

How to Become a More Effective Parent-Advocate

This five-part E-course is designed to help you gain the information and support to become an effective parent advocate for your child with special needs. My name is Lisa Simmons and I am both the author of this course and the director of the [Ideal Lives Advocacy & Inclusion Center](#) – a membership site for parents of children with special needs. We specialize in connecting advocates to the information and answers they need and we'd love to help your family too!

Now, on with your course...

Lesson 1: Get connected

Guiding your child successfully through their school years can be a full time job. You will need to be, not only your child's parent, but also their advocate. How?

- => By making sure they receive the services they need today, and
- => By teaching them the skills that will enable them to advocate for themselves one day.

So how do you become a parent/advocate?

Step 1 is to find other parents whose kids have similar needs or share similar interests. Parents with "sports oriented" kids have known this one for years. After all -- who makes up the booster club?

Forming connections will work equally well in other situations -- parents with kids who have special needs can join a local or online support group, connect with the parents of classmates before and after school or classroom activities. Many districts have parent/teacher associations or organizations that deal specifically with the issues of special education. Find out if your district has such a group and if so, how to join. If not, be sure to join the regular Parent/Teacher Organization. Special Education issues can quickly become a low priority for the district if the parents don't stay involved and active.

Bottom line -- it helps to have the support and encouragement of others who TRULY know what you are facing.

Lesson 1 Homework Assignment:

1. Find and join your ****Parent Teacher Association or Organization**** for on-going emotional support.

Contact Person/Phone Number: _____

Date of next meeting: _____

2. Contact your state's ****Parent Training & Information Center (PTI)**** to see if there are any local parent support groups available. Sometimes these groups are not disability specific -- meaning all families are welcome, but often these groups are dedicated to a certain type of special need (i.e. parents whose children have Attention Deficit Disorder). Either way, your PTI should know what options are available. If you aren't familiar with your state's PTI, use today's resource link to locate the appropriate contact information.

Today's Resource Link:

Directory of Parent Training & Information Centers

<http://www.taalliance.org/PTIs.htm>

Today's Help:

If you can't locate a local support group, drop me an email. There is an online support group to fit virtually every parent's needs. I'll be happy to try and help you locate the one that will work for you. My email address: <mailto:lisa@ideallives.com>

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Lesson 2: Start your special needs education

Step 2 is to find out everything you can about how to most effectively support your child.

- ✓ If your child has already been diagnosed with a specific disability -- learn about it.
- ✓ If your child is interested in drama -- check out accessibility at the local theater.
- ✓ If your child struggles with math -- research which educational methods have been successful and discuss them with your child's teacher or look for games and learning materials to use at home.
- ✓ Make notes about every local resource you hear about.
- ✓ Have you met a family whose child is similar to yours, but older? Talk with those parents at length and find out what resources or inclusion strategies worked best for them.
- ✓ Can they share any tips about working with your particular school district or guide you toward teachers more open to students with special needs? Take advantage of their hard won wisdom.

If you haven't already, this is definitely the time to get in touch with your state's *Parent Training & Information Center*. Most have resource libraries where you can check out books, videos, and information packets on local resources free of charge. Take advantage of this resource to help lighten the load on your budget.

Today's Homework Assignment:

1. Contact your state's ****[Parent Training & Information Center](#)****. Request any informational materials they have related to your child's disability and inclusion. Find out if they offer parent training on IDEA (the Individuals with Disabilities Education Act) or No Child Left Behind. If it is coming to your area, plan to attend.

Name of PTI Center: _____

Contact Person/Phone Number: _____

Date of next training session: _____

2. Virtually every diagnosis has it's own *****national association***** and almost all of them now have a website filled with information and resources. Visit the website most closely linked to your child's diagnosis and spend some time browsing. If you find helpful information, don't forget to jot down some notes.

Not sure how to find your association's website? Use today's resource link and type "national association + your child's diagnosis" into the search box.

For example, typing "national association + spina bifida" would bring up the national support organization for Spina Bifida (Spina Bifida Association of America).

Today's Resource Link:

<http://www.google.com>

Today's Help:

If you have trouble locating a national association for your child's diagnosis or if you don't find the association's website helpful, drop me an email. I'll be happy to try

and help you locate a reliable information site that will work for you. My email address: <mailto:lisa@ideallives.com>

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Lesson 3: Get organized

It's time to put together your supplies and create your own *Advocacy Notebook*.

Here are the supplies you are likely to need:

1. A sturdy **3 ring notebook** -- one tough enough to last K-12 & beyond.
2. **Divider tabs** -- check the list below for possible sections to set up.
3. A **3-hole punch** -- for notes or reports that don't come "pre-punched."
4. A **highlighter** -- to help you find specific information quickly the second time you need it.
5. **Page markers or flags** -- Post-It makes great flags that are already sticky & easy to use. These will save you time finding sections that you refer to on a regular basis or want to flip to quickly during a meeting.
6. A **spiral notebook or phone log** style notebook to record phone conversations or informal verbal agreements.

Your notebook should contain whatever sections make sense to you, but it is usually helpful to set up separate sections for the following:

- ✓ School records
- ✓ Medical records
- ✓ Professional evaluations
- ✓ Letters and notes from teachers/school staff
- ✓ Information you've gathered about your child's disability
- ✓ Information about special education laws/regulations (both federal laws and those in your state)
- ✓ Copies of letters you send to the school or other professionals regarding your child
- ✓ Your informal log sheets tracking information and commitments gathered on the phone
- ✓ Your personal list of "best practices" -- supports you know from experience work well with your child.

You should be able to get all the supplies you need from your local discount or office supply store. If you live in the state of New York, check out today's resource link. The Advocacy Center (a Parent Training and Information Center funded through the U.S. Department of Education) offers training to parents and professionals throughout upstate New York on a wide range of disability-related topics including one entitled, "*Creating Your Advocacy Notebook*."

Today's Homework Assignment:

1. Create your advocacy notebook. Use the sections I suggested or modify them to meet your own unique needs and situation. You may even want to print out this course to save the information and notes you've gathered and start an Advocacy Tips section.

Today's Resource Link:

http://www.advocacycenter.com/training_opportunities.htm

Today's Help:

Overwhelmed with the task or not sure how to begin? Why not call on the expertise of other parents at the Ideal Lives Advocacy and Inclusion Center. You can visit on

one of our special 3 day guest passes free of charge and join in the discussion in our forums to compare notebook sections with other parents who've been there before you or just use our comprehensive resource directory to get a jump start on your research. We're waiting to welcome you at: <http://www.ideallives.com>

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Lesson 4: Get Ready

The first hurdle you are likely to face as an advocate is determining your child's eligibility for special education services. We have lots of resources on evaluation and eligibility in our member resource directory, but in the beginning it's important to remember the value of relationships. You will need to meet with your child's school support team on a regular basis until your child completes school. Each time you interact with your child's education support team, it's important to remember these 3 tips:

****Be specific and persistent****

When you need more information, ask for what you need and keep asking until you get an answer. Ask politely and in a positive way if at all possible, but keep asking. If you would like to see something different happening with your child's therapy or education, make your request in writing and share any suggestions you have or ideas you would like to see explored. Present yourself as a part of the team and a part of the solution.

****Maintain control of your communication****

It will frequently be important to use your two greatest tools (assertiveness and persistence), but don't fall into the destructive trap of using anger or aggression. These emotions will only damage relationships and distract people from where the main focus should be - on your child.

****When in doubt, don't be afraid to get help!****

If all of this is leaving you with that "totally overwhelmed" feeling, then you may want to consider working with a professional advocate or a more experienced special needs parent. Many PTI's offer parent-to-parent programs where an experienced parent is matched with a parent whose child has been recently diagnosed or who is simply looking for moral support during a challenging time. And if you find meetings emotionally stressful (which most parents do), be sure to take your spouse or another family member or friend along for moral support.

Today's Homework Assignment:

1. Take the online quiz: "Are you assertive or aggressive" found here:
<http://www.parentsinc.org/quiz.html>

Today's Resource Link:

Listing of Professional Advocates
<http://www.iser.com/CAadvocacy.html>

Today's Help:

Not sure if your child is eligible for special education services? Check out some frequently asked questions on eligibility here:
<http://www.fetaweb.com/01/faqs.eligibility.htm>

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Lesson 5: Never Forget That YOU Are Your Child's Best Advocate!

Sometimes as parents we get overwhelmed with all we should do, and all we need to know, to do it right. It's tempting to look for some "expert" to take over, or some gimmick that will make all of the hard work, just go away.

I know that being a parent advocate is a TOUGH job. There probably isn't anything tougher.

- ✓ Your "friends" suddenly disappear.
- ✓ Your extended family or even your spouse may be in denial.
- ✓ Every melt down in a public place draws stares from strangers.
- ✓ It can seem just too much effort to even leave the house.
- ✓ You desperately need someone to talk to, but no one seems to understand.
- ✓ Sometimes you just feel like giving up.

What I want you to remember is that you are uniquely qualified to be an effective advocate for your child and you are NOT alone.

No advocate, no matter how talented, knows your child as well as you do.

No advocate, no matter how committed, wants to see your child succeed more than you do.

No advocate, no matter how compassionate, loves your child as much as you do.

There is simply no one else that can do this job the way you can. So ask for help, seek out support, and learn from the wisdom and experiences of others. But never forget, you are the very best advocate your child will ever have. And when you need some emotional support and information you can trust – come see us. The other parents at [Ideal Lives](#) know EXACTLY how you feel and will welcome you with open arms.

Today's Homework Assignment:

Do something for you. Whether it's a quiet cup of tea, a long bubble bath or a walk in the woods. Do something to nourish yourself today. Only by keeping yourself strong and healthy will you be able to meet the challenges ahead.

Today's Resource Link:

The National Respite Locator Service helps parents, caregivers, and professionals find respite services in their state and local area. The service is also useful when your family travels or must move to another state.

<http://www. chtop.com/Locator/index.htm>

Today's Help:

Sometimes the hardest part of being an advocate is finding time to look for answers. The day-to-day "stuff" of life simply fills all of the available hours. If this is one of your concerns, then I can help. One of the benefits I offer each of my website members is research help. Any member can post a "Letter to Lisa" and get an experienced researcher "on the case". Plus all the good resources I find for you are shared with other parents in similar situations. If you aren't yet a subscriber to the Ideal Lives Advocacy & Inclusion Center for Parents, it's easy to join. Just visit:

<http://www. ideallives.com/register.php>

I hope you have enjoyed this short course and found some helpful resources and ideas. If you have any comments or suggestions, I'd love to hear them. Email me at: <mailto:lisa@ideallives.com>

Here's what a few other parents have to say about Ideal Lives:

"I used search engines to find help with my questions on specific disabilities, and I e-mailed 'authorities' asking for help. I can assure you that not a single one of them replied as quickly as you did or provided a more comprehensive list of web sites pertaining to the subjects I requested. **Thank you for helping me to find answers to the many questions I had and for giving me a little peace of mind...Knowledge is power!** In that quest, your service is invaluable. God bless!"
~ Christine Milstead, parent

"I have a son who is autistic. When I came upon Ideal Lives, I was very frustrated because my son has violent tendencies and was in regression. **With your help, I was able to look in the right places for answers.** I don't know where I would be now if Ideal Lives was not there for me. You turned a tearful, frowning mom into a fighting, teaching, learning, happy machine. God bless you, and thank you. My work goes on, but I have the happy thought of knowing I have you to talk to and support me."
~ Jannette Sawyer, New York

"Thank you so much for the information! **I truly appreciate your time, effort, efficiency, and your plethora of information.** I was amazed to see a response this soon! Finding you and your home on the web has been such a treasure!" Best wishes to you and yours."
~ Leah C., Oklahoma

Have questions? I'm always just an email away. Send me a message at: <mailto:lisa@ideallives.com>

All my best to your and your family!
Lisa Simmons
Director, [Ideal Lives Advocacy & Inclusion Center](#)