White paper: ASD and/or Anorexia Nervosa

This white paper is part of the *ASD White Papers* series, which compares autism spectrum disorder (ASD) with other diagnoses, aiding in differential diagnosis and the identification of comorbid conditions.

Series objective

The outward behavioral characteristics of ASD can at times closely resemble those of other diagnoses, which can make the diagnostic process extremely complex. At the Autism Expertise Center, located in the town of Eemnes in the Netherlands, we have developed a number of white papers based on scientific research and our own clinical experience. These white papers are designed to aid in differential diagnosis (ASD *or* another diagnosis) and evaluating for comorbid conditions (both ASD *and* another diagnosis) in people with ASD or suspected ASD. The two main goals of these white papers are:

1. Providing information to diagnosticians struggling with differential diagnosis and evaluating for comorbid conditions in people with ASD or suspected ASD.
2. Helping people with ASD and their loved ones to better understand why they have (or have not) received a particular diagnosis.

This white paper

This white paper will focus on the similarities and differences between ASD and anorexia nervosa (AN).

Background

This white paper is the result of collaboration between the Autism Expertise Center (Annelies Spek and Vivian Snouckaert) and the Dr. Leo Kannerhuis/Parnassia Group (Audrey Mol), Altrecht Eating Disorders Rintveld (Unna Danner, Annemarie van Elburg, Sabrina Schröder), Emergis Eating Disorders (Jolanda Wielemaker), and the GGZ Oost Brabant Center for Eating Disorders (Jasper van Roon).

Differentiating between ASD and AN

On the surface, ASD and AN can appear very similar, especially when the eating disorder is severe. However, it is important to clearly distinguish between them, as they differ significantly in terms of their underlying mechanisms and how they are treated. Below the differences and similarities with AN are discussed for each ASD criteria.

ASD criteria	Similarities and differences to Anorexia Nervosa (AN)
Deficits in social-emotional reciprocity	People with AN sometimes have difficulty with back-and-forth interactions, but unlike people with ASD, they generally *do not show any fundamental lack of reciprocity.* Some people with AN struggle with rigid thinking about food and/or their bodies, which can interfere with interpersonal relationships and cause them to be strongly focused on themselves. People with AN often feel isolated and insecure. They show a strong tendency to compare themselves to others and are highly sensitive to other people's (perceived) expectations. As a result, they often try to blend into their surroundings. They can *accurately anticipate others' expectations and have a good feel for what is considered "socially acceptable" behavior*. Many people with ASD (especially women) also usually learn to camouflage and to compensate for any impairments due to a desire to connect with others or to appear "normal". However, this is not an intuitive process but a cognitive one. It can be highly draining, and despite their best efforts, they regularly miss the mark. In addition, autistic camouflaging does not usually lead to reciprocal relationships that leave the person with ASD feeling energized. During group therapy, people with AN will show a greater capacity for self-reflection than people with ASD. People with AN are usually *able to empathize* with others and to take others' perspectives into account. People with ASD often find this more difficult or may approach the matter in a logical, reasoned way. Clinicians will find it easier to assess the degree of reciprocity during one-on-one interactions, as people with AN often feel more comfortable in an individual setting than a group. During individual sessions, the quality of the interaction should improve over time, especially in children and young adults. This development may be less noticeable in adults with *severe, enduring eating disorders* (such as those who are extremely underweight or strongly preoccupied with anorexic thinking). They may be very introverted or feel that they are worthless, causing them to withdraw from social contact. This leaves little room for considering others' needs or for introspection. If they are confronted about their weight/self-image (even indirectly), a strong fixation or "tunnel vision" about food/their bodies will become noticeable. You may also notice a certain emotional "emptiness": nothing else seems to matter apart from the eating disorder. As the person's weight begins to normalize, their capacity for introspection will increase (and alexithymia will decrease), leaving more room for considering others' thoughts and feelings. At this point, you can expect to see more social and emotional reciprocity. People with a severe, enduring eating disorder *do not usually come across as 'odd' or 'strange' during social interactions,* as is often the case with ASD. Instead, their limited responsiveness to others is a result of their eating disorder. Unlike people with ASD, people with AN *showed no problems with reciprocity before the eating disorder started*. People with AN *do not have difficulty with back-and-forth conversations, taking language too literally, or going into too much detail* (on topics other than their eating disorder).

Deficits in nonverbal communicative behaviors	People with severe AN often appear to have a flat affect (lack of facial expression). This can normalize as weight and body image improve, as this often corresponds to a decline in anorexic thinking. They may have *trouble making eye contact due to shame and low self-esteem, but not due to an inherent inability,* such as being unaware of how long to hold eye contact, which is more typical of people with ASD. People with AN are usually *good at interpreting others' nonverbal cues*, though they often view these cues through a negative lens due to feelings of inferiority, constantly comparing themselves to others, and feeling like they take up "too much space". Apart from this, they do not show any deficits in this area. They are also good at observing and understanding interactions within a group, though here, too, there is a tendency to interpret what they see in a negative light due to their own negative self-image. People with AN are *good at reading between the lines* and have no problems telling when someone is putting up a front, unlike people with ASD.
Deficits in developing, maintaining, and understanding relationships	When it comes to social relationships, people with AN have often had negative experiences, such as bullying or conflict with their caregivers. This can make them more cautious and reserved in their interactions with others. They also have a tendency to withdraw as a result of low self-image and feelings of being "too much". When interacting with them, signs of an underlying personality disorder may emerge. Some people with AN will have been able to develop friendships before the onset of their eating disorder. However, this is not always the case, particularly if the eating disorder started when they were very young. The eating disorder makes social interaction extremely difficult, in part because eating is largely considered to be a social activity. This can make it harder for people with AN to make friends and/or cause them to lose existing friendships, especially when the eating disorder has been going on for a long time. They may feel a great deal of shame and secrecy, which can lead them to avoid social activities. It is important to note that the eating disorder itself is the limiting factor; there are *no underlying difficulties in engaging with others*, as there are in people with ASD. People with AN often feel that they are "too much", but they are *not socially awkward and have no difficulty understanding the rules of social engagement.* Friendships are extremely important and can be a protective factor in both AN and ASD. However, people with AN are fundamentally *better at developing and maintaining friendships.* People with ASD struggle more in this area, which makes social interaction more complicated and even burdensome at times.
Stereotyped or repetitive motor movements, use of objects, or speech	People with AN may show behavior that *seems* stereotyped, but is actually related to their eating disorder (for example, a rigid insistence on using a certain type of cutlery, arranging food on their plate in a certain way, or eating foods in a fixed order). You would not expect them to show any other stereotypical behaviors. People with AN *do not show stereotyped speech or movement.* However, the drive for activity can sometimes lead to trembling and pacing. The movements of people who are underweight may appear sluggish or wooden, though this should disappear once they put on weight.
Insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or nonverbal behavior	People with AN often have trouble coping when things do not go according to plan. In many cases, the eating disorder itself is the trigger (for instance, when a change of plans interferes with fixed mealtimes). *Uncertainty and lack control* (over their food intake) can also be stressful for them. These factors may be linked to a negative self-image and a tendency to set high standards for themselves. They attempt to manage the resulting stress through strict

	control over their food intake. People with ASD also have difficulty dealing with change and unexpected situations. However, this is not related to their self-image or a need for control, but to the fragmented way in which they take in and process information. They depend on routines and rituals to provide stability and make the world a more orderly, predictable place. For people with AN, *the need for control (such as rigid rules about food) is a temporary coping mechanism that they should be encouraged to let go of*. For people with ASD, however, the rituals and routines are both helpful and protective and should not be discouraged. *Rigid thinking in people with AN is related to their eating disorder.* Generally speaking, the more severely underweight someone is, the greater their cognitive rigidity. Their thoughts may be dominated by their eating disorder, which can interfere with many areas of life, including communication and social relationships. This rigidity decreases as they gain weight. People with ASD, on the other hand, will have shown rigid tendencies throughout their lives, and in areas unrelated to the eating disorder.
Highly restricted, fixated interests that are abnormal in intensity or focus	People with AN are strongly fixated on topics relating to their eating disorder (diet, exercise, weight loss, body shape, body image, appearance, lifestyle, etc.). However, they *do not appear fixated on other topics.* People with ASD usually (also) have fixated interests in other areas.
Hyper- or hyporeactivity to sensory input	In general, people with AN *are not usually sensitive to light or sound.* They may be overly sensitive to the smell, taste, and texture of their food, but this is related to their eating disorder. This *sensory sensitivity was not present prior to the onset of the eating disorder.* Tactile stimuli (touch) can be difficult for people with AN *because being touched can make them more aware of their bodies, triggering thoughts of being "fat".* In addition, we sometimes find that people with AN cannot tolerate greasy substances on their skin (such as lotions and creams or the fumes from a deep-fat fryer), not for sensory reasons but because they are afraid these substances will cause them to gain weight. Many people with ASD struggle with being touched due to heightened sensory sensitivity. This sensitivity will have been present *throughout their lives*, unlike in people with AN. Sensory *hyposensitivity* (undersensitivity) can be present in both groups. In the case of AN, we see that internal stimuli/bodily sensations are not transmitted as effectively in people who are severely underweight. This can lead people with AN to *lose awareness of themselves and their bodies* (interoception). They also usually learn to *suppress and ignore* feelings of hunger, fullness, or pain. This often normalizes after recovery. People with AN do not generally have fundamental, life-long difficulties in detecting bodily sensations like hunger, thirst, and pain, as many people with ASD do. People with ASD often have sensory integration problems. This means that their brains struggle to process information gathered by the senses (sight, smell, touch, sound, taste, and body position). Sensory stimuli can be misinterpreted or experienced too strongly or weakly, or the person may be unsure what to do with the information, preventing them from responding appropriately. People with AN who are underweight may also have sensory integration problems, but these are linked to their weight and their eating disorder. These problems would not have been present prior to the onset of AN.

Differences in the quality of social interaction

People with ASD often come across as unusual or even odd during social interactions. It may be difficult to understand their perspective or to follow along with their thought processes. It is usually easier to relate to people with AN and to understand where they are coming from. People with AN often show a greater range of emotions. They have a noticeably poor self-image and a tendency to be too hard on themselves. In people with AN, questions like, “Who are you as a person?” and “How has your past shaped the person you are today?” can lead to a productive dialogue in which you can easily understand their thoughts and feelings. People with ASD often struggle to answer introspective questions like these and may not fully grasp what it is you want to know. In a group therapy setting, people with ASD may not fit in well with the rest of the group, for example because of awkward behavior or a tendency to withdraw. In these kinds of social situations, people with ASD can become so stressed that they freeze up and are unable to respond.

It is important to ask people with ASD specific, clearly defined questions, as they can get stuck on open-ended questions. This is not usually an issue for people with AN, who are generally able to converse more fluently. People with ASD can often talk about their eating difficulties on an analytical level, but it is difficult to tell how they feel about them, partly because they do not show as many nonverbal cues. This makes it difficult to determine how much they are suffering. To avoid misunderstandings, it is best to ask them about their feelings directly. People with ASD also tend to go into a great deal of detail (often irrelevant), which can prevent the conversation from flowing smoothly. Overall, there is a general lack of reciprocity. Interactions with people with AN are more reciprocal; it is usually easier to connect with them on an emotional level and to gauge how much they are suffering.

In people with ASD, eating problems are often related to specific underlying issues. Common triggers include a lack of control over their lives, major life changes, and/or feeling overwhelmed. These can lead to internal chaos and losing sight of the meaningful whole. In situations like these, the way that people with ASD *process information* (getting bogged down in details, missing the big picture, inflexibility) can leave them struggling to cope. The world feels less predictable, and therefore less safe. The eating disorder serves as a kind of coping mechanism/ritual/routine, providing a predictable daily schedule and resulting in a predictable body, enabling them to get their stress levels and anxiety under control. For people with AN, an eating disorder may also be a form of control, but it is usually geared toward dealing with significant *emotional* problems, such as feeling insecure at school, parents’ divorce, or traumatic life events. It is mainly about control and self-image rather than about creating predictability (relating to detail-oriented information processing), as we tend to see in people with autism. This difference is also noticeable in conversation.

For people with ASD, *body image* is not usually a driving factor behind eating problems. People with ASD are usually not overly concerned with how others view their bodies. However, this is often an important factor for people with AN.

Characteristics of AN in people with ASD

People with ASD often experience eating problems and can become underweight.
How can you tell whether or not someone with ASD also has AN?
Below for each AN criteria how this manifests itself in ASD (the overlap between AN and ASD. The middle column lists how these criteria can resemble characteristics of ASD (i.e. the overlap between the two conditions). The last column contains the "additional" characteristics you would expect to see in someone with comorbid AN (i.e. the characteristics that cannot be explained by ASD or ASD-related eating problems). The information under the heading "signs of comorbid AN" will help you determine whether someone should be diagnosed with AN in addition to ASD.

	AN criteria	**Overlap between AN and ASD**	**Signs of comorbid AN**
1	Restriction of energy intake relative to requirements, leading to a significantly low body weight.	People with ASD may also restrict their energy intake (often unintentionally) as a result of: *1. Sensory hypersensitivity* Oversensitivity to smell, taste, texture, or visual aspects of food. A feeling of fullness can also be unpleasant for people with ASD. These sensitivities were already present in childhood. Assessment for Avoidant/Restrictive Food Intake Disorder (ARFID) may be indicated. *2. Sensory hyposensitivity* Restricted food intake may also occur as a result of difficulties recognizing bodily sensations like hunger. *3. Fixations* People with ASD can become fixated on a healthy lifestyle or on a particular diet. The combination of fixation and rigid thinking can cause them to take things too far, which can result in becoming underweight. *4. Stress* When people with ASD are dealing with high levels of stress/sensory overload, they may struggle to eat due to the extra stimuli involved (taste, texture, smell). If the stress persists for a long period of time, they can become dangerously underweight. They usually wish to achieve a healthy weight but may be too stressed or overwhelmed to do so. *5. Gastrointestinal problems* People with ASD are relatively likely to experience gastrointestinal problems (often due	In people with ASD who also have AN, you would expect to see a conscious (though often unspoken) decision to avoid gaining weight. Being underweight can be an extremely effective method for dampening sensory stimuli and/or emotions. They have an underlying fear of gaining weight and a distorted body image, as described in criteria 2 and 3. People with comorbid AN will keep adjusting their target weight downwards and have an intense fear of eating more than on previous days. Neither of these would be expected in someone who "only" has ASD.

		to stress), which can make eating difficult and can lead to restricted food intake. *6. Information processing and motor skills* Slow processing speeds and poor motor skills can be another cause of undereating. For example, mealtimes (such as a lunch break at work) may be too short or too stimulating. Aversions to certain foods and/or preferences for certain brands may also play a limiting factor in the diet. *7. Social contact* Eating in the company of others can be extremely overwhelming (both socially and in terms of stimuli like smells, sights, and sounds), leading to insufficient food intake. It is important to note that in the above 7 points, there is no underlying desire to lose weight and no signs of a distorted body image. They are usually able to gain weight successfully by reducing stress levels, learning about healthy eating patterns, and establishing clear mealtime routines that allow them enough time to finish.	
2	Intense fear of gaining weight or becoming fat, or persistent behavior that interferes with weight gain.	You would not expect to see an intense fear of gaining weight or becoming fat in people who have ASD. However, they may show persistent behaviors that unintentionally hinder weight gain. For example, people with ASD sometimes become *extremely absorbed in playing sports,* either due to a fixation or as a means of clearing their heads (after sensory overload, for example). Some people with ASD may *insist on eating a very limited, unchanging range of foods.* Eating has become a ritual behavior for them, which is consistent with ASD. They often have difficulty adjusting this ritual when circumstances change, such as after strenuous exercise or during a growth spurt in puberty. In the long term, rigid adherence to this ritual can lead to unintended weight loss. People with ASD may also have trouble *transitioning into independence* and may struggle to develop and maintain an appropriate diet due to factors like change aversion and executive functioning issues. For example, we sometimes	Comorbid AN clearly involves persistent eating habits designed to prevent weight gain and/or an intense fear of gaining weight or becoming fat. Compliments about being thin or being able to lose weight easily (and being socially accepted) can drive the eating disorder. In people with both ASD and AN, we sometimes see that certain foods can trigger such extreme anxiety about weight gain that it seems almost psychotic. The combination of ASD and AN seems to produce irrational thoughts about weight gain/body changes that are more rigid and harder to challenge than in people with ASD alone. Refusing to eat provides a sense of control in people with AN (with or

		see that children and young adults with ASD try to maintain the body shape and weight that they are familiar with. As a result, they are reluctant to eat more, even when they enter puberty and require more calories. They are often unaware of the consequences of undereating, leading to unintended weight loss. People with ASD may also find it difficult to transition back to normal eating *after experiencing illness.* These difficulties are not due to disordered thoughts about food or their bodies ("now I finally look good!") but because they *have trouble "switching gears"* and returning to "normal". *Predictability* is extremely important for people with ASD. This can include their dietary habits and weight. They may become stressed if their usual eating habits do not result in maintaining a stable weight. This is not related to their self-image. Some people with ASD *eat or drink excessively* (polydipsia). This can be caused by a number of factors, including a lack of satiety, becoming fixated on a certain food or drink, and/or a lack of understanding of what is normal within a given context. There is no underlying fear of gaining weight.	without ASD). This feeling of control seems to be extra rewarding in people who also have ASD, given their underlying aversions to change and unpredictability. Being underweight can also help dampen both stimuli and emotions, making them more manageable. This is another rewarding/sustaining factor.
3	Disturbed by one's body weight or shape, self-worth influenced by body weight or shape, or persistent lack of recognition of seriousness of low bodyweight.	Distorted perceptions about weight or body shape would not be expected in people with ASD. However, some people with ASD have difficulty accepting hormonal changes and the development of breasts or hips during puberty. Their body suddenly seems unpredictable and they may struggle to recognize it as belonging to them. This is related to the inherent aversion to change that is characteristic of ASD. Weight and/or body shape do not generally have a significant impact on self-image in people with ASD. When people with ASD become overly focused on dieting/losing weight, this is not usually related to self-image. Instead, they may be having trouble returning to normal eating patterns after a change or they may feel a need	People with comorbid AN will mistakenly feel that they are fat. Weight gain will cause them to feel extremely negatively about themselves and will increase their stress and anxiety levels. Their appearance and weight can have an enormous influence on their body image, self-image, and sense of self (though this is not always the case). People with comorbid AN usually deny having an eating disorder and/or refuse to acknowledge how dangerous being underweight is. This denial persists even after the dangers and potential consequences of the eating disorder have been explained to them.

		for control in a world that often feels unpredictable to them. Some people with ASD may also fail to recognize the dangers of being underweight. They may be unaware of what a healthy body weight looks like or may not realize that a restricted eating pattern is unhealthy in the long term. Once these concepts are explained to them clearly, they tend to accept them.	
4	**Restricting type:** weight loss is accomplished through dieting, fasting, and/or excessive exercise.	In people with ASD, weight loss is usually related to the issues described in criteria 2 and 3.	People with comorbid AN will not only be underweight but will also strive to avoid gaining weight or to lose even more weight. They may also be afraid of allowing themselves to feel again, as this reminds them of their lack of control over the world around them and can lead to panic (see criteria 2 and 3).
5	**Binge-eating/purging type:** weight loss is accomplished through binge eating or purging behavior (vomiting, laxatives, diuretics, or enemas).	In people with ASD, binge eating typically stems from a lack of satiety or a fixation on particular foods. Certain foods may produce pleasant sensations when eaten, which can have a calming effect and can help dampen overstimulation in other areas. Binge-eating episodes are not caused by a loss of control, nor are they followed by significant compensatory behaviors. People with ASD also tend not to use laxatives, diuretics, or enemas to lose weight, partly due to sensory sensitivities.	In comorbid AN, binge-eating episodes often stem from a loss of control and are usually followed by significant compensatory behaviors. Purging behaviors (such as vomiting and laxative use) may also occur without binge eating.