Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Arolwg Ar-lein DAB153 Ymateb gan Cyfrannog ar-lein 153	National Assembly for Wales Draft Autism (Wales) Bill Online Survey DAB153 Evidence from Online Participant 153

Please refer to questions in the Online Survey.

Question	Answer
01	Not sure Family Fund would recommend including a reference to a definition of autism spectrum disorder within the Bill and citing the WHO ICD-11 definition which will then remain up to date, rather than including a definition.
02	Not sure Yes, so long as there is clear guidance for Welsh Ministers if they look to include other neurodevelopmental disorders and what would be appropriate. For example, if the diagnostic assessment, support need and pathways are deemed to have a high degree of
03	Not sure Family Fund would recommend that rather than describing a relevant body as "a local authority, an NHS body and such other bodies as may be prescribed" which is vague, a full list of relevant bodies and their responsibilities should be included within the draft guidance. This should then be shared with each of the bodies and other interested parties to make sure that the final guidance has: 1. consistency and clarity across Wales on who the relevant bodies are, and; 2. clarity on the roles of each relevant body for the diagnosis, assessment, support and care, data collection and information and communications requirements for each body.
08	Family Fund agree with that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence (NICE) guidelines and that this should be a minimum standard, where organisations look to improve on these timescales where possible. Within the NICE guidelines (1.5 Autism diagnostic assessment for children and young people) it makes the following recommendation: "1.5.1 Start the autism diagnostic assessment within 3 months of the referral to the autism team". The Welsh Government's ASD Strategy plan pledges a 26-week waiting time target from referral to first assessment appointment, and we have previously received feedback at

	Family Fund from families saying that waiting times for diagnosis were lengthy. Family Fund agrees that the Bill should provide clarity on the timescales for all parties and asks for all guidance to provide clear timescales which are easy to find and understand for both professionals, those awaiting diagnosis and their friends and families.
09	Yes Family Fund recommend that an assessment of care and support needs should be completed within two months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting as a minimum standard. Much of the Welsh Government's ASD Strategy action plan states that action will be taken in a "timely way". Family Fund recommends having explicit timescales, as waiting times are an ongoing concern for Family Fund's parent / carers. Family Fund recommends that the guidance on assessment of care and support needs asks services to use this as a minimum service level, and there is an incentive for services to try and improve on those minimum timescales whenever possible. Collecting this data will be essential if the Welsh Government is committed to measuring the outcomes of autistic children and adults.
10	Yes Family Fund would recommend that the bill uses the NICE guidance as a basis for its own guidance. Within the NICE guidance for recognition, referral and diagnosis of ASD in under 19s, it states that: "In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a: – paediatrician and/or child and adolescent psychiatrist – speech and language therapist – clinical and/or educational psychologist. The autism team should either include or have regular access to the following professionals if they are not already in the team: – paediatrician or paediatric neurologist – child and adolescent psychiatrist – educational psychologist – clinical psychologist – occupational therapist. Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a

	specialist health visitor or nurse, specialist teacher or social worker". Family Fund recommends that the Welsh Government works with the UK Department for Education and Department for Health and Social Care, who recently conducted a consultation on transforming children and young people's mental health provision and have outlined a proposal to develop Mental Health Support Teams. There may be parallels to the guidance proposed on the multi-disciplinary team for diagnostic assessment when it comes to children and young people.
11	Family Fund recommends separate guidance on possible members of a multi-disciplinary team being made available for the diagnostic assessment of children / young people. This is because there may be different needs for children and young people, compared t
14	Family Fund would recommend that the Welsh Government collects the following data from all health boards and local authorities across Wales. Firstly, in order to understand the services that health boards and local authorities across Wales are providing
15	Not sure
17	It should happen all the time. Family Fund welcomes this campaign and feels that it could be widened to have a pan-disability focus, rather than solely on autism. Family Fund would recommend that there is a separate strand of activity which focus on children and young people and their families. The Disabled Children's Partnership (DCP) is a coalition of over 50 organisations campaigning to improve health and social care in England for disabled children, young people and their families. In 2017 it launched a campaign "The Secret Life of Us" https://disabledchildrenspartnership.org.uk/secret-life-of-us/ which explains that for many families caring for a disabled child or young person, everyday activities such as going to school or playing outside can be the most challenging tasks they face in their daily lives. DCP found that 43% of the general public say they don't know anyone with a disability, despite 1 in 5 people being disabled, and 97% of parents with a disabled child say the public do not understand the challenges they face every day. Therefore a campaign to raise understanding and awareness of the needs of all disabled people and their families is something that Family Fund would recommend. Further to this, Family Fund conducted research (October 2017,

	as part of a response to a UK Department for Transport consultation) around families raising disabled children using public transport and found that two thirds (67%) of families felt that they were being judged by other passengers. This was especially high for those with a child with ASD (75%) and those with long-term mental health condition (81%). One respondent said: "I now never tend to travel on any public transport as it's far too stressful I tend to hire a car & drive myself & my child to places." Of the families we surveyed, 60% told us that their child had a 'hidden' disability, and of this group, four in five (79%) would want transport staff to know their child was disabled. We asked if it would be useful for families to have a card explaining that their child was disabled and almost all families (91%) supported this idea. Family Fund recommends that the Welsh Government look closely at the provisions for disabled children and adults when using public transport, and perhaps an awareness campaign on public transport could be incorporated into the awareness raising.
19	Family Fund is the UK's largest charity providing grants for families on low incomes raising disabled or seriously ill children and young people. Last year, we provided 88,119 grants and services worth over £33 million to families across the UK last yea