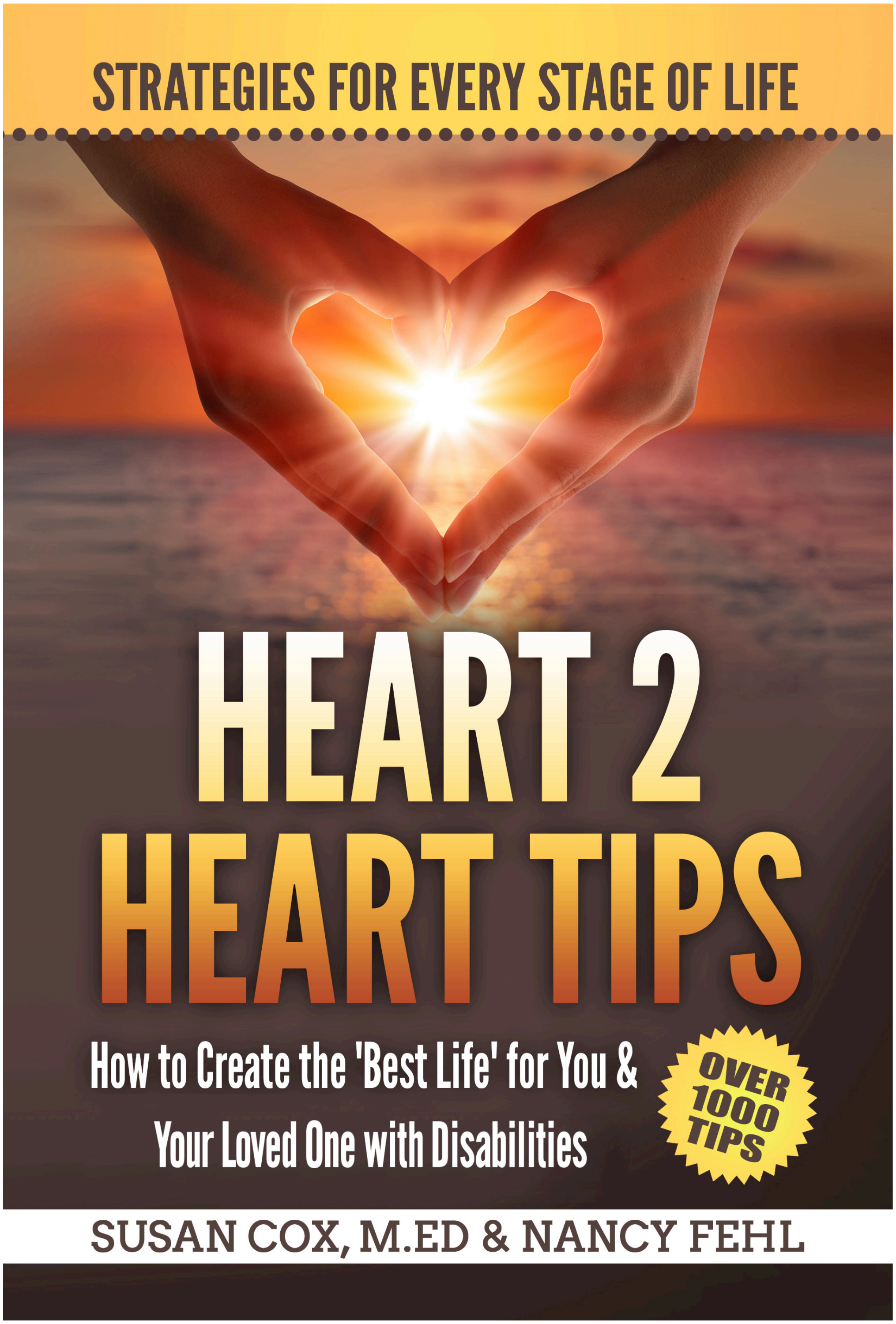

STRATEGIES FOR EVERY STAGE OF LIFE

HEART 2 HEART TIPS

How to Create the 'Best Life' for You & Your Loved One with Disabilities

OVER 1000 TIPS

SUSAN COX, M.ED & NANCY FEHL

Welcome To Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this……

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

INTRODUCTION

We *Are Moms of Kids* with Disabilities

The challenge of parenting our kids seemed overwhelming at first. When they were born (1979 & 1981) we simply were not prepared for all the roles we would need to fill: parent, teacher, advocate, nurse, therapist, and cheerleader. We chose to educate ourselves so we could better serve our children.

We sought information from other parents, disability organizations, doctors, therapists, teachers, anyone who could help us learn more about our unique situations.

Thousands of hours were logged in conversations with professionals, attending conferences, classes, workshops, and support groups. We learned all we could about*Down Syndrome and Spina Bifida* . As we grew in experience and confidence we began to share what we had learned to support others.

We worked on community and school boards and disability commissions and presented disability awareness programs. We worked with kids with disabilities in classrooms and recreation programs. As our kids grew and changed, we grew with them and learned to balance the "job" with the "joy". We learned to be better advocates and more effective parents.

This book is a result of those years of preparation and experience. We have tried to sift valuable lessons from often frustrating experiences. We wrote the book we longed to read as we raised our own children.

We are all surrounded by an evolving maze of information through which to navigate.

It's our goal that sharing these tips in a casual yet comprehensive style will help you navigate that maze, simplify and improve daily life, and head-off frustration.

We hope you will feel supported, validated in your efforts, inspired and full of hope for the unique experiences you will find on your journey.

The topics are arranged in an easy-to-use, alphabetical format, with cross referencing at the end of each topic.

Throughout the book we have used the pronouns he and she, and the name "Chris" with no intent to gender label any situation or disability.

You'll find words of praise and encouragement sprinkled throughout the book. Use these positive words daily!

We don't claim to have covered every aspect of each topic, as that would be monumental, however you will find useful tips as starting points, concrete information, and suggestions that have worked for us and others.

Please use good judgment and consider your unique situation and your child's capabilities when using this book. Again, not every suggestion will be appropriate for every child. On matters relating to your child's physical health or well-being, consult your child's physician.

Please balance our tips with your own expertise and the advice and opinions of professionals who know your child well.

This book reflects our acceptance of children with challenges as valuable, respected members of the family and community. Each has unique gifts, strengths, and talents and it is our responsibility and privilege to promote them.

- Susan Cox and Nancy Fehl

Update: 2021:

After writing this book together (1995), we were pleased with a hard copy we shared with friends and new parents of kids with disabilities. We then put it on the back burner of our 'busy' lives.

Vanessa wanted more activities and enrichment than her town offered. Sue finished a Master's degree in Special Education, founded a State approved Day program for adults and fulfilled Vanessa's dream of hanging out with her friends while doing activities in her community such as dance class, bowling, Martial Arts and life-enrichment classes at the Program facility such as sign language, acting/film making, cooking, woodworking and art classes. In 2013 we merged with Easter Seals Colorado. They wanted to expand their services to Northern Colorado. At that point Sue opened: Family Caregiver Agency, LLC for families who chose the state residential option to live interdependently with their adult child with a developmental disability. The trainings and expectations are identical to those for Group Homes or Host Home Providers, but the services are provided in the family home.

Sue picked up the book recently and realized the tips written years ago are still relevant, valuable and important to share via an E-book (with Nancy's thumbs up).

Sue expanded the original book with updated information she gleaned first-hand while directing the Day Program & the Residential program. Both have served a great variety of people's needs including: those with traumatic brain injury, seizure disorders, dual diagnosis challenges such as bi-polar diagnosis with Intellectual/developmental disability (IDD) and those individuals on the autism spectrum. People with developmental, behavioral and physical challenges are all unique yet are also similar in how they can benefit from supportive TIPS. The tips also now include how we can prepare and support kids for adult life.

Vanessa, now age 42, recently said: "I love my life!"

She lives, inter-dependently, with her parents in her apartment-like private space in the family home. She works part-time, is an artist and enjoys a variety of hobbies and activities.

Nancy also reflected on the time that has passed since writing the first edition: "Nate's fearlessness and strength carried on through the years. His life was REAL – filled with all the stuff anybody's life is filled with – realistic goals AND impossible dreams, successes AND failures, joy AND pain. It was the life he was given and he made it his 'Best Life'."

Nathan was age 33 when he passed on in 2015. Nate graduated from University of Northern Colorado with a degree in psychology. He enjoyed working at Connections for Independent Living, helping others with disabilities. Nate was never happier than when fishing or working on car projects. He was an avid Notre Dame football and Duke basketball fan. Josh, his beloved dog, was his best friend and companion for many years. Spending time with family and friends brought Nate joy. His life was a testimony to his strength, courage and perseverance in the face of tremendous challenges. He fought the good fight and was an inspiration to many.

Acknowledgements

Thanks to our family and friends for their support and encouragement.

Thanks to Bonnie Lindstrom, L.P.C. (Licensed professional Counselor) who offered years of positive support, sisterly advice and insights.

A special 'Thank You' to Kimberly Schenk who helped with revising, editing and marketing.

To our kids, our gratitude for the joys you've brought us and the lessons we've learned.

Disclaimer

The information in this book has been compiled by the authors. We're not engaged in rendering legal, medical, or other professional services. If professional expertise is required, the services of a competent professional should be sought.

Every effort has been made to make this manual a complete and accurate resource. Mistakes of omission in content or typographical errors may be present and thus our suggestion to use this manual as a general guide is prudent.

Tips contained herein should be used with careful regard to the individual child's needs and abilities. Medical professionals should *always be consulted prior to any activity which might affect a child's health or well-being.* The purpose of this text is to educate and support. The authors are not liable for any loss, damage, or injury caused directly or indirectly by information contained in this book.

Table of Contents

NOTE: Click on any topic below and the page will open.
To return to the table of contents click on the title in that section.

- A

- B

- C

- D -

- E -

- F

- G

- H

- I

- J

- L

- M

- N

- P

- R

- S

- T

- -W

ACCEPTANCE IN THE COMMUNITY & FAMILY

- Especially in the beginning, set the disability on the back burner of your mind and focus on loving and bonding with your baby.
- Differentiate the child from the disability. It's okay to not be a fan of the disability while loving the child.
- After love, knowledge is the next key to acceptance. Learn as much as possible about your child's unique personality and specific needs in relation to the disability.
- When in public, be aware that people will follow your example when they respond and interact with your child. Talk respectfully to your child and interact happily and proudly.
- Acceptance of your child will depend in part, on the attitude the parent projects. For instance, introduce your child by name, NOT his disability. Say, "I'd like you to meet Chris." NOT: "This is my Down's kid".
- Dressing your child neatly and stylishly will create a positive first impression.
- Be sure your attitude toward your child is balanced. The child should be neither the total focus, nor less important than other family members. Remember to include all family members in chores (modified as necessary), manner expectations, attention, and affection.
- Look for and reinforce positive attributes in your child, daily. What CAN my child do? For example, if he can put shoes on but cannot tie them, buy shoes with Velcro closures.
- Be an Example. Accept differences in others.
- Expect acceptance in school, church, community, and at work.
- If you haven't found acceptance in for example, a Sunday School class or Park District class, offer to teach or assist in the class or instruct your child's teachers as to his needs.
- Prejudice often stems from fear. Educate others as you learn in order to reduce their fears and prejudices.

- Point out prejudices to your child and discuss them. Kids with disabilities are not immune to bias against other differences or disabilities.
- From an early age, talk positively about differences. "Some people have blue eyes, some people have brown eyes; everyone is different." Different meaning unique and also special for their uniqueness.
- Explain about his disability to your child. For some, waiting until they ask is appropriate, for others, slowly offering information as the child is willing or able to discuss it is most appropriate.
- Expect siblings to get along with each other, help each other, negotiate solutions to problems, and act as they would be expected to if one did not have a disability. All of the siblings will benefit. Find a support group, if needed, for sibling venting and support. Some siblings are challenged with 'survivor's guilt' and benefit from talking about their feelings.
- Realize that most situations are most effectively resolved with 'brainstorming' for solutions, or positive action plans, rather than mere complaining.
- Don't expect to accept everything about your child or his disability at once. There's not a magic "permanent state of acceptance". It's an ongoing process. Deal with accepting one situation or challenge at a time.
- If friends or extended family can't accept your child as you do, it's their problem. Keep moving forward with your life. They may or may not change. Continue to offer information either way.

See: Awareness

"I enjoy you".

ACCESSIBILITY

- People with physical disabilities are sometimes prevented from participating fully in society because of architectural barriers. Those barriers which are common to most people with mobility impairments include:
    - Heavy doors
    - High door jams
    - Narrow doorways or hallways
    - Small, inaccessible bathrooms
    - Thick, heavily padded carpet
    - No parking adequate for wheelchairs or lifts
- Barriers come in many shapes and forms, as varied as disabilities themselves. A visually impaired child's needs will be far different than the needs of a child with Spina Bifida. Therefore, be aware of the particular needs of your child, and sensitive to the needs of others.
- Call before you go somewhere new to check on accessibility. If a business or activity area is not accessible, explain to the owner or manager that you will not be able to use their facility, and why.
- Be specific about your accessibility needs. You may need a ramp for your child, whereas someone else may find a one-story building with a small step acceptable. Accessibility is often in the eye of the beholder, rather than the law. You can educate others according to your needs.
- If you go someplace that's not accessible but should be (public building, park, school, business), talk or write to the owner or manager about correcting the situation. Also, contact your municipal building department and inquire as to accessibility standards and requirements. Make note of the violating building/business name and address and report it to the building department. ADA (see American Disability Act)

requires that public buildings be accessible unless it is an unreasonable accommodation.

- Most cities have a citizen commission on disabilities as part of the city government. Contact them through the city manager or mayor's office for information on municipal building codes and enforcement, disabled parking regulations, etc.
- Take note of places and businesses that need disabled parking spaces. Give the names and addresses to your municipal street department or commission on disabilities.
- Call your city street department and/or private plowing companies and request that snow not be plowed into disabled parking spaces or onto ramps.
- Check out the wonderful documentary movie: "Crip Camp. A Disability Revolution" about the disability rights movement.

See: ADA, Accessible/Adaptable Housing

"You're important!"

AMERICAN DISABLITY ACT

- The ADA was signed into law in 1990. It provides individuals with disabilities broad based protection against discrimination. Center for Disease Control report 2018: 1 in 4 US adults live with a disability.

  ADA prohibits discrimination against those individuals in the areas of employment, public accommodations, public and private transportation, telecommunications, and public services.

  From the ADA: **Employment:** Employers may not discriminate against qualified applicants on the basis of disability. The law requires employers to provide reasonable accommodations to the disabled individual to enable him to do the job unless such accommodation would impose an "undue hardship".

  Public Accommodations: The Act prohibits privately operated public accommodations like restaurants, hotels, or stores from excluding or refusing to serve people on the basis of their disability. New or remodeled buildings must be accessible and existing barriers removed, if "readily achievable".

  Transportation Public transit authorities as well as private bus or rail systems must make their systems accessible to people with disabilities, including those who require wheelchairs.

  Telecommunications All telephone companies must provide services that allow hearing or speech-impaired persons to place and receive calls to or from persons who are not impaired by way of an operator intermediary.

  Public Services: ADA prohibits state and local governments from excluding disabled individuals from participating in services, programs, or activities.

"You Rock!"

ADAPTABLE HOUSING

- Housing is considered accessible if it's fully usable by someone in a wheelchair. But a home can be "adaptable" if it incorporates a few key features, such as:
    - ☐ Location on a relatively level site with paved walkways to the entry
    - ☐ A ground level entrance or one that will accommodate a ramp no steeper than 1" height per 12" length
    - ☐ No steps on ground floor
    - ☐ Wider than standard doorways (preferably 36")
    - ☐ Wider than normal hallways
    - ☐ A kitchen and bath large enough for mobility
- **An accessible house might also include:**
    - ☐ Windows that are within easy reach
    - ☐ Light switches and outlets at a usable height (usually switches slightly lower than standard, outlets higher – chair height
    - ☐ Smoke and fire alarms that can be both seen and heard
    - ☐ Plumbing controls accessible to the wheelchair user, possibly near the outside of the tub or hand-held shower head
    - ☐ Roll-under vanity in bathroom
    - ☐ Roll-under work area in kitchen
    - ☐ Roll-in shower base
    - ☐ Lowered cabinets and counters in kitchen and bath
    - ☐ Low pile carpeting with thin (or no) pad underneath
    - ☐ Front controls on cooktop
    - ☐ Side-by-side refrigerator
    - ☐ Cabinets with lazy-Susans and drawers
    - ☐ Bathroom doors that swing out, rather than in
    - ☐ Grab bars in the bath or 2 x 4 wall reinforcements for future installation

  - Lever door handles instead of knobs
  - Adjustable shelving & lowered rods in closets
  - 5′ turning radius in bath and kitchen
  - Shower with a seat and grab bars
- Each person's needs in a home are unique. If building or retrofitting a home, take time to visit other accessible homes, contact your city for building code information, contact occupational and physical therapists, or contact the various centers such as: The National Kitchen and Bath Association, Veterans Association, Center for Accessible Housing for plans or information.
- Check with local agencies regarding whether financial assistance for your needs are available.

See: Home Modification.

"Nothing can stop you now."

ADAPTIVE EQUIPMENT

- Get ideas from your child's therapists and doctors as to the types of equipment your child needs.
- Look for local vendors under Hospital or Medical supply.
- Often, regular equipment can be used or modified to meet your child's needs. For instance: Sew hanging loops to a regular backpack for wheelchair use, purchase batting gloves for small wheelchair users.
- Check pre-school shops/catalogs for therapy tools with potential benefits of using toys for tactile, or gross motor stimulation.
- If equipment is required for a short period of time, try to borrow or rent. Many disability groups operate loan closets at little to no cost. Check local listings for a disability resource organization such as the Multiple Sclerosis Society.
- Keep equipment in good repair. For safety's sake, make a regular habit of checking brakes, bolts and locks on wheelchairs, walkers, braces and transfer benches.
- Take a wheelchair to a car wash for a good cleaning once or twice a year. The high-pressure hoses work great!
- Some simple repairs on braces or leather items might be done at a shoe repair shop.
- Check bike shops for wheel and tire repair on wheelchairs.
- Unless you're very proficient, most major repairs or modifications can be done through your vendor.

"Your smile is the Greatest!"

ADOPTION

- For information on adopting a child with disabilities, contact:
    - Lutheran Family Services
    - Catholic charities
    - Your religious affiliation's headquarters for information.
    - Organizations which represent specific disabilities: The ARC, Spina Bifida Association, Down Syndrome, etc.
    - Your local social services agency (Fostor/adoption agency)

"You're a joy!"

ADULTHOOD

- Just before your child turns age 18 look into applying for Supplemental Security Income (SSI) for her. SSI is a Federal income supplement program designed to help aged, blind and disabled people, who have little or no income. It provides cash to meet basic needs for food, clothing and shelter.
- Contact the local office in your town or county to determine whether your child qualifies for SSI.
- Be sure to complete all paperwork from your child's perspective because he is the applicant.
- Be prepared to reapply if you are turned down the first time you apply. It is typical to be rejected on the first application.
- Before you go to your application meeting speak to parents who are familiar with the process or speak to your local ARC for advice also.

Driver's License:

- Look under state government offices for the Driver's License Bureau near you. In some states the written exam can be modified or the test can be read aloud.
- If your child cannot obtain a driver's license, a state I.D. card is available at your local driver's license bureau.

See: SSI, Transitions, Taxes

"You're helpful & we appreciate you."

ADVOCACY

- Advocacy is the ongoing responsibility which parents assume to defend and support their child's quality of life and civil rights.
- Don't expect others (school or medical personnel) to take sole responsibility of caring for your child. Advocacy is OUR obligation and privilege.
- If services aren't provided, rather than wait indefinitely, look for other ways to meet your child's needs. For example, you may have a friend who is a reading teacher with whom you could trade baby-sitting for tutoring.
- If the school refuses to or inadequately accommodates your child's needs and you have not seen satisfactory results through filing a Grievance with the school district; you may need to consider other alternatives such as: Private Tutoring, or Home Schooling your child yourself for the time being.
- Don't be afraid to ask doctors, teachers, or any professionals to explain concepts or jargon. You need to know the correct terms to use and understand them to be an advocate.
- Knowledge empowers you. Learn all you can about your child's disability, as well as his strengths, needs and rights. It can be frustrating and takes time but don't give up.
- Be persistent in seeking advice and help. Be specific with questions, and document with whom you speak, the date and the information they give you.
- Keep abreast of public policy and legislation that affects you and your child. Newspapers regularly publish synopses of current legislation and contact numbers to call to contribute your opinion.
- Know your child's rights. Be persistent in seeing that they are met. Join a parent organization or contact the State Department of Education to learn your rights. The State

Department of Intellectual and Developmental Disabilities has information regarding the specific laws of your state available on their web site.

- Remember – **be assertive, not aggressive.** Try to keep your emotions under control and out of the struggle. Others will receive your requests more positively when you act like a fellow professional. Initially, write out your request and edit or delete any accusations or inflammatory remarks. Practice your statements to help you stay balanced and focused on what change you wish to see from the school, teacher, or service you're interacting with…you'll enjoy many small victories for your child and your self-confidence will grow.
- Consider volunteering to help with your child's activities. You being there will help ensure his participation.
- Your child needs to learn to eventually advocate for himself. Teach him to ask for help and understand his needs. Introduce your child to adult contacts at school in addition to his teacher such as: the secretary, Principal, or school counselor.
- Teach your child that:
  -It's SMART to ask for help and clarification.
  -It's OK to question authority figures if you don't understand what they are asking of you. It's OK to even say "NO" to authority figures. Parents: have open communication with professionals regarding your child's questions.
  -Bring questions home when you are confused or uncomfortable with something happening at school.
- Most *continuing education* programs have a Department of Resources for Disabled Students. They'll offer guidance for students to advocate for themselves or other reasonable accommodations with the institution. This department can be a real asset.
- Be sure the program described in the Individualized Education Plan (I.E.P.) continues to meet your child's needs. If your child is not making progress, discuss this first with his teacher, then with his staffing team. Monitor frequently.

- Keep records about conversations with school personnel and copies of letters/emails you write.
- If you have a disagreement with the school, make every effort to settle the problem before resorting to legal action or starting the Grievance/Dispute process. If your school district continues to be non-compliant, don't hesitate to contact your State Department of Education, or State Department of Disabilities or the Office of Civil Rights.

See: Awareness, Grievance & Dispute Resolution Policies, Hospital Stays, Individualized Education Plan, Political Advocacy, communication.

"You're a winner"

ARTS & CRAFTS

- Arts and crafts activities provide wonderful opportunities for creatively stimulating all the senses and improving fine motor skills and self-esteem for all ages.
- Always monitor your child's activity. Beware of small objects or toxic materials that might be ingested.
- Expose your child to various art mediums and art experiences. Take him to museums, galleries, craft fairs and art shows. Be aware of what interests him and where he might succeed.
- Re-introduce some skills at later times in the child's life when her tastes or abilities may have changed or evolved. Encourage all artistic attempts.
- When your child shows you his work, don't say, "What is it?" because they may not know...instead try; "Tell me about your work".
- When working on projects with your child, have a sample from which to work. It's often easier for kids to have a model rather than having to draw from memory or verbal instructions.
- Let your child 'finger paint' with pudding, add uncooked rice or beans for texture.
- Encourage and provide your child with opportunities to explore his environment. Bring opportunities to him if he's not able to initiate the activity.
- Use a brownie pan or cookie sheet to contain projects.
- Experiment with different materials: modeling clay, play dough, various paints, fabrics for collages.
- Use butcher paper ore newsprint that comes in rolls for a variety of activities. I.e. trace your child's body and then let him color himself, identify body parts, learn clothing names, while coloring. Or mount the paper sheets on the wall and use

for a “graffiti” wall mural. Contact your local newspaper office or wholesaler for paper.

- Display your child’s work on the refrigerator or bulletin board. Frame artwork completed by your child and display it proudly.
- Save old greeting cards for future cut and paste projects. Wallpaper books that are going to be discarded from paint/decorating stores are great for projects.
- Encourage your child to give their art to others as gifts. Have the printer print your child’s art work on card stock to make personalized greeting cards.
- Use the child’s photo and ‘Bio’ on the card back.
- As your child gets older add age appropriate crafts to their supplies.
- Look for Coloring Books for adults with more sophisticated drawings or download printed pages & mandalas from on-line.
- Add scrapbooking supplies, beads, jewelry making supplies, knitting supplies and photo albums for rewarding projects.
- Rather than kid-crayons switch to colored pencils, markers, pens, water color and acrylic paints or pastel crayons.
- YouTube offers drawing classes that your older child can watch, pause, learn and try. YouTube offers classes on knitting and many other crafts also.

“This is incredible! I love it!”

AWARENESS

- When we advocate for the rights of people with disabilities we have the opportunity to help society change and improve along with our lives. Society can and does change its attitudes and policies when prompted by individuals or small groups. It's vitally important to help others become more aware of your child's abilities and the options which are, or should be, open to him.
- Coach your child, yourself, and other family members in how to respond to the inevitable 'what's wrong' questions. Arm yourself with a response that is simple, yet explanatory. "Chris has Spina Bifida. That means he was born with a problem in his back. His legs are weaker than yours and mine, so he needs to use this wheelchair. He has feelings just like yours and mine."
- Tell people that no question is dumb and praise their interest in learning. Be respectful of your child's feelings if he is present; talk in a matter-of-fact manner with a positive intent.
- If someone asks a question about your child which your child can answer himself, say (with a warm smile) "Chris will answer that question" or "You can ask Chris".
- Children's questions usually stem from curiosity, not maliciousness. Explain or discuss the disability in non-frightening terms. Tell them information which may be taken for granted by adults, such as the condition is not contagious.
- When someone asks "How is Chris?" they don't necessarily want to hear the latest medical report. Strike a balance between talking openly about your child's disability or illness and obsessively focusing on your child's challenges. Remember to mention current interests and successes as you would with your other children.
- Volunteer at your child's school to conduct a mini-course on your child's disability (and mention some of her positive

personality traits) to the class and staff. You may want to ask other parents to help. Dolls or puppets are great learning devices for young children. Take in samples of orthotics or your child's specific equipment. Explain these to the children. Talk of your personal, parental perspectives to the staff.

- For a school age child ask permission to write a letter to distribute to classmates explaining your child's disability. Encourage student's families to discuss "different" and "sameness" of all types of people. Be positive.
- If your child has a developmental disability remind the students that the 'R' word (retarded) is: old-fashioned, not funny, and a hurtful term to use. Instead of saying; "That's so retarded!" Say: "That's so ridiculous, weird, unfair, so un-cool, so bizarre."
- People with Developmental/Intellectual disabilities learn, just not as fast. We all have strengths & weaknesses.
- Reading lists of books on awareness are available from national organizations representing specials needs. Read to your child about differences and self-acceptance. Help them write their own story if they desire.
- Use the most recent language available. Lead by example to make acceptance and inclusion of your child easy. They are a person first, who happens to have a disability.

Say:	**Don't say:**
Has a physical disability…	crippled
Uses a wheelchair	confined to a wheelchair
Developmentally delayed…	retarded
Disability	handicap

Try not to be offended when the most appropriate language is not used. Be a model who has the power to influence all the people in your circle of family, friends, and associates who help care for your child. Not everyone is aware of the most current terms.

See: Advocacy

"***You make me smile***"

BATHING and bathroom supports

- ALWAYS supervise your child in any amount of water, everywhere.
- Teach tub safety such as how to check water temperature. Remove electrical appliances from the tub and shower area. Install GFIs (ground fault interrupters).
- Watch the water temperature in the bathroom. Turn down the temperature of the hot water heater or check with a plumber about installing an anti-scald device.
- Mark the perfect temperature for your house by marking the shower faucet handle with a red nail polish dot to align with another dot on the wall of the shower.
- Use antibacterial liquid soap in a pump dispenser.
- For the child with mobility impairment consider installing a hand-held showerhead. Use a shower bench or seat and install grab bars for stability.
- Use clear shower curtains – they are semi-private but allow you to check for safety.
- For older children who need hair washing assistance consider hanging the shower curtain low enough for you to reach over the top to wash hair yet preserve your child's sense of privacy.
- Place baskets or trays on countertops in the bathroom to hold combs, brushes, toothbrush, toothpaste, deodorant. Having them out rather than in drawers or medicine cabinets reminds your child of what needs to be done and promotes independence.
- Do not store dangerous chemicals in the bathroom.
- Use open shelving for toilet paper and towels for easy access.
- Use a 3-tiered hanging vegetable basket to hold shampoo, soap, and toys.
- Install a hanging shelf for hair dryer and curling iron.
- Wear non-skid shoes, especially if lifting or carrying a child in the bathroom.

- If possible, install non-skid flooring in the bathroom.
- Use a non-slip mat in the bathtub.
- A thin, small tumbling or Yoga mat on the floor makes a convenient and safe place for drying and getting dressed after shower or bath, especially for non-ambulatory kids.
- If your child uses a wheelchair, try to make the bathroom as large as is financially possible. Contact a plumbing supplier for accessible bath designs and equipment.
- Use a bath mitt instead of a washcloth. These can be made from regular washcloths.
- Make bath time fun. Keep a supply of bathtub toys, write-on soaps, bubble bath, and bath nets to dry toys and dolls after use. Always supervise.
- Put toilet paper where kids can reach it; add a masking tape 'line' to the wall to show how long to pull the length of the toilet paper.
- Hold a dry wash cloth over eyes while washing hair.
- Use fat foam forms for baby's bath and sitting support rings for older children.
- Have your child bring everything to the bathroom he needs to dress. This will promote independence.
- Remove the vanity from around the sink for wheelchair access.
- Wrap water pipes under the sinks with insulation to prevent burns.
- Install towel bars at a height your child can reach and when they're able they can hang up their towels.
- Place a paper cup dispenser in the bathroom to cut down on spreading germs.
- Use pump toothpaste, shampoo and conditioner or transfer your favorite brand into a pump dispenser for easier use and optimal portions.
- Use a detangle rinse that combs in and doesn't require rinsing.
- Place a wall mirror low enough for your child, angle it out at the top using wire or chain for little ones in wheelchairs.

- Mount a large full body mirror on the back of the bathroom or bedroom door.
- If possible, install a radiant heat lamp.
- Use a shower radio. Kids love to sing along.
- Use a water squirt bottle for hair touch ups.
- Use an egg timer to teach the appropriate amount of time required for tooth brushing or shower length.
- Keep extra toothbrushes and toothpaste in the kitchen to encourage brushing more often, and to make it more convenient, especially in multi-level homes.
- For babies, bath time can be great therapy time. While on a foam mat in the tub have your baby kick and splash. Check with your therapist for ideas.
- As your child ages, work on **'transitioning to adulthood'** skills.
- Teach all Activities of Daily Living (ADLs) such as shaving, showering, teeth brushing, and all personal hygiene. This will promote more opportunities for her in the future such as being able to attend Camps or finding Respite providers.
- Teach him how to clean his bedroom and bathroom. Model and have him watch. Break jobs into small steps. Keep supplies in the room. Teach cleaning product safety. Praise efforts!

See: Grooming

"You must have been practicing!"

BEHAVIOR

- Sincerely praise appropriate behavior. ***Catch your child doing things well or right!*** "I really appreciate the way you spoke so politely to Mrs. Jones!" "You are sharing so nicely with your sister."
- Keep in mind that discipline means to teach, not punish. Keep the emphasis on preparing your child for **success,** rather than punishing failures.
- Keep rules simple, and few in number. Prioritize health and safety. "We don't hit each other in this family". "We play safely". "I need to know where you are at all times."
- Acting out behaviors are often a form of **communication.** (see communication). "I noticed that……, What's up?" "I don't understand what you mean."
- Your child will naturally evolve over time and far into adulthood they will still gain new skills you never thought they'd grasp when they were young. I.e.: Chris may not be able to contain outbursts at age 15, but, with ongoing skill development training and continued expectations, he may show marked improvement at age 25 and even be able to hold down a job.
- Expect the behavior you would of an able-bodied child (when that expectation is reasonable). A well-mannered child makes positive impressions and earns respect from others. Remember, good social skills are key elements to success in relationships, jobs, and independent living.
- The goal is for your child to be self-regulated and internalize positive behaviors, not just be able to listen to you.
- Expect and model good manners and age appropriate behavior. Adjust your expectations according to your child's development.
- Teach socially appropriate behavior, starting at a young age. For example:
    - ☐ Inside/outside voices

    - How and when to shake hands/high fives/hand bumps
    - Who can we hug? Give side hugs rather than full front hugs
    - Say: Please/thank you/sorry
    - Hello (with a smile)
    - Eye contact
    - Cooperation
    - Sharing
    - How can I help?
    - Cleaning up after self
    - Close the door when using the bathroom/flush/wash hands
- We all learn from our mistakes. Help your child remember what he has learned by identifying the experience as a learning experience. Remind them that 'F.A.I.L.' means: 'First Attempt in Learning'.
- Teach your child *friendship* skills. For example, explain what a friend is and that different friends fill different needs. Expose your child to other children and provide opportunities for friendships to develop. Teach sharing, phone skills, asking questions about interests and other conversational skills, no name calling, sportsmanship, taking turns.
- When your child is older explain the concept of 'staff' vs 'friend.' Staff can be expected to be respectful, kind and <u>friendly</u>. They are our companion during their scheduled (paid) time with us. Their main job is to support us in a program, school, the community or for Respite.

    We don't call up staff just to chat or expect them to hang out with us on a Friday night, if they aren't being paid. We don't look to them for emotional support. It's more honest to differentiate their role from the start of the relationship to avoid confusion (on the part of your child and the staff person.)
- Teach about boundaries:

The areas that your bathing suit covers is 'private'.
No one can touch your private parts without your permission.
Except for certain family members, we generally give 'side-hugs' instead of 'front-hugs' to people.
We don't hug strangers.
If someone treats you in a way that feels 'creepy' please talk with me about it and we can try to figure it out together.

- Other people may be willing to tolerate behavior that wouldn't normally be accepted. We call this the 'poor kid mentality'. Steer clear of those people or explain to them that you expect reasonable and typical behavior from your child, despite his disability.
- Calmly use time outs (your child goes to a safe place with restricted activity for a *brief* period) as a consequence of unacceptable behavior. A good rule of thumb is the number of minutes should not exceed the age of the child (i.e. age 2 = 2 minutes). After the time out, ask your child what he thought about his behavior and discuss how he might make a better choice next time. Don't make time-outs 'punishment'.
- If you find yourself getting overly frustrated or upset with your child, give *yourself* a time-out and come back fresh in a few minutes.
- When you treat your child with respect and consideration, he will learn to treat others with respect and consideration.
- Often children become what their parents say to them they are.
- No negative name calling or character assault which damages a child's heart and sense of self.
- Model calming techniques of deep breathing: "I am so MAD at that driver! I'm going to try to practice my 'breathing' to calm myself down". Take 3 breaths in and 3 slow exhales (count out loud because this helps the brain get off the upsetting topic and focus on breathing). "Boy, that helped, I

feel so much better." Then, later, at some receptive time, teach the technique to your child so they can use it on their own.

- Be VERY specific with instructions. Say; "Please turn the TV down 3 notches", instead of, "The TV is too loud."
- Use specific praise: "Nice work shoveling for the neighbor Chris…" "Thanks for putting the dishes away, that helps." "You got a grip just now really quickly, Nice!" "Thanks for sitting patiently, you're so cooperative."
- Tell the child what outcome you wish to see rather than to NOT DO something. Let them **succeed** by understanding the exact behavior you're looking to see. "Please close the door softly" vs. "Don't slam the door!". This tip works like magic for spouses, and other kids as well! "Scoop a tennis ball size of mashed potatoes onto your plate', instead of 'don't take too much!" "Please sit behind the tape line on the floor", instead of "Don't sit too close to the t.v."
- Learn and practice patience.
- Don't react to 'junk behavior' such as: eye-rolling, swearing, yelling, pacing, whining). Don't say or do anything. Continue your normal routine. Look for appropriate behavior and then say: "I'm glad you're using a quiet voice." "I'm happy to see you are playing nicely with the dog." Do not refer to their previous junk behavior.
- Expose your child to a variety of social experiences (dining out, going to museums, shopping, going to a synagogue) and teach him behaviors appropriate for each setting. Use '*social stories'* before the outing. "We're going to go to a wedding today at a church. We'll act the same as we do in our synagogue, we'll sit quietly and keep our hands, feet, and bodies still."
- Be consistent in what you teach and expect. If you correct your child for not saying 'please' on Monday, but let it go by on Tuesday, you're confusing him and making it tough on yourself.

- When instructing your child, begin with his name to get his attention. "Chris, please clean your room." This way there's no mistaking to whom you are referring. (be specific: "….by picking up the clothes on the floor and put them in the hamper.")
- To change behavior outcomes sometimes we need to **change our methods** of interacting with our child, especially as they grow older.
- Learn about 'Active Listening'. (no judgment, no lectures, just listening i.e.: "hummm," "I see", "interesting", "no kidding", "tell me about it", "sounds like…..."). Active listening works wonders to open communication.
- Learn how to make 'I-statements' vs "you….." statements. Avoids blaming and sabotaging conversation.
- Learn the difference between '*Authoritarian* Parenting' and '*Authoritative* Parenting' and the effects of each on your child's self-esteem and your life-time long relationship.
- If your goal is a long term, cooperative relationship then coercive and punitive methods will not serve you as well as positive alternatives.
- Teach them how to be the roommate you'd like to live with; after all they may be living with you during their adulthood.
- Learn about no-loose outcomes with mutual agreements.
- Get help from support groups, or **Behavior Modification specialists**. Contact your school district special education or state agency for local information and/or the library or internet has information on effective parenting skills.

See: Discipline, Rewards, coping, communication

"Good for you!"

CHOICES

- A major challenge for people with disabilities is having limited options. As parents, we need to remember to offer choices.
- The option of 'increased choices' is shown to improve one's quality of life.
- Think of how many choices you have from the time you get out of bed to when you go back to bed. What if someone else was constantly making those choices for you?
- Offer your child clothing choices, menu choices, recreation options. Be respectful of their individuality. Empower your child to be in charge of as much as they can in their own life.
- When they are older they may want to go to a movie, participate in a class, visit a friend, go to a job. The support needed may seem too inconvenient, too far, too much trouble to provide yourself. There is a win-win solution: realize that you can hire a 'provider' to support their choices. Find, train and pay for (or bill a state support program for) a "Support Provider".
- Trading support services is another option. Establish relationships with other families with similar needs and trade supports.

See: Normalizing

"I trust you."

CHORES

- Teach the work ethic by example. Discuss how work is rewarding, productive, valuable, makes one feel good as they make a contribution, and when we work we are active members of our family and society. Work can be paid or volunteer.
- Have a family meeting to discuss chores & responsibilities. Offer choices. Be loose on expectations, rather than rigid and strict. Praise efforts as well as results. Be creative, but don't invent useless chores. Children need meaningful responsibilities.
- Don't expect perfection and Don't be a dictator. Chill. Avoid thinking; "I may as well just do it myself"…Remember skill building is about them not perfectionism. Chores don't need to be perfect to be helpful.
- Break chores into manageable steps. If your child cannot carry out the trash, he may be able to open a garbage bag and put it onto the empty trash bin. Maybe he can smash and recycle cans. Allow jobs to be done at the child's speed, within a guided time frame: 'Please unload the dishwasher every day before 5:00 p.m. so we can load dinner dishes'.

  Kids love to:
  - ☐ Water plants
  - ☐ Feed animals
  - ☐ Run messages
  - ☐ Write grocery lists
  - ☐ Sort laundry (older: put into washer, switch to dryer)
  - ☐ Set the table
  - ☐ Open the curtains or pull up the blinds

  And they may be able to:
  - ☐ Make a bed
  - ☐ Empty the dishwasher
  - ☐ Get the mail or newspaper
  - ☐ Put clean clothes away

  - Put dirty clothes in a hamper or down the laundry chute
  - Smash cans to recycle
  - Bundle newspapers for recycling
- Regardless of your child's challenge, find *something* for him to contribute even if it's only buttering the toast, or ringing the dinner bell. Spending time helping others gives a feeling of happiness. Happy people have a purpose.
- Set up a family recycling center and teach your child to use it. Allow any profits to go into the children's banks.
- Dusting is easier with a feather duster or old sock worn as a dusting mitt.
- Be specific about what you want the child to do. Rather than saying, "Please clean your room." Say, "Please, make the bed and pick up the dirty clothes off the floor and put them in the hamper. Dust the dresser, and you're done! Remember to model appreciation also. "Thanks, great job, I appreciate your work."
- Apprentice your child by teaching skills for each new job or chore. Teach by showing. Talk about each step as you go through the chore. Be prepared to repeat words that work as many days in a row as is needed to master one chore. Write down instructions if appropriate, or take photos of steps.
- Introduce your child to new situations or responsibilities. Talk before and after. This increases your child's capabilities and independence. Success breeds success.
- It's relaxing and satisfying for most of us to do repetitive purposeful activities.
- It's not helpful in the long run to encourage your child's dependence on you. It does them a favor to have as many typical expectations as they may be capable of achieving. You both won't know what they can do unless you try (and maybe try again later when they have matured more).

"Fantastic job!"

CLOTHING

- Carry a change of clothing in the car in case of an accident or spill. It happens, be prepared. Have a change of clothing at school to prevent any embarrassments (for all ages). Keep disposable wipes, washcloths, & hand sanitizer in the car for quick clothes, hands, or face clean-up.
- Mark right or left on the bottom or sides of shoes.
- Pre-match outfits and hang together in the closet or put away together in a drawer.
- Put a week's worth of outfits where your child dresses (i.e. in the bathroom) so he can independently choose one each day.
- As he gets older allow him to coordinate clothes independently.
- Take your child with you when clothes shopping and consider his personal taste. Use magazines to help demonstrate how to use make-up, style hair.
- Cotton or natural fabrics breathe and are better under braces and appliances. Beware of items that may rub, especially if your child has no pain sensation.
- Purchase clothes which are easy to get on and off independently. Remember, elastic waists and knits are easy. Purchase pullover sports bras, shoes with Velcro closures instead of laces.
- Buy plastic ponchos for raincoats (great for those in wheelchairs because it also covers the chair). Replace buttons with Velcro when needed. Use a doll to practice zippers, snaps, and buttons. Or, avoid them all together if they're too frustrating; replace with Velcro.
- Your national organization may have lists of companies selling adaptive clothing.
- Mark the front of underpants with a permanent marker.

"You're a Great kid."

COOKING

- Cooking teaches self-reliance – truly a life skill
- Cook with your child. Counting stirs is a great way to learn numbers. Measuring teaches fractions. Following a recipe is wonderful practice in sequencing and following directions. In addition, it's FUN, practical, and offers great tactile stimulation with immediate gratification. Yum.
- Use picture recipes for non-readers. Picture cookbooks are available for young readers. Create your own cookbooks pages, then insert into plastic sleeves to protect.
- ALWAYS SUPERVISE YOUR CHILD IN THE KITCHEN. Teach kitchen safety such as fire safety and how to operate a fire extinguisher. Install a smoke alarm in the kitchen with batteries that work. Tip: Change the batteries when Daylight Savings Time occurs. Teach your child stove-top and oven safety such as not reaching over burners, turning pot handles away from the edge, and checking all burners and the oven are turned off when not in use.
- Focus on what your child CAN do. They don't have to prepare an entire recipe to benefit from the experience.
- If your countertop is too high, use a tray table or kitchen table for a work area, or pull up a footstool to the counter.
- Use plastic or wooden utensils. Metal conducts heat.
- Use small plastic pitchers for pouring – they are lighter and easy to handle.
- If your child can't actively participate in cooking, have him watch you and talk him through the recipe or preparation process.
- If you're remodeling or replacing your kitchen, consider putting in a stove with front controls, lowered countertops, and wide aisles for several workers or wheelchair users.
- Cooking activties most children can perform:

- ☐ Peeling potatoes & vegetables with a vegetable peeler vs. knife
- ☐ Buttering
- ☐ Making shaker pudding
- ☐ Shake meat and poultry in a coating season-mixture bag
- ☐ Ball shaped cookies
- ☐ Menu planning
- ☐ Write grocery lists (assist with spelling)
- ☐ No-bake cookies
- ☐ Decorating a bagel with a vegetable ‘face’.
- ☐ Stir
- ☐ Make jell-o
- ☐ Add toppings to pizza

See: nutrition

"You mean the world to me."

COMMUNICATION

- As caregivers, we must communicate with others constantly to assure our children's success. Good communication is an important skill to learn. Books on communication skills are available at the library and classes are frequently offered by continuing education agencies.
- Be positive. An adversarial posture is unproductive. Instead of saying, "You're a rotten teacher, my child is learning nothing!" try: "I think Johnny could be making more progress. What can we do together to help him?"
- Be assertive, not aggressive. For example, say "Because of his capabilities, I think Chris should be reading at a higher level than he's at currently." Rather than, "I think continuing to place Chris in a 2nd grade reading level stinks."
- When problems occur, contact professionals promptly.
- Express appreciation when professionals make an extra effort on your child's behalf (i.e., jot a note, send or take them a treat, make a positive phone call.) They'll appreciate it!
- Ask for clarification if you don't understand professional jargon. Keep notes, if necessary.
- Make sure you understand what professionals are telling you. Mirror your understanding back to them by saying, "Are you telling me…?"
- Don't assume THEY know the rights of your child with special needs; you need to learn about rights yourself. Information is available on your state website or contact your local ARC.
- Make lists of questions and concerns before appointments, conferences, and meetings.
- SAY WHAT YOU MEAN! For instance, don't say to your child, "Look at that! It's 8:00!" Say, "It's time to take your medicine." Likewise, be clear with your doctors, therapists, and teachers. Don't hint for help or services, ASK!
- Don't expect people to read your mind, or your child's. Tell them what you think or need. Confront people and issues

directly, clearly, honestly, and diplomatically. It can take time for you to clarify and distinguish what you want for your child amid a variety of personalities, behaviors, and institutional obstacles. When you're calm, displaying composure and specifically ask for what you want, you'll find less resistance and more cooperation and solutions.

- Send a notebook back and forth to school or day care with your child each day. Jot down any information that might be helpful to the care giver (i.e. "Chris didn't sleep well last night – she may be tired in class," or "Johnny couldn't finish his math homework because he didn't understand the concept." Arrange for the school nurse, teacher or aide to jot down significant happenings during the day, too. It's often easier for a teacher to write you a note than return a phone call.
- Use "I" statements such as, "I feel frustrated when you use jargon to explain Chris' condition."
- Keep your emotions in check when attending meetings or conferences or in front of your children. Vent your frustrations about your unique parenting role in private with your spouse, friends, or write your feelings down in a journal.
- Carry a cell phone for emergency contact with schools or babysitters. Have your Respite providers carry a cell phone also.
- Document conversations with professionals or make important contacts in writing. Be specific about who's responsible to do what and by when.
- If you're not sure how to respond or how to handle a certain situation, don't hesitate to say, "I'll get back to you on this," or simply, "Thank you for that information. I'll get back to you shortly." Think in terms of outcomes you want to see.

See: Conferences, Partnership with Professionals

COMMUNICATION AT HOME

- Talk to your child from the time they are an infant. Use a regular vocabulary. Don't simplify your language. Talk to her like you would talk to a typical child. Explain what you're doing, what you're going to do next, where you're going, what you see, smell, hear, feel, what will happen next.
- Never rush your child. Plan ahead so you can say "Let's go," rather than: "Hurry up!" This reduces a ton of stress for you both.
- Don't assume you know how your child feels. Ask him!
- Even though you are actually in charge it's important to not be too strict or authoritarian. It'll be better for you both in the long run to be 'authoritative' with respect.
- Try to avoid baby-talk and slang words for body parts. Use typical vocabulary and correct anatomical terms. You'll be glad you did when your adult child can communicate clearly to their Doctor or other professionals in his life.[i]
- Be careful not to:
    -talk about your child sarcastically,
    -put them down to others,
    -disclose to others what they told you in confidence,
    -tell others a story that could be embarrassing to them,
    --talk about their mistakes to others while they're there,
    -tease them in front of other people insensitively.
    -pranks and teasing are NOT funny, they're cruel.
    -no name-calling or attacks of their character
- Be kind and respectful to them at all of their stages and ages.
- Get help from support groups, or **Behavior Modification specialists**. Contact your school district special education or

state agency for local information and/or the library or internet has information on helpful parenting skills.

- Often use 'we' instead of 'you'. 'We need to wash our hands after we use the bathroom.' 'Let's get the dishes out for dinner now.' 'We like our house clean and picked up, so let's do some picking up right now.'
- Use "I" statements. 'I think you'd be happier wearing a coat today." Rather than: "You're dumb to not bring your coat today."
- Model cooperation/team work: 'I'll take the plates to the sink, please help by bringing the silverware.' 'Do you want to dust the family room or the dining room?'
- Say: 'Your alarm for work just went off on my phone, so it's time to get up.' Rather than; 'You need to get up for work!' (Helps to eliminate power struggles.)
- For variety bring in other authorities: 'The Dr. said it's best for our health if we eat more fruits and vegetables.'
- Explaining why we do things as we do will help your child to internalize the values rather than saying: 'just do as I say.'
- At home, keep lines of communication open. Make a dinner or family time a time for conversation. Do more listening than lecturing.
- Create situations where your child needs to express his needs. Don't automatically jump to meet his needs (or finish sentences!). As parents, we often pride ourselves on anticipating what our kids need because we understand their subtle communication. It's important to encourage language.
- When your child isn't 'acting like themselves' or are having 'acting out' behaviors he may be actually 'communicating' something that you may need to decipher.
- Notice your tone when you speak with your child. Is it condescending or impatient? Use a calm soft voice and pleasant tone.
- Help your child to identify and express feelings:
    - "You look upset; how do you feel?"

- “Are you understanding this or are you confused?”
- “Are you feeling happy?”
- “It’s O.K. to feel that way.” “You can ask me any question.”
- “I feel a little afraid in new situations too, that’s normal, let’s brainstorm about how to make this more comfortable.

See: behavior

“You must be proud of yourself!”

CONFERENCES

- Conferences are an opportunity to meet with the professionals who impact your child's life. Avail yourself of their expertise and share yours.
- Prepare for conferences (with teachers, doctors, therapists), don't just show up. List your concerns and questions prior to the meeting.
- Your perception of your child's needs or strengths may be different from that of the professional's. Both views are valid. Listen to theirs and expect them to listen to your views as well. Ask: "Why do you think that?"
- Make notes of what you need to do after the conference. For instance, if you said you would help Chris with one computer assignment each week, make a note of it and follow through.
- Before your first conference try to attend a staffing of a friend's child. You will become familiar with procedures and expectations and be better able to prepare for your own.
- Make your own assessment and goal sheets for your child and share with those working with him. Follow up to make sure goals are being met.
- Check your child's Individualized Education Plan (I.E.P.) quarterly to refresh your memory on what is supposed to be happening.
- Inform your children's teachers, therapists, doctors, and caretakers of changes in home life that might affect your child such as death in the family, birth of a sibling, separation or divorce.
- Ask your child what he would like you to discuss with his teachers, therapists, doctors.
- Stay calm!

- Ask for explanations of terms or abbreviations you don't understand.
- Be aware of options; don't always accept what the 'professionals' say as the 'only' way. They may be 'experts' in their field but you are an expert on your child. With more information, they may modify their advice and objectives too. The system changes slowly but progress is being made every year.
- Discuss s*trategies* for helping your child at home and options for assistance with skill development.
- Arrive on time and leave promptly. If you need more time, arrange another meeting at a later date. Congratulate yourself on each step forward!
- If a conference is scheduled at a time you cannot make, reschedule by sending a note or calling. Don't fail to show up without notice. It's disrespectful of others' time. It's beneficial for you to work with these people so your child gets the help and support he and your family needs.
- Document phone conversations with professionals or make important contacts in emails for documentation.
- Be specific about who is responsible to do what and by when.

See: Communcations, IEPs, Jargon

"Nothing can stop you now!"

COPING - CHILD

- We often feel we are stressed or overburdened by responsibilities, while forgetting that our kids share many of the same stresses. Some stresses are unique to them alone. These strategies may help your child cope.
- Find out what makes your child feel secure, safe, and comforted, and remember those things as stress reducers for him. Maybe it's certain movies, songs, going to the park or zoo, or Aunt Bonnie's: a stuffed toy, a back rub, braiding her hair. Remember to do these special pleasurable things not just in stressed times, but any time.
- When you come home after being gone for a while sit down and invite your child to visit, climb into your lap and get 'filled up' with your attention and love. This works wonders; they get satisfied relatively quickly and now you can make dinner, or whatever, without a clinging whiner.
- Encourage your child to tell a story or write book based on his experience or expertise, i.e. "How to Survive Getting Shots".
- Have your child keep a journal, complete a daily barometer of his feelings or events or share at dinner: 'What good thing happened today?' 'Was something disappointing or confusing today?'
- If your child can't write, create an audio journal, a video or make an art or photo notebook. Any method of self-expression is benificial.
- Honor your child's choice to read 'sad' books about other disabled children and adults if he feels the need.
- Many children don't complain but do experience hidden frustrations. Encourage him to write a "wish list" of how he

would like things to be. Then discuss possible solutions or compromises.

- Occasionally allow your child to choose a day as a break from an unpleasant but necessary appliance (such as leg braces, etc.) or activity. ALWAYS check with your doctor or therapist to be sure it will not cause harm. This gives your child a sense of control. An occasional random 'school day off' for a one-on-one outing with mom or dad is beneficial not harmful to their education.
- Encourage your child's art work. Say: 'Tell me about this." rather than 'what is it?" He will be more inclined to create more art when you show interest rather than confusion.
- Let your child choose a special activity once a month. It might be something with a friend, extended family member, or one or both parents.
- Suggest an appropriate de-escalation option for your child, such as: deep breathing, drink of water, sing a song or listen to music, headphones, lower lights, offer choices, stress ball, weighted blanket, cold wash cloth, talk.
- Make sure your child gets enough rest.
- Encourage and/or participate with your child in physical activity.
- Encourage outdoor activity, even if it is as an observer.
- Brainstorm with your child and make a list of activities he enjoys. Do one each day.
- Encourage self-soothing activities, such as listening to music, watching videos, reading, dancing, taking a walk or artwork.
- Reinforce your child's appropriate coping skills, i.e. "I'm glad listening to music makes you feel better. It was a good choice for relaxing."
- Allow your child time and a place to be alone safely. Respect his privacy.
- Provide toys and other belongings that belong only to your child.

- Respect your child's need to keep comforting stuffed animals, or special blankets for as long as he needs. (Note from Sue: 'Vanessa still has her 'Pound Puppy' stuffed toy….It's 40 years old this year.)

Rub your child's back, brush their hair, or give a foot massage.

- Play pretend games with your child. For instance, if he has a negative medical or school experience, let him pretend to be the doctor or teacher.
- Play dress-up. Keep a box of great junk props. Check garage sales, thrift shops or church rummage sales for creative dress-up materials.
- Let your child know you are available to help. If your child seems worried, upset, or angry, but isn't talking about why, try saying, "You seem worried about something, may I help?" rather than, "Is everything okay?" Often a child will respond when you name the issue for him, (i.e. worry).
- Let your child make his own photo album. Include pictures of fun times, pets & people he loves.
- Consider relaxation techniques such as biofeedback, Yoga, meditation, or massage. Contact your local hospital or Parks and Recreation Department for class information or learn from Apps & YouTube videos on-line.
- Appreciate your child's need for spirituality and provide opportunity for its expression.

See: Coping – Parent, Support Groups

"You're the Greatest"

COPING – PARENT

- There are predictable stages in the grieving process. They include denial, anxiety, fear, guilt, depression, and anger. Learn more about grieving by reading some of the wonderfully helpful books and articles available.
- Worry only if you stay depressed or stuck in any stage of grieving. Recognize anger and bitterness and strive to let them go. Grief resurfaces periodically throughout your child's life; anniversaries, birthdays, milestones, and traditional rites of passage could all trigger sorrow. Recognizing this phenomenon called: 'chronic sorrow', helps us to cope and move on. Try to remember you're not alone.
- Prioritize problems. Decide what needs to be dealt with now and worry about the other later. Motto: Always put off until tomorrow what you can't handle today!
- Give yourself a break. Everything won't be done just as the professionals would do it every time. Do the best you can.
- Take one day at a time. We're human beings, we'll never be perfect parents, therapists, teachers, or advocates. Do your best without over-stressing yourself, family or your child.
- Don't dwell on the "what if's".
- Remember: the child comes first, the disability second. Learn to separate the child from the disability. It's easy to feel enormous guilt early in your child's life because you want to be rid of the problem. Recognize that it's the disability or illness which is the disappointment you'd rather have disappear, not the child. Get professional help to deal with this if necessary. Seeking professional help is a sign of self-worth not weakness.
- Don't be afraid to express your emotions. Revealing and sharing your feelings does not diminish your strength or effectiveness. Talk with significant others in your life. Sharing

your feelings can help reduce the emotional burden. Pain divided is easier to bear than pain in isolation.

- Negativity drains energy. Spend less time with negative people. Think positively. For *balance* list your child's and family's strengths, focus on them, add this list to your notebook of Dr. visits, I.E.P. meetings, etc.
- Nurture yourself as well as your child. Don't be a martyr. Delegate some of the household jobs and responsibilities. You don't have to do 'it all'. Life goes on even if the house isn't perfect.
- Write a list of your favorite escape activities…things that comfort you. I.E: treat yourself, take a dance class, soak in a bubble bath by an aromatherapy candle, talk to a friend, watch a favorite show, work in your garden, take a walk, keep a journal, clean a closet, read a book, listen to music, do a project, get a massage or manicure, watch a movie, do Yoga, sip tea, meditate, play, laugh, go out with your spouse or friend, surf the internet, and carve out some time to follow your passions and dreams. *Balance* is key; balance your needs with your child's.
- To empower yourself and avoid helplessness, learn about your child's disability, join a parent support group, attend city committees on disabilities meetings, volunteer at school, write to your congresswoman or man or subscribe to a magazine that deals with your situation. Knowledge brings self-confidence and that makes you feel better!
- When you feel overwhelmed by too much information too fast, (i.e. from a clinic or conference), write down as much as you can. Take the list home and deal with it piece by piece as you're ready. Organize your thoughts before making follow-up appointments or ordering materials. It will save you extra phone calls and time.
- Acknowledge stress. Perceiving what you face as a challenge to be met rather than a disaster to retreat from may help.
- Accentuate any and all positives. Count your blessings DAILY.

- Establish and maintain routines. Eat right and get enough sleep. Get some exercise. Take care of yourself so you can take care of your child.
- Take a friend along to doctors' appointments or conferences for moral support and company and to "hear" what you may miss. Use a recorder for extra important meetings.
- Keep a bag with 'waiting' materials in your car. You will have to wait at schools or doctor appointments. Suggestions: note paper, pencils, books, travel games and playing cards for you and your child, a zip-top bag of nutritional snacks, hand-held computer games or a device with earphones for audio books.
- Balance "bad guy/good guy" roles, such as holding your child during shots, with your spouse/partner. Take turns with heart to heart talks, asking your child to practice the piano, do his homework. If your child needs a painful procedure, let the doctor tell him, not always only you.
- It's worth the effort to train a sitter or family member regarding the specific needs of care for your child. With their help you can give yourself permission to take 'Mom's hour off' a few times a week. Work up to a 'Mom's day out'.
- For children or adults: learn and practice 'E.F.T'.

From: www.The Tapping Solution:

"Tapping, also known as EFT (Emotional Freedom Techniques), is a powerful holistic healing technique that has been proven to effectively resolve a range of issues, including stress, anxiety, phobias, emotional disorders, chronic pain, addiction, weight control and limiting beliefs, just to name a few.

Tapping therapy is based on the combined principles of ancient Chinese acupressure and modern psychology. Tapping with the fingertips on specific meridian endpoints of the body, while focusing on negative emotions or physical sensations, helps to calm the nervous system, rewire the brain to respond in healthier ways, and restore the body's balance of energy." Clinicians are trained in EFT. See: Coping – Child, Support Groups, Success Strategies

"A smile is worth 1000 words!"

DISCIPLINE

- Keep in mind that discipline means to teach, not punish. Prepare for success rather than punish failures. You'll see faster improvement and more success.
- Spend a good deal of time praising, acknowledging, and appreciating a child's desirable behavior. This encourages and reinforces it.
- Provide choices rather than dictating orders whenever possible. Be sure you can live with the child's choice of options you present. "You can put your coat or shoes on first" or "If you feel the need to cry, please do it in your own room and come back when you have calmed down." "Do you want chicken or salmon for dinner tonight?"
- Learn developmental milestones so you don't expect behavior the child is not capable of yet and will keep expectations realistic.
- Avoid asking questions that encourage a 'no' answer. Instead of asking, "Do you want to get ready for school?" say, "It's time to get dressed for school."
- Use "I" statements. "I feel frustrated when you act loud in public" vs. "You drive me crazy." Or "I need 20 minutes to rest my eyes, please find a quiet activity while I rest."
- State clearly the result you wish to see. Not only will no one read your mind but it shows others how you want to be treated and empowers them to behave well also.
- Stop verbalizing what you ***don't*** want to see. It's a practice that brings quick rewards for your efforts.
- "Please close the door gently, your sister is sleeping." Vs. "Don't slam the door." Can you hear the difference? When you say don't slam the door, that's the image you present in the listener's mind.
- No one likes to hear, "You did this wrong!" or "You're wrong!" Statements that accuse create a defensive state of mind in the other party. "I have a different idea of how this can be

done….let me show you." Or "I have a different opinion," leaves the door open for discussion and a positive outcome.

- Praise your child for efforts and jobs well done. Catch them doing things right and tell them so they get credit for successes.
- Expect appropriate behavior. Children of all abilities want to succeed and will try and meet your expectations. Life will be easier for a child when they are equipped with knowing and acting appropriately.
- Communicate clearly, patiently, and specifically. When you don't approve of a behavior, state the correct behavior and let the child understand you still love him no matter the outcome.
- Learn positive discipline techniques (teaching skills) with your child from the beginning. Don't negatively shame or punish, and never physically punish a child. Effective techniques will produce a productive (within their capabilities) adult.
- It's hard to watch your child struggle or be frustrated, but if he behaves inappropriately, in some cases he will grow in understanding by experiencing natural 'cause and effect' consequences. If you always rescue your child from the natural consequences of his actions you are doing him and yourself a disservice. Always be sure the consequence does not pose a danger to your child. I.E; If you and he are asked to leave a store because of his tantrum, don't explain or make excuses. Leave. When you both have calmed down brainstorm how things can go next time.
- Certain behaviors in a 2-year-old, may be tolerable now but if not improved are not attractive in a 5' 10" adult.
- Parenting involves anticipating and preventing problems, not merely enforcing rules. It's about your child achieving long-term success and being someone who's enjoyable to live with. Don't you want to be someone enjoyable to live with as well?
- Use story telling Before outings to review; 'how we behave'.

- After a behavioral or emotional incident sit quietly later to reflect on how things broke down and how or what you can do differently next time for better, more peaceable outcomes for all involved.
- Take effective parenting classes offered by schools, churches, parks and recreation centers, and hospitals. Check with your pediatrician or your child's teacher for information.
- For specific issues there are wonderfully effective professional 'Behaviorists'. Research to see if a school and/or state program can help with fees.
- Try leaving a tape recorder on while you interact with your child. Listen and learn. Listen to the tone of your voice, the words you choose, and your child's reaction.
- Treat your child respectfully. Say: 'please, thank you, excuse me, I'm sorry,' etc. Kids learn from the way they're treated. Kids don't always listen, but they always imitate. Model how you want them to act.
- Use food sparingly as an incentive or reward for appropriate behavior. Find treats specific to your child's interests. 'I appreciate how you showed your good manners at Aunt Jan's house today. Let's go to the park and swing or 'let's download and print some coloring pages, or take a drive, sip our cold tea and look at the tree colors.'
- Choose your battles carefully. Some things are not worth a power struggle. Ease up on occasion if you're a perfectionist. Seek counseling for yourself if needed.
- Beginning any discussion with an accusing tone or with yelling will be counterproductive.
- Be consistent, not rigid. Every situation is different and requires thought and balance.

See: Behavior, Communication, Communication at Home, Modeling,

"You mean a lot to me."

EMERGENCIES

- If you think it will be helpful in an emergency: Notify your fire/police department of a "special need" in your home.
- Teach your child how and when to use 911. Consider adding speed dial for your emergency contact list. (Aunt Liz, the neighbor & Grandma.)
- Teach fire safety for your home, daycare, Grandma's, and anywhere else your child will be on a regular basis. (Stop, drop, roll. Exit the building if the alarm sounds off, go to a meeting place.) Have a fire drill.
- Teach your child how to properly use the house phone, and your cell phone. Post emergency numbers and your address in different stations at your house. At least one per level of the home.
- Ask a willing neighbor to be alert to the unusual at your home in case of an emergency.
- Teach your child what to do if he finds himself home alone, such as to call or go to a neighbor's house, when to answer or not answer the door and phone, whether or not to cook when home alone. Review periodically by asking 'what if…' questions.
- Carry a cell phone for emergency contact.
- Teach your child what to do if he becomes lost. Often the best advice is to stay put until help arrives. Discuss options and judgment.

"Thanks! I appreciate you and all you do."

EMPLOYMENT

- While your child is young, help him to learn socially appropriate behaviors, good hygiene and independence skills, which translate into employability.
- Adult services and options vary from community to community. While your child is in high school, learn about Integrated employment options, Supported employment, the Department of Vocational Rehabilitation (DVR), Private vocational training, and Post-secondary educational options.
- Often there are waiting lists for available services which can take years to move up to when your child qualifies for assistance. You may need to oversee and advocate for your child's post-school opportunities.
- Encourage the work-ethic with jobs around the house, contributing to the family effort in ways he can.
- Discuss the value of money and how to manage it. Consider giving your child an allowance. When they are an adult they will have 'personal needs money' from Supplemental Security Income (SSI) which they can learn how to spend responsibly or you can help oversee (you can also be their Representative Payee and manage the SSI income). You can read about SSI rules and responsibilities on-line.
- Keep an ongoing inventory file of what your child can do and relay this information to employers like a Resume. Advocate for your child. Some will grow up and be able to handle a full-time job, others may work 2 - 4 hours a week. Some will volunteer with supports. All options bolster self-esteem and have value. Revisit their desires as they grow and mature.
- Explore programs with your school district or State Board of Education which will promote your child's transition from school to the work place. Children will be ready to work at their own personal time-table. Some will want to work and have the maturity to work after High School, some won't be developmentally ready until age 30. Some may never want a job in the community.

- Volunteering allows your child to experience many different work arenas and therefore, be more able to make an informed choice about what kind of job he or she may enjoy. Be sure to add experiences to their resume. Volunteering is a fulfilling, valuable experience.

See: chores, transitions

"You did a lot of work today!"

ESTATE PLANNING

- In addition to typical estate planning, parents need to create a plan for the personal care and continued advocacy of their child for the rest of his life. Be sure you appoint an advisor, guardian, or advocate for your child.
- Designate a family member or friend to make sure your child is not neglected, abused, or discriminated against. Communicate to this person what you now do for your child and how you do it. Share written records that can be referred to in your absence. Create a Residential Comprehensive Life Review Report which will document the details of caring for your child. The report details her daily wants, needs, necessities, preferred choices. It is a valuable tool for anyone who needs to step into your caregiving shoes. A valuable tool for respite providers also. (see: free handout form on website.)
- Check on the child's eligibility for assistance from government programs. There are specific criteria for eligibility for Supplemental Security Income. Check with your local Social Security office before your child turns 18.
- Check into becoming her legal guardian, and/or obtain Medical Power of Attorney. Have a Will created.
- Check into **Achieving a Better Life Experience (ABLE)** act in your state. There are income restrictions on many benefit programs. The act enables parents of children with special needs to have a tax-free savings account to provide funds for the future care of their children.
- Prepare your child throughout his life for as much independence as he can manage by building self-confidence and self-advocacy skills.
- The ARC of the United States for people with intellectual and developmental disabilities (1-800-433-5255) has appropriate attorney referral lists or call the ARC in your county.

- Contact the ESTATE PLANNING for PERSONS with DISABILITIES (EPPD) national office or there may be a local office for your area. Their services are intended to coordinate the efforts of family members and service agencies in establishing an appropriate life plan for the person with a disability.
- It can be comforting to both you and your child if you make a 'Memory Book" or a photo collage of people your child loves. There are companies that will make a Legacy Video for you or make one yourself. Make a DVD of you or you and your spouse talking to your child as if he is sitting in front of you. The child can watch it when you've passed on.

See: Transition to adulthood, Legislation.

"I love the way your eyes sparkle."

EXERCISE

(Physical Therapy, therapeutic Exercise)

- Always check with your doctor and physical therapist before starting any exercise program. What you think may be helpful may indeed harm your child.
- Have the therapist list your child's exercises and go over them with you until you're familiar with them. Consider using figure drawings to help yourself remember correct positions.
- Explain to your child how the exercise helps condition the different body areas. 'This exercise will help you become stronger and have better balance.'
- Dress your child in comfortable clothing and have him lie on a cushioned mat for safety.
- Ask your child to help you establish a time each day to exercise that's good for both of you.
- Use an egg timer to clock the exercise period.
- Print each exercise on an index card, and note the recommended repetitions. Allow your child to choose a certain number of cards to follow each day. If your child develops favorites it may be necessary to stack the deck!
- For young children use a make-believe body parts game. Talk to Mr. Toes, Mr. Knee, etc. as you stretch them.
- Invest in an appropriate exercise DVD, or exercise to music. YouTube videos and on-line classes are available for physically challenged individuals.
- Range of motion and stretching exercises can be done while your child is watching a favorite TV show.
- Talk to your child as you exercise. This can be relaxing, one-on-one time for both of you.
- Exercise with your child. Misery loves company!
- Reward your child with a star chart for each successful exercise period. A special treat can be offered when a certain number of stars have been earned.

- NEVER use exercise as punishment.
- Encourage your child with praise. You will see improvement – let him know it when you see it happening!
- Consistency is important. Try to exercise daily so that it becomes a matter of routine.
- Modify regular exercise routines for wheelchair users; check with your physical therapist first.
- Mount mirrors low to the floor so your toddler can watch himself exercise (also great fun for creative play and self-esteem building). Older children love to play and dance in front of mirrors also.
- With an infant there are range of motion exercises for feet, hips, and leg muscles to do while they're feeding, changing diapers, and playing. It can be routine yet fun, not a chore.
- Check with an adaptive physical education teacher for fun ways to incorporate exercises into daily activities.
- Check out the YMCA or park district classes.
- **Special Olympics** is wonderful for many years of team play, meeting friends, and exercise.
- Have fun bike riding, bowling, walking the dog, doing Yoga, taking hikes, and swimming together.

See: Infant Stimulation, Therapy

"Look at you go!"

EXPECTATIONS

- Encourage your child to dream, to aspire to careers, and quality relationships. Their dreams may be a little unrealistic at first, but with growth and guidance from you they'll probably become more appropriate. Try not to impose limits on your child's dreams. Make suggestions and try to let them determine for themselves how they may modify and implement goals.
- Be sure your expectations meet your child's needs and not your own. Self-awareness is key to your evolution and theirs. For example, does he really need a traditional high school diploma, or is a modified version ok?
- As you interact with various professionals you may hear conflicting expectations for your child. You probably know your child best, so balance your instincts with what you hear and with what your child wants.
- Be sure your expectations match your child's ability level. Together set small, manageable, attainable goals. Reassess often and accentuate progress.
- **MYTH BUSTER:** There is no 'plateau' or 'end' to learning for your child. She will continue to learn her entire life. Provide and seek out enriching and varied activities for your child. 'Life-long-learning' is a goal for all of us.

See: goals, goal Setting

"I knew you could do it!"

EXTENDED FAMILY

- Set an example and tone of acceptance and expect it from others.
- Some family members may, some may not want to be as knowledgeable as you are about details of the child's challenges.
- Educate interested family members as you do yourself about your child. As your child's needs change, share the information.
- Keep grandparent/aunt/cousin time as hassle free, pain free, and duty free as possible to normalize the relationship thereby letting kids and adults just be "family".
- Remember that grandparents initially grieve not only for the child with the handicap but for you as well.
- Honestly, tell extended family what you need from them regarding your child. First and foremost, a baby is a baby and a new, exciting personality to get to know. That joy remains!
- If a night off without your child would help, perhaps a family member could babysit.
- Let your family members know you appreciate them with a note, letter, or small gift.

"Congratulations!"

FRIENDS

- Loneliness is a common obstacle to overcome, but with strategies and effort, friendships can become a reality throughout your child's life.
- Make your home a desirable hangout. Have a variety of toys you can afford (shop garage sales & thrift stores) and occasionally plan activities which your child can enjoy or share with others.
- Teach your child strategies to build and continue friendships such as:
  - ☐ Smile, say, "Hi" and make eye contact
  - ☐ Share toys, take turns, have good sportsmanship
  - ☐ Learn small talk (ask others questions about themselves)
  - ☐ Learn to listen
  - ☐ Learn manners (please, thanks, sorry)
  - ☐ Don't be a possessive friend
  - ☐ Learn appropriate phone call skills
  - ☐ Minimize 'drama'

- Friendships skills are not innate; they must be taught and practiced.
- Exposure to children of the same age will help a child learn socially appropriate behaviors.
- Become friends with other parents and invite them and their children (disabled or not) to your home. Consider joining a parent/kid group.
- Know your child's strengths and interests and capitalize on them. If your child is a good swimmer, invite a friend to the pool. If he's a good video game player, invite a school friend over for snacks and games.

- Dress your child in stylish clothes. You'll have to be in tune with what's in style and what's not. Your child may not notice but peers will.
- When going to a friend's home show confidence in your child's caretaker. Inform the caretaker of any special needs and leave your cell phone number so you can be reached.
- Utilize parks and recreation programs. Scouts, 4-H, community groups, classes, (YMCA, etc.) church groups, auxiliary programs to facilitate friendships, outside of school or into adulthood. Encourage people in those programs to meet and be with your child in a buddy capacity which could naturally lead to a friendship or to a paid Respite provider relationship.
- Do not assume that every slight in your child's experience is due to his disability. Kids are kids – some will be friends, others won't.
- Let your child define friendship in his own terms, which may be different than yours and which may also evolve over time. A phone call from an acquaintance may qualify as friendship to him. That's okay.
- Adults with similar disabilities to your child's can be inspirational, positive role models. Contact local chapters of disability groups, United Way, recreation centers, or a local university, for names of persons with disabilities who might meet with or be a 'buddy' to your child.
- Initiate friendships. Invite kids to your home. Initially they may parallel play but the exposure could lead to real friendship. Keep trying.
- After school-age check into Day Programs for adults with Intellectual and developmental disabilities. Most states have supported community connection type supports. These programs are terrific for building friendships.

"You are so much fun!"

GARDENING

- Gardening is gratifying, fun, and a wonderful tactile experience for you and your child.
- Gardening can teach sequencing skills also. "First, we plant the seed, then we water, and in a few days, we'll see a small sprout!"
- If space permits, let your child have his own garden space.
- Raised planter boxes allow gardening from a wheelchair.
- Plastic tubs (big ones where trees can be planted) are good for 'Container Gardens'. They're accessible for wheelchairs and are a good height for small children. See your local nursery to purchase.
- An alternative to tubs is using untreated timbers to create raised beds.
- Use bar-b-que tongs for picking up items dropped from a wheelchair. There are 'Grippers' on the market and some of the gadgets invented to make life easier for senior work wonderfully well for people who have a variety of challenges.
- Foam rubber or pipe insulation over handles of garden tools make them easier to grip and handle.
- A broom handle tied to the end of a hose makes it rigid and easier to manage.
- A wrist brace can be screwed to the handle of a garden implement.
- Purchase sturdy "toy" tools for your child if adult size equipment is too large. Rakes, shovels, and hoes for children are available. If a trowel is too large, let your child use a plastic cooking spoon.
- Let him know these tools are his own. Keep them in an accessible location and teach him how to care for his tools.
- Have your child water seedlings by squeezing a wet sponge over them.
- Some fun plants are: tomatoes, pumpkins, sunflowers, herbs for use in meals.

- Salt shakers or plastic herb bottles make good seed shakers for planting.
- Involve your child in all aspects of the garden plot, explaining as you go, the need to water, weed, thin, feed and finally harvest.
- Allow your child to plan menus around what he can harvest from the garden. Let him help with the food preparation for a sense of completion and reward. Share your harvest.
- Avoid pesticides and toxic weed killers. A non-toxic weed killer is: Epsom salt, vinegar, and blue Dawn dish soap mixed together and sprayed on weeds.
- Plants that repel mosquitoes are: lavender, lemon and thyme, lemon grass, catnip, garlic and marigold.
- Gardens attract bees and butterflies.

"What an imagination!"

GOALS

- Set long and short-term goals for yourself, your child, and your family. Where will my child live in 5 years? 10? 25? And ask yourself how you can assist him to attain his goals. Develop goals with your child with respect for his wishes, interests, and abilities, and work toward them.
- Be realistic and flexible. What may have seemed like an appropriate goal at one time can become an impossible task.
- Let impossible goals go and formulate new ones. Conversely, if you find your child achieving more than you dreamed, keep setting new goals. Re-assess, re-assess, re-assess!
- Remember not to underestimate or overextend your child when goal setting. Attaining goals is important for motivation onto new horizons.
- Look at goals as opportunities for growth and new experiences. Enjoy them!
- Teach your child how to set goals and the steps for himself.
- Establish a time period (a week, month, or any other time period that's appropriate) and help your child decide on an achievable goal (i.e. remembering to bring his homework assignments home all week.)
- Have your child write down the goal and then post it where he'll see it daily.
- Talk with your child about how to attain the goal. "We could buy a special homework notebook that will fit in your backpack. Do you want to write down assignments for each new day?"
- Check in with your child during the week to see how it's going. Genuinely praise success and offer encouragement if problems arise. Say, "It's wonderful you remembered to write down all of today's assignments! I'm sorry you forgot to bring it home but getting into a good habit of placing the notebook into your backpack will help tomorrow."

- At the end of the agreed time period, help your child evaluate how well he did. Was the goal reached? How? Praise any effort! Reward as pre-determined.
- Model goal setting and achieving for your child. Say, “I’m going to try and do the dishes right after dinner all this week.” Enlist your child’s help in reminding you.
- M.A.P.S. Goals should be **Me**asurable, **A**ttainable, **P**ersonal, and **S**pecific.

“You remembered!”

Grievance & Dispute Resolution Process

- Like all in all professions you may come in contact with an un-professional professional, an under-trained person or worse.
- School Districts, Day Programs, and jobs usually have Grievance and Dispute Resolution processes. Know about your child's rights in the area of service they currently are in so you can be a valuable advocate.
- Contact your local Parent Support Group or ARC for additional help when needed.

See: legislation, communication, advocacy, inclusion,

"I admire your determination."

GROOMING

- Within reason, allow individuality in regards to hairstyle, make-up, and dress (reserve outlandish dress or make-up for "at-home" wear.)
- If possible, and especially at adolescence, help your child make the transition from your assisting or doing the grooming, to his being responsible for his own hygiene. Instead of fixing your child's hair that is only combed in the front, say "Maybe you should check the back of your hair one more time." Help him with the mirror if necessary. Install a mirror by the door for a final check.
- Compliment you child when he looks nice. For instance, "You matched that outfit very well. The colors go well together and look good on you!"
- Reinforce good choices.
- Teach all areas of hygiene. Raise the standards along the way and reassess.

"You're growing up!"

GUILT

- Guilt….we all have it! You're not alone.
- After making a list of all the things you feel guilty about, cross off the things you cannot change and the things for which you are not responsible. Design action plans for coping with the rest.
- We all need to remove past guilt to find joy in our lives again. How?
  - Care for yourself. There's no need to be martyr.
  - Prioritize worries and fears
  - Have faith in your sincere desire to do your best for your child
  - Spirituality
  - Professional counseling if you're "stuck".
- As humans, we'll never be perfect parents, therapists, teachers, or advocates. Do the best you can without over-stressing yourself, your family, or your child. When you know better you'll do better.
- Don't give your child preferential treatment. Remember to balance caregiving relationships.

See: coping

"I think you're fantastic!"

HEALTH & WELLNESS

- If dry skin is a problem for your child, put socks or gloves on hands and feet after you apply lotion to help maximize absorption.
- Reapply lotion or lip balm after your child falls asleep at night.
- Use special care when dealing with lack of sensation or high pain tolerance.
  - Avoid too much lotion use in areas that may be subject to rubbing from braces or clothing.
  - Bandage bumps, bruises, abrasions, especially in areas that are easily reinjured (knees, shins, etc.)
  - Keep brace liners and socks snug and thin and use cotton. Avoid wrinkles beneath braces.
  - Dress your child in loose fitting clothing. Avoid elastic waistbands that are too tight and might cut off circulation.
- If your older child has limited sensation, be sure he understands the dangers of skin issues. Ask your doctor or therapist to show you and your child an example of skin breakdown and explain the ways to prevent it.
- Do a quick skin check at bed or bath time each day. Look for marks that don't fade, bruises, or scrapes that could be caused by shoes, braces, or tight clothing. If you notice a problem, notify your child's doctor.
- Prevent burns:
  - Wrap lavatory pipes with insulation.
  - Beware of hot seat belt buckles in your car or the child's car seat. Cut the toe off a sock to slide over the buckle, if necessary. Use a padded care seat liner or throw a blanket or towel over your car seat to prevent it from overheating.

  - Monitor waterbed, heating pad and electric blanket temperatures.
  - Teach cooking safety.
  - Turn down the temperature on the hot water tank to prevent scalding.
- Teach your child to always wear his seatbelt, bike helmet, knee pads, and other safety equipment. He'll learn by seeing you wear them too.
- Talk about 'Road-Rage' when you see it so your child can identify if their care-taker drives with Road-Rage and notify you. Talk about how texting while driving is not acceptable also and pull over to text yourself.
- Be vigilant of potential side-effects of any medications.
- Information regarding allergies is very child specific. Contact your pediatrician or allergist for specific tips regarding your child's needs.
- Record your child's allergies, especially serious allergies to such things as insect bites or medications. Keep a copy of that information in your purse or briefcase, in your car, and by the phone for emergency purposes.
- Inform those who are with your child at school and in the community of your child's specific medical needs.
- Record medications or products that are effective in treating your child's allergies.
- Consider getting your child an allergy identification bracelet.
- Always use sunscreen to prevent sunburns. Reapply lotion during the day or after swimming. Check your child's medications. Some medications create an extra sensitivity to the sun.
- For chapped lips and dry skin, increase the humidity in your home by the use of a portable or furnace-attached humidifier. Also, houseplants add to the moisture in the air, as do pots of standing water. Open your dishwasher during the dry cycle and let dishes air dry while adding humidity to the home.

- Teach and follow through preventive care in tooth brushing, regular medical and dental check-ups, and immunizations. Teach your child to take some responsibility for his own health care according to his abilities.
- Teach your child to tell you or another adult when something doesn't feel right, i.e. "My tooth aches."
- Be aware of and attempt to prevent **constipation** and/or **dehydration**. Both of these are VERY dangerous and can cause death, especially in our population.
    - Offer plenty of non-sugary liquids.
    - Eating high fiber foods is crucial. According to The American Heart Association Eating Plan: "Total **dietary fiber** intake should be 25 to 30 **grams** a day from food, not supplements. Eat from a variety of food fiber sources. Fruits & vegetables are high in fiber." Track total grams daily.
- Enjoy exercise as a family. Bike, hike, bird watch, swim, or fish together. Experiment with different activities until you find ones that are fun and functional for you and your child.
- Teach your child that the private parts of his body are those covered by bathing suits.
- Teach your child to tell you or another "safe" adult if he has been approached or touched inappropriately. Inappropriate means touching means touching parts covered by bathing suits or any contact that is unwanted or leaves the child feeling unsettled.
- Ask your dentist about having your child's teeth sealed with a protective sealant to prevent cavities.
- Encourage independence in toileting. Check with your doctor for specific information on needs and establish a good toileting routine. Attempts may not be perfect, in which case, give an evening bath.
- Teach your child proper sleeping habits. One child, when asked what time he goes to bed replied, "When my mom tells me to…" Some children can to tune into their own needs and

assume responsibility. If he's able; teach your child to ask himself "How many hours of sleep do I need at night?" Help him calculate times.

- Take photos of moles to be able to tell if they change.
- Have one person in addition to parents (perhaps your pediatrician) who oversees all of the medical professionals and your child's records to ensure adequate communication.
- Speak to your doctor regarding vaccinations like flu shots or Hepatitis B. Keep vaccinations current.
- Talk to your doctor about the use of probiotics after antibiotic use.
- Emotional wellness should not be neglected. Friends & family are emotional connections. Let your child define friendships in his terms, not yours. Teach him to care about others. Teach interpersonal skills like friendliness, eye contact, personal space, and polite small talk (especially important for maintaining jobs). Encourage generosity and thoughtfulness.
- Many ailments are stress related.
- Teach your child about stress relieving activities such as: meditation, Yoga, naps, deep breathing, taking walks, exercise, talking to others. (see: coping/child). Do these activities with your child until they choose to do on their own.
- If you have trouble speaking to your child about sexuality issues, ask a doctor, school nurse, or church person for help, or get some books. Start educating your child at a young age about sexuality, values, responsibilities, guidelines, moral issues, or contraception. Be sure to use correct terminology.
- Speak to the doctor ahead of the appointment or in the hall before she meets with your child. Mention concerns regarding sexuality or adolescence in general, or such issues as depression, peer pressure, or substance abuse. Ask the doctor to assist you by addressing those issues. Allow your child private time with the doctor. Your child may want to bring up his own questions.

- Teach proper nutritional habits by preparing healthy meals & snacks for your entire family. Include your child in menu planning. Teach appropriate portions. Model healthy choices: grab an apple instead of candy. Treats of sugar, fat, grease, too much fast food and large portions can actually harm your child. Added weight can cause knee pain, back pain, interrupted sleep, sleep apnea, diabetes and other health issues. Think of and use non-food treats such as a trip to the park, playing a game together, downloading a coloring page, calling grandma on the phone, etc.

- See: Exercise, Safety, Coping, Nutrition, Sexuality

"You look so cute (handsome) and Healthy!"

HOME MODIFICATION

- Contact your hospital, disability organization, or an architect who specializes in design for specials needs for specific information.
- Consult your child's physical and occupational therapists for tips specific to your child's needs.
- Remember to allow for your child's growth when planning your home modifications, especially if you are planning to live together into their adulthood.

See: Accessible/Adaptable Housing

"Beautiful work!"

HOMEWORK

- Kids have a range of academic ability levels. These ideas are for a child with typical academic abilities. Nathan, who had Spina Bifida, went to college after high school and earned a 4-year degree. Vanessa, on the other hand, learned to read at about a 3rd grade level and has maintained that skill.
- Have an assignment notebook or checklist that comes home with your child each day. In it, have your child, if he's able, or his teacher, if he isn't, indicate daily and weekly assignments as well as long-term projects and due dates. Having advance notice of tests and quizzes is very helpful too. *Any class can be modified.* This will also remind your child and make you aware of what needs to be done and when.
- Transfer homework assignments onto a big block calendar and keep it in your child's room or the area in which he does his homework. As assignments are completed or tests taken, your child can cross them out on the calendar.
- Designate a specific time and special, quiet place for homework or reading time. It doesn't need to be a desk. The kitchen table or a bean-bag chair is fine for reading.
- Designate special places for completed homework and notebooks (perhaps with coats and hats) to prevent a frantic search in the morning.
- Supply your child's homework place (desk or table) with the materials he might need, such as pencils, sharpener, scissors, erasers, paper, and glue. Try to position them in a way that your child can access them independently. Try using a silverware tray for easy transport or storage.
- Let school consequences for late or missing homework be adequate. There's no need to double the consequences.
- Reinforce to your child that his "job" is being a student. Homework is an important part of the job.

- If, in your opinion, your child is bringing home too much, too little, or inappropriate homework, ask the teacher; "Would 5 math problems teach the concept as well as 25?"
    - "Is this assignment serving a specific purpose?"
    - "What is your objective in this lesson? Is it the same for my child as the other students? Should it be?" Asking for modifications is OK.
- If you've helped or modified a homework assignment in any way, jot a note to the teacher telling her so. For example, "Chris understood this math concept after doing 10 problems. Because it took him awhile, I modified the assignment length."
- Save homework assignments, quizzes, and tests for the duration of the school term so they can be referred to for midterm and finals.
- Be attentive while your child is doing homework. Let him start himself but ask if assistance is needed.
- Some parents just say 'no' to homework, especially if their child comes home exhausted after school. You know what's best for your child*. Put the no-homework request in her I.E.P.*
- If there is assistive technology available that helps your child note it's use on the I.E.P.
- Teachers are with your child for the school year, you are their Educational Manager/advocate their whole life. If a teacher is un-bending, unreasonable, unaware of your child's rights or refuses to implement the I.E.P.: ask for a different placement. If the principal is not accommodating, go to the School Board. Don't give up, after all your child's self-esteem is at risk which is the most important consideration. You may be labeled: "a difficult parent". Wear that label with pride knowing you are your child's advocate and won't be distracted by intimidating labels. Some feel that learning to endure horrible teachers is an acceptable experience for a vulnerable child. Suffering in school is Not acceptable. Advocacy Works. See: Grievances and Disputes, advocacy

"You've almost got that mastered!"

HOSPITAL STAYS

- Contact the hospital prior to any procedure to see if they have pre-admission tours.
- If you have questions regarding an upcoming surgery or procedure, ask your doctor to put you in touch with a family who has experienced a similar procedure.
- Tell your child what's happening from the beginning of the hospitalization process. Most children will be more frightened if they are suddenly taken to the hospital without knowing why and for how long. Although they certainly don't need to hear the gory details, a frank discussion with your child about what is being done and why may be helpful. Continue to explain procedures, at the child's level of understanding, throughout the stay.
- Be honest with your child. Don't say it won't hurt if it will. He'll lose trust in you and the medical staff. Instead, come up with strategies to deal with the pain and discomfort. For instance, have your child squeeze your hand and count while getting a shot. Make a game of how high he can count.
- Advocate for your child. Chances are your child will not be a good self-advocate while in the hospital, so be there for him. For instance, if a lab tech has tried unsuccessfully three times to draw blood and your child is upset, ask for a time-out so your child can rest, and/or ask for another technician. If you can't be there, arrange for another family member to give you a break.
- Bring copies of your child's medical history with you. Give it to admitting nurses, residents, and nurses on the floor as needed. Keep a copy for yourself for reference. Fewer mistakes are made when someone questions each person administering any procedure about what and why they are taking action.

- Bring your child's medications in the original prescription bottles that indicate dosage and frequency.
- Limit visitors if it means you'll get more sleep. When your child sleeps, you can sleep. You can't help or entertain him if you're exhausted.
- Bring along change for vending machines.
- Wear sweats, jeans, or other clothes you can sleep in.
- If you wish to stay overnight in your child's room ask for a cot if one isn't evident.
- Ask where linens, juice, water, and ice machines are located. Check with the nurses to see if you can get those items yourself rather than calling a nurse each time.
- Be as specific as you can when asking questions or making requests. Instead of saying, "Anything will be okay for Chris' dinner," say, "Chris likes peas with dinner." It is especially important to cater to your child's needs and desires in the hospital. Sometimes a favorite dinner or snack can make a bad day better.
- If you have a complaint or suggestion try to word it in a positive manner. "I appreciate the fact you're busy, but I don't think Chris is getting the monitoring she needs."
- Bring a favorite toy, blanket, and pajamas. Make sure they are marked with your name, and alert hospital staff to ownership so items don't get taken to the hospital laundry.
- Bring a toy doctor or nurse bag or other favorite small toys for your child to play with while in the hospital.
- While in the hospital, parents can feel like the bad guys. Your child may be angry before, during, and after the hospital stay, and most of the anger will be vented on you as you're the safest authority figure in their life. Take time both before and after the stay to do fun things together. Talk about what you have done together and plan those things you'll do after. It is reassuring to your child and allows a way to readjust to the family routine.

- Be realistic about goals for recovery and length of hospital stay. Never say, "You'll be home tomorrow," if there's a possibility it won't happen.
- Be positive but honest. "Dr. Jones says there's a chance you could come home tomorrow if everything goes as he thinks it will." Then, if a stay is extended, explain why.
- Children worry when in the hospital. Be receptive to their unspoken fears. A hug or long rock in a rocking chair may help…even for big kids!
- Stick to routine as much as possible. For instance, if your child likes stories before bed, take some favorites with you.
- Purchase and wrap small, inexpensive gifts for each day your child will be in the hospital. Magic slates, story books, bubbles, word finds, IPads and puzzles can all be fun while confined to bed.
- Participate, to the best of your time and ability, in your child's care to ensure their comfort. Staff take note of involved, attentive parents and usually rise to their expectations.
- Ask questions about procedures and medications. You need to understand so you can explain to your child.
- See if your hospital has visiting therapeutic pets and if so, schedule an appearance for your child.

"I'd love to hear what you think about this."

Individualized Education Plan (I.E.P.)

- An Individualized Education Plan (or program) is a requirement of IDEA (see below). The I.E.P. consists of an educational plan specific to your child's needs; formulated by a team during a staffing meeting.

  IDEA: Individuals with Disabilities Education Act (from: Department of Justice, Department of Education):

  - The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs.
  - IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student.
  - IDEA also mandates that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of knowledgeable persons and must be at least reviewed annually. The team includes the child's teacher; the parents, subject to certain limited exceptions; the child, if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents' or agency's discretion.
  - If parents disagree with the proposed IEP, they can request a due process hearing and a review from the State educational agency if applicable in that state. They also can appeal the State agency's decision to State or Federal court. For more information, contact:
  - Office of Special Education and Rehabilitative Services
    U.S. Department of Education
    400 Maryland Avenue, S.W.
    Washington, D.C. 20202-7100
- Parents are a critical component of the team & should attend the staffing. Rather than meeting typical curriculum requirements, the school district is accountable to the specific plan for your child.
- Good preparation is important for a good I.E.P. meeting.
- Ask your child's teacher who will be attending the meeting.

- Meet with your child's teacher before the I.E.P. date to review last year's goals. Determine which have been met and which need to be carried forward to the new I.E.P. Discuss new goals for your child. Meeting ahead of time will give you added time for discussion. If you don't think the scheduled time of the formal I.E.P. is adequate you can schedule an additional meeting.

- Prepare a list of your child's recent accomplishments & positive qualities. Share your list with people at the meeting.
- Make a wish list before an I.E.P. staffing. Translate your wishes into suggestions and program ideas.
- Accompany someone else to their staffing if you've never attended one. Familiarize yourself with the procedures and expectations.
- I.E.P.s may be emotionally tough. Ask for clarification of any unclear point or jargon during the meeting. Acknowledge that this is a reminder of your child's limitations. You may need to work at regaining a positive attitude (See: Coping).
- Remember, your child is the number one factor to consider when making decisions regarding school issues, health decisions, etc.
- Bring along your spouse, friend or someone with experience with staffings. A few heads are better than one and can remember more afterward. Suggest that everyone begin the staffing by stating a positive about the child. This helps put the group in a positive frame of mind.
- Remember, an I.E.P. doesn't define everything about your child. You'll hear both negative and positive things. Focus on the positives, and work on expanding his strengths. Stress that you expect the most is to be made of your child's existing strengths. Meetings need not be a power struggle if the focus is in the child's best interest.
- Your child has needs. You may feel defensive but try to remember the group's goal is to help meet your child's *needs*. This can't be accomplished without discussion.
- You're on a team of professionals and are an equally valuable member of the team.

- Suggest that the team members introduce themselves by name, specialty, and the amount of time they spend with your child during the course of a week. This helps put people and their impact on your child into perspective.
- Parents need to separate their own responsibilities from the school's. Take notes.
- If you have further concerns or questions after a staffing, contact the school during the week while the meeting is still fresh in everyone's mind. Changes can then be addressed quickly.
- Make (and keep) eye contact with all members at the meeting.
- Make your viewpoint known to the group even if it differs from the majority. They can't read your mind. This is the time and place to speak up and brainstorm.
- Paraphrase what's been said to make sure you understand, i.e. "Do I understand you to be saying…?"
- Expect academics to be functional and in line with your goals for your child.
- Knowledge about services and rights will empower you. Contact your State Department of Education for information, services, training sessions, and rights.
- You can be assertive without being aggressive or adversarial. Look into classes or information that teach that skill.
- Discuss plans for specifics about ongoing communication i.e. notebooks back and forth to school for notes, bimonthly phone calls, etc.
- Express appreciation for when a professional makes an extra effort or when something on the I.E.P. is working well. A note of thanks sent to school is very much appreciated.
- Correct inaccuracies in your child's I.E.P. and notify your school psychologist.

- If situations, strengths, or needs change during the year, I.E.P.s can be changed. Contact your child's teacher to set up a staffing.
- Don't just ask what the school will do for your child. Ask what role you can take to augment the goals.
- Listen to your child's viewpoint of his needs. When he is older he needs to be included in his plan.
- List technology your child needs to use in his I.E.P.
- Attend board meetings or Special Education Advisory meetings. They're not as mysterious or threatening as one might fear. Contact your school administration office for dates and times of meetings. Asking questions is an indication that you care and want to grow.

For Educators / Professionals:

- Attempt to begin and end meetings on a positive note.
- Recognize that staffings can be frightening. Treat parents as you want to be treated.
- Give parents credit for being intelligent. Avoid a condescending or patronizing attitude, remarks & snarky tone.
- Give parents attainable goals and useful suggestions.
- Summarize the meeting in writing. List what follow up is needed, by whom and when.
- Opinions are not gospel…they can change.
- Check your own biases and prejudices, perhaps you may be misinformed as to best practices when situations are complex.
- Treat each child as a person first, not a list of symptoms, a diagnosis or labels. Be direct, but sensitive.
- Focus on the positive and be constructive when goal setting.

See: Communication, *Legislation,* Modifications - School, Partnerships with Professionals, School Survival Tips for Parents, Staffings

"Good for you!"

INCLUSION

- Inclusion is simply including everyone in the mainstream of life. For a child with special needs, supports are necessary to varying degrees, and strategies must be developed for each individual circumstance.
- Work with teachers, administrators, recreation and service providers in the community. As a team, figure out a way to develop natural supports for the child with special needs.
- Remember, regardless of trends and philosophies, laws or rights, inclusion may be stressful for both you and your child. Watch for signs of stress and accommodate accordingly. For example, if school is stressful, create a safe "haven" at home with special treatment, snacks, naps, and snuggle time to rejuvenate your child. Consider a vacation day as a catch-up day off if your child shows the need to recoup.
- Expect inclusion when appropriate. Ask, "Is there any reason why my child should not be included?"
- When our children are included in the community, their visibility leads to real understanding and acknowledgement as individuals, not labels. When people are aware, they're more likely to reach out, go the extra mile, and be respectful. Realistically evaluate what's best for your child.
- All children have a need for acceptance, friendship, and connectedness. In the practice of inclusion:
  - All students are regarded as rightful members of a class or school.
  - All students need integration, including children with disabilities, in common areas (lunchrooms, homerooms, art, recess, physical education) or in academic areas which are educationally beneficial. The goal is for your child to participate (with supports and aides if needed) with peers of his own age who do not have disabilities.

INFANT STIMULATION

- Infant stimulation is fundamental for kids with disabilities. It sets a foundation for growth and development and teaches parents how to teach at home and maximize their child's potential.
- Follow your doctor's advice regarding your child's specific disability.
- For referral to an infant stimulation program consult your pediatrician, or hospital social worker or contact your county department of social services for information on local facilities.
- Often, there are U
- University affiliated programs for babies with developmental disabilities. Contact your local University's Special Education or Occupational therapy or Physical Therapy department for information
- Have fun – play, sing, play music, dance, talk to your baby.
- Talk – talk – talk! Talking to a baby who is not able to respond may seem unnatural, but it is crucial to language development. "I'm changing your diaper now. Doesn't this powder feel good…you smell so nice." You may feel silly hearing your own chatter at first but your baby will love it! Talk about what you see and hear while you are in the car. Talking helps babies learn that there are words to label objects, feelings, and ideas.
- The key words in infant stimulation are Patience, Prioritize and Persistence. Do not insist on any activity that your child resists. Discontinue for a week or two and then introduce the activity again pleasantly.
- Include all family members in playing with your baby.
- Repeat learning activities to reinforce them.
- If your baby doesn't imitate you on his own you will need to teach him i.e. take his hands and model clapping.
- Mirror your baby's expressions and vocalizations.

- To avoid nagging: offer cues which can ultimately be withdrawn such as touch your own mouth when cueing them to keep their lips together instead of 'mouth breathing'.
- Smile a lot and nod encouragement.
- Take your baby from room to room with you as you clean, cook, or talk on the phone. Put a blanket on the floor and allow your baby to look at the different rooms and roam as much as possible, with supervision.
- Tactile stimulation is great fun and is good for babies. Water play, drying off with a towel, playing with whipped cream, or modeling dough. *Always supervise!*
- Make every effort to stimulate all five senses.
- Carry your baby with his head facing out so he can see. Carry him against your shoulder so he can see over it or facing outwards with your arm around his middle while supporting his head. While sitting on your lap, have your baby face outward also – it's more stimulating.
- Learn about 'normal' developmental milestones. There are checklists and books available at your local bookstore, library, or online. Know which developmental step comes next and gently encourage your child to reach it or modify the goal. Break steps into small components.
- It's inevitable you'll compare your child to others. It hurts but don't avoid being around others. The exposure to age appropriate friends will be beneficial to both you and your child. You need the social contacts and what easier way to learn developmental milestones.
- Expect your baby to grow and learn, it may take longer, but continue to encourage the next developmental step. Be realistic, yet optimistic. Kids often rise to expectations.
- Don't leave a "too good to be true" baby alone too much; enrichment is very important.
- Brothers and sisters can be wonderful playmates if they are taught what the baby can or can't do well.

- Draw attention to sounds (TV, voices, dogs, planes, dryer, doors opening and closing).
- Take walks outside with your baby. A stroller is a terrific investment.
- Rotate a variety of toys, possibly trading with friends. Garage sales and thrift stores are wonderful sources of used toys. Give them a disinfectant bath. Keep old magazines for looking at or ripping. Household items including pots, pans, spatula and wooden spoons make good playthings.
- Make or purchase an apron with pockets. Place a different object in each pocket and have your child reach in and identify the object while you wear the apron.
- Have toys available in the crib, playpen, stroller, and car. Keep them age or ability appropriate and safe. Never give a child toys small enough to fit in his mouth. Rotate toys.
- Hang a mirror at the level where your child can see himself. This is fun and helps development of self-esteem.
- Decorate your baby's room with mobiles, colorful paint or wallpaper and posters. Keep unsafe items out of baby's reach!
- Cuddle up and read aloud to your baby.

See: Exercise, Therapy

"You tried hard!

INFORMATION GATHERING

- The telephone is a great resource. Be persistent. If the first person you speak with doesn't help, find out who you need to speak with next and get the phone number. Telephone information gathering can be time consuming. Be patient and persistent. If the person you've called cannot help, ask who they recommend.
- Join support groups specific to your child's disability.
- The local ARC is helpful.
- Call friends who have been through some of the same things you are experiencing.
- Contact local hospital administration offices, community colleges, research facilities, and groups on disabilities. They have free materials, reading lists, and lists of resources.
- The internet can be a helpful source.

"Outstanding!"

INSURANCE

- Carry your insurance identification card with you at all times.
- If your insurance requires pre-admit authorization, have necessary information available.
- When in doubt, submit a medical expense to insurance. They'll deny a claim if it isn't covered, but sometimes they will cover things you may not expect. Keep records.
- If a claim is denied or only partially paid, ask your physician to write a note explaining the necessity of the charge. Resubmit the claim to your insurance company. It never hurts to try!
- Always be honest about your child's condition when applying for insurance.
- Contact national organizations of your child's disability to find out if they have any insurance contacts for either health or life insurance. They can refer you to companies which may cover your child.
- Call your State Department of Insurance to get lists of companies or companies which will insure people hard to insure.

"That's what I call a fine job!

JARGON

- Jargon is the technical terminology used in association with particular groups. For instance, medical people use terms such as ICU, Code Blue, CORE, etc. Educators use terms including staffing, ED, IEP. These terms and acronyms are meaningful to people within the system but can be frustrating and a hindrance to good communication if you don't understand them. They also morph over time and it helps to keep current.
- If professionals are using terms you don't understand, ask them to stop and explain their definitions as they speak.
- On the other hand, as a valued member of a professional team, it is your responsibility to know as much Jargon as possible.
- Some groups generate lists of their particular terms and acronyms. Ask for such lists before meetings and keep them for easy reference.

"Look at you go!

LEARNING

- Expect your child to learn. Let his pace be his, not yours. Be realistic and try not to frustrate either of you.
- Sometimes learning in one area can offset progress in another. This is usually temporary. For example, while learning to walk, talking may slow down.
- Look to your child as a guide. Is he happy and proud of himself, or worried and nervous? It it's the latter, maybe expectations are out of line.
- Strike a balance between pushing and underestimating. Remember, development can be sporadic. Don't get discouraged.
- Everyone; including YOU and YOUR child, continues to evolve and grow during their lifetime.
- Be Life-Long-Learners together.
- Create opportunities to learn. For example, recreational activities, family play times, concerts, plays, travel can be entertaining and instructional.
- Give your child adequate time to respond to questions. This is important for developing self-esteem. Allow your child the practice time he needs when learning new skills.
- Break down goals or task into specific, manageable steps. Say, "Please empty the dishwasher and wipe off the counters", rather than, "Please clean the kitchen." Remember to give plenty of reinforcement.
- Look to the internet for classes and enrichment. There are many educational resources, some are even Free. You can access classes on YouTube such as: how to knit, how to draw, how to paint, beginner's Yoga, how to cook an egg. The list is endless.

See: Expectations, Goals

LEGISLATION

- There is extensive federal and state legislation regarding the rights and education of individuals with disabilities.
- The National **ARC** for people with intellectual and developmental disabilities is a great resource for current legislation and advocacy assistance. Check to see if you have a local ARC.
  Sometimes your local state/federal funded Agency or school district doesn't share all of the relevant legislative information, but, the ARC does.
- The Individuals with Disabilities Education Act (IDEA) replaces the Educating of the Handicapped Act (PL94-142). The specific information included in IDEA is available by contacting your State Department of Education (Special Education Division). They will send you (at no charge) a copy of IDEA and its administrative notes and regulations.
- Your state Department of Intellectual/Developmental Disabilities (may have a different name in your state) will become your next resource when your child transitions into adulthood.
- A.B.L.E. (Achieving a Better Life Experience) act of 2014: "The ABLE Act allows people with disabilities and their families to set up a special savings account for disability-related expenses. Earnings on an ABLE account would not be taxed, and account funds would generally not be considered for the supplemental security income (SSI) program, Medicaid, and other federal means-tested benefits. Check with your state".

See: ADA. IEPs, Political Advocacy,

"Great discovery!"

LIBRARIES

- Libraries are a wonderful source of information and ideas regarding special needs. Children's sections have a variety of books for various ability levels. When your child is older, ask for high-interest, easy reading books. Audio books are available for people of all interests and ages.
- Parents can find ideas for arts and crafts, parties, indoor activities, and other fun ideas which encourage learning and personal growth.
- Libraries usually have audio/CDs and videos that you can check out.
- Ask your local library to subscribe to publications which may be helpful to you, such as *Exceptional Parent Magazine.*
- Libraries can borrow needed information from other libraries for free.
- Local civic groups may fund the purchase of 1 or 2 good books to donate to the library in order to educate the community about disabilities.
- Take your child to the library often. Teach him how to use the library. Help him obtain his own library card.
- Have a special basket at home where the library books are kept until time to return them.
- The library calendar will inform you of readings, shows, lectures, and other programs.

See: Reading

"You've got this."

MARRIAGE - Marital Stress

- Having a child with a disability or chronic illness does put stress on a marriage. Awareness is part of prevention.
- If either of you are stuck in a psychological struggle; seek professional help. Some people feel emotionally crushed and inadequate because they can't 'fix it'. If this is your situation get professional help to find possible solutions and hope.
- Don't blame every problem in your marriage on the child's disability.
- Acknowledge and respect that individuals deal with grief and loss differently and according to their own timetables.
- The mutual commitment to your child and his needs can strengthen your relationship.
- Join a support group, individually or together.
- Work on typical marital stressors (finances, job, stress, etc.) as they occur and attempt to simplify or eliminate them.
- Encourage your spouse to interact with your child and share responsibility. It isn't healthy for one partner to be solely responsible for the child's needs. Balance the roles.
- Create opportunities for your spouse to participate in your child's activities. Also, take turns putting your child to bed so he will feel secure with both parents.
- Give yourself permission to take time away, especially for some time to be alone with your spouse. Contact family members, church, friends, or a local respite care agency for babysitting. It may seem impossible, but it's important to develop a circle of support. Your child will benefit when you take time to refresh and consistently take care of yourself. Children need to know you and your spouse value each other.
- Make a list of your child's needs, medications, routine, etc. and post it prominently. This helps others learn about and share responsibility for your child. (see Free downloadable Comprehensive Life Review Form on website)

- See a marriage counselor, pastor, or psychologist to work on communication and other marital skills if you're having difficulties. Don't wait…go at the onset of difficulties. Seeking help is not a sign of weakness, it is a sign of being pro-active and sensible.
- Talk to each other. Don't expect your spouse to read your mind.
- Use "I need" statements instead of "you, blaming" statements. For instance, say, "I need a hug" instead of "You never show any affection."
- Balance 'good guy' and 'bad guy' roles when interacting with your child. Talk with each other so you can be united and clear regarding expectations, and health & safety rules.
- Take a walk together, maintain hobbies and activities as much as possible.
- If possible, reserve the hour after the children are in bed as "together" time.

See: Coping – Parent

"Well done!"

MEDICAL TREATMENT & APPOINTMENTS

- Prepare your child for every experience beforehand. Be honest. Don't say it won't hurt if it will.
- Ask that professionals explain their actions to you and your child as they proceed with examinations or treatments. Be alert to prevent redundancy of treatment. For example, doctors in training may perform some procedures or exams prior to the staff physician's visit. Request that anything uncomfortable for your child be done only once, if possible.
- Check with your doctor about conflicting or interrelated services and medications. For instance, "Does my child need antibiotics before dental work?" or "Does medicine 'A' mix with medicine 'B' from Dr. X?" Never be afraid to ask…many prescription drugs have miserable side-effects and those may be compounded when giving with other drugs.
- Always know the types and dosages of medication your child currently takes.
- When taking your child out of school for appointments let the teacher know in advance and request homework for what your child misses. Waiting rooms are a good place to do homework.
- Take along activities you can do with your child while you wait, such as playing cards, reading books, word puzzles.
- Take advantage of the time together which medical appointments provide. On the way to and from the appointment turn the radio off and talk or play games with your child (I spy something… or 20 Questions). While waiting in the office share a story or game. This relieves the child's stress and provides the opportunity for some quality one-on-one time.
- Take notes at doctor's appointments. This makes relaying information to other family members easier and more accurate.

- If the doctor or technician doesn't ask your child if he has any questions you can say, "Chris, do you have any questions for Dr. Brown?"
- If you know beforehand what questions you have for a doctor or therapist, make note of them and take your list to the appointment. This save time and provides you with the information you need, rather than just what the doctor remembers to volunteer.
- Keep a file of clinic or hospital reports for future reference.
- If your child can't swallow capsules, open them and add the powder to applesauce, pudding, ice cream, or a beverage.
- A syringe (without a needle) works well to give liquid medicine. Ask your pharmacist for one. Some medications can be added to juice or milk. Check with your doctor.
- When your child is ready to become more responsible for handling his own medications, get him a watch with a beeper to indicate a medication time. Parents should continue to supervise on control dosages.
- Always inform doctors of current medications when adding any new ones, to make sure they are compatible.
- Always review possible side effects with new medications and watch for them. Check to see if medications should be taken with or without food, and if there are special precautions. How often do medications get reviewed? Under what circumstances should medication be adjusted or dropped?
- If your child has any unusual symptoms following the introduction of a new medication, call your doctor immediately.

See: Hospital Stay

"You Remembered!"

MODELING

- Even though kids may not realize or acknowledge it, they are constantly modeling our behavior. Actions speak louder than words.
- Model appropriate behavior, skills, friendships and independence. Talk to your child while you're performing routine activities. For instance, "I brush my teeth every day, in the morning and at night. I remember to do it after I wash my face, and I love the way it makes my teeth feel. I know my friends like my nice breath."

See: Behavior, Learning

"You're getting better every day!"

MODIFICATIONS - SCHOOL

- Some students with disabilities require changes in school curriculum or classroom support to succeed. These modifications vary from child to child depending on ability level and teacher expectation. Modifications are your child's right and should be addressed specifically in the I.E.P. (Individualized Education Plan). (see IDEA act)
- Provide an extra set of textbooks for home use or in each classroom. This will help your child get from place to place more independently. If needed ask the teacher to provide a copy of his lesson plans. IPad, Notebook, or some other electronic device used at the school may be an option. Many assignments are online.
- Consider color-coding your child's notebooks and folders.
- Provide audio books, tapes of textbooks or favorite books. Contact your local library or school media center for access to books on tape.
- For math homework, graph paper helps line up columns.
- After an illness, hospital stay, or other absence, consider modifying school expectations. Talk to your child's teachers.
- Find high interest, low vocabulary books, or books for the 'reluctant reader' or audio books in your library.
- Contact Resource Services for college students with disabilities at the local community college or university.
- Suggestions for IEP Goals: Modify academic tasks to reflect personal interest (i.e. if a child is excited about working in the school cafeteria as a helper, modify math assignments to that interest...making change, estimating time, sequence of events..., etc.)
- Modifications:
  - Simplify sentence structure for questions
  - Give oral tests and allow oral answers
  - De-emphasize grades
  - Allow unlimited testing

- Reduce choices on multiple choice tests
- Keep modified copies of tests on file for future students
- Allow the use of calculators
- Provide study guides
- Assign appropriate reading level assignments
- Have the child participate in goal setting
- Praise efforts
- Print rather than write in cursive on the blackboard
- Reduce the number of problems required
- Provide a word bank directly on worksheets – this reduces stress
- Ask yourself, "What do I want my child to learn from this lesson?"
- Allow oral presentations, and oral substitutes for essays.

See: IEPs, Homework, School Survival Tips for Kids

"You are really learning a lot!"

MUSIC

- Music is a good relaxation device and stress reliever. Play soothing music or mood tapes (sounds of the ocean, rain forest, etc.) to your child before he goes to bed or at stressful times. Combine with deep breathing exercises.
- Sing to and with your child.
- Let your child try music lessons. If it's too challenging or frustrating, let him experience music as a listener. Possibly reintroduce lessons at a later time.
- Expose your child to different types of music. Dance with him to rock and roll, relax with him to easy listening or classical music.
- Use music in the car as a welcome diversion. Sometimes let your child pick his favorite radio station or DVD.
- DVD/CDs, I-pods, Mp3 players and headphones are fun. Teach proper volume levels to prevent hearing damage.
- Music is something to share with friends. Provide a MP3 player for your child's room. Age appropriate players are available for young children.
- Set alphabet, numbers, or memory work to music. Sing into a recorder or play an instrument for your child. Consider using rap CDs for math skills like multiplication tables.
- Exercise is much more fun when done to music.
- Rent musical videos and movies. Musicals may be more stimulating for your child than a non-musical movie.

"I love hearing what you have to say."

NEW PARENTS

- The first days and weeks after having a baby with a disability or illness are extremely difficult. If you know someone with a new baby you may be able to help:
  - Send them a card of **congratulations**. This is their new baby, despite any issues. Rejoice for and with them.
  - Welcome the baby to the family with a gift and/or visit.
  - Be sincere in praising the baby. "He's so cute!" or "What a precious smile!" Every baby is lovable.
  - Take a new parent out to lunch.
  - Buy the parent some flowers.
  - Have a cup of coffee. Be a friend.
  - Talk about something other than the baby if that's what the parent needs.
  - Ask what you can do to be helpful: for instance, the parent may feel comfortable letting you babysit if you've had similar experiences with your child.
  - Make yourself available.
- Everyone becomes ready for help or information at his own pace. By reaching out to new parents as a friend, you allow them to ask for information or help when they're ready. Don't push, let them take the lead.
- If you are familiar or experienced with the special need beware of sharing too much too fast. One can only assimilate so much information at one time, and often new parents are too busy giving routine baby care to handle much else.
- As a new parent, remember you are your child's best advocate. Learn all you can, network with other parents, and persist in seeing that your child's needs are met.

"You're a beautiful baby."

NORMALIZING

- It is important to explore and join in on activities when your child is young. You can normalize your child's home, school, and social life, including:
    - Having birthday parties and inviting friends and classmates
    - Going shopping, going to movies, going to the park
    - Encouraging your child to participate in music programs, class projects presentations and award assemblies. Be sure you go too!
    - Enrolling in community parks and recreational programs.
- Involving your child in church youth groups, later; Special Olympics, or boy or girl scout programs, 4-H, or other youth programs.
- Your child could benefit from the experience of normalized activities and others will be sensitized to his needs and strengths. It's hard work however it will be time well spent. Consider joining yourself to go along and experience how well a program suits your child.
- Help your child plan weekend or after school activities with or without friends. Make activity suggestions as needed.

See: Awareness, Inclusion, Recreation

"You are my Sunshine."

NUTRITION

- Start as early as possible to teach healthy, nutritional habits by example: balance food groups, explain basic nutrition and shop the outer aisle of the food market. Mostly avoid processed, packaged, and fast food. Include your child in menu planning. It's never too late to go 'healthy'. Just slowly cut back on unhealthy favorites & replace with fresh alternatives. Prioritize home-cooked meals of real food.
- Swap out pop/soft drinks for plenty of water: fill her pitcher with a day's worth of water so she'll know how much she's had. Bring a water bottle on the go.
- Studies show when students eat a healthy breakfast their ability to learn improves. Avoid a sugary breakfast which leaves a child hungry after the mid-morning sugar-crash.
- Pay attention to the amount of sugars and fat as well as empty calorie intake. There are studies that show 'good fats' (like avocado, olive oil, almonds, salmon,) aid brain development among other things. Organic fruits & vegetables offer fiber & vitamins young bodies crave. Good carbs are in fruit, whole grains (like brown rice, quinoa) beans and veggies.
- If you don't want your child to eat certain foods, don't bring them in the house. If you want to prevent over-eating: put a few chips in a bowl, don't hand your child the bag. Teach proper portions. Read labels; you'll be amazed at the suggested portion sizes. Use actual measuring cups/spoons to measure until you know the portion sizes.
- Some kids like to see large portions: Use medium sized plates instead of dinner size. Make large side salads. Use thin crust pizzas (add veggies) and try cauliflower crust pizza, cut into many smaller pieces to look like 'a lot'. Use extra egg whites to increase size of omelets. Add fun veggies often like pickles, olives, carrots, radishes, broccoli florets, cherry tomatoes. Low

fat Greek yogurt is a great base for 'dips'; mix with salsa or parmesan cheese, Mrs. Dash (great substitute for salt), artichoke, & other veggies.

- Keep nutritious snacks in a designated place so your child can help himself:
- Fresh or frozen fruits & vegetables.
- Ants on a log (Carrots and celery spread with peanut butter or cream cheese and sprinkled with raisins for the ants)
- 100% fruit juice popsicles
- Whole grain: breads, crackers, Pita crackers, rice cakes: add peanut or almond butter, humus, guacamole, black or green olives, pickles.
- Pre-made/measured 'energy' bags with almonds, various seeds, dried fruit, coconut, & some dark chocolate bits.
- Humus with celery or other veggies
- Whole Grain English muffin 'pizzas'.
- Baked potato with chili beans or broccoli & cheese toppings
- Low-fat Greek yogurt with fresh or frozen fruit added
- Deserts of: fresh or frozen fruit with some whipped cream, frozen real fruit pop cycles.
- Ask your pediatrician to back you up on dietary concerns. Kids will often respect the doctor's suggestions more than mom or dad's.

Don't say 'never' to a not-so-healthy choice…say: 'in moderation' by offering a small portion= win/win.

See: Cooking, Health and Wellness

"You're lookin' very healthy!"

PARTNERSHIPS with PROFESSIONALS

- Realistically, you can expect occasional frustrations while interacting with the variety of people who will be involved in your child's life. Try to be patient, positive, assertive (not aggressive), and persistent. Learn about rights and responsibilities. You are not alone. Many organizations and volunteer groups are eager and willing to help with information, assistance, or support.
- When meeting with professionals:
  - ☐ Make eye contact
  - ☐ Shake hands with a firm handshake while looking the person in the eye
  - ☐ Introduce yourself and your child
  - ☐ Dress appropriately…you'll feel more professional and 'level the field' so to speak.
- Ask professionals to personalize a situation. "What would you do if it were your child?"
- Be selective when you have a choice. If you think your personality clashes with a Dr.'s or if your child's therapist is not receptive to your child's needs, mention the problem and make an effort to correct it. Consider seeking help from other professionals. No one should go to a doctor they don't trust.
- Support good professionals by writing letters to their superiors, commending them with a word or note, passing the word along to other parents, or writing supportive, complimentary articles for local group newsletters.
- Ask effective professionals for referrals to other like-minded specialists.
- Develop your communication skills. Be assertive without being abrasive.
- You're an expert on your child. Balance other's professional expertise with your own.
- Be prepared for each meeting with the professionals in your child's life, with information and written questions.

- Act business-like. Speak up diplomatically and do your best to form a partnership to best serve your child's needs. Stay on topic. Refrain from emotional outbursts or getting off-track. This takes practice for some.
- Do not be intimidated because of others' credentials. You are not a bother if you ask questions or contribute information about your child.

See: Communication, Conferences, jargon, School Survival Tips for Parents

"Almost….keep trying!"

PETS

- If you have the ability (both time and $$) to give the care, commitment and attention required by pets, consider them for your child. Pets provide fun, unconditional love, and a golden opportunity to teach your child responsibility.
- Call a veterinarian or your Humane Society *before* re-homing or purchasing a pet, to ask for tips on the most appropriate pet for your family. Be sure not to rush into purchasing a pet. Wait for that patient animal that belongs with your family.
- The Humane Society or your local Veterinarian will likely have information on specially trained dogs such as seeing eye, therapy, or companion dogs.
- Start out small. Kids love animals small enough to handle, hug, such as kittens, gerbils, or guinea pigs. Make sure you have an animal that will tolerate being handled. Wash hands or use hand sanitizer after handling lizards, turtles, gerbils or guinea pigs.
- Respect your child's likes and dislikes. Don't get a horse if your child is terrified of large animals and would prefer a gerbil or fish.
- Fish, turtles, and hermit crabs are good beginner pets. They are small enough to have in your child's room and require only simple care.
- Give your child jobs dealing with the pet: cage/bowl cleaning, feeding, brushing, cuddle once a day, name his pet.
- Teach your child the skills to do these jobs and keep implements and food accessible.
- Keep your pet's immunization current. Contact the Humane Society for low cost locations for vaccinations and neutering.

"Your pet loves you so much."

POLITICAL ADVOCACY

- Remember that your child has the right to participate in society as much as possible. Even though Federal Laws are in place to protect your child's rights, you can help provide more opportunities for your child.
- Know what the law guarantees. Your State Department of Education can provide you with information on education policies and practices in special education in your state. Being aware of local policy is helpful in discussing your child's needs and your expectations of your local school system. Contact a local school board member for information or make it a point to attend school board meetings.
- The school district may not disclose all you need to know because it is your job, not theirs, to be informed.
- Also: be informed on current legislation that could impact you or your child. When your child is an **adult** the state agency is the Division for Intellectual/Developmental Disabilities.
- Keep addresses and email addresses on file for your local, state, and federal representatives. Local newspapers often publish a list. Notify your representatives of infractions or for information on legislation pertaining to people with disabilities.
- When writing to your legislators, remember:
    - ☐ Use personal or business letterhead, if possible
    - ☐ Give your exact address in the letter, not just on the envelope
    - ☐ Identify your subject clearly
    - ☐ State your reason for writing, and what you wish to see happen
    - ☐ Don't send a form letter
    - ☐ A telephone message is very acceptable and can be very timely.
    - ☐ E-mails are acceptable.
    - ☐ Getting your message heard is what's important.
    - ☐ Know your issues, be brief and courteous

  - Don't threaten or be unreasonable
  - Ask your representative's position on the issue
  - Try to state your position while the issue is in committee rather than after it has been approved or defeated.
- Letters should be one page at the very most, and preferably a half page in length with no more than two or three paragraphs.

  Sample letter:
  Date
  Honorable (Name)
  State Capitol building address
  City/State/Zip
  Subject: Bill #:
  Dear Senator/Representative (Name):

  I am writing to urge your support of (list name of bill by number).
  I am concerned that (describe your subject briefly).
  List one or two facts or beliefs influencing your decision to reach out and state your points clearly and simply. I think this bill will help address this problem.
  Sincerely,
  Your name
  Address
  Phone
- State your appreciation for past voting records, if appropriate. Be positive.

See: ADA, Advocacy, Legislation

"You're the best!"

PUBLIC PERCEPTIONS

- When you and your family are in public, you are ambassadors for the disabled community. Look at this as an opportunity to show the world your unique relationship with your child. Keep interactions with your child (and strangers) positive.
- For instance, teach and expect courtesy and manners from your child. If a redirection is necessary, do it quietly and discreetly. Establish cues to reinforce good behavior or acknowledge you expect improvement, such as touching your child on the shoulder if he is shouting. Or, point and close your lips together to indicate you expect a closed mouth while chewing. Sometimes a simple cue is worth a thousand words. Thumbs up with a smile is appreciated too.
- Keep your child neat and clean. Let his appearance reflect how you value and respect him and yourself.
- When people stare or seem rude, you can ask, "Is there a question I can answer?" If you'd rather not interact with them, interact with your child. Model for the passerby an appropriate way to interact with a person who happens to have a disability. Talk, laugh, hold hands. Keep it positive!
- Expose your child to different public venues: malls, restaurants, theaters, museums, so he can learn behavior appropriate for each one. As much as possible, let your child order his own meal, make decisions as to where to sit, or eat.
- When someone asks you a question about your child instead of asking your child, say, "Chris can tell you how old he is." Give your child the opportunity to speak for himself when possible.

See: Awareness, Acceptance, Advocacy

"I bet you feel proud of yourself."

READING

- Read to your child, even if he doesn't understand exactly what you're saying. Put him on your lap – you'll both enjoy the closeness.
- Continue reading to your child as he gets older. Kids are never too old to enjoy a parent's attention.
- Make use of your local library. You'll find easy reading sections, high interest/low-level reading books, and **audio books.** Ask your librarian for help if you're looking for something specific.
- Literature can provide wonderful role models for your child as he grows. Check in your library's children biography section.
- Choose books on subjects your child shows an interest, not just what you think he should read.
- Expect to read some of the favorites over and over. Make a game of letting him fill in the blanks as he memorizes the book!
- Be a reading model for your child.
- Never force reading time. Babies and children have short attention spans. If you get 15 minutes of reading time with a 1 year old you're lucky.
- Read the books your child is assigned to read for school so you can discuss them with him. Ask his teacher or librarian for an extra copy.

See: Libraries

"Reading with you is fun."

RECORD KEEPING

- Date all correspondence with doctors, social workers, school district personnel, insurance companies, therapists, and keep a copy. Document phone conversations as well. Simply jot down the date, names and a brief summary of the conversation. What's the next step after the conversation? Keep a notebook or calendar by the phone for easy record keeping. This habit minimizes the stress of trying to remember every detail.
- Create a Contact Directory of names of teachers, psychologists, and all related service people. You'll be surprised how many details you may need later and have forgotten.
- Add to your directory the numbers of service organizations, services, and people in the community who have been helpful or who are a resource for you and your child. Note the service provided next to each name.
- Use a large wall calendar to record milestones and doctor appointments. Keep it to use later for Service Plan meetings, a baby book or as a mileage log for tax returns.
- Periodically check your child's medical and or school files for errors or omissions which need to be corrected or updated.
- If a statement on any of your child's records is inaccurate, have it changed.
- Keep dated home files on your child's medical, developmental, and educational records. Corrugated cardboard closet organizers or office organizers work well and are inexpensive. Records will become an excellent indication of progress your child has demonstrated and will be useful for formulating future IEPs or other plans.
- Keep a long-term file of potentially useful information you will run across (I.e. recreational opportunities in the area, articles, advertisements pertaining to helpful products).

- Keep a fun scrapbook of strengths, interests, celebrations, homework achievements, and photos and artwork.
- Keep a chronological file of IEPs and assessments so growth can be monitored.
- Keep a chronological medical history on your child, including significant illnesses, surgeries, and hospitalizations. Take a copy with you when consulting doctors, at hospital admission, or when traveling.
- File medical insurance claims regularly and develop a filing system:
    - One file for claims sent
    - A file for processed and paid claims; attach an insurance payment receipt to your copy of the bill
    - Keep names and numbers of persons with whom you speak
- Take periodic pictures of your child if there is a health concern you want to monitor, such as moles, teeth (pre/post braces), scoliosis.
- Keep wills, insurance papers, medical power of attorney in a fire proof box or safe deposit box.
- Make a daily checklist of things you need to do for your child, such as medications, exercise routines, toileting times, nap routine. This can also serve as a checklist for a substitute caregiver.

"You have the most beautiful smile!"

RECREATION

- Encourage your child to start a collection (coins, rocks, baseball cards, stickers, stamps, dolls, stuffed animals, frogs). It's a good independent activity, and encourages learning, observation, and self-expression. Get books from the library about your child's collection and read to him.
- Investigate the possibility of your child participating in the Special Olympics. Started in 1963, **Special Olympics** is now the largest amateur sporting event in the world. For information call your local chapter or ask your school's adaptive physical education teacher, social worker, doctor, or therapist for information.
- Consider unified activities (disabled and non-disabled playing together). Contact your Parks & Recreation Department. Softball team and bowling are popular unified sports. If these activities don't exist, talk to other parents to create a team.
- Record favorite TV shows and movies for your child to watch later. Disney may be broadcast at 3:00p, but your child needs quiet time or enjoys watching at 5:00 p.m. Just record it!
- Start short 'play alone' time early. "You play here near me while I read." Or "You like playing with that truck all by yourself." If you do everything with your child all the time, he won't be motivated to do or entertain himself independently.

  Example: reading, sorting, playing with or reading about his collections, artwork (coloring, drawing, painting), playing dress-up, playing with action figures or dolls, listening to music or read along books, cutting pictures out of magazines and making a collage. Remember to place supplies needed for these activities in a place accessible to your child so he can get them and return them as independently as possible.
- Always supervise your child's activities. It's possible to monitor safety without interfering with independent activities.

- Make a list of things your child can do (play basketball, color, paint, etc.). Post it on a bulletin board or on the refrigerator, and have your child refer to it when he says he has 'nothing to do'. Be creative with the list. It might include taking a bath, calling Grampa, or making cookies with Mom. Only include yourself if you're willing to participate.
- If your child can't read make a game of reading the list to him or seeing how many items he can recall by himself or use pictures from magazines or symbols to indicate an activity.
- Try arranging special outings with your child occasionally. It might be a trip to the zoo or just going out to the park. If one parent spends most of the day with your child, those special outings may be a good opportunity for the other parent, willing friend, or extended family member to spend with your child.
- If your child can't participate fully in an activity, suggest to the coach, teacher, or director that he be given a 'manger' or 'assisting coach' position. You may need to help by assisting or teaching the coach about your child's capabilities.
- Give your child the opportunity to succeed. Don't let your dreams supersede your child's best interest. For instance, if you've always imagined your child playing baseball, evaluate his ability honestly and ask his opinion. If he wants to play and has the ability with some modifications, then go for it. If, on the other hand, playing baseball is a frustrating experience for him or requires unrealistic modifications, try another activity.
- What does your child like to do? Organize and balance leisure time. Find out about after school leisure activities.
- Contact your Parks & Recreation department for information on special classes that might be suitable for your child. Also look into their policy on including children with disabilities in non-disabled programs. Although by law your child cannot be excluded from activities, it may not be reasonable, safe, or

fun for your child to be in all non-disabled classes. Be selective. Your child should be able to succeed.

- When planning or registering your child for an activity such as a Scouts, 4-H, or a parks and recreation program, call ahead and speak with the program coordinators. Explain your child's needs so that any necessary modifications can be made ahead of time. Don't expect programs to accommodate your child's needs if you surprise them with your presence. It's in your child's best interest that his coach or teacher be prepared.
- Talk to local church youth groups, scouts, 4-H about including your child in activities. Be aware that until a certain comfort level is reached by coordinators you may have to stay with your child.
- Call your local bowling alley about classes. If you need wheelchair access, ask if they have one alley that is accessible, and if they have a bowling ball ramp or bumpers you can use.
- Roller skating can be fun, and wheelchairs roll as easily as skates! Always ask permission first before using a wheelchair on the rink, and make sure your child can get on and off safely. Also, be sure the person helping your child on and off the rink floor is reliable and that being in the rink won't endanger your child or others.
- Therapeutic horse-back riding programs may be available in your area. Call and see if they offer scholarships if needed. Many of these programs are remarkable. Most use older or 'retired' horses who are calm and loving.
- Vacation, rainy day, or alternatives to TV:
  - Go to the movies or find one on t.v.
  - Cut some autumn leaf/spring lilac/summer sunflower branches for a large indoor bouquet
  - Go to a museum or the zoo
  - Bake bread
  - Make a photo album or look through old ones
  - Make a picture book with magazine cut outs

☐ Finger paints or modeling clay
☐ Pack a picnic and go to the park
☐ Make a movie with your video camera – let your kids act and direct
☐ Visit a neighbor or friend
☐ Write a letter
☐ Plan a family vacation or outing
☐ Go swimming (ALWAYS supervise water activities)
☐ Rearrange bedroom furniture
☐ Read a book or listen to an audio book
☐ Watch You-tube 'how-to' lessons
☐ Attend a Community Fair. Give your child (i.e.: $10) to spend on their top choice, which squelches the never-ending "I wants."
☐ Make hot-cocoa or tea, sit together for a few quiet minutes
☐ Go to the library
☐ Fly a kite
☐ Work in the garden
☐ Visit a fire station or police station (call ahead)
☐ Play video games together
☐ Take a bubble bath
☐ Play board games
☐ Invite a friend over to play
☐ Listen to a recorded story or audio book
☐ Play an instrument---sing----dance
☐ Set up a tent in the back yard or in the house (modified)
☐ Go fishing
☐ Take pictures with a camera
☐ Walk the dog, or better yet, give him a bath!
☐ Create a mural on the sidewalk with chalk
☐ Set up a wading pool (supervise)

See: Art

"You're doing well!"

REWARDS

- Acknowledge your child's extraordinary efforts.
- Be sincere with praise. Encourage all efforts and use good humor. Children can sense insincere praise or patronizing comments.
- Use food as a reward sparingly. Give a smile, hug, wink, nod, a sticker or your undivided attention instead.
- Random rewards are more effective than predictable rewards.
- Be sure your child understands you love and value him as he is and for whom he is. "I love you" should not be conditional.
- Identify your child's strengths & provide opportunities to encourage growth in those areas. For example, if your child loves art, provide materials and praise. If he's a coordinated baseball player, find or organize a neighborhood team.
- The satisfaction of a job well done should belong to the child, not you. Instead of "I'm proud of you," try "If I were you I'd be very proud of myself for finishing that puzzle."
- Keep stick-on stars handy for school papers, exercise charts or use on homemade awards for special accomplishments. Some kids will prefer a 'high-five' or a quarter for their bank.
- Chart progress for specific goals or skills with your child. This encourages self-competition.
- If your child hates to see another chart respect those wishes also.
- Remember never to compare your child to any other individual. Even those with similar disabilities are vastly different.
- Post artwork, awards, and school papers on the refrigerator, walls, or in scrapbooks. Send copies to relatives.
- Create special times with your child. For example, go out to lunch, go for a drive, use surprise praise, show your love and appreciation of your child in unpredictable ways for example, a note in his lunch box, the bathroom mirror, or on her pillow.

- Catch your child doing something ‘good’ or ‘right’ and reward with a smile or hug.

See: Behavior, Encouragement

“Outstanding!”

ROUTINES

- Take note of your child's unique daily rhythms: i.e. when does he get sleepy? When is he happiest or most alert? Plan activities accordingly.
  For example: Plan recreation or therapy for high energy times. Work on academic skills after a nutritious snack and an afternoon break from school.
- Talk about changes in routines and explain why changes may be necessary before they occur. Give your child ample time to adjust beforehand.
- It's easy to become fixed to a routine as we teach our children new skills by repetition and routine. Beware however, of you or your child becoming inflexible as a result. Occasionally deviate from routine to avoid frustration when situations do change.
- Incorporate new responsibilities into existing routines, i.e. medication at mealtimes, or homework to the first or second hour after school.
- Incorporate 'fun' routines such as Sunday afternoons at Grandpa's or a monthly overnight with Aunt Bonnie.
- Sometimes a break from the routine, such as lunch out, or a bath instead of a shower, is a treat in and of itself.

"I admire your hard work."

SAFETY

- Teach safety and the 'whys' so your child internalizes and understands.
- If you're in doubt about your ability to handle any situation, call 911.
- Take a CPR and first aid certification course. Call the American Red Cross, your local hospital, or community college for course information.
- Teach your child his address and phone number.
- Install smoke detectors and O2 detectors in your home and check the batteries twice a year, to correspond to the Daylight Savings time change.
- Check for fire exits wherever you go.
- Prepare your child for fire emergencies by having fire drills at your house, grandma's house or wherever your child spends time. Review procedure every six months. Contact your local fire department for suggestions and other information.
- Don't place your child's bed in front of a window because the bed becomes a convenient climbing tool.
- Always use car seats and seat belts. Follow air-bag directions for passengers.
- Keep your car in good running order and full of gas. Keep a first aid kit and survival gear in your car.
- Keep Syrup of Ipecac in your home medicine supplies to induce vomiting, if needed. Call Poison Control for a list of toxic substances which would require the use of Syrup of Ipecac.
- Teach your child not to pet or bother unfamiliar animals.
- Cut your child's food into bite-size manageable pieces. When they're older teach them appropriate bite sizes. Learn the Heimlich Maneuver.
- Keep all medications and vitamins out of reach. When your child is older explain what he is taking, the amount and why. An adult may be able to maintain their own medication box with supervision.

- Never leave your child alone in any amount of water. Drownings have occurred in as little as an inch of water, as well as in buckets and toilets.
- Use gates to block off stairways. Use walkers or riding toys with caution.
- Post 911, fire, police, and poison control numbers in a prominent, easy to locate position. Show caregivers how you've organized crucial information.
- Teach your child how and when to call 911 or exit the house to meet at a designated meeting place outside.
- Train teachers, aides, bus drivers, and family members about safety measures necessary for your child's specific needs, such as Heimlich Maneuver for choking, care during seizures, any food or bowel protocols.

- Make note cards with emergency numbers, doctor(s) names, and your child's health concerns for family, friends, babysitters, and teachers. Laminate them for durability.
- Teach your child not to talk to or go with strangers and to tell you if he is touched inappropriately (bathing suit area) or hassled. If something happens that makes him feel uncomfortable he needs to know it's safe to speak up and tell you. Let him know you're there to help whenever something 'odd' or 'creepy' happens.
- Notify your fire department that you have a disabled child who may need extra assistance in the event of a fire.
- Be sure your child knows where the nearest exit is from any room in the house and what to do if you aren't available to help (go outside immediately and go to a neighbor's home).
- If your child is hearing impaired, install fire alarms that have audio and visual alarms.
- Keep a whistle near your child's bed and teach him to blow it for help.
- Plan two escape routes from each room, if possible.

- Teach your child to touch a door first before opening. If it is hot, he needs to use the second escape route. Practice the escape routes with the entire family.
- If your child has elopement behaviors install alarms on the doors and windows.
- In case of fire, teach your child to get low to the floor where the air is coolest, and cleanest, and crawl to the planned exit.
- Never let children use a stove unattended. Store snacks away from the stove area.

"You stuck to the job and didn't quit!"

SCHOOL SURVIVAL TIPS for KIDS

- School is a tough pace for all kids, but it's even tougher for those with special needs. Teaching your child coping strategies will help.
- Go to school with your child before the year begins to run through schedules, visit classrooms and meet the teachers. Identify those people in the building who will be helpful to your child. Teach your child to ask those people if he needs help or has questions. Introduce your child to other adults in the building who will be supportive in addition to his teacher.
- Don't expect any school to teach your child everything he'll need to know.
- Let your child pick out his own school supplies: backpacks, notebooks, pencils, paper. Label each with your child's name or a readily identifiable mark. Some modifications may be necessary such as:
    - Attach a mini-purse or wallet with Velcro so it doesn't get lost.
    - Make a fanny pack or front pack for easy access instead of a backpack.
    - Put keys on a neck chain
    - Pants with high pockets are helpful
    - Put an elastic band around notebooks to keep them together
- Tune into current fashions and allow your child to pick out some new school clothes.
- Have your child exchange telephone numbers with a buddy in each academic class to call for assignment clarification. Ask the teacher for help with this if necessary.
- If it's OK with your child ask that she be seated near the front of the classroom if she's easily distracted.
- Modify lockers from combination locks to keys. Have your child wear the locker key on a neck chain.

- In middle and high school, if your child agrees, ask that he be able to leave class a minute or two early to avoid the hallway rush.
- Talk to your child about his fears, especially when moving to a new school or from elementary to middle or middle to high school. For example: If eating in a large cafeteria is a concern, ask a buddy be assigned to your child until he's accustomed to the routine, or ask that he be allowed to eat with a favorite teacher occasionally.

  It's important that you discuss these things with your child before school starts so that you can troubleshoot for him and make the first days enjoyable.
- Teach your child to ask for help and ask questions.
- Know your child's bus driver's name and bus number.
- Keep a change of clothes at school.
- Discuss with your child who can pick him up from school.

See: Coping, Homework, modifications – School, School Survival Tips for Parents

"You're a real trooper!"

SCHOOL SURVIVAL TIPS for PARENTS

- Learn who's who in your school district. You'll need to know:
  - ☐ Child find/or placement coordinator (the person responsible for identifying children with special needs).
  - ☐ Special Education Director and assistants
  - ☐ Social Worker (school or district)
  - ☐ School Psychologist
  - ☐ Physical and occupational therapists
  - ☐ Resource teachers
  - ☐ Regular classroom teachers
  - ☐ Building Principal
  - ☐ School counselor
- Establish a positive and encouraging relationship with school staff early in the year by offering your time to help at school, sending notes of praise or appreciation, providing accurate information about your child, and communicating positively. If a problem arises later in the year, this positive foundation will promote a good working relationship
- When responding to a problem at school, always start with your child's classroom teacher and work your way up through the chain of command. The order typically is: classroom, resource of special education, building Principal, Director of Special Education, Superintendent, State Department of Education.
- Monitor your child's IEP progress throughout the year. Notify the school staff of problems before your staffing, as needed.
- Observe your child's classroom firsthand. Call his teacher first and arrange a time to visit, or volunteer regularly.
- Ask your child's teacher to tell you the strengths he sees in your child. Together, discuss ways to capitalize on those strengths.
- Explain your child's goals to all classroom teachers if the Special Education teacher has not done so. Reminders throughout the year are also helpful.

- Be diplomatic when dealing with teachers or other school personnel. Be respectful and non-accusatory. After all, the goal of your child's success is the same for all involved. Don't be critical without offering alternative suggestions. Often, teachers have not had as much experience modifying as you have had for years.
- Pick your battles with the school carefully. Over the years many problems will arise, some big, some small. Select the ones to act on that directly or negatively affect your child. Visit the school to observe the problem yourself from your child's point of view.

  "Chris worries when he doesn't understand the assignment," or "She feels left out when all the other children are working on a team project and she doesn't have a partner".

  Offer suggestions and help solve the problem. If a resolution doesn't come out of the visit, see the Principal. Document all conversations, visits and action plans. Follow up with a letter to the appropriate people.
- Evaluate the school by observing your child. Does he like school? Does she speak kindly of her teacher(s)? and fellow students? Is the work you see coming home appropriate and does it give your child a measure of success?
- Watch and listen when she plays 'school'.

See: Communication, Homework, Modifications – School, Partnerships with Professionals, School Survival Tips for Kids.

"I'm impressed!"

SEXUALITY

- People with disabilities are sexual beings just like you and me.
- When your child is young use correct terminology for body parts.
- When opportunities for a conversation come up, even though you may be uncomfortable, be honest and keep it simple. Add details as your child matures and asks.
- As your child matures update info and look into picture books to help with explanations.
- Teach about personal boundaries and offer guidelines:

  'No one is allowed to touch your body unless you say it's ok.'

  'The areas of your body covered by your bathing suit are private'.

  'You're the boss of your body'.

  'If your friends don't want you to hug or kiss them it's OK, they are the boss of themselves just like you.'

  'When you or someone else says 'NO' about hugging or touching 'No means NO.'
- Ask questions like: "What would you do if….?"
- Teach them it's OK to ask you questions.
- Discuss public behavior and private behavior & circumstances.
- When the time is appropriate: "Masturbation is normal: Please do that in the privacy of your room."
- Talk about 'side hugs' and how they are the appropriate way to hug people outside of the family.
- Discuss friendship skills and if your child is ready move on to understanding relationship skills and responsibilities, keep the discussion ongoing.
- If appropriate discuss STDs and birth control or meet with their physician to discuss.

"I love hanging out with you."

SIBLINGS

- Expect siblings to get along with each other, help each other, negotiate solutions to problems, & act as they would be expected to act if one did not have a disability. Everyone will benefit. Find a support group, if needed, for sibling venting.
- Remember not to make your child with the disability the focus of the family. Balance all of the children's needs and responsibilities, thus preventing jealousy and resentment
- Help siblings come to terms with feelings of anger, resentment, and/or other emotional stresses. Acknowledge and respect their emotions. Siblings support groups are available. Check with your county social service agency, hospital, or social worker.
- Talk openly about the range of feelings your children may experience so they won't feel they need to hide negative emotions. Explain that feelings change and evolve from moment to moment, year to year.
- Work to be an emotionally healthy parent. Join support groups, read, talk to professionals. Model acceptance and a coping attitude for your family. Set a positive family atmosphere.
- Give honest information about the sibling's disability and be ready to repeat it as the children can understand and are receptive.
- Teach your children how to explain to friends about their sibling with a disability. Teach them to model appropriate, accepting, respectful treatment.
- Spend special time with each child. Vary sibling's schedules if possible, stagger bed times, story times, or take one child at a time with you on errands. Assure siblings that you'll be there for their needs also, and then follow through.
- Don't always hold the more able child responsible.

"Remarkable!"

SOCIAL SECURITY

- For information on how to apply for Social Security benefits, contact the Social Security Administration. Look under United States Government for a toll-free number and local office numbers and addresses.
- If you have applied for Supplemental Security Income (SSI) benefits and were determined to be ineligible, you may want to reapply to see if you now qualify. It is not uncommon for previously denied requests to later be determined eligible. Be persistent!
- Being SSI eligible means, in most states, also being qualified for Medicaid.
- Fill out all forms completely and accurately. Keep a copy in case you need to reapply. Much of the information will not change. Fill out from your child's perspective since he is the one applying for the benefits. Ask how to fill out the form from the child's perspective if you're not clear on how to fill it out.
- Contact the Social Security Administration regarding SSI (Supplemental Security Income) when your child turns 18; he/she may also qualify as a child.
- As a supplement to SSI individuals with disabilities can find resources for job training. Check with Vocational Rehabilitation in your area. Maybe your child will work full time and maybe he'll work 2 – 4 hours a week. Yes, his earnings will affect the amount of money he receives for SSI. Talk to your County representative so you understand this and understand your reporting responsibilities to SSI.
- Understand your responsibilities for being your adult child's Representative Payee of the SSI income.

See: Transitioning to adulthood, taxes.

"Thanks for being YOU."

SOCIAL TIPS **(For Interaction with People with Disabilities)**

- Converse with a child with a disability as you would with any other. Make eye contact: get down to their level. Value their participation in the conversation. Remember to talk to the person, not the attendant or family member.
- If you think someone with a disability may need help, ask, "May I help you?" or "What should (or can) I do to help?"
- Don't shout at a person with a visual challenge. Chances are his hearing is fine.
- Stand next to a person with a visual impairment and verbally offer your arm rather than grabbing his arm to direct him.
- Use descriptive language when giving directions to a person with a visual disability. Instead of saying, "The playground is this way," say, "From here, the playground is about 20 steps straight ahead and five steps to the right."
- Do not finish sentences for someone who stutters or has difficulty speaking. Be a patient listener and then confirm what has been said if you have any doubts.
- Be sincere in your praise of a child with a disability. Sometimes, in an effort to be friendly or upbeat, we over-praise which can seem insincere. Guard against seeming condescending by being aware of your 'tone'.
- Ask questions to help you interact with the person. I.E.: with a non-verbal child, ask the parent how to best communicate.
- Don't ever ask, "What's wrong with…?" IF you must ask at all, Say, "Tell me about your child." Or "Do you mind telling me about your child's disability?" Be sensitive. Some parents really don't want to discuss it, and others will be very open.
- Never pet, feed, or play with a guide or companion dog. It has a very important job to perform. Consider the dog 'at work'.
- Treat all people with respect. Don't stare or point. Think about how it feels to be in their shoes. Act normal.

See: Awareness

"I respect you."

STUTTERING

- Arrange for a complete medical and speech evaluation of the speech issue and arrange for speech therapy.
- Make sure your child is courteously included in conversations both at home and at school.
- Don't interrupt your child.
- Don't supply words or finish sentences for your child.
- Use a typical vocabulary. Talk, Talk, Talk to your child about anything and everything.
- Listeners should be accepting of less than perfect pronunciation and vocabulary.
- Don't equate language difficulties with intelligence or capabilities.
- Teach your child relaxation techniques.

"You're doing much better!"

SUCCESS STRATEGIES for: Self-esteem, Self-awareness, Self-determination & Happiness)

- The basis of your child's high self-esteem is loving your child as he is.
- Consistent successful experiences are necessary for positive self-esteem. Success breeds success.
- Post lists of your child's successes or the refrigerator, bulletin board, etc. Update them frequently.
- Display artwork and school work. Create lists of positive traits and accomplishments with your child.
- Praise your child when he is acting appropriately. Praise effort, not just excellence. Be sincere with praise. Over praising becomes less effective. Random praise is most effective.
- Model acceptance and responsibility of your own errors. 'We all make mistakes'. Laugh at your own mistakes.
- Say; "We don't Blame in this family. We understand mistakes happen so we say; "Sorry.' I'll try not to do that again."
- Reassure your child when he faces difficulties. Mistakes are part of learning. Remember: F.A.I.L. means First Attempt in Learning.
- Take your child's ideas and emotions seriously. Listen to him. Let him know you enjoy spending time with him.
- Clearly define limits and rules and expect cooperation and responsibility. Keep rules simple and few. Focus on safety of all and health.
- Help your child to see and appreciate other people's strengths.
- To encourage positive self-esteem, say, "I bet you're proud of yourself," and, "If I were you, I'd sure be proud of myself."
- Have your child ask himself, "What do I like about myself? What are my strengths and talents?" "What am I grateful for?"

- Be able to support your child when he asks for it. Give the gift of your time.
- Encourage self-competition. Discourage comparisons between your child's accomplishments and those of other children, especially non-disabled kids.
- Celebrate participation and effort.
- Explain your values. Discuss the experiences that formulated your values & the reasons supporting them. Let go of outdated ideas when they are ineffective!
- Involve your child in self-evaluation. Model positive Self-Talk. Talk to yourself as you would talk to your best friend.
- Self-esteem begins with sincere praise and encouragement.
- Build strong communication with your child. Tell your child often that you love him.
- All people grow and change. Continue to notice your child's new strengths and gifts and bring them to his attention. Encourage building additional strengths by providing opportunities for the child to use them (i.e. If your child is very considerate and patient allow him to mentor another child). Rather than being helped and served, your child may enjoy the role reversal of being able to help and serve others, feel useful and valued.
- Success in life is different than success in school. Life holds far more opportunities than the classroom. Expose your child to the wealth of experiences outside of school.
- Studies show: Happy people exercise a little each day, eat healthy meals, have goals, laugh, give of themselves, do things they're good at, have friends or family they talk to each day, have choices in their life, have loving relationships, feel they have a purpose, are grateful every day for something, learn how to manage stress, think positive thoughts, feel valued and appreciated.

  *Add to this list things that help you and your child to be and stay HAPPY.

"You're so thoughtful."

SUPPORT GROUPS

- Support groups or organizations dealing with your child's disability are good resources for information, friendships, and assistance for you and your child.
- Groups provide an appropriate place to express fears, concerns, and to share coping techniques. For information on local groups contact your county social service office, the ARC, school or hospital social worker.
- If a support groups does not exist in your area which fits your needs consider starting one of your own.
    - Publicize in your local newspaper or on a local radio or TV station the date, time, location, and type of meeting you plan to share…such as: Parents of Chronically Ill Children Support Group.
    - Serve coffee and cookies at the beginning to encourage socialization and to ease anxiety.
    - Provide name tags.
    - Have all attendees sign in and provide phone numbers & emails so you can remain in contact.
    - Discuss the purpose of the group. Define if it's primarily informational (school issues, medical care) or primarily an informal group designed for moral support and encouragement.
    - Encourage those who attend to invite others they may know; family members, friends who occasionally care for your child, interested associates.
    - Establish a regular meeting time and place that's acceptable to the majority.

" I appreciate you."

SWIMMING

- Swimming seems to be a sport many children of varying ability levels can enjoy. Try it! Remember to ALWAYS supervise your child while in the water.
- Contact your local parks and recreation department or talk with your child's physical therapist or adaptive physical education teacher for names of qualified instructors for your child. Someone with experience working with kids with special needs helps but is not essential. If possible, try private lessons at first since your child may need more attention initially than is typically given in swimming classes.
- Introduce water safety to your child *first,* including:
  - ☐ The 'buddy system': Never go into the water alone
  - ☐ Floating
  - ☐ Basic swimming strokes
  - ☐ The importance of staying calm
- Use empty plastic gallon milk jugs for buoyancy and water exercise. These DO NOT take the place of floatation devices or life jackets!
- The surface of most pools and decks are often rough. Use plastic carpet runners or under-carpet nonskid pads for the sides of pools to prevent skinned knees or toes at your home pool. Tubs and spas can also be slippery. Use the same non-skid runners to prevent slips and falls. Special non-skid shoes are also available for wearing in the water.
- If sensation in feet and hands is limited or absent, have your child wear socks, tennis shoes, or swim shoes while in the water to protect feet.

See: Recreation

"Thank you for helping out."

TAXES

- Obtain information from the IRS (**available on-line**) or your tax consultant regarding the following deduction categories:
    - ☐ Medical expenses
    - ☐ Educational services
    - ☐ Transportation
    - ☐ Professional Services
    - ☐ Medical treatments
    - ☐ Medicine
    - ☐ Equipment and supplies
    - ☐ Child care
- Save all receipts on tax deductible items.
- Keep good records of medical expenses, including mileage to medical and therapy appointments, medical telephone calls, equipment (oxygen, wheelchairs, braces, modifications, etc.) food and lodging costs during your child's hospital stays, etc.
- If you are using a cell phone to stay in contact with your child's caretaker, check with your tax advisor about claiming it and the monthly bills as a medical expense.
- Some charitable contributions can be earmarked specifically. For example, "This contribution is to go directly to the local respite care facility. Please send me written verification".
- For information on all tax questions, contact a tax consultant or the local IRS informational services. Look under United States Government offices.
- Contact your Social Security office to see whether your child under age 18 qualifies for SSI (Supplemental Security Income).
- Before your child turns 18 check (again) into applying for SSI for your adult child. It is common procedure for applicants to be 'Denied" the first time they apply. Just reapply, don't give up.

- Understand your responsibilities as your adult child's 'Representative Payee.' Yearly you will be asked to update information and you will fill out a form documenting how your child's SSI money has been spent; i.e: 'Room and Board' to you plus 'P.N. money' (Personal Needs items for them like clothing, dental costs, hygiene costs, co-pays for medications, etc).
- When your child reaches adult-hood they will have more personal interests and desires than when they were a child. Remember the PN$ is for them not for you. Help them spend the allowance on things or activities THEY want or need for themselves (with your help & guidance). I.e.: If they want to save for a $200 tablet to play games on, but you think that's a silly expense....help them save their money and buy it anyway. If they want to attend an art class on a weekday night but you find that too inconvenient consider hiring a 'respite provider' to drive and support your child at the class. Honor and support **their** interests and choices.
- Keep a copy of how you fill out the form each year.
  The total of those 'costs' typically will be equal to what they receive for SSI.
- It is important to understand about the cap of $2000 in your child's savings account. If you want her to have more in savings read about the A.B.L.E. ACT (A Better Life Experience) option or talk to a professional about a Trust.
- We are not attorneys or legal consultants. This is general information; Understand your responsibilities as your adult child's 'Representative Payee.'
- Talk to the local ARC or a Parent group for current info and advice.

"Super job!"

TEASING

- A certain amount of teasing is part of growing up. Don't automatically assume your child is being teased because of his disability.
- Teach your child some strategies for dealing with teasing. For instance:
    - Help your child identify friends and advocates he can turn to in different situations (i.e. teacher, siblings, bus driver, coach, etc.)
    - Talk about teasing and give your child words to express his feelings.
    - Listen when he talks and offer sincere empathy, help to brainstorm with him on how to handle uncomfortable situations.
    - Ask your child to try to ignore teasing as much as possible. Without any feedback, verbal attacks have nowhere to go and fall flat.
- Children who are self-confident are bothered less by teasing.
- You can help by sensitizing others to your child's strengths. Conduct an awareness program at school about your child's type of disability. Focus on how much alike most kids are and work with your school district to invite guest speakers from local colleges to speak to student or parent groups.
- Encourage teachers to buddy your child with a variety of peers to develop natural friendships and discourage teasing.
- Be accepting of differences yourself, and model that for your child.
- If teasing is a persistent problem at school, contact your child's teacher or principal.

"You're one in a million."

THERAPY

(Physical, Occupational, Emotional, Speech)

- Explain why your child needs to do what you are asking him to do. Talk about short and long-term goals. Include your child and his feelings in those discussions.
- Encourage therapists to be creative and incorporate your child's interest in the therapy. Example: If your child loves baseball, playing catch or walking bases can be incorporated into therapy.
- You are a parent first, a therapist second. Don't be critical of yourself if all therapy isn't done as successfully at home as it might be by professionals. Practice takes time.
- Seek a therapist with comparable goals for your child. You'll need to work as a team, keeping your child as the main focus. Your goals need to be the same.
- Therapy is hard work, but it should be as much fun as possible and reasonable. Be creative. Use games and toys. Your child needs to cooperate.
- Contact your therapist for the most current assistive technology available for your child.
- Don't be discouraged if your effort at therapy is cyclical. You may experience periods of 'burn out'. Just don't give up entirely.
- If your child no longer needs or goes to therapy, it's still a good idea to check occasionally with a rehabilitation professional to see what more your child could be doing.
- Periodically review daily living skills and define new objectives.

See: Exercise

"Nice job."

TOILETING

- Talk to your child's occupational therapist or see a medical supply company for adaptive equipment that may be helpful in toileting (seat extensions, grab bars).
- Check mail order catalogs for less expensive incontinence supplies. Publications having to do with disabilities, like *Exceptional Parent,* carry advertisements for such companies.
- Use diaper liners (diaper doublers) available at some drug stores for extra absorbency. They are less expensive than incontinence liners, but don't replace waterproof liners.
- Have your child participate as much as possible in diaper changes. For instance, ask him to bridge or arch his back while you slip the diaper under him, or have him help pull his pants down and up.
- If possible, have your child transfer himself from his wheelchair to a cot or toilet. Carry a waterproof pad or even a plastic grocery bag with you so you can make a change anywhere.
- Remind your child to use the bathroom or do a diaper change before leaving the house.
- If toilet training is a skill your child is capable of, yet remaining a big challenge, talk with a Behaviorist who may have 'success tips' which can go around any power struggle or learned behavioral issues.

"You always amaze me."

TRANSITIONS

- A transition plan is a requirement (for students age 16 or those who turn 16 before their next annual review or earlier when appropriate) of the Federally mandated educational programs under the Individuals with Disabilities Act (IDEA). It is a method for assisting an individual to reach his goals for adult living by the development of a system of supports, interagency professionals, parents and the student participating together as a team. The child is the most important person in the process so be sure to include him in the meetings for planning his future.
- The Transition plan is based on the values of 'Person Centeredness'. 'Person Centered Thinking' and 'Person-Centered Planning' keep the focus of the team on the student. "It's important to find and supporting balance ~ between what matters to the person ("important to") and the things that help the person be safe and healthy in a way that works for him/her ("important for"). Another key in person centeredness is: recognizing the person as the expert in his/her life. This engages the person to be in control of his/her life with the necessary support and resources. It's not about 'either happy OR, healthy and safe'. We CAN support people to be happy, healthy and safe." *The concept of Important To and Important For comes from The Learning Community for Person Centered Practices © 2012*
- Attend workshops that address transition issues before your child is age 14.
- Adult service programs vary from state to state. Before your child leave high school, talk to your Special Education program director about what options are available in your community to serve your child.

- Consider the strengths of your child while preparing for the future. Determine where your child wants to go vocationally. Does he need further education or training after High school?
- Where will your child live and what kind of support, if any, will be needed? Consider the independent living skills the child already possesses and the additional skills he will need.
- Consider transportation questions, maintaining and increasing social and peer interactions, leisure and recreational activities, medical needs, advocacy needs and financial needs.
- Teach your child to advocate for himself as much as he is able. This will empower your child increase his self-esteem and sense of control over his life. Teach that it's OK to politely ask questions of authority figures.
- Encourage your school system to provide good transition planning and teaching of realistic skills. The focus of public education is academic. Supplement academics with real living goals.
- Integrate all goals into IEPs (Individual educational plans). Be specific. If your child's interest is to become a nursery school aid, incorporate the specific skills needed into their IEP goals.
- Explore job options with your child while he is growing up. Talk about what people do in various jobs, the skills needed, and the education required. Visit various places of employment such as family and friend's jobs, a local nursing home, the local ARC, Goodwill, Habitat for Humanity, fast food places, doggie day care facilities, etc. Help your child notice and be aware of his strengths and what he likes to do.
- At an appropriate age, help your child to set job goals, and discuss steps needed to reach those goals. Divide job tasks into small steps to teach and accomplish.
- Teach independence skills from early childhood. Encourage independence in self-care, money management and decision making to the extent possible. Your child may always need support, but every area where he is able to do things on his

own is an area which will reduce the need for 'paid' support people.

- Teach money management skills: Have your child handle real money, pay for purchases at the store, and talk about costs. Discuss costs of food and supplies so your child has a sense that things cost money. Discuss saving goals and pay your child an allowance. She may not be able to count change accurately, but she may be able to understand the bigger picture of money.
- With help, your child can participate meaningfully in the job world. Being in an integrated/typical environment rather than a segregated 'sheltered workshop' is a realistic goal and expectation of your community. Job satisfaction, earning extra money, and feeling valued on the job because they are contributing to society all help a person (regardless of disability) feel valuable.
- Work on job skills such as interpersonal skills, good grooming, good manners, have your child practice accepting constructive feedback from you before he hears it from employers, being on time, how to take a break at work, how to make small talk during lunch, talk topics to avoid, boundaries of fellow employees, how to take initiative by asking your supervisor if there is something else that needs to be done.
- Teach how to use public transportation if appropriate, consider vulnerability issues and create backup plans, ask theoretical questions. Carpools are sometimes an option.
- Assist your community in removing traditional barriers which could inhibit your child's opportunities or progress. Contact city building officials if physical barriers exist which might prohibit your child's employment. Also, request or coordinate disability awareness workshops at area businesses.
- Create a daily schedule respectful to your child's interests, which can continue after graduation. Routines such as planning, preparing, and cleaning up meals, hygiene routines, recreation routines and socialization routines should be

encompassed into the child's life as long-term habits to continue.

- Consider daily enrichment goals to supplement any work experience. Ask what your child can do to stay busy and intellectually enriched in the community and then network with other parents; brainstorm and share carpooling and resources. What do YOU do every day to enrich your life? Your child needs a variety of life long enriching activities also.
- Consider setting up a trust fund for your child. Speak to your accountant or attorney regarding sheltering any inheritance from situations which could interfere with their SSI (supplemental Security income) benefits. Look into the A.B.L.E (A Better Life Experience) act in your state.
- Assist your child to apply for SSI when he turns 18. Learn the expectations of you for being their Representative Payee.
- Decide if you need to seek guardianship for your child when he turns 18.
- Continue to be your child's case manager by keeping files, gathering information, creating a resume for him or a list of his strengths and experiences. Keep a folder of job experiences, names, contacts and skills gained at each job.
- See how your young adult fits into the whole puzzle of a job. Look at a job in pieces. Maybe he can do a specific piece. This is called job-carving. He can maybe count pieces for an employer but not necessarily assemble a piece. He may be able to bring water to people in a nursing home by pushing a cart from room to room. She may be great on a 2-hour shift but not be able to focus longer.
- Reassess your child's interest in employment. His views will change as he ages and he may be more ready at age 28 than at age 18.

See: Employment, Social Security, Taxes.

"I bet you feel proud of yourself."

TRAVEL

- Keep music, headsets, toys, hand-held games in the car. Do not use toys with loose pieces or balls that can roll under your feet.
- Play verbal games like: "I see something…." or 20 questions.
- Take along a clean change of clothes for your child.
- Keep damp clean-up cloths or wipes in the car.
- Keep emergency supplies in the car.
- Call before going somewhere to see if it's accessible. Check with a travel agent for resources and accessibility of destinations that are out of town. Include your child when planning the itinerary. Research your destination on-line or request materials be sent to your home in your child's name.
- Call ahead to reserve roomier or bulkhead seating on trains or planes. Don't forget to request special meals if needed or to alert staff to medical needs such as transporting oxygen.
- Take along a pillow or blanket on long trips. Consider having your child stay up late the night before the trip so during it he will sleep.
- Expose your child to new experiences by taking him with you not only to run errands, but on special excursions. For example, arrange for him and his friends to tour the local police station, fire station, post office or zoo, or take bus or train rides.
- Send your child postcards to read and remember when you all return home from your trip.
- Talk about what you see and notice while traveling. Explain new sights, sounds and experiences to your child. Keep a travel journal…Take plenty of photos. Have FUN.

See: Recreation.

"I'm Lucky to have you in my life!"

WHEELCHAIR ETIQUETTE

- Talk directly to the person in the wheelchair, not through a family member or attendant.
- Ask if the person needs or wants help before jumping in. It is startling and unsafe to grab a person's wheelchair and move them without their knowledge.
- Be sensitive to barriers facing the person in a wheelchair. Look ahead for stairs, heavy doors, high door jambs, thick carpeting or grass. Ask if you can help. Remember, independence is great, but everyone appreciates kindness and a little help now and then.
- Make direct eye contact with the person to whom you are speaking. If a conversation is going to be lengthy, seat yourself near the person or kneel next to the wheelchair so the person doesn't continually need to look up.
- Don't use the terms 'confined to a wheelchair' or 'wheelchair bound.' It typically isn't necessary to refer to the wheelchair at all.
- Unless you are assisting a person in a wheelchair, do not touch or hang onto the wheelchair or other equipment.

See: accessibility, adaptive housing and equipment, home modifications.

"You're a nice person."

-The End-
