Multicountry review: developmental surveillance, assessment and care by outpatient paediatricians

Nadia Coscini 1,2, Priya Heyes,3 Helen Bedford 4, Eyal Cohen,5,6 Anita D’Aprano,1,7 Sharon Goldfeld,1,8 Dougal Hargreaves,9 Sarah Loveday,10 Sahar Nejat,11 Gehan Roberts,1,8 Anna Sarkadi,12 Natasha Ruth Saunders 5,6, Susan Woolfenden,13,14 Kate Milner15,16

ABSTRACT
Background Care of young children with neurodevelopmental disorders (NDD) is a major component of paediatric outpatient practice. However, cross-country practice reviews to date have been limited, and available data demonstrate missed opportunities for early identification, particularly in vulnerable population subgroups.

Methods Multicountry review of national paediatric body guidance related to developmental surveillance, early identification and early childhood intervention together with review of outpatient paediatrician practices for developmental assessment of children aged 0–5 years with/at risk of NDDs. Review included five countries with comparable nationalised universal child healthcare systems (ie, Australia, Canada, New Zealand, Sweden and the UK). Data were collected using a combination of published and grey literature review, supplemented by additional local sources with descriptive review of relevant data points.

Results Countries had broadly similar systems for early identification of young children with NDDs alongside universal child health surveillance. However, variation existed in national paediatric guidance, paediatric developmental training and practice, including variable roles of paediatricians in developmental surveillance at primary care level. Data on coverage of developmental surveillance, content and quality of paediatric development assessment practices were notably lacking.

Conclusion Paediatricians play an important role in ensuring equitable access to early identification and intervention for young children with/at risk of NDDs. However, strengthening paediatric outpatient care of children with NDD requires clearer guidance across contexts; training that is responsive to shifting roles within interdisciplinary models of developmental assessment and improved data to enhance equity and quality of developmental assessment for children with/at risk of NDDs.

INTRODUCTION
Neurodevelopmental disorders (NDDs) are conditions that arise as children develop and include intellectual disability, autism spectrum, communication, language, motor, specific learning, tic, developmental coordination, attention deficit hyperactivity and other unspecified NDDs.1 Children with NDDs represent more than 50% of consultations to outpatient paediatricians in high-income countries,2 and early identification and management of these conditions is considered an essential component of the role of outpatient paediatricians. It is important for management of comorbid developmental and health conditions, ensuring access to appropriate early childhood intervention (ECI) and ongoing developmental monitoring. However, many paediatricians report inadequate training in their diagnosis and management.3–6 Additionally, limited available practice reviews demonstrate missed opportunities for early identification, particularly in vulnerable population subgroups.6–14

In this paper, we review the current situation with regards to paediatric guidance, training and practice related to assessment and ECI referral for young children with NDDs across five comparable high-income contexts. In many other common childhood health conditions (eg, neonatal conditions, epilepsy and asthma), cross-contextual review and exploration of variations in practice has driven development of consensus guidance and ultimately, improved standardisation and quality of care. However, to date, data related to cross-contextual outpatient paediatric developmental assessment practices have been unclear, and international paediatric guidance for identification and management of NDDs across diverse settings has been lacking. Thus, the goal of this multicountry review is to review current national paediatric body guidance and outpatient paediatric practice related to assessment of young children with NDDs to explore what is needed to improve developmental care for these children across similar health system contexts moving forwards.

While the focus of this review is on outpatient paediatric care related to early identification and ongoing care of children with NDDs, this is contextualised within a broader health system context. In high-income countries, at primary care level, non-specialist health professionals (eg, child health nurses and general practitioners) play a crucial role in early identification of NDDs through developmental surveillance (monitoring), defined as longitudinal observation of a child’s growth and development through a combination of observation and caregiver feedback that may also incorporate use of standardised screening tools (figure 1).15 Processes for developmental surveillance at primary care level affect referral pathways to paediatricians for ongoing assessment and care.
At secondary care level, outpatient paediatricians work alongside other health, mental and allied health professionals to undertake and support assessment, ECI referral and long-term management. Although different terms may be used, here we define outpatient paediatricians as those who have been referred children for further assessment and management, in either community or hospital-based outpatient clinics. For the remainder of this paper, unless otherwise specified, use of the term paediatrician refers to outpatient paediatricians.

METHODS
We completed a multicountry review of national paediatric guidance and outpatient paediatric practice related to early identification and developmental assessment of children with NDDs aged 0–5 years across five countries: Australia, New Zealand, Sweden, Canada and the UK. These countries were selected for their comparability as high-income economies with nationalised healthcare systems based on a Beveridge Model of taxpayersupported coverage of universal healthcare services, with free care at point of outpatient public health access.13 14 We excluded countries with alternative health structures given its criterion for age of onset from 7 years.1

Similarly, although ongoing management of children with NDDs was not the primary focus of this paper, for context, we also included information related to government funded ECI. Data were collected using a combination of published and grey literature review and expert advice from each country (see figure 2).

Published literature review included searches of Medline, Embase and PubMed using the terms ‘screening’, ‘assessments’, ‘questionnaires’, ‘child development’ and ‘paediatric clinics’ with searches limited to English language from years 2000 to 2020. Grey literature included reviews of paediatric and early child development organisations, relevant government websites in each country and internationally and reference lists of published literature. This was supplemented by additional grey literature or local data sources known by country-based coauthors, as referenced within this paper.

Country-based coauthors were asked to populate and check data related to their own country context in the template, which was cross-checked by three authors (NC, PH and KM). Following collation of data, tables were shared with the coauthor group until consensus was reached related to each data point.

Terminology
Figure 1 provides definitions of key terms used within our review, based on consideration of published literature and national paediatric documents by our international author group.

RESULTS
Figure 2 provides a summary of the grey and published literature search strategy following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.24

Country contexts: child health and developmental surveillance systems
National paediatric guidance in all countries recommended that developmental surveillance should be part of universal child health checks in primary care, followed by paediatric referral if a child was identified as being at risk for an NDD. In two countries (Sweden and UK) national paediatric guidance recommended specific timing for developmental surveillance, but in other countries, timing was not specified (table 1).
In all countries, nurses and generalist doctors provide the main workforce for developmental surveillance in primary care. However, in Canada, depending on specific region, paediatricians may also have primary care responsibilities,23 and in Sweden, paediatricians can work within primary care organisations, although not usually participating in developmental surveillance.

From a paediatric workforce perspective, the total number of paediatricians per population varied from 34 to 66/100 000 children <18 years, but data on geographic distribution or subspecialisation of the paediatric workforce were limited or lacking. Minimum duration of accredited developmental training experience required prior to certification for both general and developmental paediatricians also varied by country. For general paediatric training, duration of required accredited developmental training varied from a minimum of 1 month (Canada) to approximately 6 months in most other countries (Sweden, Australia, New Zealand and UK). Developmental subspecialisation duration also varied being 2 years in Canada and 3 years in the UK, Australia and New Zealand. In Sweden, there was no specific developmental behavioural subspecialisation per se with paediatric neurology and habilitation including a similar focus.

Potential referral pathways to paediatricians for children with developmental concerns across countries were diverse and included referral by doctors, nurses, allied health professionals and early childhood educators. However, no publicly available data were available describing the proportion of referrals coming through various referral sources.

### Table 1 Country contexts: child health and developmental surveillance systems

<table>
<thead>
<tr>
<th>Australia</th>
<th>Canada</th>
<th>New Zealand</th>
<th>Sweden</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>National paediatric organisation guidance related to child development surveillance</td>
<td>Royal Australasian College of Physicians1</td>
<td>Canadian Paediatric Society and Canadian Task Force on Preventive Health Care1</td>
<td>Royal Australasian College of Physicians1</td>
<td>National Board of Health and Welfare and National Society of Preventive Child Care</td>
</tr>
<tr>
<td>Timing of developmental reviews recommended in national paediatric organisation guidance. Each country recommends developmental surveillance included in universal child health checks and/or with any caregiver concerns.</td>
<td>Health checks in partnership with parents and families, ‘may be assisted’ by use of standardised measures.</td>
<td>Health checks at every scheduled health visit, using parental history clinical observation and standardised measures.</td>
<td>In partnership with parents and families, ‘may be assisted’ by use of standardised measures.</td>
<td>Health checks at 4w, 6m, 10m, 18m, 2.5–3y, 4y, including language, vision and hearing.</td>
</tr>
</tbody>
</table>

Demographics

<table>
<thead>
<tr>
<th>Total population (&lt;% indigenous)</th>
<th>Victoria 6 680 600 (0.8)14</th>
<th>Ontario 13 448 494 (2.6)14</th>
<th>4 783 000 (17.0)14</th>
<th>10 036 000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population aged 0–5 y (&lt;% of total)</td>
<td>1 655 000 (6.6)</td>
<td>1 980 000 (5.3)</td>
<td>301 000 (6.6)</td>
<td>598 000 (6.0)</td>
</tr>
<tr>
<td>Gross domestic product per capita, USD on purchasing power parity</td>
<td>52 316</td>
<td>46 616</td>
<td>41 085</td>
<td>51 726</td>
</tr>
<tr>
<td>Out of pocket expense as % total health expenditure</td>
<td>18</td>
<td>14</td>
<td>14</td>
<td>15</td>
</tr>
</tbody>
</table>

Health system structure.

<table>
<thead>
<tr>
<th>All countries have universal healthcare.</th>
<th>Public funding, free at point of care</th>
<th>Public funding, free at point of care</th>
<th>Free &lt;12 years, copayments &gt;12 years for primary practice, free for paediatrician</th>
<th>Free at point of care for children &lt;18 years</th>
<th>Free at point of care</th>
</tr>
</thead>
</table>

Workforce for developmental surveillance at primary care level

<table>
<thead>
<tr>
<th>National Board of Health and Welfare and National Society of Preventive Child Care</th>
<th>Nurse, GP</th>
<th>NP, family physician, paediatrician</th>
<th>Nurse, GP</th>
<th>Nurse, GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total paediatricians/100 000 children &lt;18 y</td>
<td>66</td>
<td>41</td>
<td>38</td>
<td>54</td>
</tr>
<tr>
<td>Minimum duration of developmental training</td>
<td>6 m</td>
<td>1 m</td>
<td>6 m</td>
<td>Variable*</td>
</tr>
<tr>
<td>Developmental paediatrician.</td>
<td>36 m</td>
<td>24 m</td>
<td>36 m</td>
<td>No paediatric subspecialisation*</td>
</tr>
</tbody>
</table>

Referral pathways to paediatricians


See online supplemental materials for references.

*Training embedded in psychiatry, neurology and child health centre rotations.

Available data suggested that overall coverage of developmental surveillance checks was high across countries, although there was inconsistency across countries regarding age bands for administration that limited cross-country comparison. Data related to coverage by sociodemographic variables was generally
lacking, although in Victoria, Australia, coverage of primary care developmental surveillance checks was at 12 months lower for Indigenous than the general population (64% vs 83%, respectively).27 28

Timing and incorporating standardised measures within developmental surveillance at primary care level varied. Specifically, a combination of broad-band, narrow-band and/or domain-specific measures were used. All countries used broad-band screening tools for identification of global or domain specific delays. However, specific screening tools for autism spectrum disorders (eg, Modified Checklist for Autism in Toddlers and Monitoring of Social Attention, Interaction & Communication Assessment) were not used in the UK, New Zealand or other Australian states. Some tools are commonly used internationally (eg, Strengths and Difficulties Questionnaire, Ages and Stages Questionnaire (ASQ)) while others were locally developed and were infrequently used elsewhere (eg, NDDS, Westerlund and Miniscalco language tests).

### Paediatric developmental reviews and assessments

Across all countries, there was a lack of systematically collected data related to developmental reviews and assessment by paediatricians. Data related to screening and assessment tool use was largely based on anecdotal report by country-based practitioners within the coauthor group. An exception was Australia and New Zealand data that were based on an unpublished survey of paediatricians who were members of the Neurodevelopmental and Behavioural Paediatric Society of Australasia (unpublished article, Heyes P). The use of standardised tools in paediatric developmental and behavioural assessment in Australasia, 2016. The survey included developmental behavioural paediatricians (n=121) representing a response rate of 59% (unpublished article, Heyes P. The use of standardised tools in paediatric developmental and behavioural assessment in Australasia, 2016. Ninety-four per cent of respondents reported using standardised developmental screening and/or assessment tools at least sometimes with specific tools as listed in table 2.

### Early childhood intervention

All countries offered free ECI, although structure and providers for service delivery varied. Most countries provide a nationalised...
public-funded approach, while Australia uses a publicly funded national insurance model and Canada uses a combined insurance funding model (public/private). Eligibility criteria and levels of support offered also differed between and within countries. Specialist paediatric assessment or diagnosis were not formally required for ECI access except in some parts of Canada and specifically for habilitation services in Sweden (table 3).

**DISCUSSION**

Our multicountry review explored variations in paediatric guidance and practice related to early identification and management of young children with NDD in comparable high-income settings. This adds to the limited number of previous cross-country comparative reviews of universal child health services and highlights important gaps and opportunities to improve quality and consistency of practice.

**Clearer guidance for developmental surveillance and assessment across contexts**

The WHO recognises lack of international guidance related to child development surveillance and assessment as a challenge to promoting child development at scale. In our review, countries acknowledged the importance of developmental surveillance occurring alongside universal child health surveillance. However, guidance about timing of reviews and use of standardised measures varied. In Australia and New Zealand (with the same governing body to guide physician training), no specific tools or timing for developmental surveillance visits were recommended, while in Canada, only timing was stipulated. By contrast, in Sweden and the UK, several scheduled contact points were suggested along with use of specific standardised measures.

We also found national paediatric guidance, and data about current practice, was limited with regards to developmental assessments by paediatricians. However, our clinical experience and limited survey data suggest that few paediatricians are trained in use of formal developmental assessment tools (eg, Bayley or Griffiths Scales of Child Development) and likely fewer are using them routinely. In most comparator countries, there is no specific remuneration for paediatricians individually to complete such time-intensive developmental assessments. As such, while diagnostic specific tools (eg, Autism Diagnostic Interview-Revised and Autism Diagnostic Observation Schedule) are a crucial part of comprehensive developmental assessment, paediatricians perhaps have more of a role in coordinating their use and interpreting their findings, rather than administering them directly.

Paediatric guidance regarding universal developmental surveillance and further assessment in the countries we reviewed contrasts with recommendations by the American Academy of Paediatrics (AAP). For example, the AAP recommends that developmental surveillance include use of recommended standardised developmental screening measures at 9-month, 18-month and 30-month well-child visits autism-specific screening at ages 18 and 24 months, and anytime there are caregiver or clinician concerns. We note that the role of paediatricians in the USA is often substantively different with an overall health system model that differs compared with countries in this review. However, the AAP guidance provides practitioners with clear expectations regarding the timing and content of developmental reviews. We suggest that there is a need to improve international paediatric guidance related to developmental surveillance and assessment to support early identification of NDD in young children, with approaches tailored to diverse health system contexts.

**Better data to understand and improve early identification in primary and referral level care**

Child health systems included within this review aimed to provide proportionate universal developmental surveillance and access to ECI according to need. However, basic data on coverage of developmental surveillance checks at primary care level were difficult to retrieve with almost no data on access according to important variables such as sex, ethnicity or socioeconomic status. Our difficulties in accessing such data mirror findings of initiatives such as the UNICEF Countdown to 2030: Country profiles on early child

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**Table 3 Early childhood intervention**

<table>
<thead>
<tr>
<th>Structure and governance</th>
<th>Australia</th>
<th>Canada</th>
<th>New Zealand</th>
<th>Sweden</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>NDIS – EIS ≤6 years old, and private and public allied health and behavioural services for specific developmental problems for example, language delay</td>
<td>Provincial health insurance generally funds diagnoses and interventions are variable: health, education and social services</td>
<td>Early Intervention Service, Ministry of Education 0–5 years, NASC, Disability Support Services, Ministry of Health</td>
<td>Swedish National Agency for Education regulates child’s right to support services in schools and preschools, National Board of Health and Welfare regulates conditions for rehabilitation services that are free of charge and implemented at regional level</td>
<td>The National Health Service covers medical, nursing and allied health professionals care (including speech and language therapy, physiotherapy, occupational therapy), EHCP led by the Department of Education</td>
<td></td>
</tr>
</tbody>
</table>

| Eligibility criteria | EIS: developmental delay in two areas as referred by medical, allied health or early education professionals. Paediatric review is desirable and essential for ongoing funding >6 years old. | Not universal, varies by jurisdiction | Physical, Intellectual or Sensory Disability or Autism, duration >6 months, with functional impairment. Referral from GP or paediatrician | Diagnosis required for habilitation services. Different selection criteria, but generally more severe disabilities. Psychiatric and paediatric evaluation and referral. | Referral from GP and/or paediatrician or education sources. |

| Requirement for prior developmental assessment Y/N | N | Speech self-referral. Families may pay privately or through extended health benefit plans for physiotherapy and occupational therapy without referral. Otherwise, healthcare provider referral required. | Y | Y | Y |

| Requirement for specific diagnosis Y/N | N support determined by level of need, not by specific diagnosis | Y for autism-specific services. N for other interventions. | N but requirement of assessment of functional impairment | Y support determined by level of need | N but requirement of support determined by level of need and in some areas by diagnosis but varies by region. |

See online supplemental materials for references.

EHCP, Education, Health and Care Plan; EIS, Early Intervention Scheme; NASC, Needs Assessment and Service Coordination; NDIS, National Disability Insurance Scheme.
development, which showed major gaps even in well-resourced child health systems.\textsuperscript{35} We also found marked variation in approaches to paediatric referral and subsequent clinical management. In some settings, a two-stage screening process was used prior to paediatric referral while in other settings, specialist referral was suggested after a primary developmental screen only. A range of both broad-band screening measures (for identification of developmental delay) and narrow-band developmental screening measures (for identification of increased risk of specific developmental diagnoses) were used. Our experience as practitioners is that this variability in referral pathways extends to subregional levels. For example, a recent review in Australia highlighted a wide variation between states in recommended number of well-child visits (between 4 and 13) and different tools used (ie, ASQ, Parents’ Evaluation of Developmental Status and Brigance).\textsuperscript{11}

Similarly, our findings about tools used by paediatricians in developmental assessment were based largely on our experience as clinicians in the field, rather than systematic administrative or large-scale survey data. While this variation is beginning to be noted in studies appraising differences in ASD assessments,\textsuperscript{40} the lack of data makes it difficult to objectively measure and understand how developmental paediatricians are practising, and how effectively we are reaching and assessing children who are most developmentally vulnerable from a population perspective.

Moving forwards, we suggest there is a need to improve routinely available data related to all levels within systems of developmental care for young children to understand whether pathways for early identification of NDDs effectively identify those who are most vulnerable and to drive change where there are gaps. We consider this analogous to the need for data to understand immunisation coverage, or treatment of pneumonia or meningitis, to rigorously inform contextually appropriate policy and programmes. Unless systems of early identification are informed by local data, it is difficult to assess how well we collectively deliver on efforts to ensure at-risk children are provided with timely and equitable access to ECI. This will require clearer reporting of administrative data related to developmental surveillance at primary care levels, disaggregated by socioeconomic variables as well as consideration of practitioner surveys and other means to strengthen data related to paediatric developmental assessment practices.

**Developmental training responsive to shifting paediatrics roles**

Our review also highlighted marked variation in accreditation requirements related to developmental paediatrics.\textsuperscript{37} Training requirements differ not only between countries but even within national training pathways. Questionnaires over the years (1985, 2003 and 2004) have repetitively highlighted that paediatricians feel that more training in developmental paediatrics is required.\textsuperscript{30 38 39} Our experience as practitioners is that this variability in referral pathways extends to subregional levels. For example, a recent review in Australia highlighted a wide variation between states in recommended number of well-child visits (between 4 and 13) and different tools used (ie, ASQ, Parents’ Evaluation of Developmental Status and Brigance).\textsuperscript{11}

As the role of paediatricians within interdisciplinary models of assessment shifts over time,\textsuperscript{40} it is important that preservice training and ongoing professional development reflects knowledge of referral to ECI services and long-term follow-up care. Timely access to ECI for children with NDD is important from a rights perspective as well as for health, well-being, educational and employment opportunities.\textsuperscript{41} Our experience has indicated that paediatricians continue to have a major role in supporting equitable access to ECI services and should have an understanding of local funding and eligibility requirements.\textsuperscript{42} Professional development should also continue to support the role of paediatricians in coordinating and interpreting multidisciplinary developmental assessments, excluding and assessing physical and increasingly also diverse genetic diagnoses. It should also foster knowledge in coordinating child-centred, family-focused approach to approach to children’s health in anticipating, monitoring and supporting well-being and broader needs.\textsuperscript{43}

**Limitations**

While it was beyond the scope of this review to directly include comparison with early identification approaches in low-income and middle-income countries, we consider that strengthened guidance, data and training is also needed in transitional economies where universal child health is shifting, beyond a focus on survival alone, to a greater emphasis on child development including early intervention for children with developmental delay and NDDs.

We also note that within the scope of this review, exploration of differences in early identification approaches has been largely descriptive, rather than evaluating the impact of different policy and service delivery approaches. To understand the implications of variations in approaches across contexts, there is also a need to compare variations in outcomes for children and families as well as economic analyses of cost-effectiveness.

**Conclusion**

This multicountry review highlights substantial variations in paediatric guidance and practice as well as potential opportunities to improve early identification of children with NDDs, even in settings with well-established universal child healthcare. Improved data on coverage, quality and impact of existing early identification systems, including developmental and clearer cross-contextual paediatric guidance and training to support the changing role of paediatricians are needed. Moving forwards, international and regional collaboration is also needed to further explore how to best measure impact to drive improvements in care for children with NDDs.

**Author affiliations**

1Centre for Community Child Health, The Royal Children’s Hospital Melbourne, Parkville, Victoria, Australia
2Health Services Group, Murdoch Children’s Research Institute, Melbourne, Victoria, Australia
3Department of Child Development Service, Government of Western Australia Child and Adolescent Health Service, Perth, Western Australia, Australia
4Population, Policy and Practice Department, University College London Institute of Child Health, London, UK
5Department of Child Health Evaluative Sciences, Hospital for Sick Children Research Institute, Toronto, Ontario, Canada
6Department of Paediatrics, University of Toronto Institute of Health Policy Management and Evaluation, Toronto, Ontario, Canada
7Department of Paediatrics, The University of Melbourne Melbourne Medical School, Melbourne, Victoria, Australia
8Population Health Theme, Murdoch Childrens Research Institute, Parkville, Victoria, Australia
9Department of Primary Care and Public Health, Imperial College London, London, UK
10Health Services Group, Murdoch Childrens Research Institute, Parkville, Victoria, Australia
11Department of Public Health and Caring Sciences, Uppsala Universitet Institutionen for euroasiatiska studier, Uppsala, Sweden
12Department of Public Health and Caring Sciences, Uppsala Universitet, Uppsala, Sweden
13School of Women’s and Children’s Health, University of New South Wales, Sydney, New South Wales, Australia
14Department of Community Child Health, Sydney Children’s Hospital Randwick, Randwick, New South Wales, Australia
15Department of Neurodevelopment and Disability, The Royal Children’s Hospital Melbourne, Parkville, Victoria, Australia
16Neurodisability and Rehabilitation Research Group, Murdoch Childrens Research Institute, Parkville, Victoria, Australia

Twitter Sahar Nejat @nejatshahr

Contributors NC contributed to the background literature review, completed data collection, synthesis and first and subsequent manuscript drafts. PH completed
the background literature review, contributed to data collection and synthesis and manuscript drafting. HB, EC, AD, SG, DH, SL, SN, GR, AS, NRS and SW provided country-based data and contributed to manuscript drafting and review. KM contributed to scope and structure of the paper, review of data collection and synthesis, drafting and review of the manuscript.

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ORCID iDs
Nadia Coscini http://orcid.org/0000-0002-5519-344X
Helen Bedford http://orcid.org/0000-0003-0980-1380
Natasha Ruth Saunders http://orcid.org/0000-0002-4369-6904

REFERENCES