

Strengthening Institutional Capacity of PFPID to Empower Self-Advocacy Movement in Nepal

(Sept. 2022 - Jan. 2023)

Documenting Lessons Learnt January 2023

Prepared By:



Supported By:



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Hereby, I express full commitment that the learnings documented in this report will be taken seriously, and the organisation will consider them implementing fully as we move ahead.

Finally, all my gratitude are extended to the all the persons with intellectual disabilities and their parents, their families for which this report is for who are looking a bright future despite their multitudes of issues.

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Section 1. About the Organisation

1.1 PFPID Nepal

Parent Federation of Parents of Intellectual Disabilities (PFPID), Nepal was established in 2012 with the aim of ensuring the rights of people with intellectual disabilities and their parents through organising parents and persons with intellectual disabilities, capacity building, networking, advocacy and service provision to some extent. When we established this organisation, there were 17 local associations across the country and mainly in the urban areas which now extended to over 55 districts of Nepal. As an umbrella organisation, PFPID leads the intellectual disability movement at national level whilst organising parents and sub-sequent advocacy campaign at the local level. It advocates for the protection and promotion of the human rights of people with intellectual disabilities and building an egalitarian society with identity, self-respect for dignified lives of persons with intellectual disabilities.

Since its inception, this federation has been doing activities in accordance with the spirit of the Convention on the Rights of Persons with Disabilities for people with intellectual disabilities. It mainly works in the area of inclusive education, self-advocacy, against all kinds of discrimination and violence, social security and all others in line with the CRPD.

1.2 PFPID vision

An inclusive and equitable society for people with intellectual disability where their human rights are achieved, protected and promoted.

1.3 PFPID's Mandate

Empowering and enabling people with intellectual disabilities by ensuring their access to education, health, employment and other basic needs, and ensure the all other human rights in line with CRPD.

PFPID's Goal:

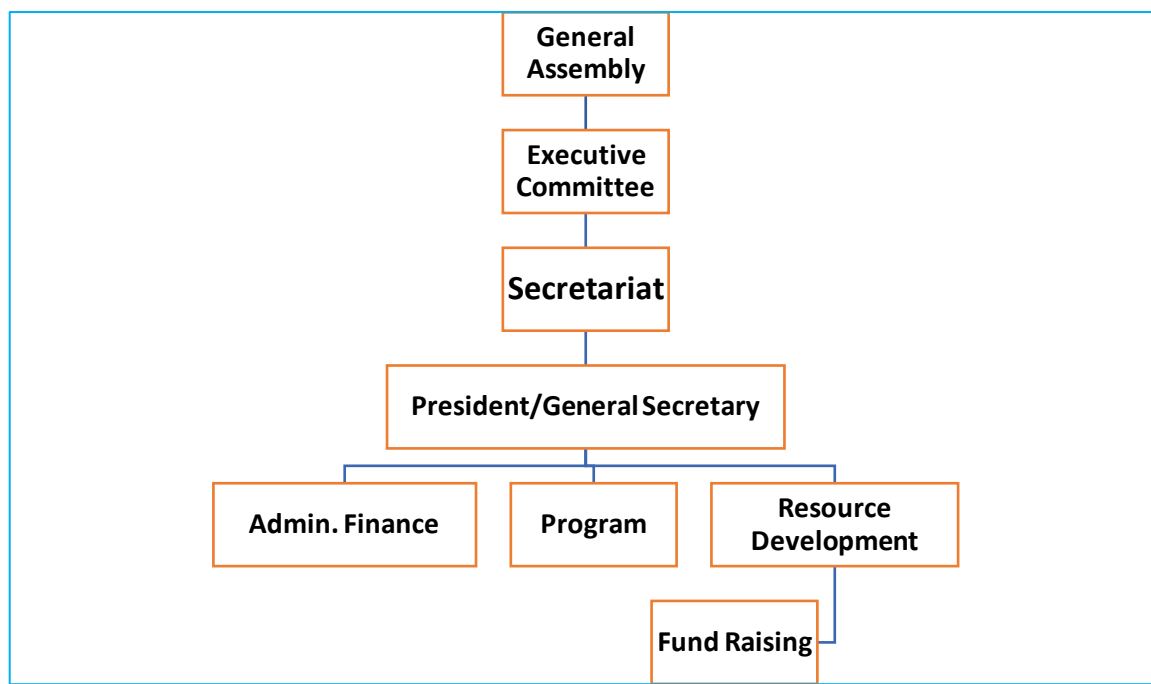
Empowering and ensuring people with intellectual disabilities and their parents to become conscious about their rights to entitlements, participation, security, freedom, human rights and quality of life (well being).

1.4 PFPID's Values:

- **Right based:** WE believe in the inherent dignity and equal worth of all human beings and hence universal rights of people with intellectual disabilities to fundamental needs.
- **Social Justice:** We believe that people with intellectual disabilities are entitled to equitable access to wealth (resources), opportunities and privileges as equal as other people of the society.
- **Inclusion:** We believe in fair and meaningful participation of people with intellectual disabilities in the social, political, economic, religious and cultural sphere and all other aspects of the society.
- **Respect:** WE believe in the inherent worth of people and honor our relationship with those whom we work with. We treat others with the highest degree of dignity, equality and trust.

- Collaboration: We believe in working together with like minded organisations and building cooperation for greater synergy and effectiveness.
- Accountability: We walk the talk, deliver on our commitments. We are accountable to each other and to our external partners.

1.5 Organisational Structure



1.6 Executive Committee:

SN	Name	Position	Address
1	Raju Basnet	President	Udayapur
2	Shila Thapa	Vice-President	Kathmandu
3	Ram Narayan Shrestha	General Secretary	Kaski
4	Bishwaraj Adhikari	Secretary	Dhading
5	Gokarna Prasad Acharya	Treasurer	Banke
6	Tika Ram Sapkota	Member	Myagdi
7	Sharada Paudel	Member	Makawanpur
8	Dhanmaya Tamang	Member	Dhankuta
9	Kapilmani Humagain	Member	Kavreplanchok
10	Shri Krishna Ghmire	Member	Lamjung
11	Jagadish Prasad Aryal	Member	Saptari
12	Junumaya Kayastha	Member	Bhaktapur

1.7 Projects-Programs:

PFPID is undertaking different project through the support of its different donors/supporting partners. In this connection followings are the projects-program being implemented or already implemented by the organisation:

SN	Name of the project	Period	Supporting Partners
1	Organisational Development and Networking	2011-2018	NFU-Norway
2	Enterprenuerships for Inclusion	2012-2026	FO-Norway
3	Adaptive Education and Social Security for the Children with Disabilities	2014-2022	MyRight/FUB, Sweden
4	Empowerment and Development of Persons with Intellectual Disabilities	2016-2022	Ministry of Women, Children and Senior Citizen
5	Reference Materials Development for the Teaching-learning of Children with Intellectual Disabilities	2015	Department of Education
6	Strengthening the Institutional Capacity of PFPID to Empower Self-Advocacy Movement in Nepal (Sabal Sanstha)	Sept. 2022-Jan. 2023	CBM-Global and CBM-UK

Section 2. About the Sabal Sanstha Project

2.1 Project and Parties in Cooperation

PFPID with the financial support of CBM Global and CBM UK implemented a project entitled as 'Strengthening the Institutional Capacity of PFPID to Empower Self-Advocacy Movement in Nepal' during the period of Sept. 2022 to January 2023. In short, this project is also called Sabal Sanstha (Able Organisation). A tri-patriate agreement was signed between CBM Global, CBM UK and PFPID Nepal on 1st Sept. 2022. The focus of this project was institutional capacity building of PFPID.

2.2 Project Background

As mentioned in the project document following is the background information of the project:

'Persons with Intellectual Disability in Nepal belong to underrepresented group not only in the society but also within the Disability right movement. As per the Nepal census report 2011, there are 14,888 Person with intellectual disability which is 0.056% of total persons with disabilities in Nepal where the percentage of disabilities in Nepal is 1.94% of total population. The census data contradicted with WHO report on "World Report on Disability 2011" which claimed that 15% are the people with disabilities. Data of Persons with Intellectual Disability remained less than the real is because of social stigma, which family considered attached with their social prestige. Also, the enumerators for the data collection of census were not properly oriented to collect information regarded Intellectual Disability. To safeguard the rights of persons with intellectual disability, both self-advocate and parents should develop their capacity and skills. This can be achieved by enhancing the capacity of self-advocates, parents, and member organizations.

PFPID as a national umbrella Organization of the Persons with Intellectual Disabilities came into

being in 2011 as OPD aiming at uniting the persons with intellectual disabilities and empower them as self-advocate to speak up and demand their right from grass root level to federal level. In the beginning PFPID was formed through the joint effort of 26 Organizations and now the number of member organizations grows up to 41 across seven provinces of the country. PFPID is a member of Inclusion International and National Federation of the Disabled Nepal (NFDN).

Despite having full functional central board and executive committee with staffs and office, PFPID has been struggling with following issues.

- Capacity of member organizations
- Organization development with update policies, strategy, and skill of Executive members
- Proper documentation and dissemination of the issues of persons with intellectual disabilities
- Individual growth opportunity of self-advocate
- Capacity of human resource

Also, the member organization of PFPID lacks appropriate knowledge on the administration of the organization. One big underlying reason is that the organizations are operated by the parents of PWIDs, most of whom are non-professionals. The ones in the board of the organization who have little knowledge are bound to look after their children at their homes as there are no provisions of caretaker or personal attended unlike developed countries. Also, their engagement in the organization is limited as they believe that they cannot contribute to the organization due to lack of knowledge. The causes behind the organizations being weak is that they have no clear definition on the organizations aspirations, lack of systems, processes, administrative routines, and structures within the local associations.

Organization has been implementing field level project with very limited scope to organizational development. Having all these things into consideration, this project is developed with due focus on institutional capacity strengthening of PFPID and its member organization to lead the right movement through influential advocacy efforts. It is equally important to build capacity of member organization along with PFPID because of two specific reasons. The first reason is that without the member organizations initiative, the issues of PWIDs are in shadow and sometimes sidelined owing to lack of proper information, knowledge, skills, techniques, and structure of respective member organization in local level. This is also significant in the sense that the local governments now have the power and authority to design, plan and implement program and activities after the restructuring of Nepal into federal system. The second reason is that there is no existence of PFPID without its member organization as the member organization composite PFPID as a federation.

2.3 Target Group

The target group for the project was PFPID, self-advocates and PFPID's member organisations

2.4 Objectives and Results

This project had following objectives with hierarchy of overall objective and specific objectives:

Overall Objective:

Contribute to ensure Right of person with intellectual disability through the united effort of self-advocate and their representative organization in Nepal

Specific Objective: PFPID and their member organizations have improved organizational

capacity and promoted as resource/advisory organization of Intellectual disability in Nepal

Result 1: Strengthened the Capacity of PFPID with updated policy and capacitated human resource in place.

Result 2: Promote PFPID as resource/advisory organization of intellectual disability in Nepal.

Section 3: Project Implementation and Key Learnings

This section presents learnings in the course of project's implementation. In total, the project had 20 different activities implemented over the project period. Whilst documenting, a summary description of each activity implementation has been described and learning connected with the activity implementation has been mentioned alongside.

Activity: Capacity analysis of PFPID based on Partnership Assessment Human resource capacity need analysis

Implementation description:

Using an external resource person, PFPID carried out Financial System Gap analysis and program gap analysis. Such analysis helped them to find out areas of strengths and areas for improvement. A report was prepared with recommendations for improvements.

Key learning:

For the regular organisational development process, it is important for the organisation to know its strengths, weaknesses, opportunities and threats so that the board have clear and updated understanding about their organisational status. In addition, having a fresh perspective from external resource persons helps organisation to improve further. On the other hand such review and reflection of organisational status can also be done by board itself on time to time.

Activity: Provide capacity building support at selected areas including Policy updates/reformation support (update Existing Human Resource Policy ensuring Inclusive provision, develop/Update Anti-corruption/whistle blowing policy, children and Adult at Risk Safeguarding policy, develop advocacy strategy)

Implementation description:

PFPID reviewed its existing human resource policy. It was also found that this policy was lacking inclusion perspectives which now have been well incorporated. PFPID have also come up with an anti-corruption policy, Child safe guarding policy and also developed advocacy strategy for the organisation to take its entire advocacy work in much structured and documented manner.

Key learning:

PFPID developed some policies HR and financial policies few years back but they were not reviewed as deemed necessary nor it was PFPID's understanding to have them updated. So, it is revealed that policies, once they are developed, need to be reviewed and updated, concurrent as external environment where PFPID is operating is changing, at some time, is in fast pace. For, PFPID, as an organisation, works in a changing world.

To be a fully functioning and well governing organisation, it needs policies on anti-corruption, child and youth safeguarding and so on. We will further develop policies in the organisation and develop them accordingly.

For better result aimed through the advocacy work, one should move ahead with a planned and well documented advocacy strategy and defined roles. For this to happen, we need to have a clear advocacy plan in place outlining desired change, key actors, influencers, power centers and our activities to influence these actors and decision makers. Further, team advocacy and self-advocacy works best. Evidence based advocacy helps to influence decision makers compared to theory based advocacy.

When the organisation talks on safe guarding others, it is also important to safe guard self (staff and board). When were preparing safeguarding policies, it was realised soon that PFPID also needs to consider such things for its board and staff. Therefore, and have incorporated some clause related to insurance and social security aspects in the organisational policies.



Financial Management Training

Activity: Financial knowledge enhancement

Implementation description:

Financial management training to finance persons from Ktm. office, relevant staff and selected board members were provided training on financial management. This was followed by regular mentoring support to the finance staff.

Key learning:

Capacity is the key to improve performance. Despite several training in the past, PFPID's financial system-documentation was not still orderly managed. The mentoring support provided for 7 weeks after the training served well to enhance understanding and manage finances.

Mentoring support also helped the trainer to identify key gaps held by the staff and frame his support in line with the need/requirement and also capacity to grasp the information/new ideas/knowledge.

Mentoring support also served to identify key policy gaps in the HR and financial policies and make provisions to address those gaps.

On site support and mentoring approach served well, and any training to be organised in the future should have both the packages. If not both, we will give priority to have mentoring support to learn things practically.

Activity: Programme strengthening support to board and staff members
- Inclusive project cycle management Training

Implementation description:

A 2-day training on Inclusion across the different stages of Project Cycle Management was provided to relevant staff and selected board members in Kathmandu.

Key learning:

It is important to have participation of relevant stakeholders as we plan a project or even an event. Such participation helps to clarify the roles of different stakeholders and get them prepared as the project kicks off. So, for the success of any project intervention-it is essential to define-clarify roles-contribution of staff, board, line agencies, local governments, local associations, parents, self-advocates etc, and get them involved accordingly.

For the better ownership of the project involvement of stakeholders need to be emphasized from the very beginning of the project along with their involvement in monitoring and evaluation to make it participatory.

PFPID has prepared an action plan for the participation of staff and other stakeholders in its upcoming projects and also ensure stakeholders participation while designing new projects.

Capacity building of staff and board: In the situation if trained staff are leaving the organisation or board members are discontinuing, trained staff or board will serve as a resource for future reference. Therefore, any capacity building event in PFPID will take consideration in this aspect.

Activity: Review of PFPID visibility in digital platform and provide support to increase digital visibility based on the finding

Implementation description:

PFPID carried out an study-audit of PFPID's presence in the Digital platform. These include website, Facebook and recommendations received for re-design of the information presentation in the media.



Digital Platform Audit

Key learning:

Website's menus need to be updated.

Information-content found to be incomplete, photo quality very poor (need high resolution photos, Policy on presenting in the digital platform-need to be developed.

We need to assign a full time employee to look after our social media.

Regular update needed for wider visibility

Wider coverage: twitter, instagram, linkedIn, tiktok, YouTube, Linking instagram and WhatsApp account with facebook page

Social media boosting, reasonable knowledge on graphic design and digital marketing training for focal person

Activity: Mobilising nearby local association representatives and PFPID representatives to form local associations and their capacity building.

Implementation description:

Through this project, we supported to establish a local association of parents of persons with IDs in 14 districts. Forming such a large local association in short time period was much difficult and challenging task however we did it very successfully despite festival season and Nepal's general election. In doing so, mobilised nearby local representatives and PFPID representatives to start the process and to build capacity of parents in new associations. This, for example, local capacity in Bara district was not sufficient where project mobilised local representatives from Saptari district (adjoining), for Gorkha project mobilised representatives from Lamjung district (adjoining) and for Tanahu and Nawalparasi project mobilised representatives from Kaski and Chitwan districts respectively. In other cases, local representatives of PFPID (board member) were mobilised. These, for example, Nirmala Bista, Central Board Member of Kailali district, was mobilised to establish local associations in the districts that are nearby Kailali, and included as Baitadi, Bajhang, Darchula. This is with these reasons, it was possible to establish 14 local associations of parents of persons with IDs. Cost wise also, it was less cost incurred compared to what PFPID used to spent in past years.



Local Association Formation-Sankhuwasavea

Key learning:

Mobilising local representatives of PFPID and representatives from nearby districts has been found to be much efficient. Cost wise it is much lower where we have spent NPR 18,000 compared to what we used to spend NPR 50,000 in our past time period. This approach also has Time efficiency as well. If we could not have adopted this way of working, it would not have been possible to have it done within the stipulated project period. Central representatives have busy time schedule and do not generally have time for extensive field visit. Even they visit, it takes 3-4 extra days just for travel only. It is not always a need to have some one visiting from PFPID-Kathmandu.

Having this approach also have more advantage. It helps to get trust and also to have language accessibility. Experience and examples of nearby district also motivate other to get involved in the ID movement.

Mobilising PFPID representatives that are residing in the close vicinity of the district is also a way of decentralising PFPID's work. It also empowers them to work and guide the movement.

As we formalised 14 more local associations, and with this a total of 57 in Nepal, it is important for PFPID to have a database of these associations and to establish prompt communication, information sharing-information sharing between the PFPID and its member organisations.

When we formalise local associations, there are expectations and hopes from PFPID since it is the federation/network organisation. Therefore, PFPID need to come up with a capacity building plan with key focus in the area of organisational development, advocacy and disability and inclusive development of these associations.

Section 4: Conclusion

The project with CBM Global and CBM UK has been a significantly contributing in those humanistic areas where rarely any organization do. In Nepal, PFPID is the only network organisation established by the parents of persons with IDs and leading the movement.

Though this project was short in nature, it has supported PFPID to expand its network in additional 14 district where PFPID now have reached out to a total of 57 districts, so 20 districts more to go in Nepal. PFPID is very impressed not because of bigger volume funds but because of its recognition to the issues of persons with IDs and support thereafter. This project appears to be one of the corner stones in the history of PFPID.

Several key learnings have been realised. This document is the documentation of all those learning for the future reference of PFPID's work. The important learning for PFPID is that we always claim to be a learning organisation however forget to document learning out of our own work. Learning remains into the 'head' of staff or members. So, to be a learning organisation in true sense PFPID need to document the head knowledge and share in relevant meetings and platforms. Infact, organisation itself does not learn but it is the people working in the organisation learn and such learnings need to be documented, shared and owned by the organisation, then it becomes organisational learning, and this is the biggest learning for PFPID through this project.

As we move ahead, we will consider documenting entire learning in the organisation and its sharing both within and outside of the organisation.