C) ACCESS TO QUALITY, INCLUSIVE HEALTH SERVICES

How the health system can drive the institutionalisation of children

c) Access to quality, inclusive health services

How the health system can drive the institutionalisation of children

Children have a right to access quality healthcare in their own communities. Yet, all too often lack of access to, or inability to pay for, quality healthcare is a key driver of institutionalisation.

This results in **children being torn from their families and placed in institutions to meet their basic needs**, such as life-saving drugs or therapies or access to supportive aids, and services for children living with disabilities.

Families that have a child living with long-term medical needs such as HIV, or a disability, often **face significant challenges accessing adequate treatment and support**, in addition to managing the stigma they may experience in the community. As a result, the child may be placed in a 'specialised institution', reinforcing the common misconception and discrimination that they cannot be supported to live in their community.

Discriminatory attitudes towards certain communities increase the likelihood of institutionalisation. All too often, disability is seen as a 'medical problem', requiring a medicalised solution in an institutional setting, rather than providing specialised support through the frame of care in family settings. Consequently, this places many children with disabilities at risk of being separated from their families.

In some contexts, decision makers and, at times, health or social workers, **are not aware of the critical importance of the attachment between a child and their family**, which is essential to a child's development in their early years. This lack of understanding can lead to, for example, a baby being moved into an institutional setting to access respiratory support, instead of providing oxygen support at home.

A phenomenon, observed in countries that Hope and Homes for Children have operated in, is children with disabilities and/or medical conditions being placed in institutions by social workers, because they perceive that in doing so, it reduces the risk to them as professionals. Even though the outcomes for the children are worse, social workers pass on responsibility to another part of the system, which then takes on responsibility for the child. This can lead, in some circumstances, to social workers being reluctant to reintegrate or place children in alternative family care because they have to continue to support and monitor the child, and will be held responsible if something happens to them.

Another important factor to consider is that disabilities or the poor health of parents or caregivers can lead to a child being institutionalised.

How institutionalisation can lead to poor health outcomes

Over 100 years of research **demonstrates the detrimental effects of institutionalisation on the health of children**. This is due to many interrelated factors, including the lack of individualised, stable care, neglect, violence, and over-medication. The lack of individualised care in institutions means that children with disabilities and/or medical conditions can see their needs misdiagnosed, worsen or go untreated. Institutions can lead to:

> Impaired or delayed cognitive development

> Impaired or delayed physical growth

> Impaired or delayed psycho-social development

> Impaired or delayed brain development. For babies and very young children, the impact on brain development is particularly acute

> Higher mortality rates and an increased risk of infectious disease or chronic illness caused by lack of healthcare, poor hygiene, malnutrition and overcrowded conditions

> Increased risk of mental health problems, psychiatric symptoms, and emotional, attachment and behavioural problems

> Detrimental effects of overmedicalisation, which is commonly used within institutions.

Major longitudinal studies show that the experience of living in institutions can cast a long shadow over a child's development, **increasing the risks of adversities through to adulthood.**[129] This can result in a need for lifelong physical and mental health services.

SUSTAINABLE DEVELOPMENT GOAL

3 GOOD HEALTH AND WELL-BEING

By building the capabilities and resilience of families and communities, and addressing the root causes of family separation, the care reform process will contribute to the delivery of SDG3: Ensure healthy lives and promote well-being for all at all ages

3.7 By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes

3.8 Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all

3.c Substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and small island developing States

The role of health services in the care reform process

The care reform process plays a critical role in identifying where universal and targeted health services are needed to support communities and prevent the separation of children from their families. While health resources remain locked up in institutions, they will draw vulnerable families towards them. And **when stigma and discrimination remain towards groups in society, there will be pressure to conform to medical models of support, rather than building inclusive communities.**

It is essential that a social model approach to disability is followed. This model concentrates on eliminating the barriers that a child or family with a disability faces in accessing what they need to maximise their inclusion in communities, recognising that their disability is as a result of how society is organised. This moves away from an outdated 'medical' model of disability which aims to 'fix' or 'treat' differences; an approach commonly associated with institutions.

The care reform process identifies **touch points in the health system which can prevent family separation**. For example, paediatric and maternity services in the community are critical in preventing abandonment and separation of babies, and have a key role in providing early intervention for the child and support and guidance for the mother and family.

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129 Philip Goldman, Marian Bakermans-Kranenburg, and others, 'Institutionalisation and deinstitutionalisation of children 2: policy and practice recommendations for global, national, and local actors'. *The Lancet Child & Adolescent Health*, *4*(8), 606-633 (2020) https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(20)30060-2/fulltext

Community health structures: Rwanda

Structures have been built at the community level in Rwanda to advocate for families in need. Community health workers provide medical assistance to families and referrals to other services. Inshuti z'umuryango (Friends of families) are in charge of child protection in the community, they provide counselling sessions to families facing challenges to reduce family separation. The National Council for Persons with Disabilities committees at the community level monitor the well-being of persons with disabilities and advocate for those who need additional assistance.

KEY RECOMMENDATIONS:
ACCESS TO QUALITY, INCLUSIVE HEALTH SERVICES

💛 Recognise that access to quality inclusive health services plays a key role in driving family separation, and that keeping children in supported families will deliver better health outcomes. The right to health should not supersede the right of family life.

💛 Ensure that national registration, reporting and monitoring systems of children outside family care include health facilities which provide long-term residential care so that they can be included in national efforts to ensure appropriate family-based care for every child.

💛 Ensure that all aspects of the health system required at different life-stages recognise the importance of family preservation.

💛 Recognise the important role that informal community structures can play in building family capabilities and early intervention support in tackling health problems or preventing them worsening.

💛 Identify and tackle stigma and discrimination that hinder access to health services in societies through policy change and awareness raising initiatives.

💛 Enshrine formal coordination between the child protection, health and care sectors so that no child falls through the gaps and is left behind.