



We would like to thank the committee for their invitation this morning. My name is Ruth Gilhool, joined by Margaret Lennon. We are two of the co-founders and admins of the DCA Warriors group. We currently represent almost 20,000 parents. Our main issues with the new Standard Operating Procedure for Assessment of Need are the lack of consultation and the failure to inform parents of the changes in this procedure. The full text of the SOP is not available on line at time of writing, and it has been in operation for some time already. Parents should be fully informed of matters affecting their children's health and wellbeing, in particular if their needs are complex.

“Diagnosis is the gateway to treatment and the subsequent reduction of symptoms and increased cognitive and adaptive functioning for the majority of children on the Autism Spectrum. Every day this is delayed leads to missed learning opportunities.” Dr Rita Honan

We in particular have issue with the initial screening process, which consists of an overly complicated application form, additional information sought by phone, and then a Preliminary Team assessment, of no more than 90 minutes. We do not consider this a sufficient amount of time to make a determination of Disability in a child. Correct assessment and diagnosis is vital for parents in order to be able to effectively advocate for their child. Under the constitution, parents are the primary educators of the child, and with complex health and educational needs, it is essential that these needs are determined under clinical best practice standards. Lack of a diagnosis hinders intervention which has an impact on health, mental health and education;

Without significant investment in staffing numbers, the new PTA(Primary Team Assessment) will pull clinicians away from their positions in EIT, SADT (School Age Disability Team) and Primary Care Teams, in order to carry out screening as part of PTA. This will result a delay to intervention and lengthening waiting lists for these services, already over 4 years in some areas, exacerbated by children subsequently being referred onto these lists after the screening process. This process moves children effectively from the waiting list for assessment of need, which has a statutory time-frame attached to it, to the waiting lists of either the Disability Network Team, Early Intervention Team or School Age Team, which don't have such a time frame. These lists are already lengthy, with waiting lists of up to 4 years being operated in some parts of the country.

Not having timely and full assessment and diagnosis, where warranted, of a child's needs, puts a child at a distinct disadvantage when it comes to having their health and educational needs met, with knock on effects into the applications for school supports, specialised school placements, ASD preschool, Home Tuition. We outline these effects in the briefing document we have supplied to you.

Early intervention is crucial, for those with milder initial presentations, as well as the more severely affected. An investment in early intervention can save a significant amount of money in the long run, not to mention the improvement in quality of life of the child and their family. If appropriate supports can't be accessed due to a child being on a lengthy waiting list, the knock on effect, in particular on the area of mental health are in some cases catastrophic, and we see examples of this from our membership on a daily basis. The proposed approach by the HSE is short-sighted and pushes problems down the line, where they will be more severe and costly to resolve.

We would like to thank you for your time and we invite any questions, which Margaret Lennon will be happy to answer for you.