EARLY DETECTION TOOLS FOR CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES

IN THE MIDDLE EAST AND NORTH AFRICA





Purpose

This technical brief was developed to support specialists in countries of the Middle East and North Africa (MENA) region to select which early detection tools best fit their needs and context by comparing various tools that have been used in the region and lessons learned in using and adapting those tools to local contexts.

Background

Early detection of developmental delays and disabilities in children followed by early childhood intervention, can greatly help children with better outcomes throughout their life course. Since formal screening is essential to initiate early interventions, there are various tools that exist and are being used in the world for detecting developmental delays and disabilities and that target various professionals both working at facilities and in the community, and for parents and caregivers to ensure that children have the essential support needed to develop and thrive.¹

While early detection and intervention are crucial for a child's development, it is also important to be aware of the risks of screening and the followings need to be considered to mitigate risks: 1) review of tools and protocols by an authorised body, 2) accuracy and validity of tools, 3) referral pathway, and 4) protocols for the users on how to address specific situation such as critical health and nutrition issues, violence and abuse.¹

Current research globally suggests that detection of developmental delays and disabilities is lower than their actual prevalence, meaning that actions undertaken in detection of developmental delays are not sufficient. In MENA, there is late detection of developmental delays due to (1) the lack of policies and strategies on early detection, (2) the lack of data on developmental delays and disabilities to build evidence-based policies and strategies, (3) the scarcity of validated screening tools in the languages used in the region including Arabic², Farsi and French, (3) the scarcity of socially and culturally adapted tools according to contexts ²³, and (4) the gaps in availability and capacity of specialized services and trained service providers to support children and families with early diagnosis and intervention once a delay and a disability have been identified.

¹ A Toolkit for Measuring Early Childhood Development in Low- and Middle-Income Countries World Bank Document

² The psychometric properties of the Ages and Stages Questionnaires-3 in Arabic: Cross-sectional observational study https://pubmed.ncbi.nlm.nih.gov/31299551/

³ Screening tools for early identification of children with developmental delay in low- and middle-income countries: a systematic review https://bmjopen.bmj.com/content/10/11/e038182

Box 1. How this brief was developed

The UNICEF Middle East and North Africa Regional Office (MENARO) collaborated with UNICEF headquarters and several country offices in the region (Iran, Iraq and the State of Palestine), who have worked on early detection, to discuss the tools and experiences they have had in their work. Additionally, the MENARO contacted specialists at UNICEF Tanzania and UNICEF Lebanon, the American University of Beirut in Lebanon, the University of Liverpool in the UK and the New York University Global TIES for Children in the USA, who have indepth experience in this area on early detection tools used in the region and globally.

To see the tools referenced in this technical brief, UNICEF employees can check the ECD repository for MENA. If you have no access to UNICEF Intranet, please kindly reach out to the authors.

There are 2 Annexes that give a summary of the tools, they are:

- Annex A Tools used in Iran, Iraq, Jordan, Lebanon, and State of Palestine
- Annex B Global tools for screening of developmental delays and disabilities used and referenced in MENA

Overview of early detection tools used in the MENA region

This technical brief summarises five tools from five countries in the region (Annex A).

- Objectives of the tools

All five tools aim to screen for developmental delays and disabilities. When used at different ages and stages of development, they are designed to identify various difficulties including physical, motor, visual, hearing and learning difficulties or delays, cognitive, social, emotional development, self-care, social adaptive skills and neurodiversity, which are less obvious at birth including autism spectrum. The screening tools are not diagnostic tools. Once a delay or disability is detected by these tools, a child may need to be referred to a specialist or a specialised facility for more detailed tests or interventions that are tailored to their needs and that help their parents address the observed delays and disabilities with activities that can be done at home.

- Global tools that MENA tools are based on

The tools currently used in the MENA are all adapted from tools which have been used globally. Annex B shows a brief summary of the global tools. Some of them have Arabic version readily available and are free of charge and include:

- 1. Ages and Stages Questionnaire (ASQ)
- 2. Denver Developmental Screening Test
- 3. Malawi Developmental Assessment Tool (MDAT)

It is necessary to check whether the tools work appropriately in a local context. All the tools which are currently used in MENA went through a process of translation, local adaptation, and pilot before being implemented more widely. Lebanon has documented this process in details when ASQ2 and ASQ3 were translated and adapted¹. The modification normally includes changing the words, phrases and activities (e.g. children's games, songs) to more socially and culturally appropriate.

Box 2. MDAT in Uganda

The Malawi Developmental Assessment Tool (MDAT) is a tool for early identification of neurodevelopmental problems in young children. It was initially created through a series of studies in Malawi to address the need of a simple, cheap and culturally appropriate way to identify developmental delays. Now, it has been used over 20 countries including low- and middle-income settings.

In Uganda, the early screening programme used the Delphi analysis to select the MDAT tool from seven tools recommended by global experts due to its ease of use, being free, wide age range covered and that the demonstration materials could be manufactured locally. In a collaboration with the University of Liverpool, who is the original developer of the tool, the Ministry of Health and UNICEF Uganda created a short version of the questionnaire (called MDAT IDEC) which could be delivered by Health facility workers, Community Healthcare Workers and the teachers of Early Childhood Development Centres. It only takes around 10-20 minutes per session. The users of the tool need to go through a 5-day training including practical hands-on training to work with children and families. Currently, children are screened at 9 months and 18 months, but the tool could be used up to 6 years of age. Parents and caregivers whose children are identified with development delays are referred for Caregiver Skills Training (CST) (a tool jointly developed by WHO & Autism-Speaks International) and Early Motor Development Support (EMDS) (a tool jointly developed by WHO & Autism-Speaks International). All children who are screened are also referred for mainstream Early Child Development services (immunisation, nutrition, early learning, responsive care giving, safety and security).

¹ Ages and Stages Questionnaires: Adaptation to an Arabic speaking population and cultural sensitivity - European Journal of Paediatric Neurology (ejpn-journal.com)

- Areas of development screened

All the tools screen motor (gross and fine), communication, social-emotional and cognitive skills.

- Target age

Tools spanned from 1 month up to 6 years with various intervals. The intervals tend to be shorter for younger age groups (1-3 months) and longer for older age groups (1-2 year or longer). The tools used in the State of Palestine have the widest coverage from 1 month to 6 years.

CHILD DEVELOPMENT BEHAVIOURAL 12 - 18 MONTHS ASSESSMENT SCALE FOR ASSESSMENT OF CHILDREN FROM 11 TO 19 MONTHS OF AGE مقياس تقييم التطؤر السلوكي 44T ALT 18-12 شهرا سرخ إجراء للقيم SEX: هل ولد الطقل ولادة ميكرة وقبل تعام أربعين أسيوعان ال تعدال لا AGE: MONTHS وَا كَانْتَ الْإِجْلُةُ نَعِمْ فَي أَنْ أَسْوِعَ مِنْ الْحَالُ وَلَا الْطَعْلِ إِنَّ DATE OF BIRTH: RESIDENCE: DAYS لتقيم الأطفال من 11-19 شهراً aul . عر الطال أشهر DATE OF ASSESSMENT: EVALUATOR: المدة الزمنية الحراء التقيير NTED NAME AND SURNAME OF THE PARENTIC hereby give my permission for assessment of my child's de SIGNATURE: PLACE/DATE: أنا الموقع إسعى أطااح الله الركاء بالرغان مومومة مكمات هي أوافق على إجراء نخيم التفور لطلقي كالمالانش يسروكمانة عركره الترقيح الازمود والمسيطان بالاشاكان Materials required for the administration of the scale: a toy car, a ball for kicking and throwing, a comb, a rattle, a set of non-stacking building blocks, sketch/notes pad without lines, markers, a set of nesting cups, sturdy book with pictu objects, a set of wooden blocks, a set of small rubber toys, a tall plastic glass (2 identical items), a staffed toyldoll. فيشائ العابدي علاماتي يخي سيار الكولود غيب بالشقاء المية أوالغية من ... بعد أن يكون ولي الأمر جرباً من النس . من حكار جوارة العامر فاتحق الفناق ويراني العراة التعيم المينزات التي تعمل علامة « يمكن الإستمكة يسوال الإداء إنهاء الأمور NOTE:

A parent/guardian has to be part of the assessment. Try each skill several times with an infant and parents/guardians. For assessment of skills marked with + ask parents/guardians. ت دن حال آن في تحديد عند المحتولات الذي وجد تاران طاعيم الدواره ام باعراء . حرايد على اطل هل إعطاء النبيم YES SOMETIMES NO 2 POINTS 1 POINT 0 POINTS ا. عطور العلام/ التواصل 1. Speaks at least 5 words clearly and Note down the words and how you hear يتول مرجيا أو العالي عاى باي ا يتراصف يوصوح عدما لا يرحب في شيء، يقول الا، يتوج وأسدار بنج الأشاء بعيد أنها.
 أن من المحكومة الأشاء بعيد أنها. يشور بياسيمه أن الشويه الذي يويهاه: خاول للاك مرات على الأقل النسيان العام". و يستعمل لأن الر التفهية المسيطة بور الماوات أو التارات تعالى؛ اقل الناب الحث عن حالاتان ال بـ الك ان الخ يجب أن متون هريمسين على حدم إستحام إيماءات ثوجّه

Figure 1. Example of the tool (State of Palestine)

- Users

Except for the State of Palestine, healthcare providers primarily do the assessment (general practitioners, paediatricians and Primary Health Care [PHC] healthcare providers, and nurses). Kindergarten and nursery teachers and specialists at academic institutions use the tool in the State of Palestine. Iraq may consider training the pre-kindergarten teachers with a simplified screening tool in the future.

- Settings

The health sector is the predominant entry point to conduct early detection using the tools as they could be the first and earliest contact point with children and families during their routine checkups, immunization session and/ or growth monitoring. In the State of Palestine, screenings additionally take place in the kindergartens, community centers and nurseries as well.

- Methods

Assessment methods include:

- 1. Observation (skill demonstration)
- 2. Interview with parents or caregiver using structured questionnaire or a set of questions
- 3. Self-administered questionnaire parents can fill out

Most countries use a combination of these three methods. Iraq includes the measurement of head circumference, length, height and weight as well.

The outcomes of the assessment are evaluated either:

- 1. Results are calculated using a scale (e.g. yes/ sometimes/ not yet) or
- 2. Results are classified into pre-set categories (e.g. red (referral), yellow (recheck through follow-up visit) and green (routine follow-up)).

If the score is lower than the cut-off value or a child falls into red or yellow categories, a follow-up visit or a referral is considered.

Persons administering the tools require training on the use of tools. The intensity of the training depends on the methods used. If the assessment needs observation (skill demonstration) and interview to parent/ caregivers, the duration of the training tends to be longer as the users need to do hands-on training on how to work with children and families. For example, in the State of Palestine, the duration of initial training ranges from 3 to 7 days.

- Duration

The duration of the screening (onsite) takes a minimum of 15 minutes (Iraq) up to a maximum of 60 minutes (State of Palestine). Time taken depends on the experience of a user and mood of the child.

- Users' experiences

The users reported the tools were easy to use and feasible in the context even though they can be time-consuming. User are required to have basic knowledge on child development and receive trainings on how to administer tools.

To overcome the challenges mentioned above, countries are considering developing a simplified version (e.g. a set of red flags) to reduce the duration of the training and time constraint.

- Effectiveness

All countries except for Iran and Lebanon are in the early stage of implementing the screening tools. Sensitivity, effectiveness and efficiency will need to be monitored and evaluated in the future. Iran has 8 years of experiences implementing the tool based on ASQ-2 before starting to use ASQ-3 and ASQ-SE and all data is computerised in the nationwide electronic medical record. This dataset could contribute to an evaluation of the tools and children could benefit from a continuum of care by linking this data to other sectors like education and child protection. Lebanon has done a rigorous study on psychometric properties of the ASQ3 (Arabic) and reported adequate reliability and validity for the children aged 4-33 months¹. Comparing to a USA normative sample, significant differences on almost all items and Lebanese children scored lower on communication and gross motor items while higher on the problem solving and personal social items. This could be due to environment and cultural norms¹.

- Support and Referral

The countries in the region have varying degree of national policies on early childhood development and strategies for early identification and intervention for developmental delays and disabilities for children.

¹ The psychometric properties of the Ages and Stages Questionnaires-3 in Arabic: Cross-sectional observational study - ScienceDirect

Box 3. State of Palestine investing in developmental delays and disabilities in early childhood development¹ In Palestine, the number of children excluded from school and affected by intellectual and physical disabilities has increased in the last ten years. In addition, these children face stigma and exclusion due to societal and environmental barriers. Technical support from international partners contributed to the formation of a multi-sectoral partnership to address the situation of children in a holistic manner involving the Ministry of Health, the Ministry of Education and the Ministry of Social Development and United Nations Relief and Works Agency (UNRWA). For example, the "Improvement of Early Detection and Interventions for Children with Disabilities and Developmental Delays" programme is coordinated by UNICEF and mainly was funded by the Government of Japan in support of the National ECD Committee implementing the National ECD/ECI Strategy. The program builds on the knowledge and experience gained from past years, and with regards to the interdisciplinary 'Child Development Assessment Tool' piloted in several locations in the West Bank and the Gaza Strip. The targeted beneficiaries include service providers from health, education and social protection sectors, NGOs and CSOs, as well as children, their families and their communities. As part of a long-term focus, children with disabilities are identified, receive assessment and support via an early childhood Intervention programme including parenting counselling and education provide early stimulation responsive care to children depending on age and development. The aim is to fully include all families with children in society. A key driver of this programme is to address the rights of children with developmental delays and or disabilities in State of Palestine.

Support to children with delays and disabilities and their families, as well as referral pathways, differ among the five countries in this technical brief.

After the screening of developmental delays and disabilities, parents or caregivers are normally given some counseling on exercises, stimulating activities, and play activities which are appropriate to his/ her age and development. Iraq uses the Care for Child Development package for counseling and identifying age-appropriate activities. In State of Palestine, the results of the assessment would lead to the development of early intervention education plans that could be implemented by therapists or parents at home.

Iran has a comprehensive system with nationwide universal early detection and referral pathway from health houses/posts (in rural/urban areas) to comprehensive healthcare centres, who can then refer to interdisciplinary Child Developmental centres (where available) or secondary health services that use the Bayley Scales of Infant and Toddler Development (BSID) for a more detailed analysis. Overall, it is still a challenge in the region to set up an early detection system with a matching referral pathway due to a lack of universally available services for early identification, and the lack of services, tools, specialists and specialised facilities to support children and families for early interventions.

Conclusion

This technical brief sheds light on the tools for early detection of developmental delays and disabilities that have been used in MENA. All the screening tools in this brief are stemming from one or more tools used globally and have been translated and adapted to local contexts. The translation and adaptation is recommended to be done with interdisciplinary teams. 1 The tools generally screen similar areas and cover similar age groups. The health sector appears to be the main entry point for early detection for now, and healthcare providers are the main user to do the assessment, while parents are the key informants alongside their children. The users of the tools normally need some level of training and the more experienced a user on child development and screening, the less the duration of the screening. All these factors will influence how rapidly an early detection programme can be scaled up nationwide. Most countries in MENA are in the early stages of implementation of such programmes; sensitivity, effectiveness and efficiency of early screening tools should be monitored and evaluated in the long run. Adequate support for a child and family and referral to appropriate services following detection is still a gap and needs to take into account multisectoral, transdisciplinary and interdisciplinary coordination among health, education, and child protection actors.²

¹ https://pubmed.ncbi.nlm.nih.gov/33772410/

² Vargas-Baron, Emily & Small, Jason & Wertlieb, Donald & Hix-Small, Hollie & Botero, Rocio & Diehl, Kristel & Vergara, Paola & Lynch, Paul. (2019). Global Survey of Inclusive Early Childhood Development and Early Childhood Intervention Programs RISE Institute

For a way forward, one of the important considerations is that screening children for developmental delays and disabilities can be inappropriate if there are not enough resources to address those delays and disabilities in a given context as this could end up being more stigmatizing for a child and family. As such, the strengthening of multisectoral and multidisciplinary systems-level programmes for diagnosis, intervention, follow-up, supporting and empowering a child and family including humanitarian settings must be considered in parallel with starting an early detection programme. The ultimate goal is that every child, including those at risk and most vulnerable, survives and thrives to realise their full potential.¹

We would like MENA countries to consider:

- Integration of strategy of early detection and interventions into a national policy on early childhood development
- Implementation of early detection programme using tools which are locally adapted and tested
- Monitoring and evaluation of the early detection tools on sensitivity, specificity, effectiveness, efficiency and impact on children and families
- Providing the service providers with tools, skills and information on how to reach and support children with developmental delays and disabilities and their families especially those living in hard-to-reach areas
- Ensuring early detection is followed up with referral pathways to link with appropriate and accessible support and services for children and families based on their needs including those living in humanitarian settings. Where services are scarce or not yet in place, early detection work to be used to help advocate for the establishment of services to meet the needs of children and families.

Box 4. Resources to support service providers, children with developmental delays and disabilities and their families

Measurement Library: Inter-agency Network for Education in Emergencies (INEE), in collaboration with New York University Global TIES for Children and the International Rescue Committee (IRC), launched a "Measurement Library" which contains a collection of measurement tools to assess children's learning, holistic development and service provider quality in crisis- and conflict-affected contexts. It is a searchable and filterable database of measurement tools that was developed through an extensive review of working papers and journal articles in English and Arabic to identify and document the details of where, in what language, and with what population measures have been used in MENA. It does not provide access to the tools themselves, but is intended as a starting point for users interested in finding measurement tools for their purpose and context (Caires, R., Shankar, A., Diaz, P., Rafla, J., Tubbs Dolan, C., & Wuermli, A. (2019, November). The MENAT CHILD measurement inventory. New York, NY: NYU Global TIES for Children)

Care for Child Development: It is a training package for frontline workers. It equips frontline workers with assessment and counselling skills on teaching parents/ caregivers how to provide responsive and nurturing care to children depending on age and development. The package has been implemented in Egypt, Iran and Tunisia in MENA. The tutorial video for children with special needs show how to counsel parents of children with disabilities in Arabic, English and French.

Caring for the Caregiver: It is a new training package for frontline workers to equip them with counselling skills to increase caregivers' confidence and help them develop stress management, self-care and conflict-resolution skills to support their emotional wellbeing. Arabic and French version are under development.

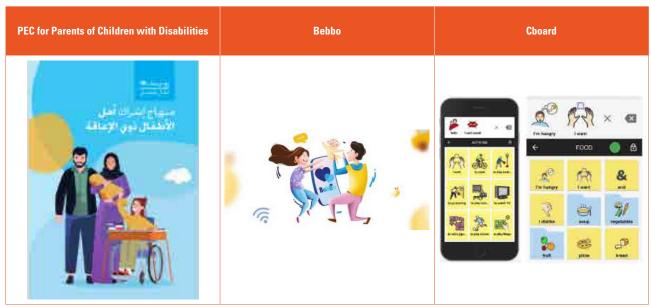
<u>Parenting Resource Pack:</u> It is a guide designed to give parents/ caregivers ideas and supports on parenting so that they could make informed choices. Arabic version is available.

Parental Engagement Curriculum (PEC) for Parents of Children with Disabilities: Lebanon has been quaked by multitude of events and continues to be unstable, with extensive humanitarian and development needs. Families who are providing care for children and especially those with disabilities have been greatly affected by the crisis situation. They could find it challenging to find appropriate services for support and referral. UNICEF Lebanon has recently developed the parenting curriculum to provide skills and strategies for parents of children with disabilities aged 0-18. The curriculum provides information on how to advocate children's rights, enhance development, encourage learning, protect from violence and understand/ manage caregivers' emotions. These resources aim to provide parents with tools and strategies with the specialized content that is targeted towards their specific needs that are not met through general parental engagement programs; while also ensure to be gender responsive and child protection components incorporated

<u>Curriculum in English, Curriculum in Arabic, Facilitator guide in English, Facilitator guide in Arabic</u>

<u>Bebbo</u>: It is a free parenting application to support early childhood development (0-6 years old) and it has inclusive sections for parents of children with disabilities. It is not available for Arabic/ Farsi/ French. <u>Bebbo - Apps on Google Play, Bebbo on the App Store (apple.com)</u>

Cboard: It is an open-source communication application for children with disabilities (speech and language impairment) and can be operated on desktops, tablets and mobile phones. It is available in Arabic, English, and French. It is open for customization and customization is very quick (few weeks max). Trainings for professionals who should support use of Cboard with parents are part of the intervention and on-line training in English is available. Cboard AAC - Google Play





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Annex A – Tools for screening of developmental delays and disabilities – used in MENA region

useObjective	Developmental areas screened	Target age	User Settings Methods	Implementation	Characteristics	Support and Referral process after identification
Country of use: State of Palestine Tool name: Child development behavioral assessment Global tool referenced: DBS developmental behavioral scales Child developmental behavioral scales Child developmental behavioral scales Complications befor during/ after pregna complications at birr pregna complications at birr pregna complications at birr pregna complications at birr pregna complication at	ment: munication ional (fine and evelopment are nd of the (not scored): pregnancy, ns at birth ematurity), iidhood ring early ring early ing haviours ge checklist manual	1 to 60 months, broken down into 10 assessment tools 1. 1-3 mo (16 items) 2. 3-6 mo (25 items) 3. 6-9 mo (35 items) 6. 18-24 mo (34 items) 7. 24-36 mo (32 items) 8. 3-4 y (43 items) 9. 4-5 y (39 items) 10. 5-6 y (42 items)	Healthcare providers (Pediatricians, general practitioners, nurses, speech/physical therapists), kindergarten/nursery teachers (with bachelor's degree), Social workers Social workers Social workers Clinics 3. Kindergarten/nursery Methods: Observation/ skill demonstration (0-2 y.o.) ask parents to help a child do skill, (2 y.o. and older) demonstrate skills to a child and ask him/ her to do skills The results are scored using the 3-level scale: 1. Yes 2. Sometimes 3. No	Language: Arabic Translation from English to Arabic. Back-translation from Arabic to English has also been done. Adaptation: Adapted to Palestinian contexts including words, Iullabies, children's games, animal sounds/ names. Also child protection elements have been taken into consideration by changing the original questions. (e.g. instead of asking ask child "to take off clothes" ask them "to put on clothes" considering Protection against Sexual Exploitation and Abuse). Training: Users need to complete a 3-7 days training (including hands-on practices). In future, local expertise is needed for a scale-up by identifying a champion among the current users to be a trainer. Scale of implementation: Around 375 professionals from health, education and social development sectors from eight governorates in the West Bank and Gaza have been trained on the use of the tool.	Time required: 20min minimum 60 min maximum Time includes a child to demonstrate skills while playing (multiple attempts may be needed), and counseling to parents. Duration depends on experience of users/ mood of child. Users' experiences User needs to have some child development knowledge in advance. Duration of screening varies and it is possible to screen a maximum of 5 children per day. May need to repeat the screening when a child is tired or not cooperative. Effectiveness: This is to be determined as tool is new and Covid delayed full implementation. It appeared to be high.	Support after screening: Following the results of the assessment, (whether the full assessment, (whether the full assessment or the short version of red flags), parents/ caregivers are provided with information/counseling and given exercises if needed to do at home with children. For some service providers, where resources are available, an individual service plan is developed and implemented for each child identified to have a developmental delay. Referral process: 1. Need to retest child with low score. Till a next retest, parents are given materials on stimulation of specific activity 2. If retest score is low and/or delay is confirmed, refer to: Children with mild/moderate delays are referred to an institution who can support family with early intervention plan focusing on specific skills (E.g. community centre, multidisciplinary clinics). If a child has severe delays and a referral to a specialized service is needed, then this is done if available. Colleagues in Palestine recognize there is not shared referral system and would like to strengthen this.

Tool name References Country of useObjective	Developmental areas screened	Target age	User Settings Methods	Implementation	Characteristics	Support and Referral process after identification
Country of use: Iran Tool name: ASO-2/ ASO-3/ ASO-3/ ASO-8/ ASO-SE (Currently using ASO-8/ ASO-SE) Global Tools referenced: Ages and Stages Questionnaire (ASO) Home -Ages and Stages Objective: Screens for developmental delays and disabilities	development: 1. communication 2. gross motor 3. fine motor 4. problem solving 5. personal-social skills	21 questionnaires with following month: 2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, 60 months Due to time constraints with using 21 questionnaires with universal coverage, Iran has selected used 5 (6,12,24,36,60 months) of the questionnaires for ASQ-2 for routine monitoring. However, if a child has been identified as "needs further assessment" through Well child programme, he/ she will undergo ASQ3 and ASQ SE appropriate to his/her agg. Healthy children born with prematurity will undergo the appropriate for 2, 6, 9, 12, 18, 24, 36, 48, 60 months.	Parents: fill out the questionnaires before vising the health facilities Healthcare providers (Primary Health Care (PHC) level): support parents when the questions are not clear for them. review and score the questionnaires and record scores on Electrical Medical Record. explain the results to parents. Settings: Primary Health Care centre (during regular check-up/ immunizations). 'Health Houses' in rural/ Health Post in urban areas Nethods: Self-administer questionnaire filled out by parents Scoring by healthcare providers using the 3-level scale for ASO3 (Yes/ Sometime/ Not yet) and 3-level scale (Often or always/ Sometimes/ Rarely or Never) for ASO-SE. ASO-SE has an option for parents/ caregivers to check "if this is a concern" (currently digitalised and stored in a nationwide electronic medical record system):	Language: Farsi Consultant who was expert in early detection tool supported translation. Adaptation: Adaptation: The same consultant contextualized the tool (e.g. traditional beliefs/cultures, urban/rural). It should be noted that same questionnaire and cut offs are used for both rural and urban areas. Pilots have been done after translation and adaptation. The cut-off points were determined by calculating 1SD and 2SD below mean. The latter representing the main cut-off point and the interval between the two representing the monitoring zone according to the ASO3 technical manual. Training: MoHME provides specific protocols, guidelines and trainings for healthcare workers to follow when using the questionnaire and to answer the questions from caregivers. Scale of implementation: Nationwide	Time required: Up to 30 min Users' experiences Fairly easy to use and feasible for Iranian context. The Iranian gov't seems to satisfy with the ASQ-2 to screen various delays and disabilities. It has been used for 8 years now. The government has started the use of ASQ-3. Effectiveness: The tool is proven effective globally, however, there may be under-reporting of disability by parents who fear stigmatization for the child. Due to selfadministration nature of a tool, there may be false positives and negatives. According to "The situation analysis of the Developmental Status (Draft)", 5% of the children under the age of 3 required referral based on the ASQ (overall items).	Support after screening: General instructions are provided in the PHC At the interdisciplinary Child Developmental centre, parents/ caregivers of children with developmental delays or disabilities receive counseling and how to give appropriate stimulation and responsive/ nurturing care. Referral process: 1.Based on Red Flags and ASQ screening test (computerised), a child is referred to comprehensive healthcare center doctor for Bayley Scales assessment. 2. If doctor at comprehensive healthcare centre has concern, then a referral is made to an interdisciplinary Child Developmental centres or hospitals. The centres are equipped with early intervention tools and various rooms to support various skill development. For children with severe disabilities/delays, referrals to specialized facilities are made, where available.

Tool name References Country Developmental areas of useObjective	Developmental areas screened	Target age	User Settings Methods	Implementation	Characteristics	Support and Referral process after identification
Loo name: No specific name It is integrated in the child health care recording file used during immunizations and growth monitoring Global Tools referenced: Monitoring Child Development in the IMCL context (PAHOM/HO) (Four development scales referenced: Bayley Scales of Infant and Toddler Development (BSID). Denver Developmental Screening Test (DDST). Exame neurologico do recemnascido de termo, and Diagnostico del desarrollo normal y anormal del nino: metodos clinicos y aplicaciones practicas) Objective: Screens for developmental delays and disabilities	Areas of development: 1. Social/ emotional 2. Language/ communication 3. Cognitive (learning, thinking, problem- solving) 4. Movement/ physical development	Well-child care and Early Childhood Development monitoring are scheduled as following months. (Ones in bold align with the immunization schedule) During the screening, 4 key developmental milestones are checked. <1 (1 week and 1 month), 2, 4, 6, 9, 12, 15, 18, 24, 30, 36, 42, 48, 54, 60 month)	Healthcare providers (PHC level, mainly doctors, either family physician doctors or general practitioners) Settings: Primary Health Care centre (during regular check-up/ immunizations and growth monitoring). Methods: Interview with structured questions (risk factors), Measurement (head, height/ length, weight) Observation/ skill demonstration Classification by pre-set criteria 1. red (referral) 2. yellow (counsel and follow-up visit) 3. green (counsel and routine visits)	Language: Arabic Translation from English to Arabic was straightforward due to simplicity of questions. Adaptation: As the four key milestones per age group were mostly straightforward and universal skills, no localization process was needed. Training; The users need to receive a 4-day specific training course. They are trained on the ECD concept and guideline including how to do the screening and how to provide responsive care. Scale of implementation: In January 2022, a pilot has been started at 12 PHC centres. After evaluation, a plan is to expand to 3 more governorates (5 PHC centres per governorate)	Time required: 15 min Users' experiences Very easy and rapid, 4 questions embedded in a comprehensive form Effectiveness: Yet, to be determined as project is new.	Support after screening: Please refer to "When a child falls into "yellow" category": Referral process: - When a child falls into "yellow" category, counselling using Care for Child Development is provided to parents on how to give responsive stimulation to a child - When a child falls into "red" category, two pediatric hospitals are available in 1st pilot phase to be referred to, in Baghdad (tertiary hospitals). - Tools used by pediatricians for further assessment of delay vary and up to a pediatric specialist. - There seems to be little publicly available specialized centres for children with severe delays/limitations (speed, motor, intellectual). - Some private centres may be available to support on developmental delays for those who can afford it.

Tool name References Country of useObjective	Developmental areas screened	Target age	User Settings Methods	Implementation	Characteristics	Support and Referral process after identification
Country of use: Lebanon Tool name: ASQ-3 *Translation and adaptation have been done in Lebanon for a part of the questionnaires!, however, currently, the Arabic version available from the official website has been used for consistency. Global Tools referenced: Ages and Stages Questionnaire-3 (ASQ-3): Home- Ages and Stages Objective: Screening for developmental delays and	development: 1. communication 2. gross motor 3. fine motor 4. problem solving 5. personal-social skills	questionnaires with following month: 2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, 60 months The questions are either yes/ no or yes/ sometimes/not yet to choose from.	Parents: fill out the questionnaires before vising the facilities, Healthcare professionals at American University of Beirut (AUB): support parents when the questions are not clear, review and score the questionnaires, explain the results to parents. * Early ECD educators (World Vision) have used the tool for Syrian refugee children. Settings: AUB neonatal continuity clinics for highrisk infants (The clinic is for babies born in AUB or those born outside of AUB and referred for checkup and follow-up) Methods: Self-administer questionnaire filled out by parents (at AUB, parents fill out during their visits to clinic (during the COVID restriction, screening has been done through a phone interview). Scoring by healthcare providers Paper format scored by hand. Compare child's scores to Lebanese cutoff points. Discuss results with parents and determine next steps. (e.g follow-up, monitoring, or further assessment. Share activities with parents if delays noted. Results- 3 levels 1. Pass 2. Suspect (Above threshold in at least domain) 3. Referral (Below threshold in at least 1 domain)	Language: Arabic ASO3 has been translated as follows in Lebanon. *ASO has been easily administered for 4-36 months age groups but not for 4-5 years old due to cultural differences² 1) A skilled translator who is a communication skills expert did a translation from English to Arabic. (2) Another bilingual translator, blinded to the original translation, did the back translation into English, (3) Arabic translations were reviewed and compared with the original English questionnaire by two specialists (medical doctors) to detect any misunderstanding, mistranslations or inaccuracies. (4) All items on the questionnaires were reviewed and discussed with a child psychologist, a paediatric occupational therapist, and an early child education expert till a consensus was reached. Items that were found to be culturally sensitive were modified. (5) Cutoff points of each domain were generated deviation from the mean score Adaptation: Face-to-face interviews with consenting parents were held to check the ease of readability and clarity of the questions. Questions were modified based on the feedback. Trainings: For the specialists working at AUB, the training guidelines/ manuals are used (going over the questionnaires) Scale of implementation: Health facility (tertiary/ referral level: AUB) for follow up high-risk infants	Time required: For parents/ caregivers to fill out questionnaire: around 10 minutess Users' experiences: very easy to use, it only takes a short time and flexible. It can be administered easily over the phone. Effectiveness: *Comparison with a USA normative sample by ASQ3 (0-3) 3: Lebanese children scored lower on communication and gross motor items across age groups. Lebanese children scored significantly higher on problem solving and personal social items. This could be due to a child rearing takes place in extended family environment with extensive interactions.	Support after screening and Referral process: The current form of universal screening for developmental delays is a checklist included in the child's health record that is offered by the MOPH to every newborn at birth. This health record contains developmental milestones' checklists that the physician or the parent can fill at different ages. The checklists are based on the Center for Disease Control and Prevention ⁴ . It is not known how widely these checklists are used. In case of developmental delay, a child is usually referred to a pediatric neurologist for further assessment. There are many services available (ex. Special kids clinic at AUBMC, Sesobel, I'dad, ARC en Ciel among others) however a comprehensive mapping of those services is highly needed.

1 The psychometric properties of the Ages and Stages Questionnaires-3 in Arabic: Cross-sectional observational study - ScienceDirect

2 Ages and Stages Questionnaires; Adaptation to an Arabic speaking population and cultural sensitivity - European Journal of Paediatric Neurology (eipn-journal.com)

3 The psychometric properties of the Ages and Stages Questionnaires-3 in Arabic: Cross-sectional observational study - ScienceDirect.

4 CDC's Developmental Milestones | CDC

Tool name References Country of useObjective	Developmental areas screened	Target age	User Settings Methods	Implementation	Characteristics	Support and Referral process after identification
Country of use: Jordan 1 2 Tool name: MDAT Global Tools referenced: Malawi Developmental Assessment Tool (MDAT) Objective: To identify children with neurodisabilities or delayed development.	Areas of development: 1. gross motor (34 items) 2. fine motor (34 items) 3. language (34 items) 4. social development (34 items) *Original version of MDAT has been used in Lebanon (Different from a short version used in Uganda)	From 0 to 5 years old	Users: Trained enumerators with some background in Child Protection, Education and Health sectors Settings: Syrian refugees and Jordanian caregivers under pilot/ research purpose Methods: Using the toolkit, The users observe a child (skill demonstration) and ask questions to parent/ caregiver whether a child can perform skills. Scoring system is used to see whether a child is "pass" or "fail".	Language: Arabic Translated from English to Modern Standard Arabic (MSA) and adapted to local Levantine dialects by translators, specialists and psychometric experts Backtranslation was done as well. Adaptation Adaptation process was conducted after translation to MSA. Adaptation included linguistic adaptation and adaptation of images and local materials that are required to test the child's abilities. Trainings: It seems to require relatively intense training on the use of the tools (e.g. how to ask questions, record the results, etc.) Scale of implementation: Syrian refugee settings who participated in a pilot research study	Time required: 30-40 min depending on age of child, Users' experiences It has been reported by the enumerators that the caregivers appeared to enjoy the use of MDAT. Effectiveness: The expected correlations with caregiver measures were not obtained, however further investigation is needed.	Support after screening: Referral process: Information not available

1 As the documentation of the implementation is ongoing, only the limited information is available for now. 2 irc-rul-reportapril27-2020.pdf (inee.org)_

Annex B - Global tools for screening of developmental delays and disabilities

This table is not an exhaustive list of screening tools used globally, but listed those used/ referenced in MENA.

Tool / Objective	Developmental areas screened	Target age	User / Methods / Trainings	Available language
Ages and Stages Questionnaire (ASQ) Objective: To detect delays early to improve child outcomes while encouraging parent involvement and education	Areas of development: 1. communication 2. gross motor 3. fine motor 4. problem solving 5. personal-social skills	21 questionnaires with following month intervals: 2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, 60 months	User: Parents/ caregivers Professionals, paraprofessionals or clerical staff Methods: Parents/ caregivers fill out a self-administer questionnaire Professionals score the questionnaire, review child's scores and compare to standardised cut-offs If scores fall in the category for follow-up, schedule the next screening and provide Trainings: Required. Can be purchased from Training - Ages and Stages	Permission from publisher required for translation. Arabic/ English/ French and other languages These can be purchased from ASQ website Translations of ASQ - Ages and Stages *How the Arabic translation has been done? ASQ3 has been translated into a standardised Arabic and reviewed by experts from different Arabic-speaking countries including KSA, Kuwait and Egypt. Adaptations have been made include: a) language to reflect Arabic grammar, b) cultural experiences, c) motor skills. ASQ-3 Arabic uses the same cutoffs as the English version. Research projects conducted to study the psychometric properties of ASQ-3 Arabic are not comprehensive enough to provide separate normative data on Arabic children at this time and should be reviewed with consideration especially in the communication and personal-social areas.
Bayley Scales of Infant and Toddler Development (BSID) BSID 4 published in 2019 Objective: To diagnose developmental delays in early childhood and plan management 2 *Considered to be standardised screening instruments and a gold standard diagnostic tool for developmental delay for infants and young children 34.	Areas of development: 1. cognition 2. motor 3. language 4. socio-emotional 5. adaptive behaviour	16 days to 42 months	Professionals (Psychologists, neuropsychologists, or developmental paediatricians are the common users. Occupational therapists, speech and language pathologists, and paediatric nurse practitioners also con utilise in practice.) Methods: Parents/ caregivers to complete questionnaires Professionals observe and facilitate skill demonstration. Then, professionals summarise standard and score Trainings: Required (webinars and workshops)	Permission from publisher required for translation. English Global TIES for Children have translated into Arabic, however it has not been tested.

¹ Bayley N. Bayley scales of infant and toddler development. PsychCorp, Pearson; 2006.

² Bayley Scales Of Infant and Toddler Development - StatPearls - NCBI Bookshelf (nih.gov)

³ Nelson Textbook of Pediatrics. 19th Edition

⁴ The psychometric properties of the Ages and Stages Questionnaires-3 in Arabic. Cross-sectional observational study - ScienceDirect

Tool / Objective	Developmental areas screened	Target age	User / Methods / Trainings	Available language
Denver Developmental Screening Test (DDST) Objective: To identify young children at risk for developmental delays and disability.	Areas of development: motor (gross and fine) language personal-social skills	From birth to 6 years	Wethods: Methods: Using Denver Development Screening forms and kit, the users identify the chronologic age of child and draw age line on scoring sheet. Test a child with items on the form along age line and then to the right of the age line until a child fails items Trainings: Required	English Arabic in limited use as follows: Revised Denver Pre-Screening Developmental Questionnaire has been translated and adapted for Madinah children in KSA Denver II has been administered by physicians in the Middle- Eastern countries, but not being widely used ² .
Malawi Developmental Assessment Tool (MDAT)3 Objective: To use as a clinical tool in early identification of neurodevelopmental problems and as an outcome measure (e.g. in clinical trials of perinatal interventions)	Areas of development: gross motor fine motor language social development *Cognitive development is measured within the domains of fine motor and language.	0 to 5 years old	User: Anyone with a high school education Can be used at primary health care level Methods: Using the toolkit, the users observe and facilitate a child to demonstrate skill and ask questions to parent/ caregiver whether a child can perform skills. Scoring system is used to see whether a child is "pass" or "fail". Trainings: Required (at least 3 days to 7 days)	Arabic, English, French, and other languages Translations Local MDAT Tools can be requested from Get your toolkit Local MDAT for free of charge. Implemented in over 20 countries In Low- and middle-income settings in Sub-Saharan Africa, South East Asia and South America Global Influence Local MDAT I Global Influence Local MDAT

1 Translation and Adaptation of the Revised Denver Pre-Screning Developmental Questionnaire for Madinah Children, Saudi Arabia (annsaudimed.net) 2 The standardization of the Denver Developmental Screening Test on Arab children from the Middle East and north Africa. - Abstract - Europe PMC

³ pmed.1000273 1..14 (nih.gov)

Other screening tool for a resource-limited setting (not currently used in MENA)

The Guide for Monitoring Child Development (GMCD) ^{1 2} is a tool for monitoring and early detection of development difficulties of children aged 0-3.5 years in low- and middle-income countries. It was originally developed in Turkey. Training required to use the tool and it takes 1 to 3 days depending on the background of the trainees. Community workers, nurses, family physicians, paediatricians and early intervention providers in 25 countries have been trained in the use of the tool. The tool has three components: 1) monitoring of development component, 2) supporting development and 3) managing developmental difficulties and integrate the concept of Care for Child Development and the WHO International Classification of Functioning, Disability and Health framework. It is a brief, open-ended, precoded interview with primary caregiver and it assesses language (expressive and receptive), motor skills (gross/ fine), relating, playing and self-help.

<u>Assessment (RNDA)</u> ³ ⁴ are tools developed in Bangladesh. DSQ is administered to mothers of children aged 0 to 24 months of age to screen neurodevelopmental status with 24 age sets with 8 questions per set. It screens motor (gross/fine), vision, hearing, cognition, socialisation, behaviour and speech. RNDA was developed to assess neurodevelopmental status of children aged less than 2 years with limited access to health screening. It can be conducted by semi-skilled health workers. It is meant to provide neurodevelopmental evaluation equivalent to a scale like BSID 3. The tool is now available to screen children up to 9 years old with domains: motor (gorss/fine), vision, hearing, speech, cognition, behaivour, seizure, and self-help (only for 5-9 years old). Training can be accessed from <u>Rapid Neurodevelopmental Assessment (RNDA) Training (rnda-bd.org)</u>.

¹ A Guide for Monitoring Child Development in Low- and Middle-Income Countries | Pediatrics | American Academy of Pediatrics (aap.

² The international Guide for Monitoring Child Development: enabling individualised interventions - Bernard van Leer Foundation

³ Screening tools for early identification of children with developmental delay in low- and middle-income countries: a systematic review LBMJ Open

^{4 &}lt;a href="https://www.researchgate.net/publication/280868267_Validation_and_adaptation_of_Rapid_Neurodevelopmental_Assessment_Instrument_for_Infants_in_Guatemala_to_Instrume

Parents' Evaluation of Developmental Status (PEDS) is a tool to provide developmental screening and behavioral screening plus ongoing surveillance for children aged 0 to 8 years old. The tool screens language (expressive/ receptive), motor (gross and fine), behaviour, self-help and school and social skills (PEDS-R will include psychosocial challenges and health problems). Parents are asked to answer 10 questions on the PEDS Response Form and it is scored using the Score Form. On the back of the Score Form, PEDS Interpretation Form is attached and shows an algorithm for deciding whether to refer, screen further, observe, counsel parents or simply reassure them. The form also has the spaces for recording and tracking decisions and actions. It is available in Arabic, English, Farsi and French.

Free screening tools with the languages used in MENA:

Caregiver-Reported Early Development Instruments (CREDI) is a an open-source tool and being used for population-level early childhood development assessment from birth to 3 years old (not for an individual screening tool to detect early developmental delays or disorders). The caregiver answers a questionnaire (short or long form). The CREDI Short Form creates a summary score for children's overall developmental status and the long form creates domain-specific developmental scores. It is available in Arabic, English, and French.

