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Dear Members of the Committee on the Rights of Persons with Disabilities,

The Tizard Centre at the University of Kent welcomes the draft General Comment No 7. We are delighted to be given the opportunity to provide feedback on the draft General Comment and inform the Committee about relevant research conducted at our department.

The Tizard Centre is the leading UK academic group working in intellectual disability, is known world-wide and has an international reputation. Members of the Centre are selected both for their academic record and for their practical experience in services. The Centre provides short courses as well as degree and diploma programmes at the University of Kent, Canterbury and also undertakes an extensive programme of consultancy and research - both nationally and internationally. The central mission of the Centre is to improve the quality of life of people with intellectual disabilities and autistic people through helping service agencies (both purchasers and providers) develop their own competence to provide and sustain high quality, comprehensive community care services, and to advance evidence based knowledge concerning the relationship between the organisation of intellectual disability and autism care services and their outcomes.

The Tizard Centre would like to comment on the following points of the draft General Comment:

**Definitions of ‘representative organisations’:**

Paragraph 14 defines ‘disabled people’s organisations’ and several other types of organisations *of* or *for* disabled people. However, under (d) a separate definition is provided for organisations of ‘self-advocates’. Based on ongoing research at our centre, this separation of organisations of self-advocates from ‘disabled people’s organisations’ (as per para 14 (a)) does not sufficiently represent the views of people with intellectual disabilities and autistic people.

* Organisations of people with an intellectual disability and/or autism have been historically labelled ‘self-advocacy organisations’ in English, however these organisations do not necessarily describe themselves as ‘self-advocacy organisations’. For example, People First groups often call themselves simply ‘organisations run by and for people with learning difficulties’.
* Furthermore, a similar label to the English ‘self-advocacy’ may not be available in all other languages.
* The term ‘self-advocacy’ is also contested by self-advocates themselves. Ongoing research at our centre interviewed 44 advocates and self-advocates who work at various intellectual disability and autistic advocacy groups in the UK and in Hungary, and it was found that there was no consensus among participants whether self-advocacy necessarily means someone with an intellectual disability or an autistic person. In fact, several autistic participants did not use the term ‘self-advocate’ at all. Instead they referred to themselves as an ‘autistic advocate’ or ‘autism advocate’. This is a shift in the language which should be recognised by the Committee.
* The separation of self-advocacy organisations from disabled people’s organisations in the present draft of the General Comment 7 does not take into account that people with a intellectual disability or autistic people are in fact disabled people. Various studies at our Centre revealed that people with an intellectual disability and autistic people strive to enjoy the same rights as everyone else, including disabled people who belong to other disability groups. Therefore, separation of the organisations of autistic people or people with an intellectual disability from organisations of disabled people is unreasonable and should not be maintained.
* Many autistic people or people with an intellectual disability already work within disabled people’s organisations (Para 14 (a)). We have strong evidence that suggests that many of these organisations (run and controlled by parents, professionals, human rights lawyers or people with other types of disabilities) regularly maintain tokenistic approaches to autistic people or people with an intellectual disability. Their involvement in the decision-making of organisations is often far from meaningful. In a recent study at our Centre, both disabled and non-disabled advocates admitted that disabled people’s organisations, and in fact the disability movement as a whole, often offers only symbolic or insufficient involvement for autistic people or people with an intellectual disability, who seldom have the chance to be meaningfully consulted on the decisions disabled people’s organisations take.
* The exclusion and tokenistic participation of people with an intellectual disability or autistic people within ‘disabled people’s organisations’ is a historic one, which has been present since the birth of the disability movement. Several studies have described how autistic people and people with an intellectual disability have been trying to have their voices heard within organisations controlled by parents and professionals who speak on behalf of them. This struggle for inclusion and self-representation is akin to the one of people with other types of disabilities who, for a long time in history were excluded from the leadership of organisations speaking for them.
* The separation of self-advocacy organisations from disabled people’s organisations runs the risk of maintaining the present power imbalance between parent-controlled organisations speaking for people with an intellectual disability or autistic people vs. organisations that are controlled by people with an intellectual disability or autistic people.

Therefore, we ask the Committee to remove Paragraph 14 point (d) altogether. It is our Centre’s assertion that ‘organisations of disabled people’ (Para 14 point (a)) is an inclusive category that applies to all disabled people, including people with an intellectual disability and autistic people who should be seen equal with other disabled people before the Committee.

We believe that only organisations controlled by people with an intellectual disability or by autistic people can and should represent them. Therefore all provisions that apply to ‘disabled people’s organisations’ under the quasi jurisprudence of the CRPD should be unequivocally applicable to organisations of autistic people and people with an intellectual disability.

The Tizard Centre remains at your service to provide more information at any time during the consultation process.

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Professor Rachel Forrester-Jones

Director, The Tizard Centre