

**PROPOSAL FOR THE
AUTISM SOCIETY OF AMERICA CONFERENCE
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**Rerouting the Road Paved with Best Intentions to
Better Climate-Controlled Land**

Title: Rerouting the Road Paved with Best Intentions to Better Climate-Controlled Land

Presenter

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Biographical Sketch: Lars Perner is an Assistant Professor of Clinical Marketing at the University of Southern California. He developed an interest in the autism spectrum after being diagnosed with Asperger's Syndrome at age 31 and has since written extensively on the topic. He serves on the ASA Panel of Spectrum Advisers.

Content Area: Behavior Issues and Supports

Target Audience: All Ages

Understanding level: BASIC - Attendees need to have little or no prior knowledge of the workshop topic

Learning Objectives:

- Understanding how well intentioned strategies can backfire
- Understanding how the perceptions of individuals on the spectrum of well intentioned offers may be perceived

Description: Parents, service providers, and other caretakers gradually learn about the very different perceptions of thinking of individuals on the spectrum. Adults on the autism spectrum illustrate and give examples of how many well intentioned plans may cause distress rather than pleasure. Emphasis is placed on such issues as sensory overload, emotional exhaustion, distress associated with surprises, and the "more is better" philosophy.

Content Plan: Ironically, those who have not experienced life on the autism spectrum face considerable Theory of Mind deficiencies when it comes to understanding the experiences and thoughts of individuals with ASDs. Many well intentioned parents, teachers, and other care givers may offer children experiences that would clearly delight, or at least benefit, most "normal" children. Unfortunately, these strategies can backfire and, in some cases, the sensory overload, surprise, and resentment that results may more than cancel out any pleasure or benefit. Based in large part on his own experiences and experiences of others on the spectrum that have been related, the speaker discusses certain "road hazards" and how these may be avoided or ameliorated.

Hazard #1: *Misunderstanding or Wishful Thinking About Special Interests.*

All-encompassing interests of individuals on the autism spectrum are, quite often, unusual and quite idiosyncratic. It is not surprising that someone who does not genuinely understand the perspective of the person on the spectrum will try to "make sense" of these interests from his or her own perspective. Yet, this type of intuitive approach often misses the *real* basis for the interest and its motivations. Sometimes, when more common motivations would seem more "normal," wishful thinking can lead a parent to assume this basis. One boy, for example, appeared to have a tremendous interest in baseball, greatly obsessing on baseball statistics and facts. His well meaning parents imagined the joy their son would treasure the experience of actually playing the sport, only to see him throw down the bat "in disgust" as he was called upon to hit. The son's real interest was in the *statistics of the game*, not in getting his hands dirty with a bunch of noisy peers. Rather than "blindly" arranging such opportunities, then, it is important to come explore the real nature of interests and explicitly asking if intended "opportunities" would actually be a welcome experience.

Hazard #2: *Emphasizing Quantity Over Quality.* Tony Attwood has aptly observed that many individuals on the autism spectrum are not averse to—and in fact in some cases desperately seek—*some* of amount of social interaction. Attwood cautions, though, that for many, the felt optimal level is a "thimble" rather than a big thirty-two ounce "guzzler." Over time, one may be able to stretch this comfort zone somewhat, but seeking too much

quantity prematurely can backfire. Having grown up with the adage that "Practice makes perfect," there is often a tendency to see "opportunity" in prolonged practice and repeated opportunities. It becomes important to clearly define what we hope to accomplish and how this can be balanced with other demands that the person on the spectrum faces. Having a child be able to actively *enjoy* a twenty minute experience at a birthday party, for example, is really more of an accomplishment than having the child "survive" a three hour party without crying or "problem behavior." It is thus important to judge the appropriateness from the point of view of the individual on the spectrum rather from the typical "built-in" values of neurotypical society. There are situations where certain skills—and the ability to persevere—must be imparted as a way to function in society. The need for an individual to learn skills that may be needed for him or her to earn a living, for example, is compelling given limited social services and financial support available after an individual reaches adulthood. Learning to socialize for long periods of time or to engage in "normal" leisure activities are not necessarily so.

Hazard #3: "*Combating*" *Preoccupation With Special Interests*. Special interests can clearly be frustrating to those who do not share them, especially when these interests get stubbornly in the way of school work and other things that *must* be accomplished. The reality is that not all tasks or learning that must be accomplished can be centered around the special interest. Thus, it is important under some circumstances to develop skills to focus on other tasks to the extent needed. It is a gross mistake, however, to reason that extinguishing—or at least greatly "moderating" these special interests—can serve as an effective stepping stone for creating a more "normal" child. The reality is that, to a large extent, special interests may provide both the best opportunities for learning and for possible long term employment, possibly with some modest "tweaking." It is often more useful to explore how an interest in dinosaurs can be turned into opportunities to learn about math and reading than it is to "fight" the interest. The way the human brain works, learning inherently involves tying new ideas to existing knowledge in the brain. The way we retrieve knowledge, generally, is by having one idea "trigger" another at the appropriate time. Because there are likely to be more "nodes" (or ideas) that relate to special interests than to something else, it is often much more feasible to find ways that the new material can be tied to the special interest. Because the context of the special interest is better known, it is also likely that executive function will be less of a problem to interfere with a deeper understanding. In case of long term employment, special interests—a source of great motivation—may be, with some flexible thinking, turn into opportunities. As an extreme example, a blind gentleman with an obsession with driving became a demolition derby driver. Because it was known that the TV cameras were more likely to focus

on “the blind guy,” he could actually negotiate better endorsement deals. An individual who is “obsessed” with the smallest details of movies might have considerable aptitude in spotting “discontinuity” in scenes shot out of sequence.

Hazard #4: *False Assurances and “Reckless Optimism.”* Telling an ordinary child that “Everything is going to be OK” and “You’re gonna have fun!” may have a calming effect. Truth be told, however, in the life of a person on the spectrum, everything is almost certainly *not* going to be OK. Many trials and tribulations are likely to be ahead. Rather than bringing comfort, then, these words of reassurance may, instead, come across as tremendously callous and are likely to result in significant loss of trust. Assurances of how a parent will be there to help the child get through the difficult situations that are likely to occur are usually much more appropriate.

Hazard #5: *Surprises and Other “Noxious Stuff.”* For many “normal” people, the idea that surprises provide special joy is so ingrained that it is difficult to fathom that this is not so for others. Yet, one man concisely and without hesitation specified “Surprises!” when asked for his vision of Hell. Many parents, in turn, learn to avoid *deliberate* surprises. Yet, many may be perplexed—and genuinely hurt—when a child acts without enthusiasm—or even negatively—when suddenly offered a sudden opportunity to experience an object of special interest. The overwhelm and exhaust that results from the surprise encounter, however, may in reality more than cancel out any pleasure that can be experienced.

Hazard #6: *Failure to Understand Individual Differences.* In an attempt to be helpful, many “gurus” of the autism spectrum have attempted to provide firm and clear instructions on how people on the spectrum can be best helped. In reality, variations within the autism spectrum are, in some areas, often greater than are the variations with neurotypical society. With many, it is essentially now held as “gospel” that persons on the spectrum tend to think “in pictures” and are highly “visual” in their thinking. That description applies to some, but to others, visualization is actually an area of special difficulty. It is important to critically examine whether characteristics that are “supposed” to apply to people on the autism spectrum actually apply to the individual in question.

Hazard #7: *“Tried and True” Methods Not Adapted for the Spectrum.* When facing challenges, it is tempting to resort to strategies that seem to have worked consistently among individuals. These strategies, however, must be examined very critically, before they are applied to an individual on the spectrum. Even if these can be applied, significant modifications must often be implemented. The strategy of “divide and conquer,” for example, is

much heralded. Breaking a big task into smaller, more "manageable" components may look like a good idea. Yet, it is important that this tool not get in the way of felt control and predictability. Asking a child who dislikes reading to read a short passage, only to ask him to read another one upon completion--when he each time expects to be done--can result in a terrible feeling of loss of control. If this method is to work, the child must, at the very least, be "let in" on the idea. The child can be told, for example, that ten passages will be read. Each time one is completed, a check can be made on a list. That way, getting to the end goal will be much more predictable, and a greater feeling of efficacy is likely to result.