

EXECUTIVE
SUMMARY

BRIDGING THE GAPS:

Towards a National System of
Early Years Care and Support

Executive Summary

This article is the executive summary excerpted from a comprehensive 2019 study that mapped available services for children affected by Congenital Zika Syndrome (CZS) and other congenital malformations at birth and developmental disorders or disabilities in the early years. The full study is available at <https://www.unicef.org/jamaica/reports/bridging-the-gaps-2019>

Background

Jamaica is one of eight countries benefitting from a USAID-UNICEF supported undertaking entitled *Prevention of the spread of Zika and provision of care and support to children affected by Congenital Zika Syndrome and their families*. The initiative was primarily intended to strengthen child care and family support for those affected by Congenital Zika Syndrome, CZS) and other congenital malformations. In Jamaica, aspects of the USAID-UNICEF undertaking were aimed at mainstreaming childhood disability and inclusion within the overall Early Childhood Development (ECD) programming for the country.

This report represents a part of the overall USAID-UNICEF undertaking, and is aimed at providing the foundation for a wider multi-sector effort to increase Jamaica's national capacity for early intervention and support to families of young children affected by CZS and other congenital malformations. Specifically, this report maps Jamaica's current national capacity and service provision of comprehensive care for young children with developmental disabilities, including CZS.

Methodology

The research methodology included a review of

the international literature on optimum services for children with disabilities; review and analysis of the Jamaican legal and institutional framework supporting children with disabilities; review of existing systems for screening, early identification, diagnostic, therapeutic and psycho-social support services in Jamaica; and determination of the perceptions of professional and parent stakeholders about the existing systems through interviews and focus groups. Gaps and strengths in the available services and pathways became evident through the review, and these formed the basis for a detailed SWOT analysis, from which preliminary recommendations for systems improvement were made. The information obtained was shared with a group of first contact professionals from the health, education and social sectors; NGOs; community and faith based organisations. Their perceptions and recommendations were received, and a final report produced.

FINDINGS

Prevalence and Impact of Childhood Disabilities

Recent studies in the USA indicate the prevalence of the ten most common childhood disabilities to be as high as 17.8% by parent report, affecting one in 5 to 6 children. Consistent with the limited prevalence data availability for children in Low and Middle Income countries (LMICs), there are no accurate figures available for the number or proportion of children with disabilities in Jamaica. Nonetheless, estimates from household surveys, national school readiness assessments and registers of persons with



disabilities offer some insight into the prevalence of developmental disability in the island.

Specifically, the findings of the Early Childhood Development Index (ECDI) administered as a household survey in 2011 indicated that 11% of children in the age group 36-59 months had developmental challenges. While more than 97% of children were developmentally on track in the physical and learning domains, only 79% were on track in the socio-emotional domain and 66% in the literacy and numeracy domain. The Jamaica School Readiness Assessment (JSRA) administered to four-year-old children nationally in 2017 and 2018 identified that 32.6% of those assessed had at least one developmental problem, the most common problems were in understanding and learning. Boys and economically vulnerable children had higher levels of developmental problems on both the ECDI and the JSRA pilot evaluation, consistent with the international literature. The voluntary register held by the Jamaica Council for Persons with Disabilities (JCPD) reported a total of 5,000 children with recognized disabilities (physical and otherwise) in 2017.

The existence of childhood disability has been associated with stigma and discrimination, increased likelihood of family poverty and child vulnerability to exploitation and abuse. There are no studies on the impact of childhood disability in Jamaica, but congenital abnormalities contribute significantly to child mortality and morbidity.

Service Provision for Children with Disabilities

Children with developmental disabilities require a comprehensive range of diagnostic, therapeutic, intervention and support services across many sectors. Children who present with physical findings of disability at birth are usually identified at birth and referred for services immediately. Children

whose symptoms of developmental disabilities emerge later on, access the health system in a number of ways: via well child clinics, private paediatricians, private physicians, education institutions, and specialist doctors. Children without obvious symptoms can be identified through screening – the evaluation or testing of individuals to identify those who have an undiagnosed problem or who are at high risk of having a problem. Of the numerous medical conditions that exist, only a small proportion is screened for, using globally tested, validated and recognized screening tests. For young children (0-6), there are five conditions for which routine screening programmes have been recommended and implemented in several countries: (i) congenital metabolic conditions, (ii) hearing, (iii) vision, (iv) developmental and behavioural disorders, and (v) Autism Spectrum Disorder (ASD). Internationally recommended screening tools exist, which guide the processes through which medical staff, parents and other care givers can initially assess the development of young children.

The majority of parents and young children ages 0-3 years in Jamaica receive health services from the public sector, through preventative antenatal care, well child care and primary curative care. Children with developmental disabilities and their families are facilitated in accessing specific health sector assistance through the removal of user fees at public health facilities. Additionally, early child care procedures are outlined in the Family Health Manual used by public health workers and available in public health facilities, which advises of schedules of well visits for children between birth and eight years, as well as growth and development evaluation and screening guidelines.

General paediatric services in the public health system can be accessed at almost all fourteen parishes (geographical units) in Jamaica, the parishes of Trelawny and St. Thomas being the exceptions. More specialised paediatric and



rehabilitation medicine services are however only available in Kingston, at the University Hospital of the West Indies (UHWI) Child and Family Clinic, Paediatric Neurology Clinic and Rehabilitation Medicine Clinic; and at the Bustamante Hospital for Children (BHC) Paediatric Neurology Clinic. Likewise, specialist paediatric surgical services are only available at public health facilities in Kingston. Investigative and therapeutic services which are required for children with complex developmental disabilities are also limited in their availability at public facilities across the island. These services are primarily available in Kingston, although some therapeutic services are available via the Early Stimulation Programme in special facilities in Portland and St. James.

Education in Jamaica is offered through public and private institutions. The public education system is the purview of the Ministry of Education, Youth and Information (MOEYI), and has offerings from the early childhood to tertiary level. Private schools also offer services from early childhood to tertiary levels. Children with suspect developmental disabilities identified at school are referred for diagnosis and treatment to both the private and public medical systems. The MOEYI provides support to young children with disabilities through two undertakings of the Ministry: the funding of the MICO University College Child Assessment and Research in Education (CARE) Centre which is the main public testing agency for children with learning difficulties, and the Ministry of Education Special Education Unit, which provides shadow support, placement in private schools and technical assistance to teachers.

The Early Childhood Commission (ECC) is the agency of the Ministry of Education mandated in law with responsibility for the co-ordination and development of the early childhood sector. Support for children with disabilities is provided through the regulation of pre-schools (with specific regulations related to support for children with disabilities), use of the Child Health and Development

Passport (CHDP) (a parent held booklet with child development and screening information) in early childhood institutions, the application of the national readiness evaluation for four year old children (Jamaica School Readiness Assessment), and the establishment and monitoring of parent places which provide support to families of children with disabilities.

The social sector supports persons with disabilities through the existence of a conditional cash transfer programme (CCT) – the Programme of Advancement through Health and Education (PATH), the Early Stimulation Programme (ESP) and the Jamaica Council for Persons with Disabilities (JCPD). The ESP is an early intervention programme of the Ministry of Social Security for children under the age of eight years who have developmental disabilities. The ESP is constrained by funding, human resources and location, however they offer community (home/school) services, centre-based services and school-based services to children with disabilities. The JCPD is the Government of Jamaica agency with responsibility for ensuring the rights of persons with disabilities are upheld and will be the agency for ensuring implementation of the Disability Act.

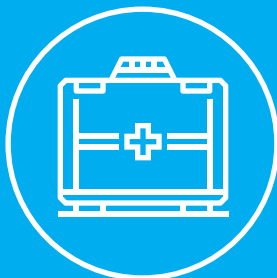
System Strengths for the Support of Children with Disabilities

Areas of strength in the support for children with disabilities include Jamaica's political stability and existing political will to support children with disabilities. There is also policy and legislative support through the signing of international treaties, such as the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCPD), and the existence of national policies, laws and plans that include support for children with disabilities, such as the 2030 National Development Plan, aligned with the Sustainable Development Goals (SDGs); Disability Policy, Disability Act and

draft Disability Regulations; National Parent Support Policy; draft Early Childhood Policy, and a National Strategic Plan for Early Childhood Development (ECD). There are government agencies that are focused on young children, (Early Childhood Commission (ECC)), on persons with disabilities, Jamaica Council for Persons with Disabilities (JCPD), and on parents, National Parent Support Commission (NPSC). There are established agencies for child protection, the Child Protection and Family Services Agency (CPFSA); and for ensuring that child rights are upheld, the Office of the Children's Advocate (OCA).

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There are also areas of strength in health, education and social sector service provision. In the health sector, there is a well-developed primary health care system with universal access for antenatal and well child care; the majority of births take place in hospital attended by trained personnel; pregnant women are screened for chronic and infectious conditions known to be damaging to the foetus, and newborns are screened for sickle cell disease. Public paediatric services are accessible to the majority of the population. A Child Health and Development Passport (CHDP), issued to all children at birth since September 2010, includes screening tools that follow international recommendations for general developmental screening. There is a clear referral



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SOCIAL

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pathway for children with obvious congenital disabilities identified at birth.

In the education sector, there is almost universal access to early childhood institutions (ECIs) between the ages of 3 and 5 years. The EC Act precludes exclusion of children because of disabilities. There is a regulatory system for ECIs that includes standards for teacher training, classroom toys, the physical environment and developmental monitoring and reporting, that support children with disabilities in the classroom. Elements of a comprehensive national ECD screening system have been developed, including the CHDP, the Family Support Screening Tool and a 4-year old school readiness evaluation (Jamaica School Readiness Assessment (JSRA)).

In the social sector, there is a successful Conditional Cash Transfer programme, and there is an established early intervention programme. Psycho-social support systems exist through the existence of local parent support groups and foundations that support families and children with disabilities. There are also successful parent support initiatives by the

ECC and by the NPSC.

A number of international and local development partners have provided financial and technical support to public sector programmes. There are also several local parent support groups and foundations which provide diagnostic, treatment and support services to children with developmental disorders.

System Challenges for Children with Disabilities

Despite the numerous strengths, there are system challenges. Implementation of policies, laws and programmes has not occurred as anticipated. The Disability Act is not yet in force, and the Disability Regulations and Early Childhood Policy have been in draft format for some time. There is no accurate data available on the prevalence, distribution and aetiology of childhood disability, including limited voluntary registration. Household surveys are known to be less accurate than surveys which include some diagnostic evaluation. The absence of accurate data precludes adequate planning for

services.

There is also inadequate co-ordination of programmes and services for children with disabilities, as indicated by focus group discussions and case reports of parents of children with disabilities. There is no clear pathway for the diagnosis and provision of services across health, education and social sectors and for developmental disabilities identified after birth, and there is limited cross-sectoral co-ordination.

There is significant stigma and discrimination co-existing with limited public and parent knowledge and understanding of developmental disabilities, the importance of screening and early identification, and the processes that have been developed to support children with disabilities.

There is inequity in access to tertiary paediatric medical and therapeutic services within Jamaica. Some of the international recommendations for screening immediately after birth are not in place, such as newborn screening for a range of congenital conditions and newborn hearing screening. There have been recent concerns about the sustainability of newborn screening for sickle cell disease; it is not fully funded by the government. Health care workers are not adequately trained in the existing screening mechanisms and in early intervention support, including psycho-social support. There is limited access to tertiary diagnostic and therapeutic services, and psycho-social supports services, such as counselling or mental health services for parents.

There is limited access to educational services for children 0-2 years. While there is almost universal access for general ECD services for children 3-5 years, there is inequity in quality due to a fee for service structure. There is very limited access to special education or inclusive education services for children with disabilities in both the public and private sectors. Though ECI standards to support children with disabilities and elements of

a comprehensive national ECD screening system have been developed by the ECC, monitoring of and compliance with standards is low, and elements of the screening system are not fully implemented. Teachers in ECIs and in special schools are not adequately trained to support children with disabilities.

There are no national social protection mechanisms specific to children with disabilities. Children with disabilities and their families must first satisfy the poverty criteria of the existing CCT programme to receive government social support. There is limited access to regular and high quality public early intervention services. There is limited parent support for parents of children with special needs/developmental disabilities. In particular, the existing programmes do not adequately support the range of children with disabilities and their families.

While donor support and services has improved services to children with disabilities, support has often not been well co-ordinated, and there are concerns about sustainability of donor-supported programmes. Jamaica, a lower middle income country, functions within a stringent economic climate that can impact the sustainability of services and the development of expanded and comprehensive services, which require additional investment in human and physical resources.

RECOMMENDATIONS

Based on the existing strengths and the identified challenges, the following recommendations are being made.

1. OPERATIONALISE THE DISABILITY ACT AND REGULATIONS

The Disability Act and Regulations should be operationalised, to provide the framework for policy and programme development.



2. REVIEW THE IMPLEMENTATION OF EXISTING POLICIES, LAWS, PROGRAMMES AND STANDARDS

Comprehensive systems research should be undertaken to review the passage of laws and implementation of existing policies, laws, programmes and plans relevant to children with disabilities throughout the Government of Jamaica ministries, departments and agencies to identify implementation gaps for attention and action.

3. ACCURATELY DETERMINE THE PREVALENCE AND EPIDEMIOLOGY OF CHILDHOOD DISABILITY

There should be accurate determination of the prevalence and distribution of the different types of childhood disability, as well as existing support services being received by children with disabilities, to aid planning for services.

4. DEVELOP A COMPREHENSIVE AND CO-ORDINATED SYSTEM OF SERVICE DELIVERY

There is need for the development of a widely accessible, co-ordinated and comprehensive national strategy for children with disabilities, with clear pathways for the early identification, diagnosis and provision of services across health, education and social sectors.

5. DEVELOP A PUBLIC EDUCATION CAMPAIGN

A public education campaign should be developed to sensitise parents and the public on childhood disability and the rights of children with disabilities to allow for early identification and early intervention, as well as reduction of stigma.

6. IMPROVE ACCESS TO INTERVENTION AND THERAPEUTIC SERVICES

Investment in training of professionals to support children with disabilities is necessary. Training of professionals will be required at

tertiary levels as well as at school, health centre and community based levels to ensure access to early intervention services for all children. There will also need to be investment in physical resources for professionals to support children with disabilities.

7. IMPROVE ACCESS TO EDUCATIONAL SERVICES

All Government of Jamaica owned and operated infant schools and Brain Builder Centre island-wide should be designated as integrated schools, and provided with the human and physical resources, to allow access to educational services for all children with disabilities.

8. INCREASE ACCESS TO AND CO-ORDINATION OF SOCIAL SUPPORT SYSTEMS

The presence of a child with a disability is associated with higher levels of poverty. A co-ordinated approach that provides adequate social support for children with disabilities is required.

9. ENSURE ADEQUATE PARENT SUPPORT SERVICES

General parent education and support services should include support for parents of children with disabilities. Additional specific parent support services should be made widely available through existing parent support networks.

10. ESTABLISH AN OVERSIGHT BODY TO ENSURE THE RIGHTS OF YOUNG CHILDREN WITH DISABILITIES ARE UPHELD

An oversight body will be necessary to ensure that the recommendations made to ensure the rights of children with disabilities are implemented. A cross-sectoral body, under the ECC's mandate is recommended.

