

Hyperlexia III: Separating ‘Autistic-like’ Behaviors from Autistic Disorder; Assessing Children who Read Early or Speak Late

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ABSTRACT

Three conditions—Hyperlexia (children who read early), Einstein syndrome (children who speak late), and “Blindisms” (in children with impaired vision)—can present with “autistic-like” symptoms, traits, and behaviors that need to be differentiated from autistic disorder. Careful attention to that critical difference has important epidemiologic, etiologic, treatment, and outcome implications. This paper describes these conditions, makes suggestions for proper identification that can prevent unnecessary worry and distress for parents and other caregivers, and suggests appropriate management.

INTRODUCTION

With the current emphasis on early intervention in autistic spectrum disorder, there is a risk of clinicians failing to properly identify and separate out “autistic-like” symptoms and behaviors from autistic disorder itself in certain conditions. In failing to make that critical distinction, a diagnosis of “autism” can be erroneously and prematurely applied to children, leading to unnecessary worry and distress for parents or other caregivers. Hyperlexia may have “autistic-like” traits and behaviors that can masquerade as autistic disorder; the same is true of children who speak late or are blind. This paper describes those conditions and makes suggestions for proper identification that can lead to appropriate management.

Children Who Read Early—Hyperlexia and Its Sub-Types

In my over 40 years of research regarding savant syndrome, I receive numerous inquiries from parents regarding the presence and implications of savant-like behaviors in their children, ado-

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lescents, or adults. Most of these come through the very active www.savant-syndrome.com website, that I maintain through the support of the Wisconsin Medical Society and Foundation. Occasionally these behaviors present as a rather startling precocious ability in very young children to read words coupled with an intense fascination with letters

or numbers. In spite of this intense preoccupation and ability with words, there are significant problems in understanding verbal language. Comprehension of that which is masterfully read is often poor, and thinking is concrete and literal. There is difficulty with, and paucity of, abstract thinking. There may be some behaviors and symptoms commonly associated with autism spectrum disorders as well, including echolalia (repeating rather than initiating conversation), pronoun reversals, intense need to keep routines (obsession with sameness), auditory or other sensory hypersensitivity, specific intense fears, strong auditory and visual memory, and selective listening with the appearance of suspected deafness.

This combination of precocious reading skills accompanied by significant problems with learning and language is called hyperlexia.

The literature on hyperlexia is quite scant, appearing only as recently as 1967.¹ Some affected children, most of whom learned to read before age 5 with little or no training, have this precocious reading ability combined with language difficulties and display significant difficulty in social relationships. Many come to speech and language disorder clinics such as The Center for Speech and Language Disorders in Elmhurst, Illinois, which has special expertise in the diagnosis and treatment of hyperlexia, with a variety of diagnoses including “autism, behavior disorder, language disorders or giftedness. The precocious reading ability is seen often as rote learning, splinter skills, or savant idiosyncrasy.”²

By the time parents of hyperlexic children send their inquiry

to the savantsyndrome.com website, their children often have gone through numerous evaluations, with various confusing and contradictory diagnoses applied including autistic disorder, pervasive developmental disorder (PDD), Asperger's disorder, attention deficit disorder (ADD), or language disorder. In other instances, there is no diagnosis applied except "precociousness." Controversy exists as to whether hyperlexia is related to a serious developmental disorder such as autism or a distinct speech or language disorder, or, in some instances, simply advanced word recognition skills in a neurotypically developing child.

The literature to-date does not provide a great deal of help for making the distinction between hyperlexia being an autistic/PDD spectrum disorder, or a separate, distinct language disorder. Importantly, though, it appears that in the latter instance, the prognosis overall is quite good. According to Kupperman and her coworkers at the Center for Speech and Language Disorders clinic, when children with hyperlexia were first seen at the clinic at age 2 or 2½, they had difficulty understanding language. They may have used a few words, but they often they were echolalic. Their behavior in some ways looked autistic. However, on follow-up some of these children emerged out of that autism, although some retained some aloofness or antisocial or oppositional behaviors. But over time, the aloneness and self-stimulating behaviors decreased dramatically as language comprehension and expressive language improved. By the time many of the hyperlexic children were in 1st or 2nd grade, many of the "autistic" behaviors had diminished and, while remaining aloof, the children had begun to socialize more.² In short, they emerged significantly from their "autism" because it was not autistic disorder at all.

A 1999 article by Nation provides a comprehensive review of the literature to that date.³ One section of the article examines the relationship of hyperlexia to developmental disorders such as autism. The author concludes that hyperlexia, while present in some children with autistic disorder, is not specific to autistic disorder or confined to that condition. Instead, hyperlexia can be seen in nonautistic persons, many of whom do have transient, autistic-like symptoms and behaviors.

Based on cases that continue to come to my attention, it has been my experience that hyperlexia needs to be subdivided into 3 distinct categories: type I, type II, and type III. In so doing, the often-expressed view that hyperlexia is, in all cases, a form of autism can be properly dispelled and prognoses appropriately applied, much to the relief of many concerned and distressed parents.

Hyperlexia, Type I

Children who fall into the hyperlexia, type I category are very bright, normal (neurotypical) children who simply read early,

to the amazement of their families and teachers. Often one or both parents have read frequently and patiently to their children. Very early, the child begins to "read" the book—this is actually rather prolific memorization of the book triggered by the words and pictures on the pages. Soon, however, the child is actually reading the words in the book, rather than just memorizing them, and that reading ability can then be transferred to other books. The child is reading at a 1st- or 2nd-grade level in preschool, kindergarten, or even earlier. At some point, most of the other children in the class catch up as they begin to read.

This group of hyperlexic children are early, or precocious readers. They are bright, neurotypical children who happen to read early and show no signs of autistic-like behaviors.

Case Example 1

JT's mother read regularly to her children at nap time and bedtime. At age 3, JT would watch her mother's lips intently as she read "Little Black, The Pony" to her. Then one day JT read the book to her mother instead of the other way around. The father was skeptical, and indicated JT had probably just "memorized" the book. Not so. Mother gave JT a newspaper article she had never seen before, and JT read it perfectly.

At nursery school, JT astonished her teachers as she read to her classmates. With formal testing, JT was reading at a 6th grade level at age 3 with full comprehension ability and otherwise neurotypical functioning. Eventually, JT's classmates caught up with her reading ability. But her advanced reading skills continued to serve her well. She went on to become a successful attorney and mother who now reads regularly to her own children.

Case Example 2

LM, now 34, began to read shortly before age 3. She was obsessed with words and letters and was never without a book. She pointed out signs and other lettering everywhere and pointed out spelling errors and typos wherever they occurred. While perhaps not understanding entirely what she was reading, the enjoyment she got from reading was what she called the "music of the language." She would sometimes begin reading in the middle of a book; it didn't really matter. Reading was soothing, no matter the story.

LM was good at math and had musical talent as well, including perfect pitch. Psychological testing was carried out to see if LM was a child prodigy. She said, "I was not, but at the end of it was proclaimed 'normal.'" Social awkwardness was a problem as a child, and she had few friends.

LM's family immigrated to the United States when she was 13. She was enrolled in a private school through a scholarship and, without any formal instruction in English, became fluent

in English within that first year. Following high school, LM completed a Master's degree in engineering, obtained a law degree, and is now a patent attorney at a large law firm. Her social skills have largely normalized. LM finds her advanced reading skills continue and said they are incredibly useful in her profession. Her memory for verbatim sketches of text is very useful in legal research. Her colleagues admire her ability to spot typos at a glance, and her very rapid reading ability continues to be an asset in her work.

LM hesitates to label her early reading ability a disorder at all. She feels, instead, her ability was an asset, not a liability, and certainly not a "disorder." She said, "I was fortunate to have grown up when that diagnosis did not exist. The only label that my parents even thought of was 'gifted'."

Others, myself included, share that hesitation to label what I refer to as hyperlexia I as "hyperlexia" at all, lest it be considered a disorder in otherwise neurotypical children. In recent years, the term hyperlexia—early reading ability—has been too often mistakenly identified as being a "splinter skill" in children with autism, which, in most instances it is not. I have received messages from adults who wrote to tell me they were in the hyperlexic I category as children and grew up perfectly normally with no lingering residuals of any autistic-like traits or behaviors.

In short, hyperlexia I is not a disorder; it requires no treatment. Rather it is a very interesting phenomenon in otherwise usually very bright, neurotypical children who startle their parents and others with precocious reading ability. While peers eventually catch up in reading skills, hyperlexia I bodes well for future academic success in those children with this unusual ability.

Hyperlexia, Type II

Children in the type II category have hyperlexia as a splinter skill as part of an autistic spectrum disorder. They read voraciously, usually with astonishing memory for what they read, and often have other memorization abilities, sometimes linked with number or calendar calculating skills. These splinter skills are seen along with the characteristic language, social, and behavioral symptoms seen in autistic spectrum disorders. They usually carry a diagnosis of autistic disorder, Asperger's disorder or pervasive developmental disorder (PPD/NOS). These cases include the several subtypes of autistic disorder such as classic early infantile autism, early onset autism, or late onset, regressive autism.

In this group, it is the hyperlexia as a splinter skill that raises the question of savant syndrome. But for even those for whom the diagnosis of autism spectrum disorder is appropriate, the precocious reading and decoding abilities can be used as a tool to support the development of language and reading compre-

hension, language expression, and social skills. Clinical presentation, course of illness, and prognosis are those seen in autistic spectrum disorders.

Hyperlexia, Type III

Hyperlexia III is a less frequently recognized form of hyperlexia. It is not an autistic spectrum disorder (ASD), even though there are some autistic-like traits and behaviors that gradually fade as the child gets older.

These children read early, often show striking memorization abilities, and sometimes have precocious abilities in other areas as well. They may show unusual sensory sensitivity, echolalia, pronoun reversals, intense need for sameness and resistance to change, specific fears or phobias, have lining/stacking rituals, and/or strong visual and auditory memory. Unlike children with ASD, however, they are often very outgoing and affectionate with family, even though reserved and distant with peers and would-be playmates. They do make eye contact and can be very interactive with persons close to them. These children seem quite bright, inquisitive, and precocious in some areas overall. Reading and memorization are conspicuous and often quite amazing. There may other autistic-like behaviors as well. But over time, they fade, and these children are then quite typical for their age. The prognosis for these children is excellent as they outgrow the "autism" they never had.

Case Example 1

A mother wrote: "Reading the summary on your website is like reading the description of my daughter in every way. She was a late talker, socially avoidant with those she didn't know well, and began reading at age 2 ½ or so (it's hard for me to tell when she started, as I assumed she was memorizing books until this point). In your words, she was 'autistic-like' but the diagnosis never seemed right on a number of measures. She was diagnosed with autism a few months before she turned 3, but it never quite fit. After 15 months of interventions, she is now a normal (whatever that means) 4½ year old, and the consensus is that she was misdiagnosed. That said, she continues to display a number of precocious skills (reading, math, spatial skills, expressive language, etc) and, while not delayed in any measurable sense, she is also an unusual child with respect to social relationships (precocious these days), sensory issues, and activity level."

This mother indicated that while she was "relieved that autism is no longer an issue," she was having difficulty making educational choices for her daughter, including whether to send her to kindergarten early based on her advanced academic functioning (generally at a 2nd grade level) or to hold her back a year because her social and emotional skills while no longer delayed were not entirely consonant, as yet, with her academic abilities.

Case Example 2

Another mother sent me a video of her son, NS, reciting the alphabet at age 23 months. He “sees letters and numbers everywhere and spells out the names of the stores.”

NS was given a “clear” diagnosis of autism by a psychologist after referral by a neurologist when the child was 12 months old because he never pointed, clapped, or waved. However, before he turned 2, NS had about 100 words, and by his 2nd birthday, he was putting 2 words together and “was doing great and was gaining more and more skills every month. He was happy and loved to learn,” said his mother. In spite of the diagnosis of autism, NS was communicating well at age 2, and while content playing alone, he did copy and imitate other children and especially enjoyed older children ages 4-6. He would give his family plentiful hugs and kisses and knew all of his colors.

At that point, his mother wrote, “Many people who meet NS—and I tell them he has autism—are surprised, I think, because for the most part he is engaged and social. He has done well with the ABA (Applied Behavioral Analysis therapy). The fascination with the letters and numbers is strange, however.”

About 6 months later, I received a follow-up on NS from his mother: “I wanted to thank you for your words of encouragement. You were right. NS is doing very well. He has caught up and is at age level for his language. He continues to be VERY social and affectionate. He still loves letters and numbers. His skills have increased, and at age 2½ years he counts and recognizes up to 40 and can tell you what starts with the letter ‘b’, ‘a’, ‘z’ and so on. He is mimic reading also. He doesn’t know how to read, but for example will read ‘b...l...u...e’ and then say ‘Yes, it’s blue.’ He is social, however he doesn’t do much pretend play. He loves to play with his cousins, run around the house, go to the park and play with other kids. From my account right now, I have a regular 2 year old who had some special extras!!”

Case Example 3

GM was 5 years old when his mother first wrote to me in 2002. “GM was hyperlexic as a child. He showed autistic-like symptoms early on, but as language emerged, they have all but disappeared. He still struggles with vocabulary and usage, but thankfully he is a motivated child who is trying so hard to develop coping mechanisms to manage this unique learning style. As you know, there is much debate about hyperlexia and into which diagnostic category it falls. You have outlined them very well, I think. It was a long and difficult road for me as a mother trying to get a handle on things. I wish I had seen the article sooner.”

I received an 8-year follow-up from GM’s mother in 2010. GM was then 13½ “and doing exceptionally well.” At that time, GM was an A/B student. He was “on the quiet side until

he was comfortable.” He had no sensory issues and did fine with friends and when in groups. “Earning a black belt in taekwon do helped with confidence on many fronts. Skills-wise GM is a musical whiz. He has what you referred to once as super-abilities. He took classical piano for 5 years and played beautiful music, but the rock star in him loves drums. Once he discovered percussion, you’d think he had been playing them forever. His talent is innate.”

“GM knows he is hyperlexic. Sometimes when there is a big group talking all at once he has difficulty following the chatter. He experiences the same when there is a lot of unfamiliar information to digest in certain subjects like history and science. That said, he copes very well and is exceptionally comfortable asking for help or clarity. He is the sweetest, most thoughtful kid. He has a very kind heart that melts mine. I couldn’t be more pleased with his management of hyperlexia. He undoubtedly falls into the 3rd group you described. Though the early years were very challenging and often lonely, I treasure his leaps and tenacity. He is my hero.”

Case Example 4

When AB was 2.3 years old, he was diagnosed by a speech therapist as having PDD-NOS in that he was reading sight words but had very little pragmatic language and delayed social skills. His parents took him to 2 developmental pediatricians, both of whom felt that while AB did have many autistic-like flags—poor eye contact, expressive/receptive language delays, lining/stacking behaviors, under-sensitivity to pain, and early reading—he did not fit the PDD-NOS clinical picture.

His mother recently wrote “that through whatever research I could find, your type III hyperlexia seemed like the best fit description of AB—and gave me some optimism. Now a year later, with the help of speech therapy and a small preschool for kids with special needs, AB is speaking in full sentences, initiating conversations, developing pretend play, and is very engaged. His language is still out of sync with his reading ability—he’s not quite there with question words, and I expect that he is still not quite at age level for expressive/receptive language, while he is easily reading at a 1st/2nd grade level. I am sure we will continue to face challenges, but it is truly remarkable how much he has changed now that his language has improved.”

In subsequent correspondence, AB’s mother listed some of the other autistic-like behaviors AB did show for a period of time: rituals and insistence on sameness, knew letters and numbers to 100 before he said ‘mama’, more interested in page numbers in a book or the color of the page than the pictures or the story, obsessed with letters and numbers, and atypical language development with a large collection of nouns by age 2 but not spontaneously combining words. At age 9 months, he carried his magnetic alphabet letters from one room to another,

always in the same (nonalphabetical) order, and at age 2 did 24-piece jigsaw puzzles in the same order each time.

AB's parents just had their first conference after AB had attended his new preschool. Mother reports that "socially, AB was described as 'the ring leader' and 'concerned about how all the kids are feeling' and 'adaptable'. 'Ironically his language was rated higher than his gross motor skills (which are perfectly fine—he has never been in OT)."

Children who Talk Late

In his book *Late Talking Children*, Thomas Sowell pointed out how often autistic-like symptoms appeared in children with delayed speech in a group of 46 such children based on parental reports.⁴ In a follow-up book 4 years later—*The Einstein Syndrome: Bright Children Who Talk Late*—Sowell wrote, "Many parents wrote to me to say they were astonished to read about things that seemed like an eye-witness description of their own child and their own family. One mother said that she got goose-bumps reading descriptions that fit her child and her family so closely, while other mothers have reported simply weeping as they read for the first time something that so obviously fitted their own puzzling child."⁵ Sowell's experience with late-talking children thus mirrored my own findings with children who read early.

Sowell was careful to point out that in some cases, the diagnosis of ASD was correct, and delayed speech can, in certain cases, be a part of an ASD or other physical condition. But he also found that sometimes cases of delayed speech were being inappropriately diagnosed as autism by persons not particularly qualified to do so. Beyond that, "There are the experts specializing in autism. They are in one sense particularly well qualified for saying whether a given child does or does not fit this category. On the other hand, to some of the experts, 'autism' is just a label to be used for sake of expediency in getting government funding of help that the child needs on other grounds. Others are engaged in a campaign to downgrade the shock of the term by applying it widely."

The 2 books together summarize experience with the 46 original families plus a new group of 239 late-talking children. Some of those fit what Sowell describes as the Einstein syndrome—exceptionally bright but exceptionally late in beginning to speak—but he recommends careful professional evaluation for any child with delayed speech. He also found, based on correspondence with parents, that some children who speak late have transient autistic-like symptoms that faded over time in children in whom a diagnosis of autism had been prematurely and mistakenly applied. With that error came the same worry, concern, and pessimism in those families that some of the parents of hyperlexic III children were experiencing as expressed in correspondence with me.

Visual Impairment

Hyperlexia is not the only circumstance where a distinction between autism and autistic-like is critical; that same differential diagnosis is important in children who are visually impaired. Teachers and parents of visually impaired children often refer to what are called "blindisms" in such children. In a 1998 article, Ek, Ferrell, Jacobson, and Gillberg point out that "blindisms"—stereotypical movements, language problems, and certain other behaviors—are common in children with congenital or other types of blindness.⁶ Hobson described the similarities in development during preschool age (3–4 years) between blind children and those with autism.⁷ In both groups, impairments in symbolic play, confusion in the use of language, and stereotypes were frequent. Many of the autistic features observed in the young, blind child without cerebral damage disappeared with age. As the child acquired a better understanding of the surrounding world, and with the development of language, a basis for sharing experiences and feelings with other people developed. According to Hobson, "blindness seems to delay rather than prevent development in these respects."

In 2010, Hobson and Lee did an 8-year follow-up study on 9 congenitally blind and 7 sighted children who met formal diagnostic criteria for autism.⁸ Follow-up of the 9 congenitally blind children with autism revealed that, in adolescence, only 1 still satisfied the criteria for the syndrome. In contrast, all of the 7 sighted autistic children did still meet the criteria for autism.

Autism, autistic symptoms, and blindisms are often confused with each other and may be difficult to separate in blind children. This distinction in visually impaired children, just as in children with hyperlexia, is critical if parents are to be spared unnecessary distress from a diagnosis improperly applied and, equally important, if the right course of treatment is to be applied to the right patient.

Other Conditions

The term "autistic-like" has its counterpart in other medical conditions. For example some patients on certain medications may have "Parkinson-like" side effects but do not have Parkinson's disease. In much the same way, some other central nervous system conditions—some transient—can produce "Alzheimer's-like" signs and symptoms but not be actual Alzheimer's disorder. Exceedingly careful history, observation, and examination is critical; it may be necessary to let the natural history of the disorder emerge before applying a definitive diagnosis or label that can have important, lasting consequences. Treatment can still be applied to target symptoms, but parents or others may be spared the unnecessary worry and fear that can accompany certain diagnoses.

CONCLUSION

The first step in treatment is to make the proper diagnosis; management follows.

When precocious reading ability and extraordinary fascination with words present in a very young child, especially when accompanied by other language or social problems that might suggest an autistic spectrum disorder, a comprehensive assessment by a knowledgeable professional or team familiar with the differential diagnosis of the various forms of hyperlexia is indicated. That same comprehensiveness and caution needs to be applied to children with delayed speech or visual impairment.

As with any disorder, the first step in treatment is to have the proper diagnosis made by a skilled clinician. In some cases, hyperlexia, for example, can be a splinter skill in a true diagnosis of autistic disorder. However, caution needs to be used before applying that diagnosis to children with hyperlexia as a presenting symptom. The need for that caution stems from the pervasive, mistaken notion that hyperlexia in a very young child is always linked to autism. When a diagnosis or label of autism is prematurely and erroneously applied to a child who may be more appropriately identified as having hyperlexia III, it produces much unwarranted stress, burden, and worry for parents and leads to mistaken predictions regarding prognosis.

The abundance of caution and watchful observation I recommend in children who read early, speak late, or have visual impairment does not preclude intervention and treatment while the “natural history” of the disorder separates out hyperlexia III, Einstein syndrome or blindisms from autistic disorder. Speech and language therapy, occupational therapy, and ABA to address the areas of speech and comprehension, sensory issues, social isolation and ritualistic behaviors, for example, can all help with the autistic-like symptoms, just as they do in those children with actual autistic disorder.

The abundance of caution works in the other direction as well. Just as there is risk in making “false positive” diagnoses of ASD in children who read early, speak late, or are visually impaired, there is also the risk of giving “false hope” in those instances where certain symptoms are a part of autistic spectrum disorder. My answer to both those risks: careful, comprehensive evaluation by skilled clinicians knowledgeable about ASD as well as hyperlexia III, Einstein syndrome, and blindisms. From

such an informed consultation, equally informed intervention strategies will emerge, whatever the proper diagnosis.

From my correspondence with parents, I found that even those parents whose children did have ASD as the underlying disorder in which hyperlexia, delayed speech, or blindisms were the presenting symptoms also were helped, and relieved, when directed to knowledgeable treatment resources in their community. Hopefully, as the literature continues to evolve on hyperlexia, there will be more clarification regarding the classification of hyperlexia into its subgroups and, correspondingly, more information will be disseminated where it will become increasingly clear that delayed speech or blindisms can be autistic-like symptoms, rather than autism itself. Then even more resources will emerge for comprehensive evaluation and tailored treatment principles for those children, into whichever group or subgroup they belong.

The beginning of wisdom is to call things by their right names. There are vital distinctions between autistic-like symptoms and autistic disorder in children who read early, speak late, or have visual impairment. Careful attention to those critical differences has important epidemiologic, etiologic, treatment, and outcome implications.

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Quiz:

Hyperlexia III: Separating ‘Autistic-like’ Behaviors from Autistic Disorder

EDUCATIONAL OBJECTIVES

1. To be able to properly identify and separate “autistic-like” symptoms from autistic spectrum disorder (ASD) in children who read early, speak late, or are blind.
2. To be able to provide examples of hyperlexia types I, II, and III for children who read early; Einstein syndrome for children who speak late; and “blindisms” for children who are severely visually impaired.
3. To understand implications for diagnosis, treatment, and outcome in each of these conditions compared to ASD.

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QUESTIONS

1. The presence of hyperlexia can be:
 - A. Evidence of a serious developmental disorder such as autism.
 - B. A distinct speech and language disorder
 - C. Advanced word recognition in a neurotypically developing child.
 - D. All of the above.
2. Hyperlexia, while present in some children with autistic disorder, is not always linked to that condition.
 - True
 - False

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3. Which of the following is not true of the “Einstein syndrome”?
 - A. The presence of exceptional brightness in children who were late in learning to speak.
 - B. The presence of transient “autistic-like” symptoms that can mirror those of children who read early.
 - C. A clear link of the delayed speech to ASD.
4. “Blindisms”—stereotypical movements, language problems, and other behaviors similar to those seen in autistic children—can occur in some congenitally blind children. Which of the following is true?
 - A. These autistic features tend to disappear with age in blind children without cerebral damage.
 - B. These autistic features persist into adolescence and adults in these blind children just as they do with matched, sighted children with autism.
5. For children who read early or speak late, identify which of the following is/are true:
 - A. The first step is a comprehensive assessment by a knowledgeable multidisciplinary team to sort out autism from autistic-like conditions.
 - B. Whether the hyperlexia, Einstein syndrome or “blindisms” are part of an “autistic spectrum disorder” or a transient “autistic-like” condition, treatments typically associated with ASD may be indicated and effective for either condition.
 - C. Eventually, there is a significant difference in outcome between ASD and autistic-like conditions.
 - D. Eventually, there is no difference in outcome between ASD and autistic-like conditions.

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