



Self-Advocates' Participation in Shadow Reporting to the UN Committee on the Rights of Persons with Disabilities

The Main Three Ways They Have Made the
Voices of Persons with Intellectual Disabilities
Heard

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EXECUTIVE SUMMARY

We researched how self-advocates—persons with intellectual disabilities (ID) who speak up for their own rights and those of their peers—get involved in shadow reporting to the United Nations Committee on the Rights of Persons with Disabilities.

We drew on our own experiences and those of recorded panels of self-advocates, and conducted interviews with self-advocates and allies with shadow reporting experience. We found that self-advocates have gotten involved in three main ways:

1. Broad coalitions involving multiple organizations with different focuses,
2. self-advocacy groups focused specifically on persons with ID, and
3. individual submissions.

Each approach has advantages and disadvantages. For example, some coalitions are more inclusive of persons with ID than others, in some places self-advocacy groups are more well-organized or supported than others, and individuals' submissions can be more or less persuasive.

Yet, recommendations for how persons with disabilities should participate in shadow reporting have focused on the coalition approach and not self-advocates' other options. We recommend instead that self-advocates be encouraged to consider different approaches that may work better for them depending on their situation. We also recommend that:

- (a) governments make their State party reports to the Committee available in accessible formats,
- (b) self-advocacy groups organize to support their members to get more involved,
- (c) other organizations find ways to make it easier for self-advocates to get involved,
- (d) and individual self-advocates not wait for an invitation from others to make their voices heard before the Committee.

ACCESSIBLE SUMMARY



- We researched the ways that **self-advocates** make their voices heard in **shadow reports** on disability rights sent to the United Nations.
 - A self-advocate is a **person with intellectual disability** who speaks up for their own rights and the rights of others like them.
 - A shadow report is written by **people and groups outside the government** about how the government is doing on human rights.
- We found **3 main ways** self-advocates have made their voices heard in shadow reports on disability rights:
 - As part of **large groups** of different organizations working together called “coalitions”,
 - As part of **small groups** led by self-advocates, and
 - As **individuals** sharing their personal views.



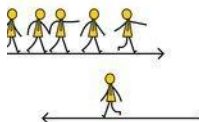
- We think that there are **positives** and **negatives** to each of these 3 ways.



- Large groups sometimes are **hard to speak up** in. But there are a lot of people who can **share the work and ideas**.
- Disability rights reports are **hard work** for small groups of self-advocates. But they can **focus on what is important** to them.
- For individuals it is **hard to know about many other people's** experiences. But they can **share their story** if other ways do not work.



- We think that self-advocates should **think carefully** about their different options for making their voices heard in disability rights reports that are sent to the United Nations.



- **Different options** will work better for different self-advocates.



- We have **4 more ideas** to help self-advocates get more involved:



- Governments can make their reports **easy to read**,



- Self-advocacy groups can **get more involved**,



- Other groups can **support self-advocates more**, and



- Self-advocates should **get started** making plans right away.

ABOUT THE AUTHORS

Fionn Crombie Angus (he/him) is an extraordinary young man with Down syndrome. Combining his love for traditional Irish music and wildlife ecology, he has played his fiddle from the Amazon to Zanzibar. Instrumental in the UK's Down Syndrome Act 2022, he has consulted with the Department of Health and Social Care to conduct focus groups across England. His Happiness Project includes 700 interviews with notable figures in various fields. As the inaugural chair of International Association for the Scientific Study of Intellectual and Developmental Disabilities' Inclusive Research Group and a 2022 Distinguished Achievement Award recipient, he keynoted at their 2024 World Congress in Chicago. He co-runs Fionnathan Productions, lectures internationally, and plans to pursue a joint doctorate with the University of Humanistic Studies (UvH, for its initials in Dutch) and Trinity College Dublin.

Caroline Naluwemba (she/her) is a dedicated self-advocate from Inclusion Uganda, championing the rights of peers with intellectual disabilities. She volunteers with the International Rescue Committee and Inclusion International's "Inclusive and Accountable" project. Born in Kampala in 1988, she holds diplomas in project planning from Makerere University and fashion design from Nagenda International Academy of Arts & Design. Caroline is organizing self-advocates in Uganda and has conducted research on disability inclusion in the workplace through interviews with employers about their attitudes towards hiring persons with intellectual disabilities. Inspired by her mother, who has always fought for her rights since childhood ever since she developed cerebral palsy, she is also the CEO of Caroline Fashions, training self-advocates in tailoring and crafts. Caroline uses her experiences to impact families and communities positively.

1. INTRODUCTION

Too often, persons with intellectual disabilities are excluded from decision-making processes that affect their lives in important ways. These can include everyday decisions about their daily lives to decisions about how to stay safe during the COVID-19 pandemic (Finn et al., 2022; Smith et al., 2023). This kind of exclusion is a big part of why the slogan of the international disability rights movement is “Nothing about us without us!” If persons with disabilities are included in decisions about their lives, then they have a chance to make their voices heard. Because persons with intellectual disabilities face barriers to being included in many kinds of decision-making processes, it is important to identify those barriers and to come up with strategies for overcoming them.

Our research focused on the involvement of self-advocates in civil society’s advocacy efforts before the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee). Specifically, we wanted to know if self-advocates are facing any barriers in making their voices heard in shadow reports that are submitted by civil society groups to this Committee. We also wanted to know what strategies self-advocates are using to overcome any barriers that they may be facing. Our hope was to come up with lessons that could make it easier for self-advocates to make their voices heard before this important Committee, so that we can share those lessons with self-advocates around the world who might be interested in getting more involved in shadow reporting.

2. KEYWORDS

Below, we explain some keywords that are important for understanding our research topic.

2.1 Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations in 2006, making it the first international human rights treaty of the 21st century. It contains important protections for persons with disabilities under international human rights law. Although international human rights legal protections have always applied to persons with disabilities, without a disability-specific treaty, persons with disabilities were often overlooked by governments and international organizations. The CRPD is a powerful tool for disability rights advocates to use in the fight against paternalistic rules and attitudes that limit the ability of persons with all kinds of disabilities to exercise their rights. For example, it includes novel protections for disability human rights that are not specifically recognized in other international human rights treaties, such as the right to accessibility, the right to living independently and being included in the community, and the right to personal mobility.

The CRPD is also special among the international human rights treaties because the process leading up to its adoption by the United Nations was so participatory. The CRPD was the first treaty where targeted stakeholders, in this case, persons with disabilities, civil society, and representatives of national human rights institutions from all regions of the world, directly participated in the CRPD negotiation process where UN member states decided what would be included in the CRPD (Stein & Lord, 2023). As described below, the expert treaty body responsible for overseeing States parties'

progress towards implementing the CRPD has kept the participatory nature of the CRPD negotiations alive in its ongoing monitoring activities.

2.2 Committee on the Rights of Persons with Disabilities

The Committee on the Rights of Persons with Disabilities (CRPD Committee) is the UN human rights treaty body responsible for monitoring the progress of the 191 States parties to the CRPD (UN Treaty Collection, n.d.). The CRPD Committee has a “periodic monitoring process” like that of the other UN human rights treaty bodies. As part of this process, each State party is required to submit to the CRPD Committee an initial report on the status of CRPD implementation in their territory within four years of their ratification, and a periodic report every two years thereafter. After the State party submits its report, the CRPD Committee will review it and send the State party a “list of questions” by way of reply. The State party then has to send the CRPD Committee written responses to these questions. Next, representatives of the State party meet in person in Geneva with members of the CRPD Committee to discuss the State party’s submissions as part of a “constructive dialogue.” Following that meeting, the CRPD Committee publishes “concluding observations” that describe areas where the CRPD Committee believes the State party is implementing the CRPD well. Importantly, the CRPD Committee’s concluding observations also detail areas where the Committee believes the State party needs to make improvements and makes recommendations for how the State party should make those improvements.

2.3 Shadow Reporting

Because UN human rights treaty bodies know that States parties may only give them one perspective on how they are implementing their treaty obligations, the treaty

bodies also welcome reports from civil society organizations to complement the States parties' submissions. Civil society organizations can participate in UN human rights treaty bodies' periodic monitoring processes in several ways. One of the most important is called "shadow reporting". Shadow reports are also sometimes called "alternative" or "parallel" reports by different groups, even though they all mean the same thing.

Shadow reports are an important way for civil society groups to make sure the CRPD Committee has an opportunity to use its periodic monitoring activities to weigh in on issues that these groups are advocating on. Civil society groups can use shadow reports to provide additional information for treaty bodies to consider that States parties have not shared in their periodic reports or replies to lists of issues. Civil society groups can also use shadow reports to criticize parts of States parties' submissions that they disagree with. These submissions are vital to CRPD Committee's work, because the Committee members may not be aware of the specific issues that persons with disabilities are experiencing in a specific place and time. Also, the CRPD Committee members, although they are nominated and elected by States parties, are independent experts who often have a long history in disability rights advocacy, and often have a strong interest in making sure that its monitoring activities are responsive to civil society groups' priorities.

2.4 Self-Advocates

A "self-advocate" is a person who speaks out and fights for their human rights. Many persons with intellectual disabilities have used this term to describe persons with intellectual disabilities who speak up for their own rights as well as the rights of other persons with intellectual disabilities. Not all persons with intellectual disabilities identify

as “self-advocates,” nor do all advocates with intellectual disabilities. Like many words used to describe “disability,” people with different lived experiences have different preferences and views about which terms should be used to describe themselves and people like them. For example, Carol identifies as a self-advocate, while Fionn prefers to call himself an “advocate with intellectual disability.” In some communities, a “self-advocate” simply means someone with or without a disability who advocates for themselves. In this report, we use the term “self-advocate” to mean the same thing as “advocate with intellectual disability.”

That said, “self-advocate” has become a popular term and is helpful to describe the groups of persons with intellectual or other kinds of disabilities who make up the global self-advocacy movement. Self-advocates have played an especially important role in promoting the rights of persons with intellectual disabilities because many persons with intellectual disabilities face barriers in speaking up for themselves. Self-advocates raise issues affecting them and others who cannot speak up for themselves. In many places, self-advocates have been leaders in making important changes to how persons with intellectual disabilities are treated, from closing large, segregated institutions used to warehouse persons with intellectual disabilities to changing attitudes so that people treat and talk about persons with intellectual disabilities with respect.

3. LITERATURE REVIEW

The CRPD was the first core international human rights treaty to be born from a participatory process, where members of civil society worked closely with government representatives to negotiate what would be included in the treaty document (Stein and

Lord, 2023). The text of the CRPD reflects the importance of participatory processes. For example, Article 4(3) requires States parties to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations” both “[i]n the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities.” The CRPD Committee’s procedures also place a high value on the participation of persons with disabilities in its periodic reviews of States parties. The Committee’s working methods welcome the submission of reports and other documentation by international, regional, national or local organizations of persons with disabilities.

Despite these features, there are reasons to wonder if self-advocates are seizing these opportunities to make their voices heard in the process of the CRPD Committee’s periodic review of State parties’ reports through shadow reporting. Part of this may be that even though shadow reports are an important way for civil society to make its voice heard as part of any UN human rights treaty body’s periodic review process, preparing shadow reports is not an easy task. Although there are opportunities for any civil society organization or individual to share their views with these treaty bodies, writing effective reports can be challenging. First, States parties’ reports to human rights treaty bodies are usually written in technical, lawyerly language. Human rights treaty obligations are legally binding on States parties that accept them, and governments have many reasons for wanting to present the best case possible that they are following through on their responsibilities. Second, because human rights treaties cover a lot of ground, States parties’ reports are very long. But shadow reports have to be much shorter than

States parties' reports. So, deciding what things to include and to leave out of a shadow report can be challenging, especially if different people contributing to the report have different priorities. Third, report writers have to think carefully not only about their advocacy strategies, but also about their safety. Governments that read their reports might not receive criticism in a productive way and report writers could be taking risks if they report things that their governments do not agree with.

3.1 Guidance for Organizations of Persons with Disabilities

For these reasons, when the CRPD Committee was just getting started with its periodic review process, the International Disability Alliance (IDA), which represents 14 global and regional organizations of persons with disabilities, wrote a guidance document to give these organizations suggestions for how to participate effectively in the process (IDA, 2010). IDA “highly recommended” that organizations of persons with disabilities form, and ideally lead, national coalitions to prepare shadow reports for several reasons related to the challenges inherent to shadow reporting.

1. First, “working in a coalition provides an opportunity to engage with other organizations working with persons with disabilities in order to share achievements, best practices, challenges and constraints as well as learn from one another.”
2. Second, a coalition “allows for a more effective monitoring of the CRPD due to the specialist knowledge of the organizations, the variety of points of view provided and the ability to present a comprehensive picture of the situation.”
3. Third, “a report by a coalition also tends to lend greater legitimacy to the information submitted and helps to avoid governmental criticism that an

organization is politically motivated, unreliable or providing information that is not factually correct.”

Since the beginning of the CRPD Committee’s periodic review process, IDA has provided technical assistance to organizations of persons with disabilities around the world so that they could participate in the CRPD Committee’s periodic review of their countries. Although shadow reporting to UN human rights treaty bodies was an established practice well before the CRPD entered into force, many organizations of persons with disabilities who had not been included in other human rights organizations’ shadow reports to other treaty bodies were inexperienced. After a decade and a half of providing technical assistance to organizations of persons with disabilities around the world to participate in the CRPD Committee’s periodic review process, IDA’s updated 2024 guidance document also only mentions coalitions as a strategy for preparing CRPD shadow reports.

3.2 CRPD Committee’s 31st Session

The most recent session of the CRPD Committee suggests that despite the Committee’s openness to organizations of persons with disabilities making their voices heard in the periodic review progress, and the CRPD’s recognition of their right to do so, some of these challenges might be affecting how much persons with intellectual disabilities are able to make their voices heard through shadow reports. During its 31st session, the Committee reviewed 9 States parties’ reports. In total, civil society organizations made 56 submissions in response to either the States parties’ reports or their replies to the Committee’s list of questions. Of the 55 submissions available in English, 11 were made by coalitions of organizations led by persons with different kinds

of disabilities, 1 was made by an organization of professionals working on intellectual disability, and 1 was made by an organization led by parents of persons with intellectual disabilities. Several, but not all coalitions included organizations focused on persons with intellectual disabilities (e.g. Ghana Federation of Disability Organisations, 2024), although the extent of self-advocate leadership of or representation in them was unclear.¹ Specifically, few of these member organizations expressly identified themselves as “self-advocacy” organizations.

Aside from the organizations or coalitions with a specific focus on persons with intellectual disabilities, these shadow reports discuss the rights of persons with intellectual disabilities to varying degrees. Some feature these issues prominently. For example, the repeated references to persons with intellectual disabilities report of the Federation of Disabled People’s Organization (FDPO) Mauritius may be due to the prominent role in drafting played by a founding member of the country’s Down Syndrome Association (FDPO Mauritius, n.d.). Several, however, do not mention persons with intellectual disabilities once. Several cross-disability coalitions or cross-disability umbrella organizations included organizations focused on the rights of persons with intellectual disabilities among their contributors or members (e.g. Disabled People’s Organisations Denmark, 2024). But it is unclear from the reports themselves how many, if any, of these organizations were led by persons with intellectual disabilities.

¹ Notably, in Ukraine a coalition of “116 grass-root DPOs and service agencies representing about 14 thousand persons with ID, their families and professionals” was formed to prepare a report that specifically focused on persons with intellectual disabilities (All-Ukrainian NGO “Coalition for Persons with Intellectual Disabilities”, 2019).

Also, it was unclear from the reports themselves how much input individuals with intellectual disabilities had, even where organizations focused on persons with intellectual disabilities were involved. By contrast, it was much easier to see the participation of organizations led by persons with other kinds of disabilities, such as blind persons, deaf persons, or persons with psychosocial disabilities. For example, the clearest description of persons with intellectual disabilities' involvement was in the All-Ukrainian NGO "Coalition for Persons with Intellectual Disabilities" submission. Even so, it was not very detailed: it stated, "a wide discussion was held in June 2019 with involvement of persons with ID, their family members and care professionals."

3.3 *Barriers Self-Advocates Might Face*

It is easy to see how self-advocates might face barriers in making their voices heard through CRPD shadow reporting. Especially in the context of broad coalitions of organizations that may lack experience working with persons with intellectual disabilities, self-advocates may have trouble making their views known. It may be difficult preparing for and keeping up with conversations at large group meetings where experts talk quickly. It may be challenging to review long drafts of reports, especially if they are written in hard-to-understand language. They may need more time to add information to reports than others are used to. The same could happen with organizations for persons with intellectual disabilities led by professionals or family members. Self-advocates may want to focus on certain points that are less important to others, or they may feel pressure to defer to others' judgment even if they have different opinions. Also, the people who believe they are supporting them might be supporting "too much," even without meaning to.

So, we wanted to explore how self-advocates navigate these challenges. Especially given the passing of Sir Robert Martin earlier this year, we think researching this topic is timely. Sir Robert, a strong advocate with intellectual disability from New Zealand, was a champion of persons with intellectual disabilities around the world. After he was elected to the CRPD Committee, he encouraged self-advocates to get more involved in the CRPD Committee's periodic monitoring process. He helped to make sure that issues important to persons with intellectual disabilities were considered by other Committee members and by representatives of States parties. And, he helped make sure that information that was important to the Committee's work was available in plain language or Easy Read formats, including the United Nations Charter itself, as well as the Committee's own working procedures and guidance (CRPD Committee, n.d. & 2017). Without a self-advocate currently on the Committee, it could be even more challenging for self-advocates to make their voices heard in the Committee's periodic monitoring process.

4. METHODS

We used different approaches in our research study. First, we learned more about the UN treaty body monitoring process. Our colleagues from the Harvard Law School Project on Disability (HPOD) trained us, and we reviewed different resources on CRPD shadow reporting for self-advocates and other disability rights groups. Next, we read reports for the CRPD Committee about our own countries, Ireland and Uganda, so that we could have a better understanding of different approaches to shadow reporting in contexts that we were already familiar with. Then, we reviewed and discussed the experiences of self-advocates from seven different countries in two recordings of

webinar events. After that, we developed a list of questions and reached out to two self-advocates and two allies of self-advocates to conduct in-depth interviews over Zoom to learn more about their experiences with CRPD shadow reporting. Each week, we met together with our colleagues from HPOD to discuss everything that we were learning. We also completed worksheets from our HPOD colleagues to help record our reflections at each stage of our research. Our HPOD colleagues took notes and used those notes and meeting recordings to prepare a draft of this report. We then reviewed the report all together several times to make sure it included the things we wanted to say.

5. EVIDENCE

In this section, we describe the important pieces of information that we collected and considered in the process of coming up with our key findings.

5.1 Self-Advocates' Experiences

We watched recordings of two online panels where self-advocates from different countries discussed their experiences getting involved in CRPD shadow reporting. The first event was organized by HPOD in 2021 and featured self-advocate panelists from Canada, Hungary, and Israel. The second event was organized in 2023 by Inclusion International and featured self-advocate panelists from Australia, Colombia, Malawi, and Moldova.

5.1.1 HPOD panel

Kory Earle, People First of Canada's President, shared his perspective on self-advocates' opportunities to participate in Canada's periodic review by the CRPD Committee. When Canada's first periodic report to the Committee came due, Canadian

civil society organizations came together to prepare a shadow report that would inform the Committee of civil society's views on the Canadian government's progress on implementing the CRPD. Kory said:

We were very excited [to] let the government know what we thought about their progress in following the [CRPD] in Canada. [...] We could give them a mark on how they were doing, according to us. Or, so we thought.... It turned out to be much more harder than we thought and there were some barriers for People First members.

Kory then described how at the outset “experts and academics” seemed to dominate discussions among civil society organizations about what should go into the report. Self-advocates had to work hard to ensure their views were reflected in the report. They also had to educate the other organizations about how to make their drafting process inclusive, especially when at certain points the group was producing different drafts on the same day. He attributed part of their success in advocating for a more inclusive process to the election of Sir Robert Martin to the CRPD Committee.

Self-advocate panelists from Hungary and Israel shared similar experiences encountering barriers to collaborating with other civil society organizations in producing shadow reports. In Hungary, after having collaborated with other civil society organizations to produce a shadow report in response to Hungary's initial State party report, self-advocates decided to produce their own shadow report in the subsequent round of review to ensure that their voices were heard. (We describe this experience in greater detail below in our interview with László Bercse.) In Israel, the barriers to self-advocates' participation in the main civil society coalition's report drafting process were so great that self-advocates declined to participate at all.

5.1.2 Inclusion International panel

Judy Huett, a self-advocate from Australia's Speak out Tasmania self-advocacy group described how her group used easy-read materials and support from her group's staff to understand CRPD shadow reporting. She then successfully applied to be part of the cross-disability coalition of organizations that prepared a shadow report. The coalition members first reviewed Australia's State party report and then discussed what had changed and what had not. Each member next went to gather information to add to the report, and Judy focused on speaking with other self-advocates to bring back their viewpoints to the coalition. Even though she felt she was able to share self-advocates' views in the coalition's report, the process was still challenging. "The papers were really big and hard. Having good support that was by my side explaining things and explaining what would happen through each step." She recommended that self-advocates try to make their voices heard in coalitions' shadow reports, even if they cannot be directly involved in the group responsible for writing the report, like she was:

Learn what you can about the Convention and about how your country is going against the Convention. Find out who is involved, tell them you or your organization want to be involved. Pick some topics that are important to you and others with intellectual disability, things that you can talk about. If you can't be part of that delegation, give information to be part of the report. Have good support. It is really important that your voice is heard.

The experience of Diana Zgherea, a self-advocate from Moldova, was similar. She described receiving support from her self-advocacy group's support person to learn about CRPD shadow reporting. Her group also participated in a coalition, and they organized focus groups with self-advocates to collect information they could share with the coalition. She said, "We felt important and heard."

Maria Camila, a self-advocate from Colombia, also described her experiences participating in a cross-disability CRPD shadow report writing coalition. She had a positive experience with her coalition and felt that the 14 different organizations learned from one another throughout the process. She described the coalition's collaborative process:

We have a meeting every month to study different articles of the Convention. We get the most important ideas and then we write and there is a drafting committee who helps us to write our ideas so we can participate more easily. We collected information attending different events and listening to self-advocates about their valuable experiences.

Last, Mark Mapemba, a self-advocate from Malawi, described his experience preparing an individual CRPD shadow report on his own behalf after his initial attempt to participate in a shadow report writing coalition did not work out well. He explained:

I was asked to prepare a report. It was hard for me because the information was not easy to read and I didn't understand the whole process. The information wasn't accessible and they asked a lot of things I was not aware of. So, [...] I went back to them and asked for them to provide information that was easier to read and to understand. [But] I had to give back the report in one afternoon. It wasn't easy for me.

Based on that experience, he is now working to make sure that more persons with intellectual disabilities in other countries are better able to participate in CRPD shadow reporting. Recently, for example, he has supported self-advocates in Zambia. Even though those self-advocates were not able to participate effectively in a cross-disability coalition's shadow report writing process, they were still able to make their voices heard in the CRPD Committee's periodic review process by traveling to Geneva to meet with Committee members during its review of Zambia's initial State party report in March 2024 (Inclusion International, 2024). He explained:

I am trying to make the information more accessible for people with intellectual disabilities. We need to be advocates because these reports are very important

to have our inputs in those reports. It is very important because we are advocating and [we need to] have a voice for people with intellectual disabilities.

5.2 Interviews with Relevant Actors

We also conducted three interviews with self-advocates and allies who are very interested in this topic:

- Rachael Thompson and Ailis Hardy of Inclusion International, who had conducted a survey of Inclusion International's members on self-advocates' participation in CRPD shadow reporting (July 8, 2024);
- Mark Mapemba of Inclusion International, who had submitted an individual CRPD shadow report based on his experiences in Malawi (July 29, 2024); and
- László Bercse of Inclusion Europe, who had been involved in three CRPD shadow reports by a parent-led organization and a self-advocacy group in Hungary (August 26, 2024).

5.2.1 Inclusion International

Ailis Hardy is Self-Advocacy Programme Manager at Inclusion International and Rachael Thompson is an intern with Inclusion International. Based in London, Inclusion International is an international network of persons with intellectual disabilities and their families. The network includes over 130 organizations dedicated to promoting the rights and well-being of persons with intellectual disabilities around the globe. Ailis and Racheal had recently completed an online survey of 47 of their member organizations from Africa, the Americas, Asia-Pacific, and Europe about self-advocates' participation in CRPD shadow reporting. They also interviewed 11 organizations in depth, as well as

7 self-advocates, about their experiences participating in the writing of CRPD shadow reports.

Rachael said that in their survey and interviews, many organizations reported not knowing much about shadow reporting and also not knowing how best to involve self-advocates more in the process. Because of the challenging nature of preparing shadow reports, including time limits, lack of resources, and the effort involved in coordinating with outside groups, some organizations said they were able to involve self-advocates in “little ways,” but not from beginning to end. The survey and interview participants expressed a recognition that self-advocates should be involved more, but also that they were not sure how best to do that.

Rachael and Ailis said that organizations wanted more informational resources about how to involve self-advocates in CRPD shadow reporting. For example, Inclusion International has general guidelines called “Listen, Include, Respect” to assist organizations to be more inclusive of self-advocates, but has not yet developed guidelines for their member organizations specifically on how to be inclusive of self-advocates within shadow reporting processes. They think that the survey and interview results show a real need for and interest in a practical toolkit on this topic, and they have begun working on it. Given the make-up of their network, they want their toolkit to be detailed enough for organizations led by parents or professionals and also easy enough to understand that self-advocates can use it, too.

5.2.2 Mark Mapemba

Mark identifies as a self-advocate from Malawi. He currently works as a Project Manager for Inclusion International working to support self-advocacy groups in Zambia

and Angola. He shared his experiences preparing an individual submission as part of the CRPD Committee's review of Malawi's combined initial and second periodic reports, which concluded in September 2023.

Mark was initially approached by a colleague from Kenya who works for International Disability Alliance (IDA) about getting involved in preparing a shadow report on Malawi. He tried to participate in a shadow reporting effort by a broad coalition of disability rights organizations in Malawi, but he found the process inaccessible.

I tried to work with them but it didn't work out. The way they presented it to me, it wasn't easy to access the information for me. They had a lot of complicated information. I had to work with my colleague [...] and fortunately they were taking time to work together to simplify the information.

Because he found working together with the coalition of organizations difficult, he decided to write his own report to ensure that the CRPD Committee heard the perspectives of people with intellectual disabilities (PWIDs).

It [would have been] nice to be involved as a group. [...] But all in all I am glad to submit a report specifically on the intellectual disability. It is unfortunate that the organizations, they are not that much focused on the intellectual disability than all other types of disabilities. So, it was like a win for persons with intellectual disabilities to have someone to report just on that topic specifically.

In the end, Mark felt that his report made a difference, even though it only reflected his individual perspective and is not representative of the experiences of all persons with intellectual disabilities in Malawi. He believes the CRPD Committee read his report and incorporated it into their concluding observations on Malawi's combined initial and second periodic report.

"Based on [the CRPD Committee's] feedback, I think it helped. They used this and included it in the final report that was presented to the Malawi government about changes that should be done on persons with intellectual disabilities."

In the future, Mark thinks that the best way to make change is for coalitions of disability rights organizations to be told by international organizations that they need to be more inclusive of persons with intellectual disabilities. He thinks that local organizations are more likely to listen to international organizations than to local self-advocates like himself.

I don't think any changes will happen unless IDA recommends me to be involved in the process. If IDA made those recommendations directly, I think it would be better than me going to them directly. They have their own people working on shadow reports. Other organizations, when IDA calls organizations, they need to insist on [including] persons with intellectual disabilities. The local organizations need direction.

5.2.3 László Bercse

László is Vice-President of Inclusion Europe and Steering Group Chairperson for the European Platform for Self-Advocacy. He is also part of the self-advocacy group supported by the parent-led organization Hungarian Association for Persons with Intellectual Disabilities (ÉFOÉSZ, for its initials in Hungarian), which is also a member organization of Inclusion Europe. We spoke to him through a translator about his experience participating in the preparation of four shadow reports regarding Hungary's initial report to the CRPD Committee, its combined second and third periodic reports, and to follow on the Committee's inquiry report (CRPD Committee, 2020).² The first experience with CRPD shadow reporting László had was as part of a coalition (Hungarian Disability Caucus, 2010).

² Although this report was submitted in reference to an inquiry procedure initiated by the CRPD Committee, which is a process that is separate from its periodic reviews of State party reports, we still consider it relevant for our research, since it was submitted to the CRPD Committee; contains information that could also be submitted to the Committee for its next periodic review of Hungary; and matches the substance, structure, and length of a typical CRPD shadow report.

There was a shadow report written by our organization together with other organizations in a cross-disability way. [...] At that time, self-advocates weren't very much involved. [...] [I]t's a good idea for self-advocates to work together with people with other disabilities. It would be good to represent all people with all disabilities in a shadow report. [But] [i]t might be difficult to work together with all the organizations and all the people.

The next two shadow reports that László participated in were prepared by ÉFOÉSZ. Each of them was different, with self-advocates having more of an influence each time. The first report was “prepared” by ÉFOÉSZ and “complemented” by a submission from the ÉFOÉSZ self-advocacy group included in the second half of the document (ÉFOÉSZ, 2017). In the second report, the contributions from the self-advocacy group were presented first, and self-advocates' contributions were written in a way that was much easier to understand (ÉFOÉSZ, 2018). With the third report to the CRPD Committee, the ÉFOÉSZ self-advocacy group had a leading role: ÉFOÉSZ self-advocates chose to write their report themselves (Self-Advocate members of ÉFOÉSZ, 2023). It was written entirely in Easy Read format, with simple language, generous spacing, bullet points, and graphics to illustrate the text.

Table 1. Evolution in CRPD Shadow Reports Contributed to by Hungarian Self-Advocates

Excerpt from 2017 report	Excerpt from 2018 report	Excerpt from 2023 report
<p>Submitted by EFOESZ's self-advocacy group</p> <p>Introduction</p> <p>Our group was formed in 2016 in Budapest. The group has altogether 10 members living with intellectual disabilities. 2 of them are working as mentors/peer-supporters of the group. The group's first topic was self-knowledge, then we talked about how we can spend our free time usefully. Now we talk about our rights. For example we are learning together about the UN Convention and deinstitutionalization. People with intellectual disabilities are often not able to enforce their rights. This is because they either do not access necessary information, or face social or legal barriers. Self-advocacy is important for us to stand up for our rights and for those of our peers. With the help of decision-makers, we would like to create a more inclusive society.</p>	<p>The opinion of the self-advocacy group about the implementation of the UN CRPD in Hungary</p> <p>People with intellectual disabilities need easy-to-read information about what is happening in the world. If we get easy-to-read information we <u>are able to</u> decide on our own and live independently.</p> <p>If something is not easy-to-understand, we do not know what and how to do. We do not know what is happening around us.</p> <p>In Hungary a lot of things are not easy-to-understand. For <u>example</u></p> <ul style="list-style-type: none"> • the news • the official matters • the school materials • the medical examinations 	<p>Key findings and recommendations</p> <p>First, we want to state, that we need change now. We keep writing and saying the same things over and over again, yet nothing happens.</p> <p>Many of us</p> <ul style="list-style-type: none"> • live in segregated institutions • are unable to make decisions and vote • cannot find support services suitable for our needs • cannot find work • live in poverty. <p>We want this to change in our lifetime. We want to live better now! We have no more time!</p>

Based on his experiences, László strongly believes it is important that self-advocates aim to have a leadership role in writing CRPD shadow reports.

Self-advocates are the ones making decisions about their own lives, so they are the ones who should speak about themselves. When they work together with other experts, it might happen that not the self-advocates' voices are the ones really being heard at the end or represented at the end of the work. [...] [Experts] have knowledge but might not be able to entirely feel the situation of people with disabilities. People with disabilities are the ones who can tell the best way to tell their needs.

He also believes that greater self-advocate participation in shadow reporting in Hungary has had an impact on the CRPD Committee's work. The Committee concluded its review of Hungary's initial report in September 2012, and ÉFOÉSZ participated in a cross-disability coalition during that periodic review. ÉFOÉSZ's first two shadow reports were submitted as part of the Committee's review of Hungary's combined second and third periodic reports, which concluded in March 2022.

We feel like the CRPD Committee is listening to what self-advocates have to say. One of the changes is that we can see self-advocates' views or at least topics getting into the Committee's work. For example, when they are writing recommendations to Hungary, we feel that they are included.

Even though self-advocates in Hungary have been increasingly able to make their voices heard in the CRPD Committee's periodic review process, this has not necessarily translated into better implementation of the CRPD by the Hungarian government in practice.

Hungary and decision-makers are hearing what self-advocates say but don't really act on that and don't really implement what we are asking. We are able to tell what we want but we don't feel very much change is happening. One topic is the closing of institutions. Hungary promised to close all institutions by 2036 and it doesn't seem like it will happen. We don't see a clear plan or schedule. That is one topic we are always mentioning on.

Even if self-advocates' increased participation in shadow reporting has not yet had a visible effect on the Hungarian government's policies in key areas,

It still sends a strong message that self-advocates are talking about their needs and the issues affecting them. It also has a strong message when we advocate nationally, and it's more authentic because they're the ones advocating for themselves. They're seeing that self-advocates are able to speak up for themselves.

5.3 Our Experiences

In addition to the experiences of self-advocates elsewhere, we thought it important to consider our own experiences with CRPD shadow reporting in our home countries as part of our research.

5.3.1 Ireland

In May-June 2021, a coalition of six organizations of persons with disabilities in Ireland, including the National Platform for Self Advocates, conducted an online survey and a series of focus group discussions to collect information on the lived experiences and views of persons with disabilities about their CRPD rights. Fionn participated directly in the series of six, 2-hour online consultations with civil society members that the coalition organized. Each consultation focused on two articles of the CRPD. A lot of information was shared ahead of each consultation, so it was difficult to keep up with it all. Although Easy Read documents were shared ahead of time, these were pretty superficial. The consultations were held almost back-to-back—they were spread out over eight days—and the limited time between meetings made the consultations feel rushed. Fionn did feel heard during the consultations, but this was in large part because he had a strong supporter sitting beside him the whole time. Some of his comments and concerns were even reflected in the final report, but that final report was not shared with him (Disabled Peoples Organisation (DPO) Coalition, 2023). He only learned about the report as part of this research project!

5.3.2 Uganda

In Uganda, a cross-disability umbrella organization of persons with disabilities called the National Union for Persons with Disabilities (NUDIPU) prepared a shadow report during the CRPD Committee's review of Uganda's initial State party report, which concluded in April 2016. The NUDIPU shadow report talks about almost every article in the CRPD. The NUDIPU report is long and not in plain language or Easy Read format. The report is mostly written by disabled people's organizations, and self-advocates were not meaningfully involved during the writing of the report. The NUDIPU report did not emphasize issues important to persons with intellectual disabilities. Caroline noticed that among the disabled people's organizations that contributed to the writing of the report, organizations of persons with intellectual disabilities were left out. As a result, important issues that persons with intellectual disabilities face are not addressed as much as they could have been. For example, although the report made important points about barriers for children with disabilities to access their right to an inclusive education, it did not address the specific barriers faced by students with intellectual disabilities, which Caroline believes warrant special attention (NUDIPU, 2016).

6. KEY FINDINGS

From our research, there seem to be three main ways for self-advocates to get involved in CRPD shadow reporting:

- (1) Self-advocates either in their personal capacities or as representatives of other organizations can participate in coalitions of disability rights and other allied groups to develop reports with a cross-disability perspective;

- (2) self-advocacy groups can develop their own reports focused on issues affecting persons with intellectual disabilities either on their own or as a lead organization with support from allies;
- (3) individual self-advocates can make submissions to the CRPD Committee about issues affecting persons with intellectual disabilities in their personal capacities and not on behalf of any organization or group.

There are, of course, other ways that self-advocates can get involved in the CRPD Committee's periodic review process. For example, they can participate in consultations organized by their governments to inform State parties' periodic reports, like Fionn has done. They can also help try to inform reports prepared by national human rights institutions in their countries. They can either participate in civil society delegations to the constructive dialogue between CRPD Committee members and State party representatives in Geneva, or arrange to meet with Committee members informally during the sessions, as self-advocates from Zambia have done. Importantly, they can meet with government representatives after the Committee issues its concluding observations to help make sure that the government follows through on them, as László has done.

6.1 Coalition Reports

We found that participation in cross-disability coalitions was by far the most common way for self-advocates to be involved in CRPD shadow reporting. These reports are written by groups of non-governmental organizations and individuals. Often, but not always, these coalitions are led by umbrella organizations of persons with disabilities, which aim to represent the viewpoints of many kinds of organizations of

persons with different kinds of disabilities. Coalition members may include self-advocates, either in their personal capacities or as representatives of self-advocacy groups or other organizations. Self-advocates may be included among the coalition's leaders, or they and/or their organizations may participate in other ways. In other words, self-advocates' participation in coalitions likely varies from coalition to coalition. For example, several coalitions have prepared plain language or Easy Read versions of their reports (e.g. Canadian Association for Community Living & People First of Canada, 2019), which may suggest a higher degree of involvement of self-advocates in the report writing process. That said, it is important to mention that just because a coalition has created an accessible version of its shadow report does not mean that the coalition's report-writing process was inclusive of or accessible to persons with intellectual disabilities from the start, as Kory described happening in Canada.

Working within these coalitions can have important advantages. Organizations that focus on persons with disabilities other than intellectual disabilities might not know a lot about the experiences of persons with intellectual disabilities. Self-advocates can use the opportunity to network and educate other disability rights movement actors in their countries in ways that can have benefits and create linkages beyond the shadow reporting process. Also, coalitions that bring together different kinds of organizations can share the resources needed for collecting information, producing report drafts, and building consensus among groups. Finally, coalition reports might be given special consideration by the CRPD Committee since these reports represent a wide variety of viewpoints.

There may also be some disadvantages for self-advocates trying to participate in a shadow reporting writing coalition. Some coalitions may be more accessible and inclusive than others. Self-advocates, in general, may have less experience than other groups with preparing the kinds of reports that would be useful to a UN human rights treaty body. Where coalition members are sensitive to self-advocates' need for information in accessible formats, like plain language and Easy Read, and where they give self-advocates real opportunities to collect information from their peers to include in the final report, then the advantages of participating in a coalition might be greater than the disadvantages. However, because the process of understanding lengthy and technical States party reports, collecting reliable information, and coordinating with other groups can be challenging, it may often be hard for coalitions to stick to processes that are inclusive of and accessible to self-advocates. As a result, self-advocates might feel that the issues most important to persons with intellectual disabilities do not receive the attention they deserve. The good news here is that it seems that self-advocates who do choose to participate in shadow reporting coalitions do appear to be capable of making the report-writing process more inclusive and accessible as they go.

6.2 Self-Advocacy Group Reports

We found one example of a self-advocacy group that had prepared its own report to the CRPD Committee: ÉFOÉSZ's self-advocacy group in Hungary (Self-Advocate members of ÉFOÉSZ, 2023). Self-advocacy group reports are reports that are primarily written and submitted to the CRPD Committee by an organized group of persons with intellectual disabilities who identify as self-advocates. These groups may or may not have support from non-disabled support persons or from allied organizations to produce

the report. Even so, self-advocates have the final say in deciding what is included in this kind of report and how it is prepared and written. Although we only found one example of a self-advocacy group that had made this kind of report, they were able to focus specifically on issues important to persons with intellectual disabilities. They were also able to write in a way that was much easier for persons with intellectual disabilities to understand. While we found several examples of plain language or Easy Read versions of coalition reports (e.g. CRPD Shadow Report Working Group, 2019), the coalition reports were not primarily or exclusively written by or at the direction of self-advocates.

There are obvious advantages to this approach, from a self-advocate's perspective. First, self-advocates do not have to worry about “experts” or persons with other kinds of disabilities focusing on issues that may be important only to them, and not to persons with intellectual disabilities. Second, self-advocates can control how accessible these reports are, as well as the process for preparing their report. Third, self-advocates can gain confidence by meaningfully participating in the process of creating a report that is sent to a UN human rights treaty body, and they can also gain knowledge from their peers about both their rights and how their rights are being protected by their governments. Fourth, self-advocates can send a powerful message to other groups, including their governments, that self-advocates are capable of making meaningful contributions to a UN human rights treaty body's periodic review process, which might elevate how other people perceive self-advocates' capabilities.

As with coalition reports, there are likely disadvantages to this approach to CRPD shadow reporting. First, without coalition members to share report-writing responsibilities, self-advocates and their supporters will have to take on a lot of

responsibility, and report writing might not be their strength. Second, self-advocates in many places are not well-organized and may not have the organizational capacity to dedicate many months of meetings, research, and writing to make a shadow report happen. Third, self-advocates sometimes need more time to reach decisions, especially when they are representing the views of their peers with intellectual disabilities, and that may not always be possible given the deadlines from the CRPD Committee for submitting shadow reports.

6.3 Individual Reports

Like self-advocacy group reports, we found one example of an individual self-advocate who had prepared his own CRPD shadow report (Mapemba, 2023). These are reports that are written and submitted to the CRPD Committee by an individual self-advocate or a small number of self-advocates in their own names and not on behalf of a larger self-advocacy group. These reports are different from self-advocacy group reports because they only represent the views of the individuals who sign the report, and not necessarily the views or experiences of a wider group of persons with intellectual disabilities.

Like self-advocacy group reports, there are some advantages to individual reports. Individual self-advocates can easily focus on the topics that are most important to them and need not worry about other persons or groups giving greater importance to different priorities. They can also use more detail about their personal experiences to show the CRPD Committee how well or poorly a government is following through on its obligations. Indeed, it may be that telling stories from personal experience, which has always been a strength of self-advocates, might be easier to do in the form of an

individual report. Also, a strong self-advocate who has a powerful story to tell can still share it with the CRPD Committee even if they live in a place where there are not well-organized self-advocacy groups. Indeed, like with Mark's experience, an individual report might be an option worth considering especially for self-advocates who try to participate in a shadow reporting coalition but who become frustrated by that process. In that way, individual reports could also be a "back-up" option for self-advocates to still make their voices heard in the CRPD Committee's periodic review process.

There are also obvious disadvantages to individual reports. A lot of information is required to prepare a strong shadow report, including understanding and then coming up with a strategy for responding effectively to a long and complex State party report. Self-advocates involved in coalitions described there being a lot of work and inaccessible information to go through, even when they were well-supported. Individual report writers might also leave out important things because not any one person can think of everything. Also, their personal experiences might not be true of the experiences of many persons with intellectual disabilities. These possibilities might also lead the CRPD Committee to give these kinds of reports less importance than reports submitted by more established and larger groups. As a practical matter, an individual report writer might need to have one or more supporters to assist with writing the report, and finding people willing to do that over a sustained period of time might be a challenge.

7. RECOMMENDATIONS

Based on what we learned, we have some recommendations for how to promote self-advocates' participation in CRPD shadow reporting. We first share general

recommendations about letting self-advocates know their full range of options for getting involved. We then share some specific recommendations for different groups of people that can play a role to promote self-advocates' participation.

7.1 General Recommendations

We think that self-advocates should be encouraged and supported to think through their different options for getting involved in CRPD shadow reporting. There are clearly very good reasons for using coalitions as a strategy for preparing shadow reports. But we think that presenting self-advocates only one option may overlook specific challenges that they can face when participating in coalitions.

Instead of just choosing one option that is recommended by others, self-advocates in each country should think carefully about both the positives and negatives from among the different options that exist for preparing CRPD shadow reports. In some cases, participating in a shadow reporting coalition could be the best way for self-advocates to make sure that their views reach the CRPD Committee. In other cases, especially where self-advocacy organizations are well-organized, those organizations might prefer to write their own reports focused on the views of persons with intellectual disabilities.

We think it is also important that self-advocates think about choosing different approaches for different periodic reviews. For example, in the CRPD Committee's review of a State party's initial report, self-advocates who have not participated in other UN human rights treaty body's periodic review processes might wish to join a coalition so that they can learn more about what the process involves. During the Committee's next review of the State party's periodic report, if those same advocates feel that it was

hard to make their voices heard in the coalition's report writing, they might want to present their personal experiences in greater detail to the CRPD Committee and could submit an individual shadow report in their own names. And during the Committee's next review, those same advocates might choose to educate their self-advocacy group members about their experiences with the process and prepare a shadow report focused on the specific issues that are most important to the group. After that, the same advocates might bring their report-writing experience and greater confidence back to the national coalition and more effectively advocate for issues important to them to be highlighted in the coalition's report.

We are not recommending any one strategy over another. We just think that self-advocates should think through their options and think for themselves about the different experiences that other self-advocates have had using different approaches. We think that self-advocates are the experts about their own lives and they are able to make decisions about which strategies will work best for them given their specific situations. Even if they make strategic decisions they later regret, making mistakes and learning from them is an important part of personal and professional growth for anyone, including self-advocates. It might be helpful for self-advocates to have a table, like the one below, for example, that summarizes the positives and negatives associated with different strategies to help them choose the one that will work best for them.

Table 2. Summary of Positive and Negative Aspects of Different Ways to Participate in CRPD Shadow Reporting

	Positives	Negatives
<i>Coalition</i>	<ul style="list-style-type: none"> • Gives an opportunity to build relationships and share resources and expertise across groups • Can speak in one voice to CRPD Committee 	<ul style="list-style-type: none"> • Some coalitions are more inclusive of self-advocates than others • Self-advocates likely have to follow others' schedule and working methods
<i>Self-advocacy group</i>	<ul style="list-style-type: none"> • Self-advocates can make their voices heard very easily • Self-advocates can focus on specific issues that affect them • Self-advocates can set their own schedule and working methods 	<ul style="list-style-type: none"> • Can be hard if self-advocates are not well-supported or well-organized • May miss opportunities to educate other organizations about their priorities
<i>Individual</i>	<ul style="list-style-type: none"> • Individuals do not need to belong to a larger group of self-advocates, which may be a good option in places without strong self-advocacy movements or if participating in a coalition goes badly 	<ul style="list-style-type: none"> • Individuals take on a lot of responsibility to make sure their information is correct • Individuals may expose themselves to greater risks • CRPD Committee may give this kind of report less weight

7.2 Specific Recommendations

We also want to make a few specific recommendations for different groups that can influence self-advocates' participation in CRPD shadow reporting.

7.2.1 Governments

Governments should make their periodic reports to the CRPD Committee easy to understand by publishing them in plain language or Easy Read formats. The CRPD Committee could also help by specifically requiring governments to do so during its periodic review process. Many governments do not always make information that is

important to self-advocates available in formats that are accessible to them, and so this is a natural way for States parties to do a better job of following through on their CRPD obligations.

7.2.2 Self-Advocacy Groups

Self-advocates need easy-to-understand information about the different ways they can get involved in CRPD shadow reporting. Beyond introductory trainings on the CRPD, self-advocacy groups can make it a point to make sure that their members are aware of these possibilities and practical steps they can take to get involved. Because different strategies might work better in different contexts, self-advocacy groups can also help make strategic decisions based on their experience with other advocacy efforts. They might also consider reaching out both to disability and non-disability organizations who might have navigated similar dynamics. Self-advocacy groups might even try creating mentorship programs that pair self-advocates with mentors who can guide them through the reporting process and provide support. Self-advocacy groups can also think about using online surveys and social media to make it easier for members to make their voices heard.

7.2.3 Other Disability Rights Organizations

Organizations and individuals that lead shadow reporting coalitions should proactively make the reporting process easy for self-advocates to participate in. This could mean doing things a little differently than they're used to doing, especially if they are not used to working with persons with intellectual disabilities. Ideally, these leaders should reach out to self-advocacy groups well before shadow reporting activities start. They might, for example, offer to co-organize or support CRPD trainings for

self-advocates together with self-advocacy groups. In the spirit of “Nothing about us, without us”, they might seek to hire persons with intellectual disabilities, especially experienced self-advocates, who might help their organizations more effectively support the self-advocacy movement in their working areas.

7.2.4 Individuals with Intellectual Disabilities

Finally, individuals with intellectual disabilities should not wait around for an invitation. There are ways for individuals to make their voices heard through shadow reporting to the CRPD Committee even if they do not belong to a broader group or organization. They can also help to start the conversation inside self-advocacy groups that do not currently have plans for getting involved.

8. IMPACT

Inclusion International is currently working on a toolkit to help organizations better support self-advocates' participation in CRPD shadow reporting. We have had the chance to review a draft of this toolkit and to give feedback based on our research. We think that this will be a very useful resource that will both call greater attention to the need to support self-advocates to participate meaningfully in CRPD shadow reporting, and also provide interested groups and individuals practical advice for how they can go about making that happen.

That said, we think that there is also more work to be done. For example, Inclusion International's toolkit's primary audience is not only self-advocates. Self-advocates will likely need and benefit from informational resources beyond this toolkit. They may need access to Easy Read versions of it, additional videos and

guides, and individualized help from knowledgeable and trusted support persons that are familiar with their local contexts.

We also think that while it's important both to empower self-advocates to participate more fully in CRPD shadow reporting and also to encourage interested organizations to contribute to making that happen, it is also important for organizations and individuals that have been leading shadow reporting coalitions to create spaces for self-advocates to make their voices heard in the report-writing process. This is where we want to highlight Mark's suggestion that organizations like the International Disability Alliance make sure that the coalitions they work with are inclusive of and accessible to persons with intellectual disabilities. It might not be enough for established organizations or broad coalitions to hear demands from individual self-advocates or local organizations that focus on persons with intellectual disabilities that self-advocates participate more fully. It might be necessary for high-profile, well-respected groups to also make those demands.

An obvious place to start is the CRPD Committee itself. The Committee leads the periodic review process and can send clear messages to both States parties and civil society organizations about what meaningful inclusion of persons with intellectual disabilities means. Also, organizations like HPOD, a global law and policy center, can add weight to these expectations. Organizations like HPOD and Inclusion International might also be able to provide technical assistance to self-advocates in specific contexts where they could use support to make their voices heard in CRPD shadow reporting processes. We think that the thoughtful demands of self-advocates and their in-country

allies, in an ideal world, should be enough to remove barriers to full inclusion. In reality, they might need powerful friends to back them up when they present these demands.

Caroline, for her part, plans to begin to apply what she has learned right away. She believes she needs to start by training self-advocates on the importance of their involvement in raising their voices through CRPD shadow reporting. In Uganda, she knows that some self-advocates have heard about shadow reports but they have never participated in drafting them. Once trained, self-advocates will likely need to engage in meetings organized by NUDIPU, the umbrella organization of persons with disabilities that has led past CRPD shadow reporting activities.

We, as self-advocates, need to get information about the time and place of these meetings, so that we can actively participate during them. Part of that will be identifying allies and support persons who can help make sure our voices are heard in these big groups. Then, we, as self-advocates, can make informed decisions about if we should continue to advocate for persons with intellectual disabilities as part of the NUDIPU-led coalition, or if we should try different approaches.

Fionn, based on his participation in the NDA's consultations, believes that Irish self-advocates should prepare their own shadow report when the time for it comes. Currently, the CRPD Committee has a working group meeting on Ireland's initial State party report scheduled for September 2025, when the CRPD Committee will develop its list of issues. He plans to get self-advocates in Ireland involved ahead of time, so that they will be ready. He will contact the Irish Human Rights and Equality Commission, the independent monitoring mechanism for the CRPD in Ireland, to seek their advice. He will also consult with several self-advocacy and allied groups, including the National Platform of Self Advocates, the National Advocacy Council, Down Syndrome Ireland's National Advisory Council, the Inclusive Research Network, and Inclusion Ireland. He will ask if their members would be interested in participating in a broader coalition like

self-advocates have done in Australia, Canada, Colombia, and Moldova, or if they would prefer to follow the example of Hungarian self-advocates and prepare a shadow report with self-advocates as the primary authors. That way, they can make an informed decision in advance about which approach will work best for them.

9. CONCLUSION

As with so many things, we expect that over time, self-advocates will participate more and more fully in CRPD shadow reporting. It may take a long time, but self-advocates have almost always found a way to advocate effectively for issues they care about. At the same time, there is likely more research that can be done to show not only barriers to self-advocates' participation in CRPD shadow reporting but also solutions to those barriers based on self-advocates' personal experiences. It would be interesting, for example, to study through in-depth interviews the experiences of various self-advocates who participated in a single coalition's report-writing activities and compare those to the perspectives of other members of the coalition. Some coalition members might perceive self-advocates to have been more included than self-advocates perceive themselves to have been. Also, it would be interesting to study support dynamics in CRPD shadow reporting. Even where self-advocates prepare a self-advocacy group report, for example, there are likely examples of both more effective and less effective support that could inform how self-advocates work with support persons elsewhere. The answers to these kinds of questions could help add to our knowledge about how best self-advocates can participate in CRPD shadow reporting and make sure their voices contribute to CRPD implementation at the highest levels.

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BIBLIOGRAPHY

- All-Ukrainian NGO “Coalition for Persons with Intellectual Disabilities”. (2019, July). *Alternative report: Implementation in Ukraine of the United Nations Convention on the Rights of Persons with Disabilities in 2015-2019*.
https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FICS%2FUKR%2F35635&Lang=en
- Canadian Association for Community Living & People First of Canada (2019, July 29). *Plain English version of: Submission of Canadian civil society organizations to the Committee on the Rights of Persons with Disabilities on the list of issues prior to reporting [Canada] to be adopted during the 22nd Session of the Committee on the Rights of Persons with Disabilities*. ARCH Disability Law Centre.
<https://archdisabilitylaw.ca/resource/submission-canada-community-organizations-and-organizations-of-people-with-disabilities-report-on-the-list-of-issues-prior-to-reporting/>
- Committee on the Rights of Persons with Disabilities. (n.d.). *Documents in plain language and Easy Read versions*. Retrieved September 30, 2024 from,
<https://www.ohchr.org/en/treaty-bodies/crpd/documents-plain-language-and-easy-read-versions>
- Committee on the Rights of Persons with Disabilities. (2020, September 17). *Inquiry concerning Hungary under article 6 of the Optional Protocol to the Convention*. U.N. Doc. CRPD/C/HUN/IR/1.
https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FHUN%2FIR%2F1&Lang=en
- Committee on the Rights of Persons with Disabilities. (2017, October 27). *General comment no. 5 on living independently and being included in the community*. U.N. Doc. CRPD/C/GC/5.
<https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>
- CRPD Shadow Report Working Group. (2019, August). *Disability rights now 2019: Shadow report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019*.
<https://dpoa.org.au/wp-content/uploads/2019/08/Plain-English-PDF.pdf>
- Disabled People’s Organisations Denmark. (2024, August). *2nd alternative report on the implementation of the UN Convention on the Rights of Persons with Disabilities in Denmark and the Faroe Islands for the 31st session*.

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FCSS%2FDNK%2F58829&Lang=en

Disabled Peoples Organisation Coalition. (2023, May). Consultation report: The views and lived experience of disabled people in Ireland in response to the UN Convention on the Rights of Persons with Disabilities.

<https://ilmi.ie/wp-content/uploads/2023/07/DPO-Coalition-Report-2023.docx>

Federation of Disabled People's Organization Mauritius. (n.d.). *Alternative report for the LOIPR on Mauritius (12th pre-sessional working group)*.

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FICS%2FMUS%2F35611&Lang=en

Finn, C. A., Smith, M. S., & Stein, M. A. (2022). How persons with intellectual disabilities are fighting for decision-making rights. *Current History*, 121(831), 30-35.

<https://doi.org/10.1525/curh.2022.121.831.30>

Ghana Federation of Disability Organisations. (2024). *CRPD shadow report*.

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FCSS%2FGHA%2F58993&Lang=en

Harvard Law School Project on Disability. (2021). *CRPD shadow reporting: Opportunities for self-advocacy* [Webinar].

<https://hpod.law.harvard.edu/events/event/crpd-shadow-reporting>

Hungarian Association for People with Intellectual Disabilities. (2018, May 1). *Submission*.

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FICS%2FHUN%2F31035&Lang=en

Hungarian Association for People with Intellectual Disabilities. (2017). *List of issues written submission – Hungary*.

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FICS%2FHUN%2F26896&Lang=en

Hungarian Disability Caucus. (2010, August). *Disability rights or disabling rights? CRPD alternative report*.

http://www.mdac.org/sites/mdac.org/files/english_crpd_alternative_report.pdf

Inclusion International. (n.d.). *Advocacy fact sheet: Shadow report on the Convention on the Rights of Persons with Disabilities*.

<https://s38312.pcdn.co/wp-content/uploads/Shadow-reporting-fact-sheet.pdf>

- Inclusion London. (2021). *Top tips for civil society shadow reporting under the United Nations Convention on the Rights of Disabled People (UNCRDP)*.
<https://www.inclusionlondon.org.uk/campaigns-and-policy/uncrdp/previous-years/uncrdp-2021/top-tips-for-civil-society-shadow-reporting/>
- International Disability Alliance. (2010, May). *Guidance document: Effective use of international human rights monitoring mechanisms to protect the rights of persons with disabilities*.
<https://www.internationaldisabilityalliance.org/resources/guidance-document-parallel-reporting>
- Mapemba, M. (2023, July). *Review of the state report of Malawi*.
https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FCSS%2FMWI%2F53326&Lang=en
- National Union of Disabled Persons of Uganda. (2016, January). *Submission in response to the List of issues of the Committee on the Rights of Persons with Disabilities for the initial review of the Republic of Uganda on the implementation of the Convention on the Rights of Persons with Disabilities*.
https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FCSS%2FUGA%2F23245&Lang=en
- Plena Internacional. (2023). *Shadow reporting & the CRPD: Online masterclass for self-advocates* [Webinar].
<https://drive.google.com/file/d/1Rtj8ezfaA7hGIAQrILTo4cPTHx9uvSwT/view>
- Self-Advocate members of the Hungarian Association for Persons with Intellectual Disability. (2023, July 25). *Follow-up on Hungary in relation to the Committee's inquiry's report (CRPD/C/HUN/IR/1)*.
https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCRPD%2FFIR%2FHUN%2F29th%2F35711&Lang=en
- Smith, M. S., Fracht, A., Mairose, D., Phillips, A., & Stein, M. A. (2023). COVID-19 pandemic experiences of group home residents with intellectual disabilities: Findings from inclusive, qualitative interviews with self-advocates in Massachusetts. *Journal of Policy and Practice in Intellectual Disabilities*, 20(4), 405-414. <https://doi.org/10.1111/jppi.12478>
- Stein, M. A., & Lord, J. E. (2023, February). *Convention on the Rights of Persons with Disabilities*. United Nations Audiovisual Library of International Law.
https://legal.un.org/avl/pdf/ha/crpd/crpd_e.pdf

- Thompson, R. (2024, June 24). *Self-advocates share their experiences on parallel reporting*. Inclusion International.
<https://inclusion-international.org/news-item/self-advocates-share-their-experiences-on-parallel-reporting>
- United Nations. (n.d.). *The core international human rights instruments and their monitoring bodies*. Office of the High Commissioner on Human Rights.
<https://www.ohchr.org/en/core-international-human-rights-instruments-and-their-monitoring-bodies>
- United Nations Treaty Collection. (n.d.). *Multilateral Treaties Deposited with the Secretary-General, Ch. IV: Human Rights, No. 15. Convention on the Rights of Persons with Disabilities*. Retrieved September 30, 2024, from
https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en