



**05**



## Light for the World **LEARNING SERIES**

### **Speaking with one voice**

The genesis of the South Sudanese umbrella organisation of persons with disabilities, 2015 - 2023

An Outcome Harvesting Case Study



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## List of abbreviations

<b>ADF</b>	African Disability Forum
<b>CBM</b>	Christian Blind Mission
<b>CEPO</b>	Community Empowerment Progress Organization
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>DIFs</b>	Disability Inclusion Facilitators
<b>ESSAD</b>	Equatoria Association of the Deaf
<b>ESSUVI</b>	Equatoria Association of Visually Impaired
<b>HI</b>	Humanity and Inclusion
<b>OH</b>	Outcome Harvesting
<b>OPD</b>	Organisation of Persons with Disabilities
<b>SSAVI</b>	South Sudan Association of the Visually Impaired
<b>SSUPD</b>	South Sudan Union of Persons with Disabilities
<b>TOFI</b>	Together For Inclusion
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNMISS</b>	United Nations Mission in South Sudan
<b>UPD</b>	Union of Physically Disabled

# 1. Introduction

## About this learning series

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Light for the World is a global disability and development organisation, breaking down barriers to enrich society and unlock the potential in everyone. Being an organisation for persons with disabilities, Light for the World respects the rights and principles of the Convention on the Rights of Persons with Disabilities (CRPD). The Convention clearly states the need to prioritise the views and perspectives of organisations of persons with disabilities (OPDs) above those of organisations for persons with disabilities. At the same time, OPDs often lack financial and technical resources, as well as organisational capacity to fully play their role as representative organisations.<sup>1</sup> Light for the World therefore collaborates closely with OPDs and supports them in their capacity development processes.

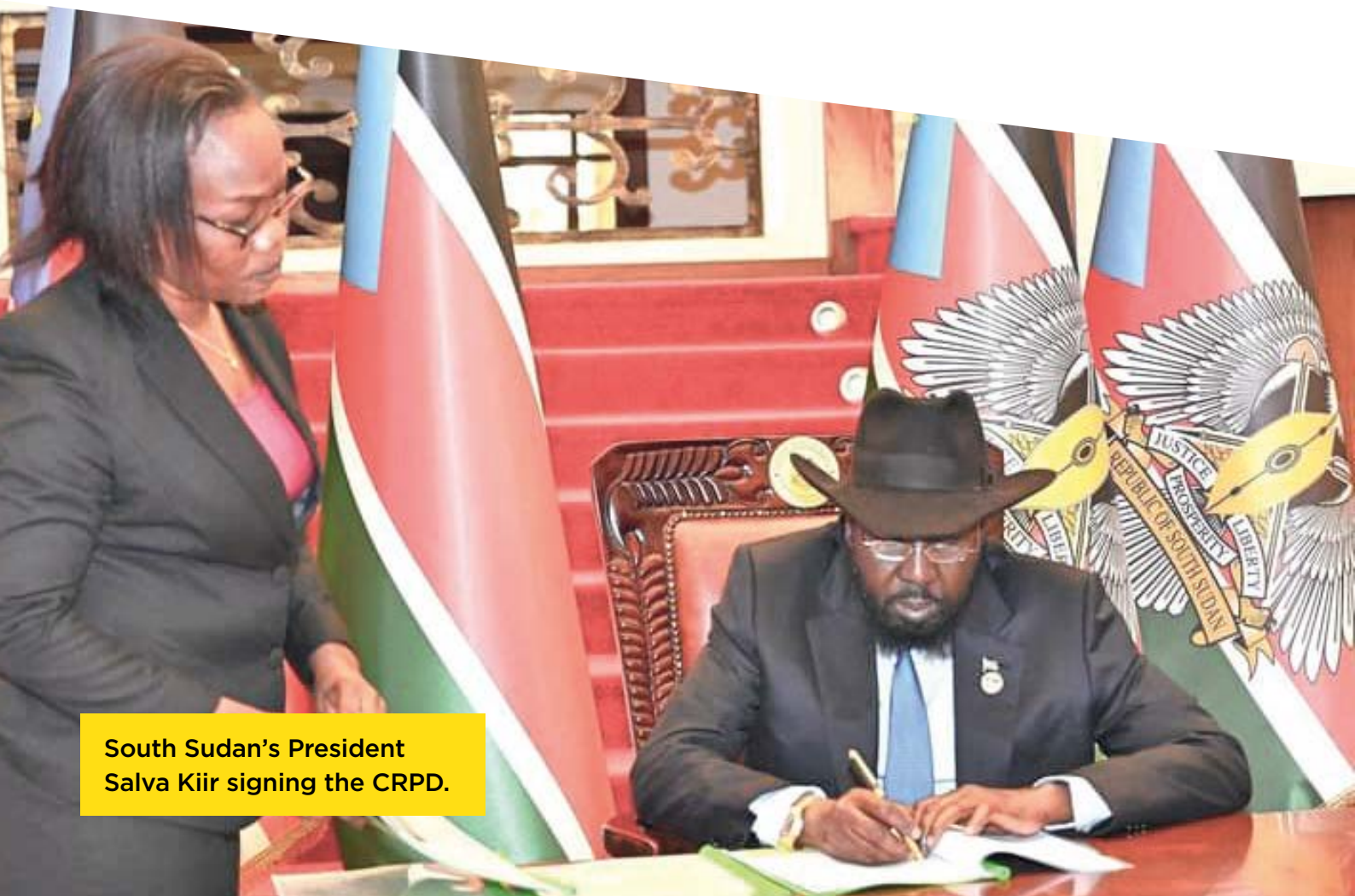
This case study documents the process of strengthening and collaborating with the disability movement in South Sudan from 2015 to 2023. A key strategy was to support the formation of an umbrella OPD in the country – the South Sudan Union of Persons with Disabilities (SSUPD). The lessons learned show that the formation of SSUPD led to more visibility and recognition of the disability movement in the country and resulted in advocacy successes. This was possible through a longer-term engagement, the provision of resources and expertise, the support on individual and organisational level, as well as increased support from other actors, including governmental stakeholders. Thus, while Light for the World and a small group of individual OPDs initiated the formation of the Union, the success is based on the efforts of many other actors.

## What are OPDs?

General comment No. 7 of the CRPD defines OPDs (or representative organisations) as organisations with the following characteristics:

- ▶ **Led, directed and governed by persons with disabilities**
- ▶ **Recognising the rights and principles of the CRPD**
- ▶ **Majority of leadership and members are persons with disabilities themselves**
- ▶ **Promoting and defending the rights of persons with disabilities**
- ▶ **Being independent and a specific type of civil society organisations, thus not being affiliated to political parties, public authorities or other non-governmental organisations**
- ▶ **Reflect and represent diversity and intersectionality of persons with disabilities**
- ▶ **On local, national, regional or international level**

General comment No. 7 also specifies umbrella organisations as one type of OPDs, which are coalitions of OPDs. Further, the comment clearly distinguishes OPDs as organisation of persons with disabilities from those for persons with disabilities. The latter provide services to or advocate on behalf of persons with disabilities. To finish, general comment No. 7 clearly notes that governments have to involve OPDs as representative organisations of persons with disabilities themselves in all affairs that concern them, i.e. „Nothing about us without us“ cast in stone.<sup>2</sup>



**South Sudan's President  
Salva Kiir signing the CRPD.**

## The context of South Sudan

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Since gaining independence from Sudan in 2011, South Sudan has grappled with a range of humanitarian challenges, including conflict, natural disasters, and the impact of the COVID-19 pandemic.

The civil war that erupted in 2013, driven by political disputes, has led to widespread violence, displacement, and human rights abuses. While the 2018 peace agreement has shown progress, key milestones have been extended to 2025.<sup>3</sup> The United Nations Mission in South Sudan (UNMISS), present since 2011, supports efforts to establish security and stability, with its current mandate extended by the UN Security Council until March 2024.<sup>4</sup>

The country is also vulnerable to disasters related to climate change. Repeated droughts and floods have been further harming livelihoods and causing fatalities and displacement. In 2023, an estimated 76% of the population requires humanitarian assistance.<sup>5</sup> South Sudan's economy, heavily reliant on oil revenues, faces external shocks due to fluctuating global oil prices, as well as the conflict in neighbouring Sudan, impacting infrastructure development and basic services.<sup>6</sup> According to data from UNHCR, 1.5 million people are internally displaced due to conflict and an additional 650,000 persons due to natural disaster. Meanwhile, 2.2 million individuals have sought asylum or become refugees in countries like Uganda, Sudan, and Ethiopia.<sup>7</sup>

Overall, South Sudan's post-independence journey has been marked by conflict, political instability, and humanitarian challenges. While these factors increase the vulnerability of the entire population, marginalised groups, such as persons with disabilities are even more affected. And the conflict has been a significant cause of disability, with the 2012 national disability assessment estimating that 21% of disabilities result from conflict.<sup>8</sup>

## The context of OPDs in South Sudan

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In the early years of South Sudan's existence, between 2011 and 2016, there were few OPDs that were working independently trying to advocate for the rights of persons with disabilities. The scattered OPD landscape resulted in organisations pursuing their specific interests with a narrow advocacy agenda, leading to low engagement of persons with disabilities in decision making processes in South Sudan. Each OPD was working in isolation and there was no organised disability movement to influence government and donor policies in a coordinated way to ensure that the rights and needs of persons with disabilities were addressed.

Light for the World could offer support for the individual OPDs to strengthen their capacity, but it was not sufficient to advocate for disability inclusion in a more systematic and sustainable way. Together with the individual OPDs, Light for the World felt that there was a need to have a united disability movement that would push for the rights of persons with disabilities in South Sudan. And Light for the World, conscious of its role as organisation for persons with disabilities, did not want to illegitimately take the role of organisations of persons with disabilities in the advocacy for sustainable disability inclusion.



Augustino Wudu, chairperson of the Union holding a speech during the 2023 International Day of Persons with Disabilities.

## Outcome Harvesting methodology

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The data for this case study was gathered by Outcome Harvesting (OH), a participatory approach for evaluation centred on social change outcomes. This process was conducted by Light for the World in South Sudan, in collaboration with the organisation's international office and an OH consultant from Southern Hemisphere, who was brought on board for technical support and guidance. The harvesting process took place from May 2021 to January 2022. To capture new developments before finalising the publication, additional data was collected between December 2022 and June 2023.

### The entire process included the following:

- 0 ▶ **Inception meeting:** Key concepts related to OH were presented and discussed, including the steps of the process, timeframes, and key responsibilities.
- 1 ▶ **Harvest design (step 1) meeting:** Following this discussion, an outcome tracker was designed and shared with those team members responsible for conducting the preliminary outcome harvest.
- 2 ▶ **Review of secondary data sources (step 2):** The review covered project documents, such as proposals and reports.
- 3 ▶ **Engagement with key informants (step 3):** Discussion with change agents to harvest the outcomes. The key informants included the chairperson of the South Sudan Union of Persons with Disabilities, representatives of member OPDs, international NGOs and government officials of the Ministry of Gender, Child and Social Welfare. Research methods included the administration of a self-completion survey and telephonic as well as physical semi-structured interviews.
- 4 ▶ **Substantiation (step 4):** The OH team reviewed the outcomes and interviewed additional key informants for validation and substantiation of data collected in step 3.
- 5 ▶ **Sense-making session (step 5):** Here the team members reflected on the substantiated outcomes and updated them where needed. Patterns or themes in the data were investigated, discussed, and assessed to determine key outcomes and potential levers or mechanisms of change.
- 6 ▶ **Data collection update:** From December 2022 to June 2023 additional key informant interviews with Light for the World staff members, the chairperson of the South Sudan Union of Persons with Disabilities and the Executive Director of the Community Empowerment Progress Organization (CEPO) were conducted. These informants also shared additional documentation for further review.

## 2. Facts and Timeline

### 2012

The first ideas, to form a union of OPDs, emerged mainly from four OPDs (SSAVI - South Sudan Association of the Visually Impaired, UPD - Union of Physically Disabled, ESSUVI - Equatoria Association of Visually Impaired, ESSAD - Equatoria Association of the Deaf); a first constitution was also drafted.<sup>9</sup>

### 2015

Individual OPDs created the CRPD task force to advocate for South Sudan's ratification of the Convention.<sup>10</sup>

### July 2016

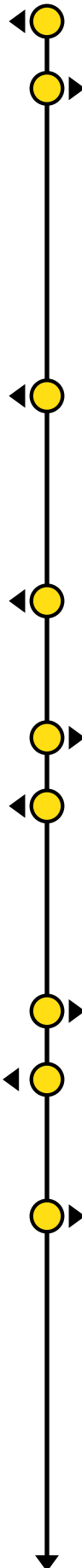
The conflict in South Sudan erupted and the work of the committee to develop a concept for creating a union was interrupted.

### 2016-2019

Johan Wesemann, a Dutch expert on the disability movement volunteered for Light for the World and travelled to South Sudan several times to coach and mentor the OPDs, and guided the process for forming the union.

### 2019

Re-establishment of the interim committee for creating the Union. This time, the interim committee was selected from the member organisations through a democratic process where 14 member organisations elected the committee members. The committee was tasked to draft the policies that would govern the Union.



### 2015

Light for the World carried out an assessment of five OPDs (those listed above plus the National Association of the Deaf) in South Sudan to understand the challenges they faced. The assessment was done by visiting their offices and conducting key informant interviews. The process gave Light for the World an orientation on how to support the capacity development of the OPDs. The five OPDs, Light for the World and the Ministry of Gender, Child and Social Welfare took up the idea again of forming a national umbrella organisation and the five OPDs formed a committee to develop a concept for creating a union.

### 2016-2017

Light for the World offered training and capacity development support to its five partner OPDs on leadership, group formation, communication and management skills, including project management.

### 2018

On-the-job training on project management: Light for the World invited its five partner OPDs to jointly implement a project.

### 2019

During this period, Light for the World also brought in the concept of disability inclusion facilitators (DIFs). DIFs are persons with disabilities who are trained on various skills and can then train other organisations on disability inclusion and advocate for the rights of persons with disabilities. The disability inclusion facilitators were selected from the OPDs.



## 2020

At the beginning of the year, Light for the World engaged a legal consultant to support the Union in the registration process. The official registration certificate was issued by the Relief and Rehabilitation Commission South Sudan in May and in September the South Sudan Union of Persons with Disabilities (SSUPD) was officially launched in Juba. In December, SSUPD held, with the support of Light for the World, its first General Assembly.<sup>11</sup> At the time of registration, the Union had eight members,<sup>12</sup> representing four national OPDs and four state-level OPDs from Jubek and Equatoria states.<sup>13, 14</sup>

## December 2021

SSUPD supported by CBM (Christian Blind Mission) proudly opened their own furnished office with computers and a generator.<sup>15</sup>

## 2023

On 24th February, the President of the Republic of South Sudan signed the UN Convention on the Rights of Persons with Disabilities. The CRPD task force which was established in 2015 had further evolved. In 2023 it was headed by SSUPD and now also included members from the government, as well as developmental and humanitarian partners: ACROSS, African Disability Forum-South Sudan, CBM, Dorcas, Humanity & Inclusion and Light for the World.<sup>18</sup>



## 2021

SSUPD achieved two big advocacy successes: (1) A disability inclusion desk was established in the office of the Vice President on Gender and Youth of South Sudan, ensuring that persons with disabilities are represented at a higher level. (2) The Undersecretary of the Ministry of General Education and Instruction signed the Inclusive Education policy in May 2021 and the process of dissemination and implementation at state level started.

## 2021

The Norwegian Consortium Together for Inclusion (TOFI) supported the Union with funds to strengthen their capacity in project implementation and to drive the disability inclusion agenda.

## 2022

SSUPD further established their organisation and enlarged their network. They held a second General Assembly in July with over 70 participants from ten States and three Administrative Areas. Participants came from OPDs, line ministries and media outlets. At the General Assembly, the Interim Executive Board was re-elected.<sup>16</sup>

SSUPD became a member of the African Disability Forum (ADF).

With the support of CBM and ACROSS, SSUPD developed a strategic plan for the period 2022-2026.<sup>17</sup>

The Union also formed alliances with other civil society organisations, like Humanity & Inclusion, CBM and ACROSS to advocate for the ratification of the CRPD.

Together with the Community Empowerment Progress Organization (CEPO), a South Sudanese civil society organisation, they initiated the formation of the Parliamentary Disability Caucus uniting 17 Members of Parliament with and without disabilities.

## 3. Findings

**The process of supporting the formation and formalisation of the umbrella OPD resulted in positive changes at different levels:**

### 1. SSUPD and its members have increased capacities

They gained knowledge on how to formally register an organisation and acquired skills for financial and human resource management, as well as effective and efficient project and advocacy implementation. By acquiring an office space, by holding regular General Assemblies with elections and by developing a strategic plan, they demonstrate an increasing level of formalisation and professionalism.

### 2. SSUPD has increased its legitimacy

The number of OPDs becoming members of SSUPD or showing interest in joining increased over time. In 2020, when SSUPD was officially registered, the eight founding members represented the national level and two states (Jubek and Equatoria). At the General Assembly in 2022, representatives from all states and administrative areas of South Sudan participated. Thus, the member OPDs are now representing persons with disabilities from all parts of South Sudan. Similarly, the members represent an increasing number of types of impairment. The growing and more diversified member structure leads to higher legitimacy of SSUPD to persons with disabilities and the disability movement.

### 3. Growing network of partners and stakeholder support

The increase in capacity, degree of formalisation and legitimacy help SSUPD to gain support from more partners and stakeholders. In 2015 financial and technical support mainly came from Light for the World. Now, SSUPD receives funding from many other partners, such as Norwegian Church Aid (NCA), African Disability Forum (ADF), CBM, ACROSS and Organisation for Volunteer Organization for International Cooperation (OVCI).<sup>19</sup> Technical support comes from national and international NGOs, for example CEPO, ACROSS and Humanity & Inclusion and international organisations (e.g. UN, EU). Government stakeholders (Ministry of Gender, Child and Social Welfare, Ministry of General Education and Instruction, Vice-President on Gender and Youth and Members of Parliament) recognise the Union as representative of persons with disabilities. By becoming a member of ADF, SSUPD is also actively expanding their international network and recognition. Overall, the growth in network and partnerships leads again to an increase in capacities and resources.



**“One of the success stories of the SSUPD is it enabled the vision and mission of individual OPDs, partners and others to shift their thinking for plans and programmes from focusing only on working for people with disabilities to working with people with disabilities.”**

Esther Ikere/Undersecretary of Ministry of Gender, Child and Social Welfare office

#### 4. Advocacy successes

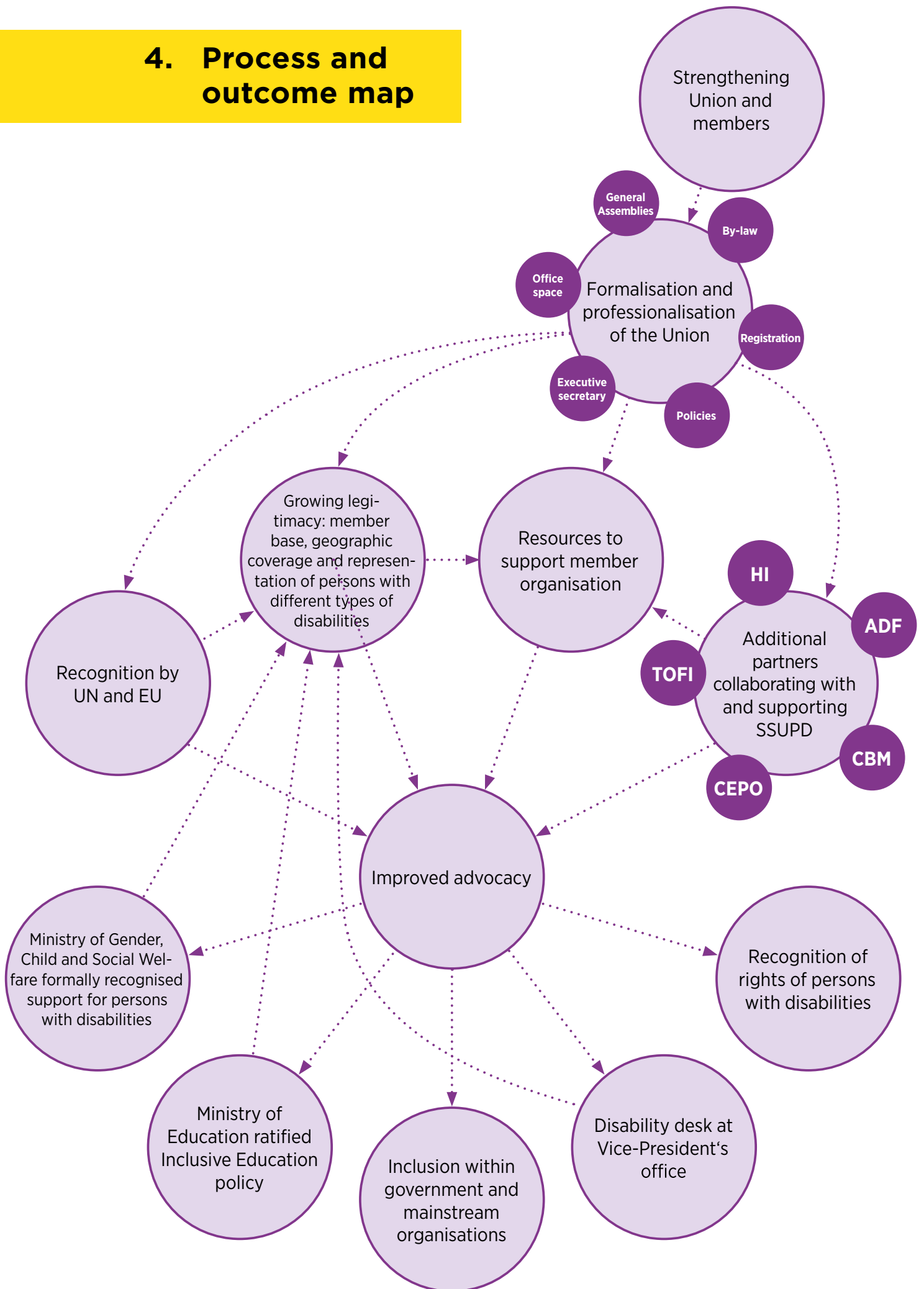
Over time and thanks to the increase in capacities, legitimacy and support through partners and stakeholders, SSUPD has achieved a number of significant advocacy gains, such as the establishment of the disability inclusion desk at the Vice-President’s office, the ratification of the Inclusive Education policy, the formation of the Parliamentarian Disability Caucus and most importantly the ratification of the CRPD.

#### 5. Rights of persons with disabilities

All the above factors lead to an increased recognition and respect of the rights of persons with disabilities. An increased level of disability inclusion can be observed in public service provision and among programmes of development and humanitarian actors. Ultimately this will lead to better living situations of persons with disabilities.

THE EIGHT FOUNDING MEMBERS OF SSUPD
South Sudan Women with Disabilities Network
South Sudan Association of Visually Impaired
South Sudan National Association for Deaf
Jubek State Union of the Physical Disabled
Equatoria State Association of Deaf
Jubek State Association of People affected with Leprosy
South Sudan Wheelchair Basketball Association
Jubek State Union of Visually Impaired

## 4. Process and outcome map





**ZOAC** **Dorcas**  
South Sudan

Help a  
**CHILD**  
SOUTH SUDAN

**LIGHT**  
FOR THE WORLD

**PRIDE!** Empowered women, prosperous communities

Graduation Ceremony of 350 youth and women supported with vocational training under the Pride! Project

**Empowering Women Through TVET**

VENUE:

**DORCAS COMPOUND, SIKKA HADID WAU**

Funded by:

**The EUROPEAN UNION**



## 5. Lessons learned

The formation of the Union can be seen as a significant success. Previously there was no unified movement led by persons with disabilities in South Sudan. OPDs had different mandates and there was no common approach among them to advocate for the rights of persons with disabilities. The legal registration of the Union created the necessary platform where member organisations can advocate jointly for the disability inclusion agenda. On the way to reaching this stage, challenges were encountered. The determination of member organisations and all actors allowed these challenges to be overcome. The lessons outlined below can be learned for similar processes.

### **Lesson 1: Patience and determination**

The idea of forming an OPD was first thought of in 2012 and since 2015, Light for the World provided financial and technical support to individual OPDs and SSUPD. This long-term support helped to create relationships based on respect and trust. Light for the World continuously strengthened the capacities of the member organisations and underlined the importance of working together as a team. Bringing together member organisations was not always an easy task and it took a lot of dedication from each and every OPD to ensure that the Union would be finally registered. This started by collectively developing suggestions on how the Union would operate and setting the policies that were to govern the Union. The overall situation in South Sudan and other external factors also interrupted or slowed down the process several times. Thus, over the years, the process went through several iterations, which was in a way helpful as it allowed revision of suggestions and creation of broader ownership among the member organisations.

### **Lesson 2: Legal guidance, formalisation and professionalisation**

Light for the World engaged a legal consultant who worked directly with SSUPD officials. This enabled them to understand their mandate as it relates to South Sudan law and ensures that the Union operates within the law and does not accidentally engage in illegal activities that can jeopardise the operation of SSUPD and its members. The legal consultant guided the development of bylaws and policies of the Union, based on the suggestions of members. He advised them when they proposed processes or practices that may conflict with the legal requirements, thus making the bylaws compliant with South Sudan Law.

Member organisations were supportive and willing to work together with the legal consultant and other experts during this important exercise. They were ready to learn and were keen to consider the advice provided.

Over the following years, other partners contributed to the journey of professionalisation and enabled SSUPD to have an office space, a growing number of staff members and to develop a strategic plan.

### **Lesson 3: Appropriate resources and diversified expertise**

Light for the World provided both financial and human resources to support the capacity development process of Union officials, member organisations and SSUPD. The support provided took different forms and was given by engaging various experts, staff members, and a volunteer. Light for the World organised formal training, consultancies for the capacity assessments and the legal support and allocated staff time for mentoring Union officials, as well as providing on the job training. The examples show that it is also important to draw knowledge and expertise from different sources. The involvement of a Dutch volunteer was helpful because he could speak from his own experience of contributing to the formation of a disability movement and he came in with time and personal motivation to build a strong relationship with the individuals concerned. While the legal consultant could share his very distinct expertise, with time, the SSUPD could further diversify and broaden the support they are receiving by engaging with other partners.

The variety of methods and persons involved enabled an environment for SSUPD members and officials with different working, communication and learning styles to take up guidance and advice.

### **Lesson 4: Supporting on individual and organisational level**

The support provided was directed to different levels of SSUPD:

- 1. On individual level,** DIFs, thus young persons with disabilities themselves, benefited from distinct training and mentoring which increased their knowledge and facilitation skills to create collaboration among OPDs, funding and mainstream organisations. Also, volunteers, board, and staff members of the member organisations and SSUPD participated in training, mentoring and coaching sessions.
- 2. On organisational level,** Light for the World provided capacity strengthening support to the member OPDs and SSUPD. Thus, both member organisations and the Union were strengthened, mainly in the areas of communications, advocacy and financial management.
- 3. On system level,** the external environment was also influenced. The advocacy and awareness raising work towards society and key stakeholders created an increasingly favourable environment for disability inclusion and for the recognition of OPDs. This in turn had a positive effect on SSUPD and its member organisations.

## Lesson 5: Government involvement and support

Government officials were willing to support the advocacy of persons with disabilities. For example, the foundation of the Union was backed by the Ministry of Gender, Child and Social Welfare and the Relief and Rehabilitation Commission. Through these government entities the Union was registered and ensured its legal recognition, which in turn contributed to its overall legitimacy for representing the rights and interests of persons with disabilities in South Sudan.





## 6. Conclusion and outlook

The case study demonstrates that creating and formalising collaboration among persons with disabilities and the organisations representing them, has a very positive impact on the advocacy efforts and the disability movement in the country. Yet, persons with disabilities in South Sudan still experience marginalisation and their rights are very often neglected. Despite significant advocacy achievements during the past years – notably the ratification of the CRPD – the promotion of rights of persons with disabilities still needs to continue. With this aim in mind, the disability movement and OPDs will need to grow further.

SSUPD also recognised that OPDs on sub-national level are often not officially registered and thus cannot yet become full members of the Union. Thus an effort will be made to formalise the whole sector.<sup>20</sup> SSUPD's strategic plan also lays out a vision of further growth and structural development, including expanding the team of the Executive Secretariat.

**For the period to 2026, SSUPD has identified the following thematic areas as priorities:**

- ▶ Advocacy and lobbying
- ▶ Economic empowerment
- ▶ Inclusive education
- ▶ Food security and livelihood
- ▶ Health care and support<sup>21</sup>

Light for the World, alongside a growing number of other partners, is committed to continue supporting SSUPD in their efforts.

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State-level OPDs: Jubek State Union of the Physical Disabled, Equatoria State Association of Deaf, Jubek State Association of People affected with Leprosy, Jubek State Union of Visually Impaired
- 14 SSUPD (2021) Annual Narrative Report, 2020, Project 'Make it Ourselves'
- 15 SSUPD (2022b) Strategic Plan 2022-2026
- 16 SSUPD (2022a) Report on South Sudan Union of Persons with Disability General Assembly (GA)
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- 20 SSUPD (2022a) Report on South Sudan Union of Persons with Disability General Assembly (GA)
- 21 SSUPD (2022a) Report on South Sudan Union of Persons with Disability General Assembly (GA)



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