Consultation Response Form:

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| Q1 – SECTION 1: Arrangements for assessment and diagnosis of autism in children, young people and adults. | | | |
| |  | | --- | | **Are the proposed requirements in this section right for service providers?** If you think there is anything missing or unnecessary, please explain in the box below. | | | | |
| Agree   |  | | --- | |  | | Tend to Agree   |  | | --- | | **√** | | Tend to Disagree   |  | | --- | |  | | Disagree   |  | | --- | |  | |
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| Do you think that the proposals will have any unintended consequences, please explain.   * **Access to occupational therapy should be based on need, rather than diagnosis.** Occupational therapists focus on health and well-being: “*Occupational therapists are active health enablers, focused on what matters to the person so that they can help them to participate in the occupations they need, want or are expected to do.”* (Royal College of Occupational Therapists (RCOT), 2016). Occupational therapists do not try to fix or cure the problem, but endeavour to fix ‘what matters to the person’. RCOT recognises that people often present with complex needs and occupational therapists rarely work with individuals who fit into neat diagnostic categories. Some people with autism manage very well, while others who don’t reach the threshold for diagnosis have great difficulty participating in daily life activities and benefit from occupational therapy. * It is welcomed that post assessment consideration should be given to identifying the need for some specific interventions, and proportionate to needs and evidence-base. However Neuro Developmental teams are not meeting the demand and capacity to deliver any post diagnostic interventions and IAS are only able to provide signposting and brief advice and support. * Diagnostic pathway for children and young people considers co-concurring neurodevelopmental conditions. This is more of a issue for Integrated AutismServices services – not able to address comorbities and are becoming increasingly challenged with the amount of presenting mental health issues. There is a need for in reach of services into IAS e.g psychiatry support to prevent young person/adult being passed from service to service. * It is welcomed that this document supports pathway development but much more work is needed to achieve this across ND, IAS and other Health and Social Care services. * ‘ * Occupational Therapists are dual trained in health and social care and are therefore well placed to work across these teams and bring collaboration and joint working together in an integrated way. * “In November 2017 we introduced a 26 week waiting time standard for children’s and young people’s assessment as a robust approach to collecting reliable and consistent information”.   The introduction of the 26 week waiting time standards supports more timely access to diagnostic processes. However, practitioners working in this area need to work purposefully to ensure that these targets do not create additional pressures around the time between diagnostic assessment and subsequent access to post-diagnostic support and interventions   * *Adult assessment services.*   Through increasing awareness of autism many adults, who were not recognised as being autistic in childhood may find access to diagnostic services very helpful as a diagnosis can help them make sense of and understand their own perceptions of not coping well in social situations and perhaps having sensory difficulties”.   * Within primary and secondary care mental health services significant numbers of service users are undergoing diagnostic assessment in adulthood. Individuals accessing our services frequently report that receiving a positive Autism Spectrum Disorder (ASD) screening outcome adds clarity and context to lived life experience * We very much welcome the recognition of the contribution multidisciplinary teams can make within the assessment/diagnostic processes. Occupational therapists can contribute robustly to the assessment processes given the often functional and sensory needs that often present. As Occupational Therapists working across primary and secondary care mental health services, we are mindful of the challenges presented by our somewhat minority professional status across Wales. Many of us work as lone practitioners with Community Mental Health Team (CMHT)settings, and this impacts significantly on service provision we may be able to offer   Individuals with comorbid ASD and mental health features should undergo diagnostic assessment within the relevant primary or secondary care mental health settings. One of the unintended consequences of the development of ASD services is that staff working in those settings with a particular interest in ASD have often been the individuals who have applied for posts in the new services, resulting in skills gaps within some areas of primary and secondary mental health services. | | | |

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| Q2 - SECTION 2: Arrangements for Accessing Care and Support | | | |
| |  | | --- | | **Are the proposed requirements in this section right for service providers?** If you think there is anything missing or unnecessary, please explain in the box below. | | | | |
| Agree   |  | | --- | | **√** | | Tend to Agree   |  | | --- | |  | | Tend to Disagree   |  | | --- | |  | | Disagree   |  | | --- | |  | |
| There are 1900 registered occupational therapists in Wales (August 2018) working across health, social care, education, the voluntary sector and in other specialist areas.  Occupational therapy is a science-based, person-centered profession, concerned with promoting health and well-being through occupation. Occupational therapists work with people of all ages who are experiencing difficulties through injury, illness or disability or a major life change. Occupational therapists consider the relationship between what a person does every day (their occupations), how illness or disability impacts upon the person and how a person’s environment supports or hinders their activity. The primary goal of occupational therapy is to enable people to participate in the activities they want, need or are expected to engage in, including work, social activities and maintaining roles and responsibilities.  Occupational therapists are uniquely trained to address mental health and physical health which means we are able to work with people in a more streamlined way. NICE (2016) identifies occupational therapists as key members of specialist autism teams for adults and recommends that children should have access to an occupational therapist if one is not included as a core member of their local autism team (NICE 2017). As members of these teams, occupational therapists contribute to the early identification, diagnosis (where appropriate) and participation of people with autism in activities that are important to them. We enable people’s participation and occupational performance by working directly with individuals and indirectly through consultation and collaboration with family members, communities, teachers, employers and other professionals. Occupational therapists identify individual’s strengths and abilities as well as the needs and challenges that hinder their participation in meaningful activities. Occupational therapists choose the most appropriate setting in which to work with people with autism, for example at home, in their workplace, at school/nursery/college, in residential settings and at diagnostic/assessment centres. In Wales, occupational therapists meet people with autism through their role as members of a children’s occupational therapy team, as independent practitioners and as members of an Integrated Autism Service.  We welcome the fact that Section 2 is clearly written lionking it to the Social Services and Well-Being Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018  We also welcome the focus on transition pinto adulthood within this section  “There is also increasing literature linking autism with gender identity/dysphoria, with a higher incidence of autistic people reporting a psychological identify with a gender other than the one they were born with. The Welsh Government has recognised the need to improve gender identity services in Wales and have established the All-Wales Gender Identify Partnership Group to provide advice, and Wales Gender Team is being created which will operate from Cardiff University Hospital”.  The recognition around existing gaps regarding gender identity and dysphoria needs is very much welcomed across our services – and we look forward to the creation of the new Cardiff based team. We have worked with a number of individuals who present with gender identity/ dysphoria, most of whom have had to access specialist services in England (away from well established support systems)  Occupational therapists have a unique contribution to make with regards to the delivery of specialist assessment to determine needs and strengths - particularly around functional tasks, roles and routines, productivity – including training and employment and leisure activities. We welcome the recommendation made by WG that OTs were a key element of IAS teams. | | | |
| Do you think that the proposals will have any unintended consequences, please explain.   * We are concerned that CAMHS are under increasing pressure and that CAMHS personnel are dealing with such high end mental health issues in children and young people to meet proposed targets, that children and young people with autism that also present with high anxiety and mental health concerns are not being seen. This leaves ND and IAS services dealing with this when they haven’t the appropriate Psychiatric or mental health skills and knowledge to meet needs, and support the child/young person and family. * “Where a diagnosis of autism is made, with the individual’s consent (or for most children their parent or carer) a referral is made to the National Integrated Autism Service promptly to ensure post diagnostic support assessments can be undertaken”. * We must not lose sight that referrals to IAS in this context should be needs-based. Many families can be successfully signposted to local support/community groups/third sector agencies at the point of diagnosis ( as well as EarlyBird/ EarlyBird Plus) * IQ is mentioned as a potential barrier for accessing social care and this should not be the case. Access to local authority social workers can, at times, be challenging – even for families who are really struggling and asking for support themselves * There has been a clear focus on the need for robust pre and post-diagnostic assessment and support throughout the development of these new services. This early focus resulted in limited availability of intervention is some areas. We very much welcome the increased focus on the provision of appropriate, needs-led and evidence based interventions. | | | |

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| *Q3 – SECTION 3: Arrangements for Training Needs Assessment and Provision of Training* | | | |
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| Agree   |  | | --- | |  | | Tend to Agree   |  | | --- | | **√** | | Tend to Disagree   |  | | --- | |  | | Disagree   |  | | --- | |  | |
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| Do you think that the proposals will have any unintended consequences, please explain.  As members of these teams, occupational therapists contribute to the early identification, diagnosis (where appropriate) and participation of people with autism in activities that are important to them. We enable people’s participation and occupational performance by working directly with individuals and indirectly through consultation and collaboration with family members, communities, teachers, employers and other professionals. Occupational therapists identify individual’s strengths and abilities as well as the needs and challenges that hinder their participation in meaningful activities. Occupational therapists choose the most appropriate setting in which to work with people with autism, for example at home, in their workplace, at school/nursery/college, in residential settings and at diagnostic/assessment centres. In Wales, occupational therapists meet people with autism through their role as members of a children’s occupational therapy team, as independent practitioners and as members of an Integrated Autism Service.   * Staff working within IAS and ND services have the knowledge and skills to deliver training. However capacity to do so is an increasing challenge whilst balancing the demand of assessment and diagnostic and post disagnostic support. * Challenge to keep maintaining the rolling programme of training required. * This section addresses well the need to involve autistic people in developing and delivering training. This brings a problem based, practical solving approach which significant assists and enables others to take on board strategies and advice that will help them increase their well-being and everyday living. * Other Specialist services within Health and Social Care can also support training, however the challenge to be able to shift resource from the the very specialist end to targeted provision is a constant challenge. * A variety of training approaches is required – large group training is not always appropriate or relevant and training need to be adapted to match the audience requirements. | | | |

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| Q4 – SECTION 4: Arrangements for **planning** of autism services | | | |
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| Agree   |  | | --- | |  | | Tend to Agree   |  | | --- | |  | | Tend to Disagree   |  | | --- | | **√** | | Disagree |
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| Do you think that the proposals will have any unintended consequences, please explain.   * There are many hurdles and challenges to be able to undertake a population assessment. Data collation and definitions within health boards and social care is different – there is a risk of double counting or not counting at all which will create an inaccurate population assessment. * Eight themes within the population assessment Learning Disabilities and Autism are in one theme. It would be better if this was separated. Collating information on LD in children and young people is a challenge - diagnosis is usually developmental delay not LD. | | | |

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| Q5 – SECTION 4: Arrangements for **monitoring** of autism services | | | |
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| Agree   |  | | --- | |  | | Tend to Agree   |  | | --- | | **√** | | Tend to Disagree   |  | | --- | |  | | Disagree |
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| Do you think that the proposals will have any unintended consequences, please explain.   * Unsure how rich the outcomes can be in terms of quantity when we have limited post diagnostic services, support and interventions. * Occupational Therapists are well placed to set goals with children, young people and their families as well as adults to determine outcomes. Advanced Clinical Decision making and Care Aims Model are being used increasingly across Occupational Therapy services which helps determine episodes of care and outcomes. Additionally, Occupational therapists working within primary and secondary care mental health services work using robust models and utilise evidence based specialist assessments and outcome measures, which would contribute effectively to monitoring and evaluation processes. | | | |

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| Q6 – SECTION 4: Arrangements for **Stakeholder Engagement** and **Awareness Raising** | | | |
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| Agree   |  | | --- | |  | | Tend to Agree   |  | | --- | | **√** | | Tend to Disagree   |  | | --- | |  | | Disagree |
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| Do you think that the proposals will have any unintended consequences, please explain. | | | |

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| Other Questions |
| |  |  | | --- | --- | |  |  | | The Welsh Government is interested in understanding whether the proposals in this consultation document will have an impact on groups with protected characteristics. Protected characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, and sexual orientation. | | |
| **Do you think that the proposals in this consultation will have any positive impacts on groups with protected characteristics? If so, which and why/why not?** |
| Please explain |
| **Do you think that the proposals in this consultation will have any negative impacts on groups with protected characteristics? If so, which and why/why not?** |
| Please explain |
| We would like to know your views on the effects that these proposals would have on the Welsh language, specifically on  i) opportunities for people to use Welsh and  ii) on treating the Welsh language no less favourably than English. |
| **What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?** |
| Please explain |
| **Please also explain how you believe the proposed policy could be formulated or changed so as to have:**  **i) positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and**  **ii) no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.** |
| Please explain |
| **We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to tell us about them** |
| Please explain   * Currently not achieveing the right amount of post diagnostic support for children, young people and their families due to demand and capacity in completing assessment and diagnosis. Much more work is needed to align and maximise service provisions between ND, IAS and other Health and Social Care services. Many users are still be passed from one service to another. There needs to be work on joint working and collaboration, flexibility of pathways to ensure best use of resources. * The Code aligning these services pathways and processes would be welcomed. |