

CLAN Child Inclusive Policy

Version No: 1.0 (January 2017, March 2020)
Date Reviewed: February 2024
Date Approved: February 2024
Date Review Scheduled: March 2026

1. Introduction

CLAN is a not-for-profit, Non-Government Organisation (NGO) created with the mission to 'Maximise the quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world.' CLAN's strategies include identifying groups of children who have the same chronic health condition, and then working with partnerships at local, national and international level to implement their strategic framework to support the children and their families.

CLAN's strategic framework rests of five pillars:

1. Affordable access to medication & medical equipment
2. Education (of individuals, families, communities, health professionals, policy makers and the international community), Research & Advocacy
3. Optimisation of medical management (including primary, secondary and tertiary prevention, with a bio-psycho-social focus)
4. Encouragement of family support networks
5. Reducing financial burdens on families that result in poverty, helping people to become financially independent so that they can provide the necessary health care for their children longer-term.

2. Purpose

This Policy is to confirm and outline CLAN's commitment and strategies to supporting with chronic health conditions, including children and their families to improve the quality of life. This includes promoting gender equality and equity and non-discrimination in regard to gender identity and disability and ensuring children's rights are adhered to and that they have a voice.

3. Scope

This policy applies to all staff and other key groups. 'Staff' refers to: full time, part time, international and national and also those engaged on short term contracts such as: consultancies, researchers, photographers etc. 'Others' refers to: visitors, volunteers, board members, trustees, staff/volunteers in partnership agencies, and any other individuals or groups that have a responsibility with respect to CLANs programs.

4. Definitions

Chronic health condition A chronic condition is a human health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time. The term chronic is often applied when the course of the disease lasts for more than three months. It can have a significant impact on the life of a person and require more than the usual amount of medical care. A chronic

health condition is not a disability but may result in a disability.

Classifications Chronic health conditions may be classified as congenital, acquired, preventable, non-preventable, communicable, or non-communicable.

5. Policy and Guidelines

CLAN is committed to, and endeavours to include opportunities for children's contributions and responses in all their programs and projects where children are included in presentations and activities. It has been shown that children with a chronic health condition who live in resource poor countries are more susceptible to disability and death than children in resource wealthier countries. CLAN is committed to building capacity and sustainability through programs to support these children to improve the quality of their lives.

CLAN's programs and projects are based on the principles of community development and comprehensive primary health care for children with chronic health disorders.

- i. groups of children are identified, who are living with the same chronic, long-term health conditions as members of a distinct, non-geographically based community.
- ii. identification of target groups, and consultation and collaboration with these communities including information obtained from the children and their families, enables CLAN and their partner/s to plan effective strategies to collectively determine the most appropriate actions for change. Research is undertaken to identify the specific needs and rights of the children and young persons to be involved in the project.
- iii. CLAN's strategies include building communities which include children who have a chronic health condition, their families, professionals, and community personnel as these communities can provide ongoing and effective support. Communities may include chronic disorders such as Congenital Adrenal Hyperplasia, Diabetes, Autism, Down Syndrome, Chronic Kidney Disease, Laron Syndrome, Hearing Impairment, Osteogenesis Imperfecta, Epidermolysis Bullosa, and Duchenne Muscular Dystrophy.

CLAN's design for each project includes research with partners, families and their children to identify specific needs for each group. Information and views from partners, families and children underpin planning initiatives for programs and projects. Projects are designed collaboratively with partners, children and their families to build sustainable communities to achieve positive outcomes.

CLAN is committed to promoting the participation of children in programs and projects. Outcomes aim to involve children in learning more about their health condition and to make decisions about managing their condition effectively. A focus of community projects involves providing opportunities for children to share their experiences with other children who have the same chronic health condition, as this can build friendships, confidence and encourage inclusiveness. Families are also involved in projects with their children and participate in learning how to manage the chronic health condition more effectively. Responses are sought from children and their families at the conclusion of each project to assess effectiveness of the project and outcomes achieved.

CLAN's partners in projects that involve children may include medical professionals, community members, and/or other relevant in-country or external professionals. CLAN will review and assess the capacity of partners prior to any agreement made. Partners need to demonstrate their commitment to be aligned to CLAN's mission and agreed goals. The need for training pre-delivery of a project includes collaboration with partners and any others who are to be involved in the program or project.

Each project is monitored during implementation to assess the outcomes being achieved for the group of children and their families. Monitoring also includes the opportunities to manage any changes that are needed to achieve outcomes more effectively.

CLAN's programs endeavour to build and continue relationships between families and their children with the local community and local medical resources in order to provide long-term benefits for children with NCDs.

Evaluation of child focused programs and projects will determine if the initial outcomes were achieved effectively and efficiently. CLAN evaluates each program/project to determine the quality of outcomes achieved for the children and their families, including outcomes associated with participation of children and families in the program/project. Such evidence is used to provide information for CLAN to feedback and future planning.

Associated Documents

Child Protection and Safeguarding Policy

Monitoring, Evaluation & Learning Commitment

Code of Ethics and Professional Conduct Disability Inclusiveness Policy

Project Design Monitoring and Evaluation