

# Minutes of the Twenty Sixth Meeting of IHREC's Disability Advisory Committee

Monday, 13 November 2023

## Present:

- Adam Harris (AH) (Chair)
- Michael Seifu (MS)
- Peadar O'Dea (P'OD)
- Jacqui Brown (JB)
- Shelly Gaynor (SG)
- Eliona Gj (EG)
- Fiona Anderson (FA)
- Adrian Carroll (AC)
- Brian Hayes (BH)
- Sinead Gibney, Chief Commissioner (CC) (joined after lunch).

## Apologies:

- James Cawley (JC)
- Vivian Rath (VR)
- Aoife Price (AP)
- John Bosco Conama (JBC)
- Rosaleen McDonagh (RMCD)
- Gary Allen (GA)

## In attendance:

- Deirdre Malone, IHREC, Director (DM)
- Dr Iris Elliott, IHREC, Head of Policy and Research (IE)
- Annmarie Townsend (Secretariat), (AT)
- Ciara Lehane (CL) (item 2.1)
- Charienne Lawson (ChL) (item 2.1, 4.1)

## 1.1 Greetings, Apologies, Quorum, Declarations of Interest

No conflicts of interest raised. A round of Introductions occurred. EG prosed the previous minutes and BH seconded the minutes.

## 1.2 Matters Arising

### *The Green Paper on Disability Reform*

Following on from DAC's last meeting, members were invited to discuss the Green Paper and its conflicts with the CRPD. A number of members highlighted the work of Independent Living Movement Ireland (ILMI) on this matter and the resources on their website, Members recommended IHREC and others make a submission on the Green Paper. JB expressed concern that the cost of disability is not addressed separately. AC advised that the Green Paper is trying to create a link between welfare and employment and experts would be of the view that this is not the right

way to support disabled people. Additionally, AC advised the tiered structure does not capture how disabled people experience disability and other methods need to be used to increase the number of disabled people in employment. PO'D advised that the consultation process was initially unclear, leading some DPOs to be left out of the consultation process. P'OD suggested looking at whether there are other international systems that are managing this better. EG advised the consultation process caused a lot of concern and may have been in violation of CRPD with regards to participation and because the model is based on the medical model of disability. A number of members highlighted that it was positive that this paper is only a Green Paper, meaning there is still time for the process to be changed.

### 1.3 Update from Deirdre Malone

DM provided two updates. The first was on work in relation to IHREC's budget and how it relates to IHREC's mandate as the Independent Monitoring Mechanism (IMM) for the CRPD, as set out in the under *Assisted Decision Making (Capacity) Act*. DM advised that IHREC has engaged with the Department of Public Expenditure (DPER) to ensure the organisation is adequately funded for its mandates. However, to date no dedicated resources have been allocated for these mandates. IHREC envisages a new unit to support the IMM function, with a ring fenced budget. IHREC are working with DPER to advocate for these resources in 2024.

The second update was in relation to the stipend for DAC members. DM noted the frustration with IHREC regarding these payments. DM has written to the NSSO CEO and invited the NSSO to attend this meeting. The NSSO advised that they are liaising with the CEO of the external software company on accessibility issues and are meeting tomorrow. The NSSO felt it would be more appropriate to meet DAC after this meeting had taken place. The Corporate Services Head is meeting with the NSSO CEO today and taking the position that if it is not resolved immediately that IHREC will have to withdraw from the platform and NSSO will have to find a solution to support this. The outcome of that meeting will determine IHREC's next steps.

A number of DAC members voiced thanks for IHREC's work to resolve the issue. BH highlighted that it has been shocking and disappointing to not access the stipend. JB advised of the significant work involved in tracking finances, such as uploading emails and receipts, noting it is time consuming. JB also wondered who the secretariat for the DAC is. MS discussed the tax implications for members who were set up on Revenue as receiving bi-weekly payments from IHREC. SG wondered about how far back members need to go to get details for payments and EG wondered about the clinic that was suggested in the last meeting. DM advised that due to overall financial governance it is not possible to make payments in any other way than through the NSSO. DM will follow up with the finance manager in relation to how members were set up on Revenue. In relation to receipts, DM will highlight to the NSSO the impact of the burdensome nature of this requirement. In relation to the clinic, CS reached out to Revenue, who are trying to determine the appropriate person to attend. IHREC will suggest that online meetings occur to save people travelling. In relation to secretariat support, IE advised of recent staff changes and that the team will be looking to allocate the role before the next meeting in 2024.

### 2.1 Assisted Decision Making Capacity (Amendment) Act

This item was moved to after the lunch break. FA gave a presentation on this item, as was circulated to members in advance of the meeting. IE wondered what the main issues for people with psychosocial disabilities were and what can IHREC do to monitor these. FA advised that the main concerns are advance medical directives. FA highlighted that the State has reservations on the CRPD and advised that the UNCRPD have said that functional capacity tests are not compatible with the CRPD. IE advised that IHREC can make a note on what articles the State has reservations on and

begin dialogue with the State. JB suggested dialogue with the HSE Human Rights Office as well as with the State.

### 3.1 Work Plan 2024

IE spoke on the DAC work plan for 2024 and the functioning of the IMM. The team is proposing that there will be six meetings next year, from 11am-4pm in the IHREC offices, with hybrid facilities. Once plenary meetings are arranged, the team will survey DAC members for suitable dates. DAC members agreed to continue with meetings in this format. IE wondering if smaller group discussions during meetings would be beneficial. A number of DAC members agreed this would be useful. DAC members made a number of suggestions for the 2024 work plan which included, DAC engagement with the State and civil society, CRPD implementation, education and the possible review of the Disability Act, the possible introduction of safeguarding legislation, hate crimes legislation, the Green Paper on Disability Reform, violence against disabled people, disability rights and climate action and housing.

A number of members also suggested that when external speakers are invited into the DAC that they are given sufficient time to complete their presentations. AH suggested inviting speakers in the morning to prevent speakers being delayed. IE highlighted that the team have developed guidelines for speakers that can be circulated. MS suggested organising themes that affect many disabled people and themes that affect the most vulnerable disabled people as a means of focusing the work of DAC. EG wondered if there were resources for a survey in order to monitor progress and IE advised that IHREC have a market research contract in place in order to do polling. JB requested that independent monitoring reports from other countries are shared with the DAC to help them understand how to advise the Commission on the IMM function. IE advised that the approach to the IMM will be as important as the work of the IMM. IE can get a sense from colleagues in Northern Ireland on what the IMM will be assessed against and suggested that Malta's new disability commissioner could help inform the advice of the DAC. AH welcomed speakers on the IMM for the first meeting of DAC next year.

### 4.1 Impact of DAC for 2023

IE spoke to this item and invited thoughts from members on what the DAC would like their impact to look like. A number of members advised that they would like follow up on where their advice has been used by IHREC. IE suggested potential for a feedback loop on work, potentially using project management to track projects where DAC have provided advice, however this needs to be manageable so the team will come back to DAC with a proposal. CC highlighted that it is crucial for the DAC to understand their vital input however cautioned against too much analysis to ensure enough time to complete work. AH advised that the Chairs can, as part of preparation for meetings, look at what the key submissions have happened in-between meetings. EG suggested that a brief update be given as part of the AOB at meetings to ensure feedback does not become a burdensome process.

### 5.1 AOB

EG advised she will be talking about violence against children at a Barnardos community event. IE informed she will share the report from the GREVIO committee once publically published. IE updated the DAC on a positive outcome at the Court of Appeal around the Assessment of Need, a case in which IHREC joined as amicus. JB informed that she will circulate the DPO network report when published.

### 6.1 Information Sharing

This item was taken with AOB.

## 7.1 Reflections on the Meeting

A number of members advised that the chat box was only allowing members to message the secretariat and not the whole group. The team will look to resolve this.