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Policy Brief

Addressing Early Identification and Intervention of Children with Disabilities and Developmental Delays in Lebanon

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It is prepared by synthesising and contextualizing the best available evidence about the problem and viable solutions through the involvement of content experts, policymakers and stakeholders.

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+ Included

Description of a health system problem

Viable options for addressing this problem

Strategies for implementing these options

× Not Included

Does not make **recommendations**

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K2P Policy Brief

Addressing Early Identification and Intervention of Children with Disabilities and Developmental Delays

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Key Messages

Key Messages

The problem

Disability and developmental delays among children aged 2-9 reaches 11% in some parts of Lebanon (Central Administration of Statistics, 2013). Children with disabilities and developmental delays in Lebanon face multiple barriers at the health system, delivery and financing levels that pose challenges for early identification and intervention. This puts children with disability and developmental delays at risk of delayed rehabilitation and treatment, multiple morbidity, physiological implications, risk of violence, exploitation and abuse and preventable delayed complications.

Elements of a comprehensive approach

Element 1› Develop and implement policies, tools and strategies for early identification and intervention of children with disabilities and developmental delays to be used in health, education, social protection and other sectors

2.1 Development of national policies targeting children with disabilities and developmental delays

2.2 Use of tools and practices for early Identification of children with disabilities and developmental delays

2.3 Implementation of practices on identified children with disabilities and developmental delays

Element 2› Enhance the knowledge and education of caregivers, healthcare providers, and educators to detect, refer or manage children with disabilities and developmental delays.

Awareness targeting parents, clinicians, and child-care professionals were associated with positive impact.

Element 3› Secure financial coverage for early identification and intervention services

Strategies include changing eligibility criteria of health insurance, making the premium more affordable, adoption of innovative enrolment strategies, improving health care delivery, and improving management and organization of the insurance schemes.

Purpose of the Policy Brief

The purpose of this Policy Brief is to shed light on the challenges of early identification and intervention among children with disabilities and developmental delays in Lebanon and related health system arrangements. The Policy Brief and Policy Dialogue aim to inform a National Strategy for early identification and intervention of developmental delays and disabilities among children in Lebanon.

Implementation considerations

To ensure maximum effectiveness in improving early identification and intervention in children with disabilities and developmental delays, a variety of implementation considerations need to be kept in mind at the level of individual, professionals, organizations, and systems.

رسائل أساسية

تعريف المشكلة

تبلغ نسبة حالات الإعاقة والتأخر في النمو لدى الأطفال الذين يتراوح عمرهم بين السنتين والتسع سنوات 11% في بعض المناطق اللبنانية (*Central Administration of Statistics, 2013*). ويواجه هؤلاء الأطفال عوائق عديدة على مستوى النظام الصحي،تقديم خدمات الرعاية الصحية والتمويل، وهي عوائق تفرض تحديات تحول دون التّعرف والتدخل المبكرين على هذه الحالات. وهذا ما يعرّض الأطفال المُعوّقين والذين يعانون من تأخر في النّمو، لخطر حصول تأخر في إعادة التأهيل والعلاج، وحالات مرضية متعددة وأثار بنيوية (فيزيولوجية)، بالإضافة إلى خطر تعرض هؤلاء الأطفال للعنف والإستغلال والأذى الجسدي وإلى مضاعفات كان ممكن تفاديها لو تمت معالجتها في مراحل مبكرة.

هدف موجز السياسات

انّ هدف موجز السياسات هذاهو تسليط الضوء على التحديات المتمثلة بالتّعرف وبالتدخل المبكرين على حالات الأطفال المُعوّقين والذين يعانون من تأخر في النمو في لبنان، وعلى إجراءت الأنظمة الصحية ذات الصلة. وهدف موجز السياسات وحوار السياسات، هو دعم سياسة استراتيجية وطنيّة للتعرّف والتدخل المبكرين على حالات الأطفال المُعوّقين وذوي النمّو المتأخر في لبنان.

ما الذي نعرفه حول العناصر الثلاث التي يتم اعتمادها في المقاربات لمعالجة هذه المشكلة؟

العنصر الأول> إعداد و تطبيق سياسات وأدوات وإستراتيجيات للتعرف والتدخل المبكرين على حالات الأطفال المُعوَقين **والذين يعانون من تأخر في النّمو** في القطاعات الصحية و التربوية و القطاع الحماية الاجتماعيّة وغيرها.

← تطوير السياسات الوطنية الموجّهة للأطفال المُعوَقين **والذين يعانون من تأخر في النّمو** استخدام الأدوات والممارسات من أجل التعرف المبكر على حالات الأطفال مُعوَقين والذين يعانون من تأخر في النمو.

← تطبيق الممارسات المتعلقة بحالات الأطفال المُعوَقين **والذين يعانون من تأخر في النّمو** العنصر الثاني> تحسين المعرفة وزيادة الوعي لدى مقدمي الرعاية الصحية والعناية الصحية والمربييّن، للكشف عن حالات الإعاقة والتأخر في النمو عند الأطفال وإحالتهم للمعالجة أو الإعتناء بهم.

ولقد كان للتوعية التي استهدفت الأهل ومقدّمي الرعاية الصحّية والمتخصّصين في مجال العناية بالأطفال أثر إيجابي.

العنصر الثالث> تأمين تغطية مالية لعملية التعرف وتقديم الخدمات لحالات الأطفال المُعوَقين **والذين يعانون من تأخر في النّمو**

الاستراتيجيات تشمل تغيير المعايير الأهلية للتأمين الصحي وتيسير كلفة أقساط التأمين وتبني استراتيجيات مبتكرة للتسجيل وتحسين تقديم خدمات الرعاية الصحية (الإيتاء)، وتحسين إدارة وتنظيم خطط التأمين .

ما هي الإعتبارات التي يجب أخذها بعين الإعتبار عند التطبيق العملي؟

لضمان فعالية قصوى في ما يتعلق بتحسين عمليات التّعرف والتدخل المبكرين على حالات الأطفال المُعوَقين والذين يعانون من تأخر في النّمو ، تدعو الحاجة الى ذكر مجموعة من الإعتبارات التطبيقية، وذلك على صعيد الفرد وأهل الإختصاص والمؤسسات والأنظمة.

Policy Brief

K2P Policy Brief

The Problem

Disability and developmental delays among children aged 2-9 reaches 11% in some parts of Lebanon (Central Administration of Statistics, 2013). Children with disabilities and developmental delays face multiple barriers at the health system, delivery and financing levels that pose challenges for early identification and intervention. This puts children with disability and developmental delays at risk of delayed rehabilitation and treatment, multiple morbidity, physiological implications, risk of violence, exploitation and abuse and preventable delayed complications.

Size of the Problem

The early childhood period is from prenatal development to eight years old (Irwin, Siddiqi, & Hertzman, 2007). It represents a crucial phase of growth, development, and life-long learning, which makes this phase critical in ensuring the child reaches maximal potential alongside his/her disability (UNESCO, 2009). In fact, providing adequate early childhood development was highly emphasized in the Sustainable Development Goal (SDG) 4.2.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Convention on the Rights of Persons with Disabilities and Developmental Delays)

Developmental Delays refers to when a child does not achieve developmental milestones within the normal age range.

Worldwide, it is estimated that there is 93 million children with disability, but numbers can be higher (UNICEF, 2017). Yet, increasing evidence suggests that persons with disabilities experience poorer levels of health as compared to the general population (Rimmer & Rowland, 2008), increased risk of other hardships including lower possibilities of attending school (World Health Organization, 2011), getting employed (World Health Organization, 2011) and increased dependency, isolation, and restricted participation (Maulik & Darmstadt, 2007).

In Lebanon, the prevalence of disability among children reaches 11%, in some parts of the country (Central Administration of Statistics, 2013).

As for Syrian refugees living in Lebanon, 2% aged 0-14 have a mental or physical disability (UNHCR, WFP, & Unicef, 2017). In addition, it is estimated that almost 30 percent of the total Palestinian refugees with disabilities are children below 18 (Grantham-McGregor et al., 2007). Despite the absence of up to date comprehensive data on the prevalence of disabilities and developmental delays among children aged 0-8 years in Lebanon, the available data indicate the need to ensure availability of systems, services, and practices for early identification and intervention of children with disabilities and developmental delays.

Underlying Factors

The following section focuses on the underlying factors at the governance, financial, delivery and sociocultural level that may have contributed to the challenges in early identification of children with disabilities and developmental delays. A systematic local assessment was undertaken to uncover such arrangements.

The following section focuses on the underlying factors at the governance, financial, delivery and sociocultural levels that may have contributed to the challenges in early identification of children with disabilities and developmental delays. A systematic local assessment was undertaken to uncover such arrangements.

At the **governance level,** In 1990, Lebanon Signed and later ratified on the United Nations Convention on Rights of Children (CRC) which is a human rights treaty that applies to all children including children with disabilities (OHCHR, 2014). Law 220/2000 was developed to protect the Rights of Disabled Persons, yet the law is still not fully in effect. The eligibility criteria of the disability card exclude many children who need the disability card but do not meet the eligibility criteria, which includes children under three years old.

Although significant efforts have been made to improve the situation of people with disabilities including children, current challenges in the regulatory framework (i.e. laws, regulations, policies) on children with disabilities hinder early identification and intervention of children with disabilities and developmental delays.

At the level of **financing,** coverage for children with disabilities and developmental delays remains a challenge. As per law 220/2000, cardholders are entitled to healthcare services. However, many disabled children are unable to attain healthcare services due to cost. NGOs contracted with MOSA face financial issues which results in charging families for the services (Human Rights Watch, 2018). In addition, the cost of education in most inclusive schools and daycare centers is high (Human Right Watch, 2018). Some services for children with disabilities and developmental delays of Syrian refugees are covered by UNHCR and UNICEF and some services for Palestinians are covered by UNRWA.

At the **delivery level**, common challenges exist across different sectors involved in the delivery of services for early identification and intervention. These challenges include; centralization of centers and specialized staff in urban areas, limited training and awareness of staff in early identification and intervention, low level of awareness among caregivers of children with disabilities and developmental delays, limited access to high quality services and weak monitoring and evaluation of services, poor financial coverage of services, poorly equipped infrastructure of facilities for disabled children, and limited availability of contextualized and validated tools.

At the **sociocultural level**, there are several challenges to identifying and intervening of children with disability and developmental delays. This includes caregiver fear of social stigma, social isolation and shame (Azar & Badr, 2006), discrimination and labeling children with disabilities and developmental delays, and limited knowledge, awareness and training, and negative attitude of healthcare professions.

Elements of a comprehensive approach to address the problem

The following three elements form part of a comprehensive approach to tackle the issue of late identification and intervention of children with disabilities and developmental delays, and therefore can be adopted either independently or could complement one another.

Element 1

Develop and implement policies, tools and strategies for early identification and intervention of children with disabilities and developmental delays to be used in health, education, social protection and other sectors

Several countries including, UK, Malta, and Malaysia among others have implemented tools and practices in healthcare centers and schools for early identification and intervention of children with disabilities and developmental delays. Tools used for the early identification of other developmental delays were able to predict developmental delay in high-risk infants (Wang et al, 2016). In addition, a validated structured interview performed by nurses increased the rate of early detection of child developmental problems (Staal et al, 2016). Several tools were also identified to support early identification of autism (Kleinman et al, 2008; Nyrgen et al, 2012; Hedley et al, 2015).

Addressing disabilities and developmental delays through policy changes have proved to be an effective strategy. As an example, policy changes that modified state agency practices through mandating screening by trained experienced professionals resulted in a 5-fold increase in the number of children eligible for early intensive behavioral intervention without waiting for a definitive diagnosis of autism spectrum disorder (Rotholz et al, 2017).

Practice improvement strategies that include routine screening and community outreach was found to increase screening and referral (Daniels et al, 2014). The use of the age of acquisition of motor skills as a screening tool for developmental delay (Arabameri & Sotoodeh, 2015), measures of letter naming fluency, phonological awareness, rapid naming, or non-word repetition accurately, the introduction of Universal Newborn Hearing Screening (Halpin et al, 2010) and vision screening (Struble et al, 2016) for preschoolers supported early identification of developmental delays and disabilities.

Intervening early on children with disabilities and developmental delays was associated with a multitude of benefits depending on the type of disability or developmental delay. The interventions include multidisciplinary therapy and family support, parent education, and medical care.

Element 2

Enhance the knowledge and education of caregivers, healthcare providers, and educators to detect, refer or manage children with disabilities and developmental delays.

Interventions targeting awareness and community involvement have demonstrated significant impact on several areas related to early identification and intervention of disabilities and developmental delays. Specifically, awareness targeting parents, clinicians, and child-care professionals were associated with positive changes in knowledge about autism (Daniels et al, 2014). Academic detailing led to an increase in the state's overall rate of screening of developmental delays (Daniels et al, 2014; Honigfeld, Chandhok, & Spiegelman, 2012);

Element 3

Secure financial coverage for early identification and intervention services

Securing financial coverage of early identification and intervention services was found to be possible through several means. Adoption of strategies such as changing eligibility criteria of health insurance, increasing public awareness, making the premium more affordable, adoption of innovative enrolment strategies, improving health care delivery [improving healthcare package, controlling prices of services, enhancing quality of services to attract eligible population];, and improving management and organization of the insurance schemes resulted in expansion of health insurance coverage of vulnerable populations, including those with disabilities (Meng et al, 2010).

Implementation considerations

Strategies to overcome implementation barriers at the individual, professional, organizational and system levels include:

- Improve collaboration among ministries on early identification, intervention and referral
- Improve collaboration among stakeholders to identify, adapt, pilot test and validate tools to detect children with disability and developmental delays
- Allocate a budget for children with disabilities and developmental delays practices for its implementation and sustainability
- Integration of education on the health and human rights of persons with disabilities into undergraduate and continuing education for all health care workers
- Raising awareness of the public on the prevention of discrimination of children with disabilities

موجز للسياسات الصحية العامة

تعريف المشكلة

تبلغ نسبة حالات الأطفال المُعوَقين ما بين عمر السنتين والتسع سنوات 11% في بعد المناطق اللبنانية (Central Administration of Statistics, 2013). ويواجه الأطفال المُعوَقين عوائق متعددة على صعيد النظام الصحي وتقديم خدمات الرعاية الصحية والتمويل، من شأنها أن تشكل تحديات بالنسبة إلى التّعرف و التدخّل المبكرين. وهذا ما يعرّض الأطفال المُعوّقين والذين يعانون من تأخر بالنمو لخطر التأخير في إعادة التأهيل والعلاج، ونشوء حالات مرضية متعددة ولمضاعفات بنيوية (فيزيولوجية)، وللتّعنيف والإستغلال والأذى الجسدي وإلى مضاعفات يمكن تفاديها لو تمت المعالجة باكراً.

من ضمن الأشخاص المصابين بإعاقات أولئك الذين يعانون من عاهات جسدية وإعاقة ذهنية أو تخلف عقلي أو عاهات جسدية، تكون جميعها إعاقة طويلة الأمد، والتي إذا تفاعلت مع عوائق متنوعة من شأنها أن تعيق المشاركة التامة والفعالة لهؤلاء الأطفال في المجتمع، وعلى أسس متساوية مع الأخرين ***(Convention on the Rights of Persons with Disabilities and Developmental Delays).***
وعبارة "التأخر في النمو" تشير إلى عدم تحقيق الطفل انجازات تنموية مطابقة للفئة العمرية التي ينتمي إليها.

حجم المشكلة

تمتد فترة الطفولة المبكرة منذ ما قبل الولادة وحتى سن الثامنة (*Irwin, Siddiqi, & Hertzman, 2007*). وهي تمثل مرحلة حساسة وبالغة الأهمية من مراحل النمو والتطور والتّعلّم مدى الحياة، ما يجعل هذه المرحلة حاسمة في ما يتعلق بضمان بلوغ الطفل أقصى إمكاناته مع اعاقته/اعاقتها (*UNESCO, 2009*). وفي الحقيقة فقد تم التّشديد ضمن أهداف التنمية المستدامة *(SDG4.2)* على وجوب توفير البيئة التنموية المناسبة للطفل في مرحلة الطفولة المبكرة.

على الصعيد العالمي، تشير التقديرات الى وجود 93 مليون طفل معوّق، الا أنه من الممكن أن يكون العدد أكبر (اليونيسف، 2017). بيد أن الأدلة المتزايدة توحي بأن الأشخاص المُعوّقين يعانون من مشاكل صحية أكثر من سائر أفراد المجتمع *(Rimmer & Rowland 2008)*، إضافةً الى كونهم معرّضين بدرجة أكبر لاختبار مصاعب أخرى ومنها إمكانيات أقل لإرتياد المدرسة (منظمة الصحة العالمية، 2011) والعثور

على وظيفة (منظمة الصحة العالمية، 2011) ودرجة أكبر من الإعتماد على الغير والتقوقع والإنعزال، وانخراط محدود في المجتمع *(Maulik & Darmstadt, 2007)*.

وفي لبنان، تبلغ نسبة الأطفال المُعوَقين في بعض المناطق 11% (الإدارة المركزية للاحصاء، 2013). أما بالنسبة الى اللّاجئين السّوريين في لبنان، فهناك نسبة 2% من بين الأطفال سن الصفر والرابعة عشر، مصابون بإعاقة ذهنية أو جسدية *(UNHCR, WFP, & Unicef, 2017).*

إضافة الى ذلك، تشير التّقديرات الى أن حوالي 20% من مجموع عدد اللّاجئين الفلسطينيين ما دون سن الثّامنة عشر، هم من ذوي الإعاقة. *(Grantham-McGregor et al., 2007)*. وعلى الرّغم من غياب بيانات شاملة حديثة عن نسبة حالات الإعاقة والتّأخر في النّمو، لدى الأطفال بين سن الصّفر والثّمانية في لبنان، تشير البيانات المتوافرة الى وجوب التأكد من توافر الأنظمة والخدمات والمزاولات المهنية من أجل التعرّف والتدخّل المبكرين على حالات الأطفال المُعوَقين والذين يعانون من تأخر في النّمو.

العوامل المسببة

في هذه الفقرة يتم التركيز على العوامل المسببة على المستويات الإدارية والمالية، كما على مستوى تقديم خدمات الرعاية الصحية والمستوى الإجتماعي-الثقافي، لأن هذه العوامل من شأنها أن تساهم في نشوء التّحديات في ما يتعلق بالتعرّف المبكر الى حالات الأطفال المُعوَقين والذين يعانون من تأخر في النمو.وقد بوشر القيام بعملية تقييم منهجي على الصّعيد المحلي، للكشف عن هذه الترتيبات.

على **المستوى الإداري**، وقّع لبنان عام 1990 على اتفاقية الأمم المتحدة المتعلقة بحقوق الطّفل *(CRC)* وصدّق عليها بعد ذلك. وفي إحدى معاهدات حقوق الإنسان المُطبّقة على جميع الأطفال، بمن فيهم الأطفال المُعوَقين *(OHCHR, 2014)*. وقد تمّ تطوير القانون 220/2000 لحماية حقوق الأشخاص المعوَقين، بيد أن هذا القانون لم ينفذ بالكامل، إذ أن معايير التأهيل لبطاقة الإعاقة تستثني أطفالاً عديدين ممن هم بحاجة الى بطاقة العجز، حيث ليس كلّ هذه الحالات، تستوفي معايير التأهيلية الموضوعة التي تشمل الأطفال ما دون الثالثة من العمر.

بالرغم من بذل جهود لا يُستهان بها لتحسين وضع المُعوَقين ومنهم الأطفال، لوحظ وجود تحديات قائمة في الإطار التّنظيمي (أي القوانين والأنظمة

والسياسات) بشأن الأطفال المصابين بالإعاقة، ما يعيق عملية التّعرّف والتدخل المبكرين الى حالات الأطفال المُعوَقين والذين يعانون من تأخراً في النمو.

على **صعيد التّمويل،** تبقى التغطية المالية لهؤلاء الأطفال مثالاً عن إحدى التحديات التي تواجههم. فبحسب القانون 220/2000، يحق لحاملي البطاقة الإنتفاع من خدمات الرّعاية الصّحية مجاناً. بيد أنه ثمة أطفال مُعوَقون كثر، غير قادرين على تلقي خدمات الرّعاية الصّحية، بسبب كلفتها الباهظة. أما المنظمات غير الحكومية المتعاقدة مع وزارة الشؤون الإجتماعية، فتواجه مشاكل مالية تقضي بفرض رسوم خدمة على أهالي هذه الفئة (Human Rights Watch, 2018) ، بالإضافة الى نفقات التعليم الباهظة، غالبية المدارس ومراكز العناية النهارية التي تؤمن التعليم الشامل للجميع (Human Rights Watch, 2018)، ثمة تغطية مالية لرسوم بعض الخدمات التي تقدمها مفوضية شؤون اللاجئين واليونيسف للأطفال المُعوَقين من اللّاجئين السّوريين، وكذلك تفعل مؤسسة الأونروا بالنسبة الى الأطفال الفلسطينيين في لبنان، المُعوَقين والذين يعانون من تأخرٍ في النّمو على مستوى تقديم خدمات الرّعاية الصّحية (الإيتاء).

على مستوى تقديم خدمات الرّعاية الصّحية, وتوجد تحديات مشتركة في مختلف القطاعات المعنية في مجال تقديم الخدمات، من أجل التّعرّف والّتدخل المبكرين. وتشمل هذه التحديات:تمركز المراكز والعاملين المختصّين في المناطق الحضرية ومحدوديّة التدريب والتوعية عند طاقم العمل في مجال التّعرف والتدخل المبكرين في حالات الإعاقة والتأخر في النمو، وتدني مستوى التّوعية في أوساط مقدمي الرعاية للأطفال المُعوَقين والذين يعانون من تأخر في النّمو ومحدودية فرص الحصول على خدمات عالية الجودة بالإضافة الى سوء نظامي الرّصد والتّقييم، إضافة" الى سوء التّغطية للخدمات المالية وافتقار البنية الأساسية لمرافق الأطفال المعوَقين الى التّجهيزات الملائمة ومحدوديّة وجود أدوات سياقية ومثبتة الفاعلية.

وعلى المستوى الإجتماعي الثقافي، ثمة تحديات عدّة تحول دون التعرّف والتدخل المبكرين في حالات الأطفال المُعوَقين والذين يعانون من تأخر في النّمو. وتشمل هذه التحديات: خشية مقدم الرّعاية من السّمة الإجتماعية للمعوقين، ومن العزلة الإجتماعية، ومن مشاعر الخجل لديهم *(Azar & Badr, 2006)*، والتمييز في معاملة هؤلاء الأطفال المعوقين والذين يعانون تأخراً في النمو، ̈وسمُهم ومحدودية المعرفة والتوعية والتدريب والموقف السّلبي تُجاه المهن المتعلقة بالرعاية الصحية.

عناصر نهج شامل لمعاجة المشكلة:

تشكل العناصر الثلاثة التالية جزءاً من نهج شامل لمعالجة مسألة التّعرف والتدخل المبكرين في حالات الأطفال المُعوَقين والذين يعانون من تأخر في النّمو وبالتالي،إما كل واحد منها على حدة، أو بطريقة تكاملية بحيث يتمم بعضها الآخر.

العنصر الأول> إعداد و تطبيق سياسات وأدوات وإستراتيجيات للتّعرّف وللتدخل المبكر على حالات الأطفال المُعوَقين **والذين يعانون من تأخر في النّمو** في القطاعات الصحية و التربوية و القطاع الحماية الاجتماعيّة و غيرها.

سبق أن أنجزت دول عدة ومنها المملكة المتحدة ومالطا وماليزيا، وسائل وممارسات في مراكز الرعاية الصحية والمدارس، من أجل التّعرف والتّدخل المبكرين على حالات الأطفال المُعوَقين والذين يعانون من تأخر في النّمو لحلّ هذه المسألة. وبفضل الوسائل المستخدمة من أجل التعرّف المبكر لحالات أخرى من تأخر النمو، بات بالإمكان توَقّع الإصابة بالتأخر في النمو لدى الأطفال المعرّضين لخطر كبير *(Wang et al, 2016)*. إضافةً الى أنه ثمة مقابلة منظمة مصدّقة، أجرتها ممرضات، أسهمت في رفع نسبة حالات الكشف المبكر لمشاكل النمو عند الأطفال *(Staal et al, 2016)*.

كما حددت وسائل عدة بكونها أدوات مساعدة على الكشف المبكر للتوحد *(Kleinman et al, 2008; Nyrgen et al, 2012; Hedley et al, 2015).*

وهناك أيضاً الإستراتيجيات القائمة على تحسين الممارسات، وتشمل الفحص الرّوتيني والتّوعية المجتمعية، والتي ثُبّت أنها تساهم في عملية التّحرّي عن المرضى والإحالة للعلاج *(Daniels et al, 2014)*.

ومن الوسائل المساعدة، اعتماد سن اكتساب المهارات الحركية أداة للتّحرّي عن التأخر في النمو *(Arabameri & Sotoodeh, 2015)* وقياس الطاقة في تسمية الحروف، والتّوعية النطقية، وفحص السرعة في تسمية الأشياء والأشخاص، أو الدّقة في تكرار كلمات فارغة المعنى، وما ساعد أيضاً على التّعرف على حالات أخرى في النمو والإعاقة باكراً، هو إدراج الفحص العام للسمع عند المواليد الجدد *(Halpin et al, 2010)* وفحص النظر *(Struble et al, 2016)* للأطفال في عمر الثلاث سنوات حتى الخمس سنوات، أي من هم في مرحلة ما قبل المدرسة.

ولقد اقترنت عملية التّدخل المبكر في ما يتعلّق بحالات الإعاقة والتأخر في النمو عند الأطفال، بعدد وفير من المنافع والخدمات، بحسب ماهية الإعاقة أو التأخر في النمو، وتشمل هذه العملية العلاج المتعدد التّخصصات ودعم العائلة وثقافة الأهل والعناية الطبية.

العنصر الثاني> تحسين المعرفة وزيادة الوعي لدى مقدمي الرعاية الصحية والعناية الصحية والمربيّن، للكشف عن حالات الإعاقة والتأخر في النمو عند الأطفال وإحالتهم للمعالجة أو الإعتناء بهم.

وثُبت أن لعمليات التدّخل التي استهدفت توعية المجتمع ومشاركته، تأثيراً كبيراً على نواح متعددة متعلقة بالتّعرف وبالتدخل المبكرين في حالات الإعاقة والنمو المتأخر، وبالتحديد ثُبّت اقتران التوعية التي تستهدف الأهل والمقدّمي الرعاية الصحيّة والمتخصصين في مجال رعاية الأطفال، تغييرات إيجابية في المعارف المتعلقة بموضوع التّوحد *(Daniels et al, 2014)* . كما أن أدت إحدى وسائل التوعية التعليمية التي تقدّم من خلالها تفاصيل أكاديمية للعاملين في مجال الرّعاية الصّحية، الى زيادة المعدل الإجمالي للكشف على حالات تأخّر النمو *(Daniels et al, 2014; Honigfeld, Chandhok, & Spiegelman, 2012)* .

العنصر الثالث> تأمين تغطية مالية لعملية التعرف وتقديم الخدمات لحالات الأطفال المُعوَقين وذوي النمّو المتأخر

ثبتت إمكانية تأمين تغطية مالية لخدمات التّعرف والتّدخل المبكرين عبر وسائل متعددة: تبني استراتيجيات مثل تغيير معايير التأهيلية للتأمين الصحي، وزيادة الوعي العام، وتيسير كلفة أقساط التأمين، وتبني استراتيجيات مبتكرة للتّسجيل، وتحسين تقديم خدمات الرّعاية الصّحية (تحسين حزمة الرعاية الصحية وضبط أسعار الخدمات وتحسين نوعية الخدمات لجذب السكان المؤهلين)، كما أن تحسين إدارة أنظمة التأمين وتنظيمها، أديا الى زيادة نسبة تغطية التأمين الصحي للفئات السكانية الضعيفة ومنهم فئة المُعوَقين *(Meng et al, 2010)*

ما هي العوامل التي يجب أخذها بعين الاعتبار عند التطبيق العملي؟

في ما يلي، نذكر الإستراتيجيات الهافة الى تخطي عوائق التطبيق على مستوى الأفراد وأهل الإختصاص على مستوى التنظيم والنظام:

- ← تعزيز التعاون بين الوزارات بشأن التعرّف والتدخل المبكر والإحالة للمعالجة.
- ← تعزيز التّعاون في أوساط أصحاب الشأن من أجل تحديد وتكييف وسائل للكشف عن الأطفال المُعوَقين والذين يعانون من تأخر في النّمو، بعد إخضاعها لاختبارات تجريبية والتّثبت من فعاليتها.

- تخصيص ميزانية للأطفال المُعوَقين والذين يعانون من تأخر في النّمو ، من أجل التطبيق والإستدامة.
- دمج مواد متعلّقة بالحقوق الصّحية والإنسانية للأشخاص المُعوَقين في التعليم الجامعي و برامج التعليم المستمر.
- زيادة الوعي لدى الناس بشأن الحد من تمييز الأطفال المُعوَقين.

Content

K2P Policy Brief-
Full report

The Problem

Disability and developmental delays among children aged 2-9 reaches 11% in some parts of Lebanon (Central Administration of Statistics, 2013). Children with disabilities and developmental delays face multiple barriers at the health system, delivery and financing levels that pose challenges for early identification and intervention. This puts children with disability and developmental delays at risk of delayed rehabilitation and treatment, multiple morbidity, physiological implications risk of violence, exploitation and abuse and preventable delayed complications.

Size of the Problem

The early childhood period is from prenatal development to eight years old (Irwin, Siddiqi, & Hertzman, 2007). It represents a crucial phase of growth, development, and life-long learning, which makes this phase critical in ensuring the child reaches maximal potential alongside his/her disability (UNESCO, 2009). In fact, providing adequate early childhood development was highly emphasized in the Sustainable Development Goal (SDG) 4.2.

Poverty may increase the likelihood of disability and may also be a consequence of disability. Poor pregnant women may experience poor health outcomes, restricted diet, and exposure to toxins and environmental pollutants, all of which can have a negative consequence on fetal development. Children living in poverty are more often exposed to a variety of risks which include inadequate nutrition; poor sanitation and hygiene; exposure to infection and illness; lack of access to health care; inadequate housing or homelessness; inadequate child care; exposure to violence, neglect and abuse; increased maternal stress and depression; institutionalization; and inadequate stimulation. (Grantham-McGregor et al., 2007; Walker et al., 2011). This poses them at a higher risk of experiencing developmental delays

Background to Policy Brief

A K2P Policy Brief brings together global research evidence, local evidence and context-specific knowledge to inform deliberations about health policies and programs. It is prepared by synthesizing and contextualizing the best available evidence about the problem and viable solutions and options through the involvement of content experts, policymakers and stakeholders.

The preparation of the Policy Brief involved the following steps:

1) *Selecting a priority topic according to K2P criteria*
2) *Selecting a working team who deliberates to develop an outline for the policy brief and oversee the litmus testing phase.*
3) *Developing and refining the outline, particularly the framing of the problem and the viable elements*
4) *Litmus testing by conducting one to one interviews with up to 15 selected policymakers and stakeholders to frame the problem and make sure all aspects are addressed.*
5) *Identifying, appraising and synthesizing relevant research evidence about the problem, elements, and implementation considerations*
6) *Drafting the brief in such a way as to present concisely and in accessible language the global and local research evidence.*
7) *Undergoing merit review*
8) *Finalizing the Policy Brief based on the input of merit reviewers, translating into Arabic, validating translation, and disseminating through policy dialogues and other mechanisms.*

compared to children from higher socio-economic status (Fernald, Kariger, Engle, & Raikes, 2009; Walker et al., 2007). In addition consanguineous marriages are associated with an increased risk for congenital malformations, autosomal recessive diseases, and higher postnatal mortality in the offspring of first cousin couples (Hamamy, 2012).

Worldwide, it is estimated that there is 93 million children with disability, but numbers can be higher (UNICEF, 2017). Yet, increasing evidence suggests that persons with disabilities experience poorer levels of health as compared to the general population (Rimmer & Rowland, 2008). They are more likely to suffer conditions secondary to their disability, such as pressure ulcers, urinary tract infections, and depression. Such preventable conditions may reduce functioning, lower the quality of life, increase health care costs, and lead to premature mortality (Nosek & Simmons, 2007). Children with disability are at increased risk of violence, abuse and exploitation (WHO & UNICEF, 2012). According to Jones et al. (2012), children with disability are 3.7 times more likely than non-disabled children to be a victim of violence. In addition, children with disability have a significantly higher risk (2 times more likely) of unintentional injury than non-disabled children (Shi et al., 2015). Moreover, one study found that children with developmental disabilities, including autism, attention deficit disorder, and attention deficit hyperactivity disorder (ADHD), were 2-3 times more at risk of an injury than those without such disabilities (Lee, Harrington, Louie, & Newschaffer, 2008).

Not only do children with disability suffer from health conditions, they are also at an increased risk of other hardships such as lower educational achievements. Children with disabilities are less likely to start school than their peers without disabilities and have lower chances of staying and being promoted (World Health Organization, 2011). In the long term, persons with disability also have less economic participation; they are more likely to be unemployed and generally earn less even when employed. Global data from the World Health Survey show that employment rates are lower for disabled men (53%) and disabled women (20%) as compared to nondisabled men (65%) and non-disabled women (30%) (World Health Organization, 2011). In addition, as a result of, lack of community support, and inadequate services, persons with disability suffer from increased dependency, isolation, and restricted participation (Maulik & Darmstadt, 2007), including restricted social and political participation.

In Lebanon, the prevalence of disability among children reaches 11%, in some parts of the country. According to the central administration of statistics, the percentage of children aged 2-9 with at least one reported type of disability is 8.2% in Beirut Governorate, 6.6-6.8% in Mount Lebanon Governorate, 5.9-9.4% in North Lebanon Governorate, 6.2-10.0% in Bekaa Governorate, 11% in South Governorate, and 8.1% in Nabatieh Governorate (Central Administration of Statistics, 2013). Moreover, as per a study conducted on 1,373 children aged 16-48 months, 153 per 10,000 children aged 16-48 months in Lebanon have Autism Spectrum Disorder (ASD) (Saab, Chaaya, & Boustany, 2018). According to the Vulnerability Assessment for Syrian Refugees in Lebanon, 2% of children aged 0-17 suffer from disability (UNHCR., WFP., & UNICEF, 2017). In addition, 14% of children aged 36 to 59 months in Palestinian camps and gatherings in Lebanon, did not meet three out of four of the Early Child Development Index (ECDI) that include literacy-numeracy, physical, social-emotional and learning (UNRWA, 2011).

Despite the absence of up to date comprehensive data on the prevalence of disabilities and developmental delays among children aged 0-8 years in Lebanon, the available data indicate that there is an urgent need to ensure availability of systems, services, and practices for early identification and intervention of children with disabilities and developmental delays.

Underlying Factors

The following section focuses on the underlying factors at the governance, financial, delivery and sociocultural level that may have contributed to the challenges in early identification of children with disabilities and developmental delays. A systematic local assessment was undertaken to uncover such arrangements.

Local Assessment Methodology

Assessment of the current mandates guiding child early identification and intervention of children with disabilities and developmental delays was performed through a review of the laws, policies, accreditation standards, and any regulatory document, with a special focus on those pertaining to healthcare facilities. The assessment aimed to identify bottlenecks and loopholes in the mandates and pinpoint deficient or overlooked areas in the current regulatory arrangements.

Assessment of the role of key stakeholders, healthcare facilities, NGOs, schools and daycare centers involved in early identification and intervention of children with disabilities and developmental delays was carried out through interviews and focused group discussions. The assessment aimed at exploring current services and practices, challenges in early identification and interventions, and areas of improvement.

Governance

At the governance level, significant efforts have been made to improve the situation of people with disabilities including children and ensure their rights (figure 1). Yet, current challenges in the regulatory framework (i.e. laws, regulations, policies) on children with disabilities hinder early identification and intervention of children with disabilities and developmental delays.

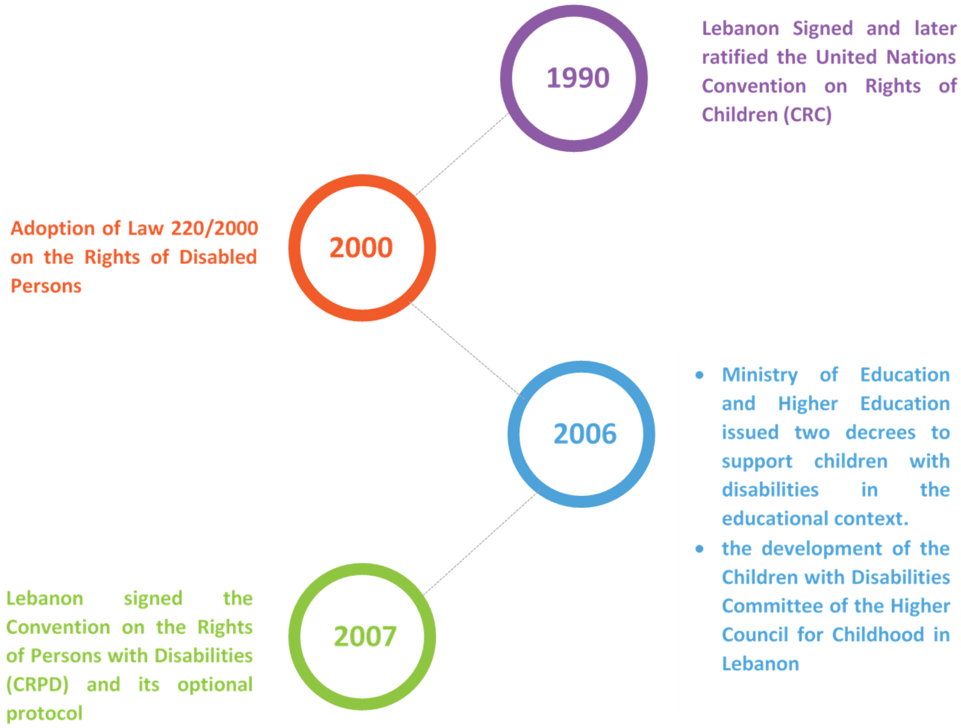

Figure 1 Sequence of Laws, Policies and Regulations

In 1990, Lebanon signed and later ratified on the United Nations Convention on Rights of Children (CRC), which is a human rights treaty that applies to all children including children with disabilities (OHCHR, 2014). The convention calls for the right of children to have a healthy, happy and safe life, to develop to the fullest; to be protected from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life (OHCHR, 1990). Article 2 and Article 23 of the CRC refer to the protection of rights of children specifically those with disability. Article 2 outlines that all children should be fairly treated; Article 23 highlights that children with any kind of disability have the right to special care and support, and effective access to healthcare, education and services so that they can live their lives to the fullest (OHCHR, 1990).

The CRC was followed by the adoption of Law 220 on the Rights of Disabled Persons in May 2000. The law focuses on all persons with disabilities (PWD) which include children with disability. The law integrates the assurance of a set of rights for PWD that include integrating citizens with disabilities into social and economic life, employment, transportation, housing quotas, and access to health and educational services (Lakkis, 2015). The law adopts the medical definition for PWD, "person whose capacity to perform one or more vital functions, independently secure his personal existential needs, participate in social activities on an equal basis with others, and live a personal and social life that is normal by existing social standards, is reduced or non-existent because of a partial or complete, permanent or temporary, bodily, sensory or intellectual functional loss or incapacity, that is the outcome of a congenital or acquired illness or from a pathological condition that has been prolonged beyond normal medical expectations" (UNESCO, 2013). Yet, 18 years after the adoption of the law 220/2000, the law is still not fully in effect.

Under the law 220/2000, the Lebanese disabled children are entitled to a disability card from the Ministry of Social Affairs. The disability card is provided upon the child's assessment in one of the eight access to rights centers in Lebanon. Persons who receive a disability card are legally entitled to a range of benefits, such as life insurance, tax benefits, and assistance paying for healthcare, educational, and rehabilitative services. Disabled children that meet the International Classification of Impairment, Disability and Handicap (ICIDH) are eligible to the disability card (Lakkis, 2015). It is noteworthy that the World Health Organization's (WHO) ICIDH was developed in 1980 and uses a medical, impairment-based approach for defining disability. Although in 2001 WHO changed the classification to the International Classification of Functioning, Disability and Health, Lebanon still uses the old classification of disability that concentrates mainly on the medical aspect of disabilities (Human Rights Watch, 2018). This results in the exclusion of many children who need the disability card but do not meet the eligibility criteria, which includes children under three years old.

In 2006, the Ministry of Education and Higher Education issued two decrees to support children with disabilities in the educational context. Decree No. 16417 determines the cases of exemption for persons with learning difficulties from the official intermediate school certificate examinations, and Decree No. 16614 determines the exemption of students with special needs from pursuing the traditional years of schooling at the general pre-university level (UNCRC, 2015).

In the same year, an administrative decision of the Minister of Social Affairs brought about the development of the Children with Disabilities Committee of the Higher Council for Childhood in Lebanon, which includes representatives from several ministries, civil society, NGOs, associations and experts. It has prepared a draft strategy for improving the situation of children with disabilities in Lebanon, but the strategy has not yet been approved by the Council of Ministers of Lebanon (The Higher Council for Childhood, 2015)

On June 2007, Lebanon signed the Convention on the Rights of Persons with Disabilities (CRPD) and its optional protocol (United Nations Treaties, 2008). Article 7 of the CRPD indicates the need to ensure children attain their full human rights, equality and freedom of expression as non-disabled children, ensure best interest of the child are considered in all situations (UN, 2006). Also, Article 25 of the CRPD clearly identifies the need to ensure early identification and intervention of disabilities among children, in addition to ensuring equal access to health insurance and access and availability of high-quality services (UN, 2006). However, 11 years since the Convention and Lebanon has not yet ratified the Convention or its Protocol (OHCHR, 2014).

In reference to the currently implemented hospital accreditation, the system has two standards concerning persons with disability, which include (1) the need to ensure accessibility of persons with disability to the health facility and buildings especially Emergency Rooms and (2) the need to have bathrooms specifically designed supportive of persons with disability.

To safeguard the services provided by organizations contracted with the MOPH, the disability unit at the MOPH conducts two inspections per year and as needed in contracted organizations that provide health services to people with disabilities. However other institutions not contracted with MOPH are not being inspected. Additionally, the Mother and Child Health Department at the MOPH regularly follows up on the daycare centers quality of care, this includes inclusive daycare centers. Currently, the department is working on classifying daycares into inclusive and non-inclusive daycares and making this information available to the public. The department also distributed to daycare centers a developmental checklist to measure the child's developmental milestones in nurseries; however, the checklist is still not widely adopted.

The Lebanese Pediatric Society has policies and guidelines for early identification intervention regarding children with disabilities and developmental delays. It has also established the first national registry for metabolic diseases. The Lebanese Psychiatric Society collaborated with the Ministry of Education and Higher Education (MEHE) to develop guidelines for the exemptions of children with learning difficulties from official exams.

In collaboration with UNICEF, the MEHE is working on the total integration of children with learning disabilities in 30 public schools, and visual, hearing, physical, and moderate intellectual disabilities in 6 public schools (Human Rights Watch, 2018). The project is presently being piloted in Lebanon where a mobile team of specialists consisting of psychomotor therapists, speech therapists and psychologists will be visiting schools once per week. Five of these schools are focused on the inclusion of children with physical disability whereas the remaining 25 are focused on children with developmental delays. Monitoring and evaluation of this project will allow the identification of the best strategies with the most effective outcomes to be generalized to all schools in Lebanon. Some private schools reported implementing inclusion of children suffering from learning difficulties and delays in regular classrooms.

Financing

At the level of financing, coverage for children with disabilities and developmental delays remains a challenge. As per law 220/2000, persons with disabilities can register for a disability card at MOSA and are entitled to healthcare services. However, up until now and after two Ministerial circulars, many governmental hospitals still do not cover hospitalization and outpatient medical services. This is mainly due to the utilization of the MOPH allocated funding at the beginning of each month thus hindering the coverage of many people including people with disabilities at the expense of MOPH (UNESCO, 2013). In addition, treatments for many genetic disorders and crucial therapies such as speech therapy, occupational therapy, psychomotor therapy, and applied behavioral analysis aren't covered by any financial party.

As per law 220, MEHE is responsible for financing specialized schools and education for children with disabilities (Law 220). However, it was reported that several cases of children attending MOSA-supported institutions were paying fees for admission, extra assistance, and transportation ranging from $70 to $300 a month (Human Right Watch, 2018).

MOSA has contracts with 103 segregated private institutions to refer children with disabilities. These institutions vary in terms of the number of children with certain disabilities the institution will accept, the type of services the institution offers, and how many residential or non-residential spots an institution can have. Although MOSA funds these institutions based on a daily rate of services provided, funding has not been changed since 2012. According to Human Rights Watch report published in 2018, MOSA is often late in paying fees for contracted institutions. As such, teachers are either not paid or institutions try to cover the bill until MOSA submits payment. Several institutions reported that they charge families at least a portion of the fee to attend the center (Human Rights Watch, 2018).

On the other hand, private schools that support the inclusion of children with disabilities and developmental delays are scarce and if found the tuition is costly, and they do not accept all cases of children with disabilities and developmental delays. Some NGOs receive funds to cover children's education in schools. However, these funds are often for a short period. Additionally, the cost of inclusive nurseries is very high and not affordable for many families. Another significant barrier faced is the high cost of drugs needed to treat children with disabilities and developmental delays. Also, most diagnostic tests required for identification of children with disability and developmental delays as well as therapy sessions are not covered by any financial party. Many insurance companies do not accept enrolling children with developmental delays or disability since they consider their case to be pre-existing.

As for services specific to Syrian refugees, UNHCR covers 75% of services that cost more than 100$ part of the cost for including life-saving cases, care for newborns, delivery and emergency cases that might lead to permanent disability, but does not cover conditions that require multiple interventions and follow up (UNHCR, 2017). Since there is limited availability of funds, priorities are pooled toward lifesaving treatments and surgeries. For family members and children with disabilities, UNHCR and partners pay 85% of the cost of laboratory and diagnostic tests for patients. The remaining 15% of the cost should be paid by the patient. UNICEF cover the specialized education and rehabilitation services for 400 Syrian children with disabilities across the country. For Palestinian refugees, UNRWA covers 90% of secondary care and 60% of tertiary care for all Palestinian refugees including children with disabilities and developmental delays.

Delivery

At the level of early identification and intervention of children with disabilities and developmental delays, common challenges exist across different sectors involved in the delivery of services. These challenges include; limited specialized centers in rural areas, limited training and awareness of staff in early identification and intervention, low level of awareness among caregivers of children with disabilities and developmental delays, limited access to high quality services and weak monitoring and evaluation of services, poor financial coverage of services, absence of crucial medications for management of certain disorders and genetic diseases, expensive medications for disorders, poorly equipped infrastructure of facilities for disabled children, and limited availability of contextualized and validated tools. In fact, some of those challenges pose major child rights concerns (Human Rights Watch, 2018).

Services provided on **early identification** of children with disability and developmental delays vary across professional associations, primary healthcare centers (PHCs), schools, and NGOs.

The ***Lebanese Psychiatric Society*** promote awareness about the mental health of children through social media, TV, websites, and events.

At the ***hospital level***, early identification of disabilities and developmental delays is guided in some hospitals by tools, that include but not limited to ADOS-2, CARS-2 GARS-3, BAILEY, VB-MAPP, and speech and language assessments. The utilization of tools remains dependent on personal physician practice or healthcare facility practice, therefore this practice varies across different hospitals. Currently early identification of disabilities and developmental delays at the hospital level is dependent on the expertise of the physician rather than on written policies and guidelines. A neonatal continuity clinic was established in a private hospital to screen for neonates at risk of developing developmental delay and disabilities, free of charge. It was evident that many hospitals lack policies regarding early identification of children with disabilities and developmental delays. The main challenge to early identification was a shortage of pediatric sub-specialties such as neuro-pediatricians and pediatric otolaryngologists. Furthermore, some hospitals reported lack of equipment required for identification of certain disabilities such as audiograms and tympanograms. At the ***PHC level***, identification of disabilities and developmental delays are done prenatal and postnatal. Prenatally, pregnant mothers are screened for children disabilities by an obstetrics and gynecologist (OBGYN) physician through an ultrasound. The physician may request additional blood tests for confirmation or rule out of disabilities. Postnatal screening of disabilities and developmental delays of children is mainly done by a pediatrician who refers to a specialist internally at the PHC or externally, to another PHC. One PHC reported the use of IQ testing and, the Test of Variables of Attention (T.O.V.A.) for early identification.

Common practices for early identification were identified among ***pediatricians and obstetrics and gynecologist*** (OBGYN) in their private clinics. At the antenatal level, OBGYN physicians perform blood tests, prescribe folic acids, review family and medical history, perform several ultrasound imaging at different stages of pregnancy, and measure the nuchal translucency to prevent and identify disabilities. However, some women do not attend the full recommended antenatal visits. Additional screening tests conducted by physicians for the early identification of disabilities include amniocentesis, Pregnancy-Associated Plasma Protein-A (PAPP-A) to screen for down syndrome and the triple test that includes the measurement of serum levels of Alpha-Feto-Protein, estriol, and beta-hCG to measure risk of chromosomal abnormalities. At the postnatal level, physicians use the Denver scale to check the developmental milestone of the child. Some pediatricians reported the use of M-Chat to screen for autism. Moreover, a team of pediatricians translated the Ages and Stages questionnaire tool to Arabic for utilization in Lebanon. This tool supports parents and caregivers to screen and follow up on the development of their children aged one month to five and half years old. Currently, the tool is being piloted across different regions in Lebanon. Another tool was developed in

Arabic and for the utilization of parents and caregivers to detect language delays among children aged zero to three years old. It is critical to denote that currently, neonatal hearing and vision tests are optional and as per the parent's request. This, in fact, may result in late detection of hearing and vision problems among newborns.

Few ***private schools*** have a variety of specialties to support identification of children with disabilities and developmental delays which include psychology, speech therapists, and special education. In some schools, screening of children with developmental delays and disabilities is conducted in kindergarten with clear referral channels from the kindergarten teacher to the social assistance or psychologist or specialize center as needed.

At the level of **non-governmental organizations (NGOs)**, some NGOs use the ages and stages questionnaire (ASQ) for children ages zero to six years old. However, most of the screening tools used are not standardized and contextualized to the Lebanese population.

UNRWA PHCs have a preconception screening unit where lab tests are performed for women that wish to become pregnant, it also provides them with folic acid to prevent any neurological malformation. During pregnancy, OBGYN physicians perform ultrasound for the fetus.

Services provided on **intervention** for children with disabilities and developmental delays vary across professional associations, hospitals, private clinics, daycares, schools, and NGOs.

The ***Lebanese Pediatric Society*** in collaboration with MOPH provided otoacoustic machines (OAE) for hearing screening for children aged 0 to 3 years old to four hospitals located in different regions in Lebanon.

At the ***hospital level***, currently intervention of disabilities and developmental delays at the hospital level is dependent on the expertise of the physician rather than on written policies and guidelines. At the ***level of PHCs*****,** one PHC provides comprehensive therapies when a child is identified with disabilities and developmental delays. Some PHCs reported having family support services for caregivers of children with disabilities and developmental delays which include family counseling, psychosocial support, food support, and social assistance. One PHC provides free therapy sessions (speech, occupational, psychomotor) for children aged six to 12 years old and suffering from developmental delays and disabilities.

Practices in ***private schools*** vary considerably. Currently, some schools do not have any inclusion practices, some have partial (one on one teaching on specific subjects) or full inclusion, and other schools developed specialized centers for children who have developmental delays, which include attention deficit hyperactivity disorder and attention deficit disorder. Few schools have the needed infrastructures to support children with physical disabilities, whereby the schools are equipped with ramps and elevators. As for family support services, some schools reported having open communication channels with the families and conduct regular meetings with the families to explain the case of their child and follow up with them. As for ***public schools***, according to a 2009 survey conducted by the Lebanese Physical Handicap Union, only five of 997 public schools are accessible for children with physical disabilities (Human right watch, 2018). Therefore, more than 50% of cardholders do not attend any schools (UNESCO, 2013). In public schools, there are no identified strategies and policies for early identification and intervention for children with disabilities and developmental delays. Some public schools reported receiving teacher trainings from NGOs, for a limited time and with no follow-up. One public school reported that with the help of an NGO, two separate classrooms that deliver specific subjects where areas of weakness are highlighted among children has been established. Another public school is currently being piloted for inclusion by MEHE. A special educator is available from grade one till grade three and is responsible for developing detailed checklist for screening of children, training teachers on the use of the checklist, conducting meetings with parents and children, and preparing a detailed assessment of the identified cases. Identified cases will be later followed up by a multidisciplinary team for diagnosis. Even though the law states that children with disabilities can attend specialized and segregated institutions funded by MOSA, the quality of educational resources at these institutions is poor. Furthermore, most of the specialized institutions are not even classified as schools by the Ministry of Education and Higher Education (MEHE) (Human Rights Watch, 2018). Regarding technical education and vocational training, most governmental vocational institutions are not accessible to students with disabilities (UNESCO, 2013).

For ***daycare centers*** in process of implementing inclusion of children with disabilities and developmental delays, common reported practices for early identification children with disabilities and developmental delays included; observation of children's interaction, using a checklist to measure the motor, emotional, and sensory skills, and parent-teacher meeting on a regular basis to discuss the child's case, and referral to specialists when needed. Some daycares have begun implementing the developmental checklist for ages 0 to 6 years of age to screen for all developmental delays. The checklist can alert the staff if there are any developmental red flags during the assessment of the child. It is critical to denote that those practices are not yet standardized across all daycare centers.

At the level of ***non-governmental organizations (NGOs)***, several activities are currently implemented for the early intervention of children with disabilities and developmental delays in Lebanon. Some NGOs are working on the integration of autistic children in schools and the community and have a vocational center for autistic children. Yet the NGOs face major challenges that may hinder providing services to children suspected or identified to have disabilities or developmental delays. One of the major challenges are the caregiver's denial to the child case and the financial constraints which hinder the caregivers from seeking additional tests to identify their child with disability or developmental delay. In addition, many NGOs provide free therapies for children, however these NGOs cannot accommodate all children and cover the treatments over a long period, and this results in long waiting lists for accept new cases.

UNHCR provides several healthcare services for registered Syrian refugees including life-saving emergencies, deliveries, laboratory and diagnostic testing, and care for newborns. Syrian refugees can also benefit from the services provided in PHCs, yet the availability of services specific for early identification and interventions remains dependent on the PHC itself. Conditions requiring long follow up and multiple interventions are not covered through UNHCR. UNHCR partners provide various community support services for people with disabilities including children (UNHCR, 2017).

UNRWA has a disability program operating under the Relief and Social services unit where artificial limbs, hearing aids, assistive devices, artificial eyes, and mobility devices are provided to children with disabilities. The CBR program has been operating since 1994 and target children aged six to 18 years old who have disabilities. UNRWA also has a home-rehabilitation service which improves the life skills of Palestinian refugees in Lebanon and supports caregivers of disabled persons (including children).

In terms of **referral of identified children with disabilities and developmental delays**, there are no standardized referral channels. Referral is often done haphazardly based on personal networks, proximity to the family's location, affordability of services, and to MOSA centers. In fact, there is no national databased of specialized and credible centers and skilled specialists in Lebanon. Therefore, very few hospitals have a pre-identified standardized referral list for children to support a quick and efficient referral. Some daycares refer children suspected to have a developmental delay to pediatricians.

Availability of **training** for healthcare providers and staff on early identification and intervention in children with disabilities and developmental delays is scarce. Despite the availability of training in some institutions and ministries, the quality and impact of the trainings is not regularly evaluated. Training provided by stakeholders and institutions include:

- MEHE is training teachers in 30 public school on total inclusion of children with disabilities and developmental delays.
- The mental health program at MOPH is working on early interventions, and they are providing trainings for specialists at the level of the PHCs.
- Lebanese Pediatric Society holds multiple CMEs across different regions in Lebanon about topics related to developmental delays and disabilities. The Society has 12 clubs chaired by different pediatric sub-specialties which advise on projects and CMEs.
- The Syndicate of Nurseries conducts around 12-18 workshops and meetings per year where topics related to child's developmental milestones are discussed.
- Order of Nurses has a neonatal development network where nurses can learn about developmental delays during one session per year.
- UNRWA trains school Counselors and relief social workers on early identification and intervention, however, the training is not continuous. Currently, a new training package is being developed to train frontline workers.
- Some private hospitals mentioned that they have departmental grand rounds in the pediatric department about early identification and interventions of children with developmental delays. One private hospital stated that they have a shadow-training program where they train shadow teachers for schools. They also have two therapists trained in behavioral analysis and can provide ABA training for other therapists.
- Some daycares conduct training for their staff and parents' developmental milestones of children on a yearly basis
- Some NGOs deliver trainings about special needs education for teachers in public schools.
- Some private schools conduct in-house trainings for their staff about early identification and intervention among children with disabilities and developmental delays

On the other hand, the Lebanese Psychiatry Society, Lebanese Order of Nurses, Lebanese order of Physiotherapy, Syndicate of Social Workers, Lebanese Society of OBGYN, Order of Midwives, and UNHCR do not have systematic continuing education provided to the healthcare workforce on early identification and intervention of children with disabilities and developmental delays. Furthermore, there is a shortage of trained staff on early identification and intervention in PHCs, hospitals, daycare centers, schools, and NGOs. In fact, early identification in hospitals, clinics, and PHCs was mainly dependent on physicians' experience and expertise and was restricted in some schools and daycares to the teacher's observation. In fact, training on early identification and intervention of midwives, social workers, and nurses remains dependent on the healthcare worker's education at universities, their area of work, and their personal effort to attend trainings.

Sociocultural

At the sociocultural level, there are several challenges to identifying and intervening of children with disability and developmental delays. At the community and family level, a case of child with disability or developmental delay in a family may lead to fear of social stigma, social isolation and shame (Azar & Badr, 2006). Children with disability or developmental delays are often labeled and discriminated against causing children to be singled out and ridiculed. This culture is in concurrence with low level of awareness and denial may cause parents to identify and/or intervene of their children with disabilities and developmental delays at a late stage, in some cases not to intervene at all or discontinue treatment. In addition, some parents that do not have children with disabilities or developmental delays refuse to enroll their children in the same nurseries and schools that enroll children with disabilities and developmental delays. Moreover, peer-to-peer support for parents is limited in Lebanon. At the healthcare workers level, limited knowledge, awareness and training, and negative attitude are present towards children with developmental delays and disabilities. Furthermore, poor communication between physicians and families about the child's case may lead to confusion and misleading information regarding the child's diagnosis and treatment plan. At the organizational level, there is discriminatory and negative attitudes toward children with disabilities with developmental delays. Although it is stipulated by law 220 that schools are prohibited from discriminating against children with disabilities, many schools still abstain from admitting children with disabilities and demand additional fees for admitting them (Human rights watch, 2018). Educational programs promoting a positive image about children with disabilities in schools are minimal (UNESCO, 2013).

Elements of a policy approach to address the problem

The following three elements form part of a comprehensive approach to tackle the issue of early identification and intervention of children with disabilities and developmental delays, and therefore can be adopted either independently or could complement one another.

Element 1› Develop and implement policies, tools and strategies for early identification and intervention of children with disabilities and developmental delays to be used in health, education, social protection and other sectors

2.1 Development of national policies targeting children with disabilities and developmental delays

2.2 Use of tools and practices for early Identification of children with disabilities and developmental delays

2.3 Implementation of practices on identified children with disabilities and developmental delays

Element 2› Enhance the knowledge and education of caregivers, healthcare providers, and educators to detect, refer or manage children with disabilities and developmental delays.

Element 3› Secure financial coverage for early identification and intervention services

Elements

Policy Elements and Implementation Considerations

Element 1

Develop and implement policies, tools and strategies for early identification and intervention of children with disabilities and developmental delays to be used in health, education, social protection and other sectors

2.1 Development of national policies targeting children with disabilities and developmental delays
2.2 Use of tools and practices for early Identification of children with disabilities and developmental delays
2.3 Implementation of practices on identified children with disabilities and developmental delays

Several countries have programs and services for the identification of children with disabilities and developmental delays. In **Manitoba**, children disability services provide early intervention services, including child development for preschoolers; occupational, physical, and speech-language therapy; and applied behavior analysis for preschoolers with autism spectrum disorders. In **Saskatchewan**, Ministry of Education supports 14 Early Childhood Intervention Programs (ECIP) which work in collaboration with regional health authorities, school divisions, and community partners to provide services related to the medical, developmental, social and educational needs of children and their families. In **British Colombia**, universal screening is offered to all babies born in British Colombia for early diagnosis of 22 treatable disorders. In **Yukon**, Stepping into Kindergarten is a local program that allows schools to promptly identify students that require additional support. An early literacy intervention for 6- and 7-year-olds facilitates identification of any learning disabilities (Government of Canada, 2014). In the **United Kingdom**, a full national screening program is implemented to ensure that children and families requiring early childhood intervention services are identified early and referred on quickly for further investigation (European Agency for Development in Special Needs Education, 2010). In **Malta**, the Child Development and Assessment Unit offers multidisciplinary services, medical assessment, and therapy to all children referred from birth to 6 years of age (European Agency for Development in Special Needs Education, 2010). In **Iceland,** a national screening programme is conducted for all children at 2.5 years and at 4 years old at the local health

S U M M A R Y

Element 1
Develop and implement policies, tools and strategies for early identification and intervention of children with disabilities and developmental delays to be used in health, education, social protection and other sectors
Element 2
Enhance the knowledge and education of caregivers, healthcare providers, and educators to detect, refer or manage children with disabilities and developmental delays.
Element 3
Securing financial coverage for early identification and intervention services

care center. Hospitals, healthcare centers, and preschools refer suspected children with developmental disorders to the State Diagnostic centers (European Agency for Development in Special Needs Education, 2010). In **Estonia**, an Educational Counselling system was issued aiming to ensure early childhood intervention in all regions of Estonia (European Agency for Development in Special Needs Education, 2010). In **Germany**, the 'National Centre for Early Aid' detects children at risk, supports families, strengthens networking between different institutions in early years, and supports research in early childhood intervention (European Agency for Development in Special Needs Education, 2010). In **Malaysia**, the Ministry of Health delivers many services for children with disabilities including: provision of and promoting early detection of disabilities; provision of initial assessment of children with disabilities; provision of follow-up treatment of children with disabilities; provision of primary health care, management and rehabilitation services including speech therapy, hearing therapy, physiotherapy and activities of daily living in hospitals and health clinics; and formulation of healthcare policies and plans for the detection, treatment and rehabilitation of children with disabilities (UNICEF, 2014)

Addressing disabilities and developmental delays through policy changes have proved to be an effective strategy. As an example, policy changes that modified state agency practices through mandating screening by trained experienced professionals resulted in a 5-fold increase in the number of children eligible for early intensive behavioral intervention without waiting for a definitive diagnosis of autism spectrum disorder (Rotholz et al, 2017).

Practice improvement strategies that include the use of screening tools have revealed promising results regarding the early identification of disabilities and developmental delays. Specifically, regarding the early identification of autism, the combination of M-CHAT tool with either phone calls (Kleinman et al, 2008) or joint attention (Nyrgen et al, 2012) resulted in the early identification of the disease. Another autism screening tool, the Developmental Checklist-Early Screen (DBC-ES)*, was found to have high sensitivity and good inter-rater agreement and internal consistency (Gray et al, 2008). When attempting to distinguish autism from other mimicker conditions, the Behavior Assessment System for Children, Second Edition, Parent Rating Scale-Preschool (BASC-2 PRS-P)* proved to have adequate sensitivity and specificity for distinguishing youth with autism spectrum disorder from those without any diagnoses, but not for differentiating between youth with autism spectrum from those with other diagnoses (Bradstreet et al, 2017). The positive role of child care workers in the early detection of autism was also realized through the use of the Checklist for Early Signs of Developmental Disorders (CESDD)*, which was found to have a discriminant power comparable to that of parent questionnaires

(Dereu et al, 2012). Another tool, the Autism Detection in Early Childhood (ADEC)* had good sensitivity but poorer specificity for the clinical diagnosis of autism spectrum disorder (Hedley et al, 2015). The same test was able to reliably discriminate different diagnostic groups, indicating that the ADEC* has the potential to be established as a suitable and efficient screening tool for infants with autism disorder (Nah et al, 2014).

Tools used for the early identification of other developmental delays included the Alberta Infant Motor Scale (AIMS)*, which was able to predict developmental delay in high-risk infants (Wang et al, 2016). In addition, a validated structured interview performed by nurses increased the rate of early detection of parenting and child developmental problems as compared to regular visits without such an instrument (Staal et al, 2016). The use of Ages and Stages Questionnaire for screening of children with developmental delays by caregivers of children increased referral rates by 224% to developmental services (Hix-Small, Marks, Squires, & Nickel, 2007). Evidence shows that the ASQ is an accurate, cost-effective, culturally sensitive (Charafeddine et al., 2013) parent-friendly tool for screening and monitoring of preschool children. Furthermore, ASQ has been successfully used for follow-up and assessment of premature and at-risk infants and in follow-up of infants born after assisted reproductive technologies. More importantly, ASQ can be used by a variety of users including pediatricians, professionals, and parents to screen for delays among children (T. Singh & Harding, 2015). Denver-II was the most feasible and valid multi-dimensional test and the ASQ-3 generally performed poorly in under 31 months (Rubio-Codina, Araujo, Attanasio, Muñoz, & Grantham-McGregor, 2016). Evidence shows that the use of Denver II screening test jointly with neurological examination at 6 months produces similar results to implementing the neurological examination at 12 months (Eratay, Bayoglu, & Anlar, 2015).

Several practice improvement strategies achieved their aim in regard to the early identification of disabilities and developmental delays. Routine screening and community outreach were found to increase screening and referral rates for autism spectrum disorders (Daniels et al, 2014). The introduction of practice parameters along with parallel information strategies resulted in a decrease of 1.5 years in the mean age at diagnosis of autism spectrum disorders (Holzer et al, 2006). Use of specialized programs such as the integrated early detection program* for autism spectrum disorder resulted in 21 months earlier diagnosis (Oosterling et al, 2010).

Other strategies targeting other developmental disabilities and delays included the use of the age of acquisition of motor skills as a screening tool for developmental delay (Arabameri & Sotoodeh, 2015). Additionally, patients with reading difficulties benefited from multi-point screening resulting in the early identification of students who are most likely in need of extra resources (Polusen et al, 2017). Moreover, measures of letter naming fluency, phonological awareness, rapid naming, or non-word repetition accurately identified good and poor readers at the end of first grade (Catts et al, 2015). On the other hand, early detection of hearing difficulties among children 0-3 years old was achieved through the introduction of Universal Newborn Hearing Screening (Halpin et al, 2010). As for early detection of visual problems, one study revealed that screening of vision* in preschool children less than 3 years of age with developmental disabilities was found to have a sensitivity of around 95%, despite limited specificity (Struble et al, 2016).

Intervening early on children with disabilities and developmental delays was associated with a multitude of benefits. Specifically, early interventions for infants with or at risk for autism spectrum disorder resulted in increases in IQ and communication scores (Landa & Kalb, 2012) and gains in cognitive skills and adaptive behavior (Bradshaw et al, 2015). On the other hand, delivery of early interventions for children with physical disabilities which include multidisciplinary therapy and family support, parent education, and medical care was able to enhance development, develop speech, improve school related-outcomes, facilitate community integration, and increase parents' satisfaction (Ziviani et al, 2010). For toddlers with cleft palate, the implementation of early intervention on speech and lexical measures resulted in a significantly greater percentage of glides as compared to those who did not receive such intervention (Hardin-Jones & Chapman, 2008). Implementation of a preschool-based multidisciplinary intervention program for boys with low socioeconomic status identified as at risk for or with developmental delays resulted in improvement in most performance skills and participation in preschool activities (Golos et al, 2011). Benefits of early interventions also extended to reach families of those who have disabilities as most parents felt competent in caring for their children, advocating for services, and gaining access to formal and informal supports (Bailey et al, 2005). Regarding the characteristics of interventions, one systematic review summed up that the most efficacious interventions for those with developmental disorders combined four specific intervention procedures: parent involvement, individualization to each infant's developmental profile, focus on a broad rather than a narrow range of learning targets, and temporal characteristics by beginning as early as the risk is detected and providing greater intensity and duration of the intervention (Wallace & Rogers, 2011).

Table 1 **Key findings from systematic reviews and single studies**

Category of finding	Element 1
Benefits	**2.1 Policy changes** 1 study revealed that policy changes that modified state agency practices through mandating screening by trained experienced professionals resulted in a 5-fold increase in the number of children eligible for early intensive behavioral intervention without waiting for a definitive diagnosis of autism spectrum disorder (Rotholz et al, 2017). **2.2 Tool and Practices targeting early identification** ***Use of tools for the detection of developmental delays*** 1 single study revealed that the Alberta Infant Motor Scale (AIMS)* scores were significantly higher in the intervention group as compared to the control group, suggesting that AIMS* can predict developmental delay in high-risk infants (Wang et al, 2016). 1 single study revealed that a validated structured interview performed by nurses improved the early detection of parenting and child developmental problems in young children as compared to regular visits without such an instrument (Staal et al, 2016). 1 single study found that the use of Ages and Stages Questionnaire (ASQ) for screening of children with developmental delays by caregivers of children increased referral rates by 224% to developmental services (Hix-Small et al., 2007). 1 single study and 1 review showed that ASQ is an accurate, cost-effective, culturally sensitive (Charafeddine et al., 2013), parent-friendly tool for screening and monitoring of children with developmental delays (T. Singh & Harding, 2015). 1 review mentioned that ASQ has been successfully used for follow-up and assessment of premature and at-risk infants and in follow-up of infants born after assisted reproductive technologies. More importantly, ASQ can be used by a variety of users including pediatricians, professionals, and parents to screen for delays among children (T. Singh & Harding, 2015). 1 single study concluded that Denver-II was the most feasible and valid multi-dimensional test (Rubio-Codina et al., 2016).

Category of finding	Element 1
	1 single study showed that the use of Denver II screening test used jointly with neurological examination at 6 months results in similar results to the neurological examination at 12 months (Eratay et al., 2015) ***Use of tools for the detection of autism*** 1 single study revealed that the positive predictive value for the combination of M-CHAT* and joint attention observation was 90%, suggesting a promising role for the combination of instruments in the early detection of autism (Nyrgen et al, 2012). 1 single study concluded that follow up through telephone calls improved the positive predictive value of the M-CHAT* for the diagnosis of autism at 16-30 months and for predicting the diagnosis at age 4, suggesting that telephone follow-up is a critical step in eliminating false positives and improving utility of the tool (Kleinman et al, 2008). 1 single study demonstrated that using the Developmental Checklist-Early Screen (DBC-ES)* for screening for autism in young children with developmental delay revealed high sensitivity, good inter-rater agreement and internal consistency, along with significant correlations with a clinician-completed measure of autism symptomatology (Gray et al, 2008). 1 single study revealed that the Behavior Assessment System for Children, Second Edition, Parent Rating Scale-Preschool (BASC-2 PRS-P)* had adequate sensitivity and specificity when distinguishing youth with autism spectrum disorder from those without any diagnoses (Bradstreet et al, 2017). 1 single study concluded that the discriminant power of the Checklist for Early Signs of Developmental Disorders (CESDD)* performed by child-care workers was as good as that of parent questionnaires, suggesting a positive role for inclusion of child care workers in the early detection of autism (Dereu et al, 2012). 1 single study showed that Autism Detection in Early Childhood (ADEC)* had good sensitivity (0.93-0.94) but poorer specificity (0.62-0.64) for the clinical diagnosis of autism spectrum disorder. Internal consistency was acceptable with α =0 .80, and inter-rater reliability was high with a value of 0.95; thus supporting the use of the ADEC* as

Category of finding	Element 1
	a screening tool for autism spectrum disorder (Hedley et al, 2015). 1 single study demonstrated that adequate inter-rater reliability and test-retest reliability of the ADEC* scores was able to reliably discriminated different diagnostic groups, indicating that the ADEC* has the potential to be established as a suitable and efficient screening tool for infants with autism disorder (Nah et al, 2014). ***Use of practice improvement strategies for early identification*** 1 systematic review concluded that practice improvement through the implementation of routine screening and community outreach resulted in an increase in screening and referral rates for autism spectrum disorders (Daniels et al, 2014). 1 single study revealed that the introduction of practice parameters along with parallel information strategies resulted in a significant, though a transient decrease of 1.5 years in the mean age at diagnosis of autism spectrum disorders (Holzer et al, 2006). 1 single study demonstrated that the use of the age of acquisition of motor skills as a screening tool for developmental delay may serve as simple, low cost, and easily available intervention as participants with developmental delay had significantly delayed the age of acquisition of all assessed motor skills (Arabameri & Sotoodeh, 2015). 1 single study revealed that screening for reading difficulties using measures of letter naming fluency, phonological awareness, rapid naming, or non-word repetition accurately identified good and poor readers at the end of first grade (Catts et al, 2015). 1 single study demonstrated that multi-point screening resulted in a gradually increased sensitivity of reading difficulties and thus early identification of students who are most likely in need of extra resources (Polusen et al, 2017). 1 single study concluded that the introduction of Universal Newborn Hearing Screening among children 0-3 years led to increases in caseload size, the percentage of caseload identified by screening, the percentage of children fit with hearing aids by 6 months of age, and percentage of children with the profound hearing loss with cochlear implants. There

Category of finding	Element 1
	were also decreases in diagnosis age, the age of program enrolment, and age of hearing aid fit (Halpin et al, 2010). 1 single study revealed that screening of vision* in preschool children less than 3 years of age with developmental disabilities was found to have a sensitivity of 95.3%, specificity of 57.25%, positive predictive value of 59.1%, negative predictive value of 94.9%, and negative likelihood ratio of 0.082 for the detection of visual problems (Struble et al, 2016). 1 single study was able to prove that the use of the integrated early detection program* for autism spectrum disorder resulted in 21 months earlier diagnosis (Oosterling et al, 2010). **2.3 Practices aiming at early intervention** including multidisciplinary therapy, parent involvement, and individualization to each infant's developmental profile 1 systematic review and 1 single study revealed that early interventions for infants with or at risk for autism spectrum disorder resulted in increases in IQ and communication scores (Landa & Kalb, 2012) and gains in cognitive skills and adaptive behavior (Bradshaw et al, 2015). 1 systematic review demonstrated that the delivery of early interventions for children with physical disabilities which include multidisciplinary therapy and family support, parent education, and medical care was found to enhance developmental, develop speech, improve school related-outcomes, facilitate community integration, and increase parents' satisfaction (Ziviani et al, 2010). 1 single study demonstrated that the implementation of early intervention on speech and lexical measures for toddlers with cleft palate resulted in a significantly greater percentage of glides as compared to those who did not receive such intervention (Hardin-Jones & Chapman, 2008). 1 single study revealed that the implementation of a preschool-based multidisciplinary intervention program for boys with low socioeconomic status identified as at risk for or with developmental delays resulted in improvement in most performance skills and participation in preschool activities (Golos et al, 2011). 1 single study concluded that the assessment of early intervention outcomes for families of children who have

Category of finding	Element 1
	disabilities revealed that most parents felt competent in caring for their children, advocating for services, and gaining access to formal and informal supports (Bailey et al, 2005). 1 systematic review summed up that the most efficacious interventions for those with developmental disorders combined four specific intervention procedures: parent involvement, individualization to each infant's developmental profile, focus on a broad rather than a narrow range of learning targets, and temporal characteristics by beginning as early as the risk is detected and providing greater intensity and duration of the intervention (Wallace & Rogers, 2011).
Potential harms	1 study found that ASQ does not adequately identify developmental delays in children at 12 months and psychomotor delays in children at 24 months (Simard, Luu, & Gosselin, 2012) 1 single study concluded that the ASQ-3 generally performed poorly in under 31 months (Rubio-Codina et al., 2016).
Cost and/ or cost effectiveness in relation to the status quo	2 single studies found that ASQ is cost-effective (Flamant et al., 2011; A. Singh, Yeh, & Blanchard, 2017)
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the approach element were pursued)	2 systematic reviews revealed that the association between early intervention for preterm children or those born with low birth weight yielded a significant but small effect size (Park et al, 2014); however, although a significant increase in mental and physical scores for preterm children was achieved, improvement was not sustained at 3 years of age (Vanderneen et al, 2009). 1 systematic review and 1 single study demonstrated that early interventions for infants with or at risk for autism spectrum disorder resulted in no significant impact on developmental outcomes (Bradshaw et al, 2015). Impact of early intervention on overall autism severity was either not realized (Landa & Kalb, 2012) or not significant (Bradshaw et al, 2015). 1 single study revealed that screening of 18-month-old children using the Checklist for Autism in Toddlers (CHAT)* did not result in an increase in the number of children receiving an autism spectrum disorder diagnosis and

Category of finding	Element 1
	treatment before the age of 3 years (Hoglund Carlsson et al, 2010). 1 single study revealed that BASC-2 PRS-P* did not have adequate sensitivity and specificity for distinguishing youth between youth with autism spectrum from those with other diagnoses (Bradstreet et al, 2017). 1 single study showed that despite having good sensitivity, the ADEC* had poorer specificity (0.62-0.64) for the clinical diagnosis of autism spectrum disorder (Hedley et al, 2015). 1 literature review of 6 studies concluded that early interventions for graduates of neonatal intensive care units demonstrated conflicting results in regard to their impact on cognition, behavior, and motor development (Garcia & Gephart, 2013). 1 single study found that ASQ has limited capacity in identifying milder delays than severe developmental delays (Lindsay, Healy, Colditz, & Lingwood, 2008)

* Description of tools and programs can be found in Annex 1

Element 2

Enhance the knowledge and education of caregivers, healthcare providers, and educators to detect, refer or manage children with disabilities and developmental delays.

Interventions targeting awareness and community involvement have demonstrated significant impact on several areas related to early identification and intervention of disabilities and developmental delays. Specifically, awareness targeting parents, clinicians, and child-care professionals were associated with positive changes in knowledge of autism-related topics (Daniels et al, 2014). At the academic level, academic detailing led to increased pediatricians willingness to implement screening for developmental delays in their practices and an increase in the state's overall rate of screening (Daniels et al, 2014; Honigfeld, Chandhok, & Spiegelman, 2012); whereas implementing a national training for developmental delays detection in Turkey resulted in an increase in the median knowledge test scores of primary health care providers (Ertem et al, 2009).

The role of parents cannot be underestimated in both the recognition and management of children with disabilities and developmental delays. In one study addressing early identification, parent language reports were as accurate as a formal language assessment regarding the prediction of language delay at the age of 3 years (Sachse & Von Suchodoletz, 2008). Home-based or parent-delivered intervention demonstrated promising results in many aspects. Parent-delivered early intensive behavioral intervention was more effective than university-supervised interventions in terms of behavioral outcomes at 2 years follow up (Kovshoff, Hastings, & Remington, 2011). Moreover, training parents to deliver interventions for young children with autism spectrum disorder resulted in improved child cognition (Kasari et al, 2014b; Rickards et al, 2007), improvement in areas of adaptive functioning, social, and motor skills (Shin & Duc, 2017), enhanced child communication skills (Coolican, Smith, & Bryson, 2010; Shin & Duc, 2017), increased maternal knowledge of autism (McConachie & Diggle, 2007), enhanced maternal communication style (McConachie & Diggle, 2007) and parent-child interaction (McConachie & Diggle, 2007; Oono, Honey, & McConachi, 2013), reduced maternal depression (McConachie & Diggle, 2007), improved parental responsiveness (Kasari et al, 2014b), and increased children's use of eye contact, directed positive affect, verbal initiations, parents' positive affect, and synchronous engagement (Vernon et al, 2012). Delivery of specialized programs by parents such as parent-focused early intervention (PFEI) program* for children with delayed language development led to a significant increase in communicative interaction among parents and children along with an increase in children's expressive vocabulary size and language skills (Ciccone, Hennessey, & Stokes, 2012).

Peers were also found to play a significant role in nurturing the development of children with disabilities and developmental delays. In one study, implementation of Stay, Play, Talk peers-mediated intervention* on young preschoolers with autism resulted in significant increases in the frequency of responses and social reciprocations (Barber et al, 2016).

As for the role of daycares, placement of children with autism spectrum disorder in a special nursery offered benefits particularly in the area of adaptive behavioral functioning (Reed, Osborne, & Corness, 2010).

Table 2 **Key findings** from systematic reviews and single studies

Category of finding	Element 2
Benefits	**Awareness** 1 systematic review revealed that awareness targeting parents, clinicians, and child-care professionals were associated with positive changes in knowledge of autism-related topics (Daniels et al, 2014).

Category of finding	Element 2
	1 systematic review and 1 single study concluded that academic detailing led to increased pediatricians' willingness to implement screening for developmental delays in their practices and an increase in the state's overall rate of screening (Daniels et al, 2014; Honigfeld, Chandhok, & Spiegelman, 2012). 1 single study concluded that implementing a national training for developmental delays detection in Turkey resulted in an increase in the median knowledge test scores of primary health providers as compared to pre-training (Ertem et al, 2009). **Parents' Involvement** 1 single study declared that results negated any difference between the accuracy of the parent report and language assessment concerning the prediction of language delay at the age of 3 years, rendering parent language report a valid and efficient tool for assessing language abilities and judging expressive language delay in 2-year-old toddlers (Sachse & Von Suchodoletz, 2008). 1 single study concluded that parent-delivered early intensive behavioral intervention was more effective than university-supervised interventions in terms of behavioral outcomes at 2 years follow up (Kovshoff, Hastings, & Remington, 2011). 1 single study asserted that individualized caregiver-mediated intervention, as compared to group caregiver education, resulted in significantly greater improvement in joint engagement and initiating joint attention (Kasari et al, 2014a). 2 systematic reviews and 2 single studies concluded that training parents to deliver interventions for young children with autism spectrum disorder resulted in improved child cognition (Kasari et al, 2014b), increased maternal knowledge of autism (McConachie & Diggle, 2007), enhanced maternal communication style (McConachie & Diggle, 2007) and parent-child interaction (McConachie & Diggle, 2007; Oono, Honey, & McConachi, 2013), reduced maternal depression (McConachie & Diggle, 2007), improved but non-sustained parental responsiveness (Kasari et al, 2014b), and increased children's use of eye contact, directed positive affect, verbal initiations, parents'

Category of finding	Element 2
	positive affect, and synchronous engagement (Vernon et al, 2012). 1 single study asserted that Brief parent training in pivotal response treatment* for pre-schoolers with autism resulted in increased children's communication skills, namely functional utterances (Coolican, Smith, & Bryson, 2010). 2 single studies affirmed that change in cognitive development and behaviour over time favoured the children who received the extra intervention of a home-based program in addition to a center-based program for improving development in young children with disabilities and the coping abilities of their families (Rickards et al, 2007), with results sustained at 1-year follow up (Rickards et al, 2009). 1 single study established that implementation of a home-based intervention program for young children with developmental delays resulted in significant improvement in areas of adaptive functioning, communication, social, and motor skills (Shin & Duc, 2017). 1 single study concluded that delivery of parent-focused early intervention (PFEI) program* for children with delayed language development led to a significant increase in communicative interaction among parents and children along with an increase in children's expressive vocabulary size and language skills (Ciccone, Hennessey, & Stokes, 2012). **Peers Involvement** 1 single study asserted that the implementation of Stay, Play, Talk peers-mediated intervention* on young pre-schoolers with autism resulted in significant increases in the frequency of responses and social reciprocations (Barber et al, 2016). **Day-cares Engagement** 1 single study concluded that placement of children with autism spectrum disorder in a special nursery offered benefits particularly in the area of adaptive behavioral functioning (Reed, Osborne, & Corness, 2010).
Potential harms	Literature review did not reveal any potential harm.
Cost and/ or cost	No cost studies were identified through literature review.

Category of finding	Element 2
effectiveness in relation to the status quo	
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the approach element were pursued)	1 single study revealed that individualized caregiver-mediated intervention, as compared to group caregiver education, resulted in mixed outcomes on play skills among children with autism (Kasari et al, 2014a). 1 single study revealed that peers' involvement as part of the implementation of Stay, Play, Talk intervention* on young pre-schoolers with autism resulted in no change in the rate of social initiations and non-sustainable gains in the frequency of responses and social reciprocations two months post-intervention (Barber et al, 2016). Training parents to deliver interventions for young children with autism spectrum disorder resulted in: - 1 systematic review and 1 single study revealed no significant improvement in global clinical status, child engagement, early precursors of social communication, parental skills (Oosterling et al, 2010), the frequency of child initiations in observed parent-child interaction, child adaptive behavior, or parents' stress (Oono, Honey, & McConachi, 2013). - 2 systematic reviews and 2 single studies revealed mixed results regarding child communicative behavior (McConachie & Diggle, 2007; Oono, Honey, & McConachi, 2013), and language outcomes (Kasari et al, 2014b; Oosterling et al, 2010; Oono, Honey, & McConachi, 2013).

Element 3

Secure financial coverage for early identification and intervention services

Securing financial coverage of early identification and intervention services was found to be possible through several means. Several strategies resulted in expansion of health insurance coverage of vulnerable populations, including those with disabilities (Meng et al, 2010). These strategies included:

- **Changing eligibility criteria of health insurance**, achieved through increasing income threshold for entering health insurance and expanding the categories of eligible population groups to include populations such as refugees

- **Increasing public awareness** through media campaigns targeting the public or awareness campaigns targeted to specific places such as areas where parents and children tend to congregate, including public benefit programs, early childhood centers, schools, hospitals and religious institutions. This strategy allowed more people to be aware of schemes and their benefits
- **Making the premium more affordable** through the use of subsidies or sliding-scale premiums
- **Adoption of innovative enrolment strategies** such as simplifying enrolment procedures through reducing application requirements; integrating sources for enrolment whereby the insurance scheme partnered with other organizations or public programs to facilitate enrolment; changing the unit of enrolment from 'person' to 'family', and improving premium collection approaches through making payments more flexible.
- **Improving health care delivery** achieved through improving health care packages; controlling price of services by adjusting the co-payment, deductible or ceiling, thereby making the services affordable for the eligible population; and improving the quality of services to attract more of the eligible population
- **Improving management and organization** of the insurance achieved through improving information systems and staff training, and adoption of a transparent management

Public funding of services was also deemed a successful strategy whereby publicly funded, center-based, comprehensive early childhood development programs demonstrated effectiveness in preventing developmental delay. This was reflected in lower rate of retention in grade and lower rate of placement in special education (Anderson et al, 2003). Similarly, public insurance resulted in lower out-of-pocket medical costs (Porterfield & DeReigne, 2011) and therefore less financial burden on families.

Table 3 **Key findings** from systematic reviews & primary studies

Category of finding	Element 3
Benefits	1 systematic review revealed that adoption of strategies such as (1) changing eligibility criteria of health insurance; (2) increasing public awareness; (3) making the premium more affordable; (4) innovative enrolment strategies; (5) improving health care delivery [improving healthcare package, controlling prices of services, enhancing quality of services to attract eligible population]; and (6) improving management and

Category of finding	Element 3
	organization of the insurance schemes resulted in expansion of health insurance coverage of vulnerable populations (including those with disabilities) (Meng et al, 2010). 1 systematic review stressed on the importance of public funding of services and concluded that revealed that publicly funded, center-based, comprehensive early childhood development programs demonstrate effectiveness in preventing developmental delay, as assessed by reductions in retention in grade and placement in special education (Anderson et al, 2003). 1 single study revealed that lower out-of-pocket medical costs per $1000 of income were incurred by children with special health care needs with public insurance and those receiving care coordination services resulting in a lower financial burden on families (Porterfield & DeReigne, 2011).
Potential harms	Literature review did not reveal any potential harm.
Cost and/ or cost effectiveness in relation to the status quo	No cost studies were identified through literature review.
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the approach element were pursued)	1 systematic review assessing the association between drug insurance cost sharing strategies and outcomes in patients with chronic diseases, revealed that the association between patient copayments and medication adherence varied across studies, ranging from no difference to significantly lower adherence, depending on the amount of the copayment (Mann et al, 2014). 1 study revealed that passing mandates requiring many private health insurance policies to cover diagnostic and treatment services for autism spectrum disorders had no statistically significant effect on caregivers' reports about financial burden, access to care, and unmet need for services. However, there is some evidence that autism spectrum disorder mandates may have beneficial effects in states in which greater percentages of privately insured individuals are subject to the mandates (Chatterji, Decker, & Markowitz, 2015).

Implementation considerations and counterstrategies

Barriers to implementation of the three elements are at the individual, professional, organizational and system levels. Counterstrategies to overcome these barriers are suggested and are retrieved from evidence and experiences of other countries.

Level	Barriers	Element(s)	Counterstrategies
Individual	High level of stigma among the public regarding children with disabilities and developmental delays	2	Conduct awareness-raising and educational campaigns for the public, as well as specific groups of professionals, with the aim of preventing discrimination of children with disabilities (UNICEF, 2007).
Professional	Limited availability of standardized and specialized training for early identification and intervention for children with disability and developmental delays (Ervin, Hennen, Merrick, & Morad, 2014)	1	More organized, effective training for healthcare providers is required through on-going mainstream efforts to develop favorable attitudes towards disability (Devkota et al., 2017). Integrate education on the health and human rights of persons with disabilities into undergraduate and continuing education for all health care workers (WHO,2014).
	Shortage of healthcare staff working in rehabilitation of people with disabilities especially in rural areas	1	Implement measures to improve recruitment and retention of specialist rehabilitation personnel, particularly in rural and remote areas (WHO,2014) Provide training and support for community workers and informal caregivers who assist persons with disabilities to access health services (Organization, 2015)

Level	Barriers	Element(s)	Counterstrategies
	Negative attitude with poor knowledge among healthcare providers and educators dealing with people with disabilities (Devkota, Murray, Kett, & Groce, 2017)	2	Conduct awareness-raising and educational campaigns for the public, as well as specific groups of professionals, with the aim of preventing discrimination of children with disabilities (UNICEF,2007). Raise a culture of respect, diversity, and openness among providers (FKA Children's Services, 2017)
Organizational	Limited availability of standardized and contextualized tool aiming at early identification and interventions for children with disabilities and developmental delays	1	Improve collaboration among ministries, health professionals, academicians and researchers to identify, pilot test, validate, and contextualize tools to screen children with disability and developmental delays
System	Limited reimbursement for children with disability and developmental delays services whether delivered within the realms of the health facility or within the context of outreach programs	3	Allocate a budget for children with disabilities and developmental delays practices for its implementation and sustainability Maintaining nationally-defined social protection floors containing basic social security guarantees that ensure universal access to essential health care and income security at least at a nationally defined minimum level is recommended (WHO, 2014). Community-based rehabilitation is an important means of ensuring and

Level	Barriers	Element(s)	Counterstrategies
			improving coordination of and access to health services, particularly in rural and remote areas (WHO,2014)
	Lack of collaboration among ministries and overlapping of efforts in regards to children with disabilities and developmental delays	1,2	Create a focal point for disability in each relevant department, as well as a high-level multi-sectoral coordinating committee, with members drawn from relevant ministries and organizations of person with disabilities. This committee should be empowered to initiate proposals, suggest policies and monitor progress (UNICEF, 2007).
	Ministries may not perceive children with disabilities and developmental delays as a national priority	1,2,3	Raising the awareness of ministries on the importance of early identification and intervention in children with disabilities and developmental delays

Next Steps

Next Steps

The aim of this Policy Brief is to foster dialogue informed by the best available evidence. The intention is not to advocate specific policy elements or close off discussion. Further actions will flow from the deliberations that the policy brief is intended to inform. These may include:

- Deliberation amongst policymakers and stakeholders regarding the policy elements described in this policy brief.
- Refining elements, for example by incorporating, removing or modifying some components

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Annexes

Annex

Annex 1 Description of Tools Used for the Early Identification of Disabilities and Developmental Delays

Tool	Description of Tool	Target Age Group	Setting	Impact
Checklist for Autism in Toddlers (CHAT)	The CHAT is a short questionnaire that is filled out by the parents and a primary health care worker at as a developmental check-up. It aims to identify children who are at a risk for social communication disorders.	18 months	Primary health care	Screening using CHAT did not result in an increase in the number of children receiving an autism spectrum disorder diagnosis and treatment before the age of 3 years (Carlsson et al, 2010).
Modified Checklist for Autism in Toddlers (M-CHAT)	The M-CHAT is a 23-item yes/no autism-screening tool designed to identify children who should receive a more thorough assessment for possible early signs of autism spectrum disorder or developmental delay.	16-30 months	Pediatrics clinic and health centers	Follow up through telephone calls improved the positive predictive value of the M-CHAT for the diagnosis of autism at 16-30 months and for predicting the diagnosis at age 4, suggesting that telephone follow-up is a critical step in eliminating false positives and improving utility of the tool (Kleinman et al, 2008). The positive predictive value for the combination of M-CHAT and joint attention observation was 90%, suggesting a promising role for the combination of instruments in the early detection of autism (Nyrgen et al, 2012).
Developmental Checklist-Early Screen (DBC-ES)	DBC-ES is an autism screening instrument derived from the Developmental	18-48 months	Clinic	Results of using DBC-ES for screening for autism in young children with developmental delay revealed high

Tool	Description of Tool	Target Age Group	Setting	Impact
	Behavior Checklist Parent/Primary Caregiver Report. The DBC-ES comprises 17 items from the original checklist.			sensitivity, good inter-rater agreement and internal consistency, along with significant correlations with a clinician-completed measure of autism symptomatology (Gray et al, 2008).
Behavior Assessment System for Children, Second Edition, Parent Rating Scale-Preschool (BASC-2 PRS-P)	BASC-2 PRS-P is a norm-referenced diagnostic tool designed to assess the behavior and self-perceptions of children and young adults The BASC-2 is a multidimensional and multi-method tool since it measures numerous behavioral and personality characteristics through several report based measures.	2-25 years	Clinic	BASC-2 PRS-P had adequate sensitivity and specificity when distinguishing youth with autism spectrum disorder from those without any diagnoses, but not when differentiating between youth with autism spectrum from those with other diagnoses (Bradstreet et al, 2017).
Checklist for Early Signs of Developmental Disorders (CESDD)	The CESDD was developed to be filled out by child-care workers in day-care centers. The instrument consists of 25 dichotomous items. If children fail two or more items, they screen positive for autism spectrum disorder.	3-39 months	Daycare	CESDD performed by child-care workers was as good as that of parent questionnaires, suggesting a positive role for inclusion of child care workers in the early detection of autism (Dereu et al, 2012).
The Autism Detection in Early Childhood (ADEC)	ADEC is a brief, play-based, effective and validated screening tool for the assessment of symptoms of autism spectrum disorder.	12-36 months	Pediatric hospital and university research center	ADEC had good sensitivity (0.93-0.94) but poorer specificity (0.62-0.64) for the clinical diagnosis of autism spectrum disorder. Internal consistency was acceptable with α =0 .80, and inter-rater

Tool	Description of Tool	Target Age Group	Setting	Impact
				reliability was high with a value of 0.95; thus supporting the use of the ADEC as a screening tool for autism spectrum disorder (Hedley et al, 2015). Adequate inter-rater reliability and test-retest reliability of the ADEC scores reliably discriminated different diagnostic groups, indicating that the ADEC has the potential to be established as a suitable and efficient screening tool for infants with autism disorder (Nah et al, 2014).
Alberta Infant Motor Scale (AIMS)	The AIMS is an observational assessment scale, constructed to measure gross motor maturation in infants. The scale is comprised of 58 items and is organized into four positions: prone, supine, sitting and standing.	From birth through independent walking	Hospital	AIMS scores were significantly higher in the intervention group as compared to the control group, suggesting that AIMS can predict developmental delay in high-risk infants (Wang et al, 2016).
Interview	A validated structured interview performed by nurses	18 months old children and their parents	Well baby clinic	A validated structured interview performed by nurses improved the early detection of parenting and child developmental problems in young children as compared to regular visits without such an instrument (Staal et al, 2016).

Description of Programs Used for the Early Identification of Disabilities and Developmental Delays

Program	Description
Applied Behavior Analysis	Applied Behavior Analysis is the process of systematically applying interventions, based upon the principles of learning theory, to improve socially significant behaviors to a meaningful degree. Applied Behavior Analysis thus focuses on improving specific behaviors such as social skills, communication, reading, and academics, as well as adaptive learning skills such as fine motor dexterity, hygiene, grooming, domestic capabilities, punctuality, and job competence.
The integrated early detection program	A program for early detection of autism spectrum disorder which encompassed professional training on recognition of autism symptomatology, use of a questionnaire, use of a specific referral protocol, and building a multidisciplinary diagnostic team.
The South Carolina Act Early Team	A program that provided focused collaboration among leaders representing state agencies, universities, health care systems, private organizations, and families to improve the quality of life for children with autism spectrum disorder. Specific focus was on implementing policy changes and training to result in the earlier identification and home-based behavioral intervention for young at-risk children.
Turkey national training program	A program that aimed at improving primary health providers' knowledge and competence regarding the promotion of early childhood development and prevention, early identification and management of developmental problems, and the identification of barriers to implementation and sustainability.
Early interventions for children at risk of autism spectrum disorder	Interventions include a wide spectrum of parent or clinician mediated activities including video feedback, responding to child’s communicative attempts, following child’s lead, use of joint action routines, use of books to elicit and reward communication, scaffolding peer play dates, use of visual supports, support of interpersonal exchange and positive affect, shared engagement, adult responsivity and sensitivity to child cues, focus on verbal and nonverbal communication, use of behavioral principles, plan individualization, behavior management, teaching joint attention behaviors, increasing mutual enjoyment, use of exaggerated prosody, use of repetitive paraphrasing, use of video aides, use of maternal sensitive and contingent responding, affect matching, use of reciprocal vocalization, use of infant-preferred activities, task variation, interspersal of preferred and neutral activities, reinforcement, increasing child attention and motivation, use of sensory social routines, use of antecedent-behavior-consequence relationships, prompting, shaping, fading, functional behavior assessment, face-to-face interactive games, turn-taking activities, clear prompts, interspersal of maintenance and acquisition tasks, use of immediate, contingent, and natural reinforcement, reinforcement of attempts, environmental arrangement, waiting, use of natural reinforcers,

Program	Description
	balanced turn-taking, modeling, contingent imitation, requesting imitation, and time delay.
The Communication DEALL Early Intervention program for children with autism spectrum disorder	DEALL program is a comprehensive program within the developmental framework, incorporating elements such as a trans-disciplinary approach and systematically planned interventions based on individual profiles. In addition to addressing the core issues of autism spectrum disorder such as sensory integration, motor execution, and learning skills, intervention is provided in the areas of motor and daily life skills, functional spontaneous communication, social interaction, play skills, cognitive, and social and emotional skills. Other features of the program include ongoing assessment, frequent family updates, and group interactions with peers.
Sleep based interventions for children with autism spectrum disorder	Interventions include melatonin therapy and other pharmacologic treatments, behavioral interventions, parent education, use of education programs, and alternative therapies (massage therapy, aromatherapy, and multivitamin and iron supplementation).
Improving parents as communication teachers (ImPACT) project	The impact is an evidence-based parent training curriculum that teaches parents to promote their child’s social-communication skills during play and daily routines.
Stay, Play, Talk strategy for preschoolers with autism	As part of the Stay, Play, Talk program, peers were taught to Stay with their friend, Play with their friend, and Talk to their friend. The child dyads played together during two, 20-min weekly sessions for 6-8 weeks.
Pivotal response treatment	Pivotal response treatment is a naturalistic intervention model derived from Applied Behavior Analysis approaches. Pivotal response treatment targets pivotal areas of a child's development, such as motivation, responsivity to multiple cues, self-management, and social initiations. By targeting these critical areas, pivotal response treatment results in widespread, collateral improvements in other social, communicative, and behavioral areas that are not specifically targeted.
Early Intensive Behavioral Intervention (EIBI) for young children with autism spectrum disorder	EIBI is a highly structured teaching approach for young children with autism spectrum disorder that is rooted in principles of applied behavior analysis. The core elements of EIBI involve a specific teaching procedure referred to as discrete trial training, the use of a 1:1 adult-to-child ratio in the early stages of the treatment, and implementation in either home or school settings. Activities include differential reinforcement, prompting, discrete-trial instruction, incidental teaching, activity-embedded trials, task analysis, and others.
Lovaas treatment	The Lovaas Model of Applied Behavior Analysis is a behavioral treatment model typically started with children between the ages of two and eight. Children transition to different services as they progress through elementary school and no later than the age of twelve. While treatment is always based on the principles of applied behavior analysis, its implementation varies based on a child's unique needs.

Program	Description
TEACCH program	The TEACCH Autism Program is a clinical, training, and research program based at the University of North Carolina. TEACCH developed the intervention approach called "Structured TEACCHing", an array of teaching or treatment principles and strategies based on the learning characteristics of individuals with autism spectrum disorder, including strengths in visual information processing, and difficulties with social communication, attention, and executive function.
The Early Start Denver Model (ESDM) for toddlers with autism spectrum disorder	ESDM is a manualized comprehensive therapy for toddlers with autism spectrum disorder. It emphasizes interpersonal engagement through synchrony, rhythms, and reciprocity to decrease symptom severity and accelerate cognitive, social-emotional, and language development.
Nova Scotia Early Intensive Behavior Intervention Model for children with autistic spectrum disorders	The Nova Scotia Early Intensive Behavioral Intervention is a model based on Pivotal Response Treatment. It is a teaching method that used highly motivating activities based on the child's own interests to provide the child with opportunities for incidental learning within an Applied Behavior Analysis framework. The model combined intervention by therapists and parents to make treatment more intense.
Frankfurt Early Intervention program (FFIP) for preschool children with autism spectrum disorder	In FFIP, individual 2:1, behaviorally and developmentally based child therapy is combined with parent training and training of kindergarten teachers.
Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) intervention for toddlers with autism	JASPER is a treatment approach based on a combination of developmental and behavioral principles. JASPER targets the foundations of social communication (joint attention, imitation, play) and uses naturalistic strategies to increase the rate and complexity of social communication. It can be implemented by parents, teachers, clinicians, paraprofessionals, and other related service providers. The intervention can be used in conjunction with other behavioral-based therapies. It can also be incorporated into inclusion and special education classrooms and everyday activities at home. The only required materials are developmentally-appropriate toys or activities.
FIAS for young children with autism spectrum disorder	FIAS is an intensive early intervention approach for young children with autism spectrum disorder. Through family involvement, intervention aims at developing children's social motivation.
Hanen's 'More than Words' (HMTW) for children with autism spectrum disorder	HMTW is a parent training program that provides support, education, and practical skills for enhancing communication in children with autism spectrum disorder.
Pathways Early Autism Intervention for children with autism spectrum disorders	Pathways is a community-based, parent-mediated, intensive behavioral and developmental intervention program for children with autism spectrum disorders. Key principles of the program include: -The role of the service providers is to work with and support families -Families are active participants in all aspects of services

Program	Description
	-Services are provided in convenient naturalistic environments such as home -The child learns new skills best during authentic activities -The density of the service providers' time is limited, often to only one visit a week
FindMe iPAD application for children with autism	FindMe application aimed to enhance the real-world social communication skills of the children through motivating and daily rehearsal of very basic sub-skills.
AutismPro system for supporting treatment of children with autism	AutismPro system supported the treatment of children with autism through combining the use of the Internet support tool and professional consultations.
Rapid Motor Imitation Antecedent Training	A classic behavioral intervention that uses motor imitation as a catalyst for vocal behavior. The child is taught to imitate a series of rapid, simple motor actions. Afterward, the child is taught to say a simple word at the end of the motor sequence in order to request a highly preferred object.
Stepping Stones Triple P for preschoolers with developmental and behavior problems	The program is an adaptation of the Triple P Positive Parenting Program for families of children with developmental disabilities. Triple P incorporates the principles of behavioral family intervention and parent management training and has proven effective in reducing behavior problems. Stepping Stones Triple P adaptations include making the content and materials more sensitive to families of children with disabilities and coverage of additional issues relevant to such parents such as adjustment to having a child with a disability, increased caregiving, inclusion and community living, and family support.
Milieu Communication Teaching	Milieu communication teaching is a practice that involves manipulating or arranging stimuli in a preschool child's natural environment to create a setting that encourages the child to engage in a targeted behavior.
Boston Prekindergarten Program for school readiness of young children with special needs	The program combined proven language, literacy, and mathematics curricula along with coaching on the language, literacy, mathematics, executive function, and emotional skills of young children with special needs.
Early language intervention for children with intellectual disabilities	The intervention was designed to improve the children's language development, communication skills, and emergent literacy. This was done using a combination of clearly established and well- documented methods: experiential and meaningful learning, anchored instruction with learning activities organized around a central theme, and interactive storytelling. Augmentative and Alternative means of Communication and computer-based technologies were also incorporated into the intervention in the most natural manner possible.
Implementation of a communication intervention for	The program was based on stimulation of vocabulary learning via the incorporation of augmentative or alternative communication into the

Program	Description
speaking and non-speaking children with intellectual disabilities	learning environment. This is typically achieved in the most natural manner possible.
Screening of vision in preschool children with developmental disabilities under 3 years of age	An early interventionist who had undergone certified training performed the screening procedure. The vision screening examination consists of eight parts: eyelid reflex, fixation, tracking, pupil response, corneal light reflection, cover/uncover, near point convergence, and visual acuity. Members of the early intervention team include physical and occupational therapists, nurses, and early childhood specialists.
Family centered (COPing with and Caring) for infants with special needs program	COPCA, a family focused intervention, included educational activities with the major goals of strengthening the family autonomy and participation and promoting infant mobility.
Routines-based early intervention (RBEI) for children with or at risk for developmental delay	RBEI is a program that focused on achieving functional outcomes, namely child's independence, social relationships with others, and parents' satisfaction through routines, i.e. by providing the children with learning opportunities in naturally occurring contexts. It systematically uses collaboration and coaching to set functional goals and implement service plans with the family.
Parent-focused early intervention (PFEI) program for children with delayed language development	In the PFEI program, parents were provided with strategies and techniques to maximize their children's language learning in everyday contexts.
A parent delivered early developmental intervention in children with asphyxia	Parent trainers introduced playful interactive learning activities and modeled them for the parents during home visits. The curriculum covered cognitive and fine motor, social and self-help, gross motor, and language skills.
Infant Behavioral Assessment and Intervention Program (IBAIP)	IBAIP is a neurobiological intervention for very low birth weight delivered by trained physiotherapists. The intervention consisted of supporting infants' self-regulation and development and facilitating sensitive parent-infant interactions until 6 months of corrected age.
An early developmental intervention program for preterm infants	A program delivered post hospital discharge that encompassed many different components and services, provided through a variety of disciplines such as physiotherapy and infant development.

Annex 2 Participating Stakeholders

List of participating Stakeholders
Ministries
Ministry of Public Health
Ministry of Social Affairs
Ministry of Education and Higher Education
Non-governmental organizations
The Lebanese Autism Society (LAS)
Early Childhood Intervention, Lebanon (ECIL)
Sesobel
Borj Barajneh Health Care Center
Maeen Center –Dar Al Aytam
Beit Atfal Somood
T.E.A.C.H.
The Learning Center for the Deaf
Youth Association for the Blind
Miza Association
الأسرة للرعاية والإرشاد
Laetitia Hatem Rehabiliation Center
Professional Associations
Order of Nurses
Lebanese Pediatric Society
Order of Physiotherapists
Lebanese Psychiatric Society
Syndicate of social workers
Lebanese Order of Physicians
Lebanese Society of Obstetrics and Gynecology
Order of Midwives

International Organizations
WHO
UNHCR
UNRWA
Hospitals
AUBMC Special Kids Clinic (ASKC)
LAU Medical Center-Rizk Hospital
Ain Wazein Hospital
Tal Chiha Hospital
Tebnine Governmental hospital
Rafic Hariri University Hospital
Tannourine Governmental Hospital
Primary Health Care Centers
Municipality Chiyyah center for primary health care
The Lebanese Association for the Handicapped
UNRWA Health Care Centers
Karagheusian center
Makhzoumi Foundation Mazraa Primary Healthcare Clinic
Schools
College National Orthodox, St. Elie (North)
Harat Houreik First Public Mixed School Public
Bar Elias Elementary School
Houssam Eddine Hariri High School
Hassan Kassir High School
Day Care Centers
La poule Rousse
Bébé Sucré
Learn and play
Futur

Dent de lait
Clinics
Obstetrics and gynecology Clinics
Pediatric Clinics
Caregivers of children with disabilities and developmental delays

Knowledge to Policy Center draws on an unparalleled breadth of synthesized evidence and context-specific knowledge to impact policy agendas and action. K2P does not restrict itself to research evidence but draws on and integrates multiple types and levels of knowledge to inform policy including grey literature, opinions and expertise of stakeholders.

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