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Organizational perspectives and diagnostic evaluations for children with neurodevelopmental disorders

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ABBREVIATIONS

ARC	Autism Reference Centres
CAR	Centres for Ambulatory Rehabilitation
MHC	Mental Healthcare Centres
NDD	Neurodevelopmental disorders
PGC	Pupil Guidance Centres

AIM To clarify organizational perspectives on diagnostic evaluations for children with neurodevelopmental disorders (NDD), with the goal to enhance interorganizational collaboration and improve accessibility.

METHOD Focus groups with expert stakeholders in Flanders, Belgium, were organized. Data were analyzed in a continuous, comparative method with researcher and data triangulation, and a member check validation.

RESULTS Fifty-nine people participated in six focus groups. Organizations had no shared vision on diagnostic evaluations of NDD. An interdisciplinary team approach was considered essential. All stakeholders agreed that a diagnostic evaluation is an iterative process along the trajectory of the child.

INTERPRETATION Diagnostic evaluations of NDD should be conceptualized as an integrated process of the child's care trajectory, differentiating needs-based goals in each phase, and requiring an interdisciplinary team approach. This conceptualization will support a health systems model, allowing interorganizational collaboration to optimize available capacity and increase accessibility.

Early detection and early diagnosis of neurodevelopmental disorders (NDD)¹ enhances early intervention, which may prevent academic failure, school behaviour problems, drop out, delinquency, and the development of more severe mental health issues later in life.² Early detection and early diagnosis has the potential to decrease future service utilization and the economic burden.^{1–3}

A diagnostic assessment can be defined as the systematic collection, organization, processing, and interpretation of information, test results, and observations regarding the functioning of an individual to support the decision-making on classification, diagnosis, or interventions.^{4–6} Diagnostic assessments are complex processes that may identify specific developmental disabilities. The evaluations are performed by specialists from different disciplines who are sufficiently competent to determine the potential presence and degree of developmental delay, using validated instruments, tools, and methodologies. Diagnostic assessments can have several goals (Table 1). The most common goal is the classification or categorization of a disease, disorder, or syndrome, including the inventory of the symptoms and their nature and severity.^{1–3,6–8} Examples of NDD classification schemes are the International Statistical Classification of Diseases and Related Health Problems, 11th revision (ICD-11),⁹ the DC:0–5: Diagnostic Classification of Mental Health and Developmental Disorders of

Infancy and Early Childhood,⁶ and the DSM-5.¹ Diagnostic assessments can also be functional, aimed at identifying disorder-related needs and indicating the types of care and support required. The International Classification of Functioning, Disability and Health¹⁰ is often used to support needs-based diagnostic evaluations,⁴ replacing the International Classification of Illness, Disabilities and Handicaps.¹¹ Additionally, (classificatory) diagnostics is also a gatekeeper instrument for access to rehabilitation programmes, settings, or financial support.^{8,12}

Children with a suspected NDD are expected to be evaluated by a multidisciplinary team in all areas of development (verbal and non-verbal cognition, expressive and receptive language, fine and gross motor development, social communication, and social-emotional development).^{1,2,12–14} While the nature of diagnostic team collaboration can differ between organizations, it often remains unclear whether teams are multidisciplinary, interdisciplinary, or transdisciplinary. Multidisciplinary collaboration draws on knowledge from different disciplines, but each discipline stays within its disciplinary boundaries. Interdisciplinary teams function with more cohesion as a collective entity. Transdisciplinarity is a collective, interactive, holistic, team-based approach, integrating all disciplinary perspectives, and transcending traditional disciplinary and professional boundaries.^{15,16}

Table 1: Aims of the diagnostic assessment of neurodevelopmental disorders

A diagnostic evaluation is the systematic collection and organization of information, test results, and observations on the functioning of the child, aimed at:

- Identifying the symptoms, their nature, and severity.
- Making a classification of a disease, disorder, or syndrome.
- Identifying the needs related to the disorder(s).
- Indicating the needed care and support.
- Creating access to specific rehabilitation programs or settings.
- Creating access to financial support systems.

Early detection and diagnostic assessments are not limited to one particular type of organization or facility. Since NDD have a complex and dynamic character, vary in grade and severity, and evolve differently according to the age and developmental stage of the child,^{1,6} different facets of the preventive, acute, post-acute, and rehabilitation facilities are involved. In Flanders, Belgium, different types of publicly regulated services offer diagnostic evaluations of NDD: Centres for Ambulatory Rehabilitation (CAR), Autism Reference Centres (ARC), Centres for Developmental Disorders (CDD), Mental Healthcare Centres (MHC), Pupil Guidance Centres (PGC), and Ambulatory Hospital Service for Paediatric Psychiatry. Additionally, many private practices offer multidisciplinary assessments. Despite the many players, accessibility is insufficient and the field is characterized by long waiting times, financial inequalities, exclusion of certain age and pathology groups, and an unequal regional distribution.¹²

McLeod et al. define assessment as the process of information gathering and interpretation, leading to the development of a clinical description of an individual.¹⁷ In clinical practice, this assessment is the cornerstone of treatment planning and is seen as an ongoing process developing from intake until termination. Such assessment assists with diagnosis, treatment planning, building case conceptualizations and monitoring, and evaluating treatment outcome.¹⁷ Flanders does not use care pathways in the NDD domain. Current diagnostic practices are a result of taking from within the regulations of each type of organization. Diagnostic assessments are currently organized as a short-term activity at the beginning of the trajectory of the child and are repeated, only if indicated, at specific time points in the trajectory to evaluate progress, rehabilitation goals, or evolving needs.

A conceptualization of diagnostic assessments of NDD as a longitudinal process within the ‘patient trajectory’ is currently lacking. The concept of the patient trajectory^{18,19} analyses the sequence of events and turning points in the diagnostic, treatment, rehabilitation, or support processes. A trajectory also considers the organization of work processes, professional patient interactions, and evolving patient needs.²⁰ A patient trajectory includes temporal aspects of the processes of care and considers patient needs and experiences, families and peers, health services, and professionals in different phases. A related but slightly

What this paper adds

- Diagnostic evaluations of neurodevelopmental disorders should be conceptualized as an integrated process of the child’s care trajectory.
- An interdisciplinary, team-based approach is considered essential for the quality of a diagnostic assessment.
- Improving access to diagnostic evaluations requires a health systems’ perspective, focusing on interorganizational collaboration.

different concept is the ‘patient journey’, which refers to the subjective experience and actions in a trajectory.²¹

Patient trajectories have no ‘standardized’ course because they are constructed within a context of ongoing interactions, with a wide range of persons and organizations. Trajectories are socially constructed within the particularities of health systems. The complexity of regulating frameworks, including financing, policy priorities, and cultures of sectors, can hamper coordination of activities and efficient and accessible care provision, especially if different types of services and organizations are involved.²²

This article is based on a research project commissioned by the Flemish authorities to provide a knowledge base to improve the diagnostic evaluation of NDD in Flanders. We clarified the perspectives of the different organizations on current practices for the diagnostic assessments for children with NDD. In addition, we explored different organizational practices and meanings given to multidisciplinary diagnostic evaluations. The insights gained were used as a stepping stone to enhance interorganizational collaboration and improve accessibility.

METHOD

This is an applied, qualitative research project collecting the views, experiences, and meanings given to diagnostic evaluations of children with (suspected) NDD, by stakeholders in the field of NDD in Flanders. Stakeholders were consulted to better understand how to guide the future organization of diagnostic assessments, taking into account the particularities of the local context.

Data collection

We initiated data collection by exploring the literature. The three main themes to be discussed during focus groups were deduced from the questions and problems that emerged from the literature. They concerned: (1) NDD and their characteristics, (2) diagnostic evaluations of NDD, and (3) health care trajectories of children with (suspected) NDD. We developed a topic list and questions related to these topics to guide focus groups with stakeholders by organization type. As such, our research was not carried out using an entirely open-ended approach.

Selection criteria for participants to focus groups were: (1) working in a specialized, governmentally regulated, and subsidized multidisciplinary organization offering diagnostics (CAR, ARC, Centres for Developmental Disorders, MHC, PGC, Ambulatory Hospital Service for Paediatric Psychiatry); (2) experienced in multidisciplinary diagnostics of NDD; and (3) knowledgeable about the diagnostic

activity in their organization. To maximize participation, focus groups were organized after another planned meeting attended by the participants.

The focus groups were audiotaped. Oral, audio-recorded informed consent was given by the participants at the beginning of the focus groups.

The focus groups were moderated (by EC) and supported by a notetaker and observer (ML). After each focus group a debriefing on content and process of each group was carried out.

We started each focus group with a ‘vignette’ of a theoretical definition, grounded in literature, of the concept of diagnostic evaluations in the context of children with NDD (Table 1). This vignette was used as the starting point for reflection.

In the next part of the focus groups, an image (Fig. S1, online supporting information) of an abstracted, linear care trajectory developed by the research team was used to initiate the dialogue of the care trajectory for the child with a (suspected) NDD.

Data analysis

We applied a thematic content analysis. Qualitative thematic analysis^{23–25} allows for a highly flexible approach to develop an interpretation adapted to the needs of this type of study, providing a rich and detailed account of data. The analysis was performed using the audiotapes. We did not use software. Our analysis was data-based, meaning that we first familiarized ourselves with the data through collaboration between the researchers (who also collected the data). In the next step, we identified – within the main themes – emerging subthemes through a coding process. During coding, we identified important sections related to a theme or issue and attached labels to it. Through a process of researcher triangulation, we classified content and labels. This process was done in a stepwise approach for each focus group, gradually building and adapting the thematic analysis. In this iterative process, differences and similarities between focus groups were analysed. EC and ML iteratively analyzed the data in a process of researcher and data triangulation.^{26,27} A member check validation was organized with stakeholders after the analysis to increase validity, relevance, and trustworthiness of the findings.^{28,29}

Ethical approval was not required for this study. Informed consent to the research and to publication of the results was given by the participants at the beginning of the focus groups and have been recorded.

RESULTS

Participation

Fifty-nine people participated in six focus groups (Table 2). The duration varied between 54 minutes (PGC - Vrije Centra voor Leerlingenbegeleiding) and 3 hours 31 minutes (MHC). The planned Ambulatory Hospital Service for Paediatric Psychiatry focus group was cancelled because of low participation ($n=3$). The PGC focus group was divided in two.

Table 2: Participation in focus groups per type of setting

Type of centre	<i>n</i>
Centres for Developmental Disorders (CDD)	4
Centres for Ambulatory Rehabilitation (CAR)	16
Mental Healthcare Centres (MHC)	12
Autism Reference Centres (ARC)	5
Pupil Guidance Centres (PGC)	
PGC GO!	11
PGC VCLB	11
Total	59

GO!, Gemeenschapsonderwijs; VCLB, Vrije Centra voor Leerlingenbegeleiding.

Providers’ perspective on multidisciplinary diagnostics of NDD

Organizations have differing visions on multidisciplinary diagnostic evaluations of NDD. Visions and opinions focus, on one hand, on categorizing diagnostics and, on the other, on functional needs-based diagnostics. Most participants considered functional needs-based diagnostic evaluations as most important but shared the opinion that a classification has added value for planning treatment or support and for parents and caregivers to ‘give meaning’ to the problem. A label for the diagnosis appeared to support understanding and coping.

Labelling the medical component of a diagnosis might relieve parents of feelings of guilt.
(CAR, participant 15)

A diagnosis can be threatening, it can relieve feelings of guilt, but it might also be a way to give answers, to exclude other causes.
(CAR, participant 12)

A good representation based on the International Classification of Functioning, Disability and Health is important and provides added value. That’s also a diagnostic evaluation. It would be easier if every organization would be willing to use this reference framework.
(PGC – Vrije Centra voor Leerlingenbegeleiding, participant 7)

Diagnostic evaluation is also the creation of a strengths and weaknesses profile of the child with which care providers can work.
(ARC, participant 3)

The meaning of diagnostic evaluations must broaden in our society. It doesn’t only consider labelling. We must invest in a shared vision on diagnostic evaluations.
(MHC, participant 10)

It was also pointed out that categorical diagnosis is required to obtain reimbursement for rehabilitation, care, and support.

At specific time points, a categorical diagnosis is needed because of the regulations.
(CAR, participant 11)

Multidisciplinarity of the diagnostic assessment

All groups considered multidisciplinarity essential for the quality of a diagnostic assessment.

In a private setting, diagnostic assessments are too fragmented. The most important is that we acquire a holistic view of the child. In private settings, the approach is too one-sided.

(CAR, participant 6)

In a CAR, the decision-making process is multidisciplinary. In private settings, the different disciplines involved pass their results to the medical doctor, and the diagnosis is made only by him.

(CAR, participant 16)

Comments were made on the difference between multidisciplinary and interdisciplinarity. Respondents argued that not only is a shift needed from monodisciplinary towards multidisciplinary assessments, but also a move towards interdisciplinary and team-based approaches in order to guarantee qualitative and needs-based diagnostic evaluations. The organization of this interdisciplinary work needs to be elaborated further.

Disciplines to be involved may vary, depending on the timing and specific diagnostic questions along the trajectory of the child.

In some cases, all disciplines must be involved when the diagnostic process is repeated later in the trajectory. But this depends on the age of the child and the complexity of the diagnostic question. After a first, in-depth diagnostic assessment, not all disciplines must always be involved in the next diagnostic activity in the trajectory.

(COS, participant 2)

Diagnostic evaluations along the care trajectory of the child with NDD

The experts stressed that it is not possible to delineate where the diagnostic evaluation process begins or ends, nor the time required for it. A diagnostic evaluation is an iterative process, especially with very young children, considering their ongoing development.

Diagnostic evaluations are intertwined with the entire care trajectory of the child. It can't be delineated.

(CAR, participant 2)

A diagnostic evaluation is a long-term trajectory.

(MHC, participant 9)

The duration of a diagnostic assessment doesn't depend on the age of the child. In some cases, already at the moment of the anamnestic interview, it's possible to confirm a diagnosis. But also in those cases, a diagnostic assessment must be performed in

order to evaluate strengths and weaknesses of the child and to set goals for rehabilitation. That's also a diagnostic process, but with a different goal than categorization.

(ARC, paediatric psychiatrist)

The timing of a diagnostic evaluation correlates with the expected content and goals. As such, one could identify what type of organization could provide assessments, based on their expertise.

The objective of the diagnostic assessment impacts on the way the assessment is organized, on its content, and the time investment it takes. A demand for a diagnostic label to get access to a specific form of care is another dimension, but also impacts on the waiting lists.

(CAR, participant 13)

Continuity of care problems in the diagnostic and care trajectory

Continuity of care problems occur at each transition in the trajectory, often characterized by long waiting periods for diagnostic evaluations as well as care and support. Moreover, care and support are not initiated if a diagnostic assessment is lacking, as in Flanders. A categorical diagnosis is needed to obtain follow-up care and support.

Accessibility isn't only a problem for a diagnostic evaluation, but also to obtain care and support. There are waiting lists everywhere, children always have to wait.

(MHC, participant 10)

It's difficult and painful, always having to tell people how long it will take.

(CAR, participant 13)

The nature of the referrer also influences the initiation of the trajectory, as well as short- and long-term outcomes.

It depends on who detects the developmental problem, where the child ends up.

(COS, participant 3)

When does the responsibility of the referrer end? ... In my opinion, referrers are better placed to start up preliminary support.

(COS, participant 4)

The often excessively long period between the first suspicion of an NDD and the onset of a formal diagnostic evaluation increases the chances of a child being excluded from diagnostic settings because of their age.

One of the problems is the early detection of NDD, as referrers wait too long before referring a family to a diagnostic organization. When children exceed a certain age, we can't accept them anymore. And there is no alternative.

(CAR, participant 4)

To address the continuity of care and accessibility problems, respondents agreed that diagnostic evaluations did not need to be the first step in the care trajectory. They considered that a trajectory of care should be initiated immediately upon detection or suspicion of an NDD, using needs-based assessments, rather than awaiting a categorical diagnosis. Participants stressed that a different perspective on the regulatory or policy logics was needed.

When you start immediately with the diagnostic assessment, you might possibly make a wrong start. If you start the support and pass to the diagnostic assessment after, for example half a year, when the child has adapted to the situation, it might result in a different profile. Starting a trajectory based on a ‘suspected’ diagnosis would be better.

(CAR, participant 15)

A change in mentality of parents and caregivers is needed. Labelling isn’t a part of the care process.

(ARC, participant 1)

DISCUSSION

This article explores the views of stakeholders in Flanders on the organization of the diagnostic process of children with suspected NDD. It is an in-depth exploration of how fieldworkers see the role of diagnostics. The classification of emerging themes by experts was supported by concepts from the literature.

Diagnostic evaluations: towards a shared concept

Experts working in different types of publicly funded organizations do not use a common framework or vision. Organizational goals and activities, regulations, and institutional and professional logics impact on how experts perceive the content and goals of diagnostic assessments.¹² Functional, needs-based assessments are considered to be the core objective, while in different stages of the trajectory other types of diagnostic assessments with particular goals can be supportive.

Shift from multidisciplinary towards interdisciplinary diagnostic evaluations

Flanders uses multidisciplinary diagnostics as a key concept. Respondents stress the importance of a truly interdisciplinary, team-based working practice, integrating perspectives in collective, team-based decisions for a high-quality diagnostic process.^{15,16} However, the disciplines involved may vary according to the specific diagnostic question. When facing specific problems along the care trajectory, a reassessment might be performed by only one discipline. Further research is needed to understand how interdisciplinary diagnostic assessments can be organized in terms of team composition at certain stages of the trajectory or needs of the child, when interorganizational and ‘transmural’ collaboration is needed, and how the assessment and collective decision-making can be organized to guarantee access to and continuity of care for the child.

Diagnostic evaluations as an intertwined part of the care trajectory of the child

Regulations in Flanders and organizational goals cause the diagnostic process to not be integrated in a trajectory perspective. It is limited in time and mostly organized at the start of a child’s trajectory. However, since NDD are complex in nature and children develop and function in a changing context at different life stages, a diagnostic and assessment trajectory is not a linear process. Conceptualizing diagnostic evaluations as an intertwined part of a care trajectory of the child with NDD would support the design of a health system (Fig. 1).

A diagnostic assessment of the ‘general’ functioning and the needs of the child should be sufficient to start a supportive trajectory, while additional activities, depending on the development and the needs of the child and their context, can be performed in later stages.¹² The diagnostic steps, with varying goals and performed by different providers, need to be integrated. Each step contributes to an in-depth realistic diagnostic assessment (rather than one-shot activities without in-depth knowledge on the functioning

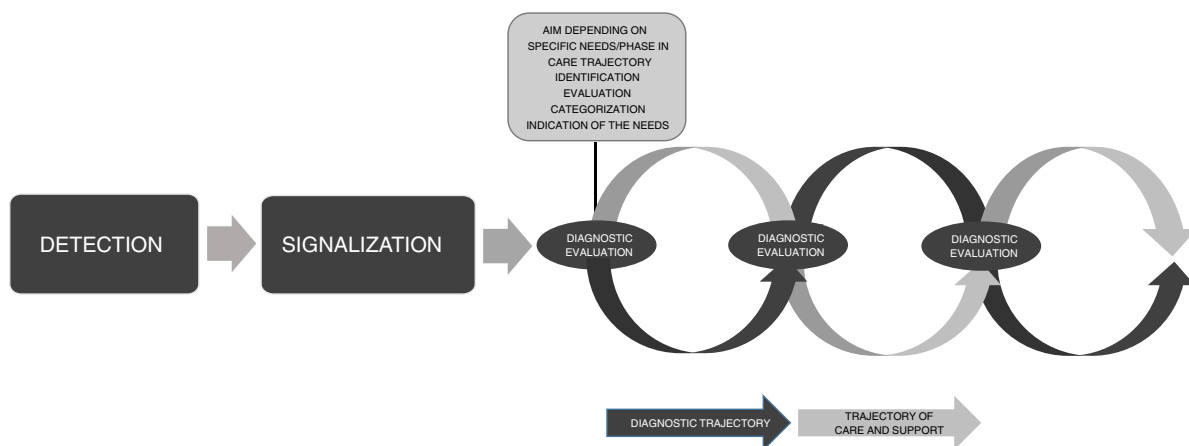


Figure 1: Diagnostic evaluations within care trajectories of children with a neurodevelopmental disorder.

and needs of the child). The team composition will vary, depending on the phase in the trajectory, the needs of the child, and the goals of the assessment. From a health systems perspective, it is important to understand when, why, and what diagnostic assessments are needed, and which providers can offer what diagnostic assessments under which circumstances.

Impact of interdisciplinary diagnostic trajectories on the organization of the field

Making the conceptual shift towards an interdisciplinary diagnostic trajectory intertwined in the child's care trajectory will cause reflection on the health systems' organization and the role and collaboration of different providers in the field. To ensure optimal organization of care trajectories and intertwined diagnostic trajectories, interorganizational collaboration with shared responsibilities and common goals will be needed, allowing heterogeneous types of health-service providers to be involved. A key challenge will be to address the question: Who can deliver which diagnostic assessments, with what goals, at which moment in the care trajectory of the child, and how can the integration of activities be guaranteed?

Methodological reflections

Some methodological limitations have to be considered. Stakeholder perspectives of Ambulatory Hospital Service for Paediatric Psychiatry (insufficient participants) and private initiatives offering multidisciplinary diagnostic assessments of NDD (outside the scope of the commissioned report) are not represented in this study, while these are relevant stakeholders. Parents mainly seek their help when waiting periods in subsidized organizations are too long, or when there is no provision of diagnostic assessments for specific target groups in the subsidized field.

There might have been a selection bias in the 'representatives' of the organizations. Selection of the participants was done by the managers of the organizations (based on criteria defined by the research team), but this pragmatic

choice may imply that more divergent opinions were missed. However, taking into account the criteria of credibility, relevance, and trustworthiness put forward in qualitative research,³⁰ the validation process with stakeholders confirmed the relevance of the analysis. We are also aware that much more in-depth qualitative analysis is needed in follow-up steps.

CONCLUSION

A shared meaning and conceptualization of the diagnostic process would support the organization of the health system in the domain of childcare. Diagnostic assessment of NDD is not a one-shot, short-term activity mostly organized as a starting point of care and support, but needs to be reconceptualized as a diagnostic trajectory, integrated along the child's care trajectory. The range of goals of diagnostic assessments within each phase in the trajectory needs an interdisciplinary team-based approach, but not necessarily with the same team composition. This framework will support developing a health system model allowing for more interorganizational collaboration to optimize the available capacity. Although this study is limited to a Flemish context, the underlying conceptual ideas are transferable to other health system contexts.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: Theoretical linear care trajectory of children with a (suspected) NDD.

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