Firstly, I would like to thank the Oireachtas Joint Committee on inviting me here today

1. **My Submission recommended to the committee that consideration be given to transferring the HSE Disability Unit including its Budget Allocation, Disability Staff and Accommodation to a specialised Department for Disability. The responsibility then would lie with the Minister for Disabilities.**
2. **I am proposing the statutory provision of a Families/Guardian/Carers liaison office within this newly formed Disability Department. This office would be the voice for same in planning services, highlighting gaps in services and be a member of the annual financial allocation team. The office would engage with Families/Guardians and Carers, solicit their views and expertise and advocate at the highest level.**

Name is David Doyle

I am firstly the proud father of a 28th year old young lady with a diagnosis of ASD, Moderate learning disability and complex Mental Health, who from an early age presented with severe behaviors that challenge that required multiple staff and family to support her.

I am a longstanding advocate of that "when a child or adult is diagnosed with Autism that is it an actually diagnosis on the whole Family, as it impacts directly on the whole family. It can impact major family discussions for your work life, social life, sporting life & takes the whole family on a new road that no one could have predicted.

My submission stems from having come from 21 years, being self-employed in a commercial unrelated profession, to now having 22 years working on the ground and at senior management level within the disability sector. I am delighted to be able to share my personal experiences and offer 2 suggestions in an alternative pathway for service delivery, but, most of all I hope my input will offer hope to families who feel that the disability sector is not catering for their needs at this time.

My motivation in submitting this submission is to help promote the importance of a "Partnership approach" in our efforts to provide children and adults with Autism and those with Intellectual Disabilities with services that suits their ever changing individual needs.

My recent professional experience has seen me work both on the front line and at senior management level, I have sat on numerous consultative forums. I currently fill the roles of development officer, complaint officer and I manage an equine therapy centre within the disability sector for my employer but my real expertise comes from being a parent with a child with Autism, Intellectual Disabilities and Behaviors that Challenge.

I have travelled and conversed extensively in Europe and North America in trying to understand the world of Autism. It was during one of these trips that I recognised the value of Equine Therapy and especially the Horseboy Method for children and adults with Autism. This led to the establishment by my employers of an Equine Therapy Centre specifically designed for people on the Autism Spectrum. But this submission is not about the values of alternative therapies but a personal holistic view for best practice for enhancing the quality of life for those with disabilities and especially the families that care for them.

Please note that this is submission is based on my own personal viewpoint, experience, observation and research. It is also important that I acknowledge the Hard Working, Caring and sometimes frustrated local HSE CHO Disability Managers, Case Managers, Multidisciplinary team members**,** Financial and Administration Staff who despite highlighting the budgeting and planning shortfalls to the hierarchy of the HSE receive little hope of ever being able to cater for the disability needs in their area. It is this lack of prioritization of disability services and a perceived lack of empathy towards children and adults with intellectual disabilities and autism services from the highest level within the HSE that frustrates families. It is so demeaning to families to constantly have to lobby Oireachtas Representatives for basic services. Unfortunately, for people with disabilities the voices at the top table when the HSE is allocating yearly budget to disabilities sector are either (a) not advocating strongly enough or (b) not heard, either way, it is time for change. Hence this Submission.

The establishment of the first Minister of State for Disabilities in 2016 gave a glimmer hope to the disability sector, but alas, it became very clear that without ministerial department control of services, finances and future planning disability would remain subservient to the acute sector.

> **For this reason, I strongly recommend to the committee that consideration be given to transferring the HSE Disability Unit including its Budget Allocation, Disability Staff and Accommodation to a specialised Department for Disability within the Department of Health. The responsibility then would lie with the Minister for Disabilities.**

Intellectual Disability and Autism is the one sector under the health remit that can be preplanned. These diagnoses are *lifelong* which makes it easy for strategic planning of services along the different stages of a person's lives. The publication of " *Value for Money and Policy Review of Disability Services in Ireland 2012"* gave great insight into where the sector was at in 2012 and what was needed to be done.

"The Vision.

-*Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;*

- *Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services.*

- *Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing.*

- *Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential;*

- *Carers would be acknowledged and supported in their caring role."*

(*Value for Money and Policy Review of Disability Services in Ireland 2012")*

Unfortunately, the HSE used the report to cut costs by top slicing all organizations thus penalizing those organisations who were already cost efficient and opted to ignore areas such as future planning for service users, multi annual budgeting to recognizing and Capital infostructure needs and family and carers supports**.**

Taking all of the above into consideration it is my personal view that HSE is not a right fit for disabilities. The lack of Respite Care, increasing waiting lists for Interventions, the lack of planning for Day Services, Residential Services, Respite Services and Multi-D Services, together with the lack of planning on specified areas, such as Autism all support my view that the HSE is not a right fit for Disabilities.

We have known for over 15 years that there is an increasing number of Children being diagnosed on the ASD spectrum but alas no plans were put in place to cope with the increasing demands on services or infrastructure. Plenty of aspiration down to the years but no multiannual financed plan. The Federation of Voluntary Bodies have constantly been highlighting the deficits in current service provision. Their 2021 prebudget submission included

"*Resources Commit to ringfenced multiannual funding. €211 million is needed per year for 5 years to address underlying needs, deficits and inequalities. The publication of the Capacity Review of Disability Services will only be of benefit and have any meaningful impact on supporting the rights of people with disabilities if: There is commitment to ringfenced, multiannual investment in line with the requirements of the report;*

- *Initial investment of €211 million is made in 2021 to address the most pressing needs, which have become even more urgent in the context of reduced supports experienced due to Covid 19;*

- *Structural and fundamental issues affecting the sustainability of services to support people are addressed – including deficits and Section 39 parity. Funding for Covid-19 related costs must be provided to enable services to provide adequate supports in 2021".*

(Pre-Budget Submission 2021 Forgotten Citizens National Federation of Voluntary Bodies)

The current Minister through lobbing from service users, families and providers secured an extra funding for the disability sector this year which in its self provides the evidence that the HSE is not advocating for disabilities. This additional is welcome but I now appeal to the minister, for HSE accountability for same. This money should be earmarked for front line service provision by way of new services, enhanced services, future planning, reducing waiting lists, reducing provider's deficits, etc.… It should not be used for reducing the local CHO's offices current deficits, this would be rewarding the HSE for years of underfunding the sector and not make inroad to the current difficulties.

Partnership Approach

I am also proposing the statutory provision of a Families/Guardian/Carers liaison office within the Disability Department. This office would be the voice for same in planning services, highlighting gaps in services and be a member of the annual financial allocation team. The office would engage with Families/Guardians and Carers, solicit their views and expertise and advocate at the highest level.

Carers, Families and Guardians play a huge part in service provision. Their efforts usually go unappreciated. This is especially evident in families with an adult with intellectual disabilities or those with autism. With the establishment of the HSE they rapidly abandoned the "Enhancing The Partnership" policy. It is truly astonishing to witness the uncaring and unemphatic approach by the HSE towards plight of families and there is still no long term financed plan. I list few examples hereunder:

Children are on long waiting lists for services with some aging out of the early intervention before receiving supports.

- *More than 1250 people are supported in the family home by a primary carer who is over the age of 70, at least 400 of whom are over the age of 80.*

- *Current resources have allowed services to resume to approximately 40% of capacity pre COVID-19, but this leaves many people without the level of support that they need.* (Pre-Budget Submission 2021 Forgotten Citizens National Federation of Voluntary Bodies)

Thank you for listening to me.

I now invite questions

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