



I have been working in a healthcare setting for almost five years now, but at twenty-one years old I was faced with a speech delayed toddler I didn't have a clue what I was doing. I would like to share with you some of the things I learned over the years while traveling with my son to many appointments in search of a diagnosis to learn from and cope with his developmental delays.

1) Take Notes

After your initial appointment when the first referral is made start taking notes. Write down your child's doctor's name, address, phone, and fax numbers with a brief summary of their findings and all the information you are given about what the next steps will be. This may seem like something you can remember, but you may be seeing several different doctors and they will likely want to forward results and observations within your child's circle of care. You will want to remember exactly who you saw and what steps have been taken.

2) Keep copies of everything

Do not rely on anyone to forward documents for you. It's very easy for the fax machine to malfunction on either side and you don't want to waste an appointment you waited months for. Bring a folder with you containing all relevant documents and results. The doctor you are seeing may also appreciate you handing him test results as you discuss your child's medical history, rather than having to stop and search through a referral package for them.

3) Travel Grants

In Canada, we can apply for reimbursement for travel in certain areas. I live in a remote part of Ontario and qualify for the Northern Health Travel Grant. For any specialist appointments, we travel a minimum of two hours and the cost of these trips adds up fast. Obtain forms for any kind of reimbursements from the office of the doctor who makes the initial referral. They will give you one with their information already filled in.

If the specialist doesn't fill out their section correctly you won't receive the grant. While you



have the specialist in the room make sure you take a good look at every part of the form and that it is filled out correctly. These doctors are very busy and it is difficult to get the form signed once the appointment is over.

4) Don't be afraid to call

When you leave a doctor's office it is often with the promise that a new specialist's office will call you within a few weeks to schedule an appointment. If that doesn't happen within 2-3 weeks call them. You can usually google the doctor and find their office's phone number. Often times I found that once I had them on the phone they knew when my son's appointment would be but were planning on calling closer to the appointment date. Obtaining this information sooner provided me with more time to plan, and the ability to call my doctors office and follow up if they hadn't received it. Wait times can be long, so I did what I could to stay informed occasionally would be given the option of being put on a cancellation list to get in sooner.

5) Show them your child is a priority

When trying to obtain speech therapy for my son I found that there was an extremely long waiting list in my area and no alternatives. We had an intake appointment where it was explained to me that the list was often bypassed if there was a child in immediate need of assistance. Without a diagnosis, my son wasn't very high on that list and was looking at over a year of waiting.

I returned to his GP and informed him that I needed help. He sent us to another specialist with the intention of proving my son's need. He was a toddler without the ability to communicate, which made him prone to fits of anger, causing him to have social issues as well. I felt that if it was not addressed in a timely manner he would be unable to cope in a school environment, and he was less than two years from entering kindergarten. The specialist agreed and wrote this in a letter, as well as listing the signs that indicated, although he was too young to be diagnosed with certainty, that he may have one of two different disorders. This put us higher on the waiting list and helped my son obtain a



therapist.

The healthcare system is like any other system of its magnitude, it is too large to be without error. Knowing your child is in need and being unable to help them is a horrible feeling. I was able to push past it by staying active and involved in his care. I found that writing lists and keeping my files up to date, in conjunction with following up and confirming appointments and making travel arrangements let me help him in my own way. I was able to get him the best possible care in a timely manner and that made me feel like the most supportive and best parent I could be to help him in his time of need.

Related Reading:

- [Record-Keeping for Your Child](#)
- Guest Post: [Advocating for Your NICU Baby](#)
- [Parent Support Groups & Mental Health Resources](#)
- [More Community Blog Posts](#)

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