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# Annual Research Review: Achieving universal health coverage for young children with autism spectrum disorder in low- and middle-income countries: a review of reviews

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**Background:** Autism presents with similar prevalence and core impairments in diverse populations. We conducted a scoping review of reviews to determine key barriers and innovative strategies which can contribute to attaining universal health coverage (UHC), from early detection to effective interventions for autism in low- and middle-income countries (LAMIC). **Methods:** A systematic literature search of review articles was conducted. Reviews relevant to the study research question were included if they incorporated papers from LAMIC and focused on children (<eight years old) with autism or their caregivers. The database search was supplemented with bibliographic search of included articles and key informant suggestions. Data were extracted and mapped onto a Theory of Change model toward achieving UHC for autism in LAMIC. **Results:** We identified 31 articles which reviewed data from over fifty countries across Africa, Latin America, Middle East, and Asia and addressed barriers across one or more of four inter-related domains: (a) the social context and family experience for a child with autism; (b) barriers to detection and diagnosis; (c) access to appropriate evidence-based intervention; and (d) social policy and legislation. Key barriers identified included: lack of appropriate tools for detection and diagnosis; low awareness and experienced stigma impacting demand for autism care; and the prevalence of specialist models for diagnosis and treatment which are not scalable in LAMIC. **Conclusions:** We present a Theory of Change model which describe the strategies and resources needed to realize UHC for children with autism in LAMIC. We highlight the importance of harnessing existing evidence to best effect, using task sharing and adapted intervention strategies, community participation, and technology innovation. Scaling up these innovations will require open access to appropriate detection and intervention tools, systematic approaches to building and sustaining skills in frontline providers to support detection and deliver interventions embedded within a stepped care architecture, and community awareness of child development milestones. **Keywords:** Autism; detection gap; treatment gap; low- and middle-income countries; low-resource settings; scoping review.

## Introduction

Autism spectrum disorder (ASD) (hereafter autism) is a neurodevelopmental disorder with global prevalence of 1–2% (Baxter et al., 2015; Elsabbagh et al., 2012). Prevalence figures from community-based studies within two low- and middle-income countries (LAMIC) vary from 0.68 to 1.1% (Abubakar, Ssewanyana, & Newton, 2016; Arora. et al., 2015). Autism is characterized by pervasive deficits in social communication skills, restricted, repetitive interests and behaviors, and sensory difficulties and is often but not necessarily associated with intellectual disability. It is known to be a leading cause of disability

in young children and has enduring lifelong consequences on individual and family functioning with significant societal and economic costs. The lifespan societal cost of autism in high-income countries (HIC) has been estimated at up to \$2.4 million per individual in the United States (Buescher, Cidav, Knapp, & Mandell, 2014; Olusanya et al., 2018); and a total of £32 billion annually in the United Kingdom (Lemmi, Knapp, & Ragan, 2017); with costs higher than heart disease, stroke, and cancer care combined (Knapp, Romeo, & Beecham, 2009). For these reasons improving access to comprehensive and integrated services for autism is recognized as a public health priority (World Health Assembly, resolution 67.8), a human right (UN General Assembly, 2007), and a requirement for attainment of universal health coverage and the United Nation's Sustainable

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Development Goals (UN General Assembly, 2015). Autism is therefore a priority for the global health agenda and, as a neurodevelopmental condition, autism has been included in the grand challenges of global mental health (Collins et al., 2011).

Early prodromal signs indicating the possibility of autism can often be identified as early as 12 months of age, and a diagnosis based on stable emerging symptoms can often be confirmed by 24–36 months (Miller et al., 2017). Early identification has potential benefits of support for parental adaptation and psychoeducation, along with initiation of early interventions for the child (Durkin et al., 2015). There is a growing autism intervention science literature of variable but increasing quality, largely originating from HIC contexts. Recent systematic and narrative reviews of this literature (French & Kennedy, 2018; Green & Garg, 2018; Sandbank et al., 2020) identify potential benefits to the early development of children with autism of a number of early-delivered psychosocial interventions. Many early interventions include direct therapist work with the child to improve relevant behaviors and skills pivotal for development. Some social communication interventions work directly through parents on naturalistic processes of social communication development in the family, aiming to improve skills foundational for social communication and adaptation, to reduce the severity of autistic impairments and adaptive difficulties downstream in development (Green & Garg, 2018). One question is how feasible such evidenced approaches could be for LAMIC and how well they have been adapted for effective use at scale.

A variety of barriers contribute to low levels of detection, diagnosis, and evidence-based interventions in LAMIC. Governments spend tiny fractions of their healthcare budgets on mental health care, of which an even smaller fraction is devoted to child mental health and neurodevelopmental disorders, with much of this spending allocated to psychiatric hospitals (World Health Organisation, 2018). The number of mental health professionals is two per hundred thousand in most low-income countries; most specialists are located in metropolitan areas, leaving remote areas with no or very few accessible services. There is almost no representation of child psychiatrists, child development practitioners, or speech and occupational therapists, who are the mainstay of care of children with autism and other developmental disabilities in well-resourced contexts. Ultimately, in the context of LAMIC, only a small fraction of children with autism are able to access services, due to a combination of the 'detection gap', which refers to the challenge of actually identifying children in a community at an early age, followed by the 'care gap', which refers to the lack of access to evidence-based interventions. While the ideal measure of the detection gap is the proportion of children with autism in the population who have

not been diagnosed, such data do not exist for any LAMIC. The closest proxy, though not ideal, is the age of diagnosis in specialist clinical referral populations. While these will inevitably show a strong selection bias toward an earlier detection age than will pertain in the general population, even these studies show the average is high, ranging from 45.5 months in Columbia (Talero-Gutiérrez, Rodríguez, De La Rosa, Morales, & Vélez-Van-Meerbeke, 2012) to 58 months in Nepal (Shrestha, Disanayake, & Barbaro, 2019).

The aim of this paper is to synthesize evidence, guided by a Theory of Change framework (ToC; De Silva et al., 2014), to inform the architecture of health policies and programs needed to realize universal health coverage (UHC) for children with autism in LAMIC. The ToC is a recommended framework to address the needs of complex initiatives and aims to describe a model of action or practice to achieving a hypothesized goal (Anderson, 2006). The ToC we develop will present a pathway from the recognition of differences in their child by families, to the access of evidence-based detection, diagnosis, and interventions, all of which are scaffolded within an effective health system and policy framework. This review aims to map the components for achieving this complex change over time.

## Methods

We applied the framework for scoping reviews suggested by Levac (2010) to synthesize the evidence from existing reviews. Our steps included the following: (1) specification of the research question; (2) identification of potentially relevant studies; (3) an iterative screening process of inclusion and exclusion of identified studies; (4) charting of the data; and (5) collation and synthesis of the results. Steps 2–5 are presented below.

### Identification and screening of studies

Using Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols guidance (PRISMA-P; Moher et al., 2015), we conducted a systematic literature search to identify reviews published before 11 September 2020 that addressed questions related to the pathways to UHC for young children with autism in LAMIC. Our search also extended to reviews on childhood developmental disability where these reviews held relevance to the autism in LAMIC context. Finally, in our consideration of the identified papers, we also included discussion of information from a small number of non-western countries with technically high income but nevertheless underdeveloped child development and healthcare systems.

Using OVID, we searched four databases: Cochrane Database of Systematic reviews, APA PsycInfo, Ovid Medline, and EMBASE. A comprehensive list of search terms was applied using Boolean syntax, requiring terms reflecting: (a) the condition (any of: *auti\**, *neurodevelopment\**, *neurodisabilit\**, *developmental disorder\**, *developmental disabilit\**, *disabilit\**); (b) the age-group (*child\**); (c) article type (any of: *review*, *meta\**, *framework*, *scoping*, *systematic*, *overview*, *synthesis*); (d) LAMIC context, global health or culture (any of: *LMIC\**, *LAMIC\**, *low resource\**, *low income*, *limited-resource\**, *middle income*, *glob\**, *cultur\**); and (e) aspects of pathways to care in

the title, abstract, keywords, or full-text (any of: pathway\*, care, help, access, service\*, recogni\*, detection, screen\*, identif\*, diagnos\*, treatment\*, therap\*, intervention\*, training, barrier\*, stigma). Our search generated 3,114 articles. Exact duplicates were removed electronically within OVID, resulting in 2,105 articles. Additional duplicates were identified and removed manually, resulting in 2,043 unique articles (see PRISMA flowchart in Figure 1).

### Study selection

All articles were screened by a group of authors (GD, KL, CE, and SB) within Rayyan (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016), a free web application designed for collaborative systematic reviews. To maximize reliability during title and abstract screening, all four reviewers first classified 10% (205) of the articles while remaining blind to each other's decisions. The remaining 1,838 articles were then distributed equally among the four reviewers. 1,969 articles were excluded at the title and abstract screening phase. 74 records were subject to full-text review and, at this stage, each article was reviewed by two reviewers, blind to the other's decision. Agreement was obtained for 180 of 205 articles (87.8%) during title/abstract screening and for 61 articles (82.4%) during full-text review. Conflicts at both stages were resolved through discussion among all four reviewers, and any unresolved conflicts were discussed with all other co-authors until consensus was reached.

Inclusion criteria were the following: (a) full text of the publication was available in English; (b) the publication type was a review that provided a clear description of the methodology used, including search strategy, and results (a wide range of types of reviews were included, including systematic reviews, scoping reviews, and overviews); (c) the publication included at least one study which had been conducted in a LAMIC setting; (d) the publication included at least one study which involved participants with autism (and this was explicitly stated); (e) the review included studies with young children or their parents or caregivers as participants; (f) the review focused on areas of socio-cultural factors impacting families of

children with autism, detection, and diagnosis, health system processes, psychosocial interventions and/or social policy and legislation. Based on these criteria, 22 reviews were included following full-text review (see PRISMA flowchart in Figure 1). In addition to the database search, nine additional articles were identified through a search of the bibliography of included studies and key informant suggestions, resulting in the final inclusion of 31 papers.

### Charting the data

GD, KL, CE, and SB worked in two teams to chart and summarize the data. Articles were reviewed across four key domains with relevance to UHC for families of children with autism in LAMIC: (a) *The social context and family experience for a child with autism*, including parenting stress during caregiving, socio-cultural influences, pathways to help seeking, community-level awareness and associated stigma; (b) *Barriers to detection and diagnosis*, including types of screening and diagnostic tools, low health worker awareness, and other challenges impeding their appropriate use; (c) *Access to appropriate evidence-based intervention* at the level of the child and family; and (d) *Social policy and legislation* with relevance to UHC. Spreadsheets charted relevant data for each domain. Reviews that covered multiple domains were analyzed by both teams, and relevant information was extracted into the appropriate tables. Given that these four domains themselves are not mutually exclusive, the classification of each review was completed by two authors blind to the other's coding. In case of discrepancies, consensus was achieved through discussion.

## Results

### Overview of included reviews

Details of the 31 publications included are summarized in Table 1. Of these articles, 17 were systematic reviews (two with additional meta-analyses; one

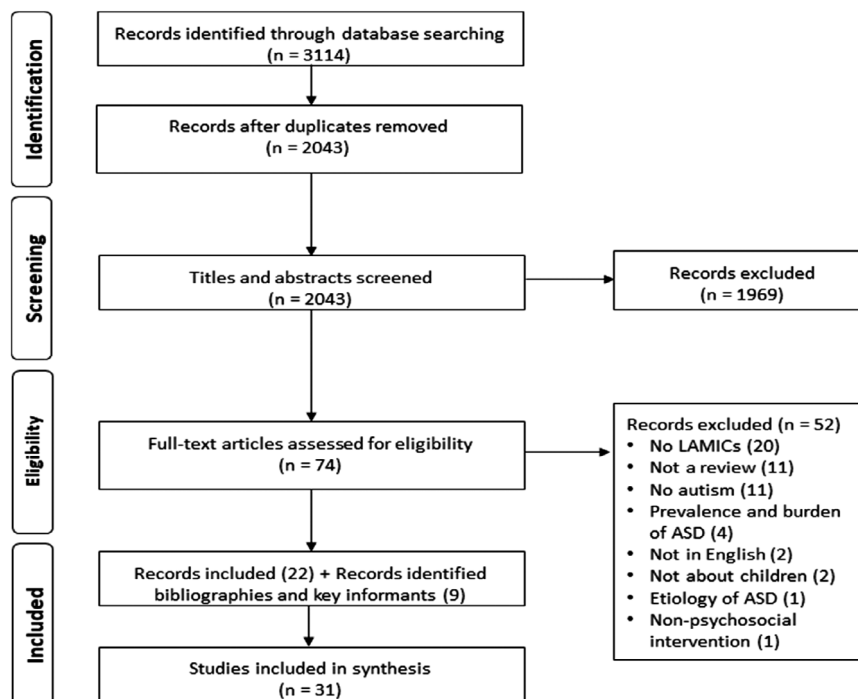


Figure 1 PRISMA flow diagram of the study selection process

**Table 1** Characteristics of all included studies

Citation	Type of review, databases, and date last searched	N of studies reviewed, Total (LAMIC)	LAMIC countries discussed	Participant characteristics Age range, number	Domain			
					1	2	3	4
Abubakar et al. (2016)	Systematic review Medline, PsycINFO, CINAHL, EBSCO, 1935–2016	47 (47)	Nigeria, RSA, Tanzania, Ethiopia, Kenya, Zimbabwe, Uganda	N not specified	✓	✓	✓	✓
Adugna et al. (2020) <sup>c</sup>	Scoping review CINAHL, Medline, Global Health, Embase until July 2017	15 (15)	All studies in low- and middle-income sub-Saharan African countries (Ethiopia, Zimbabwe, Malawi, Cote d'Ivoire, Rwanda, Uganda, Kenya, Zambia, Nigeria)	Children with disabilities Under 18 years N not specified	✓	✓	✓	✓
Al Khateeb et al. (2019)	Systematic review PubMed, Google Scholar, Springer Link, and Science Direct, Jan 2000– Dec 2016	69 (8)	Jordan, West Bank, Lebanon	0–18 years N = 1,030 caregivers	✓			✓
Al Maskari et al. (2018)	Systematic review PsycINFO, Medline, CINAHL, EMBASE, ERIC until September 2017	20 (12)	Egypt, Tunisia, Syria, Mexico, Serbia, Turkey, Iran, Sri Lanka, Jordan, Lebanon	1–13 years [mean 2.6 years] N ranged from 100 to 12,984 (mean 2,207)			✓	
Bakare et al. (2019)	Scoping review PubMed, Google scholar until June 2017	Not specified	Nigeria	N not specified	✓			✓
Dababnah et al. (2018)	Systematic review EMBASE, Family Studies Index, PsycINFO, Socindex, PubMed, and Web of Science	13 (13)	India	Children with ASD 17 months – 14 years N = 246 participants			✓	✓
Davenport et al. (2018)	Systematic qualitative synthesis ERIC, PsycINFO, Medline 2010–August 2017	5 (1)	Bangladesh	ASD 5–18 years N = 94 participants				✓
Dawson-Squibb et al. (2020)	Scoping review EBSCOhost (Academic Search Premier, Africa-Wide, Medline, CINAHL, ERIC, Health Source: Nursing Academic Edition, PsycArticles, PsycINFO and Socindex), SAGE Journals, Science Direct and Springer Link	37 (3)	India, Bangladesh, Tanzania [China included as HIC]	Parents of children with ASD Age not specified N not specified				✓
De Leeuw et al. (2020) <sup>d</sup>	No date restrictions Systematic review of ASD literature, narrative review of multidisciplinary literature Medline (PubMed), PsycInfo and the Cochrane Library, 28 August 2019	231 from search, total > 800 (not specified)	Not specified	N not specified	✓	✓	✓	✓
Frantz, Hansen & Machalicek (2018)	Systematic review PsycInfo, Education Resources Information Center (ERIC), and Medline Date not specified	41 (3)	China, Iran, Jordan	Parents of children with autism aged 21 months – 23 years N = 2,147	✓			✓

(continued)

Table 1 (continued)

Citation	Type of review, databases, and date last searched	N of studies reviewed, Total (LAMIC)	LAMIC countries discussed	Participant characteristics Age range, number	Domain			
					1	2	3	4
Franz et al. (2017)	Scoping review PubMed, Embase, the Cochrane Library, Web of Science, PsycInfo, Global Health, African NiPAD, and African Index Medicus 16 October 2015	53 (53)	Sub-saharan Africa: Ghana, Seychelles, Uganda, Zambia, Zimbabwe, Tanzania, Kenya, Nigeria, South Africa	ASD- professionals, parents and children No age limits N not specified	✓	✓	✓	✓
Hastings et al. (2012)	Systematic review Medline, CINAHL, Web of Science, PsycINFO 1990–July 2009	4 (4)	Egypt, India, Turkey, China	Pervasive developmental disorders 4–18 years N = 114 children N not specified	✓	✓	✓	✓
Hunt and Watermeyer (2017)	Selective review Databases and date not specified	85 (10 reviews) (not specified)	Not specified – called global south		✓	✓	✓	✓
Ilias et al. (2018)	Systematic review PsycNet, ProQuest, PudMed, EMBASE, CINAHL, Web of Science, and Google Scholar	28 (22)	Indonesia, Malaysia, Philippines, Thailand, Vietnam	0–20 years N = 1,639 caregivers	✓	✓	✓	✓
Lee and Meadan (2020)	Scoping review ERIC, Educational Full Text, PsycINFO, PsycARTICLE, and Family & Society Studies Worldwide.	12 (12)	Albania, Brazil, China, India, Jordan, Macedonia, Nigeria, Pakistan, Saudi Arabia, Tanzania	Children with ASD 22 months – 21 years N = 389 Parent participants N = 223 Age not specified, 1,523	✓	✓	✓	✓
Liao et al. (2019)	No dates specified Systematic review PubMed, EMBASE, Web of Science, date not specified	25 (10)	China, India, Iran		✓			
Liu et al. (2020)	Systematic review and meta-analysis CENTRAL, EMBASE, ERIC, PsycINFO, PubMed, Web of Science, China National Knowledge Infrastructure, Wanfang Data, Weipu Data until June 2019	21 (21) in systematic review; 12 (12) in meta-analysis	All studies in Mainland China, Hong Kong, Taiwan	Autism spectrum disorder 1–15 years N = 1,335 children (systematic review); 348–876 children (meta-analysis)			✓	
Marlow et al. (2019) <sup>a</sup>	Review PubMed, Web of Science, EBSCO, Google Scholar until August 2017	Not specified	Iran, Turkey, Sri Lanka, India, Indonesia, Taiwan, China, Brazil, Mexico, Pakistan, Zambia, Cambodia, Burkina Faso, Kenya, Bangladesh, Columbia, Malawi, Mongolia, Uganda, East Asia Pacific	0–16 years; predominant early and middle childhood N not specified			✓	
Maulik & Darmstadt, 2007 <sup>e</sup>	Literature review PubMed, Embase, PsycINFO, Cochrane Library Date not specified	80 (80); 1 linked to autism specifically	41 low income; 22 middle income; 14 multi-country; includes India, Bangladesh, China, Jamaica, Pakistan, South Africa	Childhood disability <5 years N not specified	✓	✓	✓	✓

(continued)

Table 1 (continued)

Citation	Type of review, databases, and date last searched	N of studies reviewed, Total (LAMIC)	LAMIC countries discussed	Participant characteristics Age range, number	Domain			
					1	2	3	4
Naveed et al. (2019)	Systematic review and meta-analysis PubMed, Scopus, Web of Science, POPLINE, New York Academy of Medicine, PsycINFO, Psycharticles, and CINAHL Until 31 December 2018	33 (2)	India, Pakistan	Children with ASD 16 months – 17 years N = 617 (summary effect)	✓	✓	✓	✓
Nuri et al. (2019) <sup>c</sup>	Scoping review CINAHL, EMBASE, MEDLINE, Global Health, and PsycINFO and Summon—Queen's library, 2006–2018	13 (13)	China, DR Congo, Ethiopia, Sri Lanka, Malawi, Mexico, Tanzania, Uganda, Zambia.	N not specified	✓			
Patra and Kar (2020)	Scoping review PubMed, SCOPUS, and Cochrane library Until 15 February 2019	159 (159)	India	Autism No age limits N not specified	✓	✓	✓	✓
Preece and Trajkovski (2017)	Narrative review Education Research Complete (EBSCO), Google Scholar, Ingenta Connect, Science Direct and Web of Science	12 (2)	Jordan, Turkey	Parents and family members of children with ASD 0–15 years N = 740 participants			✓	
Reichow et al. (2013) <sup>f</sup>	No dates specified Systematic review African Index Medicus, AFRO library, Cochrane Register, Cumulative Index to Nursing and Allied Health, Embase, Western Pacific Region Index Medicus, Literatura Latino-Americana e do Caribe em Ciências da Saúde, Medline, PsycINFO	34 articles reporting 29 studies (6)	Vietnam, Egypt, China, Hong Kong, India	Intellectual disability or lower-functioning autism spectrum disorders 0–16 years N = 1,305 participants			✓	
Scherer et al. (2019)	Systematic review MEDLINE, PsycINFO, EMBASE, Web of Science, and CINAHL, 2004–2018	19 (11)	Turkey, China, India, Iran	N not specified	✓			
Shorey et al. (2020)	Meta-synthesis CINAHL, EMBASE, ProQuest, PsycINFO, PubMed, Scopus, and Web of Science until November 2018	44 (9)	Kazakhstan, China, West Bank, India, Vietnam, Iran, Malaysia, Pakistan, Thailand	3–27 years N = 747 Asian parents of 804 child participants	✓			✓
Smythe et al. (2020) <sup>b</sup>	Systematic review Medline, EMBASE, Global Health, PsycINFO, Social Policy and Practice, CINAHL, International Bibliography of Social Sciences, January 2000–April 2018	20 (20)	Turkey, Zambia, Nigeria, Brazil, India, Belize, Ethiopia, Columbia, Serbia, Ukraine, Malawi	N not specified	✓			
Soto et al. (2015)	Review Medline, CINAHL, PsycINFO, Web of Science, ERIC, EMBASE, OVID, Mental Measurements, of Tests in Print, PubMed, HaPI, World Health Organization (WHO), and Google Scholar, date not specified	21 (6)	Mexico, China, Brazil, Jordan, Lebanon, Syria, Egypt, Tunisia	12 months–18 years N = 466			✓	

(continued)

**Table 1** (continued)

Citation	Type of review, databases, and date last searched	N of studies reviewed, Total (LAMIC)	LAMIC countries discussed	Participant characteristics Age range, number	Domain			
					1	2	3	4
Stewart and Lee (2017)	Systematic review PubMed, PsycInfo between 1992 and 2015	28 (28)	Zimbabwe, Uganda, Egypt, Kuwait, Jordan, Lebanon, Oman, Qatar, Saudi Arabia, Syria, Tunisia, Iran, Turkey, Sri Lanka, India, Indonesia, Taiwan, China, Brazil, Mexico India, Thailand	18 months to adults N > 1.8 million (ranged from 18 to 1.32 million)				✓
Trembath et al. (2019)	Systematic review Cochrane Library, MEDLINE, PsycINFO, EMBASE, Scopus, and Google Scholar 2008–2018	41 (2)		ASD 0–12 years				✓
Wang et al. (2020)	Systematic review Web of Science, Medline, PsycINFO, Scopus, Chinese National Knowledge Infrastructure database, Chongqing VIP database, Wanfang database, Chinese Biological Medical Literature, January 2015–January 2018	22 (20)	China	4 months–18 years N not specified			✓	✓

1 – Social context of autism and family experiences of a child with autism; 2 – Barriers to detection and diagnosis; 3 – Access to appropriate evidence-based interventions; 4 – Social policy and legislation.

<sup>a</sup>Included Developmental Delay.

<sup>b</sup>Included Developmental Delay, Epilepsy, Attention Deficit Hyperactivity Disorder, Intellectual Disability and Dyslexia.

<sup>c</sup>Included Intellectual Disability, Developmental Delay and Motor Disabilities including Spina Bifida.

<sup>d</sup>Included ASD, intellectual disability, cultural psychiatry, cross-cultural psychology and global mental health research.

<sup>e</sup>Included childhood disability more generally.

<sup>f</sup>Included intellectual disability and low functioning autism.



with additional narrative review), the remaining articles adopted diverse methodologies from synthesis of qualitative data to scoping reviews. These studies reviewed data from over fifty countries across regions of Africa, Latin America, Middle East, and South and East Asia. Table 1 also documents the four domains discussed within each review, with many reviews addressing areas across domains. Table 2 summarizes the barriers to UHC relevant to domains 1, 3, and 4, and recommendations to address them, based on findings from these reviews. Domain 2 is elaborated in Table 3. While these barriers were not necessarily unique to LAMICs, they are certainly exacerbated in them.

*Domain 1: The social context and family experience for a child with autism.* The understanding of autism always exists within a particular cultural context, whether in LAMIC or HIC. While autism is a universal phenomenon biologically, presenting with similar core impairments wherever it has been studied, the experience of and interpretation of its phenomenology is influenced by culture (Elsabbagh et al., 2012). Even when symptoms are recognized as atypical, complex cultural narratives and collectivist child-rearing practices may influence pathways of families to seeking care (Shorey, Ng, Haugan, & Law, 2020). Biomedical understanding of autism has to be distinguished from, or accepted within, other narratives about children's development or health beliefs. These other narratives may, for instance, drive help seeking from alternative community practitioners (Hossain et al., 2017; Shorey et al., 2020). Religious or spiritual beliefs can be an important source of alternative narratives; religious spaces can often also serve as a place of support for families, helping build parental resilience (Ilias, Cornish, Kummar, Park, & Golden, 2018).

A challenge across LAMIC is a low current awareness in families and communities about autism framed as a biomedical condition and thus amenable to the provision of detection, diagnostic, and intervention models that have evolved in HIC contexts. Apart from low levels of mental health literacy common in many LAMIC, unique cultural factors play an important role in the understanding of autism, including attributing differences in children with autism to supernatural or religious causes ('spirit possession', 'cursed ancestral' or 'God's will'). This, compounded by low community awareness across settings, reduces help seeking (Abubakar et al., 2016; Bakare, Taiwo, Bello-Mojeed, & Munir, 2019; Franz, Chambers, von Isenburg, & de Vries, 2017; de Leeuw, Happe, & Hoekstra, 2020; Shorey et al., 2020).

Nineteen reviews reflected on the experiences of parents of children with autism across countries and regions and the relation to lack of access to services (Table 2). There was a similarity between high- and low-income settings in the context of these

experiences (Ilias et al., 2018). Many studies contained reports from parents (predominantly mothers) of feelings of self-blame, depression, and an adverse impact on life satisfaction (Ilias et al., 2018; Liao, Lei, & Li, 2019; Nuri, Batorowicz, & Aldersey, 2019; Scherer, Verhey, & Kuper, 2019). A review of studies from the Middle East comprise, by contrast, a majority of fathers as respondents, and reflected more stress related to financial pressures (Al Khaateb, Kaczmarek, & Al Hadidi, 2019). The large impact of economic factors on family quality of life also emerged as a finding from a review on families with a child living with a disability in the Global South (Hunt & Watermeyer, 2017). Studies reported that these stresses affected not just quality of life and social participation but were also a reason for marital discord (Liao et al., 2019). Peer support and group-based programs could empower parents, particularly mothers, to access support, raise community awareness, advocate for their needs, and fight stigma (Adugna, Nabbouh, Shehata, & Ghahari, 2020; Franz et al., 2017). Two reviews reported the protective nature of religious and cultural belief systems; religious support in South East Asia and the sense of self-compassion in China allowed families to accept their life with a child with a disability (Ilias et al., 2018; Liao et al., 2019). Another key support structure across settings were professional organizations that, when available, provided informational as well as respite care (Ilias et al., 2018; Nuri et al., 2019).

Fifteen reviews, either entirely or in part, examined the stigma associated with developmental disabilities in general and autism specifically (Table 2). The impact of stigma was universally experienced and included feelings of being discriminated against. Stigma was perceived across multiple levels on individuals as well as on families (Smythe, Adelson, & Polack, 2020). These included negative attitudes and prejudices, discrimination and social exclusion, internalized or self-stigma and anticipated stigma.

A strong recommendation emerging from these reviews is the need to increase awareness of autism as a neurodevelopmental condition at every level, from communities to institutions, in order to reduce discrimination and create more socially inclusive societies. De Leeuw et al. (2020) suggest a need to understand the variations in parenting practices and the impact of autism symptomatology in varied cultures, which could impact the thresholds for defining autism in various settings. Along with increased education, the presence of protective social policies also plays an important role in eradicating stigma. We present our findings relevant to such policies later.

*Domain 2: Barriers to detection and diagnosis.* The observations and recommendations of thirteen publications addressing detection and diagnosis of children with autism are summarized in

**Table 2** Domains 1, 3, and 4: Identified barriers and mitigating recommendations on the path to universal health coverage for children with autism

Citations	Barriers	Recommendations
<b>Domain 1: The social context and family experience for a child with autism</b>		
Ilias et al. (2018), Abubakar et al. (2016), Shorey et al. (2020), De Leeuw et al. (2020), Maulik & Darmstadt, 2007, Lee and Meadan (2020), Preece and Trajkovski (2017), Davenport et al. (2018), Patra and Kar (2020), Dababnah et al. (2018), Franz et al. (2017), Shorey et al. (2020), De Leeuw et al. (2020), Lee and Meadan (2020), Preece and Trajkovski (2017), Davenport et al. (2018), Dababnah et al. (2018)	Socio-cultural and structural factors including: <ul style="list-style-type: none"> <li>• Gender inequality (disempowerment of women/mothers)</li> <li>• Awareness and understanding of autism, including language to describe autism and its characteristics (e.g., some cultures/languages may not have a word for 'autism')</li> <li>• Social norms and cultural beliefs around disability and autism</li> <li>• Explanatory models which include supernatural reasons (e.g., sinful acts, spirit possession)</li> </ul>	<ul style="list-style-type: none"> <li>• Culturally appropriate messaging and dissemination of services</li> <li>• Culturally appropriate terminology and frame of reference to describe autism and its characteristics</li> <li>• Healthcare providers to be mindful and understanding of traditional, cultural and religious beliefs and incorporate these in intervention goal-setting process</li> <li>• Increase public education and awareness-raising about etiology and management across communities and stakeholders</li> <li>• Train all healthcare, education, and social care providers to improve knowledge, skills, and attitudes which would allow responsiveness to early parent concerns</li> </ul>
Bakare et al. (2019), Liao et al. (2019), Smythe et al. (2020), Shorey et al. (2020), de Leeuw et al. (2020), Adugna et al. (2020), Maulik & Darmstadt, 2007, Franz et al. (2017), Abubakar et al. (2016), Al Khateeb et al. (2019), Ilias et al. (2018), Patra and Kar (2020), Lee and Meaden (2020), Nuri et al. (2019), Wang et al. (2020)	Stigma <ul style="list-style-type: none"> <li>• Negative attitudes and prejudice</li> <li>• Discrimination and social exclusion</li> <li>• Internalized or self-stigma</li> <li>• Anticipated stigma</li> <li>• Lack of tools to assess and address stigma</li> </ul>	<ul style="list-style-type: none"> <li>• Educate the public about autism, increase awareness and create a more socially inclusive community</li> <li>• Interventions needed at intra- and interpersonal, community and organizational/institutional levels</li> <li>• Parent support groups can empower parents with raising awareness, offering peer support and fighting stigma</li> <li>• Include stigma reduction as an intervention outcome</li> </ul>
<b>Domain 3. Access to appropriate evidence-based intervention</b>		
Abubaker et al. (2017), Adugna et al. (2020), Maulik and Darmstadt (2007), Hastings et al. (2012), Davenport et al. (2018), Dawson-Squibb et al. (2020)	<ul style="list-style-type: none"> <li>• Parental experiences including health providers' reluctance with 'labeling' children</li> <li>• Parent's negative interactions and lack of privacy within services</li> <li>• Parental low confidence in value of intervention</li> <li>• Support needs of parents overlooked</li> </ul>	<ul style="list-style-type: none"> <li>• Train all healthcare, education, and social care professionals to improve knowledge, skills, and attitudes</li> <li>• Caregivers and children being active participants in goal and priority setting</li> <li>• Group sessions rather than individual which are more scalable and create peer support systems among families</li> <li>• Family centered services</li> </ul>
Lee and Meadan (2020), Preece and Trajkovski (2017), Davenport et al. (2018), Maulik & Darmstadt, 2007	Lack of cultural and linguistic appropriateness of interventions: <ul style="list-style-type: none"> <li>• Lack of robust cultural adaptation of interventions, including adaptation of concepts and language used</li> <li>• Language as a barrier to access interventions, where professionals and families speak different languages</li> </ul>	<ul style="list-style-type: none"> <li>• Programs with sound cultural frameworks/adapted to local socio-cultural context</li> <li>• Strategies developed 'from the ground up' which would improve cultural relevance and acceptability of interventions</li> <li>• Use of terminology and concepts that match family understanding</li> <li>• Use of intermediary where there are language barriers</li> </ul>

(continued)

**Table 2** (continued)

Citations	Barriers	Recommendations
Adugna et al. (2020), Maulik and Darmstadt (2007)	Services fragmented/uncoordinated; inadequate intersectoral collaboration	<ul style="list-style-type: none"> <li>● Increased interdisciplinary approach with all services hosted in one facility</li> <li>● Increased intersectoral collaboration with effective coordination</li> </ul>
Liu et al. (2020), Adugna et al. (2020), Maulik and Darmstadt (2007), Hastings et al. (2012), Reichow et al. (2013), Lee and Meadan (2020), Dawson-Squibb et al. (2020), Naveed et al. (2019)	Lack of evidence-based manualized psychosocial interventions	<ul style="list-style-type: none"> <li>● Interventions that are theory-based, open-access and manualized</li> <li>● Promote evidence-based interventions which address a range of core impairments of autism</li> <li>● Promote the delivery of parent/family-mediated delivery methods which are more scalable and allow quicker generalizability; and support parental empowerment</li> </ul>
Al Khateeb et al. (2019), Shorey et al. (2020), Wang et al. (2020), de Leeuw, Happe and Hoekstra (2020), Liu et al. (2020), Adugna et al. (2020), Maulik and Darmstadt (2007), Hastings et al. (2012), Reichow et al. (2013), Franz et al. (2017)	Inadequate availability of trained personnel and few opportunities for training	<ul style="list-style-type: none"> <li>● Build capacity for training of health care providers to recognize, manage, or treat children with autism</li> <li>● Adopt a public health approach by training primary and secondary health-care providers to deliver high-quality advice, support, and practical parenting skills programs to families</li> <li>● Delivery of evidence-based psychosocial interventions and parent training by paraprofessionals/nonspecialists</li> <li>● Promote cost-effective methods of training, for example through digital platforms</li> </ul>
Adugna et al. (2020), Bakare et al. (2019), de Leeuw et al. (2020), Maulik and Darmstadt (2007), Lee and Meadan (2020), Dawson-Squibb et al. (2020)	High cost of care	<ul style="list-style-type: none"> <li>● Provide material incentives to encourage parents to bring children to health facilities, for example, toys, transportation money, disability aids</li> <li>● Involve parents in providing interventions</li> <li>● Use of nonspecialists as a lower cost human resource</li> </ul>
Adugna et al. (2020), Maulik and Darmstadt (2007), Preece and Trajkovski (2017)	Accessibility to services (such as travel distance, time, and travel options, e.g., availability of public transport services access to the internet)	<ul style="list-style-type: none"> <li>● Community-based or home-based care;</li> <li>● Fewer longer sessions where travel is required</li> <li>● Use of scalable delivery methods (e.g., self-administered, telehealth)</li> </ul>
<b>Domain 4: Social policy and legislation</b>		
De leeuw et al. (2020), Marlow et al. (2019), Wang et al. (2020), Adugna et al. (2020), Maulik and Darmstadt (2007), Bakare et al. (2019), Shorey et al. (2020), Soto et al. (2015)	<ul style="list-style-type: none"> <li>● Lack of consistently implemented developmental monitoring or surveillance of early child development</li> <li>● Lack of social policies and benefits providing protection to and support for children with disabilities</li> <li>● Poor implementation of existing policies</li> <li>● Unavailability and poor coverage of health insurance</li> </ul>	<ul style="list-style-type: none"> <li>● Focus on evidence-based public health policy and legislation, for example, supporting scale up of evidence-based interventions</li> <li>● Formulation of appropriate legislation and policy including financial support and employment opportunities</li> <li>● Inclusion of developmental assessments in child health surveillance</li> <li>● Inclusion in health insurance for care of developmental disabilities</li> <li>● Engagement with national and international agencies</li> <li>● Engagement with parent advocacy groups</li> </ul>

Table 3. A key barrier identified was the lack of validated screening and diagnostic tools with the primary roadblock being that the development of most tools has been from within nondiverse populations in high-income countries (Franz et al., 2017; Marlow, Servili, & Tomlinson, 2019; Maulik & Darmstadt, 2007; Patra & Kar, 2020; Soto et al., 2015). Various levels of adaptations were described across studies included in the reviews, ranging from translations, back translation, and pretesting to improve clarity and comprehension while ensuring equivalence (Al Maskari, Melville, & Willis, 2018; Stewart & Lee, 2017). When rigorous adaptation was undertaken, it often required investment in time and resources for a comprehensive understanding of cultural factors like a community's use of gestures (Soto et al., 2015) or the use of methodologies to

support low literacy (Marlow et al., 2019). The need for rigorous systematic adaptation of tools both for screening and diagnosis, beyond translations to local languages to make sure that they are reflective of, and valid in, the culture in which they are being used, as mentioned in Domain 1, is highlighted by this literature. However, it was also noted that these processes were not described or conducted adequately across all settings. This has resulted in the usage of tools in populations, settings, and age ranges for which they have not been optimized, thereby compromising their validity. This manifests in highly variable psychometric properties which often differ dramatically from the original tools (Stewart & Lee, 2017).

Another approach to overcoming the barrier of a lack of valid tools is that of local initiatives to develop

**Table 3** Domain 2: Detection and diagnosis of autism in low- and middle-income countries

Observations	Recommendations	Citations
<b>Assessment tools</b>		
Availability and appropriateness:		
1. Lack of standardized tools and practices to screen and detect autism and other developmental disabilities	<ul style="list-style-type: none"> <li>● Identification and/or development of cross-culturally valid screening and diagnostic tools</li> <li>● Accessibility and affordability of such valid tools</li> <li>● Capacity building in community and primary care staff on the appropriate use of these tools</li> </ul>	Marlow et al. (2019), Soto et al. (2015), Maulik and Darmstadt (2007), Patra and Kar (2020), Franz et al. (2017), Stewart and Lee (2017), Al Maskari et al. (2018), Wang et al. (2020)
2. Limited knowledge in community health and primary care staff		
3. Lack of access to established diagnostic tools		
Adaptation:		
4. Few studies report formal adaptation procedures beyond translation and presentation of materials	<ul style="list-style-type: none"> <li>● Strive for cultural adaptation beyond translation using appropriate qualitative and quantitative methods</li> <li>● Inclusion of local stakeholders in study design and implementation is a key to improve cultural relevance of the research as well as build local research and screening capacity</li> <li>● Systematic guidance on adaptation with added specific culturally relevant indicators; focus on language used to avoid misinterpretation; examples to avoid confusion about intended meaning of items; format to suit the respondent</li> </ul>	
5. Some adaptations changed words to avoid misinterpretation, added examples to clarify items and added photographs to illustrate text and overcome barriers of literacy		
6. Local collaboration reported in few studies. Types of organizations engaged in collaboration with researchers include schools, autism societies and awareness groups, and community health programs		
7. Within context factors addressed in adaptation: education levels, socio-economic status, literacy, knowledge of autism, experience of stigma		
Validity:		
8. Psychometrics of tools are often not reported, and those that do demonstrate that they differ for adapted versions of the tool	<ul style="list-style-type: none"> <li>● Studies should report the psychometric properties of the instruments used as well as descriptions of recruitment and administration methods to help establish best practices for screening in diverse contexts</li> </ul>	
9. Variable cut-points are used for the same tools across studies		
10. Sensitivity and specificities range from excellent to poor		

(continued)

**Table 3** (continued)

Observations	Recommendations	Citations
<b>Administration</b>		
Population:	Population :	Stewart and Lee (2017), Marlow et al. (2019), Al Maskari et al. (2018)
11. Inappropriate usage of screening instruments; for example, same instruments used for children with suspected developmental disability and children in the general population	<ul style="list-style-type: none"> <li>• Screening tools must be validated for the population in which it is being used be valid (e.g., age range)</li> <li>• Establish a developmental monitoring methodology with opportunities for regular observations of milestone attainment</li> </ul>	
12. Screening instruments are used for a wide age range, which limits their validity		
Personnel:	Personnel:	
13. Informants included parents, teachers, caretakers, and clinical staff	<ul style="list-style-type: none"> <li>• Promote the use of brief instruments which take less than 10 minutes to administer by community health workers</li> <li>• Community health workers should be trained to conduct these assessments</li> <li>• Two-level screening with a universal screening by community health workers followed by a level 2 screening for those scoring above a locally validated cut off administered more skilled personnel</li> </ul>	
14. Only a few community-based studies report administration by trained community members as opposed to specialist project staff		
Settings:	Settings:	
15. Duration of administration was rarely reported	<ul style="list-style-type: none"> <li>• Assessments should be delivered in family-friendly settings, including homes and during routine child healthcare contacts</li> </ul>	
16. Children screened in a variety of settings including clinics, schools, and community-based		

'home-grown' tools, which are more culturally appropriate for children in that context (Marlow et al., 2019). A key recommendation is that tools are developed that are relatively quick to administer and can be used at the level of the community for universal surveillance by routine community health workers – a practice not frequently used in the reviewed studies (Al Maskari et al., 2018; Marlow et al., 2019; Stewart & Lee, 2017). The widely used and adapted Modified Checklist for Autism in Toddlers Revised with Follow-up (M-CHAT-R/F); and the Pictorial Autism Assessment Schedule (PAAS) and the Three-Item Direct Observation Screen (TIDOS) developed and validated in Sri Lanka and Turkey, respectively; have been identified as three tools for autism that have potential to overcome these barriers and show promise for cross-cultural use (Marlow et al., 2019). It will be very important that such adapted tools are adequately validated to standards comparable to HIC use; so as to avoid a 'quality-gap' for LAMIC measures (Marlow et al., 2019).

*Domain 3: Access to appropriate evidence-based intervention.* Nineteen reviews focused entirely or partly on psychosocial interventions for children with autism and/or their caregivers, or on barriers and facilitators to healthcare access for children with

developmental disabilities more generally (Table 1). Reviews which evaluated the evidence base for autism interventions in LAMIC universally concluded that there is an absence of high-quality, robust research, particularly of adequately powered randomized controlled trials or other designs minimizing bias. This makes it difficult to draw conclusions around the effectiveness of psychosocial interventions delivered in any LAMIC context (Dababnah, Ghosh, Campion, Hussein, & Downton, 2018; Liu, Hsieh, & Chen, 2020; Maulik & Darmstadt, 2007; Reichow, Servili, Yasamy, Barbui, & Saxena, 2013). A key priority for LAMIC, therefore, is to develop the research infrastructure, funding and capacity to conduct appropriate evaluations (Franz et al., 2017). In addition to assessing overall effectiveness, there is a need for analysis of moderators and mediators of treatment effects, for example, to identify the critical and necessary components of treatment models, thereby increasing efficiency and allowing scant resources to be focused around delivery of evidenced active components (Dawson-Squibb, Davids, Harrison, Molony, & de Vries, 2020; Liu et al., 2020; Reichow et al., 2013; Trembath et al., 2019). Reviews also emphasized the need for: more pilot evaluations of feasibility, acceptability, and cultural appropriateness (Dawson-Squibb et al.,

2020; Hastings, Robertson, & Yasamy, 2012; Liu et al., 2020; Preece & Trajkovski, 2017); an increased research focus on implementation (Dawson-Squibb et al., 2020; Lee & Meadan, 2020; Liu et al., 2020) and parent outcomes (Dababnah et al., 2018); and research into the effectiveness of scalability and capacity-building strategies (Lee & Meadan, 2020; Reichow et al., 2013) along with ways to maintain intervention fidelity at scale (Patra & Kar, 2020).

Several reviews highlighted the inadequate availability and inaccessibility of specialist healthcare facilities, a lack of highly-trained, specialist healthcare workers, and little opportunity or infrastructure for the up-skilling and supervision necessary for existing personnel to deliver evidence-based interventions (Adugna et al., 2020; Dawson-Squibb et al., 2020; Lee & Meadan, 2020; Liu et al., 2020). Recommendations to address these barriers include the use of scalable delivery methods, such as parent training and parent-mediated delivery, self-administered programs, low-intensity programs, and the use of mobile and internet technology (Franz et al., 2017; Liu et al., 2020; Naveed et al., 2019; Reichow et al., 2013). An overarching recommendation made by several recent reviews is for LAMIC to integrate autism interventions within existing systems of care by capitalizing upon the local nonspecialist healthcare workforce, or on 'parent-champions', to deliver community-based or home-based care (Franz et al., 2017; Lee & Meadan, 2020; Naveed et al., 2019; Patra & Kar, 2020), and that individual countries should identify the most appropriate intervention agent for their individual contexts (Franz et al., 2017). This requires intervention programs to be designed to be delivered by skilled, but less qualified, practitioners, also called 'task sharing' (Raviola, Naslund, Smith, & Patel, 2019). It also requires that appropriate training and support mechanisms are in place for such nonspecialist care providers (Dawson-Squibb et al., 2020; Reichow et al., 2013).

Equally important as a key health service priority to optimize acceptability of these interventions is to ensure that they are aligned with community and stakeholder values and needs elaborated in Domain 1 (Dababnah et al., 2018; Davenport, Mazurek, Brown, & McCollom, 2018; Liu et al., 2020). To this end, interventions need to either be rigorously adapted to the local socio-cultural and linguistic context (Patra & Kar, 2020; Preece & Trajkovski, 2017), or be developed 'from the ground up' with close attention to both evidence-based biomedical knowledge and to contextual and cultural acceptability (Franz et al., 2017). Thus, beyond mastering the evidence-based intervention, practitioners need to understand local cultural and religious beliefs, and caregivers should be actively involved in goal-setting and intervention delivery (Adugna et al., 2020).

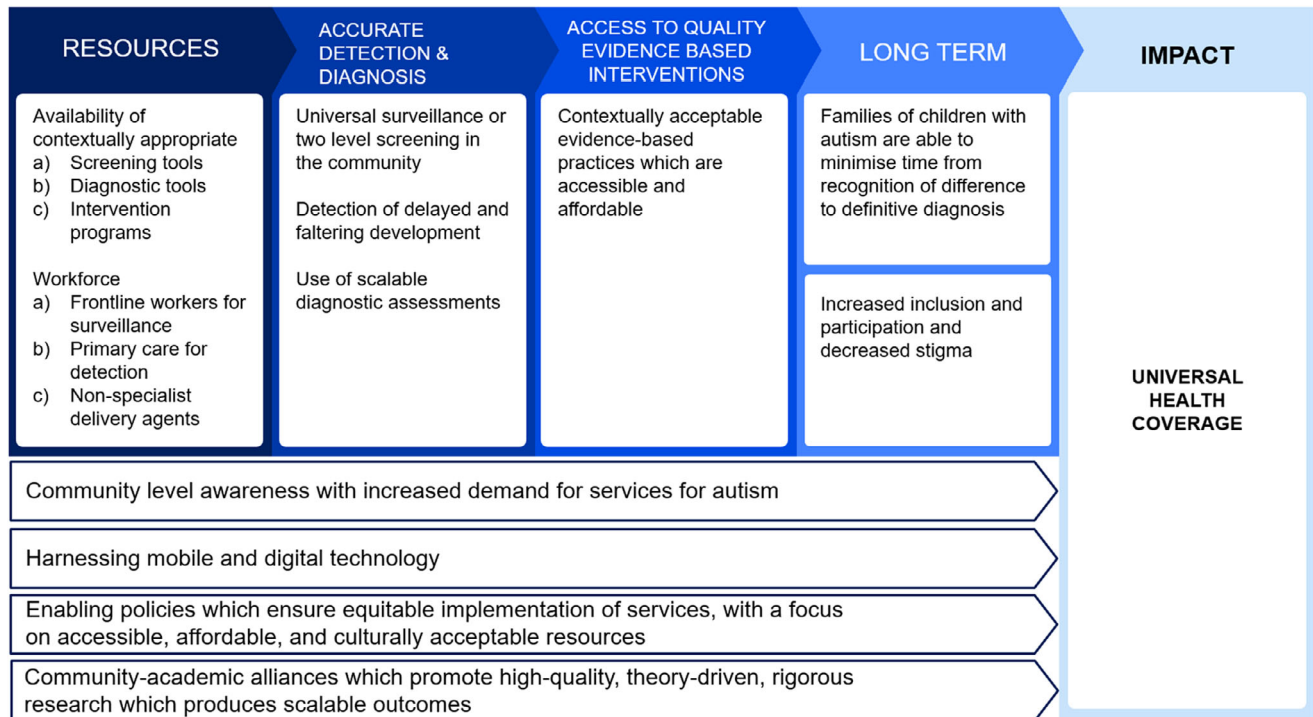
*Domain 4: Social policy and legislation.* Eleven reviews commented on the limited availability of

services with trained professionals serving as a huge barrier to care for autism (see Table 1). This barrier affects the realization of UHC in a number of ways: the absence of skilled health providers within accessible range of families and services concentrated in metropolitan centers (Bakare et al., 2019; Shorey et al., 2020); and long waiting lists to access limited services resulting in an unequal impact on families from lower socioeconomic backgrounds (de Leeuw et al., 2020). A key recommendation by Franz et al. (2017) is the development and evaluation of standardized curricula for healthcare, education, and social care professionals designed to impact on knowledge, skills, and attitudes. We add the need to accompany this with ensuring adequate deployment of these trained professionals to semi-urban, rural, and remote areas. Another key roadblock is the lack of autism or disability-specific rights legislation or, in countries where disability-specific laws were in place, an absence of support for the implementation of these policies (Bakare et al., 2019). This is compounded by low levels of awareness of autism even within the health system, in both frontline healthcare workers and professionals, with very limited opportunities for training (Al Khateeb et al., 2019; de Leeuw et al., 2020; Shorey et al., 2020; Wang, Hedley, Bury, & Barbaro, 2020), resulting in a lack of any established models of developmental surveillance. In LAMIC, the lack of a right to UHC leads to financial burden on families, since most autism services are privately accessed and result in prohibitive out of pocket expenses (Bakare et al., 2019; Hunt & Watermeyer, 2017; de Leeuw et al., 2020). This barrier is not only a significant deterrent to accessing services but also to the continuation of services when they are available.

A further overarching health system barrier emphasized in the reviews concerned the fragmentation and lack of coordination of services and authors called for greater intersectoral and interdisciplinary collaboration and the active involvement of national and international agencies (Adugna et al., 2020; Maulik & Darmstadt, 2007). For example, Adugna et al. (2020), highlighted that interdisciplinary collaboration is more likely to lead to the best possible care for the child and this in turn motivates caregivers to engage with healthcare services. Bakare et al. (2019), suggest that financial and social policies along with educational services can be coordinated to support children with autism. Maulik and Darmstadt (2007) call for national and international collaborations to be forged to use the available knowledge and limited budgets in the most effective manner.

## Discussion

This scoping review represents the current state of literature on autism and autism provision as pertaining to LAMIC. It remains currently a small and



**Figure 2** A Theory of change framework to realizing universal health coverage for autism [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

methodologically mixed literature, but it does have a wide geographical scope and the frequency of publications is increasing rapidly. Seventy percent of the reviews identified have been published since 2018. Our scoping review was guided by key domains in considering the pathway to realize UHC for children with autism in LAMIC and highlighted key progress elements within and across these domains, which, if accomplished, would ultimately contribute to the full inclusion and participation of children and their families. From this, we have then used this scoping review to inform a Theory of Change framework toward realizing universal health coverage (UHC) for children with autism in LAMIC settings (Figure 2) which could in turn serve as a framework for the attainment of the United Nations Sustainable Development Goal 3 (Health for All) for this vulnerable group (UN General Assembly, 2015).

Our Theory of Change (ToC) consists of the following key elements which also indicate interim outcomes on the road to universal coverage: (a) *access to the key resources* - practical tools and workforce provision to enable the other elements; (b) *accurate detection procedures*; and (c) *access to quality evidence-based interventions*. We identify four further overarching processes necessary to support such change: (d) *community-level services* leading to service demand; (e) *use of technology*; (f) *enabling social policy and legislation*; and (g) *high-quality research*. This pathway to universal coverage, though represented for clarity in the ToC as linear, in reality will involve and indeed require circular and mutually enhancing interaction effects between its

components, as well as differential combination of these inter-related elements in adapting to unique contexts. We recognize too, that this ultimate goal will also need environmental modifications beyond healthcare, for example, in the education sector, but this is beyond the scope of this review.

We elaborate below on the key components of the ToC represented in Figure 2.

### Access to key resources

*Access to screening, surveillance and diagnostic tools, and intervention programs:* The high costs of 'gold standard' tools, layered with additional cost requirements for training and maintaining expertise in administration, puts these established tools currently out of reach of most practitioners and researchers in LAMIC (Durkin et al., 2015). The availability of easy-to-administer, culturally adapted, open-access tools with validation data to support their use, is a key first aspiration to improve autism detection rates. From a truly global health perspective, it will be important however that these are adapted and validated to equivalently high standards, as in HIC. While surveillance and identification is an essential first step, the availability of open-source gold standard diagnostic tools also suffers similar challenges. Though our reviews noted some attempts on adaptation of proprietary diagnostic tools like the Autism Diagnostic Observation Schedule (Lord et al., 2012) and Autism Diagnostic Interview-Revised (Le Couteur et al., 1989), the costs of administration and training will remain an

impediment to scale. The open-source INCLIN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD) in India (Juneja et al., 2014), evaluated to have high diagnostic accuracy against the DSM-5 (Vats, Juneja, & Mishra, 2018), is an example of a home-grown solution emerging from a LAMIC setting.

*Workforce provision:* The first professional point of contact for most parents of children with autism in LAMIC are primary care physicians, general pediatricians, or community health providers who are unlikely to have received any training around developmental disorders. This may result in false reassurances to families resulting in a delay in help seeking (Shorey et al., 2020). Modifying and scaling up training curriculums remains a complex and daunting task; however, innovations to train providers through virtual platforms are being evaluated (Duggal, Dua, Chokhani, & Sengupta, 2020) via the use of the ECHO model (a telemedicine platform) for improving knowledge and practice in primary care physicians (Sohl, Mazurek, & Brown, 2017).

*Task sharing:* This strategy to deliver health services, including surveillance, diagnosis, and interventions through paraprofessionals (e.g., teachers, nursing assistants, community health workers) has achieved wide currency across global health as a strategy to address the paucity and inequitable distribution of health professionals. It refers to the 'rational redistribution of tasks' among various members of a work force team (World Health Organization, 2008). This strategy is integral to a stepped care approach where the most easily accessible, widely available, and least costly human resource is trained to deliver a first-level evidence-based intervention with adequate quality, allowing the scarce and expensive resource of the specialist to address more complex needs of the child and family. While the effectiveness of task sharing in global mental health is well-established (Barnett, Gonzalez, Miranda, Chavira, & Lau, 2018), its application to developmental disabilities is more recent and our reviews identified several novel examples in the area of autism in LAMIC. Task sharing through pre-existing human resources, whether through parent 'champions' or community or secondary healthcare workers, requires systematic attention to training and supervision, both for acquisition and maintenance of skills to have sustained delivery of high-quality services.

### Accurate detection procedures

The approach to detection of autism has been extensively reviewed (Marlow et al., 2019), and consensus views have emerged for either developmental monitoring methodologies (where children's development is reviewed regularly) or two-level screening (where autism screening is administered only to high-risk children). The deployment of probabilistic two-level screening appears more scalable since the alternative of developmental surveillance

### Panel 1 Innovations supporting screening and detection

Sixty Female Child Health Volunteers (FCHV) were trained on developmental surveillance for autism in Nepal using an adapted pen-and-paper checklist version of the Social Attention and Communication Surveillance (SACS-N), based on the original SACS instrument (Barbaro & Disanayake, 2010). The training included understanding typical and atypical social attention and communication development in young children; the early signs of autism, which included video clips of behaviors that distinguish children with and without autism at different ages. 1,926 children between 11 and 30 months in an urban setting in Nepal were monitored over a twenty-month period for a 'high likelihood' of autism. Criterion for further assessments were the findings of atypicality on three of five 'key' behavioral items on the 12-, 18-, or 24-month checklists. The FCHVs were also trained on how to discuss the importance of social communication milestones with parents/caregivers and how to raise concerns when children were identified on the SACS-N as having 'high likelihood' of autism. Identified high-risk children were referred to Autism Care Nepal Society (ACNS) for further assessment and diagnosis. 11 children were referred, four each at 11–15 months, and 16–21 months, respectively, and three at 22–30 months of age. Of these, 10 children had a developmental disorder, including autism ( $n = 3$ ) or global developmental delay. One child was lost to follow up. The positive predictive value for autism was 43%. In a similar development in India, a government program the 'Rashtriya Bal Swasthya Karyakram' is training frontline workers to lead the early identification of thirty health conditions in young children including developmental delays and disabilities with referral pathways to district-level early intervention centers (Singh, Kumar, Mishra, Khera, & Srivastava, 2015).

requires universal and regular child health surveillance infrastructure, currently lacking in most of the global population. This two-level screening can be the first step within a broader strategy for developmental monitoring and early detection of neurodevelopmental disorders. An example of a modified surveillance process was conducted in Nepal (Panel 1), which saw the administration of a checklist at 12, 18, and 24 months of age, and was found to be both acceptable and feasible (Shrestha, Disanayake, & Barbaro, 2020); illustrating a potential model which can be adapted in other settings. A seamless follow-up to diagnostic services that use open source tools could potentially shorten the detection gap across settings.



### Access to quality evidence-based interventions

Once a diagnosis has been established, the next challenge is access to evidence-based interventions. The availability of manualized and contextually appropriate intervention programs presents a further challenge within LAMIC. Recent reviews have highlighted that most programs subject to research are wholly or partly non-evidence-based, hybrid and/or non-manualized, making it very difficult to know the details of these interventions, identify putative mechanisms and to replicate the research (Lee & Meadan, 2020; Liu et al., 2020). A meta-analysis conducted by Leijten et al., (2016), found that parenting interventions based on strong evidence, whether developed locally or abroad, were more likely to have an impact in local contexts; irrespective of the cultural background of the origin of the intervention. This finding reinforces the profound utility and generalizability of good basic scientific evidence and is reassuring for LAMIC where resources for development may not be available. The reviews highlight the variability across many dimensions of intervention characteristics, as well as in developmental targets and delivery agents. Although the core social communication impairments are universal and often the main underlying worry for caregivers who seek help, it can often be co-occurring problems such as challenging behaviors, restricted interests or difficulty in activities of daily living that cause parents to seek help and challenge the health system to detect the underlying autistic condition (Juneja & Sairam, 2018; Kommu et al., 2017). Given these realities, intervention practice needs to be flexible and adaptive.

Most evidenced interventions for autism have been developed and evaluated in high-income settings (Green & Garg, 2018) – a potentially powerful procedure (Marchette & Weisz, 2017) is to identify the active modular components of such interventions; allowing these then to be combined and tailored for efficient and effective delivery in specific situations and for adaptive needs globally. This in turn, however, depends on fundamental mechanistic research within the primary autism intervention science literature to identify such active modular components (Chorpita, Daleiden, & Weisz, 2005), and there is to date too little of this in autism intervention science. Designing adapted interventions in this way is parsimonious and would be more scalable, since there is less to learn and it is easier to deliver a limited set of elements with fidelity. The aim must be to preserve the highest quality of evidential standards, so as to avoid potential development of an ‘evidence-gap’ between LAMIC and HIC; children with autism globally deserve the highest quality of evidenced care – and this will be depend on the ongoing development of a clinical research infrastructure across LAMIC.

### Panel 2 A systematic adaptation of an evidence-based intervention for LAMIC

The parent-mediated intervention for Autism Spectrum Disorders in South Asia Plus (PASS Plus) is an example of a systematic adaptation and expansion of an evidence-based intervention developed in a HIC. The Pre-school Autism Communication Therapy (PACT; Green et al., 2010), an evidenced intervention delivered by speech and language therapists was evaluated in the UK demonstrating long-term impact on autism symptom severity (Pickles et al., 2016) and identifying through mediation analysis the key proximal therapeutic effects that mediated this symptom change. PACT was systematically adapted for use in South Asia, using multiple steps aimed at ensuring the adapted intervention to be both acceptable to families but also to ensure its feasibility for delivery by nonspecialist providers (task sharing). These steps included in-depth interviews with families of children with autism, focus group discussions with key stakeholders and nonspecialists and specialist consultations, leading to an expert-led adaptation of the original PACT manual (PASS; Divan et al., 2015). A key adaptation was to support various explanatory models of autism, but making sure that the explanation of social communication difficulties which the intervention addressed were woven into descriptive scripts (Divan et al., 2015). An initial randomized controlled trial (RCT) of this PASS intervention against usual care ( $n = 65$ ), conducted in India and Pakistan demonstrated encouraging results (Rahman et al., 2016), though some families engaged in the intervention described important challenges with problems co-occurring with autism itself, for which they had no services. The PASS social communication intervention was therefore expanded (PASS Plus) to address conditions commonly co-occurring with autism. Families were consulted to understand the key co-occurring conditions which required support, while specialists participated in an intervention development workshop. The manualized approach developed used a clinical decision algorithm for nonspecialists workers to identify and support these co-occurring conditions (e.g., sleep and toileting problems). A second RCT in rural India ( $n = 40$ ) demonstrated the feasibility, manual fidelity, and initial effectiveness of the PASS Plus intervention delivered in homes of families of children with autism (G. Divan et al., 2019). A subsequent large scale effectiveness RCT (target  $n = 240$ ) funded by the UK Joint Global Health Trials initiative is now underway to test the scale up of PASS Plus by health system frontline workers in New Delhi, India.

There are emerging examples of efforts to adapt interventions to culturally diverse settings in Ethiopia (Tekola et al., 2020), South Africa (Makombe et al., 2019), and South Asia (Divan et al., 2015). A key strategy in the adaptation process must be to ensure the socio-cultural acceptability, relevance, and physical accessibility to local stakeholders, especially parents and caregivers (Divan, 2017) while retaining the core mechanistic active components of the original treatment. The adaptation processes should typically explore potential barriers and identify strategies to address these, such as simplifying the language, changing the delivery location for easier engagement, and incorporating cultural concepts so that biomedical constructs are introduced while respectfully challenging unhelpful beliefs held by families, thus improving their acceptability in diverse contexts (Adugna et al., 2020; Franz et al., 2017). Manualization of locally developed interventions and of the cultural adaptations of HIC-developed interventions with good evidence will be critical to produce programs that are fully transparent and available to be shared and replicated within research studies. Open or low-cost access to intervention manuals and training programs is also key to accessibility, scalability, and reproducibility within LAMIC Panel 2 describes the process of systematic adaptation of an evidence-based HIC-developed intervention undertaken in two LAMIC.

### *Community-level services*

A major challenge across LAMIC settings is the low awareness of autism among families, the community and health and education professionals. The interpretation of autism phenomenology is strongly influenced by culture and complex cultural narratives and collectivist child-rearing practices may influence pathways of families to seeking care (Shorey et al., 2020). Novel methods of combining spiritual and biomedical treatments have shown success for other mental health problems, thereby raising the acceptability of the latter approaches. A team of psychiatrists in India sensitized healers in a Sufi Shrine that sees individuals with severe mental health disorders to deliver healing while simultaneously referring individuals to medical treatments (Naraindas, Quack, & Sax, 2014). Such collaborative cross-disciplinary approaches may be critically important for autism as well.

A related challenge is the stigma that occurs across levels (organizational or institutional, community, and intra- or interpersonal) and stakeholder groups. Studies have targeted negative attitudes and stigma toward disability but have tended to focus on small-scale community initiatives (Smythe et al., 2020). While community initiatives for stigma undoubtedly have merit, as seen by the training of 'champion' health workers drawn from families of children with developmental disabilities in Pakistan

(Hamdani et al., 2014), or peers from minority communities to steer families to services in the United States (Stahmer et al., 2019); approaches which include mobilizing high-level policy endorsements and mass media interventions have the potential to scale up de-stigmatization. The United Nations declaration of World Autism Awareness Day in 2007 (United Nations, 2008), and the simultaneous establishment of the 'Light it up Blue' campaign by the not-for-profit, Autism Speaks, established a worldwide initiative to raise awareness and tackle stigma for autism which is now active in more than 150 countries. Entertainment Education, where media messaging is designed to both entertain and educate has been used successfully in other health conditions (Tufté, 2001) such as HIV/AIDS. An example from India had a well-designed television drama, increasing the understanding of and empathy for autism in the community after its broadcast (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012).

### *Use of technology*

The harnessing of mobile and digital technologies may help address a range of barriers, from promoting awareness among diverse stakeholders, to the assessment of large numbers of children who require screening and a diagnostic evaluation, to the training and supervision of providers and delivery of the interventions, some directly to parents, through task sharing. Panel 3 illustrates this potential of technology through examples from multiple settings. These technologies are currently in an early phase of development and are yet to demonstrate feasibility and validity – but hold promise for process optimization in LAMIC (Lee, Maenner, & Heilig, 2019).

### *Enabling social policy and legislation*

A number of the review articles recognized the lack of policies and legislation to support the optimal roll out of sensitized health systems for young children with autism (Table 2). Within LAMIC, the prioritization is often aimed at addressing acute communicable conditions related to high-mortality rates in children. Another underlying problem in many LAMIC is the lack of recognition of autism as a developmental disability, which may have been influenced to some extent by relative recent clarification of the specific social impairments in autism which distinguished it from overall intellectual disability (Russell, Steer, & Golding, 2011). For example, in Vietnam the classification of autism as a 'disease' results in a health system focus on putative cures, with a lack of long-term services or support (Ha, Whittaker, Whittaker, & Rodger, 2014). Bangladesh launched its first state-supported autism services in 2010 and established the South Asia Autism Network in 2011 to champion access to care across

### Panel 3 Technological innovations for the detection and care of autism

- Public health campaigns can be delivered effectively through television and social media platforms.
- National organizations ([#](http://autismresourcecenter.in/Default.aspx)) and self-advocates (<http://www.autismarticulated.com/blog/2016/10/28/meet-fazli-azeem>) have used websites and social media platforms to support families in their search for understanding of their child's symptomatology and referral pathways.
- Mobile applications incorporating video content can improve parental understanding of questions and lead to more accurate screening (e.g., ASDetect; Barbaro & Yaari, 2020). Adding advice from experts or allowing parents to upload videos for expert comments, offers potential to facilitate expert opinions where specialist resources are limited (Nazneen et al., 2015).
- The INDT-ASD, an indigenously developed and validated diagnostic tool in India, has been converted to a mobile application that is open access and freely available on Google and Apple play stores, allowing widespread access across the country and internationally.
- Some salient autism characteristics, for instance differences in gaze preference for social scenes, can be detected using tablet computers (Vargas-Cuentas et al., 2017) and use of mobile health platforms to identify eye-tracking, sensory seeking, and fine motor impairments is being tested in LAMIC (Dasgupta et al., 2016).
- Recorded DVDs have been used to support self-directed learning for parents in Albania and Thailand (Dai et al., 2018; Pajareya & Nopmaneejumrulers, 2011). In Sri Lanka, videos were shown to parents to support modeling of desired behaviors (Perera, Jee-wandara, Seneviratne, & Guruge, 2016), while video feedback of a naturalistic play session between a parent and their child is a core element of the PASS intervention (Gauri Divan et al., 2019; Rahman et al., 2016).
- Digital technologies can be deployed for training and supervision of frontline workers to deliver psychosocial interventions allowing the delivery of interventions at scale (Muke et al., 2019).

### Panel 4 Research recommendations

- The building of community-academic collaborations to ensure a participatory approach for alignment with local stakeholder values and needs (Davenport et al., 2018; Liu et al., 2020; Maulik & Darmstadt, 2007).
- An increased range of LAMICs that conduct autism research (Lee & Meadan, 2020; Trembath et al., 2019) and increased diversity of participants within studies, including both urban and rural communities and hard-to-reach families (Lee & Meadan, 2020).
- A wider range of outcomes to complement the focus on effectiveness, to include feasibility, acceptability, scalability (including implementation fidelity; Dawson-Squibb et al., 2020; Lee & Meadan, 2020) and sustainability (including economic assessments of cost-effectiveness; Naveed et al., 2019).
- The development of adapted trial designs for LAMIC contexts that include analysis of moderators and mediators of treatment effects so that scant available resources can be directed toward active treatment components and processes for efficient deployment (Dawson-Squibb et al., 2020; Trembath et al., 2019).
- Development and testing of further strategies to promote task sharing through distance learning and e-health platforms for training and supervision of non-specialists (Adugna et al., 2020; Hastings et al., 2012; Maulik & Darmstadt, 2007).
- All implementation research should be aligned with international conventions that countries are signed up to (Lee & Meadan, 2020).

the region. In India, the Persons with Disability Act 1995 did not recognize autism, resulting in parents advocating for the establishment of the National Trust Act in 1996. This was then followed by the Rights for Persons with Disabilities Act 2016, which finally recognized autism as a disability with a mandate for services and support for individuals and their families (Barua, Kaushik, & Gulati, 2017). In Nigeria, the Child Rights Act, 2003, promises equal opportunities to every Nigerian child, but many social, political and cultural factors prevent its full implementation (Bakare et al., 2019). The WHO Atlas for Child and Adolescent Mental Health Services, 2005 reported that mechanisms for funding these services are rarely identifiable in country budgets and in LAMIC services are most often 'paid out of pocket' identified as 'private' financing. This

contrasts with the core principles of equity and financial risk protection inherent in UHC. This lack of financial support for services, respite care or long-term care, are directly related to the stress that families experience (Al Khateeb et al., 2019; Ilias et al., 2018) and often drive families into more precarious financial positions. For countries that have signed up to various declarations including the Convention on the Rights of the Child and the Convention of the Rights of Persons with Disability, it is important that policies are harmonized to actualize these commitments.

### High-quality research

Our review of reviews highlights a lack of research in all areas of inquiry related to UHC for children with autism in LAMIC. For example, there was an obvious lack of primary research to derive estimates of unmet needs for care. Thus, one of our unequivocal findings is that international development funding from HICs must support the strengthening of research capacity and infrastructure in LAMIC to conduct theory-driven research addressing a range of barriers toward realizing UHC, with more details from the reviews expanded with our suggestions in Panel 4.

### Conclusions

Due to the paucity of systematic reviews devoted to studies solely from LAMIC, we included a wider range of reviews that included LAMIC in their remit. We were unable to conduct a quality assessment of studies included in each review but had predefined criteria for review inclusion based on clearly defined methods and results. Thus, while striving to ensure comprehensive coverage of all relevant evidence, there is the possibility of some relatively poor quality reviews having been included in our scoping. We restricted our search to reviews that included studies from LAMIC and were not able to review therefore examples of relevant innovation within HIC to address hard-to-reach populations or low-resource contexts. However, there may well be common lessons here between LAMIC and low-resource HIC contexts. While we limited our search to studies involving young children, we did not include reviews of exclusively school-based initiatives, which can offer a significant delivery setting for autism, albeit primarily for educational interventions.

Notwithstanding these limitations, our findings offer insights which have allowed us to map a Theory of Change pathway to universal health coverage for young children with autism in LAMIC. Our pathway suggests that we need contextually appropriate and implementable developmental monitoring and diagnostic tools to address the detection gap; skill development across the health care system, but in particular in community-based frontline workers,

with stepped care from these nonspecialist providers to specialist providers based on the needs of families and children; accessible and affordable services which can innovate to support hard to reach populations but also mitigate financial pressures on families; and supporting the capacity building across community stakeholders to increase the awareness of childhood development milestones. We have noted that there are innovations across the spectrum of care for autism in LAMIC, which could potentially be reverse-engineered to apply to the many low-resource settings in HIC; for instance the application of creative problem-solving initiatives within LAMIC to tackle barriers to access in HIC, and the necessary drive to develop efficient but effective modular intervention delivery at scale in this context could positively inform HIC practice. In closing, while there is a need for more rigorous science to identify novel ways of achieving UHC, we believe there is sufficient preliminary evidence that can be built upon, to guide larger scale implementation programs to test a suite of integrated detection and care innovations, as laid out in our ToC, toward the goal of UHC for young children with autism in LAMIC.

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