Ref: JCDM-i1441 Opening Statement for JCDM, 24.4.8.

How can DPO development be more inclusive to achieve human rights and meaningful participation for people with disabilities, across all groups, including those with complex disabilities?

Firstly, in terms of language, we in VVI, and our colleagues in Physical Impairment Ireland, use Disabled Persons Representative Organisations (DPRO), which means the same as DPO, but avoids confusion with the same acronym in other contexts, and is also faithful to the text of Article 4 (3) of the CRPD – "through their representative organizations." The UN Committee welcomes diversity when it comes to language in this matter, because we are not monochrome, and respect for our language choices reflects respect for our equality and dignity.

To the substance of the question: i.e., inclusive development of DPROs in order to achieve fulfilment of Human Rights and meaningful participation across all constituencies.

Our right of collective representation, including by impairment constituency and intersectional grouping, is a general cross-cutting obligation of the CRPD. The related obligations on the State to facilitate this are very clearly laid out in General Comment No. 7, which directly relates to Articles 4 (3), 29 (b (ii)) and 33 (3) of the CRPD.

In other words, what needs to happen is not the third secret of Fatima. Detailed obligations of compliance have been ratified by this State, and these DPRO rights are of immediate effect (see General Comment No. 1, para. 30), and not of "progressive realisation," which the State has wrongly claimed up until very recently.

Without actual facilitation of our DPRO rights, there is no CRPD, apart from window-dressing which the UN Committee will see through, immediately, when the Optional Protocol is ratified – if it is ever ratified by Ireland. In its reporting on Ireland's implementation of the CRPD the UN Committee will also raise DPRO rights as the primary failure in Ireland's implementation of the CRPD, because every other Article in the CRPD is based on consultation with disabled people through their representative organisations (DPROs).

The following is the clear roadmap which Ireland has signed up to as legally binding obligations, and which, six years on, remain ignored:

- 1. A registry of DPROs based on General Comment No. 7 criteria (and in particular, paras. 10-4). These criteria include:
- * must be run, led, directed, and mostly membered by disabled people (i.e., of the relevant constituency).
- * must have Human Rights as the core function;
- * cannot be a disability service-provider because of conflict of interest potential.
- * must be open to membership of absolutely everyone in the DPROs stated constituency i.e., not be exclusive.
- * Coalitions or umbrella-groups must be open to all DPROs in order to be legitimate in that role, and the role and structure of the coalition must be mutually agreed by all members.
- * as with the charity sector, there should be no duplication i.e., there should be no more than one DPRO per constituency. Anything else invites fragmentation and chaos, and defeats the whole point of our collective bargaining, necessary continuity of positions and standards etc.
- * DPROs cannot be sector-specific. Professions and pastimes are not, in themselves, protected Human Rights constituencies.
- * individual self-advocacy on personal issues should not be conflated with macro-disability-proofing which is a DPRO-only responsibility (CRPD, Art. 5, GC6, paras. 24-5).

- * self-advocacy organisations as DPROs are particularly referring to people with cognitive impairments etc. (GC7, para. 12C).
- * DPROs in which family-members etc., have a supportive role, e.g., representing the views of those with profound cognitive impairments, must also be recognised as DPROs (GC7, para. 12D).
- 2. For DPROs to be Legislated for and resourced appropriately, including:
- * mandatory disability-proofing of all policy frameworks and relevant legislation and designs through **all** DPROs. Not all areas will be priorities for a DPRO, depending on the constituency, but that is our choice.
- * protection of DPROs from other civil society organisations muddying the waters by implying or claiming that they are representative and prime consultees (GC7, paras. 13-4, 51). They need to be held accountable to us.
- * DPRO-only consultations re disability-proofing, as opposed to broad public consultations (GC7, paras. 44, 49),
- * awareness-raising that the views and opinions of DPROs are to be prioritised on all disability-proofing (GC7, paras. 13-4, 23, 56).
- 3. In the meantime, the State needs to make up for lost time, because enormous damage is being done. A long overdue memo needs to go to DCEDIY with the instruction for it to be send to all public bodies stating that each public body has its own obligations to honour the State's obligations to DPROs (CRPD, Art. 8).

Instead, six years on, it is like the Wild West in terms of disability-proofing, and we cannot compete with service-providers and others muscling in on our function, and usually subsidised by the State in doing so; while we get zero funding or organisational support.

Setting up DPROs is more challenging than setting up something like a residents' association. As organisers, we ourselves have communications barriers, and our members also have a diverse range of communications needs that we need proper resourcing to meet (GC7, paras. 58-60).

However, it's like Catch 22. Unless our DPRO rights are recognised – and they are mostly being totally ignored – it is difficult to attract members, and the service-providers slick marketing and referrals premium means that disabled people of all backgrounds are diverted from awareness of their DPROs and the Human Rights model into being alibis for service-provider undermining of the CRPD.

I'll finish with this. Any Human Rights-based-group worthy of the name necessarily prioritises the perspectives of those of its members with least supports and resources (including those with most complex impairments. Even if DPROs had perfect balance in terms of intersectionality, and that is a worthy expectation that even the State and well-resourced organisations find difficult to achieve – unless we can show that the DPRO concept has practical meaning and results, it will remain difficult to get many disabled people to join, stay, and get involved, let alone the desirable representative diversity of backgrounds. Nobody wants to be wasting their time.