

Shaban : Promoting participation – *and how to achieve it*

This is an independent informal paper outlining some of the lessons learned, and good practices in advancing the participation and leadership of persons with disabilities, and other disadvantaged groups, within the disability sector.

It particularly focuses on experience and reflections in promoting OPD engagement and participation as a mid-tier manager, and what can be done systematically to promote genuine partnerships and meaningful participation **within an organisation**, and how this can promote effective participation **outside the organisation** to ensure the full implementation of the UN Convention of the Rights of Persons with Disabilities (UNCRPD).

Furthermore, it presents some of the **challenges and barriers to participation** that persisted before the pandemic and the opportunities to 'Build Back Better' as the potential to learn lessons during the COVID-19 response and recovery emerged.

Global advancement towards participation

The Global Disability Summit held in 2018, hosted by IDA and the governments of UK and Kenya, was an opportunity to use the civil society forum platform, and provided a 'once in a lifetime' opportunity for the global disability movement to **shine a light** on the slow progress towards full implementation of the CRPD and corresponding SDG targets. It was a moment in time in which galvanised political will, advanced the leadership and representation of persons with disabilities and generated clear actions in response to the reality of the disability experience.

Three years on, those of us who have continued to follow up on the outcomes of the GDS2018 are asking: has the focus on leadership and representation of persons with disabilities (one of the building blocks of the GDS2018) had an impact? IDA recently released a study titled, "Increasingly Consulted, but not yet Participating"¹. As the title suggests, there is still a long way to go.

Presenting a snapshot of their global survey IDA at a recent learning event (organised by the IDDC OPD Partnerships Task Group²), confirmed what many of us already knew - that participation of persons with disabilities, (through OPDs) is increasing overall but, as expected, participation remains insufficient with regards to the standards set by Article 4.3 and General Comment 7 of the UNCRPD.

Evidence discussed in the meeting can be summarised as such, that:

- **participation is not equal across** the diverse constituencies of the disability rights movement with the most **marginalized groups having the least opportunities**.
- there were significant **barriers to participation in decision-making** remain, whether with governments, UN or funding agencies.
- **financial support remained one of the biggest challenges** for OPDs to exist as representative organisations, despite 32% of OPDs reporting their funding increased in 2020 compared to 2019.
- **preconditions for participation are regularly not met** mostly due to lack of accessibility and reasonable accommodation, poor attitudes, and lack of awareness.

¹ [Increasingly Consulted, but not yet Participating, International Disability Alliance \(IDA\) Global Survey, 2020](#)

² [International Disability and Development Consortium Task Group \(IDDC\)](#)

Promoting genuine participation

Experience has shown us that **educating a sector** not used to promoting genuine and meaningful participation of persons with disabilities is a challenge. Many disability sector organisations fail to see the **significance of co-production with OPDs** within their own organisation in delivering effective advocacy.

At Leonard Cheshire we have been looking at what can be done to change the **institutional culture of exclusion** of persons with disabilities and promote co-production within the disability sector. Building internal capacity, developing tools, and opening up entry points and embedding them in organisations' mechanisms is the first step towards enabling and facilitating meaningful participation by persons with disabilities outside of it.

Apart from the usual policy, environmental and attitudinal barriers to participation which exist, there are others less obvious such as: an organisation's **history**, the **language** it uses in communications, **paternalistic** attitudes, **branding** and a **institutional resistance** to change. All of these barriers need to shift to create a more inclusive and less offensive approach.

Leonard Cheshire's Effective OPD Engagement toolkit³ was developed as a starting point for genuine participation in influencing activities and provides guidance on how to embed this in an organisation's influencing processes. But the key to its impact, and the impact of other similar tools, will be the buy-in and utilization of the learning by the institutions in developing and maintaining good practice in participation and co-production as a result.

Innovation to Inclusion (i2i) is one such attempt...

i2i is a 3-year, UK Aid funded, consortium programme led by Leonard Cheshire working specifically with OPD partners in Bangladesh and Kenya (10 OPDs in each country). The overall aim of this multi-faceted programme is to improve access to employment in the private sector for persons with disabilities by focusing specifically on the rights of persons with disabilities and their families to an adequate standard of living and access to social protection enshrined in UNCRPD Articles 27 and 28.

While not entirely conceived as a co-produced programme, identifying gaps in policy and legislative provision in the CRPD under these articles, developing advocacy to increase participation and refocusing delivery to respond to COVID-19 situation was entirely coproduced along side Leonard Cheshire's own learning and capacity building on what genuine engagement and participation means.

Increasing participation in the monitoring and consultation by persons with disabilities in the implementation of the CRPD through **data-driven advocacy was a key element** of the i2i programme. After a period of capacity building on collecting data for evidence-based advocacy, which included guidance on how to use the Inclusion Counts

³ [The Effective Engagement Toolkit How to ensure meaningful participation of persons with disabilities in your work, Leonard Cheshire, 2021](#)

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Disability Data Tracker⁴, partner OPDs populated an international Disability Data Portal⁵ developed prior to the i2i programme by Leonard Cheshire with the data collected. OPD advocates used data they collected on articles 27 & 28 (set against corresponding SGD indicators in goals 1, 2, 6 and 8) as the basis for evidence to lobby for **correct implementation of existing laws and policy** on the rights of persons with disabilities to work in an open and inclusive labour market. Having identified the ‘gaps’ in policies and implementation (assessing legislative and policy frameworks based against 4 stages of CRPD implementation: **Championing, Established, Initiating and Weak**, OPDs in Kenya and Bangladesh worked together to develop individual OPD and a collective advocacy strategies.

‘Pivoting’ i2i to respond to COVID-19

The gaps in provision across the range of barriers (institutional, political and environmental and attitudes) inherent in the CRPD’s implementation were brought sharply into focus as the effects of COVID-19 emerged.

1. Collecting the evidence

In response to OPD partners’ requests, OPDs developed a **survey on the impact of COVID⁶** for persons with disabilities in Bangladesh and Kenya with their members. This provided an opportunity for OPDs to trial and develop the learning from i2i data-driven advocacy approach and drive calls for greater participation in the response, recovery and ‘Building Back Better’ from the COVID-19 crisis.

The demand for survey was based on the fact that despite the **global call** to protect ‘vulnerable’ groups from the pandemic, there was little or no tangible provision in place in the response mechanisms that followed for persons with disabilities. Civil society had retreated leaving the OPDs to support their members in the research and provision of information as well as giving practical support.

Conceived and conducted by OPD partners the survey gathered responses and **personal stories** from OPD members through in-depth telephone interviews and then analysed the data at country level to develop recommendations to their respective governments. Loss of employment and job security, little or no access to general public information, no access to PPE, reported disruptions to vital support to live safely and independently, and personal experience of disability discrimination in accessing vital services such as health were among the main concerns of OPD members interviewed.

2. Developing the tools

Valuable though the survey’s findings were for highlighting the inadequacies of the COVID-19 response at country level, it was the **Disability and COVID-19 Influencer Pack⁷** that had the potential to provide the tools needed to advance the participation of OPDs in promoting the implementation the legislative changes and implementation of policies, at whatever level they directed their advocacy at.

⁴ Inclusion Counts: Disability Data Tracker, Leonard Cheshire, 2020 (spotlight editions on UNCRPD’s [Article 27](#) and [Articles 28](#)) written by Lisa Adams on behalf of Leonard Cheshire and Humanity & Inclusion, and was developed in collaboration with the UN Office of the High Commissioner on Human Rights.

⁵ [The Disability Data Portal: Highlighting gaps in worldwide disability data, Leonard Cheshire](#) (online resource)

⁶ [Impact of COVID-19 on the lives of persons with disabilities: Insight and stories from Bangladesh and Kenya, i2i Innovation to Inclusion, 2020](#)

⁷ [i2i Disability and COVID-19 Influencer Pack: Resources to guide decisions affecting the lives of persons with disabilities during and after a pandemic, Innovation to Inclusion, 2020](#)

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3. Sharing the learning

Recommendations made on the basis of the survey's findings were presented by participating OPDs at a side event at the **High Level Political Forum** in July 2020. And then again at a side event at the **Conference of State Parties** in December 2020 to launch the Influencer Pack.

Obstacles and Challenges

Participation of persons with disabilities in the promoting the implementation of the CRPD and SDGs remain the same whether there is a global pandemic or not. The usual barriers of **lack of accessibility, absence of marginalised groups** and formal **institutions seen as the expert**, persist and which require a systemic institutional culture change to intentionally address the barriers that prevent participation.

The pandemic **amplified traditional exclusions** and brought them to the global attention. More crucially for OPDs leading the survey, and who developed the influencer pack, it demonstrated, at both country and community levels, the difficulties inherent in 'participation' itself when it comes to delivering advocacy. These included:

- The context itself was a challenge! The environment was not conducive to participation – fear, stigma and discrimination of amplified with underlying structural barriers heightened:
 - Norms around unpaid care and gender roles
 - Restricted mobility
 - Limited access to tech & business skills
 - Fewer social network opportunities
 - Lower self-esteem & confidence
 - Discrimination harassment and violence at work, transport and other public spaces
 - Domestic violence
- Ability to adjust to new conditions for OPDs particularly for grassroots OPDs prevented participation as movement and personal support was less available or removed altogether
- Appetite for participation amid a challenging situation
- Coordinating and developing the survey and data collection process with so many OPDs so widely spread ran the risk of losing valuable stories and experiences upon which to build an evidence base
- Ensuring the quality of the data across the countries of Bangladesh and Kenya – the localisation of the data collection and analysis ran the risk of skewing results
- Ensuring representative contributors (sampling) – the voice of the most marginalised – while there was a good balance of men and women, persons with more complex needs from intersecting communities or language and communication needs became further isolated because of internet connectivity issues in the rural areas where people had to return to when the lockdowns kicked in

Further challenges associated with accessing knowledge, evidence and skills for developing calls for change, who to direct it at and what advocacy actions are most appropriate require less by way of mechanisms but more in terms confidence, opportunities and allies.

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If the general rule of 4.3 is not respected, or Article 33 is not being implemented, there is no easily identifiable entry point for OPDs to engage or direct their advocacy. In a COVID-19 context with governments moving into emergency measures targeted actions and evidence collection then becomes much harder to navigate.

Good practices in promoting the participation

Participating OPD partners tell us that key among the success of both these activities was:

- Putting into practice the learning from the workshops and tested data-driven advocacy methodology (CRPD tool)
- Provided much need evidence to identify key messages to support recommendation to the Government
- Learned advocacy by doing advocacy
- Provided new information from the survey in identifying vulnerable members (eg loss of income)
- OPDs provided the context (from immediate personal experience) upon which analysis/recommendations could be drawn
- New relationship between OPDs and government departments emerged e.g. OPD received grants from to provide emergency support along side of NGOs
- Supporting and providing mechanisms for the amplification of advocacy through access to global platforms (HLPF/COSP) and social media

Conclusion

COVID-19 shone a light on a number of protracted challenges and barriers that persons with disabilities have had to grapple with since the inception of the CRPD. There is now no excuse for continuing this pattern of exclusion but every opportunity for advancement of inclusion.

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