Contacts: info@cheshire.org.pg|Tel: 3230256/3230274/73124454/78109394/

Cheshire disAbility Services Papua New Guinea.

Inclusive Development for People with disabilities and other chronic conditions

1. About Cheshire disAbility Services PNG (CdSPNG):

Started in 1965, Cheshire is one of the leading disability service, non-governmental organization located in Port Moresby and with programs in NCD, Central Province, AROB and Milne Bay. Cheshire aims to make a positive difference to the lives of people with disabilities, their families and care givers, by creating opportunities for inclusive participation and an environment in which they are treated with dignity and respect. Cheshire services has directly impacted the lives of over 10,000 people with various disabilities and other chronic conditions in PNG. Our work involves working together with bot the disabled and non-disabled persons their families and friends in order to promote social inclusion based on human rights principles.

2. Location and Contact Address.

Cheshire PNG is located in Lot 1, Section 32 Hohola, Wards Rd, National Capital District, Port Moresby, and the Capital City of PNG. It is located in its own Government leased land, where the main office, Medical and Rehabilitation Clinic, Inclusive Education Resource Center and Respite Care and Protection Center are located. A few properties for lease are also located in the same compound.

Address: P.O. Box 1306,Boroko, National Capital District,Port Moresby.

Telephone: +6753230256/3230274/73124454|Email: info@cheshire.org.pg |Website: wwwcheshire.org.pg

3. International and Local Affiliations

Cheshire PNG is a member of the Global Alliance of Leonard Cheshire Disability International (LCDI) UK, with networks in over 53 countries globally. It is affiliated to the University College of London which is a subsidiary for Leonard Cheshire on research related projects. Regionally, Cheshire PNG is a member of the East Asia and Pacific Council with over 14 member countries whose head office is based in Bangkok. Cheshire PNG is the only member from the pacific region. All Cheshire organizations are autonomously managed internally by councils or Board of Governors.

Locally, Cheshire PNG is a member of the National Board for Disabled Persons which is a statutory establishment by the Government of PNG for all service providers in disabilities and social protection.

4. Cheshire PNG's Contribution to Government's Strategic Development Plans and vision

Cheshire PNG has been one of the key stakeholders and partner in the development of various Government Development plans and policies such as the National Disability Policies, National Health and Education Plans, PNG Development Strategic Plans. Cheshire's own Strategic plans are aligned to the National Government Development plans. Cheshire has trained and supported various target communities to form and register their own associations and supported them to develop their own strategic plans which have assisted them to mobilize resource from various partners to achieve their wide range of social and economic development needs.

5. Governance

Cheshire board comprises 9-volunteer members. Both nationals (6) and experts (3). Diversity in board composition is demonstrated by 4 females and 5 men with highly diverse skills, ranging from entrepreneurships, legal, banking and finance, and project management backgrounds. The management, led by an expert General Manager, oversees over 60 staff members (70% females). The staff, comprise people with Medical, Rehabilitation, Education, Respite Care and Protection as well as Community Development backgrounds. Cheshire is compliant with all relevant due diligence requirements which include; Duly Audited Financial statements up to 2017,revised Finance Policy, HR Policy, Strategic Plan 2016-2020,Child protection Policy, Anti-Fraud and Risk Management Policy. Cheshire's development plan are aligned to the PNG Government Development Strategic Plan 2010-2030 as well as sectoral policies such as health, disability policy and education.

6. Partnership and Funding

Cheshire's main source of funding is through partnership built in signed MoAs, arising from approved submissions for project related actvities.Respite care and protection program is supported by well-wishers' donations (individuals, businesses, churches etc.) through food and services. Sale of hot dogs through sausage sizzle every Saturday. The government does not fund the organizations activities except for 6 teaching positions which are funded by the Government through the Department of Education. Current program funding partners include; Digicel Foundation. Cheshire prefers long term partnership secured in MoA so that its services can be strengthen, sustained and expanded to other regions to reach the unreached. This could

be possible through partnership with Development partners, corporate, consortia with other INGOs etc

7. Cheshire's priorities/services in promoting Inclusive Development for PWDs

Cheshire's Program Development priorities are focused on;

a) Preventing disabilities through campaigns on early detection and interventions especially among children and youth. This is done through grassroots and door to door surveys for identification purposes and promotion of primary health care components
b) Managing established disabilities and treatment of chronic medical conditions to restore and maximize their functional abilities-through intensive medical care and rehabilitation, habilitation and provision of customized assistive devices.
c) Advocating for the rights of PWDs to social inclusion and participation in economic development.

8. Target Group for our programs interventions

The primary target for our programs intervention are:

- Children with and without disabilities of ages 5&6 for Inclusive Early Childhood Care Education and Development and ages 7-15 children with disabilities for early intervention. The older children with disabilities are considered for those who delayed accessing school due to their disabilities or delayed developmental milestones.
- Youth with disabilities and those without disabilities
- Parents and friends of disabled association (PAFODA)
- Mainstream school children without disabilities for awareness to accept and appreciate CWDs in their midst
- Mainstream school teachers and teacher aides through in-service programs to prepare them to manage children with disabilities.
- Mainstream community members through advocacy campaigns to change their attitude, foster acceptance and reduce stigma associated with disabilities.
- School board of management to help them improve their School Learning Improvement Plans for enhanced accessibility for CWDs.
- Community leaders, Education officials to influence policy change and attitudes towards CWDs/PWDs
- Adults with disabilities, chronic and lifestyle conditions

The types of disabilities/impairments targeted include: Hearing and visual disabilities. Learning/intellectual disabilities, behavioral and physical disabilities.

The beneficiaries receive holistic support through qualified Educationists and Rehabilitation specialists through individual education plans for education and Case management plans for those under medical rehabilitation. All management plans are developed together with parents and care givers who are trained hands-on to continue with the management at their homes in order to speed up the recovery/improvement process.

9. Cheshire's programs and service delivery model

In order to effectively deliver the above services, Cheshire has the following chore programs through which the services are delivered through hands-on approach.

9.1. Community Based Rehabilitation and Inclusive Development Program

Introduced in NCD communities in 2010 following the first ever Strategic Plan 2010-2015 by Cheshire, has benefited over 8,000 PWDs and trained over 10,000 parents and care givers on skills of rehabilitation. Over 400 children with disabilities have been enrolled in schools after successful rehabilitation with over 200 adults having their social participation levels improved and integrated into the communities.CBR is a WHO initiative which aims to have education, health and social intervention services transported to the door steps of PWDs and those at risk.

Benefits of CBR approach to inclusive development

- Leads to early detection of disabilities since door to door survey is conducted to identify those with disabilities and those at risk. Some of whom may have been hidden due to cultural beliefs around disabilities
- Services are taken to the beneficiaries at their homes/houses hence affordable, made available, accessible and customized to their needs making it acceptable-**4As Inc. dev. principles**
- Recovery process/improvement is faster due to quality time the technical staff spend with the PWDs and family, unlike the hospitals where queue is long with less contact hours from therapists/medical team whose appointment can go up to 3 months. Transport costs are also saved since transport for PWDs on public transport is a big challenge.
- The beneficiaries are directly involved in the rehabilitations process. The family members are trained and therefore able to continue with home programs on their own, making progress faster and convenient. Making the services sustainable and affordable.
- Local resources are used or improvised to assist in the rehabilitation process thus making it affordable and sustainable.

- Community is made aware of the various disabilities. PWDs are educated about their disabilities and trained on what/how they can make the best out of their residual abilities to maximize their functions and break the barriers. This reduces stigma and encourages social participation of PWDS in communities.
- Women of child bearing age, are educated on the risks of disabilities during pregnancies and encouraged to seek prenatal, antenatal and post-natal care. Majority of disabilities among **children occur as a result of maternal or child health complications and often occur either before, during or after birth. There is often a history of poor or lack of pre, ante and post-natal care.**

Who is involved in CBR (key change agents, beneficiaries and management model?

- The General Manager/Project Manager leading the team of therapists, nurses and educationists, have the technical mandate to train, supervise and assign CBRFWs in the communities they work in.
- Trained Physiotherapists, teachers and nurses from Cheshire train CBR workers with skills of basic assessment and therapy skills. CBR workers are either the care givers, parents or community members thus the skill is entrenched within the community/family.
- Cheshire supports medical, education, rehabilitation and social inclusion needs for people with various types of disabilities and medical conditions which might degenerate into disabilities If not intervened in good time. The types of disabilities include; visual, hearing, sensorial, cerebral palsy, intellectual, physical and behavioral among others.
- Each PWDs is visited at least 3 days per week for at least 2 hours per visit for as long as they improve, by the team to provide assessments, administer treatment, exercises, improvise aids, pass on the skills to parents and care givers and monitor progress from the baseline position until they attain improved social participation levels.
- Each PWD/client has a customized Case Management Plan (CMP) entrenched in a database which monitors the implementation of the rehabilitation process from medical perspective towards complete social participation level with evaluation carried out every 3 months.
- The primary client with disability, parents and care givers are all engaged in the assessment process and equipped with skills to carry on with assignments given at home on a daily basis.
- Record of activities performed is taken to include the number of visits and hours taken from the initial assessment to final date of discharge. Clients have a form which they

sign to confirm attendance of CDS team. All activities are free of charge as per the program sponsors.

- Human interest stories from success stories and challenges are documented and shared by the team and partners to demonstrate lessons learnt, learn from experience and to devise ways for more improvement including appeal for further assistance where need be.

9.2. Physiotherapy Outreach and Training Clinic

The physio clinic, with current caseload of 400 clients per month, is located inside Cheshire. It takes care of clients who are referred from other facilities such as POMGEN, NCD clinics and other partners. The clinic, with an average of 10 new clients per week, performs the following functions;

- Acts as referral pathway for new clients from the community to Cheshire and from Cheshire to other facilities. It receives at least 10 new referrals/new clients in a weekly basis
- Provides training platform for new CBRFWs and staff capacity development by the management and partners as per the annual work plan
- Provides physiotherapy services for children with disabilities attending inclusive education center, and for PWDs in the Residential Care facility.
- Support screening outreach clinics to Central province and referring to the center for treatment.
- A site for mobility aids fabrication, modification and training on use to referred clients
- The clinic operates on Thursdays for community clients, and Tuesdays for school children.
- By training family members and following up on their home reintegration and progress, the clinic has assisted over 100 children with improved functions and now in school. Over 20 severely injured spinal cord and stroke patients have made it from being bedridden or condemned by Drs that they will never walk again, to being fully mobile and back to their employment and livelihoods ventures. The reason many patients are deserting POM clinic to attend to CDS clinic.

9.3. Inclusive Education and Early Childhood Care Education and Development

The programs priority, is to provide access to inclusive learning for children with and children without disabilities in either center based resource facility, home based education and to mainstream schools depending in the disability and the level of preparedness. The program has benefited over 1500 with disabilities and over 5000 children with disabilities since 2010. Children with disabilities referred to the resource centers are beneficiaries from CBR programs who have been rehabilitated and considered suitable for school enrolment and support.

Children who are a bit more severe but progressing well with CBR are supported through home based education where trained teachers and teacher aids attend to them at their homes to provide them with one on one education support using well developed education materials and improvised resources at home. From home based education, when they become of age and improved cognitive abilities, they are either referred to the resource center or directly to the mainstream schools or to the ECD centers.

The main activities of the program include;

- Screening children from CBR who are of school going age, and enrolling them into schools. Either SERC, home based, mainstream or ECD centers.
- Accepting children without disabilites of ECD level to learn together with CWDs to promote inclusion before they are integrated into mainstream schools.
- Training/in servicing to mainstream school teachers from elementary, primary and ECD centers on inclusive learning practices to increase access of CWDs in mainstream settings.
- Developing learning materials suitable for CWDs to be used by resource teachers and mainstream teachers.
- Conducting assessments to mainstream schools in preparation for integration of CWDs
- Conducting home based education for CWDs who are still under active home therapy sessions and bridging educational needs.
- Developing Individual Education Plans (IEP) for each child and monitoring their progress towards increased social participation levels.
- Conducting referrals of CWDs/YWDs to other technical vocational institutions and informal skills.
- Training parents on positive parenting skills for managing CWDs and support with basic home based education interventions.
- Promoting participation of CWDs and CWoD in cultural and inclusive sports within NCD and internationally.
- Promoting school health activities to ensure clean and safe environment for all children.
- Participation in ability sports with non-disabled children peers

9.4. Respite Care and Protection Program

The oldest program and the full time respite care hosts 18 PWDs who are on a 24 hour observation and management schedule. The residents, majority of whom were rescued after being found abandoned, neglected or abused, were brought into the facility by catholic priests, the government social welfare department and the police. The facility is mainly supported by well-wishers who donate food and services on ad hoc basis.

The activities for the unit include;

- Training of less severe residents to be independent in their daily living skills
- Supporting the nutritious feeding and good care of all residents to support and maintain their health
- Daily and routine medical checks, physiotherapy and medical treatment to improve and sustain their lives.
- Identify social and employment opportunities for self-care residents
- Support technical education for less sever residents for self or wage employment
- Support the medical and respite care operational costs of the facility.
- Train the care givers with basic care and management skills including basic physio skills.

9.5. The Young Voices and Livelihoods program

The program, with over 40 YWDs, and 150 parents, targets youth with disabilities and care givers of children with disabilities, or adults with severe disabilities. The Youth and parents are those who should be empowered either educationally, technically and economically to be able to fend for themselves. The program also aims to empower the youth and parents with human rights knowledge so they can advocate for the rights to social inclusion and barrier free society.

The activities to the program include;

- YWDs trained on human rights, and communication skills so they can better advocate for a just and barrier free society. Also trained and empowered for possible job placements.
- YWDs are supported to secure scholarships, technical education and employment opportunities so they can be self-reliant in their activities of everyday living and social wellbeing. Over 10 YWDs have benefited from scholarships with AAS and APTC. Over 20 have received employment with various business houses through Cheshire's interventions.
- Parents and Friends of Disabled Association (PAFODA) trained on business management skills and supported to run their own business which would boost their economic potential to fend for themselves and support their dependents with disabilities. Over 100 care givers and parents have benefited from the economic empowerment through groups formed and registered and supported to access funding.
- Most women, mainly from settlement communities, are into gardening, tailoring, floriculture, piggery and poultry. Cheshire has linked them with Microfinance institutions for ongoing capacity building and access to loans for business expansions and diversifications.

10. challenges

1. Lack of Government funding yet Cheshire is complimenting government services to its people and contributing to the implementation of government development priorities.
2. Lack of adequate funding and resources from key development players like DFAT due to Cheshire's national status and lack of international appeal and bargaining power. DFAT has however appreciated the role of Cheshire and recommended for Cheshire to build networks with other INGO as a consortium to be able to access funding to create bigger impact.
3. The need for rehabilitation is long term and adequate resources are lacking to support, sustain and achieve a lasting social inclusion for PWDs.
4. Stigma and discrimination still affecting equitable distribution and allocation of resources to finance implementation of disability policy and related programs
5. Economic hardships skyrocketing the cost of living shifting priorities from social development to economic development.
6. The high cost of running the respite care unit due to its 24 hour operations and the severity of most residents requiring 24 hr. nursing care, medical and sanitary supplies and feeding
7. High cost of maintenance to the aging facility ranging from carpentry, electrical, civil and property. The physio clinic and classroom are smaller and poorly maintained. They needs expansion

11. Why Cheshire services are unique and life-changing to the beneficiaries

1. Services are taken to the people who need it. Not them looking for the services. Cheshire recognizes that PWDs face barriers which prevent them from accessing the same services they need. By taking the services to the community, accessibility, availability, affordability and acceptability, which are the key pillar of inclusive development are guaranteed.
2. We reach out to the unreached. By door to door survey, those hidden or have never seen light of day due to stigma and cultural bias are identified and enrolled in the program.
3. Community Based Rehabilitation workers and teacher aides trained and employed or as volunteers, are preferably derived from the project communities so that the skills and services remain with the community for time to come.
4. We transfer skills of rehabilitation and education to the parents and care givers so they are able to perform them daily at home using basic improvised facilities in the absence of trained therapists and educationists.

5. Therapists and field workers visit each client at least 3 days per week for at least 2 hours per visit until the client improves depending on the disability.
6. Our assessment is inclusive and the goals set are monitored at each level. Client, family, and Cheshire. A data base is in place to monitor the transition of each client from one baseline assessment level to the next until high social participation level is achieved.
7. Diversity of skills within Cheshire, including educationists, medical team and social development workers play critical roles from the baseline assessment, throughout the management and social inclusion process.
8. We engage successful PWDs and care givers as role models to mentor and motivate clients who experience depressive tendencies due to their disabilities.
9. We improvise local available materials to produce customized assistive devices for PWDs
10. We create networks and aspire to secure broader partnerships under MOA with both national and international partners.MoAs are result-based and tied to key performance indicators

Become a partner of Cheshire in the following possible ways;

- *Enter into a consortium through signed MOA to deliver impacting outcomes to both with and without disabilities.*
- *Donate or contribute either in cash, kind, skill, services, volunteering for the cause or to a program of your choice from the listed above*

Either of the two will help support Inclusive Development for PWDs in PNG so that they can be self-reliant and contribute to nation building and for their own development!

Refer to the WHO-CBR Matrix upon which Inclusive Development Services for PWDs is premised.

Contacts: info@cheshire.org.pg|Tel: 3230256/3230274/73124454/78109394/