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The Friesland study

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Summary

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From clinical experiences and from research, it is known that the co-occurrence of a pervasive developmental disorder in mental retardation leads to many additional problems for children and their environment. Therefore, health and educational workers in the area of mental retardation should be aware of pervasive developmental disorders in this population, to enhance early identification and appropriate support. Three factors contribute to early identification and appropriate care. First, instruments are needed to measure pervasive developmental disorders in children and adolescents with mental retardation. Second, information on the prevalence of pervasive developmental disorders will increase the awareness of professionals on the occurrence of these disorders in this population. Third, insight into the additional and specific effects of pervasive developmental disorders on (mal)adaptive behavior of children and adolescents with mental retardation, will facilitate providing effective support. The objective of the present study was to contribute to the knowledge concerning the issues of identification of pervasive developmental disorders in children and adolescents with mental retardation, the prevalence and the relationship with (mal)adaptive behavior (*chapter 1*).

In *chapter 2*, the Scale of Pervasive Developmental Disorder in Mentally Retarded persons (PDD-MRS) and the Autism Behavior Checklist (ABC) were investigated. The aim was to examine their psychometric qualities, and their value for screening children and adolescents with mental retardation for pervasive developmental disorders, by comparing their classifications to each other, and to the Autism Diagnostic Interview-Revised (ADI-R), the Autism Diagnostic Observation Schedule (ADOS) and a clinical DSM-IV-TR classification. The agreement between the PDD-MRS and the ABC was limited. With respect to the validity, the PDD-MRS highly agreed on classification with the ADOS and less with the ADI-R. For the ABC this was reversed. Two factors are considered to contribute to this pattern of agreement between the instruments. First, the underlying concepts differ between the instruments, i.e. the spectrum of pervasive developmental disorders or AD only. The second and most important factor is the fact that the classifications of the instruments are based on information from different sources, either parents or professionals. With respect to the clinical DSM-IV-TR classification, the validity of both screening instruments was high. The PDD-MRS is very sensitive, which may lead to being over-inclusive. The ABC is more specific, yet this may lead to missing

children who actually have a pervasive developmental disorder according to the DSM-IV-TR criteria. Although the PDD-MRS and the ABC measure pervasive developmental disorders differently, the instruments have their own specific contribution to the identification of pervasive developmental disorders.

A follow-up on the previous study is described in *chapter 3*. The objective was to investigate the clinical value of the ADI-R and ADOS in the individual diagnostic process of a child or adolescent with mental retardation. The agreement on classification between the instruments was not more than fair. Besides differences between the ADI-R and ADOS with respect to underlying concepts and sources of information, the time period considered for a classification is a specific factor in their level of agreement, i.e. '4-5 years' or 'ever' for the ADI-R, 'current' for the ADOS. The agreement between each instrument and the clinical DSM-IV-TR classification was high, with the ADOS being more sensitive and the ADI-R being more specific. Although the instruments are not meant as the sole criteria for a diagnosis, they provide the clinician with a lot of specific information on the behavior of the child. Therefore, the combination of the ADI-R and ADOS is recommended as part of an individual diagnostic assessment when considering a pervasive developmental disorder in children and adolescents with mental retardation.

Chapter 4 reports on a prevalence study, which aimed to establish a reliable and well-founded estimate of the prevalence of pervasive developmental disorders in children and adolescents with mental retardation. The prevalence rate based on the clinical DSM-IV-TR classification is 16.7% in the total population, 9.3% in the mild and 26.1% in the combined moderate/severe/profound levels of mental retardation. The prevalence rates estimated with the instruments (PDD-MRS, ABC, ADI-R, ADOS) range between 15 and 20%, with a general increase in the lower levels of mental retardation of 2.5-3 times compared to the mild level. However, the prevalence rates based on the clinical DSM-IV-TR classification are considered to be the best founded estimate. These prevalence rates represent the most recent DSM definition of the spectrum of pervasive developmental disorders (including AD and PDD-NOS), take into account information of parents and professionals, and consider current behavior and the developmental history of the child.

The main objective of *chapter 5* was to investigate the Vineland Adaptive Behavior Scales (VABS), as an instrument to measure adaptive behavior. Despite its wide use in children and adolescents with mental retardation, no data were available

on the structure, the reliability, and validity of the instrument in this population. This study provided empirical evidence for the applicability of the VABS in children and adolescents with mental retardation. This finding implicates a need for supplementary norms for this population, additional to norms for the general population.

In the study presented in *chapter 6*, we aimed to examine the value of the Children's Social Behavior Questionnaire, CSBQ, in measuring problems in subtle social skills, in order to contribute to differentiation between verbal children with mild and moderate mental retardation with and without a pervasive developmental disorder. The specific value of the CSBQ seems to concern identifying slightly different aspects of social behavior that play a role in level of mental retardation, compared to aspects of social behavior that play a role in pervasive developmental disorders. The effect of mental retardation seems to be related to problems in orientation in a situation and fear of changes, whereas the effect of a pervasive developmental disorder is mainly visible in the tendency to withdraw. Since the CSBQ contributes to refining the specific effects of both diagnoses, it is considered as a valuable measure of subtle social behavior in children and adolescents with mental retardation only, or when an additional diagnosis of a pervasive developmental disorder is considered or already exists.

Chapter 7 describes the last study, that aimed to examine the interrelationship between autistic and general behavior problems, adaptive behavior and academic achievement, in the highest functioning children and adolescents with mild mental retardation (IQ 60-70). In this narrow IQ group, adaptive behavior was found to be the only factor that directly affects the level of education. Yet, behavior problems directly influence the level of adaptive behavior. Particularly problems related to pervasive developmental disorders have such a restrictive effect on adaptive behavior, that a child does not attend the level of education that matches his/her intelligence level. Besides a corroboration of the negative effect of pervasive developmental disorders on adaptive behavior, these outcomes implicate that adaptive behavior should receive more attention in the admittance policy of schools for children and adolescents with mental retardation.

In *chapter 8*, the general conclusions of the study are discussed in relation to strengths and limitations of the study, and the implications for clinical practice and research. The main strength of the study, i.e. its total population based character,

improves the representativity of the reported results and therefore provides a solid basis for the conclusions that are drawn.

From a clinical perspective, early and accurate identification of pervasive developmental disorders is concluded to be of major importance. The recommended procedure for this purpose is an extensive, individual assessment, evaluating the current behavior of the child, his/her developmental history, and perspectives of parents and professionals. The ADI-R and ADOS are recommended as standardized instruments to facilitate such an assessment, however without totally replacing it. For the ultimate, individual diagnosis, all information collected with instruments on behavior, and the clinical classification should be integrated and thoroughly considered. Besides specific information on pervasive developmental disorders, information on adaptive behavior should be integrated too, to define the specific effects of the disorder for this particular child. The VABS is recommended for this purpose. With such an extensive procedure, the diagnosis is more than a label: it specifies the effects of that label for this particular child and forms the basis for measures or support, to meet his/her specific needs.

With respect to future research, the present study raised several questions. The present study did not provide information on the stability over time, of the classifications of pervasive developmental disorders with the various instruments and the DSM-IV-TR. Investigation of this stability will improve the insight in the definition and the instruments. Additionally, investigating factors that play a role in whether or not a child is initially identified as having a pervasive developmental disorder, and whether or not this leads to an individual diagnostic process and appropriate care, may contribute to improvement of mental health care for children and adolescents with mental retardation. Besides, scientific foundation of (the effects of) measures, interventions and treatment, will improve the effectiveness of provided care. Extending the knowledge on these issues is therefore highly recommended as the focus of future research.

