

Whole-Person Care for People Living in Dependencies in Rural Tribal Communities

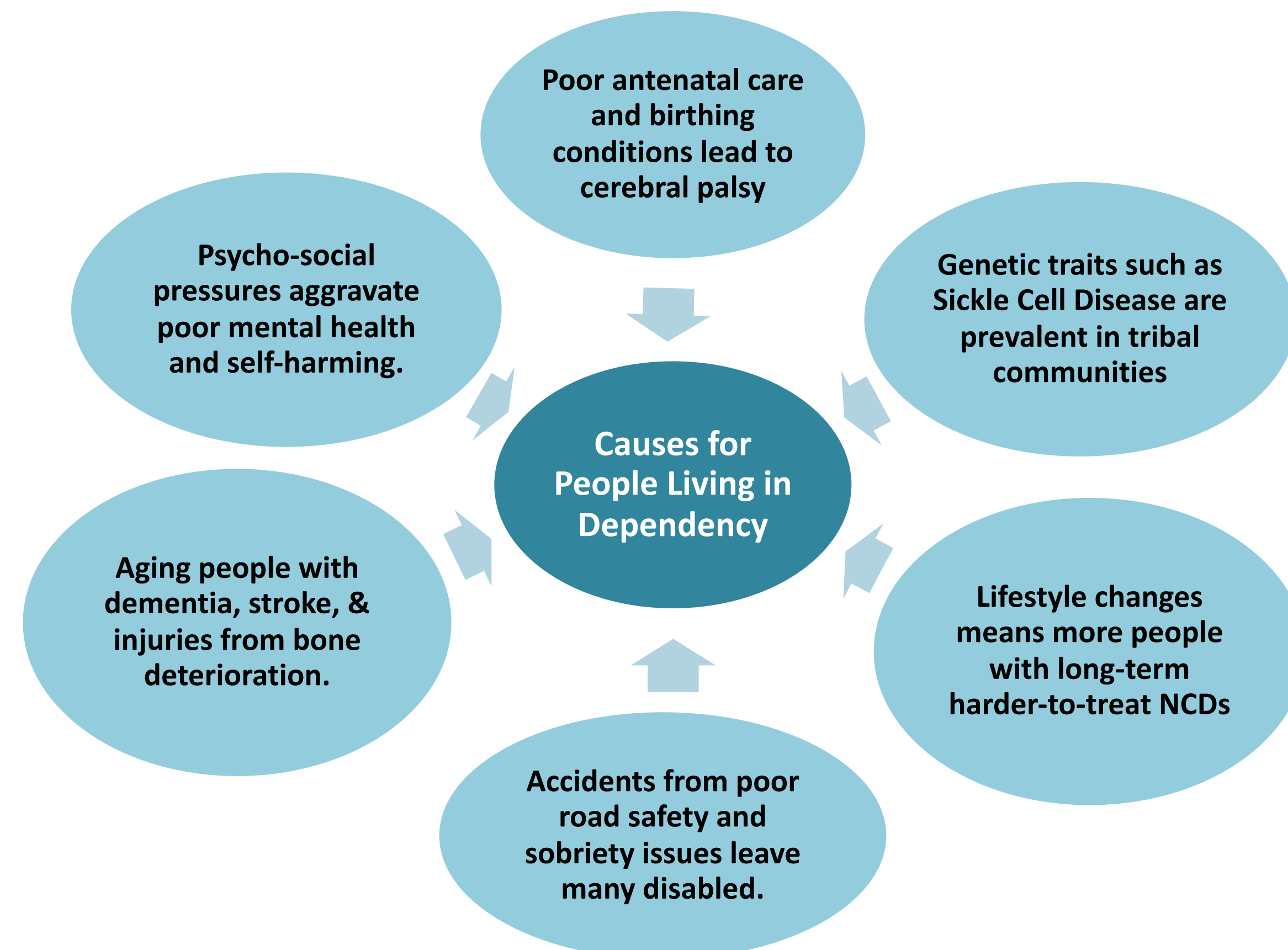
Organization: Asha Kiran Society

Author: Pauline Cherian



The Unmet Need: People Living In Dependency

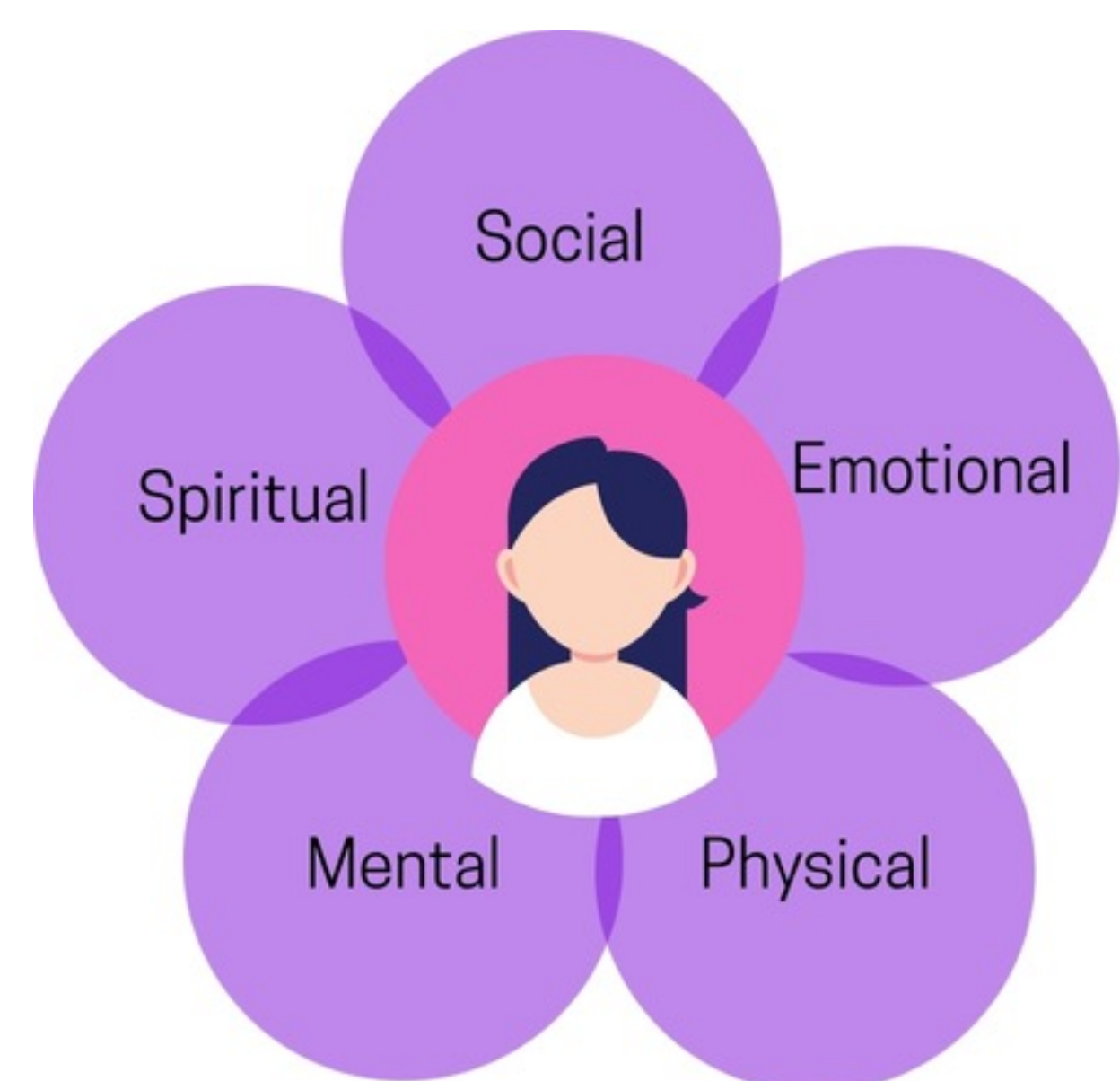
People Living in Dependency (PLID) are those with long-term conditions which leave them unable to fully care for themselves and dependent on others for day-to-day living. They suffer from poor quality of life and higher mortality. In rural tribal communities they are often "hidden" because of the stigma associated with them.



Challenges in caring for PLIDs in rural tribal communities

- Basic medical care is either unavailable or too expensive.
- Conditions without quick or complete cure are left untreated or neglected, sometimes leading to untimely deaths.
- Without timely interventions, certain conditions can lead to deformities and life-long limitations.
- Ignorance, wrong beliefs and illiteracy leads to wrong treatment/life choices causing long term effects.
- Those living in dependency need caregivers and the daily challenges of long-term care can be overwhelming.
- Agrarian tribal communities equate value of life with productivity, hence do not have a mind set of caring for those who may not contribute to the family economy.

What we want to see



Whole person care for PLIDs in villages of Lamtaput and Khairput blocks of Southwestern Odisha leading to a measurable improvement in their quality of life.

What we do

Identify new PLIDs through awareness and screening

Assess and enroll eligible PLIDs, make Treatment plans

Regular Home Care visits by mobile team according to need

Nursing, Palliation, Counselling, Rehabilitation inputs at home

Counselling, training and support of family caregivers

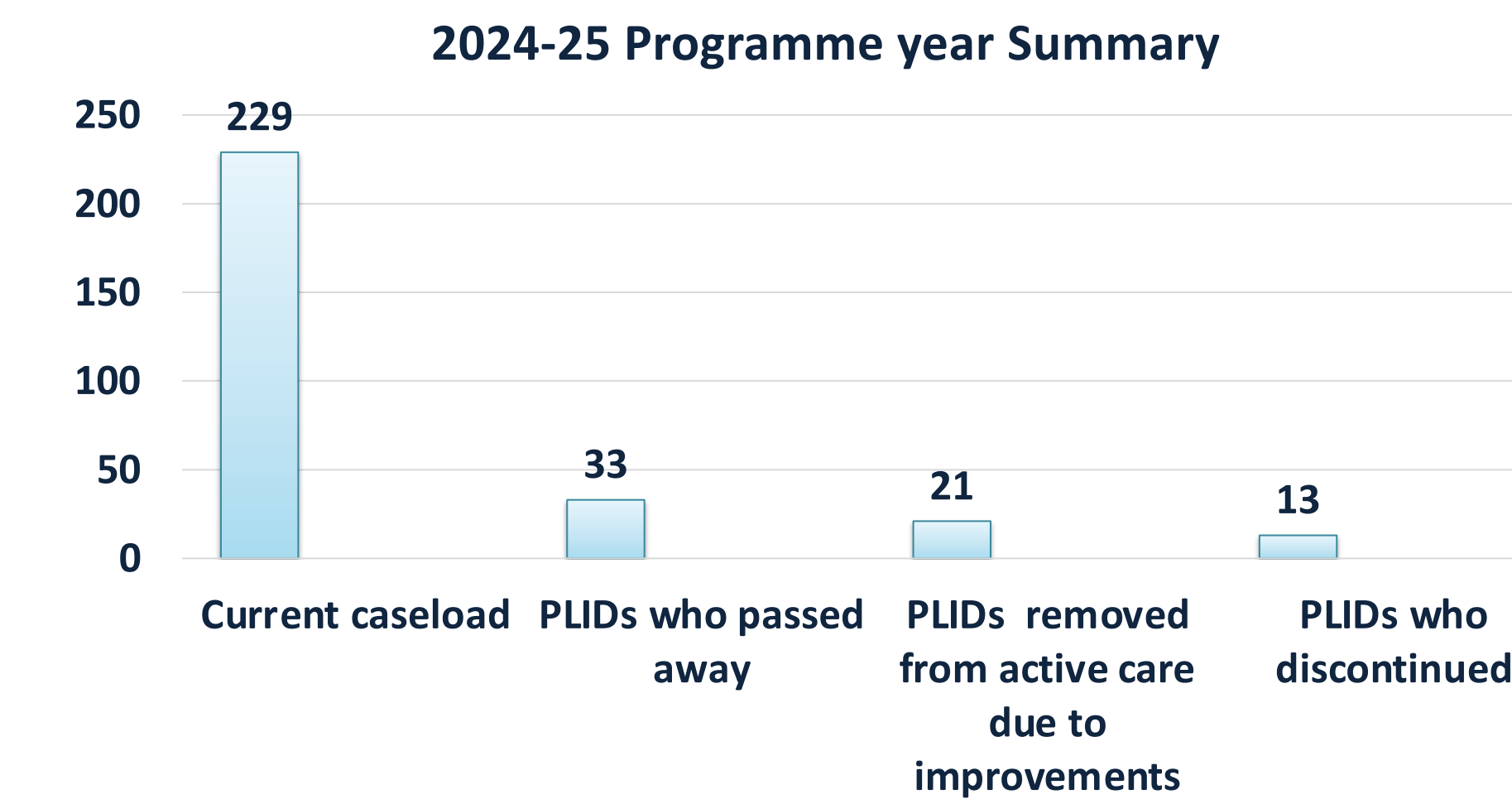
Awareness meetings on disability and other diseases in villages

Support group meetings for PLIDs and their families

Advocacy for rights and community organizing for long-term changes

Hospital support by Asha Kiran Hospital and referral to higher medical centers for appropriate interventions

Outcomes



An avg. increase of 5% was seen in ADL score after an avg. of 24 months of care (range: < 1 to 72 months (n=226))

6 main Disease / Conditions of PLIDs measured	No of PLIDs	% Score Improved	Avg. Months treated
Cerebral Palsy (> 2 years)	38	27%	31.3
Severe Mental Illness	26	100%	28.1
Seizure Disorders	18	200%	28.0
Stroke, Spinal Cord injury & Traumatic Brain Injuries	53	22%	17.5
Skeletal & Bone Deformities	13	14%	16.3
Cancers	27	0%	12.6
Total	175	49%	22.3

Stories From The Field

Rahim: Family involvement in Cerebral Palsy care



At 3.5 years, Rahim weighed 5 kgs and could only push himself on his tummy. He was put on a rigorous diet to help with nutrition and frequent visits for therapy.



With his family involved, Rahim is now an active and cheerful 5-year-old, who can crawl quickly, is learning to stand, walk, dress himself and is getting toilet-trained.

Visits to his home are a great opportunity for village education on ante-natal care and Cerebral Palsy to those who come to his therapy.

Samari: Caring through times of suffering



Samari is a woman with hemiplegia who has severe contractures due to neglect. With the death of her husband and young daughter, she was left without an active caregiver.

The team cared for her during her bouts with severe psoriasis, bathing her regularly, helping with medication and ointments, teaching her exercises to be as active as possible, and monitoring her blood pressure.

In the past two years of care, Samari ma has learnt to move around by herself and take care of her basic needs. She joyfully welcomes the team as her own family and continues to receive free medicines from the hospital.

Learnings

Our rural communities have a huge backlog of treatable conditions – especially in mental health. Timely interventions can make a great difference.

Patients who are on long-term medications need to be followed up for adherence to medication for good outcomes.

Continued health education on disabilities and long-term illnesses are needed at patient, family and village level for lasting changes.

Following up infants at risk from the hospital birth registers is helpful to initiate early intervention.

Stroke patients who begin home-based therapy as soon as possible show greater possibilities of improvements and early return to work.

Home based care for long term illnesses is practical, specific to the context and benefits the whole family.

Distribution of medical conditions among our patients

