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Promoting service engagement for families of children with developmental disabilities in Nairobi and Kilifi: Lessons from SPARK's Implementation

Background

In Africa, families of children with developmental disorders/disabilities (DDs) including autism experience multiple barriers to accessing appropriate care and services. These include lack of awareness, stigma and exclusion, high cost of care, and long travel to access services. Primary healthcare (PHC) facilities lack available services and health personnel have limited capacity to diagnose and manage DDs. We describe SPARK's innovations and approaches to enhance community and frontline health professionals capacity for early identification and referral, diagnostic assessments, and linking families of children with DDs and their caregivers for mental health and other relevant services.

Methods

SPARK (SupPorting African communities to increase the Resilience and mental health of Kids with developmental disorders and their caregivers in Kenya and Ethiopia) is an international research collaboration funded by the NIHR-UK (NIHR200842). In Kenya, the study was implemented in rural Kilifi and informal settlements in Nairobi (Ruaraka and Dagoretti sub-counties) and implemented in catchment areas of 25 public health facilities.

This paper describes results from a multi-phased mixed-methods study, which included: i) conducting workshops with community representatives and professionals to identify needs, map service points, and develop site-specific resource-kits; ii) training of community support workers to identify and refer children at risk of delayed development using a novel detection tool; iii) training of health professionals on the principles of the WHO mental health Gap Programme (mhGAP) and increase their capacity to conduct formal assessment in primary care settings; iv) referral and linkage to health, education, and other services by trained PHC providers and study clinicians using resource-kits/information guides; and, v) evaluation of service engagement using quantitative and qualitative approaches.

Results/lessons

Stakeholder workshops highlighted most caregivers were unaware of services available in their locality. Stakeholders recommended the importance of providing comprehensive information about these services in resource-kits/guides e.g. location, costs, operational hours, contacts, and educational messages. Caregivers reported learning and visiting places listed in these resource-kits for instance, caregivers'mental health support, medical assessments, and therapy services. Challenges included the need to increase awareness about processes involved in educational assessment and school placement for learners with special needs. Access to specialist care e.g. occupational and speech therapy, comprehensive care for children with intellectual disabilities and autism remain a challenge.

Conclusion

Improving information access and proactively identifying mechanisms to link families to relevant services is one step to enhancing the care seeking journey, particularly for families receiving first-time diagnosis. Concerted efforts from state and non-state agencies are necessary to improve the state of services, while ensuring these are accessible, affordable, and constantly available.

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