

# NFU Strategy for International Solidarity Work 2015-2020

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## Introduction

This strategy document will guide NFU's international solidarity work during the period 2015-2020. It provides a context analysis, outlines the goals and principles, and provides a framework for our work. The strategy will help NFU to contribute effectively to making a difference in the lives of persons with developmental disabilities<sup>1</sup> and their families in developing countries. It will also serve as an external document explaining NFU's work to other stakeholders.

## Background

The UN Convention on the Rights of Persons with Disabilities (CRPD) provides NFU with a framework and an obligation to use its position, network and experience to contribute to change. Article 32 in the convention states that it is the duty of state parties to facilitate change and provide technical and economic assistance, and thus act as change agents to inspire and support initiatives and influence decision makers in Norway as well as internationally. NFU's general assembly has taken on this responsibility and decided to work in accordance with this strategy to promote the rights of persons with developmental disabilities in developing countries<sup>2</sup>.

It is estimated that one billion people, about 15% of the world's population, have a disability (WHO/WB 2011:261)<sup>3</sup>. Of these, 190 million (3.8%) have a "severe disability". 95 million (5.1%) of children have a disability, of which 13 million (0.7%) have "severe disability" (ibid). There is a lack of accurate statistics on the prevalence of persons with developmental disabilities in developing countries. However, it is estimated that the prevalence globally is around 1% (Pallab et al 2011)<sup>4</sup>. The highest prevalence is among children and youth. Disability disproportionately affects vulnerable populations. There is higher disability prevalence in lower-income countries than in higher-income countries. People from the poorest wealth quintile, women, and older people have a higher prevalence of disability compared with the rest of the population (ibid:262).

All over the world governments fail to ensure that the human rights of persons with disabilities are respected. The most common barriers are: Inadequate policies and standards, negative attitudes, lack of/poor quality of services, inadequate funding, lack of accessibility, lack of consultation and involvement, and lack of data and evidence (WHO/WB 2011:262-263).

Persons with developmental disabilities are among the most marginalised groups in a population and face disproportionately severe barriers in society. The majority of women, men and children with developmental disabilities face discrimination, exclusion, isolation, stigma and

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<sup>1</sup> A person with a developmental disability has a cognitive limitation, inherited or early acquired. It is a permanent condition that requires support to learn and to manage an independent everyday life. It is estimated that around 2% of a population has a developmental disability.

<sup>2</sup> NFU's work programme 2012-16, principle 1.3: "Persons with developmental disabilities and their families in the third world must have their living conditions and human rights improved. NFU will therefore continue its solidarity work. The strategy for NFU's solidarity work should be the basis for this".

<sup>3</sup> World Report on Disability 2011

<sup>4</sup> Pallab K. Maulik, Maya N. Mascarenhas, Colin D. Mathers, Tarun Dua, Shekhar Saxena (2011). *Prevalence of intellectual disability: A meta-analysis of population-based studies*. Research in Developmental Disabilities, Volume 34, Issue 2, February 2013, Page 729 . Please note that this study uses the term intellectual disabilities, but for consistency we use developmental disabilities in this strategy document.

even abuse, violence, neglect and exploitation in institutions, within their families, in their local communities and in society at large. Many persons with developmental disabilities live in extreme poverty, without access to education or employment opportunities, and face a range of marginalizing factors. They are often denied the right to vote, the right to own or inherit property, and the right to make decisions affecting their lives. The discrimination they face is widespread, cutting across geographical boundaries and affecting people in all spheres of life and all sectors of society.

Women and girls with disabilities face double discrimination – for being disabled and for being a woman. Almost 80% of women with disabilities are victims of violence, and they are four times more likely than other women to suffer sexual violence (UN 2012)<sup>5</sup>. Women and girls with intellectual disabilities are at a particularly high risk of violence, including sexual violence.

For many persons with developmental disabilities assistance and support are prerequisites for participating in society. In most countries, and even more so in developing countries where there is a lack of government services, many persons with developmental disabilities depend on their family members and the community for care and support<sup>6</sup>. Such informal care is an important way of providing quality community based care, and should be recognised and supported. Inadequate support can cause social exclusion, emotional stress and enhanced poverty of families and particularly women who often have the responsibility for domestic labour. Finally, as caregivers grow older they are concerned about what will happen to their child when they are no longer able to provide care for the person with a disability (WHO/WB 2011:141-42).

### **This is NFU**

Norwegian Association for Persons with Developmental Disabilities (NFU) is a human rights organisation of and for persons with developmental disabilities and their families. NFU works for full participation, equality, and against discrimination. We work to secure the interests of persons with developmental disabilities and their families vis-à-vis the government at all levels. NFU is a democratic organisation with around 8000 members and local branches in all districts of Norway. NFU fights for the human rights of persons with developmental disabilities as stipulated in the Convention of the Rights of Persons with Disabilities (UNCRPD). The Convention states that persons with disabilities must enjoy all human rights and fundamental freedoms on an equal basis as everyone else. The basis of NFU's work is that persons with developmental disabilities have the same value, basic needs and fundamental rights as every other human being. We aim to contribute to enabling persons with developmental disabilities to have a voice and ensure that they are listened to. NFU believes that families are best placed to assist persons with developmental disabilities to have a voice and claim their rights, while we are cautious of the risk of overprotection. This means that families also have a legitimate right to receive support. We also believe that the wider community and society have a responsibility to include as well as to support and protect the rights of persons with developmental disabilities and their families.

### **Strategic partners**

NFU works in close collaboration with key networks and strategic alliances in Norway and internationally. In Norway, NFU is a member of the Norwegian umbrella organisation for disabled people's organisations (DPOs) involved in development work, the Atlas-alliance. Among the Atlas member organisations, NFU works particularly close with the Norwegian

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<sup>5</sup> UNHCR (2012) Thematic study on the issue of violence against women and girls and disability. Report of the office of the UNHCHR <http://www.ohchr.org/documents/issues/disability/thematicstudyviolenceagainstwomengirls.pdf>

<sup>6</sup> In the USA, 75% of adults with developmental disabilities live at home with family caregivers.

Association of the Disabled (NAD). Internationally, our most important strategic partners and networks are Inclusion International, which is the global federation of family based organisations working for the human rights of persons with developmental disabilities world-wide, and Enabling Education Network (EENET), which is an Inclusive Education information-sharing network, open to everyone. We are also part of the International Disability and Development Consortium (IDDC). We are actively working to encourage and promote collaboration between the Nordic and European sister organisations (Inclusion Europe) in the international solidarity work.

### **Strengths and added value**

As a human rights organisation of persons with developmental disabilities and their families, our strengths in the international solidarity work are that:

- ***We have extensive experience in addressing a range of problems facing persons with developmental disabilities*** such as discrimination and stigmatization, social exclusion, institutionalization, fighting for community living, parent and youth empowerment, self-advocacy, pros and cons with both inclusive and special education, balancing demands for a medical/diagnosis focus with a generic human rights focus, etc. We know where to find expertise in all these areas. We are the street-level, bottom-up experts.
- ***We have extensive experience in running a membership based interest organisation***, and we know how to overcome obstacles in terms of limited time and capacity of members and difficulties in fund raising. We therefore invest in long term partnerships.
- ***We have access to a Norwegian and Nordic network of likeminded disability organisations***, which helps in creating synergies in selected programme countries. NFU has ***access to an international network of parent organisations*** and are able to call on regional and global action in support of our work. We can facilitate international networking, experience exchange and connecting people.
- ***Based on our experience, we know that an inclusive education system is the cornerstone in, and a precondition for, an inclusive society.*** Access to education in the local community within mainstream structures is crucial for persons with developmental disabilities. It ensures social contact with peers and a sense of being a full member of society. Inclusive education is a precondition for us all to develop an understanding of human diversity and respect for persons with developmental disabilities.

### **Vision**

NFUs **vision** is “a society for all”. This is a society where persons with developmental disabilities are included and given the opportunity to develop to their full potential and where they are participating in all spheres of life on an equal basis with others. In the international solidarity work, we focus on five areas of inclusion, each with a specific goal<sup>7</sup>:

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<sup>7</sup> In line with the Community Based Inclusive Development (CBID) approach. This is the latest generation of CBR (Community Based Rehabilitation), which was initiated and formed in the 1980s. It has changed from a medical dominated approach with focus on individual rehabilitation, to a holistic, multidisciplinary approach with a holistic focus on human rights. Disability has been redefined as a societal problem rather than an individual problem. CBID therefore seeks to remove barriers and promote social change and inclusion, not just medical care and rehabilitation. It is a strategy to empower people with disabilities and their families and to support stakeholders to fulfil the rights of people with disabilities in all aspects of life.

**Education:** Persons with developmental disabilities access quality, child friendly education in their communities within an inclusive education system and life-long learning to fulfil their potential.

**Health:** Persons with developmental disabilities access health services on an equal basis as everyone else.

**Livelihood:** Persons with developmental disabilities and their families access financial services, vocational training, employment opportunities, social protection and poverty reduction schemes on an equal basis as everyone else.

**Social inclusion:** Persons with developmental disabilities are valued, encouraged and supported within their families. Barriers preventing persons with developmental disabilities and their families from participating in social roles and activities are challenged and addressed, and they receive support in their communities.

**Empowerment:** Persons with developmental disabilities are able to make informed choices and decisions; they are active participants and contributors in their families and communities. Persons with developmental disabilities and their families come together and form their own groups, organisations, and work to address their common challenges.

## **Mission**

NFU's mission is to act as an agent for change by mobilizing, networking, demonstrating, documenting and advocating for our vision in collaboration with other likeminded stakeholders and partners in Norway, internationally and in partner countries.

## **Values**

NFU's values coincide with the principles of the UNCRPD as stated in article 3:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

In the international solidarity work, NFU also adhere to certain principles for good development aid:

- **Local Ownership:** We acknowledge that our partners are the experts on their local situation and believe that they should take the lead in setting priorities based on their experienced needs and concerns. Our support is strategic, advisory and financial, and tailor made according to needs. We do not implement or advocate locally without ensuring that partners are in the driving seat. We cooperate with partners around clearly defined goals and agreed strategies.
- **Sustainable results in a long-term perspective:** Real societal change takes time. Although NFU has a long-term perspective in our solidarity (10-20 years), we

acknowledge that our support is time bound. To ensure sustainability we work through existing local structures, focus on building capacity and avoiding dependence on our support. We agree on phase out plans with milestones at least two years in advance.

- **Inclusive Partnerships:** We believe that openness, trust, mutual respect and a focus on mutual learning are at the heart of good development work. We cooperate with partners around shared values and a vision of inclusion.
- **Transparency and accountability:** We strive for transparency and mutual accountability vis-à-vis our partners, the target group, the members in NFU, our back donors and the general public.
- **Do no harm:** We are aware that development aid potentially can do more harm than good and will base our work on solid analysis of local context and risks to minimize harm. We strive to use local consultants and resource persons who are aware of the context when commissioning assignments and research.
- **Harmonization:** We aim to listen to our local partners and coordinate our support to ensure complementarity, avoid duplication and minimize the administrative burden on our partners.
- **Anti-corruption:** NFU recognizes the negative effects of corruption on development and practices a zero tolerance for corruption through helping our partner developing sound management systems and taking proactive measures against financial mismanagement and corruption.

### **Theory of change**

In order to move towards our vision of an Inclusive Society, NFU applies a human rights based approach. A human rights based approach is about empowering people to know and advocate for their rights and increasing the ability and accountability of those who have the duty to respect, protect and fulfilling human rights (first and foremost the government, but also other duty bearers). This means giving people greater opportunities to participate, organize and influence the decisions that impact on their human rights. It also means increasing the ability of those with responsibility for fulfilling rights (duty bearers) to recognize and respect those rights, and make sure they can be held to account. A human rights based approach is about ensuring that both the standards and the principles of human rights are integrated into policymaking as well as the day to day running of organisations.

NFU has a long history and extensive experience in applying a rights' based approach to fight for the rights of persons with developmental disabilities in Norway, and since 1981 also across the world. We believe that a twin track approach will lead us closer to our vision:

1. Our experience shows that change can happen if persons with developmental disabilities and their families meet others with similar experiences and share their concerns and hopes. By organizing into vibrant organisations, articulating their aspirations, and taking action to address their situation, they can claim their rights vis-à-vis the government (duty bearers) and hold them accountable to their commitments and obligations. We use our experience (as parents and self-advocates in Norway) to empower persons with developmental disabilities and their families (rights holders) and to support them to organize and take effective action to change the conditions in their respective countries and communities. We aim to do this through;

- **Empowering persons with developmental disabilities and their families** to know their rights, form groups and advocate for their rights through CBID or national organisations.
  - **Strengthening organisations of and for persons with developmental disabilities and their families.** We cooperate directly with parent organisations in a few carefully selected partner countries to enable them to develop their organisations, empower their members and advocate for rights and inclusion vis-à-vis the government. We will also support efforts to strengthen self-representation and advocacy of persons with developmental disabilities themselves in these organisations.
  - **Contributing to building a movement of persons with disabilities that include persons with developmental disabilities and their families.** We aim to support networking among organisations and strengthen the voice of likeminded organisations.
2. The UNCRPD confirms that it is the responsibility of the governments as duty bearers to fulfil the rights of persons with disabilities on an equal basis as everyone else. However, our experience tells us that all over the world governments fail to fulfil these rights because they lack the will, competence and/or capacity, and because they are not held accountable to their obligations in the UNCRPD. We want to contribute to addressing this problem by:
- **Advocating for and supporting inclusion by governments in the selected partner countries.** We want governments at all levels to include persons with developmental disabilities in mainstream development policies and programmes, apply community based inclusive development strategies (CBID) and provide earmarked budgets for realisation of these. We also advocate for consultation of organisations of persons with developmental disabilities and their families in decision-making.
  - **Advocating for and supporting inclusion in Norwegian and international development aid.** In cooperation with the Atlas Alliance, Inclusion International and our partner organisations, we work to influence and support politicians, authorities, development agencies and civil society organisations to include persons with developmental disabilities in their programmes.
  - **Developing concrete CBID pilot projects for demonstrating successful community based inclusion as a basis for advocacy and scaling up.** We cooperate with NAD to create synergies and develop rights based and affordable models of inclusion at community level, using the CBID approach (focusing on health, education, livelihood, social inclusion, and empowerment). In particular, we will use our experience within inclusive education and pay specific attention to the most marginalised groups of disabled to ensure that they are included on an equal basis.

### Crosscutting issues

- **Gender and gender based violence:** Women and girls with disabilities in general and developmental disabilities in particular often experience double discrimination – for having a disability and for being a woman. Women and girls with developmental disabilities are particularly vulnerable. Many of our partners work on this already and we want to continue to support their work on this.
- **Research and documentation:** We cooperate with research institutions/universities and organisations to undertake mappings, studies, pilot projects and research that can

support advocacy efforts and capture, systematize and share lessons learnt and experiences. We encourage our partner organisation to share their experiences and lessons learnt with their peer organisations, thus enabling South-to-South sharing.

### **Objectives for NFU's international solidarity work 2015-2020**

Based on the above assumptions, the overall objectives for NFU's international solidarity work 2015-2020<sup>8</sup> are:

- Democratic and sustainable organisations of persons with developmental disabilities and their families represent and promote rights in four countries.
- Networking between organisations of persons with developmental disabilities and their families is strengthened and their experiences and opinions are included in regional, national and international decision-making processes.
- Partner country governments and community level programmes include persons with developmental disabilities and their families.
- CBID pilot programmes are established in four countries with a particular focus on Inclusive Education and the inclusion of marginalised disability groups demonstrating inclusion in practice.
- Norwegian and international aid programmes (in partner countries) include marginalised groups of persons with disabilities and their families.
- A knowledge base on the situation of persons with developmental disabilities in the global south is developed in order to support advocacy and program development.
- Gender is mainstreamed across NFU's partner organisations and programmes.

### **Strategic choices**

NFU has made a number of strategic choices that will contribute towards the achievement of our objectives:

- **Geographic scope:** NFU engages in a limited number of countries. We give priority to countries where we can collaborate with relevant stakeholders and make an effective contribution. In the period 2015-2020, we support organisations in Malawi, Zambia, Tanzania and Nepal, in addition to the regional network Inclusion Africa. While we are not currently expanding geographically, we will increase the scope and reach of our programmes as outlined in this strategy.
- **Resources:**
  - **Financial:** NFU seeks to increase the size of our programmes and thereby the impact of each programme. NFU does not have the capacity to engage independently in fundraising towards the international solidarity work. Our main source of funding is and will remain from Norad through collaborative programmes within the Atlas-alliance. We rely on the Atlas Alliance to represent NFU's financial interests in dialogue with Norad, and other potential donors. Should the co-payment of 10% remain a requirement from Norad, NFU will work through the Atlas-alliance to find a common source of funding.
  - **Human:** NFU is ambitious with regards to the growth of our programmes. As we increase the size of our programme, we aim to complement the growth in

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<sup>8</sup> These overall objectives for the NFU international solidarity work are operationalised in a more detailed steering document/results framework with indicators to monitor step-by-step progress. The steering document is mainly a tool for the NFU board and staff. This is included in appendix 1

programme size and financing with adequate human resources in order to ensure high quality project management.

- **Information and communication:** NFU continues to work towards increased awareness among its members concerning the international solidarity work, and will seek to also involve the NFU International Committee in this process. The NFU secretariat will continue to contribute to the bi-monthly NFU magazine Samfunn for Alle. If capacity allows, the NFU secretariat will seek other ways of raising awareness about our international efforts, and become involved in the Atlas-alliance information committee.
- **Peer support:** NFU and partner DPOs are grappling with many similar experiences, opportunities and challenges, and as such have a lot to learn from each other. We seek to facilitate peer support and information exchange between partners, and between partners and NFU, where appropriate and useful.
- **Innovation:** Disability inclusion is a field without ready-made solutions, which requires local innovators to draw on international experiences in order to develop locally adapted solutions. NFU is an active participant in national and international discussions on how best to fulfil the rights enshrined in the UNCRPD, and seek to collaborate with local partners in developing such locally adapted innovative solutions.
- **Broad inclusion:** NFU recognise that disability inclusion does not automatically lead to the inclusion of all persons with disabilities. Some persons with disabilities tend to be considered more difficult to reach, including persons with development disabilities, and are often left out even when full inclusion is intended. NFU seeks to ensure broad inclusion, and will specifically promote broad inclusion in all aspects of our programmes.

## Appendix 1 – Code of ethic

## Appendix 2: - Results framework