Our flight with Rina

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How medication and behaviour management have facilitated inclusion for Rina, an 11 year old with Down syndrome and ADHD

Early inklings

I already had an inkling of my daughter Rina's uncrushable spirit at one week of age, as I watched her struggling to turn her head from side to side. Gone was the lethargic figure I had beheld in the hospital. As she grew older, it was obvious that the so-called "typical" profile of children with Down syndrome being "laid back and easy going" just did not apply to her. At around age two I took her to the "International Center for the Enhancement of Learning Potential" (ICELP-Feuerstein Center) in Jerusalem, requesting ideas on how to best work with her.

While there, Rina attacked the papers stored on the lower level of the evaluator's desk, gleefully spreading them across the floor. I was told that there are a significant number of children with Down syndrome who have a tendency to the "hyper" side, and that Rina obviously fell into this group.

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However, she added that the question of whether Rina had indeed ADHD (Attention Deficit with Hyperactivity Disorder) or not would need to wait several years, and was not important right now. The good news, I was told, was that these children tend to be very curious, and thus easier in some ways to teach.

[Just as an aside to show how discouraging negative viewpoints can be: The next day I had an appointment with Rina at the local child development clinic. There, Rina also proceeded to turn the office upside down. The doctor looked on, silently pursing his lips for two to three minutes. He then pronounced in a solemn tone, "I do not like this hyperactivity. Does she have any hyperactive siblings?" I felt crushed, and only avoided extreme discouragement due to the upbeat attitude I had encountered the previous day at the ICELP.]

The age of "the great escape"

From age two to four, Rina advanced quickly both physically and mentally. She was very active, on occasion doing daredevil antics that made my heart tremble, yet simultaneously striding forward in cognitive achievements. Between the age of three and five, she became an expert in "the great escape": slipping out of playschool, or exiting the house (often in various states of undress). Usually she didn't get too far, but on occasion did cross busy roads. Thus, each and every escapade was a heart-stopper for us. We quickly learned (even her siblings) to always lock the door. I also tried in various ways to "label" her with our address and phone numbers, by way of necklaces, watches, and tags. Nevertheless, my viewpoint at this time was that she was certainly not a child with ADHD.

She was simply impulsive and a child with a "spunky" personality.

Behaviour problems emerge

As Rina grew older (ages 5-7), her natural love of learning seemed to decrease and she became very adept at using avoidance techniques. She also loved getting attention, and used negative behaviour to obtain this. She continued to study well with me, but was able to wrap nearly all of her therapists "around her finger". Therapist after therapist found her extremely difficult, if not impossible, to handle. I started being picky about the personality of new therapists, choosing those who I thought would not let Rina "get away with murder". And, while she would study with me, she tried my patience whenever we were outside of the house, continually "acting up" in stores and on buses.

It also became obvious by six years of age (here the DownsEd AdviceLine helped me) that her problems with toilet training were behavioural. [She was attempting to gain attention (even if negative) with "accidents".] A few therapists mentioned the possibility of ADHD. However, I was sure that this was not the case, as I was able to study well with her. I saw the problem as purely behavioural.

Rina would "lose contact" every few moments, and needed to be brought back to the task

Slowly I started using behaviour modification techniques with Rina. She earned prizes for not tapping people on the back when we travelled by bus. She received *no* attention (well, almost) for toileting accidents. I found a tutor for "preparation for first grade" who was friendly yet exceedingly firm. In addition, I tried to ensure that Rina was in bed on time every evening, as lack of sleep also seemed to be a trigger of negative behaviour. An operation to remove her adenoids to correct sleep apnoea seemed to help her behaviour for a while.

 ISSN: 1463-6212
http://www.down-syndrome.info/library/periodicals/dsnu/05/02/

Nearly diagnosed – but not quite

At this time, I was battling for an inclusive placement for Rina for first grade. One morning she was evaluated by staff from the local school system. Rina actually behaved very well, knowing that "first grade" was at stake, and they were impressed. However, the tester mentioned to me that Rina would "lose contact" every few moments, and needed to be brought back to the task. She recommended that we see a neurologist. I considered seriously for the first time that Rina might have ADD or ADHD.

By now, Rina was nearly eight years old. The neurologist we contacted recommended a test of Ritalin. He recommended five milligrams of Ritalin each morning, for three weeks. We saw absolutely no difference in her behaviour, and dropped the idea of ADD/ADHD. My belief that most of her problems were due to poor behaviour management and the condoning of misbehaviour in a special child was vindicated in my eyes. While today I still see behaviour management as the primary need that Rina has, I also realise that at her weight, this initial trial of medicine was "too little and too short".

As the school year started, Rina turned eight. No school in our area was willing to include her, and the city education services did not give us a placement. As I continued to fight for my daughter's right to an inclusive education, I hired a private teacher and sent Rina to "first grade" three hours every morning. This teacher was excellent, handling Rina's misbehaviour systematically, and encouraging in Rina a positive outlook towards her studies. She taught Rina that it is OK to say, "I want a break". In addition, she taught her that it is also OK to stretch oneself for five more minutes before that break. We taught Rina about her disability, and allowed her to say that something was "hard". She also learned the concepts of "trying hard", "succeeding", and "satisfaction". However, in spite of all these positive developments, Rina became obviously more distractible and hyperactive. We also had several incidents where she "disappeared" (escaped), even after turning our backs on her for only a moment. These escapes did not seem to be calculated behaviour, but rather sudden impulses on her part.

Medications

As the situation worsened, I went to our paediatrician, and requested a re-trial of Ritalin, but at a bigger dosage. We tried seven and a half milligrams daily, and quickly upped the dose to ten milligrams each morning. At this point, the effect of the Ritalin became obvious. Her impulsiveness decreased, and her ability to concentrate improved. The proof was that the rare morning that I would forget to give Rina her pill, the teacher would invariably comment "I don't know what got into Rina today…", or she would call and ask if we had forgotten.

Rina learnt that it is OK to say, "I want a break" but that it is also OK to stretch oneself for five more minutes before that break

I think that it is important to note that we are not giving Rina the medication to control her behaviour per se. We give her the medication as a tool, which helps her concentrate and filter out distracting stimuli. This gives us a chance to teach her the techniques needed to overcome her impulsiveness, to see beyond this moment, and to relate to her studies as a productive, positive experience.

The next year we obtained an inclusive placement for her and at first Rina did very well. We tried varying times and dosages of her medication, in an effort to cover the entire school day (to 1.30 p.m.). The problem was twofold. Firstly, Ritalin only covered a four-hour period. Even greater was the problem that the "rebound effect", as the medication wore off, was quite pronounced in Rina. At times, we felt that the rebound effect was worse than Rina without Ritalin at all. (The month that the rebound effect hit her at 11.30 a.m., I was afraid that we would lose her inclusive placement). In addition, her behaviour problems increased as the schoolwork became harder for her.

As she neared ten years of age, I had Rina evaluated by a neurologist who is not only expert in ADHD, but in ADHD coexisting with other major difficulties. In addition, she is also very pro-inclusion. This evaluation was stretched over several visits. Both the teacher and I had several forms to fill out describing Rina's behaviour, and Rina was tested by the neurologist. In addition, a computerised test to check her impulsivity and her distractibility was done. This test was even repeated, with a slightly increased dose of Ritalin, to see if a larger dose would be significantly helpful.

Rina at 8 years old

We received a "definite" diagnosis of ADHD. Even though Rina is not terribly hyperactive, her impulsivity, belligerence, and distractibility clinched the diagnosis. (Impulsiveness, belligerence, and distractibility are also markers of ADHD, no less than the hyperactivity which people are more familiar with.) The doctor recommended a higher dosage of medication for Rina (partly because of her above-average weight), and a switch to Concerta. Concerta solved Rina's "rebound" problem, as she does not experience it with the Concerta, which tapers off more gradually than regular Ritalin. In addition, the twelve-hour dosage solved problems of the logistics of in-school dosing. It also covered the afternoon and early evening hours, which made life much more pleasant at home (and at homework time!) for Rina and for everyone else.

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[An aside about swallowing of medication: We had previously taught Rina to swallow her thyroid

 ISSN: 1463-6212
http://www.down-syndrome.info/library/periodicals/dsnu/05/02/

medication and her Ritalin tablets (both small) with water, with varying success. With trepidation I viewed the large "forbidden to chew" Concerta. I found that with a spoonful of yogurt, Rina was able to swallow it without problems.]

Educational modifications

However, correct medication was only a partial answer. In addition, we needed, and succeeded, in working out a better program for Rina at school. We gave her more frequent breaks, and more one-to-one preparation for harder subjects. We switched the prize for good behaviour to something *she* wanted, computer time. These all helped Rina considerably in controlling her behaviour. It must be noted that while we had an immediate improvement in her behaviour after rearranging her schedule (within a week), things did not become perfect. Unlearning negative behaviour problems is a slow and difficult process. In addition, any tension at home, lack of sleep, or having a "substitute" aide would make the day trying for Rina, and she would have difficulty behaving.

Medication was only a partial answer. We also gave Rina more frequent breaks and more one-to-one preparation for harder subjects. We switched the prize for good behaviour to something she wanted, computer time

I would love to be able to claim that Rina's behaviour is well controlled, but this is unfortunately not yet the case. However, we have made great strides in managing her behaviour. For example, Rina has always hated leaving class with the aide for one-to-one, preferring to be with her friends, and often threw full-blown tantrums on being taken from class. We recently succeeded in gaining her cooperation in leaving class, but only with a food prize promised for the end of the day. (As she learns that she understands better with preparation, and thus fits into the class better, we hope to fade the food prize out.)

We are trying to develop in her a realisation that independence and friendship go hand-in-hand with responsibility and respect for others

She is still very sassy, impulsive, and at times downright ornery. (As she is now 11, I would not be surprised if some of this is due to her nearing the teen years.) She is also smart (knows just what she wants!), loving, and self-aware. And, she is definitely trying to be more cooperative. We are trying to develop in her a realisation that independence and friendship go hand-in-hand with responsibility and respect for others.

The other day a fawning stranger said of her: "Oh what a doll!" I smiled and said, "That's not exactly how I would define her…." Loveable? Yes, definitely. Smart and sensitive? This is surely true. A cute, quiet, passive doll? Well, "Hardly".

Glossary

ADD: Attention Deficit Disorder. This is a disorder, which is characterised by distractibility.

ADHD: Attention Deficit with Hyperactivity Disorder. This disorder, characterised by an increase in distractibility, also has the characteristics of impulsiveness, belligerence, and/or hyperactivity.

Concerta: A medication identical to Ritalin, but which is manufactured in layers, and releases slowly over a twelve-hour period.

Rebound effect: A negative effect resulting from the sudden drop in a medication. Common in Ritalin, it may result in negative feeling/behaviour on part of the child.

Ritalin: A stimulant medicine, which has a therapeutic effect in nearly all children with ADD or ADHD, causing them to be less distractible, and increasing their ability to concentrate. Improvement in the child's behaviour/study abilities with Ritalin may even be an aid in confirming a diagnosis of ADD or ADHD.

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 ISSN: 1463-6212
http://www.down-syndrome.info/library/periodicals/dsnu/05/02/