Towards a Cross-Sectoral Approach to Inclusion of Children with Disabilities

POLICY BRIEF
This policy brief has been developed based on the "Assessment of Capacities of Services provided by Health, Education and Social Sectors for Inclusion of Children with Disabilities." To download the comprehensive assessment visit www.unicef.mk

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All children have enormous potential. Focusing on a child’s disability without first seeing the child constrains that potential. Like any child, children with disabilities carry the promise of happy, meaningful lives, of vital community participation, and of making contributions to build inclusive and sustainable societies. A society cannot be equitable unless all children are included, and children with disabilities cannot be included unless the environment around them changes to support their participation.

This policy brief provides guidance on the future reforms of services for children with disabilities provided by the health, social and education sector. Lack of cross-sectoral collaboration and coordination coupled with limited availability, accessibility and affordability of necessary services, contribute to late identification, referral and appropriate care for many children and families. This leads to discrimination and exclusion. Presented in two parts - Analysis of the Current Situation and Possible ways Forward - this brief provides evidence-based guidance for both policy makers and service providers in order to address system barriers that prevent children with disabilities from taking up their rightful place in society.

The analysis takes as its framework the human rights-based approach. This approach recognises: that all services should be provided on the premise of rights, not charity; that all children have the right to participate in everyday life in the community and in education; and that services should promote these rights. These services are a means to realisation of rights and not an end in themselves.

Participation across the life-course perspective was used to highlight issues of transition and to give a common vision in promoting optimal developmental trajectories for children and their families. Effective services need to understand and consider the inter-relatedness of child life domains along with their developmental trajectories, the importance of transitions, critical life events and turning points. The human rights-based approach combined with a life-course approach therefore provides the philosophical and conceptual underpinning for cross-sectoral collaboration.

A vision based on rights and needs
Analysis of the Current Situation

GENERAL ANALYSIS OF THE SITUATION
highlighted an over-all lack of awareness in society for the rights of children with disabili-
ties and a predominance of the charity model which sees people with disabilities as victims of their impairments deserving of pity. The view that the state is responsible in taking care of such children - seen mainly as needing medical attention or protection - is widespread. Few understand the social and rights-based model which regards disability to be a result of the way society is organised and emphasises the need to remove environmental barriers to participation. This is also reflected by a tendency for professionals to be guided by laws and rulebooks rather than professional standards of good practice.

A lack of clear process enabling effective collaboration between professionals and services, across all levels of health care and with other sectors, was identified as the main issue in the HEALTH SECTOR. The consequence of this is an overload of services at the tertiary care level due to inappropriate referrals and an overlapping of activities. An example of this being the duplication of the assessment process (carried out by the categorization commissions) and the diagnostic process (carried out by developmental paediatric units). This service is uniquely available in primary health centres in Skopje and Bitola. Patronage nurses are an important element in both the early detection and early intervention schema. They provide routine home visits checking all children notified by the maternity hospitals as being at risk. However it is unclear how the process of continuity from notification to follow-up is assured, especially in view of the fragmented landscape of the health services. There is a general weakness of services at the secondary level where most interventions should be delivered. Currently these mid-level services are underdeveloped; they are not formally recognised as the contact point for referrals from primary health care services. Additionally there is both a lack of defined standards for the training of non-medical professionals, such as special educators and a lack of proper and systematic recruitment of human resources.

The SOCIAL SECTOR is responsible for formally identifying children with disabilities, following their families and ensuring they receive the services they require. However, due to a lack of staff, resources and competing obligations, the Centres for Social Work (CSW), - the primary entry points for families - are unable to fulfil their mandate. Identification of children with disabilities is delegated to the health sector; it often comes too late, does not necessarily lead to the provision of services and wherever possible, is avoided by parents. This identification happens without reference to any of the health services already provided to the child. As a result, it happens without the benefit of any assessments that might already have been made. Moreover neither communication nor collaboration between CSWs - who are familiar with the environment, (hospitals/maternity hospitals and education systems) exists. Each works in a non-communicating silo. In addition, it is evident that still today, more money is invested in institutional care than in supporting families who typically receive a small disability benefit. Kindergartens do not have the capacity to welcome children with disabilities. Despite the introduction of a portfolio containing all relevant information concerning the child, transitioning to school is not easy. Staff working in kindergartens are not adequately trained and there is a lack of adequate materials and guidelines; consequently it is difficult to meet the specific needs of both children and their families.

Within the EDUCATION SECTOR, the amended law on primary education (2008) prohibits discrimination and ensures equal access to education for children with disabilities. Education is free of charge, transport is guaranteed, textbooks should be adapted and personal assistance provided. The Law on Primary Education stipulates in Article 3 that the education of children with disabilities is the responsibility of the primary education system. The identification of a disability in the context of education however is regulated by the Law on Social Protection. Access to regular schools is dependent on the level of disability (mild or moderate) as established by the commission. It is presumed that children with “severe disabilities” will be taught in special schools and/or by special educators. Financial resources made available by the state for inclusive education are used differently across municipalities. At times the block sum awarded to schools is used in other ways than intended by the law. Special schools seem to be funded through different mechanisms and in some instances, seem to have more staff available in proportion to the number of children, than necessary. Due to a teaching style focused on test outcomes the national examination and the certification systems of teachers are perceived as barriers to inclusion encouraging the exclusion of low-achieving children. In general, schools seem to be rather isolated and teachers left alone to deal with difficulties. Moreover issues related to the capacity to promote inclusive education are present in schools. Teachers and schools lack the conceptual tools and guidelines to support inclusive education. Knowledge on disability is still very medically oriented with the consequence that information provided by the commission on the difficulties of individual children does not inform teachers’ planning or teaching. Barriers to including children in regular classrooms are present and promoting the learning of children with disabilities is still seen as the responsibility of a specialist.

From the perspective of children with disabilities and their families, it is evident that most services have a limited mandate and a short-term perspective. Professionals and services think exclusively within their area of responsibility. Generally they are limited to providing only the specific service offered by their institution.

CIVIC SOCIETY AND THE PRIVATE SECTOR are becoming more involved in both raising awareness and promoting inclusive services. The widespread range of activities in which almost all the Disability Persons Organisations (DPOs) are engaged underlines the potential strength that this sector could bring to a policy aimed at changing the perception of disability within the general population. Networking, especially at the national level, dependence on foreign or private funds and an ability to involve disabled people on the governing bodies of DPOs are some of the weak points.

PARENTS, the other major stakeholder group, are active partners of the government. They actively plan and implement measures that have a direct impact on the civil, political, economic, social and cultural rights of disabled children. Parents’ awareness and information however is still limited; they lack the knowledge necessary to develop successful strategies in demanding rights.
THERE IS A HIGH LEVEL OF STIGMATIZATION TOWARDS CHILDREN WITH DISABILITIES

More than half of respondents find it unacceptable for:

- 53% of respondents believe that environmental barriers, such as physical barriers and those created through attitudes and stereotypes need to be removed for children with disabilities to fit in to society

- 48% of respondents agree with the statement that children with disabilities need medical care, rehabilitation services and other special services to fit in to the society

- 30% of respondents feel sorry for children with disabilities, and thinks that they need help and financial assistance in order to fit in to society

- 53% of respondents believe children with disabilities should go to special schools, and

- 33% believe that they should be segregated in special classes within the regular schools, only

- 4% support attending same classes at regular schools.

THERE IS LOW SUPPORT TO INCLUSIVE EDUCATION

Children with disabilities include:
- Children with Down Syndrome
- Children with Autism
- Blind children
- Children who do not understand the spoken language
- Deaf children
- And children with intellectual disability

4% of respondents find it acceptable for:

- 50% to be in a “same pupil school/kindergarten” relationship/acquaintance
Based on a strategy developed by kindergarten inclusive teams, should Early identification and intervention A unified screening check-list, based Support for mothers and families Children born with a recognised risk Childhood and Youth CHILDREN WITH DISABILITIES WHO RECEIVE QUALITY CARE AND DEVELOPMENT OPPORTUNITIES, ESPECIALLY IN THE EARLY YEARS OF LIFE, ARE MORE LIKELY TO REACH THEIR FULL POTENTIAL AND ENJOY PRODUCTIVE LIVES.

- Children born with a recognised risk of developmental difficulties should always be considered alongside the mother and the family.
- Support for mothers and families should be a priority.
- The family doctor should be the key stakeholder. Ideally she/he would coordinate, refer and have an overview of all available resources.
- A unified screening check-list, based on ICF-CY, (International Classification of Functioning, Disabilities and Health, Version for Children and Youth) should be in use for early identification of children with disabilities.
- Early identification and intervention services through the use of patronage nurses should be strengthened leading to improved access to counselling and other specialized services.
- The earlier the child can be admitted to kindergarten the greater the prospects of inclusion.
- Kindergarten inclusive teams should establish strong cooperation with family doctors. They should coordinate, refer and have an overview of available resources at the local level.
- Based on a strategy developed by both the kindergarten and the school, transition should be meticulously planned.

The more children are exposed to interaction and experiences outside the immediate family, the easier the transition into compulsory education will be.

- Children acquire basic cultural and life skills, and competencies related to literacy and numeracy, based on the foundational capabilities that they have acquired at home and in preschool settings.
- For some children formal identification of their disability only starts when they enter compulsory education.
- At this stage some parents know more about the disability of their child than the education professionals themselves, therefore strong parent-teacher collaboration is important.
- School inclusion team teachers, social workers, school psychologists, pedagogues and special educators need systematically to collaborate in order to support inclusion.
- Personal teaching assistants should be made available at the child’s local school.
- At present services are dependent on where a family lives and if they are familiar with their rights and the available services.

At this stage young adults should develop professional skills and competencies relevant to living as independent and responsible adults.

- The requirements of the Convention on the Rights of Persons with Disabilities are only fulfilled when young people are enabled and empowered to become independent.

TRANSLATING LAWS INTO PRACTICE IS RIGID. The system of centralised governance “flushes up” all problems at the policy level and addresses them through new legislation and rulebooks. However, in order to find adequate and flexible solutions good practice should be informed not only by legislation, but also by the local situation. Professionals have to be able to solve problems when pre-defined solutions are not available or not feasible. They require guidelines in order to help them with the implementation of both laws and rule books. Lack of a mid-level service system, where organisations, institutions and professionals actively engage in developing guidelines or “codes of practice” helping translate legislation into practice is seen as barrier to cross-sectorial collaboration and practice. This is due to each sector only following its own laws. The work of the commission could be the nucleus of such a mid-level service system.

FORMAL IDENTIFICATION AND ACKNOWLEDGMENT OF DISABILITY OCCURS TOO LATE IN THE LIVES OF CHILDREN. The work of the categorisation commissions is too isolated and therefore often not followed up with adequate services. Along with late identification comes a lack of information and data useful for planning and monitoring purposes. There is no general consensus about which information should be shared between professionals and services to ensure inclusion.

FINANCIAL MECHANISM such as block grants do not ensure that necessary resources are available in schools and kindergartens. It seems that funding schemes favour specialised institutions thereby promoting exclusion rather than inclusion. Some Disability Persons Organisations (DPO) have funds for service provision; what services they are providing and to whom, needs further investigation.

Bottlenecks and Core Problems

INSTITUTIONAL CAPACITY NEEDED TO IMPLEMENT LEGISLATION AND DEVELOP PRACTICES IS LIMITED. Schools, primary health care centres and the categorisation commissions focus on implementing the law. Generally they continue to lack the institutional capacity needed to develop their own practices. Procedures are bureaucratic, lacking the flexibility needed to develop local solutions. Limited capacity is evident. There is a lack of infrastructure, tools, organisational structures and expertise of professionals.

PROFESSIONALISM AND COLLABORATION COULD BE IMPROVED. Professionals in general work in isolation. There is no apparent bridging between professionals from different sectors (medical, social, education), each works in a silo-like system. There is little transfer of knowledge, experience or tools across services, sectors or regions. Training standards need to be developed to include both a life-course approach and interdisciplinary collaboration. The horizontal partnership between services and professions needs to be strengthened.

A LACK OF INTEGRATION OF SERVICES AND TRANSITION PLANNING is a result of these core problems. The services have no shared vision of how they could collaborate to create a comprehensive system that is responsive to the needs of families and their children. A further consequence of this lack of coordination is that the process of transition between early childhood, preschool and school levels is not successfully supported. The life-course approach is lacking and therefore a vision on how to connect services across sectors and across time is not present.
The way forward towards the vision of available integrated services across the life-course of children with disabilities is not straightforward. All major stakeholders must develop a road map together. There are some basic premises for development that will help in developing national and local plans. These include:

**PROMOTING INCLUSIVE APPROACHES:**
Inclusive systems of services for children with disabilities require inter-sectorial strategies and collaboration. In order to avoid marginalisation of children and families due to disability, a multi-institutional network is necessary. The development of inter-sectorial systems of services should primarily strengthen the primary systems in order to manage diversity and to develop inclusive practices.

**PARTICIPATION OF ALL STAKEHOLDERS AND SHARED RESPONSIBILITY:**
Inter-sectorial collaboration should be promoted under the basic premise that all individual services are to be held accountable for the outcomes of all children with disabilities, and not for their specific mandates. There is a need for shared responsibility of all stakeholders to ensure inclusive and effective services. If ensuring participation becomes the guiding principle of service provision, then responsibilities need to be shared not compartmentalised.

The International Classification of Functioning, Disability and Health (ICF) as a common framework could help promote shared responsibility and ownership. Developing a shared set of indicators (based on the ICF) that can be monitored across services and systems might be useful.

**CREATING A CONTINUUM OF SERVICES:**
In order to be effective, services need to be accessed. Primary entry point should be where parents and children seek advice or local services, such as primary health care centres, kindergartens, regular schools or other available services for example patronage nurses. Where these generic services are inadequate or specialist knowledge is required, multi-disciplinary, secondary level hubs should be widely available in all regions. A useful strategy would be to think of and develop a "three tier approach": universal, high quality services at the local level, specialised services for predictable and identifiable needs at the regional level and highly specialised services for intense and complex needs or where children and their families find themselves in unique situations.

**IMPROVING RESPONSIVENESS OF SERVICES:**
Service providers need to feel accountable not only to the responsible authorities, but more importantly to the public and crucially the service users themselves. Improved responsiveness can be met by the introduction of common frameworks such as the ICF and International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY); ensuring compatibility, but also helping services to complement each other; introduction of the principle that the body best positioned to provide the service should do so – independent of legislative or ministerial affiliation; and by broadening professionals’ scope so that they operate over and above their generic service.

**BUILDING PARTNERSHIPS AND NETWORKS TO MAKE THE OVER-ALL SERVICE PROVISION MORE SUSTAINABLE.**
In order to bridge the gaps between sectors (government, civic and private) - and services for different age groups, partnerships and networks are needed. A shared vision needs to be developed: what should be viewed as a public responsibility (e.g. respect of peoples’ rights and avoiding exclusion), what is the core responsibility of the state (e.g. the progressive realisation of rights through the development of its institutions), and which services or roles can best be promoted by private organisations.

ICF/ICF-CY should be used as a common language to facilitate the life-cycle approach, compatibility and complementarity of services, data collection and monitoring.
Identified Need for Change

One of the most important, yet demanding needs for change is related to basic social values and attitudes. Stigma remains widespread. It is crucial to raise awareness, especially of the importance of including children from an early age. Even the most inclusive and progressive services are unsustainable in a society that is grounded in a charity approach to disability, efforts to promote awareness and a sense of personal responsibility – rather than a delegation to the state – are vital.

Children with disabilities CAN REALIZE THEIR FULL POTENTIAL if society changes the way it sees them.

AT THE POLICY LEVEL, much has been done. The Convention on the Rights of Persons with Disabilities to guide the development of inclusive services has been ratified. The change is needed less at the level of individual laws or rulebooks and more with the overall governance mechanism.

AT INSTITUTIONAL AND SERVICE DELIVERY LEVEL, IMPROVING GOVERNANCE AND CAPACITY BUILDING IS REQUIRED TO OVERCOME, a child- and family centered approach to providing integrated services with a life-span approach. There is a need for greater decentralisation and participation. There may be a need to review financial mechanisms or increase the level of accountability at the municipal level. A result of the current prescriptive governance system is that service organisations and institutions are guided by legislation. They have a strict sectoral perspective of their limited mandate. Strengthening the capacity of organisations and institutions in order to develop guidelines of cooperation and service integration is necessary. Besides issues of governance, lack of competent (adequately trained) staff must be addressed. In order to increase the responsiveness of institutions and services, monitoring mechanisms need to be strengthened and a system of complaints, that can be recorded and heard be established.

AT PERSON LEVEL, there is a need to develop awareness, attitude, skills and competences of the individuals involved, recognising that they are the main driving force behind inclusion. This leads to diverse practices and has the potential for discrimination. Following the principles of a human rights-based approach with a life-span perspective many professionals have only limited capacity to assess and provide services. There is a clear need for capacity building through training and education. Parents need education and training in order to undertake basic exercises and activities that will promote the well-being and healthy development of their child enabling them to thrive. The Parent Resource Centre could play a critical role in exchanging experiences and developing effective strategies in order to access the necessary services.

Inclusion is about acknowledging that ALL CHILDREN – REGARDLESS OF THEIR ABILITY – may need special support.
Strategies for Change

Strategies that could help bring about these changes are explored. They address the over-all governance mechanisms, development of multi-sectorial structures, partnerships across sectors, and capacity building.

**OVER-ALL GOVERNANCE OF SERVICES** for children with disabilities will require much time to change. Within the scope of improving cross-sectional collaboration it may be a more feasible goal to develop a common agenda, national plan or road map. Moreover, some more tangible aspects of governance could be tackled, for example, money allocated to a child should follow the child, focussing on the provision of services and not solely on benefits. In addition if new services are to be created or current services upgraded there will be a need for increased funding. Another important area of good governance is the availability of relevant data that can inform practice and information sharing. Clearly, a common language would be necessary to enable the flow of information. The ICF is seen as the most adequate tool in developing a common understanding of functioning, disability and health across sectors and the life-span.

**DEVELOPMENT OF MULTI-SECTORIAL STRUCTURES** by creating multidisciplinary regional centres that may be mandated to identify and provide primary level services for families. When establishing such a nation-wide network of secondary services, those services already in existence and provided by non-governmental organisations and the private sector, should be taken into consideration. Some services do exist, but only on an individual basis and not covering the entire country. Successful practice, such as the patronage nurse system or Roma mediators, should be given more visibility and scaled up to cover the entire country. Such a process of institutionalisation of services should be accompanied with accreditation activities to ensure that capacity building is recognised and sanctioned by the state. This is also important in the area of inclusive education, where many teachers have built their capacity and are providing good services, but are not recognised as such by the state.

**BUILDING PARTNERSHIPS ACROSS SECTORS** in order to strengthen the over-all service provision of children with disabilities is a promising strategy that will improve the responsiveness and effectiveness of services. This will require a change in mind-set of those involved in this process away from a top-down approach that is primarily guided by rulebooks and regulations. The introduction of a case management system could help facilitate the building of partnerships between organisations and services. Such a system could also help improve the referral system which is currently weak. Supporting financial incentives for collaboration and implementing pilot experiences of cross-sectorial partnerships in local settings where the conditions are especially favourable could be the way forward.

**CAPACITY BUILDING** is a key strategy needed to improve the responsiveness of services. One way to address this, previously mentioned above, would be to initiate a (self-) evaluation or mapping process to better understand current limitations and to define a common starting point. In addition to such a process attention needs to be given to capacity building of professionals. Future training activities should focus on practice rather than knowledge alone. Ideally, representatives from all relevant constituencies should be involved in promoting cross-sectorial capacity building. The recently established accreditation process for the hospital services could be an opportunity where higher standards across the whole network of services is the goal. There is a need to identify an appropriate set of indicators, in schools, education and the licensing of teachers that is linked to the performance level of their classes. The ability to successfully include children in their classroom should be used as one of the criteria of a well-qualified teacher. Professionals and institutions (supply side) need to engage in capacity building, as well as communities and families (demand side). If families and communities are not aware of services and unable to be partners in supporting a child with disabilities, even the best services will not be sufficient. A strategy to help their capacity building is therefore important.

The development and implementation of such far-reaching strategies should be implemented by the stakeholders themselves. Children, parents, service providers and policy representatives should come together for this purpose. The Convention on the Rights of Persons with Disabilities could be the starting point in developing a shared vision and strategies for a way forward.