

## A Case Report for Diagnosing Anxiety in People With Intellectual Disability: The Role of Nurses<sup>1</sup> in the Application of a Multidimensional Diagnostic Guideline

Addy Pruijssers, MSc, Berno van Meijel, PhD, and Theo van Achterberg, RN, PhD

Addy Pruijssers, MSc, is a health psychologist and member of the Research Group Mental Health Nursing, Institute of Advanced Studies and Applied Research, INHolland University, Amsterdam, the Netherlands, and a psychologist at Esdégé-Reigersdaal; Berno van Meijel, PhD, is an associate professor, INHolland University, Amsterdam, the Netherlands, and head of the Research Group Mental Health Nursing; and Theo van Achterberg, RN, PhD, is Professor, Scientific Institute for Quality of Healthcare (IQ Healthcare), Medical Centre for Evidence Based Practice, Radboud University, Nijmegen, the Netherlands.

### Search terms:

Anxiety, diagnosis, intellectual disability, multidimensional, nursing

### Author contact:

addy.prujssers@inholland.nl, with a copy to the Editor: gpearson@uchc.edu

First Received September 6, 2009; Final Revision received August 31, 2010; Accepted for publication September 9, 2010.

doi: 10.1111/j.1744-6163.2010.00294.x

**PURPOSE:** The purpose of this article is the presentation of a multidimensional guideline for the diagnosis of anxiety and anxiety-related behavior problems in people with intellectual disability (ID), with a substantial role for the nurse in this diagnostic process.

**DESIGN AND METHODS:** The guideline is illustrated by a case report of a woman with ID with severe problems.

**FINDINGS:** It appears that a multidimensional diagnostic approach involving multidisciplinary team efforts can result in a more accurate diagnosis and improved subsequent treatment.

**PRACTICE IMPLICATIONS:** Nurses should be engaged in the diagnostic process because of their ability to make direct observations and to actively participate in carrying out all parts of the guideline.

Anxiety, as an emotional response, is quite common in daily experience. A commonly used definition of anxiety is: "The apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension. The focus of anticipated danger may be external or internal" (American Psychiatric Association, 2000). At optimal levels, anxiety is normal, motivational, protective, and helpful in coping with adversity (Muris, 2007). Pathological anxiety occurs when the intensity or duration of anxiety is disproportionate to potential harm, or when there is no recognizable threat to the individual (Cooray & Bakala, 2005).

Anxiety disorders are among the most prevalent disorders in the normal population (Vollebergh et al., 2003). According to Richards, Maughan, and Hardy (2001), anxiety disorders are even more prevalent among people with intellectual disability (ID).<sup>2</sup> People with ID are possibly more vulnerable to

anxiety disorders than the normal population (Ramirez & Lukenbill, 2007). There are several reasons for this increased vulnerability, including:

- hereditary factors (Dykens, 2000; Gullone, 1996; Sullivan, Hooper, & Hatton, 2007);
- attachment problems (van Ijzendoorn, Scheunel, & Bakermans-Kranenburg, 1999; Wijnroks et al., 2006);
- cognitive problems, lack of coping abilities (Cooray & Bakala, 2005; Sullivan et al., 2007); or a greater incidence of trauma and life events (Hastings, Hatton, Taylor, & Maddison, 2004; Levitas & Gilson, 2001).

Because anxiety problems are reported as one of the most common forms of psychological distress among people with ID, it is essential to focus on the diagnostics of anxiety and anxiety-related behavioral problems (Deb, Thomas, & Bright, 2001; Emerson, 2003). However, assessing the presence and

sub-average general intellectual functioning (b) significant limitations in adaptive functioning, and (c) onset before the age of 18 years. Over time, this condition has been redefined and renamed many times. Since 1998, the term "intellectual disability" (ID) has been used with increased frequency, as in this article.

<sup>1</sup>For the readability of this paper, we have chosen to use the word "nurse" for both nurses and social workers, because in the Dutch situation, the duties are largely similar.

<sup>2</sup>Note: The *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revision; DSM-IV-TR) uses the term Mental Retardation to denote the individual differences in cognitive abilities: (a)

precise nature of mental health problems, in this case anxiety in individuals with ID, is a complex process (Došen, 2005a; Mohr & Costello, 2007). It requires special expertise in the face of atypical presentation of anxiety complaints and behavioral disturbances, communication difficulties, and the frequent absence of subjective complaints raised by the patient (Andries et al., 2003; Emerson & Hatton, 2007; Evans, Canavera, Lee-Kleinpeter, & Taga, 2005; Hurley, Folstein, & Lam, 2003; Sevin, Bowers-Stephens, & Crafton, 2003). Diagnostic overshadowing, that is, unusual behavior erroneously ascribed to ID rather than to a mental disorder and lack of diagnostic instruments for this special group, presents major barriers to the diagnostics of anxiety problems (Barnhill, 2001; Reiss, 1994). These problems in diagnostics have major implications for clinical practice. Most importantly, anxiety and anxiety-related behavioral problems may go unrecognized and consequently underdiagnosed in the ID patient population.

Nurses can play a key role in the multidisciplinary diagnostics of anxiety and anxiety-related behavioral problems within this target group because they generally have extensive contact with the clients and are therefore in a very good position to observe them systematically. Their observations can add considerable value in supporting multidisciplinary diagnostic procedures (Cutler, 2001; Gibbs & Priest, 1999).

However, nonpsychiatric nurses working with intellectually disabled people often lack the requisite in-depth knowledge of psychiatric disorders and symptoms (Costello, Bouras, & Davis, 2007). Educational content and clinical experience in undergraduate nursing education are limited. As a result, nurses working with this population have little background to support their assessment and decision-making. Beyond this lack of knowledge, there is little in the way of methodical support (i.e., guidelines) to help nurses in their diagnostic work. Despite its recognized importance, there is surprisingly little information on training programs for healthcare providers to improve care of persons with ID (Krahn & Drum, 2007).

Given the complexity of diagnosis in intellectually disabled people, a multidimensional diagnostic approach, with contributions from a multidisciplinary team, can result in a more accurate or more robust diagnosis and subsequent treatment. Therefore, the authors, with support of a multidisciplinary expert group, developed a multidisciplinary guideline based on the empirical literature and existing models for the multidimensional diagnosis of anxiety in patients with ID (Pruijssers & Van Meijel, 2009). In this guideline, explicit attention is given to the nurse's role in the diagnostic process. For the development of the guideline, we started with a systematic literature review. Next, a first draft guideline was constructed and reviewed by the expert panel. After approval of the guideline by the experts, a pilot study was conducted to assess the feasibility of the guideline in clinical practice. The outcomes

of the pilot study were again presented to the expert panel for review. Based on their comments, the authors constructed the final version of the guideline.

The purpose of this article is to provide a summary of the guideline and then to illustrate the application of the guideline by using a case report of a woman with ID and psychiatric comorbidity.

## A Multidimensional Diagnostic Approach

A multidimensional diagnostic guideline may provide solutions for the barriers regarding the effective diagnostics of anxiety and related behavioral problems in patients with ID (see Table 1). The guideline consists of the following five steps:

1. The identification of existent problems, in combination with the description of consequential harm. Consequential harm arises when persistent anxiety complaints lead to dysfunction in one or more areas of everyday life. In this stage, protective factors in the client's life are also identified.
2. A provisional analysis of the identified problems, which forms the basis for causal hypotheses to be tested during the diagnostic process. These hypotheses are designed to facilitate accurate diagnosis which, in turn, direct care and treatment.
3. The testing of the formulated hypotheses by the members of the multidisciplinary team.
4. The formulation of an integrative diagnosis and, based on this diagnosis, a treatment plan is drawn up.
5. In the last stage of the diagnostic process, the diagnosis and treatment plan are discussed with the client.

The case report that illustrates the application of the guideline is about a woman called Rose. She was referred to specialized health services for people with ID. The specialized services employed a multidisciplinary team approach, utilizing a nurse, a psychologist, an ID physician, a psychotherapist, and a consulting psychiatrist. Given Rose's complex (behavioral) problems, the multidisciplinary team decided to work with the guideline for the multidimensional diagnostics of anxiety and anxiety-related behavioral problems in patients with ID.

**Table 1.** Guideline for the Multidimensional Diagnosis of Anxiety and Anxiety-Related Behavioral Problems

	Steps
1	Identification: <ul style="list-style-type: none"> <li>– Problems</li> <li>– Consequential harm</li> <li>– Protective factors</li> </ul>
2	Problem analysis/formulation of hypotheses
3	Testing of hypotheses
4	Integrative diagnosis
5	Treatment plan

One of the important features of the specialized service is that the nurse visits the client at home during the diagnostic process. The role of the nurse is to win the patient's confidence and make observations that are useful for all the professionals on the multidisciplinary team. Given that clients with ID often lack motivation for an extensive diagnostic examination, the primary focus is on helping the client solve practical problems. While Rose was being helped to solve some of her problems in daily living, there was ample opportunity for the nurse to make systematic observations. During the first weeks, the nurse, who visited Rose for a period of 4 months, helped Rose with her financial problems and facilitated her communication with the housing association. The concrete working methods of the multidisciplinary team, and especially those of the mental health nurse, are outlined in the following sections.

## Case Description

### Background

Rose, a 51-year-old woman, was treated in 2005 as an outpatient in a general psychiatric service. She was diagnosed with histrionic personality disorder and a conversion disorder. During childhood and adolescence, she had experienced various parent-child problems, including (sexual) abuse. In recent years, she suffered from a number of physical problems, including scoliosis, migraine, premenstrual syndrome, and indefinable pain. During mental health treatment, Rose's situation worsened. With each consult, Rose reported new and more complaints. She was loud and combative with the psychiatrist and failed to follow his advice. She was constantly dissatisfied with her medication. The disappointing outcome of treatment resulted in Rose's increased agitation and dissatisfaction.

In 2007, an intelligence assessment was conducted and it became clear that Rose had a mild ID (the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision, identifies having an IQ in the range 50–55 to 70 as mild). The general psychiatric service sent her to a specialist psychiatric center for people with a dual diagnosis (DD) of both ID and mental health problems.

This case report is based on the care provided by the team of this specialized service.

### Personal History

Rose was the youngest child in her family. Rose reported a home environment filled with domestic violence and abuse. She attended school until her fifteenth birthday, after which she began to work. Rose married twice and lived with a third partner for some years. During her first marriage, she gave birth to three children: one son and two daughters. It was

reported that her husband had sexually abused these children and had abused Rose as well. Her second husband was unable to father children and he forced Rose to have sex with a family friend to produce a child. In the meantime, it became evident that Rose was unable to care properly for her children. Her son was placed in a children's home because of behavioral problems. Rose broke up with her second husband and continued to live with the family friend, producing another daughter. During this relationship, there were bizarre incidents of abuse and incest involving Rose and her partner as offenders and all three daughters as victims. The eldest daughter reported the abuse to the police and Rose and her partner were convicted. Rose was kept in detention for 9 months. She eventually lost her parental rights. Following detention, Rose lived on the street until she was offered an apartment. She tried to get her life back in order, but soon there were new problems. She developed several physical complaints, mood disturbances, difficulty tolerating frustration, hyperventilation, feelings of loneliness, and anxiety when she was left alone.

In June 2007, when specialized services became involved, Rose's situation had deteriorated perceptibly: Her physical complaints had worsened considerably, and there was a threat of losing her home. Rose's financial situation was equally dire and characterized by huge personal debt. She was unable to buy food. Her son, previously diagnosed with schizophrenia, had left his group home and was temporarily living with Rose. He frightened her with his unpredictable behavior and aggressive outbursts.

### Step 1: Identification of Problems, Consequential Harm, and Protective Factors

Rose requested help by asking the staff, "Tell me what is wrong with me, and help me with my life." More specifically, she requested help in dealing with her previous experiences of sexual abuse and the abuse of her children. During the initial visits, the nurse gathered information by asking Rose about her personal history, her problems, the consequential harm, and possible protective factors. The nurse used the Adult Behaviour Checklist (Achenbach & Rescorla, 2003), a standardized questionnaire for behavior problems and psychiatric disorders, to better understand Rose's problems. Rose mentioned the harm of losing contact with her youngest daughter, having no safe place to stay, financial problems, fear of being alone, and her son's aggression. From the perspective of the nurse and the other professionals (ID-physician and psychologist), other significant problems were present: her physical functioning, her cognitive and social-emotional impairments, her ineffective coping, and her poor social background. The ID-physician and the psychologist gathered relevant information from her files and contacted previous care providers, among them, the psychiatrist from the mental

health service. Rose's habit of surfing the Internet was her sole protective factor: Only then she was able to relax.

## Step 2: Problem Analysis and Hypothesis

After collecting the information for step 1, the multidisciplinary team met to discuss possible causes of the identified problems. The nurse's impressions and observations, gained during her initial visits with Rose, were brought forward in the team discussion: They clarified Rose's living conditions and the way in which the multitude of problems affected her psychosocial functioning and her quality of life.

The multidisciplinary team constructed a problem analysis and formulated hypotheses about the causes and factors influencing the problems identified at Step 1. To perform a comprehensive analysis, it is necessary to consider all dimensions of functioning (biological, physiological, psychosocial, psychiatric, and environmental dimensions; Došen, 2005a,b).

Rose's problem analysis reads as follows:

Rose is a 51-year-old woman with a mild ID who has been negatively affected by adverse life-events and trauma (as was her entire family). Because her ID was not recognized before, her care and support were never focused on her disabilities, and for that reason, her cognitive, social, and emotional abilities were initially overestimated. As a result, she could only manifest her problems by expressing physical complaints. Her aggravating life-events, the resultant traumas, and the excessive demands on her coping skills are all possible causes that explain her conversion disorder, anxiety problems, and/or personality disorder.

The analysis led to the following hypotheses: (a) overestimation of cognitive and social emotional functionings; (b) histrionic personality disorder; (c) conversion disorder; (d) separation anxiety disorder<sup>3</sup>; and (e) reduced levels of social and emotional functionings occasioned by extremely stressful life-events.

After formulating the hypotheses, the multidisciplinary team developed a diagnostic plan aimed at finding additional support for the formulated hypotheses. All members of the team participated in the diagnostic process, contributing their professional skills and competence. The team discussed the results of these diagnostic procedures in a subsequent meeting.

## Step 3: Testing of Hypotheses

The nurse played a significant role at the stage of hypothesis testing and she was involved in exploring all five hypotheses.

<sup>3</sup>Separation anxiety disorder is a psychological condition with experiences of excessive anxiety occasioned by separation from home or from people to whom there is a strong emotional attachment.

She observed Rose's social and emotional functional levels and coping strategies. She also completed the Scheme of Appraisal of Emotional Development (Došen, 2005a) and a Social Self-Management Scale for people with ID (Kraijer, Kema, & De Bildt, 2004) to support the testing of hypotheses overestimation and separation anxiety. The characteristics of the alleged disorders were observed (hypotheses: histrionic personality disorder; conversion disorder; separation anxiety disorder), as were her physical complaints (hypothesis: the conversion disorder). Together, with Rose, she constructed an anamnesis and overview of Rose's life-events (hypothesis: life-events). The psychologist coached the nurse in her diagnostic efforts. She made use of several observation tools, which are part of the multidimensional guideline, to support these targeted observations.

The first time Rose and the nurse met, Rose spoke very emotionally and dramatically about her situation. As Rose increasingly felt that the nurse was taking her problems seriously, her behavior became calmer. She trusted her problems and her failures in life to the nurse. She expressed her anger with the staff of the mental healthcare facility because they did not take her seriously during her past treatment. It seemed that Rose's penchant for drama and theatricality was a direct reaction to her feelings of not having been heard and understood in the past. These observations were used for the verification of Hypothesis 2.

After some time, it became possible to speak with Rose about her fears and, together, she and the nurse were able to identify a hierarchy in Rose's anxiety symptomatology. Her fear of being left alone seemed particularly extreme, as was her fear of darkness and aggression. Rose's fear of being alone was so strong that she tolerated the presence of her son in the household despite his aggression and threats. The nurse observed recurring distress in Rose when her friends or son left her house. Rose then became anxious, was concerned about everyone, and her physical complaints seriously increased. Throughout her life, Rose always chose to stay with her partners despite extreme incidents of abuse and adultery. The nurse and Rose identified and discussed ineffective and even destructive ways of coping with her anxious feelings, such as staying awake all night or enticing strangers into her house with alcohol.

Creating Rose's life story was an important part of the diagnostic process (hypothesis: reduced levels of social and emotional functioning occasioned by extremely stressful life-events). Together, the nurse and Rose started to make a genogram. A genogram is a pictorial display of a person's family relationships that allows the patient to visualize hereditary patterns and psychological factors, such as repetitive conflicts and complex interactions that punctuate relationships. The nurse used the genogram to help Rose recognize her vulnerabilities (e.g., her low economic status and a lack of cohesion in her family), and hereditary



tendencies (e.g., her low intelligence and the transgenic relation aspects in her family).

As part of the testing of hypotheses, consultations were arranged with the psychiatrist because of Rose's assumed personality disorder and the conversion complaints. The psychologist assessed her intelligence level and had several conversations with her. The ID-physician examined her for her physical complaints. To support their diagnostic judgments, these professionals made use of the information provided by the nurse.

Halfway through the period of assessment, Rose met a man named J., on "Second Life" (a virtual world on the Internet), and after some time, they arranged to meet in real life. Later they decided to live together. At first, the nurse was concerned that this relationship would once again be a relationship filled with violence and abuse but, fortunately, J. appeared to be a friendly, nonviolent, and caring man.

#### Step 4: Integrative Diagnosis

The integrative diagnosis, Step 4 of the guideline, aims to illuminate the pathogenesis and provides a narrative explanation of Rose's situation. The following conclusions were drawn.

From childhood to the present, Rose's abilities have been overestimated, especially her cognitive and social-emotional functioning. There is also a striking discrepancy between her cognitive and social-emotional developments: Her cognitive abilities are relatively strong in comparison with her social and emotional coping skills. Anxiety and behavior problems arise because of the constant pressure to do things she cannot handle.

Most of Rose's basic emotional needs and social motivations were at the level of a child aged 18–36 months. Thus, Rose had an urgent need for a secure bond with other people.

Many of Rose's symptoms and behaviors resembled characteristics of a histrionic personality disorder and a conversion disorder. However, her ID and, in particular, her low level of social emotional functioning are the main causes of her deregulated emotions, her suggestibility, her physical complaints, her specific speech and communication styles, and her dramatic behavior. For this reason, the hypothesis of Rose suffering from a diagnosis of "histrionic personality disorder" could not be confirmed.

Rose's problems and impairments negatively affected her personality development. She was observed to behave immaturely, indicating that growth to an adult personality had not been completed. Her weak psycho-emotional and social functionings were judged to be the determining factor in the onset of her separation anxiety, induced by a lack of basic trust. She constantly feared being alone and clung to relationships that were destructive for her personal well-being. As a result, Rose experienced many abusive situations and extreme life-events. These events further negatively affected her emotional and

social functionings, manifested in signs of conversion, anxiety (feelings of loneliness, hyperventilation), and other maladaptive behaviors.

#### Step 5: Treatment Plan

As the last step of the guideline, a meeting was arranged with Rose, her new partner J., the nurse, and the psychologist to discuss the integrative diagnosis and the treatment plan. A major recommendation for Rose was to start with structured support because of her need for a secure bond with her care providers and family members. The treatment plan consisted of support from the nurse three times a week: Together they discussed daily problems, made attainable plans for the coming week, and talked about how Rose would address difficult situations, especially regarding her contact with her son and her neighbors. The overall aim was to avoid overestimating her abilities and matching the tasks and demands of Rose's life with her coping skills.

Furthermore, structured ego-supportive interventions were planned to address her anxieties. Rose and the nurse developed a list of coping skills that Rose could use when confronted with her fears. These skills were practiced under the structured supervision of the nurse. As one example, Rose started a computer diary to record her thoughts and fears. She also chose a favorite computer game to play when she felt lonely. She bought a cell phone to make phone calls to her caregiver or to her friend. Rose thus had the opportunity to call them when she felt alone or tense. She also practiced new relaxation techniques under the guidance of the nurse: deep breathing, chatting with her friend, or taking a shower.

Another part of the treatment plan was to complete her life story. Rose told the nurse that writing her life story was very emotionally upsetting for her. Nevertheless, it was helpful for her to deal with her previous experiences of sexual abuse, although she was unable to understand the bad intentions of others. The nurse and the psychologist were aware of the risk to Rose of a relapse into her dysfunctional coping and behavioral patterns, so they decided to provide additional support to her when working on her life story.

Regular appointments were arranged with the general practitioner and the ID-physician to treat and evaluate her physical complaints. Because of the magnitude of her financial problems, help from an administrator was arranged.

#### One Year Later

Overall, Rose is doing very well. She is now married to J. and her life has stabilized. A nurse provides twice-weekly supportive care, and Rose regularly visits an ID-physician for her physical problems. Her physical symptoms are less prominent. J.'s presence as her life partner, in combination with the application of anxiety management techniques, has resulted

in a lessening of Rose's fears. The structured nursing interventions have led to a more stable environment, which contribute to a higher level of emotional and social functionings on Rose's part. In total, the interventions ensure that Rose's basic safety has been strengthened and her anxious feelings have been reduced. Rose said she sleeps better and is generally less worried. She is better able to live her own life.

However, despite all of the care she has received, occasional problems continue to arise, including problems with her neighbors and quarrels with child protective services about visiting her youngest daughter. Sexual problems are an ongoing complication for Rose, resulting from her previous history of sexual abuse. Rose continues to decline therapy, but she has asked for help with her sexual relationship with J.

It is striking how communication with Rose, especially between her and her nurse, has changed in a positive way. Communication is now more in accordance with her personal capacities, and this positively influences the working alliance with Rose. She feels she is taken more seriously and better understood.

## Discussion

Several authors (Charlot, 2003; Došen, 2005a,b; Greenspan, 1997; Sturmey, 1999) have pointed out the necessity of integrating the assessment results derived from different dimensions and disciplines when diagnosing anxiety and related behavioral problems. We developed a multidimensional guideline entitled Guideline Anxiety and Behavioural Problems in People with ID to improve the quality of diagnosis of anxiety and related behavioral problems in this patient group. This new guideline comprises a four-dimensional approach: biological/physiological, psychosocial, psychiatric, and environmental contributing factors are assessed in order to obtain a full picture of (the possible causes of) existent symptoms and problems.

The case presented in this article illustrates the need for ongoing, systematic assessment. Rose's case is not exceptional; many people with ID and mental health disorders deal with complex problems in all areas of their lives. A lack of knowledge of ID in the general mental healthcare community is most likely the reason ID is not being recognized, resulting in inadequate diagnostics and treatment. More attention should be paid to the early recognition of possible ID in people with low social-emotional functioning and behavioral problems.

The diagnostics and treatment of people with ID and comorbid psychiatric disorders require small steps, more efforts per step, and adapted communication and motivational strategies to achieve success. The central themes in the care and treatment are preventing overestimation and overwhelming the patient. The proposed guideline for the diagnosis of anxiety and anxiety-related behavioral problems in

people with ID addresses these issues and, thus, can improve the quality of care and treatment for this patient group. It can help clinicians recognize the wide variety of vulnerabilities to anxiety as well as to protective factors that play a role in this type of psychopathology, in addition to taking into account the developmental aspects that are involved. The identification of various personal, family, or environment-related difficulties and strengths may be helpful in making optimal decisions about the most appropriate intervention strategies.

The application of the guideline leads to the reinforcement of multidisciplinary cooperation and improvement in the quality of the diagnostic process, resulting in an integrative diagnosis and treatment plan. The integrative diagnosis provides comprehensive insight into the processes that have led to the disorder and enriches one's understanding of the concrete manifestation of the disorder. When anxiety is regarded as the main problem, and there is a hierarchy of problems, it is possible to make improvements in multiple components of performance by treating the anxiety symptoms or the anxiety arousal.

Rose's case illustrates how a multidimensional diagnostic approach helped to identify underlying causes of problem behaviors. In previous assessments, the diagnosis of separation anxiety was not clearly identified as the key contributing factor to her problematic functioning. When, in Rose's case, anxiety came to be seen as the main problem, we were able to evaluate it in combination with several other contributing factors: her low level of social and emotional functionings; her cognitive impairments; her insecure attachment; the traumas she experienced in the past; and the low socioeconomic environment in which she was raised. Because of this understanding, care could be tailored to her personal experiences and needs. The quality of care improved in several respects:

1. The care was adapted to her intellectual, emotional, and social abilities, lessening the burden on her limited coping skills.
2. The communication style was tailored to Rose's capabilities, so that she felt respected and understood.
3. The quality of therapeutic alliance improved significantly.
4. We were able to interrupt the repetitive pattern of her problem behaviors.
5. We were able to better understand and regulate the concrete somatic and behavioral manifestations of her pathology.

People with ID show behavior that cannot be linked directly to anxiety. This behavior often masks their anxious feelings and thoughts (Došen, 2005b; Evans et al., 2005). In Rose's case, it was difficult to immediately connect her theatrical and dramatic behavior with underlying feelings of fear and anxiety. It was also hard to differentiate between separation anxiety disorder and a histrionic personality disorder. To further complicate matters, Rose displayed dramatic and the-

atrical behavior because of the unsatisfactory communication she experienced with mental healthcare professionals. Because her intellectual impairment and atypical symptomatology were initially not recognized, mental health professionals communicated in a manner that was not tailored to Rose's capabilities.

People with ID often face life-events that they are unable to cope with successfully. New or difficult situations require novel coping responses or greater levels of autonomy than people with ID can easily handle. Knowledge of these life-events and their influence on a patient's functioning can lead to an accurate diagnosis and point to therapeutic solutions (Levitas & Gilson, 2001). The violence in her early years, the (sexual) abuse later on, the separation from her partners and her children, and the time in prison are life-events that contributed to Rose's problematic functioning.

In the era since deinstitutionalization, more individuals with ID are receiving care in the community. However, in cases such as Rose's, it is very difficult for community mental health services to effectively manage treatment because of the special challenges associated with ID and comorbid psychiatric disorders. The problem is bidirectional. Psychiatric care is not well prepared to care for persons with ID, but ID systems are also not well prepared to provide psychiatric care. As a result, many cases go undiagnosed. A multidimensional approach, as described in this guideline, is essential for diagnosing anxiety and other psychopathologies in people with ID.

Working with the proposed guideline is labor intensive and therefore costly. The diagnostic process takes at least 4 months and requires the contribution of a range of disciplines. In the long term, working with the guideline is cost-efficient number of diagnoses. Discovering the underlying causes of problem behavior will better enable professionals to design effective treatment plans. It is important that the implementation of the guideline be adjusted to the local situation and to available resources. An essential precondition for effective implementation is the availability of a multidisciplinary team because of the multidimensional approach of the guideline.

The positive results of the pilot call for further empirical study on a larger scale. The next step in our development and research process is to conduct a multiple comparative case study aimed at a better understanding of the diagnostic process and the outcomes of the guideline. Only then can the guideline be adequately reviewed for effectiveness.

### Implications for Nursing Practice

One innovative aspect of this guideline is the increased role of nurses in the diagnostic process. The nurse becomes indispensable because of her direct observations involved in Steps 1 (problem definition) and 3 (testing the hypotheses) of the

guideline. In Steps 2 (problem analysis) and 4 (the formulation of an integrative diagnosis), the nurse brings her specific nursing expertise to the multidisciplinary meeting. The nurse and the psychologist participate in the last step where the diagnosis and the treatment proposal are discussed with the client.

A strong therapeutic alliance between the nurse and the client with ID is vital to achieve a successful outcome. The nurse is able to adapt herself to the client's needs and skills and so avoids overestimation. The nurse also has direct, regular, and ongoing involvement with the client and, as such, has the best opportunity to observe the client's idiosyncrasies. These qualities are very valuable when it comes to winning confidence, which is absolutely necessary for clients with anxiety problems. This alliance is the key to every successful diagnosis and treatment plan. It takes specialized professional skills to properly interact with clients with ID and psychiatric disorders (DD), to win their confidence, to carry out diagnostic activities properly, and to recommend the right care and treatment approaches for them. Cross-over training between psychiatric and ID nurses can be a valuable strategy to share knowledge and expertise and, more generally, to strengthen the competencies of healthcare professionals for the adequate care and treatment of this vulnerable patient group. In the case of Rose, the guideline shows that on the basis of a new, positive working alliance with the nurse, the client was able to make more positive choices, contributing to positive changes in the quality of her life over time.

To care for clients with ID, nurses need to extend their knowledge base to include an understanding of the psychopathology (especially of anxiety and anxiety disorders), the ability to interpret behaviors, make appropriate choices regarding support, and adapt to patients' communication styles. The complexity of working with clients with ID requires these skills in order to provide high-quality care. Some of the findings presented herein will be useful to clinical personnel working with people with ID and anxiety problems, helping them to provide effective and responsive help to this population with their special needs and problems.

### References

- Achenbach, T., & Rescorla, L. A. (2003). *Manual for the ASEBA adults forms & profiles* (pp. 18–59). Burlington, VT: University of Vermont, Research Center for Children, Youth & Families.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.
- Andries, J., Bauwens, S., Cuyppers, W., De Muer, W., Morisse, F., & Weyts, E. (2003). *Observatie en behandeling van volwassenen met een verstandelijke handicap met bijkomende*

- psychiatrische en/of gedragsproblemen. [Observation and treatment of intellectually impaired adults with a mental illness and/or behaviour disorder]. *Psychiatrie en Verpleging*, 79, 279–302.
- Barnhill, J. (2001). Behavioural phenotypes: A glimpse into the neuropsychiatry of genes (part II): Analysis of behavioural phenotypes social anxiety in fragile-X syndrome and autism. *NADD Bulletin*, 6(4), 1–12.
- Charlot, L. R. (2003). Mission impossible? Developing an accurate classification of psychiatric disorders for individuals with developmental disabilities. *Mental Health Aspects of Developmental Disabilities*, 1, 29–38.
- Cooray, S. E., & Bakala, A. (2005). Anxiety disorders in people with intellectual disabilities. *Advances in Psychiatric Treatment*, 11, 355–361.
- Costello, H., Bouras, N., & Davis, H. (2007). The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20(3), 228–235. doi: 10.1111/j.1468-3148.2006.00320.x
- Cutler, L. A. (2001). Mental health services for persons with mental retardation: Role of the advanced practice psychiatric nurse. *Issues in Mental Health Nursing*, 22(6), 607–620. doi:10.1080/01612840120623
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. I: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495–505. doi: 10.1046/j.1365-2788.2001.00374.x
- Došen, A. (2005a). *Psychische stoornissen, gedragsproblemen en verstandelijke handicap: Een integratieve benadering bij kinderen en volwassenen*. [Psychiatric disorders, behavioural problems and intellectual disabilities: An integrative approach to children and adults]. Assen, The Netherlands: Van Gorcum.
- Došen, A. (2005b). Applying the developmental perspective in the psychiatric assessment and diagnosis of persons with intellectual disability: Part I—assessment. *Journal of Intellectual Disability Research*, 49(1), 1–8. doi: 10.1111/j.1365-2788.2005.00656.x
- Dykens, E. M. (2000). Annotation: Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry*, 41(4), 407–417. doi:10.1111/1469-7610.00626
- Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47(1), 51–58. doi: 10.1046/j.1365-2788.2003.00464.x
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493–499. doi: 10.1192/bjp.bp.107.038729
- Evans, D., Canavera, K., Lee-Kleinpeter, F., & Taga, K. (2005). The fears, phobias and anxieties of children with autism spectrum disorders and Down syndrome: Comparisons with developmentally and chronologically age matched children. *Child Psychiatry and Human Development*, 36(1), 3–26. doi: 10.1007/s10578-004-3619-x
- Gibbs, M., & Priest, H. M. (1999). Designing and implementing a “dual diagnosis” module: A review of the literature and some preliminary findings. *Nurse Education Today*, 19(5), 357–363. doi:10.1054/nedt.1999.0341
- Greenspan, S. J. (1997). *Developmentally based psychotherapy*. Madison, WI: International University Press.
- Gullone, E. (1996). Normal fear in people with a physical or intellectual disability. *Clinical Psychology Review*, 16(8), 689–706. doi:10.1016/S0272-7358(96)00041-4
- Hastings, R. P., Hatton, C., Taylor, J. L., & Maddison, C. (2004). Life events and psychiatric symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 48(1), 42–46. doi: 10.1111/j.1365-2788.2004.00584.x
- Hurley, A. D., Folstein, M., & Lam, N. (2003). Patients with and without intellectual disability seeking outpatient psychiatric services: Diagnoses and prescribing pattern. *Journal of Intellectual Disability Research*, 47(1), 39–50. doi: 10.1046/j.1365-2788.2003.00463.x
- Krahn, G. L., & Drum, C. E. (2007). Translating policy principles into practice to improve health care access for adults with intellectual disabilities: A research review of the past decade. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 160–168. doi: 10.1002/mrdd.20149
- Kraijer, D. W., Kema, G. N., & De Bildt, A. A. (2004). *SRZ/srzi Sociale redzaamheidsschalen voor verstandelijk gehandicapten*. [SRZ/srzi Social ability scales for people with intellectual disability]. Amsterdam: Pearson.
- Levitas, A. S., & Gilson, S. F. (2001). Predictable crises in the lives of people with mental retardation. *Mental Health Aspects of Developmental Disabilities*, 4(3), 89–100.
- Mohr, C., & Costello, H. (2007). Mental health assessment and monitoring tools for people with intellectual disabilities. In N. Bouras (Ed.), *Psychiatric and behavioural disorders in developmental disabilities and mental retardation* (pp. 3–17). Cambridge: Cambridge University Press.
- Muris, P. (2007). *Normal and abnormal fear and anxiety in children and adolescents*. Amsterdam: Elsevier.
- Pruijssers, A. C., & Van Meijel, B. (2009). Diagnostische stilte. [Diagnostic silence]. *Verpleegkunde*, 24, 14–19.
- Ramirez, S. Z., & Lukenbill, J. F. (2007). Development of the fear survey for adults with mental retardation. *Research in Developmental Disabilities*, 28(3), 225–237. doi:10.1016/j.ridd.2006.01.001
- Reiss, S. (1994). *Handbook of challenging behaviour: Mental health aspects of mental retardation*. Worthington, OH: IDS Publishing.
- Richards, M., Maughan, B., & Hardy, R. (2001). Long-term affective disorder in people with mild learning disability. *Brief Journal of Psychiatry*, 179, 523–527. doi: 10.1192/bjp.179.6.523
- Sevin, J. A., Bowers-Stephens, C., & Crafton, C. G. (2003). Psychiatric disorders in adolescents with developmental disabilities: Longitudinal data on diagnostic disagreement in 150 clients. *Child Psychiatry and Human Development*, 34(2), 147–163. doi: 10.1023/A:1027346108645



- Sturmey, P. (1999). Classification: Concepts, progress and future. In N. Bouras (Ed.), *Psychiatric and behavioural disorders in developmental disabilities and mental retardation* (pp. 3–17). Cambridge, UK: Cambridge University Press.
- Sullivan, K., Hooper, S., & Hatton, D. (2007). Behavioural equivalents of anxiety in children with fragile X syndrome: Parent and teacher report. *Journal of Intellectual Disability Research*, 51(1), 54–65. doi: 10.1111/j.1365-2788.2006.00899.x
- van Ijzendoorn, M. H., Scheungel, C., & Bakermans-Kranenburg, M. J. (1999). Disorganized attachment in early childhood: Meta-analysis of precursors, concomitants, and sequelae. *Development and Psychopathology*, 11, 225–249. doi:10.1017/S0954579499002035
- Vollebergh, W., De Graaf, R., Ten Have, M., Schoenmaker, C., Van Dorsselaer, S., Spijker, J., & Beekman, A. (2003). *Psychische stoornissen in Nederland: Overzicht van de resultaten van NEMESIS. [Mental disorders in the Netherlands: Survey of the results of NEMESIS]*. Utrecht, The Netherlands: Trimbos-instituut.
- Wijnroks, L., Jansen, C., Epskamp, S., Kloosterman, D., Mispelblom-Beyer, I., Post, T., . . . Storsbergen, H. (2006). *Onveilig gehecht of een hechtingsstoornis. [Insecure attachment or an attachment disorder]*. Utrecht, The Netherlands: Lemma.