

If you decide on a **biomedical intervention**

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Courtesy: PDD NETWORK Newsletter

The cause of autism has been a hotly debated subject for years, and seems to be growing in intensity as supporters of different theories square off against one another. A great deal of research has been done on a number of medical and pharmaceutical interventions, on various possible environmental origins, and on genetic contributors. Be that as it may, we still do not have any concrete answers. What many professionals believe however, is that there are a number of causes, and there even may be different 'types' of autism. For example, many children display abnormal development from birth, and others at least seem to develop normally and then experience a regression of skills. In some families, other members are affected in similar ways, yet other families show no evidence of genetic factors. Some individuals are affected more seriously than others; indeed there is a vast spectrum of symptoms and ways to express those symptoms (i.e. anxiety can be conveyed through quiet withdrawal or by angry outbursts). Hence the question - are they all the same, or are they different?

As a result of what we do not know about autism, families are often torn between trying new and experimental interventions, and listening to more conservative advice. This is after all, their child, and the feeling that they need to 'do all they can' can motivate experimentation, for what parent among us wouldn't throw ourselves into a fire to help our child? It is important however, for parents to keep some perspective on what they are being told and what they are willing to risk in trying some of the more controversial treatments out there (sheep brain injections come to mind...). Whatever treatment you may consider, please get information, do some detective work, and when (and only when!) something is shown at least to be safe, use a systematic approach to introducing it. Many times, families in their zeal will make the mistake of trying several different interventions at the same time, for instance starting a new behavioral program at school at the same time as starting the gluten and casein-free diet and a vitamin supplement regimen. The caution is simply this: if your child should show some improvement, how will you know which one was the reason? And how will you know which you can eliminate? And how will you know whether or not all three each help, and to what varying degrees?

Please be aware that biomedical interventions of any kind have not been proven by researchers to be helpful, although a few have been supported by some (but not all) families that have tried them, the gluten and casein-free diet is a good example.

Digestive differences

The connection between autism and the digestive system was largely investigated because of the common complaints from families of their autistic children having gastrointestinal symptoms. Some research has indicated that at least some children with autism have abnormal

peptides in their urine, and other similar unexplained findings abound. These findings have led to several different hypotheses ranging from the abnormal breakdown of peptides in digestion to the accumulation of metals in the bloodstream. *Again, there has been no conclusive theory reached at this point in time, so beware of anyone who claims to have the answer!*

Many questions still remain with respect to research into dietary and other nutritionally-focused interventions such as vitamin regimens and enzyme supplements. Most critically - why would the intervention of choice not work for all individuals with autism? Additionally, while some researchers believe 'leaky gut' and the resulting digestive distress causes autism itself, others believe that serious food allergies are to blame for the intestinal difficulties separate from the autism, and that the allergy causes great discomfort which of course, would affect behavior in sensorily sensitive children. Consequently, if you remove the discomfort the symptoms will improve – but not because the autism has been 'cured'. Many children who do not have autism can be behaviorally affected by food allergies as well.

What is known is that if a child is going to experience any improvement, large or small, by using a nutritional intervention the change would be apparent fairly rapidly (within a few weeks, depending on the particular choice). In respect to the gluten and casein-free diet (one which essentially eliminates all milk and wheat products), it has been established that it is not harmful, at least not if balanced nutritional habits are utilized. This is good news, because it can be tried with little risk. While this is not the only dietary intervention available it is probably the one most talked about. It must be said, however, that this particular diet is a very difficult one to maintain for a number of reasons, and that adherence to the 'rules' will affect the outcome, even in the children who seem to benefit. Some researchers have suggested that families try eliminating EITHER the gluten or the casein first, and see if they can achieve results this way, rather than eliminating foods that need not be avoided.

Unfortunately, controversy still reigns even on the nutritional front. For example, the Autism Research Institute (Dr. Bernard Rimland's organization) reports the following findings on dietary interventions:

(Chart does not print for a web page)

As we can see, even simply reducing chocolate is 'shown' by this (very) unscientific study to improve symptoms 49% of the time (which is certainly much simpler than the gluten/casein-free regimen, and seemingly almost as effective). If this chart is to be taken at face value, it's a wonder we still have any autistic children. It looks so easy to recover from a complex neurobiological condition!

On making decisions

When deciding whether or not to try any intervention that involves nutrition or the ingestion of any substance for that matter, information and research are essential. These decisions have complicated repercussions, and all aspects of the intervention need to be considered. For instance, with respect to the gluten/casein-free diet, families must consider well how the diet will affect the entire family, not just the child with autism. It would be unfair to expect the child to adhere to a strict regimen while the rest of the family continues to eat his favorite foods, at least while he is present. It may also be difficult to keep a child within the diet guidelines on a regular basis, depending on the age and independence of the child. For instance, keep in mind that he will not be able to have that piece of cake for a classmate's birthday. While this may not be as much of

a problem for a child placed on the diet young enough so he/she has no experience with 'cake' (similar to children with dangerous food allergies like peanuts), what about the kid who had always been allowed cake before, and LOVES cake? Likewise, he will never be able to 'buy lunch' in the cafeteria. Eating in a restaurant certainly presents many problems. Can your child actually order something he is allowed to eat, but may not like, while his brother orders a burger and fries or he sees his favorite dish on the plate at the next table? How will you explain the situation to him without having many a meltdown (some right in the middle of the restaurant!)? Will you be able to count on him not to share a friend's dessert if offered? What will he do on Halloween while his siblings and classmates (with a lot of prior classroom talk about the subject) are out trick-or-treating? We as parents worry often about our kids 'looking different' from their peers, but this particular diet and many like it, may also make them appear 'different'. These are all questions that need to be considered. It may, however, be an option to TRY the diet on a limited-time basis first, to see if it has any effect, and how dramatic an affect before making these more long-term decisions. For example, if you try the diet and it has no effect, you do not even need to make further decisions at all, and can rest assured that that particular stone was not left unturned. If the child is one who is very affected behaviorally and life is difficult, and you seen notable improvements on the diet that can make the lives of the family as well as the child easier, you may feel that these conditions are well worth the trouble. It is an individual choice, and each family may choose differently.

At the very least, all family members should be consulted in regard to any intervention that is likely to affect them, and they should at least be at peace with the changes (even if they may not be happy about them!). It would be advisable to be discrete with the reason for the new lifestyle, because a child should never be given the message that his parents are trying to 'fix' him – fixing something implies that it is not good enough the way it is.

Systematic changes

Anytime a new intervention is introduced, no matter what kind, it is critical to document the 'before, during and after' in order to eliminate chance, wishful thinking, or the coincidental affect of another change. For instance, if a child begins a vitamin regimen on the same day a new highly trained and very-structured teacher takes over his class, any improvement in behavior may not be the result of the vitamins, but of the lower anxiety level experienced at school. Likewise, the bated-breath expectancy that many parents go through can subtly change the dynamics in the home. This change can in fact be so subtle that family members are unaware of it, when in fact they may be spending more time with the child just to 'see' if there are changes or not, and this added attention may change his typical behavior. For example, the parent may feel inclined to play his favorite board game all afternoon to see if he can better handle losing a turn, and may respond positively when he manages it, reinforcing this more appropriate behavior. Does this mean his autistic symptoms have truly improved, or that he has enjoyed and responded to the extra attention and praise?

Behavioral charts that cover the entire day (not just at school or home) for a few weeks before the initiation of a new intervention, during the new intervention period, and after it has stopped are critical to determine the actual objective level of improvement. Videotaping would be a great additional record. How many breakdowns did he have before the change, and how many during or after? Is it a significant change overall, or did he just have one or two good days (especially if it's during a school holiday)? If you don't know what to look for, you may want to try choosing behaviors from a few categories, such as attention, mood, communication, rituals and

repetitive behaviors. If the school is 'in' on the change and are doing charting, ask them for their opinions. If you do not choose to inform them of the change, do they call you asking what miracle has occurred that has changed him/her so significantly? If you call them, and ask if they see anything different, be careful how you direct the question - you may inadvertently affect their answer, rather like asking someone 'how do I look?' The answer might be what they think you want to hear. In any case, it is important to get the opinions of a variety of people who are regularly involved with the child, grandparents, maybe neighbors, the babysitter, anyone who knows him/her well. If you are the only one who has noticed a difference, it may not, in reality, be a change at all. The real test for success? If the intervention seems to actually be successful, take him/her off of it (do NOT do this with medication interventions without checking with your doctor first). Do the symptoms return almost immediately? This is how researchers test their own theories, and is a critical step that is often missed. While it is hard to imagine that you would ever WANT the symptoms to return, even for a short time, this is the final test that would 'prove' that there are no other factors contributing to the change. If the symptoms do return, you can decide what your long term goals are, and restart the intervention with careful planning if you wish. If they do not return, investigate other answers for the changes and pursue the resulting possibilities.

Caution!

Approach any new intervention with a good amount of skepticism and caution for one very simple reason. **If there was a cure, we would all know about it, and we would all have our children on it.** The news media would be in a frenzy, and the researcher who discovered it would win the Nobel Prize and be on the cover of every news magazine on the shelf. It would not, in other words, be something that parents would need to 'seek out'. I know of no intervention provider (such as a doctor who tests blood for mercury, or promotes vitamin therapy) who offers a money back guarantee, or even a free consultation. There is a reason it is expensive to see these 'specialists'. Quite frankly, they make a lot of money on families who are in need. Many families have spent thousands of dollars on promises. But worse than the money loss is the devastation that results from hopes pinned far too high. There is, to my knowledge, no reliable study that has been done on just which types of children might benefit from which individual intervention, how much they might benefit, what the impact of the intervention (good or bad) has been on families, or whether or not they were able to maintain the benefits over time. The practical view of dietary intervention is that you can buy a book about the particular diet, and if a parent sees no results after a few weeks, they can simply resume their normal eating routine.

The good news is, there has been much media focus on the autism spectrum recently, due mostly to pressure from parent advocacy groups. This media attention, along with the alarming increase in the numbers of affected children, has resulted in dramatic increases in funding for scientifically based research. Researchers are working feverishly to answer the puzzle of just where all these kids are coming from. Fame and fortune would follow any professional able to solve this mystery. The challenge is on, and we have only to wait, and hope for the answer to come soon. **This is not to say that we should wait for the answer before we do anything!** Many successful educational, social, and behavioral interventions already exist, and should be the primary focus of parents whether or not they use a diet or similar intervention. Why? Because we already KNOW these work. Much can be accomplished while we are waiting, and our children will benefit from our diligence. Even for those who are attempting biomedical or pharmaceutical interventions, please remember that they do not REPLACE the educational, social and behavioral interventions we have access to, they only compliment them. In other words, even if your child is

on the diet, or on antidepressants, or using vitamin supplements, or even wearing irlin glasses (special glasses designed for visual processing issues), they *must* also be involved with programs that teach skills they need to become happy and independent adults. This is not an option! Parents must use all the tools we have at our disposal, even if they do require a great deal of effort. Currently, these are the ones that have the most success. There is not now, nor is there likely to be, a 'magic pill' that fixes everything. Remember, even parents of 'typical' kids do not lead carefree lives; their children have issues of their own. Research shows that even for 'typically developing' kids, the best predictor for how successful they will be in school, and how likely they will be to engage in dangerous behaviors (i.e. drugs, gangs) is the degree to which the family is involved in their lives. This holds true for kids with special needs as well. They are after all, kids first, and kids with autism second.

For more information about nutritional and other biomedical interventions, contact the Autism Society of America, 800-3AUTISM; The Autism Society of Connecticut (ASCONN) (203) 234-7401; or the Autism Research Institute (619) 281-7165.

Related books:

Autism – Now What? The Primer for Parents, by Abby Ward Collins

Special Diets for Special Kids, by Lisa Lewis, PhD

Food Allergy Field Guide, by Theresa Willingham

Can't Eat, Won't Eat - Diet Difficulties and Autistic Spectrum Disorders, by Brenda Legge

User Guide to the GF/CF Diet for Autism, Asperger Syndrome and ADHD, by Luke Jackson