Dialogue Summary

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

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Dialogue Summary

+ Included

Definition and contextualization of the priority issue

Summary of stakeholders' deliberations on options

Recommended course of action

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

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Knowledge
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Center
K2P

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The views expressed in the dialogue summary are the views of the dialogue participants and should not be taken to represent the views of the Ministry of Public Health or United Nations Children's Fund (UNICEF) or the authors of the dialogue summary.
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Dialogue

The Policy Dialogue about: Addressing Early Identification and Intervention of Children with Disabilities and Developmental Delays in Lebanon was held on November 23, 2018, at the Gefinor Rotana Hotel, Beirut, Lebanon. The policy dialogue was facilitated by Dr. Fadi El-Jardali, Director of the K2P Center.

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Preamble

The K2P Policy Dialogue, conducted on November 23, 2018, hosted 22 diverse stakeholders from multi-disciplinary backgrounds. These included representatives from

- Ministry of Public Health
- Ministry of Social Affairs
- Ministry of Education and Higher Education
- Syndicate of midwives
- Order of nurses
- Syndicate of professional nurseries and Syndicate of Nursery Owners
- Caregiver
- National Primary Health Care Network
- UN agencies (UNRWA and UNICEF)
- Local non-governmental organizations (NGOs) such as ECIL and Miza association
- Physicians, schools and researchers

The policy dialogue was facilitated by Dr. Fadi El Jardali, the Director of the K2P Center, in the presence of Dr. Walid Ammar, the Director General of the MOPH.

Deliberations about the problem

Dialogue participants discussed the overall framing of the problem of early identification and intervention of children with disabilities and developmental delays. It was highlighted that there is a need to differentiate between development delays and development disorders. All participants agreed to the need to address this issue in Lebanon.

Stakeholders agreed that there is a lack of up to date data on the topic, yet this does not diminish the importance of addressing the challenges of early identification and intervention. One stakeholder mentioned that the upcoming Multiple Indicator Cluster Survey (MICS) in 2019 will

Background to the Policy Dialogue

The Policy dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action.

Key features of the dialogue were:

1) Addressing an issue currently being faced in Lebanon;
2) Focus on different underlying factors of the problem;
3) Focus on Three Elements for addressing the policy issue;
4) Informed by a pre-circulated Policy Brief that synthesized both global and local research evidence about the problem, recommendations and key implementation considerations;
5) Informed by a discussion about the full range of factors that can inform how to approach the problem and recommendations for addressing it;
6) Brought together many parties who would be involved in or affected by future decisions related to the issue;
7) Ensured fair representation among policymakers, stakeholders, and researchers;
8) Engaged a facilitator to assist with the deliberations;
9) Allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
10) Did not aim for consensus. Participants' views and experiences and the tacit knowledge they brought to the issues at hand formed key input to the dialogue. The dialogue was designed to spark insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue and by those who review the dialogue summary.

reveal up to date data on the issue. It was also agreed that availability of data at every age level is also critical in order to meet the needs of the child at each age. It was mentioned as well that there is a need to emphasize on the importance of completing the data related to APGAR and the growth milestones on the child health/medical cards, by the pediatricians.

Stakeholders discussed that disabilities and developmental delays affect the whole family, physically, mentally, socially and financially. Therefore, aside from supporting the child, there is also an impelling need to support the family and develop interventions that are focused on the care givers to provide them with the adequate practices to deal with their child.

Stakeholders mentioned that early and consanguineous marriage, early pregnancy, and In vitro fertilization (IVF), lead to prematurity, congenital abnormalities, more low birth weight children, and higher rate of children with disabilities and developmental delays. As such, addressing those underlying factors can be critical to decrease the prevalence of disabilities and developmental delays. Moreover, participants agreed that early identification and interventions starts prenatally.

Participants mentioned that the lack of early identification tools and the subsequent low rates of identification of cases may lead to low demand for inclusion in services. Moreover, there is a deficiency in nurses and specialized staff such as speech therapists and psychologists in public schools. As a result, participants emphasized that there is a need for securing the availability of registered nurses and other specialized staff at schools, aiming at enhancing identification of children with disabilities or developmental delays.

Some stakeholders mentioned that some parents may not report to schools or nurseries that their child has a developmental delay due to fear of stigmatization or denial. This raises the need to raise awareness of parents, nurseries and schools on the necessity of early identification and intervention for children with disabilities and developmental delays. In addition, participants agreed to the need for adequate capacity building for staff in schools and nurseries.

Underlying factors

The participants proceeded to discuss the underlying factors of delayed identification and intervention. Most participants agreed that there are multi-level underlying factors, including those at the levels of governance, delivery, sociocultural and financing.

Some participants mentioned that the law 220/2000 is not fully in effect. This puts the rights of the children at risk. Moreover, as per law 220/2000, children with disabilities have the right to a disability card. However, the disability card provided by the Ministry of Social Affairs does not cover all the care needed. The process to get the disability card is perceived as humiliating and the centers providing the card are not disability friendly. In addition some stakeholders reflected on the need to adjust some regulations at the Ministry of Education and Higher Education to ensure that all schools have the adequate staff for early identification and intervention of children with disabilities and developmental delays.

Some stakeholders mentioned that the care of children with disabilities is integrated within the National Mental Health strategy at the Ministry of Public Health. Participants reflected on the need to follow up on the implementation of the strategy.

Deliberations highlighted the need to ensure coordination among ministries on early identification and intervention of children with disabilities and developmental delays. This includes coordination with the Ministry of Commerce which has a role to play in regulating the financial coverage of services by insurance companies. In fact, currently there is an inter-ministerial strategy for early childhood development that is underdevelopment under the patronage of the Higher Council for Childhood and which need to emphasize on disabilities and developmental delays. Furthermore, it was agreed that there is a need to ensure coordination among the different centers providing interventions for children with disabilities and developmental delays. Participants discussed that currently both a list of qualified referral centers as well as a clear referral pathway are largely missing. This in fact may deter the child's chances of receiving care. Moreover, there is no monitoring or evaluation of the performance of the centers providing services to children with disabilities and developmental delays.

Stakeholders mentioned that there is a **lack of context-specific tools** that are validated and standardized for early identification and intervention. The participants stressed on the need to work on validating and standardizing the tools and utilizing them in healthcare facilities, clinics, schools, and nurseries.

Participants emphasized that the **cost of assessment** for developmental delays and disabilities and the cost of specialized schools and nurseries is very high and at times unaffordable to the parents or caregivers. Moreover, public nurseries are still limited in Lebanon; where by the only currently available public nurseries are in the Ministry of Social affair's SDCs.

Stakeholders denoted that various types of organizations are **deficient in specialized staff** such as speech therapist, clinical psychologists, and registered nurses. Stakeholders discussed the required organizational resources and strategies for the early identification and intervention. These included the need to integrate early child development in curriculums at universities; provide training to healthcare providers and educators; and integrate licensed clinical psychologist, nurses and midwives in the spectrum of identification and intervention. Moreover, it was agreed that providers providing trainings on early identification should be qualified and competent.

Parents **awareness** was another aspect discussed. In fact, stakeholders mentioned that there is limited awareness among parents on early child development, referral channels, and the disability card. In fact, it was highlighted that there is a lack of structured awareness programs for parents and parents support groups. Participants agreed that the awareness can be provided by the media and specifically social media. Participants mentioned that there is also limited awareness among various healthcare providers, including pediatricians, and educators in schools and nurseries on early child development.

It was strongly denoted, that a major factor to inadequate early identification and intervention of children with disabilities and developmental delays is the lack of collaboration between the different sectors. As such participants agreed that a partnership between the various sectors would unify efforts and aid in the successful identification and intervention of children with disabilities and developmental delays

Deliberations

Deliberations about the Elements for Addressing the Problem

Dialogue participants discussed the three elements that were examined in the Policy Brief.

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

This element addressed the role of policy changes in enhancing the eligibility for services among children with disabilities and developmental delays. It also presented various tools that have a proven role in the early detection. In addition, evidence-based practice improvement strategies aiming at the early identification or intervention were identified.

Participants discussed that despite the availability of an array of tools, the presence of unified, standardized, and evidence-based tools is still very limited. To add to the complexity of the issue, the reports produced as a result of the use of such diagnostic tools are not uniform and at many times not very informative. Moreover, there are no standardized protocols for the diagnosis of various types of disabilities and developmental delays, frequently resulting in over or under diagnosis of cases. As such, participants agreed that there is a need to unify, contextualize, and validate available diagnostic tools and develop standardized diagnostic protocols. They also agreed that a ‘navigation’ or referral tool that assures the connectedness of patients to service providers may be essential for securing that they receive their much needed diagnostic interventions and treatments in a timely, smooth, and effective manner. Participants also agreed that strategies aiming at early identification and intervention should start very early on, as early as the pre-partum phase when applicable.

Aside from the problem of the limited availability of contextualized and validated tools, a number of participants discussed a related problem regarding the limited availability of specialized staff such as speech therapists, clinical psychologists, and occupational therapist. Such problem is reported to be worst in the rural areas. As a result, participants agreed that efforts should be made to secure the availability of qualified specialists across all regions.

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

This element presented the evidence from a number of systematic reviews and single studies that have demonstrated effectiveness of enhancing knowledge, awareness, and participation of key stakeholders involved in the care of children with disabilities and developmental delays. These comprised healthcare providers, parents, peers, and daycare centers. Interventions included implementation of national training programs, academic detailing, parents training, language assessment performed by parents, home-based programs, peers' interaction and play, and placement in specialized daycares.

At the professional level, participants agreed that healthcare providers should be well informed about the referral pathways available for the management of children with disabilities and developmental delays. Participants also discussed that professional education and training should be both integrated in educational curricula and in Continuous Medical Education (CME) plans. Such programs should target all professionals involved in the care of children with disabilities and developmental delays including physicians, physiotherapists, psychotherapists, speech therapists, and others. Few participants even suggested unifying the training programs (such as a standardized diplomat) for all involved personnel, aiming at building a unified approach to management.

At the community level, extensive deliberations stressed on the importance of public awareness through media, which can also play a vital role in un-stigmatizing disabilities and developmental delays and simultaneously shedding light on the benefits of the Disability Card and on the available channels and services. In this regard, participants agreed on the importance of extending awareness to issues children with disabilities and developmental delays are particularly vulnerable to such as bullying. Participants also discussed the role of parents' support groups which can provide patients and their families with valuable technical guidance and psychological support. Discussion also uncovered other potential stakeholders who can play a vital role in supporting children with disabilities and developmental delays and their families, including municipalities and parents’ committees at schools.

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

This element identified various funding schemes for services targeting children with disabilities and developmental delays. Specifically, one systematic review identified strategies for expanding the health insurance coverage of vulnerable populations, including those with disabilities. Other studies stressed on the importance of public insurance and public funding of services.

As a strategy to overcome financial challenges, participants agreed that ministries and third party payers should have a separate budget targeting services for children with disabilities and developmental delays. Participants discussed that interventions in this regard should also involve insurance companies through the Ministry of Commerce, aiming at optimal coverage of diagnostic and treatment interventions. Given the scarcity of the financial resources, participants agreed on the need to map the available services, aiming at identifying deficiencies and simultaneously ensuring the proper utilization and distribution of existing services.

Next Steps

Recommendations and Next Steps

The deliberations about the three elements were successful in creating consensus among the different stakeholders. The international published evidence is consistent and clear about the impact of these elements on the early identification and intervention of children with disabilities and developmental delays. A consensus was reached among participants that one governing body should lead, guide, and oversee all the national efforts targeting early identification and intervention on children with disabilities and developmental delays Most of the emphasis was placed on the need for collaboration between the different ministries and sectors for early identification and intervention of children with disabilities and developmental delays, delivery of services, training of healthcare providers, and making use of existing resources.

Participants discussed and agreed on the following recommendations.

Recommended action	Stakeholders involved
Develop an inter-sectoral National Strategy on Early Identification and Intervention of Children with Disabilities and Developmental Delays	→ Ministry of Public Health → Ministry of Social Affairs → Ministry of Education and Higher Education → Ministry of Commerce
Develop a network for early child development that provide services for children with disability and developmental delays service centers across Lebanon through mapping existing resources, capacities and centers. Develop standards to monitor the quality of services within the network.	→ Ministry of Public Health → Ministry of Social Affairs → NGOs
Secure financial coverage for screening, treatments, and drugs needed for children with disabilities and developmental delays	→ Ministry of Public Health → Ministry of Social Affairs
Raise awareness about early identification and intervention of developmental delays and disabilities through educational courses,	→ Ministry of Public Health → Ministry of Social Affairs

Recommended action	Stakeholders involved
media campaigns, guiding manuals, diagnostic and treatment protocols, and quality assurance practices	Ministry of Education and Higher Education Ministry of Information Order of Nurses Order of Physicians Order of Midwives Universities NGOs
Revise the child health record to be a useful tool for all health professionals and parents to guide the detection of disabilities and developmental delays	Ministry of Public Health WHO Researchers/Physicians
Train physicians, nurses, social workers, teachers, and midwives on early identification of disabilities and developmental delays	Order of Nurses Order of Physicians Syndicate of Midwives Syndicate of Social Workers
Contextualize and validate tools for early identification and intervention for children with disabilities and developmental delays	Ministry of Public Health Researchers / Physicians
Include early identification and intervention of children with disabilities and developmental delays (including children under 3 years of age) in the curriculum of medical schools, nursing schools, special educators, social worker and midwife education	Ministry of Education and Higher Education Universities
Establish a task force from the key Ministries and other stakeholders to follow up on the implementation of the recommendations.	Ministry of Public Health Ministry of Social Affairs Ministry of Education and Higher Education
Extract data on the prevalence of disabilities and developmental delays at various ages.	Ministry of Social Affairs UNICEF Academia NGOs