

Making it count:

The power of youth advocates in the disability movement

Impact, learning and recommendations from 2030 and Counting



Acknowledgements

This report is authored by Leonard Cheshire and funded by Open Society Initiative for Southern Africa (OSISA). It was produced as part of the pilot evaluation for Leonard Cheshire's 2030 and Counting programme.

The report was led by Dr Ola Abu Alghaib (Director, Global Influencing and Research) and was written by Susanne Wilm (Consultant) and Phil Hanks (International Partnerships Manager). Lucy Bentley (Writer and Editor) provided support with editing and finalisation.

We would like to thank the following individuals and organisations who were instrumental in the project's delivery and who provided feedback for this report:

- 2030 and Counting lead reporters and citizen reporters from Kenya, the Philippines and Zambia
- Action Network for the Disabled (ANDY)
- Leonard Cheshire Disability Philippines Foundation Inc. (LCDPFI)
- Zambia Federation of Disability Organisations (ZAFOD)
- Cainta, Rizal Federation of Persons with Disabilities
- Polomolok Association of Persons with Disabilities
- On Our Radar

We would also like to thank the following individuals and collaborating organisations who joined our implementing partners and lead youth reporters for the project's evaluation workshop in March 2019:

- Youth with disability ambassadors from India and Norway
- European Disability Forum (EDF)
- Include Me TOO

Making it count:

The power of youth advocates in the disability movement

Contents

1. Youth with disabilities: Why a seat at the SDG table matters	4
2. 2030 and Counting: How the project worked	6
3. Project snapshot: Facts and figures	8
4. Reflecting on the methodology and achievements	10
5. Key learnings from the project	25
6. Recommendations for future project design	28

1. Youth with disabilities: Why a seat at the SDG table matters

In 2016, the 2030 Agenda for Sustainable Development officially came into force. Its 17 Sustainable Development Goals (SDGs) and 169 targets call for action to achieve sustainable development for all, ensuring that no one is left behind. This focus presents an important driver for the inclusion of youth with disabilities in development processes. It highlights the importance of listening to their voices and responding to their needs.

The 2030 and Counting pilot project sought to give youth with disabilities a seat at the table on the SDGs – providing them with the tools and confidence they need to become their own agents of change. This report provides an overview of the project, together with learnings and recommendations for the future.

The 2030 Agenda and its SDGs are distinctly different from their predecessors, the Millennium Development Goals (MDGs). Whereas the MDGs remained silent on disability, the SDGs include 11 references to persons with disabilities and disability. These include targets related to the areas of poverty eradication, education, employment, reducing inequalities, sustainable and inclusive cities and peaceful and inclusive societies. In addition to disability-specific indicators, the global monitoring framework has also included an overarching principle of data disaggregation by disability.

The Agenda's core commitment to **'leave no one behind'** emphasises that the SDGs cannot be achieved unless they are met for **everyone** – young women and men with disabilities included. But all too often, they fall through the cracks.





A lack of data regarding their situation makes it harder for stakeholders such as Disabled People's Organisations (DPOs) to identify the key issues youth are facing and effectively advocate for their interests.

Youth programmes practice little disability inclusiveness, and disability programmes do not often target youth with disabilities.¹ Mainstream development programmes also rarely include or target youth with disabilities. They are often left out of civic opportunities and advocacy efforts. Only a few DPOs have organised systems of youth groups or offer targeted training. Youth with disabilities are rarely brought in to represent the voice of young women and men with disabilities, or given leadership training.

The underrepresentation of youth with disabilities from the development, youth and disability agenda and within DPOs leaves young women and men with disabilities in a particularly vulnerable place, and often without the means of raising and advancing their interests.

The SDGs and the historic commitments on disability inclusion in the 2030 Agenda present a huge opportunity to highlight and address the challenges that youth with disabilities are facing. At the same time, the implementation of the SDGs offers vital space for their participation in related planning, decision-making and monitoring processes that transform the SDGs into action.

Youth with disabilities have the potential to be strong agents of change. This is especially true with the potential of social media and other internet-driven tools for civic participation to affect the governance of social and political bodies and stakeholders. Having a seat at the table on the SDGs will give young women and men with disabilities the power to have an impact on their communities, their own lives, and that of future generations.

2. 2030 and Counting: How the project worked

In its pilot year, 2030 and Counting brought together young women and men with disabilities and DPOs from Kenya, the Philippines and Zambia to report on and advocate for their rights through the framework of the SDGs.

The project focused on realising the potential of youth with disabilities by empowering them to see themselves as experts of their own experience. The aim was to bring a deeper understanding of the challenges they face in selected SDG areas and make their voices heard.

The 2030 and Counting pilot was implemented between January 2018 and March 2019. It supported youth with disabilities in monitoring national commitments on disability and the SDGs through technology and social media, in close cooperation with DPOs.

The overall objective of the pilot was to 'strengthen the role of young people within the disability movement to monitor and advocate disability inclusion within SDG planning through the use of technology'.

The pilot tested an approach that combined grassroots communication training and an accessible mobile reporting system. This enabled a network of community reporters to collect constituent perspectives, providing insights that informed advocacy and peer support. It used the commitments of the SDGs as a way for youth with disabilities to frame their experiences and hold governments accountable.

The project placed youth with disabilities at the heart of issues affecting their lives by developing them into agents of social change. A core component of this was delivered through a youth-led approach, empowering youth with disabilities to identify issues important to them and link them to the 2030 Agenda. Youth with disabilities would decide which SDGs the project should focus on; learn through peer-to-peer cascaded training; design and lead their own community action plans; and present their own findings to decision-makers alongside DPOs.

The overall objective of the pilot was to 'strengthen the role of young people within the disability movement to monitor and advocate disability inclusion within SDG planning through the use of technology'.

This was broken down into six key sub-objectives:

- 1. Engage a diverse range of youth with disabilities in SDG monitoring**
- 2. Build the confidence and leadership capabilities of youth with disabilities**
- 3. Connect youth with disabilities to the disability movement**
- 4. Maximise the role of technology in data collection**
- 5. Generate evidence on the situation of youth with disabilities**
- 6. Strengthen the advocacy capacity of DPOs and youth with disabilities**

The project was a cooperation between Leonard Cheshire, the UK-based communications and technology agency On Our Radar, and two national DPOs – Action Network for the Disabled (ANDY) in Kenya and the Zambia Federation of Disability Organisations (ZAFOD). In the Philippines, it was implemented by Leonard Cheshire Disability Philippines Foundation Inc. in cooperation with two local DPOs (Cainta, Rizal Federation of Persons with Disabilities and Polomolok Association of Persons with Disabilities), in the absence of a national umbrella DPO.

The project had three consecutive phases:

Phase 1: Training

Phase 2: Story gathering (data collection)

Phase 3: Influencing

Phase 1 focused on the mobilisation of youth reporters; prioritisation of SDGs; the design and delivery of a training of trainers session; cascaded training on the 2030 Agenda, mobile multimedia reporting and advocacy skills; and the set-up of a reporting hub that captured the reported content.

Phase 2 involved the collection of data by youth reporters on the barriers, challenges and opportunities that youth with disabilities face in the areas of health, education and employment. Content analysis was then carried out by DPOs and youth with disabilities at a national level, and by Leonard Cheshire at a global level. This was in order to identify key themes and powerful stories for social media.

Phase 3 rounded off the pilot with the preparation and dissemination of advocacy messages and tools; the delivery of national advocacy events; and social media activity. Social media activity happened throughout the project but was at its height in the final phase.



3. Project snapshot: facts and figures

Phase 1 – Training

- Five youth with disabilities² and three DPO representatives³ attended the initial four day training of trainers session in London in March 2018 to become lead reporters.
- Between May and September 2018, five cascaded training workshops and a further five refresher training workshops were delivered by lead reporters.
- A total of 67 youth with disabilities across the three countries received this cascaded training from the lead reporters.

	Reporters receiving cascaded training	Reporters submitting reports	% dropped out
Kenya	26	21	19%
The Philippines	23	20	13%
Zambia	23	18	22%
Total	72	59	18%

Figure 1: Number of lead reporters engaged after cascaded training and data collection phases

Phase 2 – Data collection

- In total, 332 reports were collected between June and September 2018.
- The highest number of reports were submitted under the theme of Education (44%), followed by Work (33%), and Health (14%). The category of Other, which almost entirely focused on discrimination in daily life, accounted for 8%.⁴
- 80% of reporters had smartphones,⁵ offering the potential to increase the use of this feature in future.

	Kenya	The Philippines	Zambia	Total
SDG 3: Good Health	22	N/A ⁶	24	46
SDG 4: Quality Education	45	58	45	148
SDG 8: Decent Work	36	63	10	109
Other	5	10	14	29

Figure 2: The number of reports submitted by country and theme

Phase 3 – Advocacy

- Six key advocacy events were organised for 30 policy makers across the three project countries.⁷
- A UK parliamentary reception was hosted by lead citizen reporters in the Houses of Parliament to coincide with the evaluation workshop of the project.
- By the end of April 2019, #2030andCounting had more than 300 mentions on social media, including by the Chair of the UK’s International Development Select Committee, Stephen Twigg MP (Figure 3).
- Over 200 print copies of a global report⁸ were disseminated, that set out key priorities identified by youth with disabilities and DPOs in all three pilot countries.
- A documentary series ‘Missing Voices’ was launched by Leonard Cheshire, highlighting the experiences of six youth with disabilities in their own words.

Figure 3: An example high-profile social media post



4. Reflecting on the methodology and achievements

The project addressed various factors: poor policy implementation for youth with disabilities in relation to the SDGs; limited evidence and capacity of DPOs to engage in disability-related monitoring and influencing; a lack of opportunities for youth with disabilities to become change agents; and the opportunities that technologies offer in relation to participation and accountability. Planned as a pilot, it produced a wealth of results and lessons learnt.

1. Engaging a diverse range of youth with disabilities in SDG monitoring

The project was successful in enabling a range of youth with different disabilities to participate and significantly increased understanding of the SDGs.

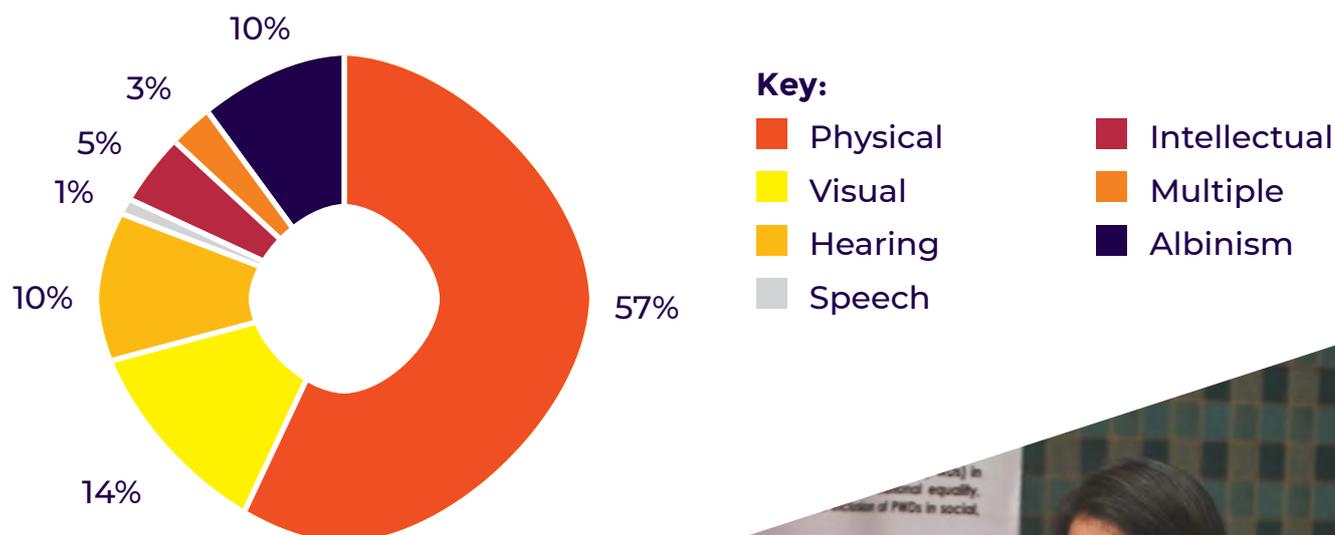
The majority of participants (57%) had a physical disability. Other types of disability, especially those with intellectual disabilities, were less represented in the group of reporters.

More than 50% of participants were female, bucking the trend when it comes to the participation of young women with disabilities in training or leadership opportunities.⁹

	Female	Male	Total
Kenya	15	11	26
The Philippines	14	9	23
Zambia	11	12	23
Total	40	32	72

Figure 4: Sex of reporters by country

Figure 5: Distribution of disability across the cohort of reporters



a) Participant diversity

It was not surprising that persons with physical disabilities accounted for the majority of reporters as this group already enjoy greater levels of participation compared to other youth with disabilities, such as those with intellectual impairments.

The experience highlighted a number of factors that are important in order to make sure there is a balanced representation of different disabilities, and those that are most marginalised. For one, sufficient time needs to be allocated to allow for the identification and mobilisation of youth with different disabilities, especially those that are hard to reach.

Furthermore, recruitment and mobilisation strategies need to be more diverse in order to be inclusive and accessible. Online advertisements may be complemented by other means such as direct contact and cooperation with different organisations that work for or represent persons with different disabilities.

Existing networks were predominantly used. However, there were some



examples of reporters creating links with new DPOs. For example, in the Philippines, the lead reporters reached out to a Hard of Hearing network which supported recruitment of youths from this network, which in turn increased the number of Hard of Hearing youth sharing their experiences to reporters.

Bringing together youth with disabilities to form advocacy groups provided space for them to meet and interact. Through this, the project created a notable spillover effect: working together has significantly increased the mutual understanding among the youth reporters for each other's disabilities, the challenges they face and their related needs.

b) Knowledge and understanding of the SDGs

The knowledge and understanding of the 2030 Agenda and the SDGs was limited among the majority of youth reporters at the time of recruitment. Youth with disabilities have been largely sidelined or left out of related policy formulation, implementation, and the monitoring of various disability and other laws and policies in their countries.

Through the engagement of youth with disabilities in SDG monitoring, the reporters deepened their understanding of advocacy and the SDGs. Youth reporters realised the importance of being self-advocates to address their concerns, which they felt are left out in the inclusion debate, in “a language that they understand”.

By the end of the project, 94% of reporters strongly agreed they knew a lot about the SDGs, compared to 17% at the start of the project.



“ In the past persons with disabilities, especially youth with disabilities, could not actively participate in the monitoring of government commitments, but we are excited that this project enabled youth with disabilities to speak out boldly and be active agents of the change that they want to see. ”

ZAFOD representative

“ It was important for the youth to understand the SDGs for them to be able to report. They had to engage and use the SDGs as reference which was quite inspiring and useful for future advocacy work. ”

ANDY representative



% of participants who strongly agreed with the following statement:

I know a lot about the Sustainable Development Goals



2. Building the confidence and leadership capabilities of youth with disabilities

Until this pilot, youth with disabilities were not represented or visible in disability advocacy across the three project countries. Just over a quarter (27%) of reporters told us at the start of the project they felt confident to share their experiences with influential people in their community.

The youth-led approach within the project ran participatory training and a supported environment within the DPO structure which positioned youth with disabilities as experts in their own experience.

This, coupled with project phases which allowed the space for youth with disabilities to make decisions about the project's implementation in their own community, had a positive impact on youth with disabilities' belief in their ability.

In each country, a small number of youth with disabilities were recruited to be lead reporters. This provided a leadership pathway for those youth with disabilities who had already had some engagement on disability rights issues.

The two roles – of reporter and lead reporter – enabled the project to highlight youth with disabilities who would benefit from extra responsibilities and become positive role models, but also not exclude others with less experience.

The small number of drop outs which happened between training and submitting reports (18% overall – see facts and figures page 8) was largely attributed to a lack of time to effectively commit to the project. A range of reasons were cited for this including changes in medical circumstances, family commitments and/or study schedules. Follow-up with these youths was important to ensure there was

no perceived lack of failure to complete the project because, as training recipients, they will be able to use their new skills in whatever they do next. On the whole, youth reporters became excited at the opportunity to share their stories and contribute their own perspective; they evolved throughout the project and in the Philippines even exceeded their story targets. They motivated other youth with disabilities to share their experiences (eg in accessing education or employment) through social media.

Including a social media component in the project, which most youth with disabilities are familiar with and use regularly, helped the transition into the advocacy phase.

Not only did social media help make the connection between real-life experiences and advocacy, it provided peer support and motivation through the online networking groups (both within and between countries).

“ The 2030 and Counting project has transformed the youth with disabilities reporters from ‘complainers’ to advocates. They are now actively speaking out about issues and also involved in providing solutions on issues affecting them. ”

ANDY representative

% of participants who strongly agreed with the following statement:

I feel confident to share my experiences with influential people in my community

Before 2030 and Counting



27%

After 2030 and Counting



86%

“ They [youth reporters] have engaged with local persons with disabilities federations and Disabled People’s Organisations (DPOs) while looking for respondents. ”

LCDPFI representative

“ Power to the people! It [2030 and Counting] has given us a platform to speak for ourselves. ”

Youth reporter, Kenya



3. Connecting youth with disabilities to the disability movement

DPOs and youth with disability leaders together are strong influencers in advocating for the rights of persons with disabilities. Establishing successful linkages between these two was an important aspect of sustainability for this project, ensuring support for their concerns and opportunities to engage in related advocacy beyond the project lifetime.

During the project period, both partner DPOs kept close contact with the youth reporters. Regular meetings ensured follow-up and provided the opportunity to receive updates on the number and type of stories, and discuss feedback on the submitted reports and the performance of individual reporters. In addition to the partner DPOs, some youth reporters also engaged with additional local DPOs in their communities to identify interviewees.

Over the project period, a strong bond developed between the youth reporters and the DPOs. All implementing DPOs and partners are continuing their work with the reporters beyond the project period.

In Zambia, the Federation will continue working with the youth reporters in their disability advocacy work, in order to strengthen their voice. In Kenya, ANDY will work with the youth reporters among others on a future research project that looks into employment opportunities for youth with disabilities, and enlist them as members of the organisation. They continuously engage them in their advocacy activities, for internship opportunities and to represent the organisation in relevant (policy) processes and events to provide input (eg the current review of the National Youth Policy).

The development of youth with disabilities' leadership during the stages of the pilot led by DPOs also cemented the belief among DPOs that youth with disabilities telling their stories in their own voice is more powerful than stories told on behalf of youth with disabilities.

However, the motivation of some reporters fluctuated due to the lack of stipend available for reporters. The importance of financial incentives became apparent in all countries to maintain motivation and should be revisited in future projects. One implementing partner distributed certificates and awards to the reporters to acknowledge their work.

Due to the high transport costs for the participants (many reporters required accessible transport), it was challenging to bring all youth reporters together on a regular basis.

“ The introduction of working with youth with disabilities has taught ZAFOD that youth with disabilities are experts of their own lives and their voices are important in the development process. ZAFOD now believes that self-advocacy is more appropriate and effective as compared to other people, that are not really affected, talking on behalf of youth with disabilities. ”

ZAFOD representative

In order to address this situation, one DPO established a WhatsApp group. However, this did not prove effective as a platform for group discussion and dissemination of information because of access barriers, for example for persons with visual impairments.

The cooperation with DPOs opened up opportunities for youth with disability engagement with policy and decision makers to share the challenges and issues that emerged from the real-life stories. In Kenya, for example, they attended a parliament hearing and had the chance to speak with state actors.

“ The youth reporters are continuously being engaged within ANDY for internship opportunities and representatives of the organisation in forums and workshops which require youth voices to contribute as well as offer their input in policy changes or realignment. ”

ANDY representative

% of participants who strongly agreed with the following statement:

I feel my voice is an integral part of the disability movement in my country



4. Maximising the role of technology in data collection

The technology component was highly successful in allowing youth with disabilities with a range of devices – from smartphones to the most basic handset – to participate.

On Our Radar's communication platform acted as a single, adaptable tool that turns even basic mobile handsets into broadcasting tools, without the need for credit or data. While 80% of participants owned a smartphone, 20% used a basic handset (especially in Zambia) or did not own a phone at all and submitted their content through a family member's phone with permission.

For the youth reporters, using mobile phones proved a quick and accessible way to gather information in real-time. The youth reporters used mobile phones to collect data and send it to a reporting hub. The reporting hub received reports in all formats (text, voice and video reports).

However, the vast majority of youth with disabilities chose to report via text. Given the potential to tell compelling stories through film, this component will need to be strengthened in future projects.

Aside from poor internet connectivity in some rural areas, the only technical problems related to the sending of videos, audio and some minor issues with the reporting hub (eg the reporting hub not consistently sending auto-replies to confirm receipt of reports).

The flexibility for reporters to either use the text and voice functions on a mobile handset or download an App and report through a smartphone was an important aspect. The project experience also showed that the App can be used by persons with different disabilities. Many reporters used the smartphone accessibility features for persons with visual or hearing impairments. But the technology can also be adapted to make it accessible for different needs, as the code design process is flexible. The collaborative process during the scoping and design phase involving participants, partners and On Our Radar was of great importance in this regard, in order to understand the users and their needs.

So was the close monitoring to identify challenges that the reporters may face. Partner DPOs realised the key role and use of technology in gathering evidence to influence policy and bring about change. In fact, there is interest in relevant knowledge transfer to develop their own App.



Number of reporters with a smartphone: 80%

Number of reporters who did not own their own phone: 3%

“ At an organisational level, ANDY has realised that the use of technology is key in gathering stories which influence policy changes. The App is useful as it can be used by all types of disabilities as well as all types of phones. ”

ANDY representative



5. Generating evidence on the situation of youth with disabilities

SDG 17 focuses on global partnerships and includes a target on increasing the availability of data and statistics and related capacity development.¹⁰

In this regard, the project has greatly strengthened the evidence base around disability across all three project countries and the partner DPOs. The project facilitated the collection of stories that had never been told or given attention before. It provided vital evidence about the realities of youth with disabilities in their local communities in the areas of health, education and employment.

The findings revealed a lack of implementation and monitoring and evaluation frameworks for progressive policies, as well as gaps in government policies and practices with regards to disability inclusion (eg inaccessible sexual reproductive health services and schools). The evidence and related tools (one global report and national reports for each country) have been taken up and informed various actors.

The evidence-based report on the situation of youth with disabilities really strengthened the position of the DPOs. All DPO partners have incorporated the data into their other ongoing advocacy projects and programming, ensuring impact of the data beyond the project period. Together with the nation-specific reports they offer a vital basis when addressing policy makers to promote the rights of youth with disabilities and their inclusion in SDG-related programmes and processes.

However, they are also using the project findings in other areas: In Zambia for example, ZAFOD will be providing training on disability inclusion for health personnel and sharing the results of the 2030 and Counting project with the participants. They are also using the information to add a strong evidence-base to their funding proposals. Moreover, the pilot's cascaded training developed the capacities of youth reporters and DPOs to develop and implement data collection plans and strategies, which they will benefit from far beyond the project lifetime.

The partner DPOs have also shared the information with other advocacy organisations including DPO affiliates in their countries, which helped to generate a broader support base on the various advocacy points that emerged from the data and drew attention to the situation of youth with disabilities. In Zambia, the report has also already been used by researchers as secondary data for a disability research project.



As far as government actors and other stakeholders are concerned, the stories that were drawn out from the pilot project served as an eye opener. The presentation and discussion of the project and the findings increased the awareness of the situation of youth with disabilities among the target audience across all three countries.

The feedback so far revealed a great interest in the results. Government representatives realised that the number of issues that youth with disabilities face is larger than anticipated and that they are lagging behind in realising the commitment of the 2030 Agenda to leave no one behind for youth with disabilities. In Zambia, the presentation of the findings has already sparked the motivation of government officials to mainstream disability back in their departments. As the partners in the Philippines acknowledge, the information may serve as reference for policy makers in drafting or amending policies and legislation, making them more responsive to the needs of youth with disabilities. Youth reporters were invited to the biennial Philippines Youth Parliament to share initial findings from the project in the form of draft bills.

The whole process, and being involved in the way DPOs operate to achieve their objectives, impressed upon youth with disabilities the importance of evidence-based influencing. In addition, the emphasis on qualitative data, in the form of stories told directly by youth with disabilities, had a profound impact on their understanding of, and motivation to highlight, the range of issues facing youth with disabilities in their community.

“ The stories that were drawn out from the pilot project have served as an eye opener among government agencies and other stakeholders to raise their awareness on various issues of persons with disabilities. This made them conscious now of the need to revisit the implementation of existing laws, policies, programs and services for persons with disabilities. ”

LCDPFI representative

% of participants who strongly agreed with the following statement:

I am very aware of the issues affecting persons with disabilities in my community

Before 2030 and Counting



36%

After 2030 and Counting



100%

“ We learnt that advocacy based on evidence is crucial. ”

Youth reporter, Zambia

“ The project has helped us to collect evidence for our advocacy work in that it has uncovered a number of concerns and irregularities in the way government policy is being implemented. ”

ZAFOD representative



6. Strengthening the advocacy capacity of DPOs and youth with disabilities

DPOs and implementing partners unanimously highlighted that the project strengthened their profile and overall role in advocating for the rights and inclusion of persons with disabilities in their countries.

The experience provided them with important insights into youth-led programming and the effectiveness of self-advocacy for youth with disabilities. It also added a vital perspective to their influencing work. They learned about the impact that real-life stories can have in advocating policy change or implementation, and the advantages of using technology in the collection of such information.

Having involved a broad range of state and non-state actors in their activities, as well as using various means to communicate the project findings and methodology (print reports, social media, TV, meetings and advocacy events), DPOs' visibility has considerably increased over the course of this pilot. They are now recognised for the evidence they generated and their work with youth with disabilities within the disability movement, government and wider civil society. This has led already to consultations and engagements on related issues, such as employment for youth with disabilities and inclusive policy development.

“ The stories have also been shared with other advocacy organisations, including the ZAFOD affiliates, so that we can have a united voice in engaging government on the various advocacy points. ”

ZAFOD representative

The DPOs and youth reporters involved a broad range of ministries in the national advocacy events¹¹ and other activities to present the project and discuss the pilot's findings. However, the project extended the DPOs' scope in particular with regards to the 2030 Agenda and SDG monitoring, which they have not been involved with before. As a result, they are now engaging with relevant stakeholders (eg the Ministry of National Development Planning in Zambia) and processes (for example ZAFOD was nominated to become a member of the Sector Advisory Group at the Ministry of National Planning and Development).

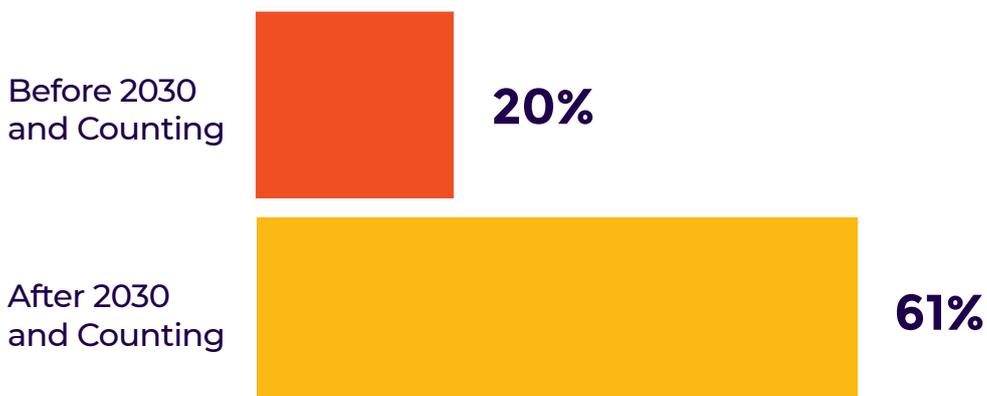
Having the evidence base and subsequent reports really strengthened the position of the DPO partners in their advocacy. For example, ZAFOD in Zambia works with the Ministry of Health on how to make their health programmes more inclusive for persons with disabilities. The evidence base has also been shared with other organisations to further strengthen the disability movement's united voice.

“ ANDY has advanced its profile in the national disability movement and civil society thus leading to consultations and engagements, especially on issues of youth with disabilities, like in youth with disabilities employment and disability friendly policies development and enactment. The country is now reviewing the National Youth Policy and ANDY is ensuring that the citizen reporters are attending the meetings. ”

ANDY representative

% of participants who strongly agreed with the following statement:

I have the necessary skills to advocate for the rights of persons with disabilities



DPO partners have already identified a range of opportunities to continue their engagement for and with youth with disabilities and SDG monitoring. In Kenya, ANDY is launching an inclusive employment consortium project, and plans to organise a roundtable to present their national 2030 and Counting report further. In Zambia, ZAFOD is planning, for example, further engagement with the Ministry of Finance to discuss the inclusion of DPOs and youth with disabilities in the development of national budgets and the budget tracking for disability programmes.

“ This project has increased ZAFOD’s engagement with policy makers tremendously. ZAFOD developed a Memorandum of Understanding with the Ministry of Health after a number of advocacy meetings... The 2030 and Counting project has enabled ZAFOD to have more evidence to share with the ministry on the challenges that youth with disabilities are currently facing in accessing health services. ”

ZAFOD representative

“ Youth with disabilities were motivated and empowered even more because of new ideas and perspectives drawn out from the real-life stories of respondents. ”

LCDPFI representative

5. Key learnings from the project

2030 and Counting was planned as a pilot and generated vital lessons learnt for future programming:

Recruitment of youth with disabilities

- Existing networks were predominantly used to recruit project participants. While some new partnerships were established, the project highlighted a need to engage more organisations which hold strong relationships with marginalised youth with disabilities.
- The lead reporter group was not a fully representative group of different types of disability (almost entirely youth with physical disabilities). This may have been a factor in why more diverse channels of youth with disabilities were not as well established.
- Creating two distinct roles, that of reporter and lead reporter, was effective in creating leadership roles for youth with disabilities with previous engagement on disability rights issues, while also not excluding youth with disabilities with less experience.

Training

- Training schedules should remain flexible – some countries preferred to hold the two-day cascaded training on consecutive days; other groups preferred to hold them on non-consecutive days. In both contexts these approaches were the best way to ensure full participation of all reporters in all parts of the training.
- Finding a suitable venue to meet all accessibility needs at low cost was difficult. For example, in Kenya they found a building with enough space and with ramps for those in wheelchairs, but it did not have accessible toilets.
- It is important to make sure that training materials are accessible for all participants throughout the learning journey.
- Simulation exercises, for example on interviews, were incredibly valuable. These should be expanded to include rapport-building and networking with duty bearers.
- The training provided space for youth with disabilities to meet and interact and learn from each others' disabilities and challenges. It is important this is facilitated in addition to core training content.

Data collection

- Transport around the community was difficult for youth with mobility problems. Public transport was often not accessible and/or budget was not sufficient for those with personal assistants.
- How translation services will be provided needs to be considered further. Translation of stories from Tagalog to English in the Philippines was time consuming. In Kenya and Zambia all youth reported in English. If the project was to reach some of the most marginalised youth with disabilities it was felt some people would prefer to tell their stories in their mother tongue (eg Swahili in Kenya; Tagalog or Visayan in the Philippines; or Nyanja or Bemba in Zambia).
- Strong rapport-building with interviewees and wider community is essential. Some reporters were denied access to schools and hospitals in order to carry out reporting as there was mistrust or a lack of understanding of the project. Some respondents had a cynical view of mainstream media and needed to understand how their stories would be used.
- It is important to define which communities and geographical areas are being included in the data gathering as it will impact on available budget.
- The most productive data collection activities materialised from reporters who had prior communication with interviewees and set up a specific time and date to gather their stories.

Advocacy

- Governments in all countries were receptive to the project's work. However, securing appointments with government officials was challenging because of already full diary schedules.
- The date of the national advocacy event was delayed in two of the three pilot countries because of lack of availability of the relevant policy makers. However, in some instances, the Ministers did not attend the events in person but sent representatives.
- There was little engagement with mainstream organisations dealing with the SDGs. This was partly due to capacity and partly due to a lack of interest from external organisations. This is something that could be strengthened further.

Technology

- While the reporting hub received reports in all formats – text, voice and video reports – the majority of youth with disabilities chose to report via text.
- Equally important was a close follow-up to ensure the timely identification of possible barriers to usage onsite.
- All partners had limited experience of using digital advocacy tools. Supplementary user manuals could support partners to maximise engagement.

Timeframes

- The three cycles of the pilot – training, data collection and influencing – were completed within a 12 month period.
- The typically short timeframes of a pilot did not provide ample planning and coordination for key objectives of the project. In particular this affected the recruitment of diverse groups and ensuring a wide range of key stakeholders at advocacy events.
- Regular refresher trainings boosted confidence, tracked progress and provided further technical assistance for youth reporters to fully understand the issues.
- It should be factored in that more training time may be needed for persons with different types of disabilities, in particular for those with visual or learning disabilities.
- Policy changes and influencing require long-term advocacy strategies and commitment, which exceeded the scope of the pilot project.

Methodology

- The methodology worked very well in bringing information on the situation of youth with disabilities in their local communities from the field to the surface, turning their experiences into expertise.
- The methodology proved to be an easy and accessible way for youth with disabilities to communicate their needs.
- This community-led approach that empowers marginalised groups to reveal key issues as they experience them was new for all three pilot countries. As such, it really filled a gap for youth with disabilities who, so far, have been largely invisible in disability advocacy work in all pilot countries.



6. Recommendations for future project design

There is a consensus among all involved that this pilot has been very rewarding and successful and needs to be scaled or extended. The joint reflection of this experience generated the following recommendations:

Promoting a diverse cohort of youth reporters

In order to promote a balanced representation across different types of disabilities, it is important to:

- Recruit a more diverse range of lead citizen reporters to be more representative of the larger cohort.
- Employ a broader range of recruitment strategies to maximise outreach (eg social media, online advertising, working with different organisations that represent different disabilities).
- Allocate sufficient time to build relationships with organisations that can support the identification of harder to reach youth with disabilities.

Maximising the effectiveness of the youth reporter training

In order to maximise the effectiveness of the preparation for all youth with disabilities, it is important to:

- Accommodate the needs of those groups that may need more training time, such as youth with intellectual disabilities.
- Provide the instructional materials in accessible formats (eg Braille or audio).
- Enhance the training of the reporting hub for youth with disabilities and DPOs to make greater use of the content, including more real-time reporting.
- Include more simulation exercises for the interview situation.
- Consider including field visits of partners to provide technical support onsite.

Remunerating the efforts of the reporters

Youth reporters committed significant time to help deliver on this project. In order to maintain their motivation, it is important to:

- Provide allowances for lead reporters as a minimum.
- Increase the transport allowances to facilitate the story collection and follow-up.

Increasing the engagement of policy makers

Maximising the time spent with duty bearers is crucial to ensure the project's findings are used effectively. To support this the project should:

- Set up meetings with policy makers before the cascaded training to share information on the project and ensure 'buy-in'.
- Schedule follow-up meetings with representatives from ministries who attend events to ensure actions are taken.

Extending the scale, scope and reach of the project

The pilot experience highlighted several opportunities to extend the scale, scope and reach of future projects:

- Deliver the project in more rural areas.
- Extend the timescales for projects to a minimum of two years, in particular to provide more time to work with the results and develop advocacy strategies.
- Explore the potential for the inclusion of other SDGs in new projects based on the priorities identified by youth with disabilities and DPOs.
- Build further on the networks formed through Leonard Cheshire's Young Voices programme, which operated in 23 countries.



References

- 1 Groce, N. & Kett, M. (2014). Youth with disabilities. Leonard Cheshire Disability and Inclusive Development Centre working paper series no. 23. London: LCDIDC.
- 2 Two participants from Kenya, two from the Philippines, and one from Zambia.
- 3 One participant from Kenya, one from Zambia, and one from a Southern African DPO (in the absence of a national umbrella DPO in the Philippines, the local Leonard Cheshire office acted as implementing partner but did not attend the training).
- 4 The number of Health reports was lower in part due to only two of the three countries choosing this as a focus area.
- 5 47 of 59 youth with disabilities who submitted reports.
- 6 The Philippines group decided to focus on SDG 4 and SDG 8 as the most important issues to them.
- 7 Attendees included those from Councils on Disability Affairs, Ministries of Health, Education, Social Welfare or Development, as well as representatives from several non-governmental organisations (NGOs) and the private sector.
- 8 Available at www.leonardcheshire.org/our-impact/our-international-work/youth
- 9 Available at www.gpcwd.org/uploads/2/6/0/9/26097656/global_mapping_exercise_and_needs_assessment_report.pdf
- 10 17.18 By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts.
- 11 For example: Ministry of Health, Ministry of Education, Ministry of Gender, Youth and Social Services in Kenya; Ministry of Community Development and Social Services, Ministry of Education, Ministry of Health, Ministry of Labour and Social Services and Ministry of Finance in Zambia; National Council on Disability Affairs, Commission on Higher Education, and Department of Social Welfare and Development in the Philippines.

**Leonard
Cheshire**



Leonard Cheshire

International department
66 South Lambeth Road
London SW8 1RL

+44 (0)20 3242 0200
international@leonardcheshire.org
leonardcheshire.org/international

Published May 2019

Leonard Cheshire Disability is a registered charity no: 218186 (England & Wales) and no: SC005117 (Scotland),
and a company limited by guarantee registered in England no: 552847.
Registered office: 66 South Lambeth Road, London SW8 1RL