Disabled people’s voice, participation and empowerment

1. Summary

1.1. There is a growing recognition of the need for approaches to development which are more inclusive of disability issues and disabled people (DP), as reflected by the Post-2015 ‘Leave no one behind’ agenda, and by this Parliamentary Inquiry. This submission does not seek to repeat the arguments for disability inclusion, but instead focuses on the importance of voice, participation and empowerment in achieving development processes which are more inclusive of DP.

1.2. The right to participation is explicit in international law through several conventions, including the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Participation/voice are also a key strategies for making development efforts more effective in reaching the poorest and most marginalised in societies, and they depend on and feed in to empowerment processes.

1.3. DFID has actively supported the voice and participation of DP in the post-2015 process. This approach now needs to be scaled up and institutionalised within DFID at all levels, both to strengthen disability inclusion in DFID’s work, as well as to influence other development actors and processes.

1.4. We therefore urge DFID to ensure that the voice, participation and empowerment of DP is promoted systematically across all its programmes and partnerships through:

- Accountability and funding mechanisms which include a requirement to engage with DP in all consultation, participation and accountability processes.
- Providing country programmes and implementation partners with the support and resources needed to become effecting in engaging with DP.
- Funding and other support to initiatives/channels for the voice, participation and empowerment of DP, such as DPOs.

2. ADD International

2.1. Since 1985 ADD International has worked with DP’s Organisations (DPOs) in Africa and Asia, from grassroots to national level, to strengthen their capacity to bring improvements to the lives of their members, and to advocate for the inclusion of DP in all aspects of political, social and economic life. Drawing on this direct experience we work

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1 In this submission we use the term ‘disabled people’ to reflect the terminology of the UK disability rights movement, but we recognise that in different contexts ‘people with disabilities’ is used, while the UNCRPD refers to ‘persons with disabilities’.
as an ally to the disability movement in influencing development policy and practice at all levels to become more inclusive of DP and disability issues.

3. Why are voice, participation and empowerment important in making development more inclusive of disabled people?

3.1. DP’s participation in development is a right: The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is clear on the right of DP to full and effective participation and inclusion in society (Article 3 – General Principles), their right to participate in public affairs, including the work of NGO’s, and the obligation of states to encourage DP to participate and to promote an environment where they can do this ‘without discrimination and on an equal basis with others’ (Article 29). The obligation of the UK government to adhere to these principles in all aspects of international cooperation is also clear (Articles 11 and 32).

3.2. Development processes are more effective when they are based on the lived experience of DP: The past 2 decades has seen a shift in understanding of disability from a ‘medical model’ to ‘rights based’ approaches which focus on the social and environmental barriers that exclude DP. By listening to the voices of DP themselves (through their active engagement at all stages of the development process; analysis, policy development, planning, implementation, evaluation), decision makers can gain an understanding of the barriers and social dynamics which contribute to their exclusion and limit their opportunities. Based on these insights it is possible to develop interventions which target the causes – rather than just the symptoms - of DP’s exclusion.

3.3. Empowerment is a precondition for effective participation… and greater participation leads to empowerment: The disempowerment which DP experience as a result of social exclusion and discrimination leads to isolation, low levels of education and skills, and low self-esteem. Through interventions which support their individual and collective engagement in economic, social and political life, DP increase their confidence and their status within their communities. This creates the conditions where DP can become agents of change in their own lives as well as in the lives of others by coming together (through DPOs and other CSOs) to advocate for sustainable social and structural change, holding duty-bearers to account in delivering on their commitments on the rights of all DP.

3.4. Increased engagement between disabled and non-DP challenges the assumptions and negative attitudes which lie behind discrimination and exclusion: When DP become active participants in economic, social, cultural and political life, they become more visible in society and engage more with non-DP. ADD International’s experience (examples below) shows how this process of engagement is a critical element in tackling discrimination, changing attitudes, and removing barriers to inclusion in all aspects of life.

4. What works?

4.1. DP’s Organisations (DPOs) - representative organisations ‘of’ DP – and national disability movements are a key channel for the individual and collective empowerment of DP by promoting their voice and active participation in all areas of life - social,
economic, political and cultural. They do this by: Bringing individuals out of isolation through mutual support; Building a common identity and status for DP; Providing opportunities for DP’s personal and economic empowerment; Advocating for access to services and other development support; Raising awareness of and challenging disability discrimination, negative attitudes and stigma. Acting through the disability movement, DP were at the heart of the process which led to the adoption of the UNCRPD in 2006, and have also been key actors in getting states to ratify, and in influencing the development of the legislation needed for states to meet their commitments under the convention.

4.2. **Strengthening organisational capacity** is a critical element in ensuring that DPOs become effective in promoting the voice, participation and empowerment of DP in all aspects of life, and in development processes. Over 28 years’ working with DPOs, we have learnt that the high levels of exclusion and disadvantage experienced by DP, including exclusion from education, often means that the capacity building needs of DPOs are greater than those of other CSOs, and it can take longer to achieve sustainable progress. Practical challenges relating to mobility and communication are also factors which may mean that more time and resources need to be invested in capacity building processes.

4.3. DP do not represent a homogenous group, and the challenges faced by individuals are also linked to other **intersecting factors of exclusion and inequality** such as gender, age, ethnicity etc. In promoting the voice, participation and empowerment of DP it is important to analyse and address these factors and to take active steps to remove the additional barriers. Through an accompaniment approach to capacity building, ADD has worked with partner DPOs to build awareness and understanding of these issues within disability movements, and to develop strategies to address them. With regard to gender, this has included the creation of women’s DPOs / women’s departments in DPOs, as well as quotas to improve the representation of disabled women within DPO executive boards and to encourage the emergence of disabled women as leaders.

4.4. Active steps also need to be taken to reach impairment or identity groups which are **highly excluded** as a result of social norms and beliefs, and to facilitate their inclusion and engagement in development processes. In Uganda, for example, people living with/affected by albinism are subject to extreme discrimination and vulnerable to violence and abuse relating to superstitious beliefs and practices. This results in extreme isolation, where women who have children with albinism are often rejected by their husbands, and people living with albinism (PLWA) are often hidden away by their families from childhood through into adulthood. The Elgon Foundation for Persons with Albinism (EFPA), established and run by PLWA, engages with communities, local government and civil society actors to increase recognition, awareness and protection of PLWA. An evaluation of this project (2013) found that as a result of this initiative, more children living with albinism are enrolling in and staying in school; police vigilance in protecting the rights of PLWA has increased; more PLWA are becoming members of other civil society organisations; local authorities are explicit in stating that services should include PLWA; and PLWA report they feel they are more respected within their communities. A key aspect of this process has also been to work with DPOs so that PLWA are recognised as DP and included within the wider disability movement: In the areas of EPFA’s work, PLWA now occupy leadership positions within district level DPOs.
4.5. The need for systematic disaggregation of data by disability as well as gender and other factors is crucial, and is covered in more detail in other submissions (DDG / International Centre for Evidence in Disability). However, data alone is not enough to build the understanding needed for effective interventions – also essential are participatory initiatives which produce qualitative evidence by eliciting and capturing the perspectives of DP themselves. The 'Voices of the Marginalised' participatory research project (ADD International/ HelpAge International/ Sightsavers/ Alzheimer’s Disease International) represented a channel through which DP, older people and people living with mental health issues could feed in to the post-2015 policymaking process – and project participants also reported that they found the process itself empowering. The resulting report, ‘We can also make change’(2013), provides evidence of the issues and dynamics which contribute to the exclusion of older and DP and makes recommendations (relating to livelihoods security, access to public services, and ending bullying and violence) which are grounded in their direct experience and analysis.

4.6. Engaging non-disabled stakeholders is an important element in participation and empowerment processes. In Cambodia ADD worked with DPOs to address the extreme marginalisation of people intellectual disabilities (PWID) in rural communities by building their capacity to participate in social and economic activities. A final evaluation found that the engagement of stakeholders at all levels of the community, with an initial emphasis on building understanding of intellectual disability, had been a key factor in achieving success. Furthermore, as PWID participated more in family and community activities, the community actively sought opportunities to secure their access to services (e.g. inclusion in free healthcare services) and mainstream development opportunities (e.g. income generation grants).

4.7. Positive discrimination approaches, including quotas, can contribute to increasing DP’s participation in economic and political spheres. In Uganda, where the parliamentary system makes provision for 5 directly elected MPs representing DP (and who must be DP themselves), disability issues are prominent in policymaking and legislation (Uganda’s 2012 report to the UN Committee on UNCRPD). Drawing on Uganda’s experience, a similar approach is now being developed in Kenya. Approaches involving setting and monitoring quotas can also have a positive impact in the private sector: In Bangladesh, as a result of influencing work carried out by ADD and DPOs, the Bangladesh Garments Manufacturing and Export Association BGMEA issued a letter to all its members asking them to recruit DP. DP who have received appropriate training (through their DPO) are now able to secure work in garments factories, while the recruitment of DP is also leading to changes which will support disability inclusion in the long-term such as adjustments to improve access, and improved attitudes towards DP.

5. DFID’s current approach

5.1. Despite leading the way on thinking on disability inclusion with its paper on Disability, Poverty and Development in 2000, and despite the UK government’s obligations under the UNCRPD and the UK Disability Discrimination Act, DFID currently has no written policy commitments on disability inclusion. As a result there is no reporting...
requirement or funding incentive for DFID programmes to ensure or to demonstrate that
the promotion of DP’s voice and participation has been incorporated as a strategy to
increase impact in all interventions.

5.2. Despite the existence of guidelines which emphasise the importance of DP’s voice and
participation, knowledge and uptake of these across DFID’s programmes has been
very limited. The 2007 How to Note on Working on Disability in Country Programmes,
for example, recommends action on involving DPOs in all civil society consultations, and
in 2010 all DFID country programmes were sent a Guidance Note on how to improve
educational access and quality for children with disabilities, which included
recommendations on participatory approaches. A study conducted in 2012 by an NGO
Informal Working Group on DFID and education for children with disabilities found that
only half of the country offices surveyed had read the Guidance Note. However, the
research also found that, although the country offices surveyed had not involved DPOs
closely in the planning and monitoring of education programmes, they were open to
doing this in the future, and would welcome support in putting this into practice.

5.3. Promotion of the voice, participation and empowerment of DP should theoretically fall
within the scope of action point 2.1. of DFID’s current Business Plan (Build open
societies and institutions in our partner countries), and DFID’s pledge to ensure 40
million people have more control over their own development and hold their governments
to account. However, without clear obligation to ensure that DP are included in these
initiatives, and support to achieve this, they are easily neglected: For example, a recent
ICAI (Independent Commission for Aid Impact) evaluation of DFID’s empowerment and
accountability programming in Ghana and Malawi makes no reference to DP at all.

5.4. DFID is currently investing in strengthening the disability movement as a channel for
the voice, participation and empowerment of DP through funding to ADD International
(PPA), the Disability Rights Fund and a small portfolio of NGO projects. However, these
initiatives represent a very small proportion of overall DFID support to participation,
empowerment and accountability initiatives. Furthermore, while strengthening DPOs
represents an essential step in promoting DP’s empowerment and participation, it is also
important to build opportunities for the voice of DP to be heard within other movements
and fora, such as the women’s movement.

5.5. Despite the absence of a strategy or policy on disability inclusion, DFID and the UK
government have played an important role in ensuring that disability inclusion has
been firmly on the agenda in the post-2015 process, as reflected in both the HLP and
Secretary General’s reports. In carrying out this influential role, DFID was able to draw
on the qualitative evidence based on the voice and experience of DP through
participatory projects such as the Voices Research Project (see above). DFID has also
been very supportive of the principle of DP’s representatives participating in key fora
within the post-2015 process, such as the HLP panels in Liberia and Bali, and has
actively engaged with the disability movement and with disability focused INGOs such as
ADD International to make this happen.

5.6. We recognise that the commitment and engagement of key individuals within DFID
and the UK government has been an essential element in ensuring this focus on
disability issues, and the inclusion of DP’s perspectives, in the post-MDG discussions.
The same individuals are currently championing disability inclusion within DFID, through
initiatives such as the commitment to ensure schools built with DFID funding are
physically accessible, and the recent rejection of some business cases which ignore
disability. However, without this commitment becoming institutionalised within a strategy and systems, these gains could be lost as individuals move on.

6. Recommendations

6.1. We support the BOND DDG’s call for DFID to make a **high level commitment to disability inclusion, supported by a TOC, strategy and systems** for implementation and accountability which locate disability within the wider context of equity and inclusion.

6.2. These structures must **emphasise the importance of promoting the voice, participation and empowerment of DP**, making clear links with DFID’s commitments and initiatives on accountability, empowerment and governance.

6.3. Funding decisions for direct DFID programmes, bilateral funding, and work through partner organisations should be linked to **a requirement to include DP in all consultation, participation, empowerment and accountability processes**, with accountability mechanisms in place to ensure this happens, including the requirement for **data to be disaggregated** in order to monitor the inclusion and participation of DP.

6.4. In order to **create the conditions for DP’s individual and collective empowerment, and the channels through which their voices can be heard**, DFID should fund – and encourage others to support - initiatives which promote the emergence of the disability movement and other civil society structures through which DP participate and gain empowerment. In doing this, DFID should ensure that specific measures are taken to ensure the equitable participation of those DP who are furthest from power as a result of other factors such as gender, age and location.

6.5. DFID should **continue to champion and support the participation of DP in the post-2015 process**, to ensure that the focus on disability inclusion achieved thus far is not lost in the final drafting of the post-2015 development framework. We call on DFID to use its influence to encourage other countries to engage with disability movements in country-level negotiations on post-2015 commitments, and where necessary, DFID should provide support to partner countries to do this.

6.6. DFID country offices should **engage directly with DP** through their organisations, both to inform DFID’s understanding of disability and how better to include it in country programmes, and also to support DP’s empowerment through access to information and knowledge on development processes.

6.7. DFID should carry out and fund **research and evaluations** to inform good practice on engagement with DP, and to identify effective approaches to strengthening participation and empowerment.

6.8. Resources and advice must be made available within DFID in order to support programme staff in making **reasonable accommodations** which may be necessary for DP’s participation in consultation processes. DFID should strive to model good practice regarding the equitable participation of DP within its own teams, structures and facilities.