

**ARFID**  
Avoidant/Restrictive Food Intake Disorder:  
The Fear of Food

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## **Introduction**

A few of years ago the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-V) came out with a diagnosis that is new to the mental health community. Avoidant-Restrictive Food Intake Disorder (ARFID) is the new name for an eating disorder that I have seen years earlier. It is very different from the other three eating disorders, Anorexia, Bulimia, and Eating Disorder, NOS, and Binge Eating Disorder. It is a sensory disorder as I have discovered in my treatment of these children and a few adults. And, I would suspect (because there is no real research, yet) that it could be classified as a brain disorder as well.

It is hard to believe that anyone would be so hungry that they are literally starving, but cannot eat. The fear of food, choking to death, vomiting, or stopping breathing because of the choking and vomiting is so overwhelming, that the ARFID individual cannot eat. The malnutrition in this disorder is high and the anxiety is as high. The ARFID individual becomes afraid of many things and has a heightened alter system that creates social anxiety, depression and isolation. The families of these kids and adults are also consumed with fear that their loved one is not eating and they have no control or influence to help.

Through my work, my ARFID clients have guided me through a place to help them heal and live without

fear of food, choking, vomiting, or cessation of breath. This ARFID treatment is a labor of love for my patients, their families, and the work I do. My hope is to help practitioners learn my tool set, including intuitive nuances of the art eating disorder therapy, to help many more ARFID and other eating disordered individual's recovery from this disease.

My first case where I saw that ARFID is devastating and knew I must make a change in my treatment was with a young man I lovingly call "French Fry Boy". His loving parents brought him to treatment and my care over ten years ago. The family was frustrated and scared. They felt a huge amount of shame and anxiety from not being able to help their son, while being judged by their social contacts as well as the medical community. French Fry Boy ate only French fries from In and Out burger from the time he was two years of age, until I started working with him at the age of fourteen. He had multiple health issues including heart disease and osteoporosis. He parent's only wanted their son to eat. Under doctor's advice to not feed French fry boy until he ate something else, led to days of watching their son 'starve', cry, in an intense amount of physical and emotional pain. They could not bear to see and feel the torment, so were locked into getting their son the only thing he could eat.

My expertise in the areas of eating disorder treatment and nervous system dysregulation has lead me to a new successful specialty treatment of

Avoidant/Restrictive Food Intake Disorder (ARFID). I am offering the training for clinicians interested in helping ARFID individual's recovery and rebalance their lives. Sign up for ARFID treatment training can be found at [www.ARFIDcare.com](http://www.ARFIDcare.com).

Lovingly,

Dr. Kim DiRe'

# Chapter #1

## Definition and Criteria

Avoidant/Restrictive Food Intake Disorder (ARFID) is unlike any other eating disorder. There is specific criteria for ARFID in the Diagnostic and statistical manual of mental disorders, 5<sup>th</sup> edition (DSM-V). The new diagnosis replaces the previous diagnostic category of 'feeding disorder of infancy or early childhood'. There are also unique differences in each patient with ARFID even though the general criteria will give a practitioner a diagnostic code. The diagnostic code makes it easier for patients to have insurance coverage. Additionally, the diagnosis gives patients and their family's validation that there is something more to this fear of food and the body's response than 'just in their heads'. ARFID is real.

The DSM-V criteria indicators are:

a.

- An eating or feeding disturbance so pervasive that the person is unable to meet appropriate nutritional needs, resulting in one (or more of the following: significant weight loss, nutritional deficiency, and dependency on nutritional supplements or interference in social functioning.

- This problem with eating is not explained by lack of food being available.
- This is different from both anorexia nervosa and bulimia nervosa in that the problems with eating are in no way related to what the person believes about his/her size, weight, and /or shape.
- This disturbance is not caused by a medical condition or another mental disorder.

b. Eating issues seen: associated with being uninterested in eating, sensory characteristics of the food. Concern about the consequences of eating, refusal to eat anything other than liquids or soft foods, an intense fear of choking, or limited intake to only a specific brand/type of food.

c. While indication that the issues develop prior to age 6, there are often cases of ARFID in late childhood, adolescence and it may also persist into adulthood.

d. ARFID is associated with anxiety disorders, depression, the autism spectrum, obsessive-compulsive disorder and attention-deficit/hyperactivity disorder.

e. Very little research has been done on the development, course and treatment of ARFID.

f. Higher rates of feeding problems are seen in children whose mothers suffer from an eating disorder (DSM- V, American Psychological Association, 2014).

ARFID has specific nuances for each child even with all the criteria and diagnosing indicators, to make the intake disorder more difficult and complicated to treat. Many times the event that caused the ARFID behavior to ignite and appear is difficult to pinpoint for the parents. Children are unable to tell the events because of pre-verbal events of in utero or early childhood development. Through a child's point of view, a trauma will feel very different from what their parents see as a normal event. I believe a trauma story that hold a memory in language for adults transfers to a memory in the ARFID patient's body tissues. Very little has been researched and written about ARFID. I will therefore write what I have researched through case after ARFID case and share what I find in clinical practice.

What I see, clinically, is more children are referred to eating disorder practitioners from the medical field such as doctors and hospitals to date. Awareness that 'picky eating' is not something that some children grow out of is becoming apparent. The medical field recognize that persistent failure to eat and fear attached to vomiting and/or choking on food impacts the child nutritionally, emotionally, and socially. Doctors observed disturbances in sleep and distress causes mood changes as well as a heightened sensory

characteristics (Kenney & Walsh, 2013). This type of feeding disturbance is more than a child that refusing to eat liver, onions, or broccoli. The medical field grasps ARFID patients need psychological intervention and treatment. Referrals from medical clinicians are increasing due to collaborative understanding of the medical and psychological fields.

Children with ARFID have serious medical or clinical problems. The persistent fear of eating and therefore restricting can lead to detrimental consequences. Weight loss, failure to grow, nutritional deficits, which affect their abilities in school, socially, and ability to regulate their nervous system are a few of the ARFID medial and psychosocial outcomes. Many ARFID children have social anxiety due to their highly anxious systems. It puts them at odds with eating situations that are such a big part of our social culture. School lunchtime, birthday parties, and family holidays leave a window of opportunity for the ARFID patient to feel shame and the want to hide their eating disorder and the issues around food fear.

Today's parents are more astute about their children's habits and eating issues than parents decades ago. Parents are able to research at the press of a button to electronically search their child's symptoms. Information (although small) about ARFID is available on-line for parents to receive. On-line, parents receive explanations that a name and treatment for this unusual



mental, sensory, fear of food is available. This is a good thing that parents are generally more aware.

Unfortunately, the medical community is not as aware (although making great strides) and make comments like, “Just make him/her eat”, “He’ll/She’ll grow out of it”, “If you wait long enough, eventually, they’ll eat”. The unfortunate part about all of this is if you wait long enough and do not find treatment, “eventually they will starve” or have an amount of malnutrition and nutritional deficiencies. Along with the medical community not having a full educational view about ARFID, treatment is difficult to find.

What I have found in my clinical practice is normal eating disorder treatments do not work for ARFID patients. A series of treatment regimens that well meaning and helpful practitioners, medical clinicians and other health workers have tried to combat ARFID leave them stumped and frustrated. Behavioral modification, exposure therapy, cognitive behavioral therapy, occupational therapy, and pharmacological interventions do not work, although may help with outlying issues. The ARFID patient is fearful of death from food or the outcome of having the food. A reward or punishment system does not work to heal ARFID. Occupational therapy in swallowing and eating function does not work, because these ARFID patients have the swallow mechanics of their systems in place and working well. The swallowing and chewing system is

constricted when there is a sensory trigger for the ARFID individual. Exposure therapy only exposes the ARFID patient into more of a hyper-vigilance and constricts the digestive track more. Exposure therapy will trigger more of a traumatic response than become helpful. There may be some helpful elements of Dialectical Behavioral Therapy (DBT which is similar the cognitive behavioral therapy) in dealing with emotion regulation and mindfulness to calm the body as helpful life skills or tools. These therapies do not get to the root of ARFID, which is sensory in nature.

There is a sensory component that is prevalent with the ARFID population. If the sensory issues are not treated in the therapy, I see only small progress made. Or, when the ARFID patient is stressed, the automatic constriction of the mouth tissues, tongue, esophagus, stomach and digestive tract re-engage. Additionally, ARFID patients have a high adrenal overload and cortisol influence. Therefore, their sensory issues are intensified and altered by this continual hormonal flow. The adrenal overflow (and therefore the cortisol sent to shut-off the overflow) needs to be shut off as part of the treatment. A main symptom that shows itself in assessed ARFID patients is anxiety. And, the previous explanation is why. There is a constant cycling of heightened alert or vigilance for the ARFID patient.

A major part of my work is done with Somatic Experiencing touch treatment to rebalance the nervous

system and shift the chemistry in the body. I also work with the sensory system to help adjust the constriction by using expansion of the tissues. Whatever, or whenever an ARFID individual tissues expansion shows up in the sessions is what I use as an opening to start the ARFID recovery. That tissue expansion is a therapy tool to work with ARFID recovery. I have had much success with ARFID patients using therapeutic sensory methodology. I also recommend that ARFID patients get allergy food tested as part of the treatment. A therapeutic sensory methodology, which I have developed, is a successful treatment for ARFID. Treatment and recovery is shared in the following chapters of this book.

## **Chapter #2**

### ARFID Population

Avoidant/Restrictive Food Intake Disorder (ARFID) is a relatively new diagnosis (3 years). Many medical practitioners do not know the diagnosis exists or that it is a condition that needs intervention or treatment. Because the ARFID individual has high anxiety, sensory issues, and often avoids social situations, other diagnosis are often assigned. For the reasons listed above, it is very difficult to give statistics on the ARFID population in America.

What we do know is that ARFID does not discriminate between cultures, race, gender, and/or age. Although, many children are in ARFID treatment because their parents notice that something is wrong with their child's eating, which goes far beyond being 'picky'. The ARFID population corresponds with families that have genetic links to other sensory issues, high anxiety, mental disorders, eating disorders, addiction, and/or attachment issues.

## Chapter #3

### Sensory issues, Characteristics, and Symptoms of ARFID

There is very little research on ARFID. Much of my information about symptoms, sensory issues, and characteristics come from my work clinically with ARFID patients. All of my ARFID clients have sensory issues in texture, visual, touch, and smell with gag reflexes, choking, nausea, and purging if trigger foods are introduced or forced to eat. Often these ARFID individuals will go without food when they are physically hungry to the point of pain. In order to tolerate the pain or hunger, the ARFID individual learns fast to shut out hunger cues and hunger pain. Therefore, they are able to tolerate being hungry without normal hunger cues. They often have odd reasoning for picking food groups or brand names for a particular group. For example, French Fry Boy (explanation of French Fry Boy is in chapter #7) would only eat IN and Out French fries. French fry boy could not eat French fries from other fast food chains. Brand names items to eat are picked by ARFID patients due to the nuances of their sensitive sensory system. Patients with ARFID will eat foods that are all white, or all round items, or all small as a seed as long as it is cut up that way, etc. Or, they will eat only one brand of chicken nuggets. Tricking them into another brand is not possible. The ARFID individual's detection from their private eye sensory

that can notice the slightest of changes in a recipe or brand.

Many of the sensory issues go beyond the digestive track. Many ARFID patients report sensitivities to touch. Families share that many ARFID children do not like being hugged or touched by other people because it doesn't feel good or hurts. Many times they have to have tags cut out of their clothing because the tags have a feeling of being too rough. Socks need to be worn inside out for the seam not to disturb them. Smells are a big factor in regulation for ARFID patients. Many times aromas of food cooking can shut down the digestive track. Other aromas such as the slightest bit of body odor or mold can be detected and turn the ARFID's stomach, so to speak. The look of things can also distract an ARFID individual. Many times the ARFID patient has to divert their eyes or disassociate (pull back being present) in order to tolerate the intensity of what they see, smell, or feel. Some of the ARFID patients are misdiagnosed with being on the autism spectrum due to these sensory issues and the way the symptoms outwardly appear. On the flip side, many individuals on the autism spectrum have ARFID due to sensory overload, which shuts down the digestive track. That is another story to tell.

The constriction of the digestive track from fear and anxiety is one of the most common characteristics of ARFID. The digestive track reaches far beyond the lips

and mouth in the ARFID individual. Sight and smell even the sound of food (preparation and food sounds of people eating) are impetus to constriction that can be a periphery as wide as a mile. This may not seem believable that a sight or smell a mile away can constricts one's digestive track. But it does. Think of an animal that has it's sensory system so heightened, that it can see in the dark, smell predators from long distances. The ARFID individual has a super hero sensory system. The ARFID individual is in a constant survival mode. The digestive track is the first track to shut down, so they can conserve energy to survive their feared world.

There are many common characteristics of ARFID behavior, emotions, and uniqueness. ARFID patients often have no skill for voicing opinions or an appropriate way they ask for what they want. They are often not able to identify emotions other than happy, sad, or anger, and often will avoid feeling or expressing anger. Often, they are often malnourished, and have ashen skin, brittle hair, dark circles under their eyes, and a glazed over their eyes. Some ARFID patients have learning disabilities, but the majority of the individuals I work with are what would be classified as a gifted learner. Many ARFIDs are perfectionist in work at school (adult ARFID is perfectionist at work) and will go to great lengths to get "A"s. Some ARFID patients have an element of depressive mood and can be diagnosed with a depressive disorder. Some ARFID children are

given a misdiagnosis or labeled as oppositional defiant because of the refusal to eat even though they are hungry and/or literally starving.

The ARFID individual has a complex system. The fear of food as well as an intense sensitive sensory system and an overwhelm of nor epinephrine and epinephrine and cortisol overload make this eating disorder difficult. This is not something that can be outgrown. Or, it is not a picky eating syndrome that in time allows the individual to make more choices in their food intake when they get 'hungry enough'. This complex eating disorder needs extensive treatment using sensory therapy as well as other skills work for the individual to change and allow more acceptance of food without being activated by a fear response.



## Chapter #4

### Sensory system

The sensory system in Avoidant/Restrictive Intake Disorder (ARFID) individuals has been tinkered with somewhere in the development and evolution of their experience. The tinkering has been driven by the fear of death, which may be described by the ARFID individual as the fear of choking (to death), or vomiting (to death). The brain and body of an ARFID individual has the same as other humans without those fears, but it has been tweaked or a stimulus as flipped a switch making the reptilian (the brain stem), limbic (emotional part of the brain), and/or the prefrontal cortex (logical/thinking part of the brain) signal danger.

The stimuli are certain foods in sight, smell, taste, touch, and sound or tones during eating. The stimuli shift the chemistry of the ARFID individual sometimes through adrenal and cortisol overload. These effects make the taste buds interpret fresh food as rancid. Or, sometimes the inside membranes of the mouth are stimulated that certain food feels like shards of glass. Certain shapes of food also feel threatening. Shapes in the mouth can also be detected as unsafe. A round of the same food cut into a triangle or square can be detected in an ARFID individual as unsafe. The sight of certain foods can give the same results in internally stimulating a fear response. Smell seems to be the most misinterpreted by

the ARFID individual. Many ARFID individuals smell sensories are so heightened that they can smell and report baked bread, fried foods, and other food aromas from as far as 800 feet to a mile wafting through the air. The body's protective mechanisms respond to sensory stimuli without logical thought. The ARFID individual can logically know that smell does not threaten them, but the closing of their throat as a response they cannot control feels out of their minds to control.

Certain stimulus around sound are part of the relationship in that I have found the ARFID individual has a heightened awareness in hearing abilities. It seems as if they can hear through walls. Sounds and tones can affect the taste buds in that human chemistry is shifted by sounds and tones to create different tastes in the mouth. Soothing music is going to be an optimum focus during the treatment of ARFID.

Having people around while an ARFID individual eats can also be frightening. An overwhelming sense of lots of emotions including shame for having an ARFID dictate seemingly odd and out of control behaviors occupies the ARFID patient's social responses. Often, ARFID patients will avoid many normal social functions, including having a family dinner at the dining table.

## **Chapter #5**

### ARFID and Surgical Procedures

An abrupt ignition of ARFID can occur with a surgery or surgical procedure. These rare circumstances, which ARFID seemingly comes out of nowhere, can occur with throat surgeries or endoscopies. The patient becomes afraid at one point or another of choking and/or not being able to breathe. Their fear can be conscious or an induced subconscious state from an anesthesia given for the procedure.

A handful of patients have come under my care immediately after a surgery and can pinpoint the effects of the fear because of their eating habit changes. Often, a patient becomes so anxiety ridden with fear that their food choices and variety of foods become limited. In some of the cases, the weight loss is immediate and drastic that they seek help faster than others where ARFID has become more of a way of life.

ARFID is easier to work with in a recovery model when an ARFID candidate comes into my office with a single surgical occurrence. If there is only one activation event for the ARFID, it seems that the treatment is done in a short amount of time. My experience is two to three months of treatment are all that is needed for a single medical ignition of ARFID. The same protocols as in

other ARIFD individuals are used for the patients triggered by a single medical event.

## Chapter #6

### Treatment of ARFID

Working in psychotherapy with trauma and eating disordered individuals has allowed me to understand the complexity of treatment. The brain, body, and emotions are all tethered together in a large complicated and sometime chaotic mess when working with trauma and eating disordered individuals. When I first started treating ARFID, many of the standard eating disorder treatments did not work. ARFID has a treatment all it's own. Luckily, my patients have be patient with me to learn a treatment pathway that works. I have been taught by the best experts in ARFID to date, my patients.

ARFID treatment has many forms and is best, I found, when integrated together. The first is the assessment. The beginning process is very difficult for the ARFID patient. Talking about food issues and their personal struggles create a great deal of emotional overload. The assessment must be handled with gentleness like no other session. The possibility of breaking each session into two parts to relieve the patient's overwhelm is a suggestion.

The part of the ARFID that seems to affect the ARFID individual's heightened sensory is the adrenal and cortisol overload. Shutting off the adrenal glands from

secreting nor epinephrine and epinephrine along with the steroids, cortisol, is the first part of treatment as well as a continuum throughout treatment. Skills in deep breathing, mindfulness, and orienting as well as psycho education on how eating is the best medication for anxiety can be taught in session. The skills can be assigned as homework. But, the best adrenal and cortisol function release is using Somatic Experiencing (SE) touch therapy.

Somatic Touch (SE) touch therapy is a non-verbal sensory form of treatment I have found helpful to work with a non-verbal sensory disorder. Some ARFID patients have no story to tell other than they are frightened. Dr. Peter Levine has developed a treatment therapy for trauma healing that uses the completion of self-protective responses to heal the trauma. The touch work is part of that same dynamics of completion of self-protective responses, but using the tissue's memory as a place to do that work. As you can guess, some training is needed to be able to produce some tissue responses for this part of the ARFID recovery.

Another opening to tissue expansion in the digestive track is drumming. Drumming seemingly does not inhibit children with ARFID. Adult ARFID patients have trouble breaking out in session to drum. Any deeper vibrator response the body has will work in these cases. Voice voicing can create the same effects as the vibration of what a drumming vibration can do to the body to

open it up in the digestive track. Both voicing and drumming are effective in creating a more favorable avenue for the intake of foods.

Objection without constriction is a vital part of ARFID treatment. This technique or skill is for the ARFID individual to validate their objection to new foods, while taking them in for good nutrition. The way it works is to use a favorable food to open up the pathway for the challenge food or new food to come in without the patient constricting the pathway. Then, when the pathway is open, the ARFID patient keeps it open and pendulates back and forth between the favorable food and the new challenge food. This back and forth skill can be used first using imagination. When the patient feels more confident in using the skill, then real food is used to create the pendulated opening.

Along with vibration and objection without constriction, food graphing can be used to find openings for ARFID individuals to find new challenge foods to eat. The sight, touch, images, and smell of foods can be triggering to the ARFID individual. The work of food graphing is very taxing to the ARFID patient's body system. Food activates their adrenal function and can send the patient into overwhelm very fast. I prepare the ARFID patient with lots of orienting and grounding before I start this work. I often break the food graphing into smaller portions and complete the work one sensory system at a time. Food graphing is very different from exposure

therapy. I use the sensory of sight, touch, and smell to complete this treatment. I let the patient know that they will not be eating the food and I will not ask them to either. A sense of safety needs to be present in the food graphing sessions.

Exposure therapy does not work with ARFID patients in that the sensory system is so stimulated into exhaustion that the exposure causes more fear resulting in more of the gagging and vomiting responses, not less.

Behavioral Modification is another treatment that is not useful in ARFID care. Many ARFID individuals will go for the reward to eat, because the fear overrides the bribe.

The thing to remember about this so called 'picky eaters' disorder is that there is help and recovery.

ARFID is a sensory disorder and needs to be treated through sensory treatment. An integrated sensory approach has many successful case studies in ARFID recovery.



## Chapter #7

My first ARFID case.

I was fairly new to the world of eating disorder treatment when I heard about the boy that only ate French fries. I had only been practicing for a year. In spite of my new practice, I had seen a lot of diversity in the eating disorder world. The owner-director of the eating disorder agency was supervising me. She assigned me the case. My previous career was as an elementary school teacher so there was a natural transition into working with children.

He was doe-eyed and naturally polite. There was something innocent with this fourteen-year-old boy. He was surprisingly willing to do the therapy work and what ever that might entail. He seemed to have a trust in me that was unwarranted. The rapport was instant. That helped for the work we were to do and move through. I did not know at the time, but this was my first ARFID (avoidant/restricting food intake disorder) patient.

I endearingly have named this unknowingly ARFID patient as French fry boy. Since the time he was two, French fry boy had only eaten French fries. He had two orders of In and Out French fries for breakfast, lunch, and dinner. French fry boy was riddled with a multitude of medical issues. Not only was he malnourished, he had been diagnosed with osteoporosis and heart disease. His weight was becoming medically threatening, too.

The medical term used for his condition is obese.

Obese and malnourished individual have major medical complications and abnormal hormonal shifts in the body. Puberty seemed delayed and French fry boy's muscle mass had no nutritional support. His shape was more of a dough like shape. At times he was mistaken for an elderly woman from behind. This appearance had created some poor self-talk accompanied by shameful feelings and low esteem.

French fry boy was very likable, although, the peculiar eating caused social isolation. There was even more isolation as French fry boy came towards puberty. Thank goodness for a handful of grade school friends that liked be French fry boy's company. This group of friends helped disband some of the myths that ran through French fry boy's head that he was unlikable or not worthy. Through out our therapeutic work and as the nutritional variety increase and fear decreased. French fry boy made some risky social moves. He tried out for a talent show, joined the drama club at school, and at one point took a summer exercise class where the student's rallied around his exercise efforts.

French Fry Boy had many fears. One of the biggest fears, outside of different foods, was cooking for himself. He was afraid of kitchen appliances, cutlery, and fires. Many times he would cry that his parents were not coming home fast enough and that he would die of starvation. This is a very complicated situation. On one hand, French fry boy was afraid of other foods to eat,

but once there was a generating of other foods, he was so afraid to prepare them. Smells induced a fear and somatic response. French fry boy could smell things from a mile or more away and gag from the wafting aromas.

French Fry boy also felt responsible for protecting his sister and parents emotionally. Mind you he was very sensitive emotionally, and very mature and nurturing by nature. There was a great degree of loyalty in the family, a kind of all for one and one for all expression. Each member of the family had a burden and a pride in doing for the others what they could not do for themselves emotionally. To untangle French fry boy from taking care of his family would be a tender situation. I needed to go slowly for him to gain his independence.

Keep in mind this was my first ARFID case. I did not know what I was looking at other than it was unlike my other eating disorder cases. As always, I had to think outside of the box and do something different if there were going to be changes. We walked and talked. We played games. We pulled the family into treatment and restructured the home. We made small changes in calming the nervous system. There was a building of 'I cans' in other areas of French fry boy's life along with getting confident with asking for changes in the family. The family started to eat together at least one time a week. We also collaborated with a nutritionist that ate with French fry boy. A big success came one week when

French fry boy at a strawberry on his own without gagging. I can't remember how far into the treatment before this big shift happened. I can remember the feeling of elation that something was working and we were moving forward. Just one strawberry became a pinnacle of change.

I learned from this young man how to work with the sensory system to make mental and chemical shifts in the body. He taught me how to be courageous in the face of adversity. He never gave up. After two years of treatment, French fry boy was able to cook 5 different dinners for himself. He had a variety of healthy foods to select from to eat and could eat at any given time or day. And, there was a social aspect of joining some clubs in high school along with trying out for a school talent show that gained him notoriety and popularity. I am always grateful that I get to do the work that I do. I am very grateful I got to learn my work from amazing people like French fry boy who patiently allow me to find a way for their bodies to change and accept food without fear.

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