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The Friesland study

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Chapter 8

Main conclusions and discussion

8.1 Introduction

The present study had three main objectives: 1) investigation of the psychometric qualities and clinical value and utility of instruments for identification of pervasive developmental disorders in children and adolescents with mental retardation, 2) establishing a reliable estimate of the prevalence of pervasive developmental disorders in this population, and 3) increasing the insight into the role of pervasive developmental disorders in the (mal)adaptive behavior of children and adolescents with mental retardation.

In this chapter, the general conclusions of the separate studies that contributed to these objectives, will be discussed in relation to strengths and limitations, and clinical and research implications.

8.2 Identification of pervasive developmental disorders in children and adolescents with mental retardation

To provide information on the psychometric qualities and clinical value and utility of instruments to identify pervasive developmental disorders in children and adolescents with mental retardation, four instruments were investigated: the Scale of Pervasive Developmental Disorder in Mentally Retarded persons, PDD-MRS (Kraijer, 1997, 1999), the Autism Behavior Checklist, ABC (Krug, Arick, & Almond, 1980), the Autism Diagnostic Interview-Revised, ADI-R (Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedule, ADOS (Lord, Rutter, DiLavore, & Risi, 1998; Lord et al., 2000). With respect to the PDD-MRS and the ABC, we aimed to examine their value for screening children and adolescents with mental retardation for pervasive developmental disorders. Concerning the ADI-R and the ADOS, we were interested in their clinical value in the individual diagnostic process of a child or adolescent with mental retardation. The validity of all four instruments was investigated, by comparing their classifications to each of the other instruments, and to a clinical classification based on the DSM-IV-TR (APA, 2000).

With respect to the instruments, three main conclusions can be drawn from the studies. First, the agreement on classification between the PDD-MRS and the ABC, and between the ADI-R and the ADOS was limited. Second, the validity of the PDD-MRS was higher when compared to the ADOS than compared to the ADI-R, whereas this was reversed for the ABC. Several factors contribute to this pattern of agreement

between the instruments. First, the underlying concepts may play a role. The PDD-MRS and ADOS were developed to identify the spectrum of pervasive developmental disorders, including AD and PDD-NOS, the ABC and ADI-R were constructed to identify AD. The second and probably most important factor concerns the fact that the classifications of the instruments are based on different sources of information. The ABC is a parent questionnaire, whereas professionals complete the PDD-MRS. The same holds true for the ADI-R, an interview with parents, and the ADOS, an observation by a professional. Last, for the ADI-R and ADOS, the time period considered for classification ('4-5 years' or 'ever' for the ADI-R, 'current' for the ADOS) leads to a specific contribution to the diagnostic process. The third conclusion of the instrument studies was that all four instruments have a high validity compared with the clinical DSM-IV-TR classification. The ADOS and the PDD-MRS are very sensitive, which implies that these instruments identify many of the children who are classified as having a pervasive developmental disorder by the DSM-IV-TR. However, this merit may lead to being over-inclusive. The ABC and ADI-R are more specific, yet this may lead to missing children who actually have a pervasive developmental disorder according to the DSM-IV-TR criteria. The outcomes implicate that each instrument has its own specific contribution to the identification of pervasive developmental disorders in children and adolescents with mental retardation, and therefore its own specific clinical value.

Two limitations should be kept in mind when interpreting the results. In the first place, different instruments were used in the different sources. Collecting information from different sources with the same instrument, would have shed light on the extent to which the level of agreement is influenced by the underlying concept of the instrument, or by the source of information. However, it is known from earlier research that even with the same instrument in different sources the level of agreement is low. Szatmari et al. (1994) for example, used the ABC for both parents and teachers, and still found a low correlation between the scores of both informants. Recently, Koot and Dekker (2001) developed the Dutch version of the Developmental Behavior Checklist (DBC), for investigating behavior problems in children and adolescents with mental retardation. The instrument has a version for parents (DBC-P) and one for teachers (DBC-T), yet also with this new and well-founded instrument, agreement between the sources is only moderate (Dekker, Nunn, & Koot, 2002). These studies corroborate the emphasis on the informant as the most important

factor that contributes to a low level of agreement, more so than the concept of the instrument.

Additionally, using the same instrument in various sources is not always possible, e.g. administering the ADI-R to a teacher for example, or an ADOS observation by a parent, does not make any sense, since these instruments were specifically developed to be used as an interview of a professional with a parent, and an observation of a professional of the child. Hence, this would only be possible for the ABC, and perhaps to a lesser extent for the PDD-MRS, although this instrument was also specifically developed for professionals, and would thus need to be adjusted for completion by parents.

Nevertheless, identifying behavior problems or disorders in children and adolescents is always based on an external source of information, regardless of who this source is. Particularly in young children or in the population with mental retardation, self-reports will probably be too difficult or lack reliability. Obviously, the information is influenced by what the informant observes as a problem. What problems are reported, is related to the norms or expectations of the informant, with respect to behavior that should or should not be present in children. Additionally, the experienced burden of the informant influences the report. A parent or teacher who has the feeling that he/she can handle a child well enough, may report no problems on a child, whereas another parent or teacher may have a much lower threshold for experiencing specific behavior as problematic. Notwithstanding the informant specificity and subjectivity of the reported problems, fact is that the informant reports them as problems, and may ask for help or assistance. To provide appropriate support, it is then important to specify the actual child specific factors (e.g. diagnostic assessment, including other sources) and the informant specific factors (threshold-levels, experienced burden, child rearing skills, external resources, etc.).

Second, the clinical DSM-IV-TR classification in our study did not totally reflect the course usually followed in clinical practice to assign an individual diagnosis. Since the classification was based on information from parents, collected with the ADI-R and on information of the child by reviewing the videotape of the ADOS, the agreement between these instruments and the clinical classification may be inflated. However, we emphasize that no algorithm information was available to the clinicians, which kept the independence as large as possible. The factor that plays a far greater role in this agreement, in our opinion, is the combination of information from various

sources and time periods. This results in a more complete picture of the developmental history and current behavior of the individual, which is required for a diagnosis of a pervasive developmental disorder, as is known from clinical practice. Despite this limitation, the fact that a clinical classification was part of the Friesland study can certainly be considered to be a strength, since most epidemiological studies are based on instruments only.

Due to their specific contributions, it is important to bear in mind the specific purpose when choosing which instrument, or combination, to use in a specific situation. Considering the ABC and PDD-MRS from a research perspective, they seem useful in sampling and describing symptomatology of pervasive developmental disorders in participants, when large populations are investigated. When sample sizes are smaller, more extensive instruments, such as the ADI-R and ADOS will provide more detailed information.

From a clinical perspective, in two specific situations the PDD-MRS and the ABC can provide valuable information. On a general, policy level, the PDD-MRS and ABC may be used for planning services. Planning measures and services for children with mental retardation and co-morbid pervasive developmental disorders should be based on reliable information, or at least a rough estimate, on how many children have a pervasive developmental disorder. For example, when a school starts planning services in this area for a next period of time, it is important to know how many children of their population need these services. Based on these numbers, the school can decide to reserve more or less money to increase the expertise of teachers, for intensive behavioral therapy to train adaptive skills, or to start or extend classes with a very structured approach (e.g. 'autism-groups'). Since the information needed in this example, is information from the professionals working with the child, the PDD-MRS seems to be most applicable. However, the ABC could play a similar role when an institution or day-care facility plans services for parents, such as psycho-education, or coaching parents in child rearing skills.

Moreover, the PDD-MRS and the ABC may be of great value on an individual level. Obviously, the PDD-MRS nor the ABC can replace an individual diagnostic process, not even when they are used as a combination. Nevertheless, the value of the instruments lies in the ability to specify general concerns that are raised by parents or professionals. Evaluating specific behaviors can extend the insight into the background of behavior problems shown by the child. Therefore the screening

instruments may function as a first indication, to identify children or adolescents who might need a more intensive diagnostic assessment. The fact that they are relatively short and uncomplicated to complete, adds to their clinical applicability.

Although the ADI-R and ADOS are not meant to replace a diagnostic assessment either, and cannot be considered as the sole criteria for a diagnosis, they facilitate an extensive assessment of a child. From a clinical perspective, applying the combination of both instruments seems to be most valuable. In that case, the slightly different aspects measured by each of the instruments, the current behavior and the developmental history, and the perspectives of parents and a professional, can be evaluated, providing the clinician with a lot of information.

In the area of autism research, the ADI-R and ADOS are currently considered to be the gold standard. The instruments are often applied as the basis for sampling of the participants. Moreover, scientific journals often require them as such a basis. The fact that the agreement on classification between the ADI-R and ADOS is not more than fair implicates that the combination of the instruments would be the most meticulous way to decide whether or not to include a child in a sample. However, in practice many studies base their sampling on either the ADI-R or the ADOS. Especially when investigating the spectrum of pervasive developmental disorders, the concept of the ADI-R, i.e. AD, seems too narrow to contribute to meaningful criteria for sampling.

Both for clinical and research practice it is important to realize that the clinical value of the ADI-R and ADOS is higher in children with mild or moderate mental retardation, than in the lower levels of mental retardation. This does not seem to be a specific limitation of the ADI-R or the ADOS. It can largely be explained by the fact that children and adolescents in the lower levels of mental retardation often show very limited behavior, and that the behavior that is evident, shows a large overlap with behavior as seen in children and adolescents with pervasive developmental disorders. Therefore, the discussion should not be whether or not the ADI-R and ADOS are helpful in differentiating between pervasive developmental disorders and low levels of mental retardation, but whether or not a differentiation between pervasive developmental disorders and low levels of mental retardation can or should be made at all.

The finding that the ADI-R and ADOS do not solve the issue of differentiation in low functioning individuals corroborates this recurrent debate. However, the ADI-R

and the ADOS are the only available, extensive, diagnostic instruments. When they are used in children with lower levels of mental retardation, this should be done very carefully. In individual, clinical processes, the information obtained with the instruments can probably more easily be combined with other information, such as teacher/facility staff information, or a clinical impression, to ensure a more reliable clinical diagnosis. For research, this may be different, especially when the criteria of sampling are the classification of the ADI-R and/or ADOS. Therefore, cautious interpretation of the findings in research with individuals with low levels of mental retardation is recommended.

A complication for using (the combination of) the ADI-R and ADOS in clinical practice and research, is the time consuming character of the instruments, particularly of the ADI-R. Clinical time and finances are limited, and efficiency is a high value in clinical practice nowadays. Nevertheless, these time, financial and efficiency limits should never be at the cost of an individual child. A pervasive developmental disorder is a severe disorder, with severe implications for the child and his/her environment. Therefore a thorough procedure of investigation of the individual child must take place when a pervasive developmental disorder is considered. The time consuming and sometimes confronting character of the instruments is also a burden for parents and the child. The child needs to be moved from his/her natural situation for observation, which may cause extreme stress preceding the observation and afterwards. The parents need to find 2.5-3 hours to answer questions on their child, which may cause them to take a day off from work, organize someone to look after their (other) children, etc. From practice we know, that even if they can be interviewed in a relatively uncomplicated way, talking about their child for such a long time, and with respect to such crucial problems, generally wears them out. To prevent an unnecessary burden for child, parents and clinicians, the value of this process for the particular child should be evaluated on forehand.

Unfortunately, the ADI-R and ADOS can definitely not be administered without specific training, even in the case of experienced professionals and researchers. Accordingly, one could conclude that the instruments actually have a low reliability. The inevitability of specific training complicates the use of the instruments in clinical practice. At least in the Netherlands, but also in other European countries, the main problem is the limited accessibility of the workshops, due to the fact that they are not organized regularly. Combined with long waiting lists for each workshop, this means

that even if clinicians or researchers want to use the instruments, they cannot be trained accordingly. Training more trainers would add to a higher accessibility, since each workshop would then be accessible for more participants. Moreover, on a policy level, the importance and the time consuming character of the organization of a workshop should receive more emphasis. This would lead to better opportunities for trainers to regularly organize a workshop, and its pre- and post-course requirements. Besides accessibility, the time consuming character of the training and its pre- and post-course requirements seem to limit the use of the instruments. Some clinicians and researchers start training, yet never finish, due to time limits. Although the workshops are intensive, and the post-course requirements are strict, practice shows that this is not only valuable but also necessary. The ADI-R and ADOS are instruments that need a lot of training before applying them, and at least as much effort afterwards, to keep consensus on administration and scoring. When this is established, the ADI-R and the ADOS are valuable instruments for clinical practice and research.

8.3 Prevalence of pervasive developmental disorders in children and adolescents with mental retardation

To establish a reliable estimate of pervasive developmental disorders in children and adolescents with mental retardation, we investigated a total population with the four instruments described above, and the clinical DSM-IV-TR classification. The best founded estimate that we could establish is the prevalence rate based on the clinical DSM-IV-TR classification, viz. 16.7% in our total population, 9.3% in the mild, and 26.1% in the combined moderate/severe/profound levels of mental retardation. These prevalence rates represent the most recent DSM definition of the spectrum of pervasive developmental disorders, including AD and PDD-NOS. Additionally, they take into account information from parents (as collected with the ADI-R) and from professionals who observed the child (by reviewing the videotape of the ADOS). Furthermore, through this procedure, information about the current situation is combined with the developmental history of the child. The method we followed for the DSM-IV-TR classification most securely approaches the diagnostic process on an individual level. Nevertheless, the final step in this process is absent in the present study: an individual assessment, in which all instruments and the clinical

classification are integrated and thoroughly considered. Based on such an assessment, an ultimate, individual diagnosis can be assigned. Perhaps, this procedure could be completed in a future study.

The prevalence rates based on the instruments take into account only specific aspects of all information needed for a reliable diagnosis. As described above, the source of information, and the underlying concepts differ for the various instruments, leading to differences in the height of the prevalence rates and to differences in which individuals are included in the various prevalence rates. Besides, the prevalence rates based on the ADI-R (total 16.8%, mild 11.3%, combined moderate/severe/profound 21.5%) and the ADOS (total 19.8%, mild 10.2%, combined moderate/severe/profound 32.1%) seem to be overestimates, due to their tendency to be over-inclusive, particularly in the lower levels of mental retardation.

All of these prevalence rates were based on the observed population and could not be corrected for non-response, which limits the interpretation of the prevalence rates to some extent. Assuming the prevalence of pervasive developmental disorders to be lower in the non-response population, would lead to the conclusion that all three estimates are likely to be somewhat inflated. The prevalence rates from the screening, 15.9% based on the PDD-MRS and 15.2% based on the ABC, were corrected for non-response and therefore represent reliable screening prevalence rates. The prevalence in the combined moderate/severe/profound levels of mental retardation was found to be 2.5-3 times higher than in the mild level.

Compared to previous studies, we found relatively low prevalence rates. Besides the fact that it was complicated to exactly compare the prevalence rates, due to our more recent instruments and concepts of pervasive developmental disorders, the features of the investigated populations seem to play the largest role in the differences. Compared to our total population, other studies mostly investigated relatively high-risk populations, such as individuals from institutions, day-care facilities, or observation clinics, individuals with mental retardation and epilepsy, or individuals with severe and profound mental retardation only.

The main conclusion that can be drawn from the prevalence rates that we established, is that pervasive developmental disorders commonly occur in children and adolescents with mental retardation. This corroborates the need for specific and professional knowledge and expertise with respect to this disorder in this population, in three specific areas. First, on the individual level, the concept of pervasive

developmental disorders should be an almost automatic concept to be considered in the diagnostic process of a child or adolescent with mental retardation. Second, appropriate services should be provided, from a professional and theoretical framework and specifically developed for children and adolescents with a dual diagnosis. Third, on a policy level, providing such services, and improving the expertise of health and educational professionals, should be organized in relation to the relatively large proportion of the population that needs them or will at least benefit from them.

8.4 (Mal)adaptive behavior in children and adolescents with mental retardation and pervasive developmental disorders

To investigate the influence of different diagnoses on adaptive behavior, instruments are needed, that reliably and validly measure adaptive behavior in children and adolescents with mental retardation. The Vineland Adaptive Behavior Scales-Survey Form, VABS (Sparrow, Balla, & Cicchetti, 1984), are an internationally well-known and widely used instrument to do so. However, the structure of the instrument, and its reliability, validity and norms reported in the original manual, are based on research in American, typically developing children. Despite its wide use in children and adolescents with mental retardation, no previous information was available on the psychometric qualities or applicability of the VABS as a measure of adaptive behavior in this population. To contribute to a more founded and evidence-based use of the VABS in this population, the psychometric qualities and applicability were investigated in our sample. This study revealed that the original structure of the instrument with respect to the arrangement of the items into (sub)domains and developmental order, is largely recognized in the population with mental retardation. Additionally, the reliability and validity are high to very high in this population. The largest differences in psychometric qualities of the VABS compared to the general population are found in the lowest levels of functioning. The construct of adaptive behavior seems to have a different character and a different value in the lives of children and adolescents on these levels of functioning. Concluding, the study provides empirical evidence for the applicability of the VABS as a measure of adaptive behavior in children and adolescents with mental retardation.

Now that the VABS proves to be of clinical value in this population, the need for supplementary norms for children and adolescents with mental retardation grows. In the United States, the VABS is currently undergoing a thorough review and standardization process, and we hope supplementary norms will be added to the norms for the typically developing population in this process. For the Netherlands and Belgium the situation is reversed. At the start of the Friesland study, the VABS was only used on an internal basis, without official status. No norms were available for any Dutch speaking population. Based on our population, we developed norms for children and adolescents with mental retardation, for the total population, and for the mild, the moderate and the severe/profound levels of mental retardation. An official translation of the instrument, a manual, and these norms have been published recently (de Bildt & Kraijer, 2003). This means that for the Netherlands and Belgium, norms are only available for children and adolescents with mental retardation, yet norms for the typically developing population are still lacking. We hope that the existing plans to develop these norms will be realized in the near future.

Norms for the typically developing population are important in the diagnostic process of mental retardation itself. In the definition of mental retardation, adaptive behavior has become increasingly emphasized, besides intelligence. To investigate the level of adaptive behavior of a child suspected with mental retardation, he/she needs to be compared to adaptive behavior of typically developing children. This comparison reveals the size of the deficit in adaptive behavior and the character of deviancies of the adaptive behavior profile.

From a clinical perspective, the norms for the population with mental retardation have specific value in the diagnostic process of individual children. With such norms, it is possible to compare the profile of adaptive behavior of an individual child with mental retardation to other children of the same level. This is informative with respect to identifying possible problems additional to the diagnosis of mental retardation, since atypical deficits in certain areas of adaptive behavior are made visible. When a profile of adaptive behavior matches the norms for mild mental retardation, for example, except for the socialization domain, this provides information on the particular area of delays and, accordingly, on what specific behavior to investigate more thoroughly, or on what intervention to start. In the treatment process, the VABS is valuable as well. Determining a baseline of adaptive behavior skills before

intervention, makes a careful evaluation afterwards possible, by specifying the areas in which the child has profited from the intervention.

In sum, the clinical value of the VABS will improve substantially, with the availability of norms for the typically developing population, and supplementary norms for specific groups, of which the population of children and adolescents with mental retardation is probably the largest.

Another instrument that was investigated is the Children's Social Behaviour Questionnaire, CSBQ (Luteijn, Minderaa, & Jackson, 2002). Our aim was to see whether this measure of subtle social skills would contribute to differentiating between children with mild and moderate mental retardation with and without a pervasive developmental disorder. The outcomes show that adding this measure of subtle social behavior to a measure of basic social skills is informative in differentiating between levels of mental retardation, and between children with and without pervasive developmental disorders. 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. Children with mild mental retardation are better able to overlook activities or situations, than children with moderate mental retardation, yet experience more fear when the situation changes. This could probably be explained by a slightly better grasp of the world in mild than in moderate mental retardation (viz. orientation), as long as life and its situations are straightforward and predictable. When changes occur, children and adolescents with moderate mental retardation may be less aware of the change, the new arisen situation, or its consequences. In contrast, children and adolescents with mild mental retardation may notice the change, but then lack the skills to handle the new situation, which may lead to fear of changes. Since the CSBQ contributes to refining the specific effects of each diagnosis, 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.

Nevertheless, these conclusions should be interpreted with appropriate care. They are based on verbal children with mild or moderate mental retardation only.

Since children with lower levels of mental retardation show less differentiated or subtle behavior, presumably the conclusions do not apply to them. Additionally, children with and without pervasive developmental disorders were classified based on the ABC only. Therefore, this investigation of the value of the CSBQ as a measure of subtle social behavior in differentiating between children with mental retardation with and without pervasive developmental disorders is no more than an initial, and small, step into specifying the effects of each disorder on (mal)adaptive behavior. Accordingly, research in groups of children with mental retardation with a more thorough assessment and a better founded classification of pervasive developmental disorders, is highly recommended. Additionally, other measures of subtle social skills, e.g. extensive Theory of Mind-measures, may contribute as well.

The last study presented in the dissertation also aimed to contribute to the insight into the effect of pervasive developmental disorders in mental retardation. In this study, the interrelationship between autistic and general behavior problems, adaptive behavior and academic achievement was examined, in the highest functioning children and adolescents with mild mental retardation (IQ 60-70). The objective was to investigate how (mal)adaptive behavior influences academic achievement. The main conclusion from this study is that adaptive behavior is of major importance for academic achievement. In this narrow IQ group, adaptive behavior even is the only factor that directly influences the level of education a child reaches. However, behavior problems in the area of pervasive developmental disorders and general 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 reach the level of education that matches his/her intelligence level. General behavior problems play an additional role, but have a less restrictive effect.

From a clinical perspective, this has two main implications. First, the restricting, and literally 'pervasive' effect of a co-morbid pervasive developmental disorder is emphasized once again. Therefore, a careful diagnostic procedure to identify the disorder and to specify the effects for the individual child, followed by appropriate interventions, are highly necessary to limit the consequences as much as possible, and to help the child develop optimally within his/her boundaries.

The second important implication is that adaptive behavior should play a more pronounced role in the admittance policy of especially the lower level of education (in

Dutch 'ZML', currently also known as 'cluster 3'). Although often the strict requirement of an IQ of 60 or below on a standardized intelligence test is applied with some flexibility for children with additional problems, it is sometimes unclear what severity of the additional problems leads to admittance of the child. Conversely, it is often very difficult to put forward a child with many and severe additional problems that clearly limit his/her adaptive behavior, yet with an IQ around 70. In both situations criteria for the level of adaptive behavior would clarify the procedure of admittance.

In all probability, no criteria can ever be found that satisfy everyone. There will always be children who, from a clinical perspective, would profit optimally from being in the lower level of education, yet who cannot be admitted due to the fact that they do not meet official admittance requirements. Nevertheless, if these official rules have to be applied, they should be as clear as possible. Adding a requirement of a maximum adaptive behavior score to the requirement of a maximum IQ score would be helpful, especially when they are considered as a combination. Since instruments to measure adaptive behavior, resulting in such a score, are available, e.g. the VABS, but for the Netherlands and Belgium also the Social Functioning Scale for the Mentally Retarded, SRZ (Kraijer & Kema, 1994), this should not be a limitation. Besides, regarding both intelligence and adaptive behavior corresponds to the recent developments in the field of mental retardation (AAMR, 2002).

8.5 Conclusion

To summarize, the Friesland study reveals a prevalence of pervasive developmental disorders in children and adolescents with mental retardation, of approximately 15-20%, depending on the instrument used to establish it. With respect to the different levels of mental retardation, the prevalence is generally 2.5-3 times higher in the lower levels than in the mild level of mental retardation. These prevalence rates implicate that there are many children and adolescents with mental retardation, who are also affected by a pervasive developmental disorder. Additionally, the study once again corroborates that the diagnosis of a co-morbid pervasive developmental disorder severely affects children and adolescents with mental retardation. Children with both diagnoses are equipped to cope with life even worse, than children with mental retardation only. A pervasive developmental disorder heavily influences adaptive behavior, with far reaching consequences for

other areas of functioning, such as education. From a clinical perspective, it is therefore of major importance to raise the awareness of, and the expertise on, pervasive developmental disorders in this population, both on the individual and on the policy level. Early identification, leading to appropriate measures and support, may limit the consequences for the child and his/her environment to some extent, and help the child develop optimally within his/her boundaries.

The instruments for identifying pervasive developmental disorders that were investigated in the Friesland study (PDD-MRS, ABC, ADI-R, and ADOS) all proved to be valid and valuable in the population of children and adolescents with mental retardation. Each of them has its own specific contribution to a meticulous diagnostic assessment, based on the underlying concept, the source of information and the time period considered for classification. To measure the effect of a pervasive developmental disorder on adaptive behavior, the VABS is recommended. This instrument proved to be a reliable, valid and valuable instrument for measuring adaptive behavior in the population of children and adolescents with mental retardation. The CSBQ, although less thoroughly investigated in this population yet, also seems to add to refining the specific effects of pervasive developmental disorders on (mal)adaptive behavior, particularly in the social area.

The main conclusions mentioned above, gain in value, when we consider the main strength of the study: the fact that a total population of children and adolescents with mental retardation in a designated area was thoroughly investigated. All levels of mental retardation and all types of facility were included. No children were excluded based on etiology of mental retardation, presence of sensory or motor impairments, or co-morbid psychiatric disorders or behavior problems. Notwithstanding the fact that a total population study is a very intensive investigation method, it improves the representativity of the reported results and therefore provides a solid basis for the conclusions that are drawn.

Therefore, with respect to the prevalence of pervasive developmental disorders, this study has resulted in prevalence rates that are representative for the total population of children and adolescents with mental retardation, more so than most previous prevalence studies, that often considered relatively specific and 'high-risk' populations. Additionally, for the investigation of the value of standardized instruments for pervasive developmental disorders and for (mal)adaptive behavior, our large, population based and representative samples were definitely a merit. With

respect to the ADI-R and the ADOS for example, no earlier studies were conducted previously in such large numbers of children with mental retardation, although research in this area was needed and recommended. Besides, investigating the total population of children and adolescents with mental retardation contributed to the scientific foundation of the applicability of the VABS and the CSBQ in this population. For the VABS, we developed a manual and norms for children and adolescents with mental retardation, that has been published recently (de Bildt & Kraijer, 2003). Similar norms will be developed for the SRZ (Kraijer & Kema, 1994) in the near future, to update the existing norms. Additionally, children and adolescents from the present study were included in the manual and norms of the CSBQ (Luteijn et al., 2002) and the Dutch version of the DBC (Koot & Dekker, 2001).

Besides these tangible outcomes, the main clinical implication of the Friesland study is that pervasive developmental disorders occur in children and adolescents with mental retardation relatively often, and that the effect on adaptive behavior, and therefore on other areas of functioning, is literally 'pervasive'. Therefore, the identification of a pervasive developmental disorder should be based on a careful procedure. For clinical practice we recommend an extensive, individual assessment to assign this severe diagnosis, 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. They not only provide the clinician with a lot of information on the individual child, but also make a comparison possible with information collected on other children with a pervasive developmental disorder. Although the classifications of these instruments can never be the sole criteria for a diagnosis, they improve the insight into the specific problems of a child. The ultimate, individual diagnosis should be based on integration and thorough consideration of all instruments and a clinical classification. In this individual diagnosis, not only specific information on pervasive developmental disorders should be considered, but also information on adaptive behavior, to define the specific effects of the disorder for this particular child. The VABS is recommended for this aspect of the diagnostic process. With such an extensive procedure, the diagnosis is more than a label: it then specifies the effects of that label for this particular child and forms the basis for measures or interventions, to meet his/her specific needs.

For research, the same thorough assessment should be followed to classify participants as having a pervasive developmental disorder. In practice this is often impossible, due to time and financial limits. Nevertheless, results and conclusions are only valuable when based on a population that is thoroughly classified and defined according to specific criteria. The ADI-R and the ADOS, the current gold standard, are highly recommended for this purpose. A clinical classification, corroborated by the instruments would be the best alternative for an individual diagnosis as recommended for clinical practice. With respect to control groups, extensive assessment is not efficient, therefore screening instruments could form the basis for further assessment. An additional factor in research is the fact that the objective of the study and the selected population influence the classification procedure. For example, investigating a clinical population does not involve a screening anymore. Yet, even when an individual diagnosis was assigned previously in the clinical process, for research this diagnosis should be corroborated with the ADI-R and the ADOS (if not available already), to improve standardization and comparability with other studies.

To conclude, the Friesland study has provided clinicians and researchers with valuable information on pervasive developmental disorders in children and adolescents with mental retardation. The study extended the knowledge on the value of standardized instruments that may facilitate identification of pervasive developmental disorders in children and adolescents with mental retardation, on the prevalence rate of pervasive developmental disorders in this population, and on the specific effects on (mal)adaptive behavior and instruments to measure these effects.

Nevertheless, the study has also raised further questions. For example, 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. Although pervasive developmental disorders are considered life long disorders, investigation of the stability of the classifications would improve the insight in the definition and the instruments. Additionally, an interesting and clinically relevant issue is how many of the children identified as having a pervasive developmental disorder in this study, have actually been individually diagnosed and receive specific services, or support. 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. Accordingly, another clinical question concerns the effect of measures or interventions that are provided for children and adolescents with mental retardation and a pervasive developmental disorder. Scientific foundation of (the effect of) measures, interventions and treatment procedures, will improve the effectiveness of provided care. Children and adolescents will directly profit from effective treatment, yet also on an organizational level, efficient care can have positive (financial) consequences. Extending the knowledge on these issues is therefore highly recommended as the focus of future research.

