

DCC Meeting 2:30 p.m. 10/11/2021

In attendance: Thomas Morrin, (Chair), Michael Murchan, Richard Brophy, Billy McCarthy DoH-, Alison Harnett, DFI; Dharragh Hunt, NDA; Derval McDonagh, Inclusion Ireland; Marie Lynch, DFI; Geraldine Graydon, National Parents & Siblings Alliance /ASFAN; Tom Casey, DSG.

Apologies: Patsy Carr, DoH; Anne Melly HSE; Una Nagle, BOC; Cathy McGrath, DFI.

1. Minutes of meeting held 16/6/2021

Minutes agreed and adopted.

2. Disability Services COVID update

As Anne Melly was unavailable to attend this meeting, it would not be possible to provide a COVID update from an HSE perspective. The Chair informed the committee that day services was being ramped back up towards full level provision since 22nd October 2021. DFI stated that a full level of day service provision isn't evident from its perspective owing to staffing absences/ illness COVID related.

Inclusion Ireland stated that the provision of respite services appears to be very patchy across the country and well below full service. She added that there has been a scattering of issues regarding the provision of PDS supports and services and an increase in waiting lists for therapeutic services.

Reports on the ground indicate that this is as a result of the lived COVID experience coupled with staffing shortages.

Geraldine Graydon reported that two transport operators in Lucan and South Dublin are experiencing serious problems providing transport to ASD services. This is a result of an ageing fleet repaired as required, but never replaced, this coupled with the rising price of diesel, has resulted in this crisis.

The Chair stated that Minister Rabbitte will be announcing funding of €8 million for the upgrading and improvement of the transport options for HSE funded organisations as a disability transport initiative in the coming days. This cash injection was badly needed and welcomed.

Michael Murchan stated that the level of COVID cases /outbreaks in mental health services has been very low, owing to several factors, including the huge effort of staff. He outlined that while mental health services had been impacted by the effects of COVID, CAMHS had managed a 90% services level provision, largely being maintained and improved with the roll out of the vaccination programme.

Urgent cases have continued to be seen, this has been possible and achieved with a greater use of blended care in conjunction with the use of Technology.

He added that waiting lists have increased over the last number of months but not substantially in comparison to pre-Covid times.

One waiting list area in which there has been a recognisable increase is in eating disorders, this has been a feature of COVID. €20m funding has been provided in funding this year to the HSE in conjunction with its partners for service provision; €10m has been earmarked in the budget for next year, this will be reflected in the HSE's National Service Plan.

Tom Casey expressed his disappointment that there hasn't been a more comprehensive update from the Department of Health, the Chair took on board his comments and agreed to more detailed reports and issuing of covid updates by mail to committee members.

Alison Harnett outlined that service providers have been experiencing difficulties in the provision of services due to the absence of staff members presenting with COVID symptoms. The impact has been a lot more significant this week.

She said that a letter will be issuing to the 3 Health Ministers and to Dr Tony Holohan, Colm Henry, Professor Karina Butler, Chair of the National Immunisation Advisory Committee (NIAC) and others on behalf of the National Federation of Voluntary Service Providers and the Trinity Centre for Ageing and Intellectual Disability calling on Government to consider the evidence of elevated risks present for people with intellectual disabilities and the value already demonstrated by prioritisation and recommend that people with ID (including those under 60 years of age) be included in the booster vaccination programme as a matter of urgency.

Action – forward COVID update to committee ASAP.

Secretariat to provide Alison Harnett with e-mail addresses for submission of letter as outlined above.

3 (a) Update on move to DCEIDIY

The Chair outlined that there had been a meeting earlier in the morning between DCEIDIY and DoH in relation to the move /transfer. He stated that the existing DCC committee and its equivalent in DCEIDIY shall remain in place for the first year.

It was suggested that this is an opportune time to examine the Terms of Reference (ToR) of the committee. Dharragh Hunt stated that insofar as he is aware, the ToR for every Department's DCC is the same and perhaps the existing ToR may need to be reviewed.

Action – Secretariat will e-mail current ToR to committee

The Chair will bring the issue for examination to the NDIS Steering Group

3(b) Longer term relationship between DoH & DCEIDIY

The Chair stated that the specific details of the relationship going forward are not available as there are certain issues that have yet to be agreed and finalised.

Any updates in relation to same will be forward to the committee in due course.

4 - Update from NDIS meeting.

The Chair outlined that all major Disability Umbrella Groups/ organisations have submitted comments on the UNCRPD Consultation Plan to the DoH and these have been forwarded to the Dept/Justice for assimilation.

He added that there is a lead Department in respect of each action in the plan.

5 AOB 1 – Personalised Budgets (PB) update.

Una Nagle asked for an update in relation to this. The Chair stated that the PB scheme is on-going, but progress has not been as had hoped, COVID being a chief factor in this. There are circa 100 people on board at present, (co-managed and direct payments options), exact breakdown not available. It was hoped to have 180 participants on board by 2022, this will not now happen.

The evaluation process is on-going and being co-ordinated by the NDA, the NDA is trying to get ethical approval from the majority of the service providers. Dharragh Hunt said that he didn't have any specific information as to why would be participants dropped out of the scheme before taking it up.

Geraldine Graydon stated that a lot of ASD people ranging from their late 20's up to 50's are high functioning and are depending on the PB scheme for some meaningful way of life, 1% of the population are on the ASD spectrum (circa 45K) and that the State will have to pay in the long term for providing residential support for this cohort which will be far more expensive. She added that the PB scheme was working in in the UK and other jurisdictions and that she had flagged at the PB Task Force that the PB scheme could never be implemented from within existing funding.

Marie Lynch stated that if there are to be reduced numbers in the scheme, it is essential that the numbers are balanced regarding representations from various groups and impairments.

AOB 2- Use of the term Intellectual Disability (I D).

Una Nagle requested this item on the agenda.

She said that they have feedback from persons supported, families and members of its Board of Directors who feel that this term is no longer appropriate when used to describe the persons supported and wonder if the Department is looking to change it into the future to come in line with focus of supporting ability rather than disability.

Following a brief discussion, overall, the committee did not have any issue(s) with the term, I.D., cognisant of this and other phrases being used regarding people/persons with a disability.

Geraldine Graydon stated that the term I D is used in respect of ADHD, Dyspraxia and ASD, she added that some people use the term "mild autism" which is incorrect, a diagnosis of ASD means autism, period.

Alison Harnett stated that she has some text in relation to language used pertaining to people with disabilities that she had sent on to the National Consultative Committee for their

consideration and that she will forward same to the secretariat for consideration in this debate.

Action: Alison Harnett to forward text in relation to I D and associated terminology to the secretariat for circulation to the committee.

AOB 3 – Michael Murchan outlined that an additional €24m additional funding has been secured in the Budget in respect of Mental Health Intellectual Disability Services in 2022. Details of this funding is being teased out with the HSE; €2m is earmarked specifically for ADHD, the HSE's 2022 National Service Plan will have a detailed breakdown of the additional funding.

Respite – The Chair outlined that an additional €105m has been secured in the Budget for 2022. Next year, there will be 1 new respite centre in each CHO, he cannot give specific details in respect of in-house respite as these figures are being worked on presently and will be detailed in the 2022 HSE Service Plan.

He added that additional funding has been secured for additional therapists, more specific details will be available at the next meeting.

Action – The Chair will forward details in respect of respite provision to Geraldine Graydon once NSP is finalised.

AOB 4 – Alison Harnett expressed disappointment that the Budget did not address the Disability Capacity review findings.

Derval McDonagh stated that for projects to have meaningful results (she instanced the Congregated Settings initiative) financial allocations to such initiatives need to have multi-annual budgets allocated thereto, if such funding is not provided, such projects are likely not to be successful.

6 Next meeting

Once the dates for the 4 NDIS meetings have been selected, the 2022 quarterly DCC meeting dates will be set and notified to the committee.