Towards equitable access to quality services for children and young people with disabilities in Ireland.

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About this Report: This report was commissioned by Disability Services, Community Operations, of the Health Service Executive. Its purpose is to provide an independent opinion and offer recommendations. The views expressed in this report are the author's views and should not be taken to be the views of the Department of Health, Health Services Executive or any other stakeholders in the disability sector.

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Report Summary

There is tremendous potential to create dramatic improvements in disability services for children and young people in Ireland. Both service users and service providers are strongly motivated to achieve this. The role of service users, including the families of children and young persons with disability, should be dramatically increased; and in full consultation with them.

Communication for both service users and providers requires considerable improvement. Progressing Disability Services (PDS) has an ethos of service provision and an approach to structural change that is supported by a broad range of stakeholders. Given the structure of the Irish disability and related services, achieving effective reconfiguration of these services is complex and challenging. Implementing PDS is long overdue and must be an immediate priority; however, this alone will not address all the problems. More resources are also urgently needed; as is the opportunity for, and the embracing of, greater working flexibility by practitioners.

The approach to Assessment of Need (AON) should be distilled, shortened and distinct from diagnosis. A tiered approach to assessment, which reflects the complexity of case presentation, is both prudent and appropriate in the Irish context. There is no agreed international best practice in this regard. There is no evidence that the tiered approach to assessment suggested by the HSE constitutes any significant risk to service users or service providers; while the risks of not implementing such an approach are already clearly demonstrated. These risks include long waiting times, inequitable access and the inevitable confounding of the difficulties being faced by children and young people with disabilities, and their families. Assessments could legitimately be undertaken by a single practitioner; with appropriate training and experience. As staff skills rather than staff types, is the critical issue, a range of different professions could undertake such assessments.

Practitioners have legitimate concerns that deviation from practices recommended by their professional bodies may compromise safety or effectiveness. The HSE, professional bodies, and other stakeholders, should collaborate on empirically exploring and identifying the necessary skill mix for relevant tasks to be effectively and safely undertaken within the specific service provision context extant in Ireland.

Due to the complexity of the disability sector in Ireland, stakeholders have focused on the issues most proximate to their own concerns and have sometimes neglected the ultimate aims of the service, which can only be achieved through closer and more constructive partnership between all stakeholders. This report makes some generic suggestions regarding the overall approach to disability services for children and young people with disability; as well as 34 immediate and specific Recommendations for Action. It is intended to supplement and continue the momentum produced by a plethora of other recent and related reports and not in any way to replace or supersede them.

As the Disability Act (2005) preceded the adoption of the United Nations Convention on the Rights of Persons with Disabilities (in December 2006); the Act should be reviewed to revise terminology and more clearly support service users to enact their rights; with regard to Ireland's belated ratification of the Convention.

1. Introduction

The UNCRPD (2006) was ratified by Ireland in 2018; being the last country in Europe to do so. Ratification means that the State agrees to be held to account for implementing the Articles of the UNCRPD. The Preamble of the UNCRPD states that "Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child". The convention goes on to detail rights with regard to health, education, participation and many more.

Within Ireland, there exists a rich policy context for access to services for children and young people with disability. This includes the Primary Care Strategy; A Vision for Change: Report of the Expert Group on Mental Health Policy; Progressing Disability Services for Children and Young People; Best Practice Guidelines for the Assessment and Diagnosis of Autistic Spectrum Disorders for Children and Adolescents (Birth to 18 years); National Policy on Access to Services for Children and Young People with Disability and Developmental Delay; Framework for Collaborative Working between Education and Health Professionals 2013; Outcomes for Children and their Families – Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Services; Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services; Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders; Assessment of Need Standard Operating Procedure; HSE Autism Spectrum Disorder (ASD) Diagnostic Protocol – Discussion Paper and the Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders, Value for Money and Policy Review of Disability Services in Ireland; and the Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders. In addition, there is the Education for Persons with Special Education Needs Act 2004 and the Joint Protocol for Interagency Collaboration between the Health Service Executive and TUSLA - Child & Family Agency to Promote the Best Interests of Children and Families; these both being examples of the need for cross -sectoral working.

2. Progressing Disability Services

Transforming Lives is a broad programme of change being undertaken by the HSE and partners within the disability sector. This includes *Time to Move on from Congregated Settings* (regarding residential centres), *New Directions* (regarding adult day services) and *Progressing Disability Services for Children* *and Young People* (regarding services for children). Progressing Disability Services (PDS) is therefore the key policy document for the disability sector pertaining to children and young people with disabilities. PDS seeks to make access to the services children need easier; to provide services in a way that is considered fair; and to enable health services to work with families and education services to support children and young people with disabilities to achieve their optimal potential. PDS requires that services be needs-based rather than diagnosis-based, and that they be provided in the locality where people live. The achievement of these aims requires a number of important changes in the way that services are currently provided; including different organisations providing disability services in a given area working together in Children's Disability Network Teams (CDNT). This may require staff to move, or organisations to change aspects of their service provision. It may also require that families with a child with a disability change the practitioners they have previously been supported by. The process of moving from single organisation, diagnosis-based services, to needs-based Children's Disability Network Teams, many of them multiagency teams, is referred to as reconfiguring the service. The country is divided into nine areas; progress at reconfiguring PDS varies considerably in these different areas. Depending on population size each area has one or more implementation teams. There are 24 Local Implementation Groups (LIGs) which include parents and all the services in their area. Some areas have not yet reconfigured their services in a way that meaningfully impacts on service users.

There are a number of guidance documents that have been developed to facilitate the change process and the establishment of CDNT. These include: Guidelines for Local Implementation Groups on developing a Governance Structure and Policies for Children's Disability Services; Guidelines on Training and Development for Children's Network Disability Teams; Guidelines on Parent and Service User Representation on LIGs; Framework for Collaborative Working between Health and Education; Guidelines on Reconfiguration of Services; Guidelines on Individual Family Service Plans; and Guidance on Specialist Supports; Guidance on Family Forums; National Policy on Access to Services for Children with Disability or Developmental Delay; Guidelines on Communication for LIGs; Interim Standards for Children's Disability Network Teams; Policy Framework for CDNTs.

3. Tullamore Workshop

On being invited to act as an advisor to the HSE Disability Operations Team; the author of this report, suggested that a two-day meeting with a full range of stakeholders would be an appropriate way of addressing both broader issues of access to services and of discussing specific issues regarding Autism Spectrum Disorder (ASD). The facilitator asserted that ASD was chosen to provide more focus for the meeting, although the workshop would address other types of disability. The aim and design of the meeting was at the initiative and discretion of the facilitator, who was supported by the HSE National Disability Operations Team, in identifying participants, the venue and timing. The workshop was undertaken on the understanding that the facilitator was independent, not representing the HSE or any other stakeholder; and would make recommendations for how to improve access to services for all stakeholders.

This report is based on the workshop held in Tullamore in September 2018, *and on other discussions* which the author has held with a variety of stakeholders over the last few months. The aim of the workshop was to “Improve equitable access to quality services for children and young people with disabilities, especially for those with Autism Spectrum Disorder (ASD)”. The motivation for the workshop was to understand and address the significant variation in the time that children and young people with disabilities must wait for access to services, in different parts of the country. ASD was especially highlighted as a condition for which there are particular backlogs. Considerable and justified frustration with the service is a response to the reality that it is failing to provide for the needs of service users and failing to adequately provide for their rights under the Disability Act (2005).

While it was acknowledged at the beginning of the workshop that PDS was the context within which our discussions would take place it was important not to frame the workshop simply within these terms – i.e. implementing PDS; as there are other structures in place at local and national level to progress PDS. Instead, a broader approach was taken with the hope that participants would reflect more generally on disability services; while also allowing for focused discussions on specific issues as the workshop progressed. The schedule for the first day was therefore quite structured while for the second day it identified only broad themes to allow us to respond to challenges and issues that arose from the first day. It must be acknowledged that this more open approach – because it is less certain – may have been uncomfortable for some participants who would have preferred more structure and more clarity from the outset. Such an approach is also more challenging; and it is important to emphasize that this was the case for all participants, including those from the HSE Disability Operations Team.

4. Workshop Approach

The facilitator undertook to provide a report with specific proposals to address barriers in the system; and that this would be circulated to participants of the workshop for comment regarding any factual errors, before the final draft was submitted to the HSE. This report was to identify themes arising from the workshop and related discussions and does not seek to summarize the workshop per se or to comment on any specific policies.

The facilitator also asked for the development of an ethos within the workshop that reflected a sense of the challenge of service provision being a shared problem; where different perspectives exist and that participants really wanted to understand why others may see things differently; and that we were mutual resources to each other. The facilitator also asked that the conversation be conducted in the room, not outside it on social media or by communicating with others elsewhere.

5. Workshop Structure and Process

The first day included presentations from parents of service users, the National Disability Authority, the Health Services Executive and the facilitator. There was a very strong level of engagement and of constructive questioning from a broad range of stakeholders after these presentations. There was also some querying of the motivation, objectives, scheduling and process of the workshop. There was a considerable degree of suspicion and distrust expressed by some participants, especially from parents. While individuals were clearly very motivated and often talked positively about service users, colleagues or the objectives of their work; attitudes towards service provision more generally was, at times, extremely negative; and it was evident that this attitude was exhausting. My own sense was that service users and service providers often felt that the best they can do is to focus on their own most proximate issues, rather than addressing broader systems issue. On the first day of the workshop in particular it was difficult to establish a narrative that saw the objectives of the meeting addressing a shared problem; which would necessarily require shared solutions, rather than diverse professional perspectives of the problem. There was also – at least from some participants – suspicion that the motivation of the facilitator was other than had been stated; or that he was being used, or was naively complicit in some sort of deception, or perfunctory consultative exercise. The repeated statement of the motivation and objectives that were stated at the outset, seemed not to be accepted by all participants.

After such a challenging first day it would have been understandable if many had not attended for the second day; but in fact the vast majority of those who were able to come back for the second day, did so; as well as some who had not been able to attend on the first day. Participants were conscientious, returning promptly from breaks and engaging with the process. The second day had a stronger sense of determination to make some sort of progress. People worked well in groups and there was strong engagement in the plenary discussions. While this was achieved, it was at the expense of not fully tackling some important issues (such as Assessment of Need – discussed later). Nonetheless, some very useful discussions emerged, as well as a stronger collective sense of the need to move things forward.

It is also important to state that some of the conversations I have had in private with individuals offered an important perspective on the workshop, from people who felt they were not free to contribute more publically. That they should perceive that there is a dominant narrative which is not wise to question publicly, is concerning. The workshop represented a microcosm of the larger challenges and frustrations, as well as the enormous dedication of those engaged with the system – on both the service provision and service users' sides.

I want to reiterate the considerable frustration expressed by the parents of service users. On the first day there were two different presentations from parents of users of children's disability services. The first highlighted very clearly the inadequacy of services in one area; perhaps most clearly demonstrated for children who had received an Assessment of Need being referred to an intervention service, which effectively did not exist. Such referrals have persisted for close to five years, and represent a catastrophic failure to meet the obligations of services provision, and a tremendous loss of opportunity for intervention, access to education, improvement in the quality of life and to prevent problem-escalation for service users and their families.

The second presentation more explicitly addressed the positioning of disability and disability-related services, within Irish society. It also promoted a model of support and intervention where the families of service users were strongly involved in supporting users, and in supporting each other through networking and exchanging experiences. This approach is characteristic of the drive for much greater empowerment and inclusion of people with disability, which is embedded in the UNCRPD, recently ratified by Ireland. This approach also challenges the privileged position of clinicians within a medical-model of disability; and is likely to be an enduring theme in Ireland in the decades ahead. However, it is also important to acknowledge that many clinicians are also promoting a stronger orientation toward family-centered and community-based services.

ISSUES AND RECOMMENDATIONS

6. Fully Implement Progressing Disability Services

A considerable period of time has elapsed since PDS was introduced and the majority of services have yet to be fully reconfigured into Children's Disability Network Teams as described in PDS. It is also important to note that, as one workshop participant remarked "PDS addresses structure, but not capacity"; that is, there is a perception among some, that to date while PDS may reorganize services, it does not necessarily provide more resources. As stated below, more resources are needed to build capacity to deliver equitable services; however, poor structures erode existing capacity through inefficiencies and inequities; while better structures have the potential to capitalise on – but not compensate for a lack of –existing capacity. It is surely evident that the implementation of PDS is incredibly complex within the structure of the Irish disability sector and serious challenges remain. In 2017 a conference was held to demonstrate the achievements of Community Disability Network Teams (CDNTs) and to share learning from areas which have reconfigured, demonstrated innovative practices and partnership with families. This is a promising initiative and much more needs to be done in this regard, especially concerning promoting equitable access to services and this will inevitably require more resources.

Nonetheless the was a strong endorsement for the ethos of PDS at the workshop and – it seemed to the facilitator – by some, an assumption that implementing PDS would adequately address service needs. During the workshop some examples of good practices were offered in areas where reconfiguration has occurred. These practices reflected the motivation, flexibility and ingenuity of clinicians, however it was not clear that these good practices necessarily arose from the characteristics of PDS. For instance, the establishment of AON assessment-only-teams or the incorporation of private assessments to shorting waiting times do not necessarily promote equitable access to services. The ethos of PDS is admirable; the structural, organisational and practice changes needed to achieve it are substantial. Even with such changes, without additional resources; the efficient use of resources and greater flexibility in the system, it will not be possible to meet the stated aims of PDS. Greater flexibility need not undermine the quality of care or the safety of the service.

Recommended Actions:

6.1 A *Score Card for PDS reconfiguration* should be established and made publically available. This could be informed by a set of data and indicators which are seen to be crucial for the structural changes to occur. As Key Performance Indicators (KPI's) are already in use these should also be publically available. Such a score card should however go beyond KPI's and reflect where services are in the process of change; and be an important instrument for service evolution, for advocacy by service users; and for transparency for the HSE National Disability Operations Team.

6.2 A core element of PDS is to support effective teamwork. It is important to identify *which arrangements and structures best support team work*; what good teamwork 'looks like'; to what extent it is facilitated by shared-leadership between clinicians and/or with service users; and to what extent parents or children and young people with disability are involved in such teams and service development initiatives.

6.3 The *initiation of reconfiguration of services* within a locality should be an important news event, with regular updates and strong community involvement. It should engage with well-known personalities to give it a strong and positive profile. Given the changes to be overcome, it is important to find ways of strongly motivating both service users and service providers to engage with the necessary short-term disruption, for longer-term gains. The systematic collection of data on the above (6.1) and other PDS-related issues can be one element contributing to this motivation, and would provide evidence from previously reconfigured services, that such changes are worthwhile. The existing guidance notes on reconfiguration processes are valuable in this regard.

6.4 *Additional resources are required to implement PDS in an equitable manner.* Specifically, a) the extant recommendation from the HSE (2018) to provide an additional 400 posts for an adequate level of service, should be implemented; b) the co-location of practitioners as called for in PDS has real capital costs and these should be budgeted for and addressed as a one-off allocation that will also stimulate the change process required by PDS, c) there should be an investment in more administrative support for the local provision of services, to allow the clinicians to spend more time on direct work with service users.

6.5 *Person-centered care requires new ways of working*. This in turn requires increased resources (as described above); structural changes, such as developing network teams and implementing the National Access Policy; and for clinicians to prioritise their time towards the provison of intervention services and supports to service users.

Some of the Action Points below are also related to the implementation of PDS and develop points made above.

7 Empower Service Users and Families

There were strong opinions expressed about the importance of families being more aware, being more informed, being incorporated as a resource, and of the whole process of engagement being much more family-centred. “Parents need respect. Why bother with AON when it won’t change the service received. Respect isn’t there for parents, parents need respect, need communication … [services are] not in partnership with parents”. Suggestions for addressing this included that we “need a family-centred process – building relationships with family”; “embedding the ethos of family-centred practice from the top down”; that “community resources need to be improved to empower families”. There is a “need for resources to allow families to participate as stakeholders in discussion and decision making”. Indeed we should “develop the capacity of the family – peer support is very important - …[there is] potential to upskill families as a solution – utilising families as peer workers” and that “parents should be involved in … extension of AON”.

Many parents felt bewildered and misinformed about what is best for their child, and about how to access services; they felt they have to navigate the system of access to services alone; and that this adds to the stress of needing to access the services in the first place: “whose job is it to guide, inform, and support parents – we need to know!” This need extends to what might be called ‘service literacy’ as well as to how to find and interpret information: “The HSE, NCSE … have loads of information on websites but parents are not getting this. Parents get information from other parents, which is often outdated”. This highlights the value of person-to-person social networks, of learning from and supporting each other, through formal and informal information sharing. This process should be supported by the broader system.

Recommended Actions:

7.1 *Strengthen Service User and Family Networks*; at community, regional and national levels. Such networks exist often through the initiatives of enterprising parents or service users; however sometimes they are positioned (both by themselves and the HSE) as ‘outside’ the system; rather than as an integral and valued part of the system. Recognition as the latter will require some level of funding for meetings, and at a regional/ national level some support for personnel.

7.2 A *study should be conducted on the needs for and means of providing better access to information* for service users and their families. This study should consult extensively with service users and identify good practices from elsewhere. Possible options for improving access to information might include short, funded courses for service users and their families, or an App for guiding users through available information.

7.3 *Develop a Knowledge Hub* for children and young adults with disabilities and their families. This Hub should provide information on the types of services available, from whom and what factors should be considered to prepare for and benefit from such services. This Hub would not only promote ‘service literacy’ (being able to understand and ‘find you way around’ services); it would also provide information on intervention engagement for service users and their families. As community-focused, collaborative interventions become a stronger element in service provision the Hub will be able to support this. The Hub should therefore bring together information, user experiences and good practices; as well as serve as a resource to develop and implement these.

7.4 *Develop a consultation framework* for service users and parents; which outlines how they can most effectively engage with the HSE and other service providers; and indicates their obligations and those of the HSE in such consultation. The latter to ensure that action results from consultation and that the evaluation of such action is undertaken in consultation with service users and their parents.

7.5 *Every service provider organisation should have representation from service users* on their Board of Directors (or equivalent) and on Committees overseeing service implementation and evaluation. This should be in addition to service-user representative bodies.

8 Improve Communication

Improved communication is closely aligned to the need for empowering service users and families, as just discussed. More generally in terms of improving communication, it was suggested that greater awareness of and policy coherence was needed between PDS and for example the National Prioritisation Policy and the National Access Policy. How these can work most effectively together, in conjunction with each other; and for stakeholders, was of particular interest. It was considered equally crucial to “all have the same understanding of the policy, and definitions and concepts. Furthermore “there is a need for information on the implementation plan [for PDS] to filter down to all stakeholders”. A sense of policy confusion, ambiguity and a lack of information, were frequently conveyed by participants in the workshop: “there needs to be improved communication from the top down throughout disability services and in related services such as education”.

Recommended Actions:

8.1 The HSE National Disability Operations Team should develop *guidelines on the consultation and design process for the development, implementation and evaluation of new, or revision of existing, policies and protocols.* This should be in conjunction with a broad range of stakeholders.

8.2 The HSE National Disability Operations Team should have *quarterly consultation meetings* with a broad range of stakeholders, and especially service users and their families. These should commence from March 2019 and be geographically distributed to allow different stakeholders to contribute. These consultations should become a normal way of working rather than one-off events and should feed into a major *Stakeholder Conference* every three years.

9 Improve Administration

Participants identified some fundamental administrative shortfalls. These included the "need for standardized governance and accountability for AON; from the top-down". Interdepartmental communication was also stressed: "need for links between Education and the Department of Children and Youth Affairs – need for alignment across departments to ensure a child-centred approach". One suggestion in this regard was that a child should have one file, rather than multiple files in different locations.

Recommended Actions:

9.1 An *electronic records system*, shared between departments, with service users, their families and service providers, having access to the one file; should be established.

9.2 *Clarifying the meaning of terms* frequently used in the sector could be helpful in that it may help avoid confusion of terminology and reduce administrative or other misunderstandings. The development of an online thesaurus of terms for the service would be one possibility.

9.3 The *Framework for Collaborative Working between Education and Health Professionals* which has been recently developed, should be implemented.

10 Increase Resources and Equity

As well as a lack of resources, the stability of resources was a considerable concern: "we need stable resources. We cannot continue all the good things we know that work in practice; if we don't have stable resources". It was argued that, due to issues regarding resources, there are staff leaving jobs that they love for the good of their mental health. It was suggested that staff recruitment through a central panel was not working at the local level and that such recruitment should take place locally. It was also suggested that because of the proportion of women working in the sector, there was a need to be proactive rather than reactive in personnel planning; particularly with regard to anticipating the covering costs and availability of people for maternity leave or sick leave. It was also suggested that intellectual disability nurses should be included on CDNTs.

Participants were concerned about inequities arising from the use of AON: “in some areas it’s being used as a gateway into services. Never intended and should be [used for this]”. This was linked to PDS “I just feel …if PDS was properly implemented these (AON referrals) would go away”. Similarly, “if resources from AON were put into funding PDS teams sufficiently, then a child and family can get all the assessment and intervention they need, when they need it”. This echoed a number of points suggesting that resources were effectively being misdirected into AON due to the legal right and the associated pressure on the government and HSE; that this was being done to gain access to service provision, but was in fact undermining the ability to provide such services, as resources were being taken away from implementing PDS.

Clinicians also expressed unhappiness with the situation whereby children are given different access to and type of service depending on how they are referred; and that all children should be entitled to the same level of access to services. It was also forcefully noted that delayed assessment and intervention for a child now would inevitably mean more intense, longer and more costly intervention being required later; and probably with less success; thus costing the State, the individual and the family much more in both service provision, opportunity costs and quality of life.

Recommended Actions:

10.1 *Shorter term contracts should be recruited for, locally*; with permanent contracts recruited centrally. It should however be recognised, that where staff with the required competencies cannot be recruited locally and in a timely fashion, then national level recruitment would be necessary.

10.2 A *workforce plan for Children’s Disability Services* should be developed

10.3 *HSE employees should not undertake private AONs*. Such activities may provide perverse incentives for practitioners; as the longer the wait time for an AON then the greater will be the demand for private AON. Furthermore, the practice of private AON by HSE employees constitutes a significant inequity as it allows better-off people the possibility to be assessed more quickly than those less well-off.

10.4 In the context of scarce resources, *the government should prioritise access to intervention and implementation of PDS*; this may require reinterpreting AON as described in the Disability Act (2005) and stipulating that the completion of AON is not in itself a mechanism for reducing the wait for service intervention. While this is now more widely understood, it may not be understood by all service users.

11 Support Practitioners

Clinical staff and other practitioners who work at the interface with children and their families, are under considerable pressure without the means to address needs in the ways in which they wish to: "how can we support clinicians who are feeling pressure?" The lack of resources may put practitioners in situations where to assist one client they need to seek ways of getting around 'the system'; which may disadvantage another client. Practitioners are very uncomfortable with being put in this unreasonable position.

Again, relating to AON it was suggested that there should be more support for assessment officers' decisions regarding whether to proceed or not with AON. Due to confusion with the approach to be taken to AON it was argued that "training and support for the clinicians completing the process for AON – sharing experience and improving the experience of the team overall" is needed.

Also related to this was the "need for sufficient quantity of experienced staff", that clinicians should not "work slavishly" adhering to a particular protocol and that it is important to avoid a "one size fits all" approach in assessment or treatment; and that there should be a "less prescriptive approach from HSE for assessment of children".

Thus while practitioners wanted some degree of standardization and fairness in access to services, including AON; they did not necessarily want their practice to be overly restricted by specific procedures. There was a desire for people to be fairly treated by competent practitioners who had the discretion to make clinical decisions based on recognised assessment practices, and their own experience.

Recommended Action:

11.1 *Support for Assessment Officers* determining the appropriateness of AON, and for those conducting AON would be valuable. Collection of nationwide data on criteria and methods used, with outcomes, could be very informative for practitioners and allow them to weigh their own practice against anonymised national data.

11.2 The provision of a virtual and anonymous *Help Desk service*, that can offer guidance on AON, could also be helpful and offer a point of personal contact, if requested by the service provider

12 Clarify Assessment of Need

The procedure for Assessment of Need (AON) is a right under the Disability Act. It has recently been a focus of attention in the Dáil, of legal action and of dispute between the HSE and clinical professions. However, as already noted, AON is only one aspect of access to services, and the focus on it has been rather disproportionate; a consequence of, rather than a cause of, inadequate service provision. Several times it was argued that where services worked well (and where CDNTs were established), there was little or no demand for AON, as clients didn't need to request them to access services; and such services incorporated assessment in their normal practice. It was therefore important to address the issue of access to services much more broadly and to try and establish how much openness and flexibility there was, to considering ways of achieving the goals of improving services.

The Disability Act (2005) allows an individual to apply for an AON for a person whom they believe has a disability. If such an assessment is deemed justified by an assessment officer, then the assessment must be started within 3 months of the application and should be completed within 3 months unless there are exceptional circumstances. If there is a delay in undertaking or completing an AON, then the applicant must be told the reason and given a timescale for its completion. A substantial number of applications are currently not provided with an AON within the specified time frame.

The AON report should indicate if the person has a disability and, if so, provide a statement on the nature and extent of the disability, the health and education needs arising from the disability, and the appropriate services that are required to meet the needs. Furthermore, it should state the period within which a review should be conducted (which should be no more than 12 months hence, from issuance of the report). Importantly, the AON does not consider the costs of providing for the needs identified, nor whether the capacity to provide such services currently exists. This puts clinicians in an invidious position of having a legal obligation to assess needs without necessarily having the means to address them. As already noted, the identification of such needs without action to ameliorate them, is likely to be enormously frustrating and stressful both for those seeking such an assessment and for those wishing to provide it. Making service users aware of such needs without providing for them is both morally and ethically problematic; as it is likely to add further angst to an already distressing situation. It should be noted that the Disability Act states that assessment "shall be carried out without regard to the cost of, or the capacity to provide, and service identified in the assessment as being appropriate to meet the needs of the applicant concerned." It does not refer to the cost of providing the assessment and so the Act contributes to, rather than helping us, to address these difficulties.

Views expressed by workshop participants included that the first contact with the service should provide some level of support and/or intervention and that assessment should be "needs-led rather than diagnostics-led"; that it should "balance assessment and intervention in one pathway", rather than seeing them as discrete activities; that we should recognise "assessment is a process, not dictated by time frames, and [it should be] more family centred"; that "assessment must be interwoven with intervention – you cannot assess just once"; that "assessment should address positive change in the child's life … and goal setting…"; and that more clarity was needed on "what an assessment is – clinical [aspects], goal-focus, who should lead it, [and] what families want".

It was also clear that participants felt a significant degree of ambiguity and variation regarding AON; there is a "need for agreement regarding what constitutes an AON"; that "clarity [is] needed on the AON statutary requirments"; and that we need to "agree a baseline and contents of what is needed in an assessment according to best practice". The idea that "resources need to be provided from the first point of contact" was mentioned several times.

It was also suggested that there was a need to identify the professional requesting the AON and for what purpose, and this may encompass "training for public health nurses to reduce inappropriate referrals". That AON does not "fit with [a] service model [of] family centred practice' was suggested. In relation to PDS more generally, it was suggested that "To us, the AON is something that's at the side … I think it's very separate … I think it's a very separate question"

One driver for AON from the service user's perspective, may be to establish a diagnosis, so that in turn, the child can access educational supports; such as special classes, home tuition or a Special Needs Assistant. However, while the AON incorporates a statement of the "nature and extent" of disability; this is separate to diagnosis. This may not be widely appreciated, either by service users or service providers. It is important that this distinction between AON and diagnosis is made; so that Irish services for people with disabilities can catch up with the broader international recognition that a medical/deficit model of disability be replaced with a rights/social model. There is no necessary relationship between the diagnosis of a condition and the needs that arise from it; especially in conditions occurring along a spectrum, such as Autistic Spectrum Disorder, which constitute the vast majority of AON requests received in Ireland. This is not to deny that many people with disabilities have real health problems and can greatly benefit from interventions from health practitioners. The bundling of AON with diagnosis, effectively restricts the range and pool of practitioners who are sanctioned to undertake these procedures, while to improve access to services we should be seeking to extend the range and pool of practitioners who are available and skilled to do this. However, to reiterate, improving the number of and rate at which AONs take place, will not in itself improve access to services, unless and until the approach to AON is modified and/or greater resources for and means of intervention are introduced.

A response to a draft of this report stated that in the respondent's area "the culture is that all ASD diagnostic assessments are accessed through AON. In our opinion this culture will not be changed unless changes are made to the Disability Act". This issue was raised a number of times in the workshop too. Attempts to adopt more flexible approaches by some practitioners "meet with considerable resistance" from others.

A repeating theme in both the workshop discussions and comments made on a draft of this report, has been that clinicians feel constrained and frustrated by the Disability Act (2005); but bound by their legal obligations. They are aware that their fulfilment of such obligations may not provide - and may even diminish - access to interventions; due to scarce resources having to be allocated away from intervention. Furthermore, the contestation of these obligations by families, Assessment Officers, clinicians and legal teams; is greatly erosive of goodwill and further distracts from the prioritisation of interventions.

It is beyond the scope of this report - but nonetheless noteworthy - that considerable controversy surrounds the utility and validity of commonly used psychometric assessments of ASD. Conner, Cramer and McGonigle (2019) reviewed such instruments for use in adults and concluded that "none of these measures are very accurate" (p. 1); recommending that clinical judgement is necessary, but providing no evidence that this, in itself, is any more accurate. Others argue that the diagnosis itself – across all age groups - is not valid (Waterhouse, London and Gillberg, 2016). What is however clear, is that early identification of behaviours characteristic of ASD (such as, social impairment, restrictive repetitive behaviours and atypical sensory responsiveness) is critical; in order that timely interventions can be provided to address these difficulties and prevent further difficulties developing.

Recommended Actions:

12.1 Currently, access to services is front-loaded (in many places) by AONs which displaces resources from intervention. *The level of detail required by the AON should be dramatically reduced*. It should include a brief probability statement of the likelihood of the person having an impairment/disability; the most characteristic features of that impairment /disability; how the impairment/disability primarily affects the life of the person; and the services likely to be of benefit to them and their families. The veracity of these statements would be clarified upon intervention and on-going assessment. The Disability Act 2005 currently requires a categorical 'Yes' or 'No' determination of disability. Such a categorical determination can of course be made, but like any such determination, it should be open to new evidence and revision; and so is by its nature a probability statement.

12.2 *Disability terminology should be replaced with "impairment"*. This is more than a cosmetic change of nomenclature, for it allows us to recognise that a child with an impairment, may become disabled, entirely because of their lack of access to services that have the capacity to provide a beneficial intervention.

12.3 Detailed *assessment should take place as part of the intervention cycle*, and be on-going.

12.4 *Where a diagnosis is sought this should be separate* to either an AON request or the routine clinical assessment process; although it may well arise from such a process. It is noteworthy that some AON appeals have resulted in the ODAO (Office of the Disability Appeals Officer) and the High Court directing the HSE to provide diagnostic assessments under the terms of the Disability Act. While well intentioned such a direction fails to achieve its desired ends; of providing access to an intervention. (see 12.5).

12.5 *The Disability Act (2005) should be amended* to focus on the right to a supportive intervention, rather than an AON. Budgeting should address the costs of providing for interventions; which should be based on a level of assessment and diagnosis that is appropriate to the complexity of difficulties that a person presents with (see next section). The Disability Act (2005) should also be amended to clarify the ambiguity that was reported by some workshop participants regarding their statutory obligations.

12.6 A *Code of Practice for Assessment Officers and Clinicians* should be developed to guide the implementation of an amended Disability Act. This could contribute to the provision of a similar standard of service throughout the country, provide direction and some protection to clinicians, and clarify ambiguities for service users and providers.

13 Match Assessment to Complexity of Presentation

Data available from the HSE and presented during the workshop clearly indicates that in practice the time taken to assess (diagnosis/AON) children varies considerably and can take as long as 100 hours. This likely reflects a number of factors, including variation in the practice of clinicians and in the complexity of impairments presented by children and young people. In my view, a standardised approach is sometimes misunderstood to imply that all children should be assessed in a uniform way – all should go through the same sort of assessment, regardless of their presentation, or the ability of the assessing clinician to make a determination. Instead a *standardised* approach is one that falls within an acceptable range of size, amount, quality; that is, it reaches a certain standard. On the other hand, a *uniform* approach is one that is unvarying; everybody gets the same. This is not a trivial difference; rather it is at the root of the difference between equality and equity. Especially within the domain of impairment and disability this is a central issue of fairness: so that people can enjoy similar opportunities, they require different types of support to give them the same level of opportunity. This is enshrined in the provisions for “reasonable accommodation” demanded within the UNCRPD. In the context of scarce resources, providing a uniform service, almost certainly guarantees that many people will be denied the same level of opportunity.

Another area of confusion is the conflation of *intensity* of assessment with the *comprehensiveness* of assessment. Some service users may believe that if an assessment is not intensive, then it is not comprehensive. In fact, intensive assessment may be focused on some areas of functioning, but not on others. Comprehensiveness refers to addressing all, or nearly all, elements or aspects of something; and it therefore more about scope; or covering the range of difficulties. An assessment may be comprehensive without being intensive or intensive without being comprehensive; and it can be both or neither, intensive and comprehensive.

It has been proposed that the time taken to assess children should vary according to the complexity of their presentation. The HSE has suggested a three-tiered approach. The first is where it is relatively clear that a child has an impairment and it is relatively clear the sort of services they are likely to benefit from. The second is where the presence or absence of disability is unclear, or the nature of it is unclear and thus it is difficult to estimate the services that would be beneficial. The third is where a child may have multiple disabilities and/or other factors that make it difficult to establish the services best suited to help the child. This is the approach recommended within ASD assessment protocol. This proposal has been controversial.

The participants in the workshop were asked to discuss a diagram that might help to tease out how different approaches could be taken to children presenting with different levels of complexity. However, there was resistance to doing so, from some participants. These issues are also a matter of on-going discussion between unions and management. Union representatives involved in those discussions felt it was important to clarify the limits to their involvement in workshop discussions and proposals, regarding a consensus agreement for a model of ASD assessment. Their objections to such discussions resulted in these discussions not happening in this forum. This was very disappointing as the issues affect a broad range of stakeholders who were also present; rather than being solely an industrial relations matter. Without the benefit of a wider discussion and, notwithstanding the remarks already made above, I feel that it is important to make some remarks on best practice in this area.

It was suggested that the approach to assessing children and young people with disability "should be based on best-practice and the recommendations of professional bodies". This suggestion, while seeming quite reasonable, does not recognize the ambiguity surrounding best-practice in this area, or the vested interests of professional bodies in making practice-related recommendations. It is important to acknowledge that this places practitioners and unions in a difficult situation; as has been pointed out to me; "within the HSE staff are required to comply with HSE policies on Quality and Patient Safety and to practice in alignment with professional body guidelines, which are evidence based, in accordance with their relevant professional codes of ethics". However, if claims to best practice are based on a misunderstanding of research, or research is used selectively, or it seeks to privilege certain groups, then this is problematic.

It is also problematic if some tasks are inappropriately restricted to some groups. We must continue to be awake to the challenge that Dubois and Singh (2009) signalled; a decade ago: "International variations in the scope of practice of health care professionals suggest that groupings of skills into professions are often arbitrary and owe more to custom, traditions, incentives, professional politics, and power than to logic and providers' actual skills"(p.

13). Particularly in the context of scarce resources, restrictive practices - if they exist - must be challenged.

There is considerable scope for establishing practices that are effective within the Irish context, by considering the characteristics of that context that are specific to Ireland, rather than seeking to simply replicate best practices from elsewhere. Such an empirical invesigation of effective practices within the Irish context should certainly be informed by the views of professional bodies and unions; as well as other stakeholders.

Such an approach within the Irish context is necessary as the notion of best-practise for ASD assessment is extremely problematic. Internationally, no such best practice exists. A recent review of the literature by Penner et al (2017) reported the results of an international analysis of the clinical personnel and psychometric tools recommended for the "diagnostic assessment" of ASD. They found that the assessment procedures approved by different professional organisations or jurisdictions varied considerably in terms of the professional qualifications of practitioners undertaking the assessment; the instruments or procedures used to make the assessment, or the time given to make the assessment. They noted that "There was little supporting evidence for team and personnel recommendations" (p. 517). As such, there can be no simple appeal to international best practice. Instead, we need to establish what will be optimal within our own setting in Ireland; informed by the wealth of experience within Ireland.

In a contemporaneous review, Hayes et al (2018) assessed twenty-one documents relating to guidelines that they found "varied in recommendations for use of diagnostic tools and assessment procedures. Although multidisciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested in practice one experienced healthcare professional was sufficient" (p.1). Thus, while the appeal of different professional perspectives is clear for intervention, the evidence for its value in assessment, even detailed assessments, is not present. Single practitioner assessment alone, could produce a dramatic increase in the number of people receiving an AON and/or intervention. Hayes et al also stressed the importance of considering "Social factors in operational, interactional and contextual areas" noting that these added considerable complexity to guidelines "but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes." (p. 1).

Again, we must look to ourselves and the Irish context to decide what is optimal and pragmatic, given the challenges and the resources available to address them. "Overall, there was a bewildering range of options for HCPs [Healthcare Professionals] in the assessment process, … Navigating this framework in practice is, therefore, likely to be less systematic than the guidelines might suggest, allowing for, as it must, social and contextual influences" (Hayes, et al, 2018; p.23). Hayes et al (2018), writing about the British NHS context – whose constituents have much greater similarity between services than does the Irish context – conclude that "In reality, the clinical pathway for autism diagnosis differs across health systems and trusts

…leading to the potential for a great deal of variation in diagnostic decision-making" (Hayes et al, 2018; pp 23). Furthermore "We would not recommend greater rigidity within CPGs [Clinical Practise Guidelines] when evidence for best diagnostic practice is inconsistent" (p.23). This is also echoed in the contribution of one of the participants in the workshop: 'We need to look at what is working all over the country', not one size fits all putting everyone through AON process.'

In Ireland, with a patchwork of different service provision cultures, and variations in staffing, we must develop an approach to assessment, intervention and diagnosis which is realistic and pragmatic. In this regard, I consider the HSE document suggesting a new approach to Standard Operation Procedures (2017) to be valuable, realistic and drawing on an appropriate range of good practices; while also fitting within the realities of the Irish context. It does not and should not be interpreted as reflecting any diminution of professionalism, practice or efficacy. Where such concerns are voiced, then these should inform the establishment of different models so that they can be empirically evaluated against one another. The blocking of progress in adopting such an approach will, in my view, ultimately be counterproductive, for all involved. In parallel to developing effective approaches to assessment/intervention/diagnosis there should of course continue to be strong advocacy for more resources, supporting clinicians who are already desperately overstretched, while maintaining their commitment to providing quality services. Such arguments will however be best founded when based on a comparative analysis of alternative approaches within the Irish context.

Recommended Actions:

13.1 A tiered approach to AON should be undertaken based on the complexity of the presentation. This could be distinguished on the basis of two (rather than three) types of presentation: Type 1: Relatively clear presentation with relatively clear indications of interventions that would benefit the client. Such an assessment should be completed in one session of between one and three hours. Type 2: Relatively unclear presentation and/or relatively unclear indication of interventions that might benefit the client. Such an assessment is likely to take more than 3 hours. In this latter case, intervention should be considered as a legitimate means of gathering further information to allow a better understanding of the presentation and of likely beneficial interventions.

13.2 One experienced practitioner should be able to undertake an AON on their own (for Type 1 above); while the contribution of colleagues from other disciplines should be welcomed (for Type 2), where resources and time permit, within the context of managing the overall case load for intervention within a CHO. It should be noted that private AONs are often undertaken by single practitioners and are accepted as legitimate assessments by HSE managers who sign off on them. Involvement in conducting AON for more than 2 years should be sufficient to deem a practitioner suitably experienced.

13.3 The *first point of contact should present intervention options* and indicate activities that parents and families can engage with to support the client, to gather further pertinent information and to engage with other parents and families with similar experiences and challenges.

13.4 Where there is insufficient capacity within the existing service, a *waiting list initiative should be implemented*; where staff are given the opportunity - on a voluntary basis - to work extra hours for extra payment. All staff involved in the service should have an opportunity to participate, allowing additional work to be allocated on an equitable basis.

13.5 An AON could be undertaken by *any practitioner specifically trained* for the purpose. Practitioners with a background in Psychology, Occupational Therapy, Speech & Language Therapy, Psychiatry or Paediatrics; are likely to be most familiar with such assessments; but those with different professional backgrounds may be equally suitable. In essence, it is a skill-set rather than a staff-type that is required to conduct the shortened form of AON recommended here.

13.6 The *above actions should be implemented immediately with a tracking study* over two years that can inform the development of future standards and practices for shortened AONs. In this context, it might also be informative to establish the sort of services provided by private contractors in recent years; so as to contribute to help identifying optimal practice. The Department of Health; National Disability Authority and the Health Information Quality Authority; along with a strong representation from service users and providers, relevant professional bodies and unions, should convene a review conference after two years to consider the results of the tracking study with a view to reviewing and improving practices and service responsivity.

14 Open Up to New Possibilities

To contrast the Irish situation with one in a much poorer country which has few or no practitioners available in rural areas; an example of innovative practices in Pakistan was presented at the workshop. Through a dial-up system parents could get a good estimate of the likelihood that their child had a disability; and through an avatar and community support service (with no practitioners physically present) they could be provided with an intervention, which is producing promising results (Hamdani et al, 2015). The idea of presenting this example of practice was to illustrate that there are very different approaches to assessment and intervention; and this is something that should stimulate fresh thinking in the Irish context. It is ironic that in one of the poorest countries in the world it is now possible to receive an assessment which has clinical validity in a matter of minutes; while in one of the richest countries in the world it can take years to have an assessment, the occurrence of which may block intervention for years.

In this context it is interesting to note that the Psychological Society of Ireland recently co-hosted a one-day conference showcasing a wide range of different examples of e-therapy and e-community support which all have the potential of increasing access to psychological therapies and psychological support within the community. Such innovative practices – not as a substitute for resources but as a different approach to using resources - should be considered in the disability context too.

From a psychological services perspective, the British Psychological Society has been active in trying to promote greater access to psychological therapies through the Improving Access to Psychological Therapies (IAPT) programme. Rather than using only fully-qualified clinical or counselling psychologists, this programme has provided and used therapists with shorter and more focused on-the-job training (either mental health profession graduates or graduates from non-mental health professions). Outcomes from these innovative service models are very good (Clark et al, 2018a) and the UK's NHS has embarked on a programme to expand delivery through this model to 1.5 million service users. This programme of increasing access to therapies has embraced the ethos of promoted by Dubois and Singh (2009): "In order to use human resources most effectively, health care organisations must consider a more systemic approach - one that accounts for factors beyond narrowly defined human resources management practices and includes organisational and institutional conditions".

Recommended Actions:

14.1 Representatives from the Department of Health National Clinical Effectiveness Committee, and from relevant HSE Quality and Safety Committees, should explore with the HSE Disability Operations Team; the scope for researching and developing *new standards that can increase access to interventions for disability, while ensuring quality and safety*, for both service users and service providers.

15 Conclusion

The recent agreement regarding the grade and recruitment of CDNT Managers, is an important and strategic step for making progress on implementing PDS. Also, the budget announcement of an additional 100 therapy posts in the disability sector for 2019 is very welcome; both reflecting the increasing commitment of government and the increasing capacity of services to meet the needs of service users. These two new initiatives should be both motivating and invigorating for the sector. The disability sector in Ireland should also embrace the excitement and potential of new innovative practices. Traditional models of service provision will continue to be needed for some people, but the potential to promote access through new thinking and new approaches offers the possibility of achieving much greater impact. A recent global review of services and supports for children with developmental delays and disabilities concludes that "Parents and caregivers who receive training in psychosocial interventions and ongoing support can help children with delays and disabilities thrive in context" (Collins et al, 2017). It is now recognized that it is not just the efficacy of a scientific treatment which is important, but also the way in which the service is actually implemented (Clark et al, 2018b). This reinforces the need for Ireland to be innovative and imaginative and to take seriously the context of our own service needs and resources (McVeigh et al, 2016); as these continue to evolve with the implementation of PDS, and beyond.

16 Acknowledgements and Declaration

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18. Presentations

The Power-Point Presentations from the Tullamore Meeting are available at the following location:

https://www.maynoothuniversity.ie/all-institute/all-perspectives