BRIEF REPORTS

Technology-Assisted Early Disability Identification and Monitoring in Children: A Model for Middle- and Low-Income Countries

Binoy Mathew K.V.[1] Mary Elizabeth Tidiya Walarine [2]

1.Department of Physiotherapy, Composite Regional Centre for Skill Development Rehabilitation and Empowerment of Persons with Disabilities, Kozhikode, India

2 Department of Medical Surgical Nursing, MIMS College of Nursing, Malappuram, India

ABSTRACT

The initial 1000 days after birth is the period of major brain development. It is found that children with various neurological, musculoskeletal and developmental disorders and those "at high risk of disability" show early identifiable signs and symptoms. If an appropriate level of intervention is initiated at an early age, when neuroplasticity is at the maximum, positive changes could be made to a great extent in their overall development. Recent advances in the technology could be used for early screening and monitoring of children. In this brief report the authors discuss a technology-assisted early disability identification and monitoring system which is ideal for middle- and low-income countries.

Key words: *disability, early identification, early intervention, assistive technology, children*

INTRODUCTION

Early identification of children with disabilities and "at high risk of disability" is of great significance during gestation and in the first 3 years after they are born. Neuroplasticity of the brain is higher during the initial 1000 days after birth, hence starting early intervention strategies during this critical period in children with developmental problems has shown better clinical outcomes.

Developmental delay is a delay in achieving age-appropriate development compared with typically developing children in cognitive, motor, speech,

[*]**Corresponding Author: Email: binoy9797@gmail.com**

language, and social domains (Abo El Elella et al, 2017). In India, around 10% of children experience developmental delays with a risk of disability (Shekhawat et al, 2022). It is reported that only around 50% of developmental problems among children are detected before the age of 5 years (Singh et al, 2017). Developmental disorders such as Autism Spectrum Disorders, hearing impairment, visual impairment, motor impairment, intellectual impairment, and behavioural conditions can be detected in the initial years of a child (Lipkin et al, 2020). Evidence from observational studies shows that preterm delivery is one of the leading causes of various neurodevelopmental disabilities in children. Visual, hearing, cognitive, and motor disabilities are frequently seen in preterm babies. Hence, close monitoring of these children for developmental milestone achievement delays and behavioural changes in their initial years of childhood is recommended(Scharf et al, 2016). Experts recommend screening of children aged 18 to 24 months for early identification and management of Autism Spectrum Disorder (ASD) (Sanchack & Thomas, 2016). Cerebral Palsy (CP) is one of the most common physical disabilities among children and is usually diagnosed after 2 years of age. The delay in diagnosis has negative consequences in the development of these children (Byrne et al, 2017). A follow-up programme conducted in the United States of America among babies admitted in neonatal intensive care units showed that early identification and intervention in cerebral palsy is feasible(Byrne et al, 2017). Spinal Muscular Atrophy (SMA) is the most common neurodegenerative disease in childhood, and early identification and intervention during infancy show substantial improvement in neurodevelopmental outcomes (Vill et al, 2021).

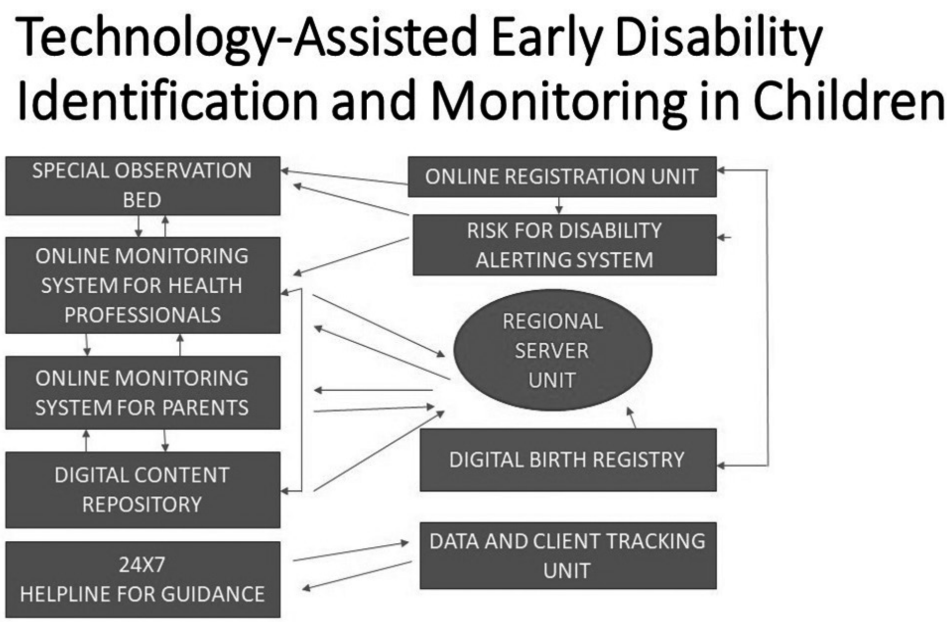
Developmental Monitoring (DM) is a dynamic and ongoing process of gathering information regarding the developments of children by health professionals and making clinical judgments based on it and on personal experience. Developmental Screening (DS) is a more formal and structured evaluation using validated developmental screening tools. Growing evidence recommends using both DM and DS in tandem for better clinical outcomes (Barger et al, 2018; Barger et al, 2022). However, such a DM- and DS-system is currently not integrated into primary healthcare in low- and middle-income countries. Thus, keen observation and monitoring of children for any developmental problems by parents, caregivers, and health professionals are of great relevance. Using a parent-completed screening questionnaire has been found to be relatively accurate, economical, and time saving (Singh et al, 2017). However, such text-based screening tools are considered to be passive. Telephone-based developmental screening for developmental problem detection seems promising (Nelson et al, 2019), although an e-screening tool for developmental delay with rich multimedia content was found to be more engaging and easily comprehensible compared with routine text-based screening tools (Cheng et al, 2017). It has been reported that by restricting screening to disabilities that can be diagnosed at pre-school age, a large segment of children who are at risk for developing disabilities is being missed (Masefield et al, 2021). Even in countries like the United States of America, where well-established early identification and screening is available and 85% of development monitoring agencies are involved in developmental screening for ASD, only 39% are conducting diagnostic assessment before the age of 3 years (Williams et al, 2021). Another major reported concern is poor follow-up adherence for early intervention in spite of positive referrals from developmental screening centres (Schoeman et al, 2017). The South Carolina Early Intervention Programme, which was a 2–tier screening programme, led to a five-fold increase in referrals for early intervention services for children "at risk for ASD". Only 2.5% of those identified children were found negative for ASD (Rotholz et al, 2017).

Considering all these aspects, it was felt that effective use of technology would enhance the sensitivity of at-risk children with disabilities and disability identification systems. The authors propose an active disability surveillance system model using technology.

Technology-Assisted Early Disability Identification and Monitoring in Children

Components of the system are as depicted in Figure 1.

Fig 1: Components of Technology-Assisted Early Disability Identification in Children



1) **Online Registration Unit**: Here, mandatory online registration of all new-born children into the screening and monitoring system will be done along with birth registration. The unit will activate the "Risk for Disability Alerting System" if there are identified risk factors for disability in collected data, such as history of a differently-abled child in the family, a mother more than 35 years of age during gestation, a preterm baby, low birth weight, neonatal respiratory distress, and neonatal seizures.

2) **Special Observation Bed**: The special observation bed will be of adequate size to accommodate children up to 2 years of age and will have safety features like padded edges, padded railings, accessible doors and a safety net above. The bed will be equipped with a face analysis system, speakers in multiple locations, a series of colour lights, a mobile visual display unit, a high-resolution camera with video recording, and image capture capabilities. The facial analysis system compares the facial image of the child and detects facial dysmorphism and facial abnormalities. The sound speakers in multiple locations randomly emit sounds of various frequencies and help in monitoring the response of the child. A series of coloured lights

that emit light randomly will help in detecting the visual responses of the child. A mobile visual display unit, showing audio-visual content moving overhead across the bed, will help to detect the audio-visual tracking ability of the child. The high-resolution camera will help capture images and videos of good clarity, which will be compiled in a digital content repository. With the aid of artificial intelligence, analysis of audio-video content can help detect abnormalities among infants, such as weakness, paralysis or reduced activity of limbs, reduced eye contact, absence of visual tracking of objects, and non-responsiveness to sound.

3) **Online Monitoring System for Health Professionals**: The system has dynamic developmental screening and monitoring tools to aid in the surveillance of children with disabilities and at risk for disabilities. Age-specific developmental milestone-based modules will be created and integrated into the system. This helps in tracking the age-specific motor, social, and language milestone levels of each child. Putting the age of the child in the artificial intelligence-integrated developmental screening and monitoring system will help in checking the extent of age-appropriate achievement in motor, social, and communication domains of developmental milestones. Online registration data, initial screening data, and periodic follow-up data will be integrated to reduce duplication of entries and promote ease of access for all related health professionals. Additionally, the system will allow data to be shared after masking sensitive personal information for policymaking and research purposes. To further enhance the surveillance, data of gestational mothers who are at high risk for delivering a differently-abled child can be added to the system for close monitoring of such children after birth.

4) **Online Monitoring System for Parents**: This component of the system facilitates more parental participation and information sharing about certain disabilities like ASD, communication disorders, and muscular dystrophies where the child will develop symptoms a few months after birth. Here, each parent will have access to the data and related documents of their child. Parents can upload images and videos of their child, related to developmental monitoring, for health professional feedback. Specific guidelines will be prepared regarding the distance, light, sound, angle, orientation, file size, length, and resolution of uploading images and videos. Parents can download selected data files for further medical consultation, rehabilitation, and social security measures. They can register for online consultation with

health professionals for expert guidance in developmental monitoring and interventions.

5) **Digital Content Repository**: All digitally entered data will be securely stored in this repository with easy retrieval capabilities. The repository will be connected to all other components of the system.

6) **Risk for Disability Monitoring System:** This is the most important segment of the proposed model. This highly sensitive system will track if any risk for disability is detected by other components of the system such as the online registration unit, special observation bed, online monitoring system for health professionals and online monitoring system for parents, digital content repository or data and client tracking system.

7) **Data and Client Tracking Unit:** The unit ensures that all health professionals provide periodic developmental monitoring by online/offline consultations, and enter data related to such visits. Reminder email/messages will be sent to the parents regarding the date and time of consultations. If a developmental monitoring follow-up visit is missed, the client will be tracked, and a new follow-up visit date will be arranged with the help of the 24x7 Helpline Unit. Parents will also be reminded to upload images and videos of their child at pre-specified periods for developmental monitoring purposes.

8) **24x7 Helpline for Guidance:** The helpline assists in the smooth functioning of the system by providing multilingual audio, video and email-based communication. Web robots will be enabled in the related website for customer assistance. The unit works in coordination with the data and client tracking unit for better efficiency of the services through the proposed model. Parents and other stakeholders can reach the helpline for support and guidance in using the system. Multilingual and disability-friendly interfaces provide smooth and hassle-free communication.

9) **Regional Server Unit:** For providing better data safety, privacy, and security, a regional server unit will be maintained. The regional server can be at the sub-district level, district level, or state level based on the population density and data volume. The server unit will help identify regions of high disability risk and effective policy- making and utilisation of resources.

Integration of Proposed Model with Digital Birth Registry

The integration of the proposed model with the Digital Birth Registry at hospitals or at the regional level is advised for better coverage of disability risk screening. This will help to closely monitor children born with a risk for disability, including those with low birth weight, those that are born preterm, and those with neonatal seizures.

Mandatory screening of all new-borns in a specially designed observation bed in Neonatal Units prior to their discharge is recommended. This robotic-controlled unit records and analyses the information received using big data analysis. The proposed system will self-disinfect after each session. Big data analysis and machine learning integration in the database will help to identify children with risk factors through data mining and analysis of images and videos uploaded into the system. The proposed model can also be used for monitoring the efficacy of interventions through periodic recording of images, audio and video of beneficiaries and their analysis. Incidence, morbidity, and mortality-related data of various disabilities among children can also be generated from this system. Apart from the online consultation, referral to healthcare institutions, early intervention and rehabilitation units can be done through this platform.

For the successful functioning of the proposed model, effective collaboration of technical experts, healthcare professionals, allied healthcare professionals, rehabilitation professionals, social workers, and policymakers is essential. Accessibility can be enhanced with the integration of desktop and android versions of the proposed model. The level of investment in early childhood development will determine the quality of productive human resources and the progress of the nation. Although the initial investment for implementation will be higher, the system will be cost-effective on a long-term basis. Resource mobilisation can be done through pooling of Corporate Social Responsibility funds of companies, crowdfunding, and providing tax incentives for donations to the project. Cross-subsidisation can be considered by collecting service charges from the affluent segment of the population and providing free services for people from poor financial backgrounds.

Use of voluntary services of retired healthcare professionals and an educated segment of the population for digital verification of documents, related entries, regional-level deciphering, and translation of contents into English for pan-country access can be sought. Such a double review process will reduce the error rates in the system and mitigate problems that may arise due to the use of regional languages in documents. Training for related staff can be done through direct instruction, online instruction, or hybrid instruction. Online guidance and a 24-hour helpline will be helpful. The proposed model can later be modified and upgraded into a holistic repository of medical, rehabilitation and social security data of the beneficiary, with varying levels of accessibility for all concerned stakeholders.

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