professionals who know the children and their families well. From the start, the leadership of Fundamor had conversations with the personnel about care transformation and the implications for their professional futures. This included opportunities to be trained and redeployed in new services.

Other institutions undertaking care transformation should attempt where possible to ensure personnel are offered opportunities to work in new services developed under the new licence (where applicable) or in family-based care alternatives. Alternatively, some personnel might wish to become foster carers.

4. Financing care reform

When undertaking a process of transforming care, there are several financial aspects to consider. Firstly, the institution must be replaced with community-based services that support children to live in families, and these services must become sustainable. It is therefore desirable that the running costs of the new services should be similar to – or, if possible, less than – the costs of running the institution. This increases the feasibility of long-term sustainability for the new services. The aim is, where possible, to redirect the budgets from institutions to fund community-based services instead.

Secondly, there are one-off costs involved in establishing the new services. Such costs may include:

- assessment and preparation of children
- training of personnel
- development of new service infrastructure
- support to families to prepare for children to come home
- production of materials related to the care transformation
- behaviour change communications activities
- monitoring the process of change.

Thirdly, there are transitional costs. The new services must be established and begin providing support to children and families before children can move into families and the institution can be closed. This means that the institution and the new services will operate in parallel for a period of time. Additional resources are required during this time.

This section provides an analysis of each of the three types of costs in relation to the care transformation process at Fundamor. This analysis provides a basis for recommendations to assist future programmes of care transformation in Colombia and elsewhere.

Running costs comparison: Institutionalised vs. family and community-based care

Institutional care

The cost of looking after a child in the Fundamor institution was, on average, 27,600,000 pesos a year. While most of this was funded by ICBF, 37% of the cost had to be fundraised by Fundamor itself.

The table below provides the costs to the state of institutional placements for children with different needs:

- For a child living with a disability living with a disability in an institution the cost to the state is 17,483,686 pesos a year. ICBF's contribution to supporting the HIV-positive children and young people living with HIV/AIDS in Fundamor was made at the same rate as that for children with disabilities.
- For a child living without a disability in an institution the cost to the state is 15,240,468 pesos a year.
- For a child living in an institution that requires psychosocial support the cost to the state is 25,275,108 pesos a year.

2017 annual ICBF institutional care costs[80]		
Type of institutional care placement	**Per placement cost to ICBF (COP)**	**Per placement cost to ICBF (USD)[81]**
For children with disabilities	17,483,686	5,597
For children without disabilities	15,240,468	4,879
For children requiring psychosocial support	25,275,108	8,091
Average	**19,333,148**	**6,189**

On average across these three types of care, the cost to the State of institutional care of a child each year is 19,333,148 pesos or US$6,189. Note that this is almost equivalent to Colombia's GDP per capita of US$6,301. However, the funding provided by the State is typically supplemented by an institution's fundraising efforts in order to meet the true cost of caring for an institutionalised child.

The level of supplemental funding that an institution may provide, in addition to ICBF funding, depends of the institution's ability to fundraise to meet these additional costs. Therefore, the proportion of the true cost of institutionalised care covered by ICBF funding varies per institution. The proportion of funding raised by institutions themselves can range from less than 37% up to the equivalent of 40% of the total cost of care for a child.

Based on the information available, on average, the annual state contribution to an institutional care placement is US$6,189 or 63% of the total placement cost. When accounting for supplementary funds typically provided by service providers (approximately US$3,635 per placement), the actual cost per child is US$9,824 year.

In 2018, there were 11,201 children in institutions in Colombia.[81] If the figures provided by ICBF and Fundamor are extrapolated for all children in institutions, the annual costs for institutional care are therefore more than US$110,000,000.[82]

Foster family care

On average, the State meets 75% of the cost of foster family care for families recruited by ICBF and 50% of the cost of foster family care for families recruited by a service provider. The rest of the cost is expected to be met by the foster family. The cost to the State of supporting a child with a disability in an ICBF foster care placement is 6,616,224 pesos and in a service provider foster care placement, it is 6,175,152 pesos each year. The cost to the State of supporting a child without a disability in an ICBF foster family care home is 5,194,044 pesos and in an NGO foster family care home it is 5,144,580 pesos each year.

80. ICBF (2018) Lineamientos de programación. https://www.icbf.gov.co/gestion-transparencia/transparencia/planeacion/lineamientos-programacion?page=2 [Accessed 13 March 2019]
81. All currency conversion using exchange rate US$1 = 3,124 Colombian pesos.
82. Information based on request for information by Lumos to ICBF.
83. Please note, this figure only includes children in social institutions. It does not include the approximately the approximately 50,000 children in residential boarding schools run by the Ministry of Education.

2017 Foster family care costs[84]			
Type of foster family care placement	**Annual per placement cost to ICBF (COP)**	**Total annual placement cost (COP)**	**Total annual placement cost (USD)**
ICBF foster placement for children with disabilities	6,616,224	8,821,644	2,824
Service provider foster placement for children with disabilities	6,175,152	12,602,352	4,034
ICBF foster placement for children without disabilities	5,194,044	6,925,392	2,217
Service provider foster placement for children without disabilities	5,144,580	9,893,412	3,167
Average	**5,782,500**	**9,560,700**	**3,060**

On average across these different types of foster family placements, the annual cost to the state per child is 5,782,500 pesos, though the full cost is 9,560,700 pesos, or US$3,060.

In 2017 there were 10,312 children in foster care.[84] Using the total cost average of $3,060, the annual national cost of foster care is estimated to be more than US$31,000,000.

Family support

When an institution is going through the care transformation process, it is obliged to support family reunification. However, the State currently provides no additional resource to deliver this service. As part of transforming care, Fundamor employed additional personnel to work on family reunification. This team was comprised of a professional with expertise in family support, a psychologist and a social worker. Fundamor also provided support to families – such as school supplies, clothing and food – to ensure families in poverty have the resources they need to look after their children. The cost for this team to successfully reunite a child and support them to live with their family in the community was 5,376,000 pesos, or US$1,721 a year.

Cost comparison

The average cost of one year of institutional care in Fundamor for one child is equivalent to the cost of supporting 5 children to live with their family in the community. This is under the assumption that the placements in Fundamor would cost the same as the average cost of placing a child with disabilities with a foster family, as ICBF's contribution to Fundamor was made at this rate.

Type of placement/support	Total annual cost (COP)	Total annual cost (USD)
Fundamor institution	27,600,000	8,835
Foster family care	10,711,998	3,429
Family support	5,376,000	1,721

83. ICBF (2018), op. cit.
84. Information based on request for information by Lumos to ICBF.

The evidence from Fundamor demonstrates that institutions are not only a more expensive way to look after vulnerable children, they are also not good value for money, due to the poor outcomes for children. Supporting children to live in families is less expensive and can result in better outcomes for children, making it the most cost-efficient option.

Costs and outcomes of the care transformation process

Initial one-off costs when transforming care

Fundamor's care transformation programme cost 45,399,473 pesos – or US$14,532 – for a year. This included the recruitment and training of families for family-based care, supporting independent living for young people, advocacy, and management of the programme.[85]

Transitional costs

During the care transformation process, there is a period of time where the new family and community-based services have been established and the children are gradually moving into new placements. During this time, the existing institution must remain open. This means the new system and the institution must be funded concurrently, which requires additional funding. This ensures that children are not harmed by the premature closure of institutions without adequate services in place. These are usually known as transitional costs.

When new services are developed as part of transforming care, it is ideal if the funds in the institution can be 'ring-fenced' or protected and then redirected to finance the new community-based services. The closure of the Fundamor institution was the first time ICBF had engaged with a systematic care transformation process. Unfortunately, there are, as yet, no regulations to enable the redirection of resources from the institution to the family and community-based services and there are no additional funds to cover transitional costs.

Due to the lack of ring-fencing of resources invested in institutional care, Fundamor would not have been able to meet the costs of transforming care while maintaining sufficiently high-quality ongoing institutional care for the children and young people who had not yet moved from the institution. However, with financial support from Lumos, Fundamor was able to cover these transitional costs. This funding gap existed because currently in Colombia – as in many countries – institutions are funded on a 'per child' basis. Therefore, as Fundamor gradually moved children to family-based care, ICBF funding decreased.

85. NB. From Lumos' experience elsewhere, this is an unusually small amount of additional resource. However, in this case, there was no need to develop additional building infrastructure for new services. Therefore, it is likely that in transforming care in other institutions, a higher investment will be required.

The grant provided by Lumos to Fundamor to enable a higher-quality transformation process was as follows:

Activity	Cost (COP) [87]	Cost (USD)
Financial gap coverage for Fundamor's institutional care programme	112,600,527	36,044
Funding for a team, including a professional with expertise in family support, a psychologist and a social worker, to support foster care service providers with the recruitment and training foster parents for six months	13,000,000	4,161
Care transformation programme costs (Percentage of personnel costs required for care transformation, recruitment and training of families, establishment of independent living for some young people, recreational costs for activities, advocacy, administration, etc.)	45,399,473	14,532
Total	**171,000,000**	**54,738**

Comparative running costs for Fundamor

Between 2016 and 2017 the number of children living at Fundamor decreased by approximately 24%. During the same period the relative cost of caring for a child at Fundamor increased as the cost of running Fundamor's institutional service only decreased by around 20%.

In 2016, Fundamor had 49 children and young people in their institutional care. In 2017, during the care transformation process, the number of children in residence decreased to 37 children and young people. While the cost of running Fundamor's residential service did reduce between 2016 and 2017, it reduced at a faster rate than the number of children. This meant that the cost of looking after a child increased from US$7,709 to US$8,176 during that time.

Comparative running costs			
Year	**Fundamor budget (COP) [88]**	**Fundamor budget (USD)**	**Cost per Child (USD)**
2016	1,180,000,000	377,721	7,709
2017	945,000,000	302,947	8,176

Barriers to change

Inadequate ring-fencing or protection of budgets

Successful care transformation requires the 'ring-fencing' - or protection - of resources in the institutional system and redirection towards new services. Family and community-based care is less expensive per child than institutional placements. However, transforming care must not be viewed as a cost-cutting exercise. Instead this should be a process of reinvesting funds in higher-quality services that meet the needs of a greater number of children.

86. Grant agreement between Lumos and Fundamor on file with Lumos.
87. Personal communication with Fundamor on file with Lumos.

As Fundamor began the care transformation process, their funding from ICBF decreased. This is because ICBF funding is linked to the number of children in institutional care. As Fundamor was able successfully to reunite children with their families or find suitable foster family placements, this funding from ICBF decreased. Such a decrease in resources would have been prohibitive to a safe process of care transformation, were it not for the financial support Lumos provided Fundamor to cover this shortfall. Without the ring-fencing and redirection of resources, and without the provision of transitional costs and one-off costs, institutions will not be able to transform care safely and sustainably.

Financial disincentives to care transformation

There are currently financial incentives to keep children and young people in institutions when they may otherwise be able to live with a family. One young man who was living in Fundamor was unable to live with a family interested in adopting him, and who had recently adopted one of his close friends from Fundamor. This is because joining their family would have resulted in him losing his university scholarship of approximately four million pesos (US$1,280) a month from ICBF.

ICBF funds the further education and training of children in institutions, but if a child is adopted or successfully reunited with their family, their education is solely the responsibility of the family and ICBF's funding is withdrawn. This inadvertently discourages children and young people from leaving institutionalised care for fear of losing the chance to go to university, as an otherwise suitable family may not be in a position to provide this support. It should be noted that in addition to four million pesos per month, ICBF was obliged to continue paying for the young man's institutional care – an additional 17.4 million pesos a year. If funding processes could be reorganised, the young man could have been adopted and continued with his education scholarship and the State would have saved 17.4 million pesos (US$5,570) a year.

In addition, there is considerable under-investment in foster family care or support services for birth families. This can make it difficult to find sufficient numbers of foster families and to reunite children. Yet foster care is much cheaper than institutional care and family support is even less expensive.

If regulations were established to redirect funding from institutions to foster care and family support, the State could increase budgets per child in family care and significantly reduce the number of children in institutions.

5. Conclusion and recommendations

Transitioning to new forms of care and ensuring that all children's needs are met in the community can be a challenging prospect. Particularly when countries are struggling with inequality, violence, war, poverty and insufficient universal services at community level, especially in rural areas. Transforming care can be even more challenging when caring for children and young people with special health care needs such as HIV. There are often concerns that family and community-based services may not be able to meet children's needs effectively and that it will be a more expensive form of care and therefore unsustainable in the long term.

Despite these challenges in Colombia, Fundamor took the courageous decision to become a pioneer in care transformation. Fundamor is to be congratulated for its tireless efforts to ensure transformation was as positive as possible for the children and young people. ICBF at the national level was equally courageous. It was conscious that it was not yet ready to undertake care transformation, but understood and supported Fundamor's decision. It is striking that the first institution to transform its care was a provider for HIV-positive children. In most countries, care transformation begins with the 'easier-to-place' children. Fundamor and ICBF understood that an HIV-positive status renders children extra vulnerable, making their care needs more complex. They decided to prioritise some of the most vulnerable and marginalised children in the country and have led the way to shift reliance from residential to family and community-based care.

The experience of Fundamor has demonstrated that it is possible to undertake high-quality care transformation in Colombia. Follow-up reports by Fundamor, show positive trajectories for children placed into family and community-based care. Contrary to fears at the outset of the care transformation process, improvements were reported in children's physical and mental health, as well as in their behaviour and educational performance. What is more, people often believe it is 'too late' for teenagers to move from institutions to families and that they will not benefit from the change. The Fundamor process demonstrates that, when prepared well, teenagers from institutions can be placed in families and have excellent results.

The results for a minority of children were of concern as they demonstrated a deterioration in health and happiness. This highlights gaps in the system and legislative restrictions that hindered the care transformation process. In particular, rigid approaches to licensing service-providers, financing based on the number of children in institutions, and restrictions that did not allow Fundamor experts to follow up children and support their families, meant some placements were not as stable as they should have been. In addition, because this was a pioneering process and, as yet, there are no protocols or standard operating procedures for care transformation, individual employees of ICBF and family advocates responded inconsistently to the needs and rights of children. This resulted in a certain arbitrariness in decision-making, the consequence of which was inappropriate placement decisions for some children, new services were not developed in time and insufficient time given to prepare children to move to their new placements. To an extent, this was influenced by negative attitudes to – or a misunderstanding of – HIV. With hindsight, there was clearly a need for awareness-raising and an agreed set of principles and procedures for all stakeholders, prior to embarking on transforming care.

When transforming care, the plans need to be based around the needs of the children. Setting arbitrary targets for when children move without considering the services available and the preparation needed, is not conducive for an effective process and may even be harmful for the children. Following up the children's progress is also essential, but the highly experienced team from Fundamor was legally prevented from doing this is some cases.

It is clear in this case, both Fundamor and ICBF underestimated the time necessary to ensure high-quality care transformation. They also underestimated the necessary finances and did not anticipate bureaucratic obstacles to care transformation.

Understanding and planning the finances well, in advance of care transformation, is essential to quality of process and sustainability of outcomes. Based on the learning from this case, ICBF should ideally develop specific regulations and standard operating procedures for the care transformation process. This should include, at least:

- Principles that put the best interests of every child at the centre of decision-making. Commit to ensuring every child leaving the institution moves to a better placement. Do not transfer children to other institutions.
- Allocating adequate time and resources to every aspect of care transformation.
- Minimum requirements for managerial capacity to implement care transformation.
- A mechanism to ring-fence and protect institution budgets as the number of children reduces, so that quality of care can be maintained throughout the process. Once all children have moved, this mechanism should facilitate the redirection of finances from the institution to fund the ongoing running costs of the newly designed services that replaced the institution.
- A process to identify the funds required to develop the new services as well as funds to cover the transitional costs for the period of time when the new services and the institution are operating in parallel.
- The full and meaningful participation of children and young people.

The process carried out by Fundamor demonstrated that:

- Individual service providers can lead transformation of their own care service.
- Children and young people can be supported in families and communities, including those with special health care needs such as HIV.
- Family and community-based care results in better outcomes and is less expensive than institutional care.

It is hoped the learning from this experience provides evidence and insight to inform the development of a comprehensive national action plan for transforming care in Colombia. This would eventually guarantee the right of every child – including the most marginalised – full access to all their rights to health care, education and protection, as well as their right to grow up and thrive in a family, fully included in the life of their community.

Recommendations

National ICBF:

- Lead the development of a national action plan for transforming care, working closely with Ministries of Education and Health and civil society organisations.
- Commission a financial analysis of the system to estimate costs involved in implementing the national action plan.
- Develop a clear regulatory framework to support initiatives to transform care, ensuring the best interests of the children are the central focus and removing barriers to effective care transformation. This should include standard operating procedures for care transformation, that should be obligatory for all state and civil society stakeholders involved in transforming care.
- Ensure the resources currently in the system are ring-fenced so that funds cannot be diverted away from the children and families during the care transformation process.
- Ensure collaboration and consistency of approach between ICBF at the national and regional levels.
- Ensure universal and targeted services for families, children and young people are available and accessible.
- Work in close cooperation with NGOs involved in the provision of institutions and other children's services.
- Prioritise the development of support services for young people transitioning from care to independent living.
- Empower children and young people to take a lead role in care transformation.

Regional ICBF:

- Support and coordinate effectively with local care transformation processes.
- Follow regulations, policies and standard operating procedures provided by ICBF national office.
- Undertake training and awareness raising with all key stakeholders locally to support care transformation.
- Develop clear agreements with institutions who wish to transform their care and allow flexibility in the regulations to ensure an effective process in the best interest of children.
- Raise awareness about the benefits of transforming care with institution service providers.

Family advocates:

- Strengthen the process to ensure that parents and carers are properly prepared to receive the child, including visits to build or rebuild relationships. Ensuring appropriate matching of children with foster and adoptive families.
- Ensure that regular ongoing monitoring and support for the carer or child's family meet their needs.
- Ensure formal follow-up effectively evaluates the placement, including to ensure that the child is safe, their needs are being met and their outcomes are positive. Involve the institution personnel in follow up as they know the children well.
- As new children require support, refer them to family and community-based services rather to institutions, especially not to any institution going through care transformation.
- Give children and young people opportunities to express their wishes and, where possible, take them into account when planning their care placements.

Governments involved in transforming care for children who are HIV positive:

- Ensure that families and children have access to a comprehensive set of universal and specialised services.
- Ensure health ministries are given responsibility to monitor the health and development of HIV positive children, wherever they live.

- Ensure benefits, such as transport allowances, are available in advance to families, so they can access medical care and medicines on time. An additional allowance should be provided to foster carers or families who care for children with additional or complex health needs.
- Ensure that sexual education for adolescents and families is mainstream in health, community and educational settings, to promote behaviours to prevent or reduce the risk of HIV, other sexually transmitted infections (STIs) and teenage pregnancy.
- Ensure that families and young adults have comprehensive support after a new placement.
- Develop a strategy to address stigma and discrimination, particularly involving government departments responsible for health, education and child protection.
- Involve children in advocacy and raising awareness about HIV to address stigma and discrimination
- Provide training programmes for families and other carers and families on managing children's health needs, attachment, separation and loss, safeguarding and understanding and managing behaviours.

NGOs and institutions interested in completing a care transformation process:

- Identify and raise awareness about care transformation among critical stakeholders, including at government level.
- Seek official support from national and local government before embarking on a care transformation process.
- Empower children and young people to participate fully in the transformation process.
- Allocate adequate time and resources to the care transformation process.
- Provide careful preparation for children when moving or leaving a placement. Communicate openly and honestly with their children and, where possible, take their wishes into account.
- Work with the relevant governmental authorities to establish and implement joint monitoring of the process.
- Provide regularly follow up and support to families once children have moved from the institution and until they are settled in their new environment.
- Document learning and share this with other institutions and NGOs.

Donors:

- Enact internal regulations to prohibit investment in institutions and divert funds to care transformation.
- Prioritise investment in family and community-based services, such as inclusive education, community health care, family support services and alterative family care.
- Prioritise investment in care transformation.
- Support the Colombian Government by funding demonstration programmes in care transformation.
- Provide funds to strengthen capacity to undertake reform.

Annexes

Annex I: Definitions

Adoptable	Law 1098 establishes that children and adolescents are adoptable when: 1. They are declared adoptable by the family advocate, by resolution, or by the family judge, when the first loses jurisdiction. 2. The family advocate authorises the adoption according to the cases provided in Article 66 of Law 1098, specifically, the absence of the father or the mother because of death, a mental illness or serious psychic anomaly, certified by the National Institute of Forensic Medicine and Forensic Sciences.
Casa de acogida	Full-time care for children who have been released from organised armed groups age 15 to 18, lasting 30 to 60 days.
Casa hogar	Group homes for up to 12 residents for a maximum of six months; open to children, adolescents and/or pregnant and breastfeeding women.
Casa de protección	Continued care for adolescents (15 to 18 years old) who, following phase I of the process of care (casa de acogida), either do not have family, the family is not guaranteed the rights and/or child protection issues have been identified.
Child labour	ICBF defines child labour as any work either carried out by a child/adolescent who does not reach the minimum age for admission to employment or prevents the child's education and full development, or dangerous work.[88]
Child maltreatment	Colombia's Code of Childhood and Adolescence (2006) defines child maltreatment as all forms of injury, punishment, humiliation or physical or psychological abuse, neglect or negligent treatment, ill-treatment or sexual exploitation, including abusive sexual acts, rape and all forms of violence or aggression on the child/adolescent by their parents, legal representatives or any other person.[89]
Disclosure	The process of revealing a person's HIV status, whether positive or negative.
Emergency Centres Emergencia)	Short-term, emergency residential care for children/adolescents; maximum of eight (Centro de days.
Externado	Non-residential day care
Family advocate	A lawyer who determines all aspects of the child's case, such as what type of care the child will be placed into, how often the case is reviewed, if the child is moved and if the child is declared adoptable. The Family advocate (which falls under ICBF) is the municipal official in charge of the PARD.
Foster care (hogar sustituto) Hogar de paso	The placement of the child or young person who cannot remain with their birth family, into a family that is committed to providing the necessary care. Short term care in families or group homes for children/adolescents; maximum eight working days (Article 57 of Law 1098).

88. ICBF at https://www.icbf.gov.co/programas-y-estrategias/proteccion/trabajo-infantil
89. ICBF at https://www.icbf.gov.co/sites/default/files/publicacion-37.pdf p4

Management homes	Residential care for children and adolescents with disabilities, victims of armed conflict and young adults over 18 years of age with an acute mental disability.
Multidimensional Poverty	Multidimensional poverty is made up of several factors that provides the basis for poor people's experience of deprivation – such as poor health, lack of education, inadequate living standard, lack of income, disempowerment, poor quality of work and threat from violence.[90]
Programme for independent living	A residential service similar to a small group home, where young adults can start living more independently while still being overseen by carers. Children in this type of care are given responsibilities for their own care, such as cooking, going to medical appointments or handling their own money. Work training and other support is provided with the aim of helping them develop an independent life.
Psychoactive Substances	The Colombian Drug Observatory defines psychoactive substances as "any substance that is introduced into the body, by any route of administration, which produces an alteration of the functionating of the central nervous system and is likely to create dependence, whether psychological, physical or both. In addition, psychoactive substances have the ability to modify the consciousness, mood or thought process of the person who consumes them".[91]
Small Group Home	A high-quality residential care service provided in very small units, each housing around 4–6 children. These homes should be integrated into the community, taking the form of a regular house on a regular street, and staffed with sufficient numbers of highly-trained personnel.
Support interventions	This consists of either psychosocial support or specialised psychological support and involve the provision of services in the beneficiaries' home and/or family-based care setting.

Annex II: Resources

Children's rights organisations' websites

Better Care Network: www.bettercarenetwork.org
Fundamor: www.fundamor.org
Lumos: www.wearelumos.org
RELAF: www.relaf.org
UNICEF: www.unicef.org

Further information about HIV/AIDS

AVERT: www.avert.org
HIV.gov: www.hiv.gov
LACASSO: Consejo Latinoamericano y del Caribe de Organizaciones No Gubernamentales con Servicio en VIH/SIDA: www.laccaso.net
Liga Colombiana de lucha contra el SIDA: www.ligasida.org.co
Ministerio de Salud Colombia – Observatorio VIH/SIDA: www.minsalud.gov.co/salud/Paginas/ObservatoriodeVIH-SIDA.aspx
Panamerican Health Organization: www.paho.org

90. Oxford Poverty & Human Development Initiative at https://ophi.org.uk/policy/multidimensional-poverty-index/ [Accessed 23 February 2019]
91. http://www.odc.gov.co/problematica-drogas/consumo-drogas/sustancias-psicoactivas

Portalsida: www.portalsida.org/about
UNAIDS: www.unaids.org
UNICEF HIV and AIDS: www.unicef.org/aids/
US Department of Health and Human Services AIDS Info: www.aidsinfo.nih.gov/
World Health Organization: www.who.int/hiv/en/

Selected further reading

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- Vermund, S. H. (2014). Global HIV epidemiology: A guide for strategies in prevention and care. Current HIV/AIDS Reports, 11, 93-98.

Annex III: An overview of Colombia's legislation and policy on HIV/AIDS

- In the 1990s, the Colombian Government issued ***Decree 1543*** in 1997 which provided a framework for the management of HIV/AIDS cases. In the same year, ***Law 360*** outlined that victims of sexual assault have the right to examination and treatment for the prevention of HIV/AIDS.[92]
- In 2003, the national Sexual and Reproductive Health policy was developed. This policy established guidelines for the response to HIV/AIDS with six specific strategies:

  1. Promotion of reproductive and sexual health through information, education and communication strategies
  2. Intersectoral and interinstitutional coordination
  3. Strengthening of institutional management
  4. Strengthening participation
  5. Enhancement of social network support
  6. Research and development.[93]

92. Article 15, Ministerio de Salud Y Protección Social (2014) Plan nacional de respuesta ante las its-vih/sida colombia 2014-2017. http://www.nationalplanningcycles.org/sites/default/files/planning_cycle_repository/colombia/plan-nacional-respuesta-its-2014-2017.pdf p 30 [Accessed 17 January 2018]
93. Ministerio de Salud Y Protección Social (2014) Op.Cit p 40

- In 2005, Law 972 allowed standards to be created to improve the care provided by the State to the population suffering from serious illness, especially HIV/AIDS. This law stated the importance of the fight against HIV/AIDS and mandated the Social Security Health System to supply medication and strategies for the diagnosis and treatment of HIV.
- In 2006, Resolution 3442 adopted the recommendations of the Model of Program Management, which includes actions for the development of programmes, plans and relevant projects to respond to the HIV/AIDS epidemic. The integral care guidelines for HIV/AIDS were also adopted.[94]
- In 2011, Law 1482 established the obligation to formulate a ten-year plan for public health. This plan included a strategy for an HIV response plan with four components:

  1. Promotion and prevention
  2. Comprehensive health care
  3. Support and social protection
  4. Monitoring and evaluation.[95]

94. Ministerio de Salud Y Protección Social (2014) Op.Cit p31
95. Ministerio de Salud Y Protección Social (2014) Op.Cit p39

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