

Artful Advocacy for Patients: Skills for You, Your Family, and Your Community

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Let's Talk About Advocacy!



What Is Advocacy?

Advocacy is an on-going process of building **partnerships** so that others will act for and with you, turning passive support into educated action.



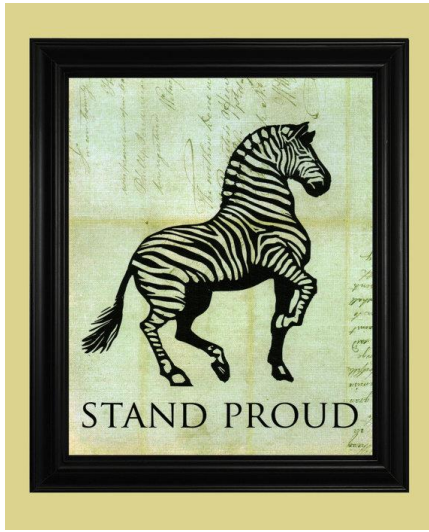
Advocacy Happens Everywhere!

- Medical settings
- Families
- Schools
- Community



But how do we advocate in a way that
our message is heard and
our needs are met?





Be Confident!

You are the expert of you!

Your story and experiences are valid and valuable!

You are the perfect advocate for you and those you love!

Advocacy Skills Can Be Learned...



Being A Great Advocate Means....

- Speak up for yourself.
- Know what you want to say. What is your message or goal? What do you need?
- Know your rights.
- Take responsibility for yourself, your decisions, and your actions.



Great Advocacy Skills Include....



- Believe in yourself and the importance of your message.
- Educate yourself about your condition and know where to find additional resources.
- Consider the knowledge level, positions and constraints of the people you are speaking to.

Great Advocacy Skills Include....

- Bring someone with you to appointments, the hospital, or when advocating for our community.
There is strength in numbers.
- Practice what you are going to say before you need to say it...be prepared.



Great Advocacy Skills Include.....

- Make eye contact.
- Be courteous and concise.
- Treat others with the same calmness and respect as you want to be treated.

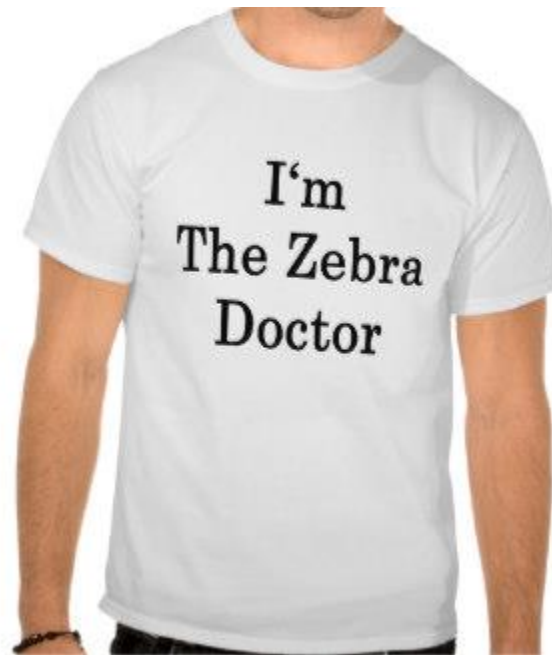


Great Advocacy Skills Include...

- Know that when one approach doesn't work, try again with a letter or email ~ go to a supervisor ~ have a friend or family member help.
- Be persistent!

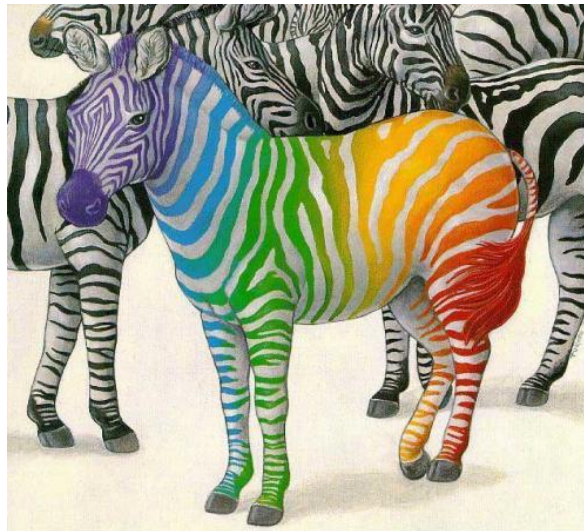


Doctor Appointments For You And Those You Love



Advocating At Doctor Appointments

Advocating well with doctors for yourself, your child, or another loved one can make a difference in the care you or your loved one gets.





Have A Goal!

Why are you having this appointment?

- Create a specific goal based upon your symptoms or what you need from this appointment.
e.g. What can I do about my muscle spasms?
- Limit to two goals per appointment.

Have Reasonable Expectations!

- Understand the limits of modern medicine.
- There is not always a cure or “fix”, but it is often possible to manage symptoms.
- Be open to treatment options your doctor proposes if they are not contraindicated for your conditions.





Have Reasonable Expectations!

- Doctors cannot read medical articles or go through your 3-ring binder during an appointment. Keep resources brief or send information before the appointment in enough time for the doctor to read if your doctor agrees.
- Doctors cannot be experts in all genetic, acquired, or developed health conditions. Learn all you can about your conditions and find doctors willing to learn about them with you.

Advocacy Is About Partnerships ~ Not Battles!



- Sympathize with the challenges and pressures your doctor is under.
- Use words like “We” and “Us” to emphasize you are a team.
- Find ways to laugh together or things you have in common.
- Compliment and thank your doctor.
- Grow a relationship so that you get better care.

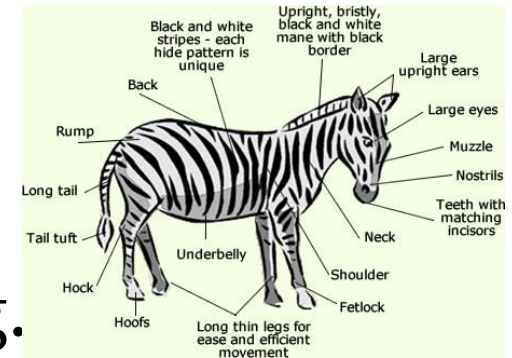
At the Appointment ~ Plan Who Is The Point Person



- You need a good thinker and advocate at the appointment. It may be you or it may not be, but plan ahead who will be the speaker.
- Bring a family member or friend as a support and extra pair of eyes and ears.
- Take notes during the appointment or ask to record the appointment ~ it is too hard to remember everything.

At The Appointment ~ Remember:

- Your doctor is the expert of the human body and you are the expert of you.
- You are not looking for validation, but are looking for problem solving.
- The focus is on information sharing, identifying priorities, and discussing treatment options.



At The Appointment ~ This Is Key!

- Be open to trying different treatment options.
- If you say no to everything proposed, then your doctor's toolbox of treatment options is empty.
- See more information about having great Doctor Appointments in our Appendix.



Advocacy In Hospitals



Have A Goal!

- Advocacy in hospitals and emergency rooms leads to better patient outcomes.
- Know what support you are seeking before you go, e.g. I am not sure if my leg is broken or dislocated.
- Goals are often adjusted as circumstances change.



Have Reasonable Expectations!

- The role of the ER is to stabilize patients so you can see your local doctors or so you can be admitted into the hospital.
- Hospitals and ERs are not the best places for non-urgent diagnosis, primary care, general health, or pain management.
- Outcomes might include continuing care with your doctor or by adding new specialists to your medical team.



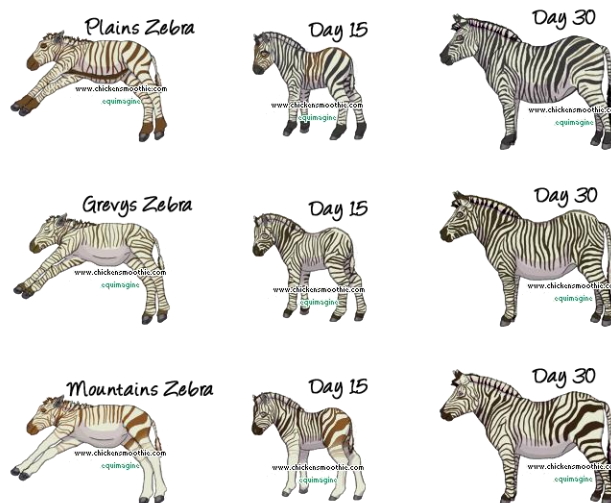
Advocacy Is About Partnerships ~ When It Has To Be Quick!



In limited time and an often hectic environment,
we need to create an **information exchange** and
build trust to advocate for our best care.

Advocacy Includes Information Sharing ~ Preparation!

- Bring a support person.
- Short sheet - include diagnosis, medicine list, doctors.
- Bring accurate EDS information (see appendix).



Advocacy Includes Information Sharing ~ During Care!

- Ask Questions! Question everything! Now is the time to be curious about it all.
- Give unsolicited information. Even good doctors and nurses can inadvertently pass over an important detail.
- Take the initiative to self-report.



Advocacy Is About Partnerships ~ Build Trust!

- Know your staff. Who is your nurse? Doctor? Use their names if you can.
- State your needs clearly, firmly and politely.
- Be in the know. What is the next step? What is the discharge plan? Pay attention in rounds.
- When it's time, let the doctors and the staff do their jobs.
- Thank everyone!!!



Advocacy With Family Members





Have A Goal!

- Consider what you are trying to accomplish with this person or in this situation, e.g. I am looking for activities we can all enjoy together.
- Every family system is different in history, dynamics, and needs.
- Goals should reflect the needs of the whole family.

Have Reasonable Expectations!



- Those who have not experienced EDS can't know exactly what it is like. Similarly, those with EDS can't know exactly what it is like for the ones who love us.
- It is impossible for one person or caretaker to be everything you need.
- Family dynamics can change over time. It can take time for a family to adapt to new situations.

Building Partnerships Means Balanced Communication

- Focus on your goal and work together to create possible solutions.
- Listen as much as you share.
- Be willing to approach an issue in new ways.
- Consider setting times for checking how each other's day is, including EDS status.
- Plan times for no EDS mentions.



Building Partnerships Means Taking Care Of Each Other

- Be aware that venting might make you feel better, but it can make the listener feel helpless.
- Create opportunities for humor, problem-solving, and allowing others to help you.
- Nurture aspects of the relationship that have nothing to do with EDS.



Building Partnerships Means Taking Care Of Each Other



- Use resources around you for support and help your partner/loved ones to do the same.
- Remember your responsibility to others' needs. Caretakers **NEED** care too!!!

Advocacy Is About Partnerships ~ Not Battles!

- State your needs clearly.
- People are not mind readers.
- Keep explanations simple and matter-of-fact. Don't feel the need to over-explain.
- If the way you are trying to solve a problem is causing a roadblock, adjust your strategy in a way that promotes partnerships.



Advocacy With Schools





504 Plans And IEPs

- Understand the goal of these programs: it is to give your child the same opportunities to learn as other students. They cannot guarantee your child will succeed or have all the ideal supports.
- Please see our Power Point Appendix for what a 504 Plan and an Individualized Education Plan or IEP are and how they can help your child.



504 Plans And IEPs

A 504 Plan is great for students who are *not significantly delayed* in any area but need accommodations to have equal access to the learning environment, e.g. textbooks at home.

An IEP is great for students who *do have significant delays* in one or more areas of learning and need special education services to address those delays, e.g. a speech therapist.



504 Plans And IEPs

- Some children with EDS do not need either program.
- Some with EDS benefit from having accommodations in a 504 Plan to learn what they need to in school.
- And there are some with EDS who have significant delays who need more intensive services to learn what they need to in school.

Advocating With Schools ~ Have A Goal!

- What exactly is challenging your child?
- Specifically, what would help her access the learning environment?
- Don't focus on what your child *can't* do but what he *can* do if he has support.
- Be clear about what will help.



Have Reasonable Expectations!

- School budgets are tight and teachers have limited time to work with individual students.
- A plan for your child needs to be achievable, so consider supports that are possible within your school and for her teacher(s).



Advocacy Is About Partnerships ~ Not Battles!

- Be calm.
- Be clear in what you are needing.
- Be empathetic to the challenges and pressures school staff are under.



*You can catch more flies with honey than
vinegar!*

Advocacy In The Community



Avenues For Advocacy

Advocating for the EDS community can take many different forms.



It is important to consider your interests, skills, and strengths. Also take into account your energy and time available.

Great Advocacy Skills Include...

- Emphasize your strengths: are you a good public speaker? A better researcher? One who makes others feel accepted?
- Find a way to advocate in your community that builds on your strengths..





Advocacy In The Community Ideas

- Speaking at government meetings or public hearings
- Getting your story on TV or in print
- Teaching what EDS is at schools, PT offices, doctor practices, and hospitals
- Volunteering to be a “Practice Patient” for medical schools or teach a class at medical schools
- Holding an awareness event at a community fair, gym/night club, or social club meetings
- Decorating your car, wearing T-shirts, or placing signs in your yard about EDS...then talking with people



Have A Goal!

- Be clear about what community or issue you are representing.
- Get to know the decision-makers.
- Understand who else is advocating on this issue and their positions.
- Use the strength of your story rather than attempting to be an expert of the issue.

Have Reasonable Expectations!



- It takes a long time to change laws or change the hearts and minds of the public ~ So be patient yet persistent.
- Many different people want to be heard ~ So make your message concise and powerful.
- Not everyone will agree with you ~ So don't take it personally.

Advocacy Is About Partnerships ~ Not Battles!

- Research all players and look for commonalities in your experiences, positions, or beliefs.
- Introduce yourself to fellow advocates and decision-makers. Develop partnerships where possible.
- Write thank-you notes to those with whom you speak.





You Are The BEST Advocate!

- Make a Goal!
- Have Reasonable Expectations!
- Advocacy is about Partnerships ~ Not Battles!

These same strategies can be used anytime you advocate...whether with doctors and at hospitals, with family members, with schools, or in your community!

Thank You!

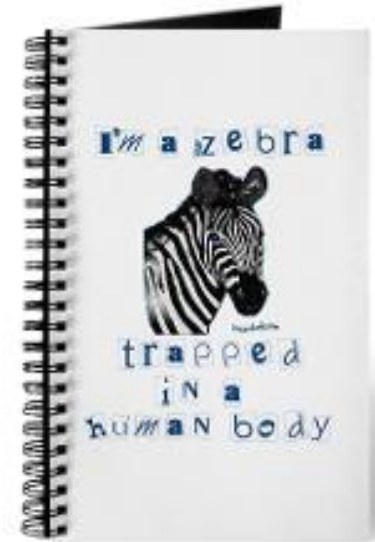
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Appendix



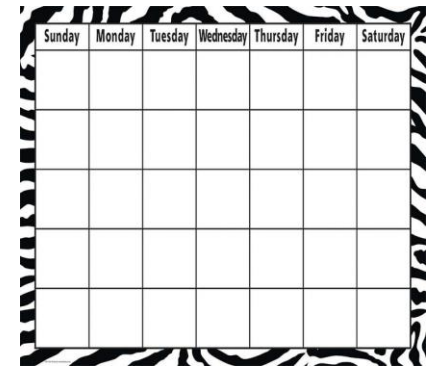
Self-Advocacy Resources



- <http://www.msfocus.org/article-details.aspx?articleID=334>
- <http://www.edac.org.au/letmespeak/html/selfadvocacy.html>
- Kids As Self Advocates (KASA): Great resource for helping kids learn how to advocate for themselves: <http://fvkasa.org/index.php>

Doctor Appointment Agenda

Prepare for your appointment with an Appointment Agenda.



Your Appointment Agenda may include:

- Goal
- Timeline of symptoms or medical history
- List of medications
- What you have tried and how that has worked
- Samples, Charts, Pictures, or Short Video



Sample Doctor Appointment Agenda

- **Date:** 8-7-15 **Doctor Seen:** Dr. Smith **Weight:** **BP:**
- **Goal of Appointment:** Determine cause and review treatment options for increasing dizziness.
- **Pre-existing Conditions:** Ehlers-Danlos Syndrome, Hypermobility type, POTS, Osteoarthritis
- **Current Medications:** Tramadol ER 300mg/day, Vit. D3 2000IU/day
- **Health issues new since last visit:** Becoming dizzy as many as 7 times per day, especially when standing for more than 10 minutes. Reported symptoms to pain management specialist Dr. James on 6-12-15 who said to consult you.
- **Notes:**
- **Questions:** 1. Should I buy a blood pressure monitor? 2. Can you recommend one? 3. When should I seek emergency medical care with this symptom?



Sample Doctor Appointment Agenda

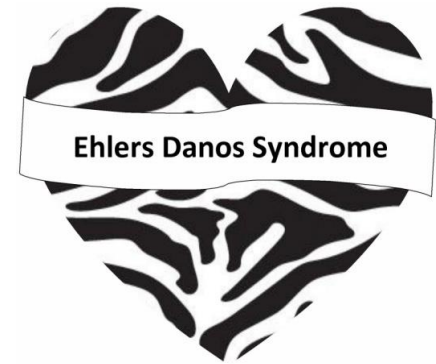
- **Date:** 8-7-15 **Doctor Seen:** Dr. Smith **Weight:** 120lbs **BP:** 98/52
- **Purpose of Appointment:** Determine cause and review treatment options for increasing dizziness.
- **Pre-existing Conditions:** Ehlers-Danlos Syndrome, Hypermobility type, POTS, Osteoarthritis
- **Current Medications:** Tramadol ER 300mg/day, Vit. D3 2000IU/day
- **Health issues new since last visit:** Becoming dizzy as many as 7 times per day, especially when standing for more than 10 minutes. Reported symptoms to pain management specialist Dr. Smith on 6-12-15 who said to consult you.
- **Notes:** *Dr. said to increase sodium to 4000mg/day and to buy Thermatabs. Agreed to chart when dizzy, what I had been doing, how much fluids/salt I consume, and how that is working.*
- **Questions:** 1. Should I buy a blood pressure monitor? 2. Can you recommend one? 3. When should I seek emergency medical care with this symptom? 4. *Where can I buy Thermatabs?* 5. *Does the sodium include what I eat?*

EDNF Resources



- EDNF's Medical Resource Guides:
<http://ednf.org/resource-guides>
- Shani Weber's and Heather Butler-Pierce's 2014 EDNF Conference slides, "The Empowered Patient, Ways You Can Get the Most From Your Medical Team":
<http://ednf.org/sites/default/files/Shani%20Weber%20and%20Heather%20Butler-Pierce.pdf>
- Shani Weber's and Heather Butler-Pierce's 2014 EDNF Conference slides, "Better Together..."
http://ednf.org/sites/default/files/Better_Together_Weber_Butler-Pierce_2013_Handout_S.pdf

EDS -Specific Resources



- Ehlers-Danlos Syndrome, Classic Type
<http://www.ncbi.nlm.nih.gov/books/NBK1244/>
- Ehlers-Danlos Syndrome, Hypermobility Type
<http://www.ncbi.nlm.nih.gov/books/NBK1279/>
- Ehlers-Danlos Syndrome Vascular Type
<http://www.ncbi.nlm.nih.gov/books/NBK1494/> and
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1971255/>
- Ehlers-Danlos Syndrome, Kyphoscoliotic Type
<http://www.ncbi.nlm.nih.gov/books/NBK1462/>
- COL3A1 haploinsufficiency results in a type of EDS- Vascular type with delayed onset of problems and a longer life expectancy <http://www.ncbi.nlm.nih.gov/pubmed/21637106>

Caregiver/Family Support



- <http://www.helpguide.org/articles/caregiving/caregiving-support-and-help.htm>
- <http://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784>
- <http://www.caregiveraction.com/i-just-realized-im-family-caregiver-now-o>
- <http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-A-Guide-for-Caregivers.pdf>
- <http://goodmenproject.com/featured-content/marriage-20-tips-for-men-on-supporting-a-partner-with-chronic-pain/>
- <http://www.medicalhomeportal.org/living-with-child/navigating-transitions-with-your-child/transition-to-adulthood/self-advocacy>



School Resources

- 504 Plan explained:
<http://www.greatschools.org/gk/articles/section-504-2/>
- Individualized Education Plan (IEP) explained:
<https://www.understood.org/en/school-learning/special-services/ieps/understanding-individualized-education-programs>
- “An Educators and Parents Guide to the EDS Child”, good resource to share with your child’s school:
http://ednf.org/sites/default/files/EDNF_ParentsGuideForEducators.pdf

504 Plan



- A 504 Plan is a part of the Rehabilitation Act of 1973 that prohibits the discrimination of those with disabilities. A 504 Plan is for students who need accommodations to access the learning environment and receive an appropriate education. The disability must substantially impact the student's ability to do the things necessary for an education including but not limited to sitting, thinking, speaking, self-care, seeing, hearing, walking, concentrating, and learning.

Possible 504 Plan Accommodations

Physical Education/Sports Needs

- Modified Physical Education or Alternative Health related credit in lieu of PE
- Limit time in the sun
- No contact sports



Possible 504 Plan Accommodations



Hallway or Classroom Needs

- Allow storage of ice packs or heating pads
- Allow rest periods and a place to rest when fatigued or in pain
- Provide two sets of books, one for the school and one for at home
- Priority seating
- Allow use of a chair instead of the floor for activities

Possible 504 Plan Accommodations

- Allow use of the elevator
- Allow passes for frequent restroom breaks
- Allow use of bag with wheels rather than a backpack
- Provide help with note-taking
- Allow extra time between classes to get to the next one, i.e., leaving class early
- Allow extended time on tests and/or assignments

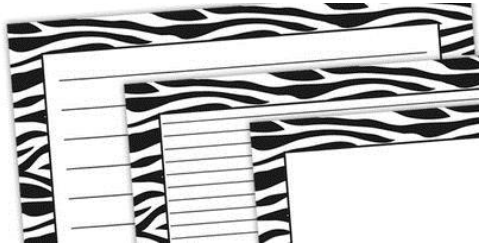


Possible 504 Plan Accommodations

Assistive Equipment

- Provide or allow a chair with extra cushion or support
- Provide or allow use of recording devices or keyboards in lieu of writing
- Allow alternative pencil grips





To Get A 504 Plan

- Conduct all communication in writing.
- Contact your child's school or school district representative for students with special needs.
- Have child's doctor(s) write report about child's limitations and health needs.
- Simply having a diagnosis is not sufficient for getting a 504 Plan.
- To be eligible, your child must be a "qualified disabled person" which means your child must have "a physical or mental impairment that substantially limits a major life activity." Examples of a "major life activity" are walking, learning, hearing, seeing, concentrating, thinking, etc.

Individualized Education Plan ~ IEP

An Individualized Education Plan or IEP is a written document containing goals for students who are disabled so that they can have a Free and Appropriate Education (FAPE) in the Least Restrictive Environment (LRE).



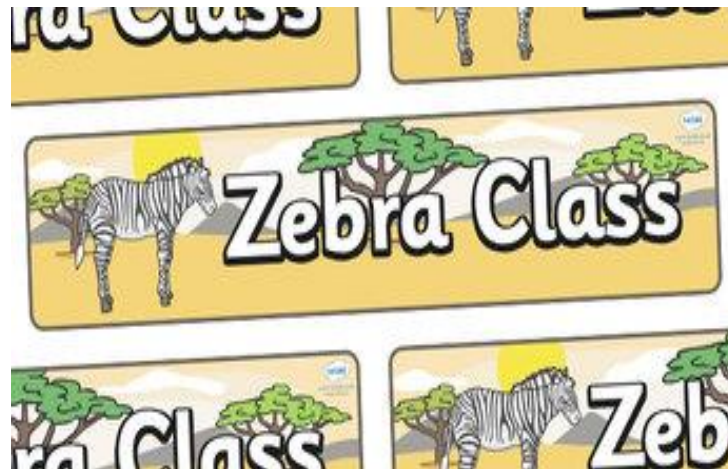
Individualized Education Plan ~ IEP

The IEP is for special education services to help a students with disabilities who have significant delays in the areas of Cognition, Speech and Language, Gross Motor, Fine Motor, Social-Emotional, and/or Self-Help Skills.



Individualized Education Plan ~ IEP

You can talk with your child's teacher about being assessed for special education services or contact Child Find in your school district to arrange eligibility testing for special education services.





IEP Goals

Goals in the IEP must be measurable, specific, and reasonable. A goal of “Jane will improve reading skills” is not adequate.

A good IEP goal would be, “Jane will read orally using a second-grade level book a minimum of 130 words per minute with no more than 4 errors”.

When goals are mastered, new goals are developed.

IEP Team



The IEP is developed and enforced by the IEP Team. The parent is an important member of this team. There will also be a special education teacher or coordinator who serves as the case manager. Often other interested parties are part of the team including a Physical Therapist, Speech-Language Therapist, Occupational Therapist, Child Psychologist, or other specialists who will help with mastering the IEP Goals.

IEP Changes And Disagreements

The parent can call an IEP meeting at any time if they feel there needs to be changes to the IEP.

If there is ever disagreement about the IEP, either what is provided or about the goals, the parent can request in writing a mediation meeting or file a due process complaint.





Community Awareness

- Creative Fun-Raising Events to Help Raise Awareness and Funds

http://www.alz.org/kyin/documents/School_Awareness_flyer_Alz.pdf

- Ideas for Raising Awareness from Kivi

<http://www.nonprofitmarketingguide.com/blog/2014/02/19/top-ten-ideas-for-raising-awareness/>

- More ideas <http://ezinearticles.com/?25-Ways-to-Increase-Awareness-for-Your-Cause&id=5214005>