

CONFERENCE ABSTRACT

Integrated care for diagnostics along the disease trajectory of children with a neurobiological developmental delay or disorder. A network approach.

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Introduction: Children with a (suspected) neurobiological developmental delay or disorder (NDDD) are clinically expected to be diagnosed by a multidisciplinary team as early as possible, given the impact on subsequent development. In different stages of the disorder trajectory and health care use trajectory of the child, diagnostics are needed to clear out development, evolution and recent symptoms. Currently, there is no evidence on the types and organization of diagnostics and follow-up care children with NDDD need, related to the phases of the trajectory.

Methods: Systematic literature review on neurobiological developmental disorders, (multidisciplinary) diagnostics, disease trajectories.

Results: Neurobiological developmental delays and disorders (NDDD) are dysfunctions in the development, involving a large variety in etiology, expression and severity. Assessment at all areas of development (verbal and non-verbal cognition, expressive and receptive language, fine and gross motor development, social communication, social-emotional development) is needed. Classifying and action-oriented diagnostics can be distinguished, as well as mono- and multidisciplinary diagnostics. Mostly, diagnostics are followed by interventions (rehabilitation, support), which may prevent academic failure, behavior problems, dropout, delinquency and the development of more severe mental health issues in later life. These interventions are based on the diagnostic outcome and partly determine the health care use and personal functioning trajectory of a child.

Discussion: Diagnostics with different goals are needed at different stages of the trajectory of the child, because of the complexity and dynamic characteristics of NDDD. Mono- or multidisciplinary diagnostics and classifying or action-oriented diagnostics need to be organized in an effective and efficient way and should be easy accessible both on population level, and in different stages of NDDD trajectory. This type of services can be provided in a network model of services integrating types of diagnostics and care. Literature on policy or mandated interorganizational networks suggests that network approaches help to tackle

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complex problems, if autonomous settings offer complementary services and become mutually dependent to reach common goals.

Conclusion: Children with NDDD follow a non-linear trajectory of diagnostics, rehabilitation and support. Specialized diagnostics are needed at different stages along the trajectory of the child. An integrated health care approach taking into account the characteristics of trajectories needs to be enhanced through whole (mandated) networks.

Lessons learned: Timely accessible multi- and monodisciplinary classifying and action-oriented diagnostics are needed during the trajectory of a child with a NDDD. Integration of diagnostic and other health services can be realized through (mandated) networks taking into account the health system characteristics.

Limitations: This review is conceptual in nature and needs further empirical validation. The empirical part would allow to better understand how local context and health system-characteristics affect the development and implementation of effective networks.

Suggestions for future research: Further research on disorder trajectories, health care use trajectories and personal functioning trajectories of children with a NDDD is needed, as well as research on the implementation of (mandated) networks in order to provide accessible quality care for children with a NDDD.

Keywords: developmental delays and disorder; trajectory; mandated network; multidisciplinary diagnostics
