OPENING STATEMENT OF GARETH NOBLE, CHILD LAW SOLICITOR, KOD LYONS.

Firstly, I would like to thank the Chair and this joint committee on Children, Disability, Equality and Integration for the kind invitation to attend today's session. I do so in the context of an excellent study by the Ombudsman for Children in relation to the unmet needs of children whose assessments are required and where services are badly needed. I come before the committee today as somebody who has attempted to use advocacy and legal avenues to highlight the challenges, deficits and gaps in provision brought to me on behalf on children and their families and to assist those families navigate the system and the hurdles they face.

The Disability Act of 2005 created a most progressive path for children in having their assessments and services identified. The intention of the Oireachtas at the time was to ensure that children within a short space of time could have their assessment needs determined. The purpose of the Act is to ensure that assessments are conducted to ascertain whether or not a child has a diagnosis or a disability and the extent of that disability. The Disability Act sets out very clearly that the provision of an assessment must be commenced within 3 months of its initial referral and completed without undue delay and certainly no later than 3 months from its commencement.

It is a national scandal that 91% of children do not receive their assessments within the timeframe prescribed and mandated by law. It has led to untold and ongoing damage, stress and real prejudice to children. It cannot be dressed up as being anything other than a breach of their rights. It is also hugely significant to note that the Oireachtas made it clear under the Act that an assessment should be carried out without regard to costs or capacity to provide the assessment.

The dilemma faced by many parents when their children are not meeting their developmental milestones, are presenting with challenges, are being left behind by their peers, where they may be non verbal, unable to perform basic tasks independently, totally reliant on their care givers, is to how best to proceed to meet the needs of their children in a timely manner. The Disability Act provides them with a mechanism to achieve a pathway to progress. Sadly however it is not just the letter but the spirit of this legislation that has been, and continues to be bypassed, circumnavigated and routinely ignored. The overall health budget for 2020 as set out in the approved service plan was some 17 billion euro and yet the priority provided to children in assessing and meeting their needs remain woefully inadequate.

Why do children require assessments?

It is always important for any parent to determine the needs of their child. It is also crucially important for children that they receive that intervention and assessment in a timely manner and to ensure there is no further regression, prejudice or loss of opportunity. An assessment of need is often a gateway to other services - to an appropriate type of school learning environment, to Special Needs Assistant provision, to resource teaching hours, to applications for Domiciliary Care Allowance to help support their needs.

The New Model for Assessing Children

Against a back drop of failing children and their basic legal entitlements the HSE in January 2020 introduced a new model of how children are to be assessed and they did so without any adequate communication with the representative bodies. They did so without any adequate concern for the needs of the children in question and their families. They have in effect sought to kick the can down the road in the proper assessment of children and they have sought to do so in a blatant and cynical way. Under the new model children will no longer be assessed as they have heretofore under the Act. There will be no multidisciplinary assessments which seeks to determine what the act requires i.e. to determine whether or not a child has a disability and the extent of those needs. Instead we have a triage system where an initial assessment will be conducted to ascertain whether further assessments are required. The child in need of the ASD assessment will not have that assessment commenced or completed within the 6 month time limit prescribed by law or at all. Instead the HSE have sought to include such assessments in Service statements which they will then claim are subject to resources.

How can we create a Service Statement setting out the services needed for children when we haven’t assessed what those needs are in the first place? How can this model possibly be said to be in compliance with the Disability Act? Whose interests does it serve? One thing is clear; it does not serve the interests of children requiring early intervention.

In a High Court Affidavit provided and endorsed by the Court over 2 years ago, the renowned expert in Autism Dr Rita Honan set out the clinical rationale for early identification and early service delivery. In her affidavit she said that the diagnostic assessment is the gateway to treatment and the subsequent reduction of symptoms, increased cognitive and adaptive functioning for the majority of children on the Autism spectrum. Every day this is delayed leads to missed learning opportunities. Ms Honan stated that retrospective analysis suggests that differences in development between typically developing children and those with Autism maybe be apparent at an early stage in a child’s development. Detecting young children at risk before the full impact of the syndrome is present and implementing treatments can alter the course of early behavioural and brain development, thus resulting in improved outcomes.

The HSE is well aware of the critical need for early diagnosis and dedicated intervention. The Ombudsman for Children report clearly highlights the continuing challenges faced by children and by their families. During the Covid 19 Pandemic the UK parliament amended legislation that suspended the operation of certain legal requirements for children. To the great credit of this Oireachtas we did not do the same. The Disability Act remains in force and stands tall as a progressive piece of legislation. It simply requires the HSE to implement it.

I fear very much that a substantial further number of children face the real risk of being lost and their childhoods diminished as a result of the new model and that service delivery will therefore be even more out of reach than previously.

So, what can this committee do next?

I would very much welcome a motion on both floors of the Oireachtas, taken on a cross party basis, reaffirming the Oireachtas's intentions and aspirations regarding children and their assessments under the Disability Act. A reaffirmation of these assessments being delivered in full, on time and as provided for within the six month period set out in the Act. That would be a powerful response to what is emerging. It would vindicate the position of the Ombudsman for Children and the representative bodies holding the line against this non child centred approach. It would recognise the campaigning efforts of many groups I have had the pleasure of working with on childre'ns rights issues – the DCA Warriors, Dyspraxia Ireland, Down Syndrome Ireland, Family Carers Ireland, AsiAM, the Involve Autism D6 group, the D12 campaign for an autism specific school and inclusion, the Children's Rights Alliance and many others. Most fundamentally of all it would show to children and their families that the Oireachtas has not forgotten the importance it attaches to the full workings of the Disability Act.

Can I thank this committee for bringing this vitally important matter for children into the public arena. It is incumbent on all of us to ensure that the needs of these very vulnerable children and their families are met and their potential as fully functioning young people and adults can be realised. I know many TDs and senators have often said to me how busy their constituency clinics and email inboxes are from families on this issue. It is a very real challenge up and down the country and it is therefore vital that we get this right. This is about enabling children. It is about helping them to be the best that they can be and removing unnecessary obstacles and barriers to allow them to reach that full potential.

Many thanks