



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

How to Develop a Child's Best Advocate

By Darrell Cookman, condensed from a workshop presented at the CdLS-USA Foundation's 21st International Conference by keynote speaker, Patty McGill Smith

Advocacy should "start at the grassroots, in your yard, at your own house, with your own child." The most reasonable choice for a child's best advocate is, of course, her or his parent(s). The challenge is how to get . . . to the point of successful advocacy. In the first year, "you're not really able to be your own advocate. You're too beat up yourself, you're too worried, you're too confused, and you're too . . . everything . . . its really hard.

"The answer to becoming a good advocate is education, it's knowledge, it's knowing what you're talking about. And then it's learning to know how to present knowledge, how to make your point, how to let people know what your needs are, not to be intimidated.

Years ago, a movement known as "Normalization . . . a body of ideas and thoughts . . . A complete way to approach taking care of people with disabilities" was created. It encompassed concepts such as age appropriateness, considering a developmental model, and the evaluating the degree of risk and experience to which a person should be exposed.

"I've always been so taken that parents of kids who are disabled, they don't want to let them fall down. They want to stop them from ever getting hurt . . . And I'm not advocating that you get your kid hurt, but on the other hand, how did you learn some of the things you learned? You learned by experience, and so if you keep them so encapsulated that they can't try stuff, then they can't learn, at least from that experience. And so I urge all of you (to) give them the opportunity, however you go about it, to experience as much as they possibly can . . . That's how they learn, it's part of discipline too . . . Sometimes we encapsulate children so much that they don't even have the opportunity to learn."

Basic Rules for Successful Advocacy

1. Develop for yourself a formula for success - Form a business plan, work from your strengths, make it personal.
2. Learn to say "no" - Don't get spread too thin once you become good at this.
3. Have confidence in yourself - An advanced degree or training is not necessary.
4. Refuse to be intimidated - "You are the expert for your child. You know more about what's happening with your child than anybody else."
5. Know your rights - "What are the rights for your child? The right to education is a CIVIL right. It is a civil right and it's in the Constitution. It's the 14th Amendment and it says that children have the right to what everybody else has . . . You're going to find out that it might be difficult to get those rights enforced and so learn what they are."



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

- a. Individuals with Disabilities Education Act (IDEA 94-142) - Become familiar with this piece of legislation; there are capsulated, readable versions available. Bring up the elements of this law that apply to your child at the next IEP meeting and ask how they're going to be addressed. "Schools aren't able to say they can't afford provisions in an IEP. If it's in the IEP, they have to get it done."
6. Communicate effectively - Develop your own style. Speak up and speak out. Share your success; learn from each other.

"If you ever get denied anything, you remember that Patty Smith said you appeal, you appeal, you appeal. You never accept anything without appeal. . . Appeals are won at the level of 50% on the first appeal."

A few keys to success:

- * Tenacity
- * Know your rights
- * Be resourceful, innovative
- * Follow your own instincts
- * Learn to articulate your needs
- * Be willing to "Rock the Boat"
- * Avoid haste
- * Never lie, exaggerate
- * Convey courage
- * Expect unexpected
- * Keep good records

"Get the door open for one, get the door open for two, and the first thing you know, you've got the door open for a whole bunch of people."

Systems Advocacy

If you want to change something at the local, state, or federal level, every one of you can articulate your story and you can make that change happen . . . "Not that everybody is going to do that. I don't want you to think that. I want you to just keep yourself open to the possibility."

The Katie Beckett Medicaid Waiver is a good example of what one person can do at the federal level. They parents could not facilitate medical equipment for home use to get their child home from the hospital. It cost the government more to treat their daughter in the hospital than it would at home. They petitioned their legislator and eventually a waiver of Medicaid regulations was approved. Now, people all over the country can utilize this waiver.



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

Check out these helpful advocacy resources:

You Will Dream New Dreams: Inspiring personal stories of parents of children with disabilities, Stanley D. Klein, Ph.D. & Kim Schive (Includes You Are Not Alone by Patty McGill Smith)

Parent-to-Parent: Connecting Families of Children With Special Needs, Betsy Santelli, M.Ed., Florene Stewart Poyadue, M.A., Jane Leora Young

www.nichcy.org, The National Information Center for Children and Youth with Disabilities (NICHY)

The Center on Human Policy (CHP), a Syracuse University based policy, research, and advocacy organization involved in the national movement to insure the rights of people with disabilities.