Parent Forum: Autism—Road towards recovery

Jan Westcott and Jennifer Smith

Abstract

Autism is treatable. Through the sustained efforts and devotion of parents, doctors, and researchers, children on the autism spectrum are moving forward on the road towards recovery.

From Gordon's Story:

Then: "….Gordon Westcott is 7 years old. He was diagnosed with regressive autism and a leaky gut when he was 5 years old….Gordon was severely affected."

Now: "Gordon has done marvelously even starting later than many children….Gordon is now able to take part in conversations both with adults and other children. He can play with toys imaginatively by himself and with his brothers and close friends….all the things we have been working on are coming together and Gordon can apply what he is learning to real life situations. Every parent needs to maintain hope, read as much as they can, and keep moving forward, because autism is treatable."

From Ryan's Story:

Then: "Just before Ryan's third birthday, he received the devastating diagnosis, DSM-IV autism – severe to moderate."

Now: "Ryan is 3 months shy of his fifth birthday….Psychologists and his teachers now say he won't qualify for autism or developmental delay."

Keywords: autism; leaky gut; MMR vaccine; gluten-free diet; DTaP; cod liver oil; Urocholine

Gordon's Story

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My youngest son, Gordon Westcott is 7 years old. He was diagnosed with regressive autism and a leaky gut when he was 5 years old. We believe that his development was normal for the first 13 months of his life. He had an Apgar score of 10 after birth. He successfully met all the developmental milestones for the first 13 months. For example, he held up his head, sat up, rolled, crawled, pulled himself up and fell over like a typically developing child and just like his two older brothers. He babbled and said his first words. At 13 months he received the MMR vaccine. His speech and language did not continue to develop as we expected. He lost words that he had said previously and he failed to acquire speech as we expected. He babbled less, we questioned his hearing, but all hearing tests came back fine.

After this we noticed changes in Gordon's development. Previous to the MMR vaccine he played with different toys that we had at home, after the MMR vaccine Gordon would only play with one toy, a train set, all day every day. He was not interested in any other toys for the next four years. It became difficult to play with Gordon after the vaccine, it was difficult to get his attention, and he didn't interact in the same way as before. He babbled less and the words he'd had we never heard again. He cried a loud high pitch cry that went on seemingly forever. He would be very hot at night but was cooler in the morning. By the time Gordon was 27 months he had around 12 words in his vocabulary and was able to get what he wanted by pointing and taking me or his dad to whatever he wanted. His understanding appeared good; he could find things at home we asked him for, such as his jacket and shoes or a video.

I breast fed Gordon as a baby and toddler, I stopped the last feed when he reached his third birthday. Over the summer of that year he started to have nightmares about spiders; the dreams would wake him but it was as if he could still see the spiders in the room. He was very distressed.

Our Health Visitor assessed Gordon at three years and three months and found that he did not meet the milestones expected for that age. My Health Visitor later told me how surprised she had been at how Gordon had not met the milestones. At three years and five months Gordon became unwell with a tummy bug for a few days. I noticed during this time that he seemed to loose further skills in both expressive and receptive language. It was very unusual, as he seemed to have a skill for a few days then lose it then get the skill back only to lose it again, then sometimes the skill just didn't come back. I felt at the time there was a strong connection between his ability to do things and the growing problem of severe constipation.

When Gordon was three years and three months he began to attend a group for speech and language therapy. He did not acquire speech and language skills there but continued to regress

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and lose skills. At 3½-years Gordon struggled to work on two-word level. The group stopped completely in the March of the following year due to the therapist being ill. As time went on, Gordon's behavior became increasingly unusual. He had echolalia utterances, he was unable to play, he was very frightened of people, and noises, animals and insects, and he became obsessed by the number 7 and with the color yellow. It was difficult walking to school with my two older sons and Gordon as he became afraid to stand on the little white stones that are on pavements, believing that they were spiders. He was very frightened. Gordon was not toilet trained and suffered constipation.

When Gordon was 5 years old, Dr Kenneth Aitken of Edinburgh diagnosed him with regressive autism and a leaky gut. Gordon was severely affected. It was a relief to get a diagnosis as this meant we could investigate the underlying health issues Gordon had, then look at the treatment options that would help, and plan the type of education that Gordon needed. We sent a sample of Gordon's urine to Sunderland University where it was tested to find out if it contained IAG. IAG is trans Indoloyl-Acryloyl Glycine. Information about this testing and research can be found at www.osiris.sunder land.ac.uk. The results showed that the levels of IAG in Gordon's urine were very high. These results indicated that we should try a gluten free diet to reduce the levels. Gordon Westcott is pictured above before starting his gluten-free diet.

We began the gluten-free diet during the latter part of September 2003. It was fairly easy and straightforward. I replaced ordinary pasta for gluten-free pasta, cut out regular biscuits and pancakes and bought limited amounts of gluten-free equivalents. At the time, Gordon's diet consisted of Rice Krispies for breakfast, dry bread, plain pasta, apples and bananas. It was fairly easy to change such a limited diet to a gluten-free diet. Gordon had large, bulky stools that measured 6 to 8 inches long by 2 inches wide. After being on the gluten-free diet for one week we found that the size of bowel movements were reduced. Gordon also slept in the afternoon during the first week; something he had not done for years.

We continued to follow the gluten-free diet using fresh fruit, vegetables, gluten-free cereal, gluten-free sausages, pasta and yoghurts. In Scotland we cannot get a prescription for Gordon for gluten-free products. Only patients with coelic disease are entitled to this. The price of a very small gluten-free loaf was about £3 (US$5); we were not in the position to buy this every week and began the diet without it. This has turned out to be a blessing in disguise, for when I decided to splash out one week and buy the gluten-free bread and give it to Gordon, we observed that he became more constipated. We therefore do not include gluten-free bread in Gordon's diet. We use gluten-free crackers and pancakes instead. In the January of the following year we changed our shopping/eating habits and started to buy our vegetables and fruit from a local farmer running an organic box scheme. Gordon was much more willing to try different fruits and vegetables. He didn't always like what he tried but it was a start. I did attempt to make many different gluten-free recipes for a while but they all ended up in the trash. I decided to let Gordon eat whichever gluten-free foods he preferred, which meant mealtime would consist of an apple and banana. Over time, Gordon has tried lots more foods, he eats apples, bananas, grapes, pears, strawberries, kiwis, melon, dates, raisins, a little vegetable in juice specially made, carrot, cucumber, different flavors of yoghurt, roast potatoes, chips, bacon, chicken, eggs, gluten-free pizza, gluten-free cereals with gorilla munch being a favorite. We are still working on diet and variety but we've come along way. Its very gradual and at his pace. Gordon is shown above sometime after the gluten-free diet.

As the diet continued, we found that the size of his bowel movements reduced even further. I had noticed that when Gordon was constipated his behavior was very different, he lost concentration, his speech became slurred and he lost skills he knew days before. Furthermore, as the diet continued and as the stools became a more normal size, it was easier for Gordon to pass stools, this meant it became possible for us to toilet train Gordon. During periods of constipation, Gordon was very reluctant to go to the toilet; he would hide, and he needed a great deal of support and encouragement. Although it has not resolved completely, as the diet continued and Gordon became constipated less often, toilet training became a more attainable achievement.

The diet progressed and the levels of IAG that Gordon had in his urine dropped. Dr Aitken explained to my husband and I that the gluten in the food Gordon had consumed was not being properly metabolized and that this leaked from the gut into his blood stream and had an opiate like affect. Dr Aitken explained that this affected the front part of the brain where short-term memory, language and emotions are situated. These were all of the areas with which Gordon had difficulty. Dr Aitken explained that if we removed the gluten from Gordon's diet, it would mean Gordon would have a greater chance in gaining language and learning about emotions.

I think it is important to say that in the year previous to starting the diet, Gordon attended a local pre school nursery 4 mornings a week, a speech and language session on a one to one basis for 45 minutes 1 morning a week and in addition to this I would teach him myself 5 afternoons a week. During this pre school period we made only a little progress with following simple two-step instructions. For example, clap your hands then touch your nose. Gordon did not make significant progress until he was on the gluten free diet. It was once he was on the diet that he began to make a lot of progress in both expressive and

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receptive language. I noticed that although Gordon was making huge gains in language he appeared to be having difficulty with concentration at certain times in the day. A hair analysis was carried out to ascertain levels of toxic and nutrient elements. Gordon showed no evidence of accumulation of heavy metals such as mercury or antimony however he showed evidence of lowered levels of calcium and magnesium and an imbalance in the ratio of these, and also a copper-zinc imbalance. The minerals, which Gordon was low in, affected his concentration. Once the mineral supplementation started we could see that Gordon was indeed able to concentrate better and for longer periods. Gordon's lowered mineral levels are addressed by supplementation.

Before the gluten-free diet, Gordon struggled to answer simple questions, such as "What is your name?" I checked every day to see whether he remembered it, and some days he didn't. During the pre-school year Gordon was working at 3-word level: He struggled to put three words together. In speech therapy he practiced, "I like juice." Gordon was not able to communicate how he felt or what he needed. His understanding was now behind his expressive language; he understood very little of what we said to him. I often used drawings to illustrate what we were going to do that day or to explain where we were going. I had one of those cameras that develop photographs instantly, and I used that to show Gordon what happened in his day. And of course Gordon could show the photo to other people.

I remember when Gordon attended the speech and language therapy group the therapist introduced animal noises to the children. Gordon then started to use these animal noises as a means of communication. I felt at the time that this showed that Gordon had little understanding of what communication with other people was about. I also felt that the group therapy had a pre set curriculum to follow no matter what the needs of the individual child were in order to achieve progress.

Rather than send Gordon to school, we officially began our home-based education program in August 2003. We made a progress with play early on in our program. However, when the gluten free diet was introduced at the beginning of October 2003 we started to make huge progress in the following areas, speech, language, communication, behavior and play. As the diet continued further progress was made. We based our program mainly upon the curriculum in an Applied Behavior Analysis (ABA) book.

We were also able to develop the program of play with both toys and games. For example, before the gf diet, Gordon was unable to look at a doll, they frightened him, by the December of that year, Gordon was able to look at a doll and begin to learn how to play with one. Which was immensely helpful in teaching he/she his/hers as we could do this with the aid of a girl and boy doll. I used speech therapy materials and adapted them to suit how I was teaching Gordon. I used the format of telling (instruction). Instruction may also include the use of cued articulation and visual aid.

Cueing to the correct response. At the beginning this meant I gave the whole answer. I would then ask Gordon to say the answer with me. Then I would ask Gordon to say the answer by himself. I praised Gordon's correct response each time. If he did not manage it at any stage I would repeat from the telling stage. As Gordon progressed with this format I would gradually reduce the cue. Until he eventually reached the stage where I could ask the question and Gordon could respond with the correct answer. This is the format I used with all areas of speech and language.

We worked 7 days a week, including evenings with Gordon.

I met a lady in early spring 2004 who suggested that I change all of my chemical cleaners, soaps etc. I switched to organic soaps, shampoo and toothpaste. I use a steam cleaner around the house and for washing I use Ecover. I had not expected Gordon to react so differently with the soap: we ran out of the organic one and I put out our usual brand until I got to the market. Within minutes of Gordon using the old brand of soap, he was licking the walls. My mum made a mission to get the soap we needed right away!

As the diet, education and play progressed, the differences in Gordon became enormous. Before the diet he struggled to concentrate on listening to me read a picture story book for a toddler; but after being on the diet several months, he listened to the books A Dog So Small, then The Magician's Nephew, followed by The Lion, the Witch and the Wardrobe. When we started to play games Gordon struggled with Connect 4, he can play that now as well as draughts and chess!

The change in Gordon after removing gluten from his diet is remarkable and undeniable. Because there are many pathways to autism, it is unlikely that every person with autism will benefit from this diet; this is not a good enough reason for not giving parents information about the diet.

I know we are fortunate. Gordon has responded very well to the gluten-free diet and the education program…the gluten-free diet and individualized supplementation optimized Gordon's success with the education program. Gordon checks with me or other adults to ensure that something is gluten-free before he eats it. He takes his minerals with no trouble.

In the material that follows you will find the information on our education program and how Gordon is doing now.

Education

When I first read about ABA - Applied Behavior Analysis - I was very sceptical. Dr Kenneth Aitken suggested that I look at the book *Behavioral Interventions for Young Children with Autism* by Catherine Maurice, Gina Green and Stephen C Luce. I looked immediately at the section "what to teach" and I could see right away that this book would form the main part of our educational program. I bought a copy as quickly as I could. I had my teaching experience, and I felt that it was possible to put together an education program that would suit Gordon.

As there was no way that we could employ therapists to implement and run this program, I began to organize it so that I could run it for the majority of the time myself and be able to leave my husband, Ian, to do it one morning a week. This meant I got a couple of hours for myself, which was good for me, as I went to an art class and had time to do something I enjoyed; this in turn gave me the energy I needed to keep Gordon's program going.

I got all of my resources together. I purchased some and I borrowed some from both the local speech and language therapy department and local nursery school. I decided what things

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would make a difference to Gordon by reading through the programs in *Behavioural Interventions for Young Children with Autism*. The sections split up into beginning curriculum guide, intermediate and advanced. I came to this book late: Gordon was almost 5 and half years old.

Gordon has done marvellously even starting later than many children. I do wonder what the difference this curriculum and the diet would have made if Gordon had started both earlier in life. Gordon first attended speech and language therapy for assessment when he was 19 months old. The educational psychology department knew him from the age of three years 9 months. At three years and five months a Consultant Paediatrician assessed Gordon. A Community Paediatrician assessed Gordon at four years old. Despite being known to the local health and educational professionals, Gordon was not diagnosed formally with autism by this team. Gordon was almost 5-years old when he diagnosed with regressive autism and a leaky gut.

How I organized the programs

I made up 5 files to contain the work that Gordon would work on.

The **first file** was made up of the following:

1. Listening skills, using resources from the *Leap Into Listening* book
2. Following directions, using resources from books by Jean Gillian De Gaetano
3. Sequence picture cards
4. Sound work, using resources from Black sheep press
5. Game for sound work
6. Story with cut out pictures or hand made puppets
7. Cued articulation

I found *Cued Articulation* by Jane Passy very helpful. I was able to borrow a video on how to use Cued Articulation from Stass Publications. The book *Cued Articulation* was very helpful to teach Gordon to how to make sounds. Each sound has both a hand movement and either a colored single or colored double line under the sound, which means that the system transfers easily into teaching reading. All I needed was a packet of colored pencils to draw either a single or double line under the sound that Gordon was having trouble with when reading. I used the book as a tool; we only used the actions and lines for the sounds that Gordon needed. Gordon found *Cued Articulation* very helpful and grasped it very quickly. We made a lot of breakthroughs by using *Cued Articulation* as a tool.

The second file:

1. Micro Lads by Laureate Learning
2. Dotbots

As our program developed I found that the Laureate Learning program Micro Lads was absolutely fantastic. We started with Microcomputer Language Assessment and Development. I came across this company through the Winslow catalog; there was an address to contact to send for a free demo, which turned out to be wonderful. With Micro Lads we very quickly began to see great improvement in Gordon's understanding of language and his receptive language. The program is highly structured and gives both training and testing. It records progress, and the program can be set at different levels to suit an individual child. The animations after each correct response are very motivating. Gordon had a great deal of trouble with 'he' and 'she' and the program alone was not enough for Gordon to grasp these; I used Cued Articulation with it; by drawing the correctly coloured coded line for the sound 'h' on to a small piece of paper, I then attached the paper with some blu-tac to the computer screen when the micro lads program was on to remind Gordon of the Cued Articulation work he had covered for the sound 'h'. This helped Gordon tell the difference between the 'h' sound at the start of 'he' and the 'sh' sound at the start of 'she'. I removed the color coded lines from the computer screen as he progressed; I stopped the hand sign that I was doing at his side; Gordon was able to work through the levels of the program involving he and she and completed it correctly.

I was very happy with the amount of progress Gordon made using the Micro Lads programs, so I decided to get several other programs. I found the series Words and Concepts particularly good, as well as the games on the Concentrate series. We had a huge amount of success with these programs.

Dotbots was a favourite with Gordon. There are 6 little Dotbots: cardboard rolls with a Dotbot printed on and each has a colour. The activities that followed consisted of both practical fun things to do with the Dotbots and worksheets that were made into little books. The Dotbots covered mainly prepositions.

The third file:

1. Lilac: book with speech and language activities.
2. Making a model activity from the DLTK Website. Gordon was very enthusiastic about making models, and I used this as a teaching opportunity, such as in the area of prepositions. I would also tie the work in with the work being carried out in the other files.

The fourth file:

Project work, Say and Do activity worksheets.

I used these sheets to build Gordon's vocabulary. He enjoyed them. As I worked with the Micro lads CD', I could see that it was important to apply the same kind of format in presentation of teaching each and every word.

The fifth file:

1. Concepts, first, next, last
2. Prepositions
3. Pronouns

This file contained mainly worksheets from Blacksheep Press. They have very good clear illustrations and supported the work that was going on in the other files. Primarily, the worksheets could be used as games.

Each file contained one hour's work. The file was kept in the kitchen where we worked at the table. The files were easy to

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use as I had everything in the one places, so I didn't waste time looking for different books and items.

I found that it was best to present each activity to Gordon in a similar format: Tell/demonstrate, cue an answer, praise a correct response, then gradually fade the cue and then the demo and always praise each correct response. I found that he would settle to his program if he had a cup of tea beside him. If an answer was wrong, I would simple repeat the demonstration, give a cue and praise the correct answer.

As we finished items we would replace them with new activities. I found that starting the day with the listening skills activity was a good way to get focus. In between files I would play with Gordon.

Play:

When we began our program, Gordon was able to play with his Thomas the Tank train; he would push it around the track all day long. He could not tolerate anyone playing next to him or with him. He would scream if anyone came into his space or touched his train.

I began by sitting across the track from him when he was playing. I watched what he was doing. To begin with, I tried to sit for fifteen to twenty minutes, but I found this very difficult. I cut the time down to two to three minutes, and I really concentrated on what he was doing. I was able to push the train along the track for a short distance. Gordon would scream if it went too far. Then I noticed that he would hum the Thomas the Tank tune every so often, so I decided to copy that, and I discovered that the train I had could travel a bit further if I hummed that same tune. It was accepted! Over days and weeks I built on this: I increased the time I spent at one playtime; I was able to get the train all around the track, and then I started to put obstacles in the way of the train. I'd say things such as "Oh no! I can't get past, there is a tree stuck on the track." Gordon then became involved in helping me lift the tree off the track so that the train could make its journey. We continued with this kind of play every day, 3 or 4 times a day for 10 to 15 minutes. I extended the playtime to include different toys. The castle and soldiers were popular. I would show Gordon how to make the soldier climb up the ladder into the castle, and then he would copy it. Then I extended it to the soldier climbing the ladder into the castle and rescuing the princess. We demonstrated different sequences with the toys for every toy there was. We would give the toys a little problem, such as "Oh, dear, my car has broken down," to get Gordon to attempt to join in play with me. Sometimes I would take a box and say it was a mountain for the car to go over. This started to give Gordon the idea of pretend play. Gordon really enjoyed making things, so we used this enthusiasm to help teach speech and language targets we had planned and to help play with the toys. We built a road for the cars, with boxes for hills to go over and other boxes that we made into garages. Gordon got play skills from them and they also provided teaching opportunities, since I could teach prepositions such as "in"," on" or "behind" using the cars.

We didn't use every file every day, although some days we did. If I missed a file one day, I made sure it was used the next day. We worked 7 days a week. I also made up two other files for math/number work and reading/language work.

The reading file:

1. I used Jolly Phonic, because this place emphasis on teaching all the sounds before getting a reading book. Teaching the sounds first fit in with the speech work we were doing. The Jolly Phonics material had many resources, and it teaches sounds by giving each sound an action. There are videos to watch and jigsaws and lotto games to play.
2. I also used Schofield and Sim workbooks to teach sounds; these books are clearly illustrated and I used the methodology of demonstrating the sound to Gordon. I demonstrated how to color the picture in the workbook; he would repeat the sound and receive praise. Then he would do the next picture sound by himself: say sound, then color the picture. I would use the same language that I used from the listening file.
3. In the third file, I would have an activity where we made a model from the DLTK Website, and I would try to have the model match the sound we were working on that day. We were very flexible in what model Gordon wanted to make; it was fine if he chose something, since prior to implementing the gluten-free diet he did nothing unless directed.
4. I also used the free resources at the Website Starfall. It's a great site with animated books, each book for a particular sound with worksheets and games to print and play.

Gordon began reading his first book from the Jolly Phonics set in the spring of our first year of home education. He has completed level two reading books and we have started the third level this school year.

He is doing very well. Jolly Phonics also has Jolly Grammar books and Jolly Spelling.

Math/numbers:

To begin with, we had to work on Gordon recognizing numbers without the trains from Thomas the Tank. Again, I found that if I used the procedure "show and tell the number," then ask Gordon to point to the number, then praise, it made a big difference. We then went on to work with the Schofield and Sim workbooks for numbers and math. The layout was clear and the characters were enjoyable for Gordon. Continuing on from that, we started SPMG materials for math and number work, which is used in schools locally.

Gordon can count numbers up to 100, and he can add and subtract. Over the summer he was telling me that he knew that 2 lots of 3 equals 6; he had noticed this when building with his Lego® bricks; he was very excited to show me.

Games:

We used many different games throughout the day, including: card games where you need to remember where a certain card was; worksheets from Blacksheep Press, such as games to remember what the monster ate; An Elephant Never Forgets. "Wizard" is an electronic game that lights up and makes different patterns for the player to copy. We found this was very helpful in improving Gordon's short-term memory.

We played games outside, including a variation on Eye Spy: "What can you see? I can see a ____." Then Gordon had to tell me what he could see outside. This was very helpful. Gordon

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would be outside and not notice anything going on around him no matter how big or unusual. This game helped him to take notice of where he was.

We played Connect Four, then draughts and chess. Gordon always wanted to win, so I played best out of 5 games, letting Gordon win on the first two, then I would win game 3, and Gordon won the last two games, Dr Aitken explained to us that strategy games would be very good for Gordon to play as he would have to work out his own move, and would also have to think about what the other person might do at the same time.

During days out shopping, visiting relatives and going to the park, we used these opportunities to continue the work from the files in an informal way.

One of the biggest breakthroughs in behavior happened when I couldn't figure out why Gordon had started to scream and become distressed at certain times in the day. Dr Aitken advised me to try to figure out what happened before the screaming and note it. I had tried to figure out what was going on before the screaming, but I just couldn't see what it was. Then it clicked: Gordon had left the room and came back into it and expected me to be able to rewind our conversation just like the video machine would rewind his Thomas tapes. I then drew out pictures of the video machine and TV and a plug to show clearly that it worked by electricity. Then I drew some more pictures of mum and dad to show that they were not worked by electricity and could not rewind the conversation exactly. I read through these homemade books with him at a calm time, so that he had heard the story. The next time he left the room and came back in and started screaming, I brought out the books and sat with him and showed him the pictures and read the story. He screamed through it to begin with, but settled with the calmness of my voice and his own interest in the pictures. When he was calm the next day, I went over the story again. We went through this routine a few times, and then this behavior stopped.

Things got even better when Dr Aitken demonstrated the Mind Reading program to us. It is fantastic. Mind Reading is by Cambridge University. It is an interactive guide to emotions: there are 412 different emotional concepts to study. Altogether over 1000 emotions are mentioned. It is wonderful! Each emotion is illustrated using both video and audio clips, notes, and mini stories. The clips are of people young and old, male and female. Its split up into a learning centre where there are lessons to improve recognition skills and quizzes to test you. The lessons are placed on planets in space, which is very attractive and interesting to look at. The levels of difficulty can be adjusted. There is an emotions library and a game zone. There is a manager and resource pack, you can track progress and monitor time spent on areas. Best of all is the wonderful reward collection system for getting the correct answers. Gordon is very motivated by the rewards; he will stay on the lessons just to get more in his collection. And, no wonder, the rewards are fabulous. Gordon started with collecting trains, carriage by carriage, then once he had collected a whole train he could run it on a track through the countryside. All on the computer screen! The flag collection is very popular, as are the collections of birds, where he can collect video clips of owls and ducks. The instrument collection is super also; he collected enough instruments so that he could bring them all together to play a tune. I can't rate this program highly enough. The good thing about it is that Gordon has a great deal of control over what emotion he wants to learn about, and he can click on a video clip as often as he wants. We talk about what is happening in the clips and I find that what he is learning from the CD is being applied in daily life; he certainly notices emotions in other people and has far better understanding of them. He is so much better at recognizing emotions than he was. The program goes up to adult level. I wouldn't be without this.

Six Thinking Hats: This is brilliant! *Six Thinking Hats* by Edward De Bono encourages people to separate fact from opinion, and to look at all the opinions, both positive and negative. It helps you look at things differently and creatively, and it helps you to discover how to turn a difficult problem into a better opportunity. It does this by using Six Hats. The Six Hats are explained in great detail and with the use of interesting, challenging and creative activities. I use this not just with Gordon but with my two other sons, as well. It is enjoyed very much by all of them. I have found that the boys use what they have learned here in every day life. This is one program that teaches thinking skills, and this helps prevent misunderstandings form getting out of control. The age range for this is from 5 to adult. I wouldn't be without this.

Where Gordon is now

Gordon is now able to take part in conversations both with adults and other children. He can play with toys imaginatively by himself and with his brothers and close friends.

The other day we visited my grandmother, who is 93, who was admitted to the hospital after breaking her hip. Gordon asked her if she would like to play a game of nothings and crosses (tic-tac-toe) my grandmother looked a bit uncertain; she wasn't sure if she knew how to play. Gordon could see this by looking at her expression and he understood. He then explained to my grandmother how to play the game by drawing her an illustration of how the 0's would win if three were placed in a straight line, then illustrated to her how the X's would win if they were all placed in a straight line. My grandmother looked delighted—she knew how to play it! Gordon went first and then asked my grandmother where to put her cross. By my grandmother's expression, Gordon could see she needed a bit of help, so he gave her some clues. He gave her enough clues so that his great-grandmother could win! My grandmother was really pleased, and Gordon was happy to see her happy. It was amazing to watch, since just two years ago Gordon could not understand how to play this game, and when he did play a game he had to win, or the screaming started. It was amazing to see him think about my grandmother's feelings and how it would have upset her if she had lost.

This shows that all the things we have been working on are coming together and Gordon can apply what he is learning to real life situations. Every parent needs to maintain hope, read as much as they can, and keep moving forward, because autism is treatable.

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Appendix 1. Educational Resources

www.blacksheep-epress.com
Speech and language worksheets

www.dltk-kids.com
Craft activities

www.ecomserver.us
Stass Publications for Cued Articulation books by Jane Passy

www.edwdebono.com
Six Thinking Hats
Lessons for Schools
By Edward de Bono

www.jollylearning.co.uk
Jolly Phonic Reading scheme
Jolly Phonic videos, lotto and puzzles
Jolly Readers
Jolly Grammar and Spelling

www.LaureateLearning.com
Laureate Learning CD ROMs
Micro Lads
Words & Concepts
Concentrate

www.proedinc.com
www.taskmasteronline.co.uk
Behavioural Intervention for young children with Autism
A Manual for Parents and Professionals
Catherine Maurice, Gina Green and Stephen C. Luce

www.schofieldandsims.co.uk
Large variety of workbooks for different levels of ability

www.starfall.com
Animated reading books plus worksheets

www.winslow-cat.com
Dotbot Language Activities by Cathie Mulder
Laureate Learning CD ROMs
Leap into Listening by Thomas Webber
Books in the Listening Skills Series by Jean Gillian De Gaetano
Say and Do worksheets by Sara Jackson and Anita Robins

Additional References

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Ryan's Story

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Ryan was born December 4, 2000. He was extremely healthy at birth but started to deteriorate over the next few days. He developed acute jaundice at Day 3 and screamed and arched his back around Day 5. His birth pediatrician missed the diagnosis of acute jaundice due to ABO blood incompatibility (I am blood type O and Ryan is blood type A). All of the neurologists who have examined Ryan over the past four years agree that the birth pediatrician could have irreparably harmed Ryan by not treating the jaundice. Brain damage from untreated jaundice (a condition called kernicterus) can include extreme upper body weakness (including cerebral palsy), speech delay (most children do not speak before age 5), clumsiness, sensory problems, hearing impairment and inability to focus. The IQ is usually not affected and when children do gain speech, the communication is normal. Obviously, there is a large overlap between kernicterus and autism, which could make early diagnosis difficult.

I joined several mothers' groups for kernicterus kids, and noticed how much they had in common—lack of speech, lack of focus and severe sensory impairments. But at one of the meetings I commented, "and then there is the spinning and the violence. Don't you notice how these kids seem to spin much of the time? And Ryan is so violent towards his younger sister and kids he runs into when we are out. And do you remember the horrible reactions to the vaccines, especially the DTaPs?"

I was greeted with a room of blank stares. And then I realized that maybe the last neurologist was right—maybe there was something else going on in addition to the untreated jaundice issues.

One month before 4th round of shots (including DTaP)

After 4th round of shots Ryan looks like an addict

The First Year

Ryan received the Hep B at 2-weeks old. Ryan received four shots, including DTaP, at two-months of age. He responded with hours of high-pitched screams which the new pediatrician said was "completely normal and to be expected." His medical records note that his head circumference was in the 60th percentile. We returned to the doctor two weeks later and he was diagnosed with a horrible skin/fungus infection.

Ryan received the second set of four shots including DTaP at four-months of age. Again he responded with high-pitched screams, but this time his head circumference was noted to be in the 70th percentile.

At the six-month visit, he received four more injections and now his head circumference was in the 90th percentile.

At nine-months he was diagnosed with rotavirus and had 3 straight months of horrific diarrhea. At 10- months old, he had the first of what was to become six horribly painful ear infections, each of which was treated with oral antibiotics.

We have a picture of Ryan when he was 11-months of age. He still had a bright smile on his face and light in his eyes. That was the last we were to see of our gorgeous boy for almost 2½ years.

The Second Year

Ryan received a fourth DTaP around 13-months of age. There was some high-pitched screaming, but mostly he was a zombie. We have pictures of him on Christmas morning 2001 just lying on the tile for hours on end, refusing to move. It broke our hearts.

At 14-months old he started having asthma attacks. At one visit to the pediatrician he told me that Ryan would need to have the MMR and Varicella. I pleaded with the doctor to reconsider and said that I did not think that Ryan's immune system could handle even one more vaccine. I was nine months pregnant and exhausted. The doctor said that if Ryan were to contract measles in his condition, Ryan could die. I relented and allowed the vaccine.

Surprisingly, Ryan had no reaction to the MMR and life continued, although the 12-24 month period can best be described as nothing more than constant visits to the emergency room and doctor's office for asthma, allergies, ear infections and pneumonia. The MMR and chicken pox vaccines were the last vaccines Ryan has received.

Looking back, had Ryan been our second child, we would have been much more concerned. However, we were also caring for our newborn daughter, Katie, and my mother who was dying of cancer. The one thing I swore is that Katie (unlike Ryan) would never be vaccinated for Hep B, would never receive multiple shots, and if she ever did react to vaccines the way Ryan had, that vaccine would be her last.

And we had an answer for every concern. We attributed his complete lack of speech to the fact that our babysitter spoke Spanish and also to the newborn jaundice. His weird hand movements—well he must be imitating the Wiggles. The constant illnesses—we figured he was exposed to many viruses at the hospital. He did not walk until 18 months – we attributed that to his large size. And on it went. We had an answer for everything.

The Third Year – It Only Got Worse

Ryan's health continued to deteriorate. After several months of no new ear infections, he was greeted with the most painful ear infection of all. This time (around age 2-1/2) my husband

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took Ryan to an ENT (from Lebanon) who gave us some of the most valuable pieces of advice we ever received. These are direct quotes:

"Please take him off milk immediately. I do not know why, but when we take 'these' children off milk, many just start to get better. But, please do not tell your pediatrician. He will not forgive me and will believe that you are harming Ryan."

"Please give the vaccines a rest for a while. Your son was on a very aggressive schedule, and I am not sure he can handle much more."

"Please take him to Children's Hospital to have him evaluated by a developmental pediatrician. Ryan may be able to benefit from speech, occupational and physical therapy."

What we had not told the pediatrician or the ENT is that when Ryan was baptized at age 2, he bit my hand so hard during the ceremony that I had blood gushing down my arm. We also learned that he could never be alone with his sister because the violence had become so severe that we thought he might kill her. He had started running away from me in parking lots, and several times almost got us killed. It was my husband's parents who first gave us the diagnosis – they said that Ryan had changed and they believed that he was, in fact, autistic.

My husband and I knew the truth, that Ryan was being tortured from something deep down inside. We decided that, at that moment, we would not stop until we had helped Ryan. Just before his third birthday while we were awaiting our first appointments at Children's Hospital, my husband decided to stop working because I could no longer handle him. He was too strong, and emotionally I simply could not handle what had happened to my baby.

My husband did one of the single most selfless acts I have ever seen—he walked away from his successful career and decided to devote himself to Ryan and his baby sister, Katie.

Just before Ryan's third birthday, he received the devastating diagnosis, DSM-IV autism—severe to moderate. He would not get worse and maybe some day might even get better. Instead of going back to a neurologist for the diagnosis, we went to a developmental psychologist so as to keep the diagnosis confidential.

It is important to note that while Ryan was violent, he remained emotionally attached to us. He would run to me when I entered a room (although he would always fall down before he got to me) and always smiled when he saw me. Throughout the ordeal, Ryan and I stayed devoted to each other.

Ryan Turns Three

Rather than go the route of ABA and public schools, we put Ryan in about 10 hours of week of private speech, occupational and physical therapy through Children's Hospital, and Rob started an intense program with him at home of sensory integration therapy. We did not put him in the public schools, because we knew Ryan would get better and we did not want violence anywhere on his school record.

The first change we noticed is that Ryan recovered from his last ear infection several days after we took him off of milk. Ryan has not had an asthma attack or ear infection since that time.

Ryan also became more aware of his surroundings with the removal of milk, so we decided to try to start reducing other sources of dairy as well.

I also started using every second of free time to search the internet to find more about autism. While the initial news from organizations like the Autism Society of America was very bleak, I started finding more and more references to vaccines and autism. Eventually I found myself in a Yahoo group called Autism_and_Vaccinations run by Deborah Delp. I was still in complete denial that my son was autistic and felt in my heart that one day he would wake up and everything would be okay.

I was shocked to learn that many on the list really believed autism was nothing more than misdiagnosed mercury poisoning. Quite frankly, I thought these wonderful and well-intentioned individuals were not on the right track. But I knew Ryan had had horrific reactions to his vaccines and so I asked for advice on what to do about future vaccines. The pediatrician was calling to say that Ryan needed to be brought in immediately for his Hepatitis A vaccine. My answer was somewhere along the lines of "Over My Dead Body."

Beginning BioMed

Someone on the list told me about the book entitled *What Your Doctor May Not Tell You about Children's Vaccinations* by Dr. Stephanie Cave and Deborah Mitchell as a good way to prevent future reactions. One section of the book discussed DTaP and autism.

This excerpt was taken from *What Your Doctor May Not Tell You about Children's Vaccinations* by Dr. Stephanie Cave and Deborah Mitchell, and it refers to Dr. Mary Megson's work: "One or both parents who have a genetically inherited defect called G-alpha protein defect (which manifests itself as night blindness and/or various parathyroid, thyroid and pituitary gland conditions) may be at high risk of autism. If these children receive the pertussis toxin in the DTP or DTaP vaccines, which inserts a G-alpha protein defect and depletes children of their existing supply of Vitamin A, they will develop autism. That's because the toxin causes the G-alpha protein to separate from the retinoid receptors, which are critical for vision, sensory perception, language processing and attention. The CLO replenishes the Vitamin A and the Urocholine stimulates the hippocampal retinoid receptor." Doctor Megson reported that she has moved many children off the spectrum who have this G-alpha protein defect.

I have several immediate family members afflicted with thyroid problems so we immediately found a new pediatrician who was willing to give this medication a try. Several months before his fourth birthday, Ryan was discharged from physical therapy because they said he would never be able to jump and that after 12 months of trying, he still could not descend stairs correctly -- erect and alternating feet. We started Cod Liver Oil, and within two weeks he was running down stairs alternating feet. A $25 bottle of Nordic Naturals CLO accomplished more in two weeks that $25,000 in physical therapy from a premier Children's Hospital. After a period of time, we introduced the Urocholine, and I can only say that he slowly over the next six months Ryan lost the DSM-IV diagnosis.

This is only one treatment for a very small subset of ASD

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children, but if a child is one of the ones affected, it might be worthwhile to have a DAN doctor look into Dr. Megson's protocol. I flew to Chicago to hear her speak at the Autism One conference, and I was not disappointed. Interestingly, she presented the results of her study, and I discovered that Ryan's progress almost mirrored those of the children in her study. Also, Ryan did not progress in the same areas (like social awkwardness) where the children in her study did not progress. After a while his progress stopped, and even though he was unrecognizable from the violent, spinning, nonverbal 3-year-old my husband had left work for, Ryan was by no means fully recovered.

We also learned that Ryan had a high measles titer, which we treated with high-dose Vitamin A for 2 days, which should only be done under medical advice and supervision. That reduced OCD behaviors significantly.

Evidence of Harm

In April 2004, I read EOH and it changed my life forever. I learned that in 1999, the FDA knew that children were being poisoned with mercury from childhood vaccines, and only encouraged manufacturers to move away from mercury containing vaccines. This allowed children (including my son) to be poisoned by the current vaccine schedule for at least six more years. In my mind, the decision to not recall Thimerosal-containing vaccines was evil – and should be punished as felony assault.

I realized from EOH and the Autism One conference that, in addition to his horrific reaction to the DTaP, Ryan might also suffer from mercury poisoning. I learned about chelation and how some children had been completely recovered after undergoing years of chelation with experienced DAN doctors. We ran a urine test which confirmed that he has dangerously high levels of mercury in his body.

I joined the Yahoo Group ChelatingKids2 run by Ann Brasher ("Anna Grammy"). If I had my way, she would win the Nobel Peace Prize. Chelation is one of the most difficult, time consuming and frightening endeavors I have ever encountered. Not only has she recovered one child from autism, she is now working on a second child. Chelation involves more supplements and rules than one can imagine. Every time you think you have something nailed, you learn that there is someone else who has discovered a better way or a better medication. And every day, Anna Grammy and this group of wonderful ladies field e-mails from thousands of mothers like me, all seeking desperately to end their children's suffering.

For the first time in my life, I am really beginning to understand heroes and how blessed my family has been to have been touched by them—the first Ear Nose and Throat Specialist who had the guts to step outside the accepted medical practice rules to help save Ryan's life, the therapists at Children's Hospital who came to Ryan's fourth birthday when many of the MDs in my family would not, Deb Delp for helping me find out about the book that played such a huge roll in Ryan's progress, David Kirby, everyone who helped put Autism One together, and Ann Brasher and the great people who run CK2 who are so giving of their time and advice.

Ryan Today

Ryan is 3 months shy of his fifth birthday. We started the process toward chelation in May of this year and started chelation about two months ago.

Here is a summary of Ryan's progress:

CLO and Urocholine: Huge improvements in speech (expressive communication was much slower than auditory comprehension); eye contact and gross motor skills. He became naughty in a normal way (started teasing his sister) and began appropriate interactive play, shared enjoyment and stopped biting and other forms of violence.

Getting ready for chelating:

Probiotics: Helped with the mood swings. Ryan was better able to take turns and accept losing.

Yeast Treatments like Nystatin: He is no longer hyperactive.

Vitamin C: Helps with chronic constipation which is still an issue.

Methyl-B-12 shots: Huge for speech. He lost his expressive communication delay shortly after beginning M-B-12 shots. He still has a 33% conversation delay. He started asking why and answering questions in the past tense. He now asks his little sister with an awkward but comforting hug, "Katie, why are you crying?" At his last DAN appointment, he asked the doctor to check his heart and then quickly added, "Katie wants you to check her heart too."

Chelation: Too early to tell.

Areas to improve: Upper body strength, ability to have a conversation at an age appropriate level, mood swings, night sweats, acne (yes he is four), ability to focus, social awkwardness.

Psychologists and his teachers now say he won't qualify for autism or developmental delay. At the playground, Ryan climbed up a ladder before his sister; he stopped, turned, and offered her a helping hand. I can say, "Ryan, I need help," without specifying exactly with what, or, "Ryan, take care of your sister," without specifying exactly how.

At 11-months old, the lights went out; at 13-months old at Christmas 2001, Ryan was lying on the floor. Now, at Christmas time 2005—within 3 years of taking Ryan off of milk and within 2 years of beginning bio-medical intervention, the lights are back on in Ryan's eyes (as shown in the photo at right), and everyone is here warmly welcoming him home.

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