**Committee on the Rights of PERSONS with DISABILITIES**

Draft General comment on article 4.3 and 33.3 of the convention on the participation with persons with disabilities in the implementation and monitoring of the Convention [[1]](#footnote-2)\* (as dated 16 March 2018)

Response prepared by the Northwest Forum of People with Disabilities

**About the Northwest Forum of People with Disabilities.**

The Northwest Forum of People with Disabilities was established in April 1994 following a conference entitled “Setting the Agenda”. Participation at the conference was led by persons with disabilities across the North West of Northern Ireland.

We recognised the need to collectively organise ourselves as disabled people to speak for and on behalf of persons with disabilities ensuring that our voice informed and shaped the public and social policy agenda in the North West, Northern Ireland and elsewhere to promote and protect our human rights.

The Northwest Forum is 100% led by persons with disabilities. We are a pan disability organisation and are based in the North West of Northern Ireland (one of the most Western parts of Europe). Membership of our organisation includes people with mental health issues (psychological disabilities), learning disabilities (intellectual) and persons with physical, sensory and hidden disabilities.

The members of the Management Committee are volunteers and come from different socio-economic and political backgrounds. Membership of the organisation is open to all persons with disabilities, aged 18 or above. The Northwest Forum includes membership reflective of the multiple identity of persons with disabilities including women, older persons, men, those with a different sexual orientation, religious belief and political opinion.

At present we have no representation from children/young people and those persons from an ethnic minority background although the Forum’s membership is open to all adults regardless of ethnicity, gender, sexual orientation, religious or political opinion or socio-economic status.

While the Management Board does not include children and young people we have engaged with children and young persons with disabilities from a wide range of backgrounds through our peer advocacy and policy consultation services.

**Mission Statement**

The Northwest Forum seeks to uphold our human rights to ensure that our voice is represented in all areas affecting our daily lives. We do this through the following activities:-

* Policy consultation and engagement with public authorities including local, regional and national government and internationally;
* Peer advocacy service to support those of us who require assistance to articulate and convey our views;
* Promotes self advocacy among its membership through the development of user-led public life training programs subject to available resources;
* Disability Equality and Human Rights Training. This includes prompting awareness of the UN Convention on the Rights of Persons with Disabilities among people with disabilities and wider civic society including the promotion and awareness of the UN Committee’s concluding observations relating to the UK periodic examination in 2017.

With the logistic, financial support and encouragement from Disability Action Northern Ireland, the Northwest Forum of People with Disabilities was fortunate and privileged to have representation and participation within the UK wide delegation (Disability Action Northern Ireland Delegation) at the UN during the sessions of engagement with the UNCRPD Committee concerned with the UK Periodic Review Examination March/August 2017.

Committee members will be aware that Disability Action, a pan-disability Northern Ireland wide organisation, prepared and drafted the ‘Key Issues Paper’ and the Northern Ireland Shadow Report in consultation with disabled people and their representative organisations for the UK Periodic Examination and Review in 2017.

**Formal Submission**

**Overarching Comment**

The Northwest Forum of People with Disabilities welcome the opportunity to respond to the Draft General Comment concerned with the substantive meaning, purpose/objectives of Articles 4.3 and 33.3.

Our focus is concerned primarily with the standardisation and strengthening of key concepts such as “close consultation” and “active participation” through encouraging a stronger focus on the need for concrete consultation outcomes relating to Article 4.3 and the role of the Independent Mechanism with respect to Article 33.3.

We consider the scope and depth of the interpretation of Article 4.3 within the general comment as being too narrow. It fails in real terms to consider any guidance in relation to the fundamental importance of ensuring that States parties deliver qualitative and quantifiable outcomes as a result of close consultation, active participation/involvement in decision making processes.

In our view for the general comment to have any real value in enhancing our engagement with States parties and the ideal fulfilment in particular of Article 4.3 an authoritative explanation is required to clarify the importance of outcomes that result from effective and meaningful consultation with persons with disabilities.

It should never in any way be considered good enough for the States parties to claim ‘we have consulted with persons with disabilities’ as being the only measure in which full realisation of this particular article is deemed to be understood or properly and effectively implemented.

Hence States parties must be clear on how the close consultation and/or active participation has brought about real and meaningful change to the States parties intentions to fully realise the purpose and objective of Article 4.3 – regardless of whether they are policy, legislative or programmatic.

**Proposed Amendments**

**Organisations of Self Advocates**

**Paragraph 14**

Organisations of self advocates should cover all persons with disabilities including those with physical and sensory disabilities and those with complex support requirements. We are an organisation of self and peer advocates. We believe that all persons with disabilities should be encouraged to self advocate. Many disabled people, regardless of impairment, lack the confidence and have experienced a long history of not being allowed to speak our own behalf. Therefore **the term self advocate should be extended to include all persons with disabilities i**ncluding those persons with intellectual disabilities, autistic persons or persons with psychological disabilities.

We provide a peer advocacy service to support disabled people to engage with authorities and civic society to articulate their wishes. However we believe it is the right of all disabled people, where possible, to speak on their own behalf and to act in their own interests, without hindrance from others (including other disabled people unless there are invited to do so to support the self advocacy/peer advocacy processes).

**B. Scope of Article 4.3**

**Paragraph 18**

It is our experience that States parties tend to adopt a narrow interpretation of the term closely consult and have a limited understanding of the term active/effective participation or involvement of persons with disabilities within consultation processes.

One absolute measure of success to consider beyond, in our view, any other is whether or not active/effective participation or involvement of persons with disabilities delivers tangible outcomes for persons with disabilities or at the very least demonstrates to what extent we, as persons with disabilities, have influenced and informed the outcome of States parties consultation processes.

We would urge the Committee to fully recognise the historical position of persons with disabilities within consultation processes, where our views are generally non-existent when seeking to inform and influence the outcome of consultation processes. This is true within a wide variety of areas including; in the initial development and changes to public policy, legislation and programmatic activities undertaken by the States parties that have a direct or indirect impact on our lives.

The involvement of persons with disabilities within formal structures such as ad-hoc advisory committees and advisory boards, even those that seek the ongoing active participation of persons with disabilities should and must only be considered as a starting point to properly considering the concept and delivery of close consultation or effective participation in the consultation process by persons with disabilities.

The progressive full realisation of Article 4.3 and intrinsic relationship to all other articles within the Convention must be ultimately concerned with the delivery of concrete outcomes as a result of our close consultation, or active involvement, active participation in consultation processes.

The general comment should offer the highest standard possible when offering direction and clarity as to the purpose and objective of Article 4.3.

While we appreciate that members of the Committee are mindful of the global economic crisis and the restriction by some States parties of an effective dialogue on equality and human rights. The general comment, both subsequent and future authoritative statements from the Committee must always adhere to the ideal interpretation of an Article and its progressive realisation rather than being bound and limited solely by the politics of the present moment.

What value does any consultation or engagement process have with the States parties if the outcomes are not informed or influenced by persons with disabilities?

Whilst process is important, including accessibility, the numbers involved, extent of representation, resources allocated and support provided it is ultimately the outcomes of that process matter most.

**Additional text for insertion at the end of paragraph - States parties should be pro-actively encouraged to show evidence that demonstrates conclusively** the extent persons with disabilities have informed or influenced consultation practices, procedures and outcomes.

We believe that in addition to considering the multiple identities of disabled persons **reference should be made here to the inclusion of those persons with intellectual and high level support and communication requirements** as this particular group are more likely to face greater exclusion than any other particular demographic with the disabled persons movement.

**Paragraph 22**

The importance of including children with disabilities is paramount, although we believe an additional paragraph should be included that specifically refers to the inclusion of children with high level support requirements and communication needs. Children, more generally, are often excluded from consultation processes even where those processes are concerned with the individual child’s future. Committee members will be aware of the historical evidence that children with disabilities by default are often excluded from decision making processes regarding their care. This is even more likely with **children who have high level support requirements and communication needs (interpretation services and safe environment)**.

A recent example in the last 6 months the Northwest Forum undertook a case to advocate on behalf of a young person under the age of 18 regarding his relationship with his parents who were in the process of a legal separation. The Social Worker (court appointed advocate for the child) made recommendations about the child’s future without meeting the child and ascertaining their views. Through our experience of delivering advocacy services, the exclusion of children from genuine engagement about their future is unfortunately common practice, particularly children with high level support requirements and communication needs.

**Obligations of States Parties**

**Paragraph 34**

We believe that States parties should do more than take into account the evidence given to them as a result of consultations. We believe that States parties should demonstrate how persons with disabilities, through their DPO’s and OPD’s, **have influenced and informed the outcome of the consultation process.** Clear evidence must be provided that demonstrates how the State Party has informed disabled people how they have reflected their views. For example, many of the issues in relation to Welfare Reform Legislation in the UK were highlighted to the State during the consultation process. However, the State made very few changes to the policy and legislation as a result of that consultation.

As we have previously stated in our view it is insufficient to require the States parties to closely consult and actively involve disabled people without consideration of consultation outcomes and measuring to what extent the process delivers meaningful and concrete outcomes for persons with disabilities.

**Paragraph 36**

Please insert in addition to groups outlined **persons with high level complex support requirements and high level communication needs.**

**Paragraphs 42, 43, 44 and 45**

**Advocacy, Capacity Building and Directing Funding and Resources to DPO’s**

We very much welcome the spirit and direction of these paragraphs with respect to capacity building advocacy and resources. We hope the final draft retains these paragraphs with one caveat **states parties should ideally support DPO’s in particular to deliver their own capacity building programs with the co-operation of representatives of the state party - added to paragraph 43.**

A separate paragraph should be added after paragraph 44, stressing **the importance of disabled person led advocacy services both in relation to self and peer advocacy and the funding of capacity building programs for that specific purpose.**

**Paragraph 47**

Please insert in addition to groups outlined persons including women and children **with high level complex support requirements and high level communication needs.**

**Relationship with other provisions of the Convention**

We have observed that some of the previous General Comments adopted by the Committee are referenced in a number of paragraphs such as general comment No 1 (Article 12) Equal Recognition before the law, paragraph 60 and general comment No 5 (Article 19) Independent Living.

It would be helpful to reference all previous general comments with respect all other articles, with corresponding subject specific paragraphs for ease of reference, editorial consistency and their relationship in particular to the understanding, importance, scope and purpose of Article 4.3 and Article 33.3 where appropriate:-

* Reference general comment No 2 (Article 9) Accessibility within the corresponding subject specific paragraph 58;
* Reference general comment no 3 (Article 6) Women and Girls within the corresponding subject specific paragraph 52;
* Reference general comment no 4 (Article 24) Education within the corresponding subject specific paragraph 64;
* Reference general comment no 6 (Article 5) Equality and non- discrimination within the corresponding subject specific paragraph 53;

**Paragraph 72**

The Committee should encourage NHRI’s, Independent Mechanisms, to be exemplary models of good practice by developing consultation models of formal and structured ongoing engagement with Disabled Persons Organisations (DPO’s), Organisations of Persons with Disabilities (PDO’s) and other representative organisations, by ensuring the work of these bodies is influenced and informed by us.

**Paragraph 73**

We would recommend the removal of the word “**Even**” it suggests that DPO’s or OPD’s have a lesser entitlement to representation within the structure of focal points or coordination mechanisms than Civil Society Organisations. This could be interpreted as undermining the involvement of DPO’s or OPD’s whose organisations are led by a majority of persons with disabilities. (As defined in the draft general comment paragraph 14 (a) adopted from the CRPD Guidelines on the Participation of Disabled Person’s Organisations (DPO’s) and Civil Society Organisations (CSO’s).

**Conclusion**

We wish the Committee members well in your further deliberations on the draft comment and we hope that you will consider our response helpful and informative in that regard.

We would urge the Committee in particular to consider additional commentary on Article 4.3 and the importance of outcomes of persons with disabilities linked to the full realisation and implementation of this article.

1. **\*** Adopted by the Committee at its nineteen session (14 February – 9 March 2018). [↑](#footnote-ref-2)