Natasha Ryan
Assistant Secretary
MBS Policy & Special Services Branch
Medical Benefits Division
Department of Health, Canberra

21 May 2018

Via email: Mary.Warner@health.gov.au.

Dear Ms Ryan,

We refer to your letter of 5 April 2018 to the Royal Australasian College of Physicians (RACP), seeking feedback in relation to potential changes to Medicare Benefits Schedule (MBS) funding arrangements for Fetal Alcohol Spectrum Disorder (FASD). The RACP referred the issue to the relevant specialty bodies affiliated with the College.

The Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA), the Australian and New Zealand (ANZ) FASD Clinical Network and FASD Research Australia have collaborated in the preparation of this response which is a presented as a joint position from the three organisations in respect to the issues raised. As discussed with Ms Mary Warner, we appreciate the extension of time.

The NBPSA is a society for doctors (mainly paediatricians) who have a specialist clinical interest in child development and behaviour disorders. NBPSA has over 400 members working in public and private practice and academia, including the majority of paediatricians specialising in neurodevelopmental and behavioural paediatrics in Australia. The aim of the NBPSA is to build excellence in neurodevelopmental and behavioural paediatric clinical practice.

The ANZ FASD Clinical Network is a collaboration of clinicians and researchers involved in the diagnosis and management of FASD whose aim is to coordinate, expand capacity and standardise approaches relating to FASD referral, diagnosis and management in Australia and New Zealand. Opinions were sought from the Australian membership in the preparation of this response.

FASD Research Australia is an NHMRC funded Centre of Research Excellence (2016-2020) that harnesses the skills and experience of multidisciplinary research and clinical teams to support quality, high-impact research to address diagnosis, management and prevention of FASD.

This joint letter provides a brief response to the questions posed, including a short-term solution for FASD, outlines the nature of contemporary neurodevelopmental paediatric practice and suggests a more equitable and clinically appropriate approach to accessing care and support for FASD and other neurodevelopmental and behavioural paediatric conditions for the long term.

Response to specific questions

- **"Is FASD considered a PDD?"**

This is a difficult question, for both clinical and linguistic reasons. Pervasive Developmental Disorder is no longer current diagnostic terminology. PDD embraced a set of disorders whose functional impact was primarily in the area of social communication and related behaviour. The specific disorders that were previously described under PDD in DSM IV are now generally described in the DSM 5 classification of Autism Spectrum Disorder (ASD). There is however, significant overlap in functional presentation between FASD, ASD and other neurodevelopmental and behavioural disorders. It is due to this ambiguity that the term was discarded in the DSM version upgrade.

There is no doubt that FASD is a pervasive, developmental, disorder, within the natural meaning of those words, in contrast to the definition used in DSM IV. It is a complex neurodevelopmental condition requiring confirmation of severe impairment in multiple domains of functioning for diagnosis. In other words, the impact of FASD is pervasive impairment. FASD has developmental and behavioural features in common with a number of other complex neurodevelopmental conditions, such as ASD. For example, a diagnosis of FASD requires impairment in at least 3 of 10 specified domains of function (e.g. Cognition, Motor Skills, Adaptive Behaviour) with a history of confirmed prenatal alcohol exposure

For these reasons, expert clinical consensus does not support the use of diagnosis specific MBS item numbers in neurodevelopmental and behavioural paediatrics. We explain a better approach for facilitating sound, and efficient clinical practice below.

- **"If so, whether the existing MBS items 135 and 289 could be amended as per the proposed changes at Attachment A."**

We do not, as a matter of principle, support the use of diagnosis specific item numbers for neurodevelopmental and behavioural paediatric practice. However, as a short term, time limited solution to the presenting problem of access to MBS funding for FASD presentations, we do support the addition of FASD to the list of varied developmental conditions in item 137.

We understand that this would facilitate access to assessment and care for children with FASD concerns in similar way to the proposed use of 135 and 289 item numbers. Item 137 also presents a clearer clinical logic than connecting FASD to the now superseded classification of PDD. Although it is feasible to include FASD in item 135, it would be more clinically consistent to include FASD in MBS item number 137**,** along with 16 other specified neurodevelopmental or genetic syndromes with a known aetiology. The proposed change to item 135 by the addition of FASD to ASD will increase confusion. As items 135 and 137 and the related care pathways have the same rebate value, this approach would not increase costs to Medicare.

- **"If you are aware of other avenues currently being used for the diagnosis and treatment of FASD, particularly in the public hospital system."**

FASD Diagnosis most commonly occurs in specialised FASD clinics, or developmental clinics where clinicians are skilled in FASD diagnosis (e.g. Gold Coast and Sunshine Coast Child Developmental Services). These are typically based in the public hospital systems.

Most FASD cases in NSW are diagnosed at The CICADA Centre NSW (Care and Intervention for Children and Adolescents affected by Drugs and Alcohol), at The Children's Hospital at Westmead, a state-wide diagnostic FASD service established in 2016.
A diagnosis of FASD may also be made by community-based paediatricians working with local multidisciplinary teams or individual therapists; in child development units; by geneticists or

psychiatrists, although many of these children are also referred to CICADA for confirmation of diagnosis.

The PATCHES and FASD CARE Clinics provide private assessment and care services in urban, remote and rural Western Australia. PATCHES also provide private services in the Norther Territory, where there is limited access to diagnosis through the public health system.

Due to the interests and work of particular paediatricians, FASD diagnostic assessments are occurring more commonly in Western Australia, Queensland and New South Wales than in other states and territories, based on surveillance of FASD diagnosis by paediatricians through the Australian Paediatric Surveillance Unit.

The various approaches in both the public and private systems are supported through Medicare funding, state health funding and community organisations. Most struggle to provide fair and equitable access to care as the current arrangements are poorly configured to support efficient and effective neurodevelopmental paediatric practice. Overall, the number of services available to diagnose and manage FASD is low, however this is true for neurodevelopmental problems more generally.

We appreciate that the proposal to include FASD within an MBS item number arises as a partial solution to the fundamental problem arising from using diagnosis specific MBS item numbers in neurodevelopmental paediatrics. However, the assessment, diagnosis and treatment of concerns about FASD can and should be managed in the same way as other neurodevelopmental conditions: with the functional needs, level of impairment, diagnosis (when available), and social and environmental circumstances, determining the nature and level of support and treatment provided.

Aligning MBS items with effective and efficient neurodevelopmental paediatric practice

Outpatient paediatrics

Current MBS codes were built around a 20th century medical model of paediatric outpatient need. The nature of outpatient paediatric workload, however, has changed over the last 10-20 years. This has been termed the 'new morbidity' in paediatrics, characterised by problems that are:

- more complex (e.g. bio-psycho-social rather than just medical); and,
- more chronic (requiring pro-active longitudinal care).

More than 50% of standard paediatric outpatients is in this area now. This pattern has been described recently in the Journal of Paediatrics and Child Health. [1]

[1] Hiscock H, Danchin MH, Efron D, Gulenc A, Hearps S, Freed GL, et al. Trends in paediatric practice in Australia: 2008 and 2013 national audits from the Australian Paediatric Research Network. J Paediatric Child Health. 2017 Jan 1;53(1):55–61.

From the Abstract: One hundred and eighty paediatricians (48% of those eligible) contributed 7102 consultations. The proportion of developmental/behavioural conditions rose from 48% (SD 31%) to 60% (SD 30%) in new and 54% (SD 28%) to 66% (SD 28%) in review consultations in 2013 compared with 2008. More paediatricians reported diagnoses of autism spectrum disorder (39–56%, P = 0.002), attention-deficit/hyperactivity disorder (47–55%, P = 0.05) and intellectual disability (18– 36%, P = 0.001) in first consultations.

Neurodevelopmental Disorders

A Neurodevelopmental Disorder is one of known or presumed biological origin, where the clinical impact is manifest in development, learning and behaviour. Examples include Intellectual, Learning, Social (including Autism), Motor (Cerebral Palsy, DCD), Self-Control (ADHD, Executive Function) and mental health problems.

The paediatric care of these children is about the longitudinal support of children through to adulthood. In this way it is similar to other paediatric chronic disorders such as cystic fibrosis and diabetes. The primary attributable clinical outcome is to optimise the physical and mental function of children as they transition to adult life.

MBS Codes

The proliferation of diagnosis specific MBS items for neurodevelopmental paediatrics is not consistent with effective and efficient clinical practice.

For example, the current MBS codes for ASD arose at the time of the Helping Children with Autism (HCWA) package, which is in the process of being transferred to NDIS. HCWA was based on presumptions of prevalence of the condition being relatively low, and effectiveness of treatment being superior to the treatment of other neurodevelopmental conditions, both of which have been shown to be incorrect. The HCWA is a well-intentioned package that has helped many children; although not as effectively or efficiently as it could have.

The diagnosis specific approach to MBS codes has created several problems:

1. potential over diagnosis – the availability of diagnosis specific services may influence any diagnostic uncertainty towards a particular outcome.[2, 3] There is pressure on parents to obtain (and sometimes purchase) a preferred diagnosis and also huge emotional pressure on paediatricians to diagnose against their clinical judgement;
2. discrimination by diagnosis - against children who don't have ASD or one of the diagnosis listed in item 137 but do have equally (or greater) complex special needs. FASD is a primary example;
3. assessment practices contrary to best care principles – usual medical diagnostic practice seeks a cause for the problems that present from a list of possibilities (differential diagnosis). By contrast, the 4 allied health assessment codes for ASD presume diagnosis before the assessment commences. If the assessment says 'this is not autism' it doesn't actually say what is going on. The present item number approach establishes an emphasis for the medical consultation on diagnosis rather than a focus on a more practical, detailed and useful assessment of the patient's needs, management and prognosis;

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[2] May T, Sciberras E, Brignell A*, et al*. Autism spectrum disorder: updated prevalence and comparison of two birth cohorts in a nationally representative Australian sample; *BMJ Open* 2017;**7:**e015549. doi:10.1136/bmjopen-2016-015549

From the Abstract: 1:40 Australian parents (2.4%) self-report that their child has an ASD diagnosis.

[3] Skellern C, Schluter P, McDowell M. From complexity to category: responding to diagnostic uncertainties of autistic spectrum disorders. J Paediatric Child Health. 2005 Aug;41(8):407–12.

From the Abstract: In the absence of definitive biological markers, ASD remains a behavioural diagnosis that is often complex and uncertain. In response to systems that demand a categorical diagnostic response, specialists are providing ASD diagnoses, even when uncertain. The motivation for this practice appears to be a clinical risk/benefit analysis of what will achieve the best outcomes for children. It is likely that these practices will continue unless systems change eligibility to funding based on functional impairment rather than medical diagnostic categories.

4. potentially ineffective therapy services (e.g. speech and occupational therapies) – services are not accountable to meaningful outcomes. We believe that the therapeutic marketplace has expanded, in part, because of financial incentives.

Recommendations

1. That the multiple and varied Medicare codes relevant to neurodevelopmental paediatrics be systematically reviewed to reflect an equitable epidemiology of child disability need. Specifically, rather than establishing arbitrary diagnostic restrictions, that the codes allow and support sound clinical practice in assessment and therapy.

2. That the referrals to allied health for treatment services also be reviewed at the same time. The codes do not support best practice approaches for multi-disciplinary assessment, and in some cases, there is also a problem of accountability. For mental health referrals this is managed through assessing change in mental health symptoms using standardised questionnaires. In disability, the equivalent is function. It is recommended that, when clinically appropriate, referrals be accountable (as they are with mental health care referrals) by:
    - addressing areas where function is shown to be problematic (e.g. language); and,
    - evaluating changes in function (note, changes in function have to be greater than changes that would have occurred without intervention, so percentiles or standardised scores need to change).

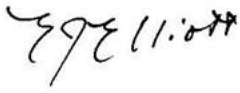
We appreciated that the scope of these recommendations is well beyond the questions posed in your letter and may take some time to consider, adjust and implement.

Accordingly, our support for the inclusion of FASD within item 137 is offered as a temporary measure, subject to a systematic review of relevant neurodevelopmental paediatric and allied health item numbers being undertaken as a matter of priority.

We ask that the proposed review of outpatient and community paediatrics item numbers through the Consultant Physician Consultations Committee of the MBS Taskforce Review, be expedited.

We would be pleased to provide whatever assistance we can. Please do not hesitate to contact Greg Rochford, NBPSA Chief Executive Officer, at greg.rochford@nbpsa.org or on (0412) 196 172.

Yours sincerely



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