

Module 1: INTRODUCTION TO RESPITE

What Is Respite?

Respite is time off for families who are caring for children with demanding special needs. During Respite, a NAMI Maine Family Certified provider cares for the needs of the identified children.

Respite is short term, usually lasting less than a full day and never lasting more than three weeks. NAMI of Maine Family *Respite is not day care* and cannot be used while parents are working.

In the State of Maine, only individuals holding a license from the Department of Human Services may care for a child *in the provider's home* for more than 23 continuous hours. However, care may last for more than 23 continuous hours *in the child's home*.

NAMI Maine Family Respite is a state-wide contracted service of the Department of Health and Human Services (DHHS). NAMI Maine Family Certified Respite Providers are paid for their services as per diem Nami Maine employees with funds made available by DHHS. The following agency administers the NAMI Maine Family Respite Program for the entire state of Maine.

History and Orientation: Whom do we serve?

Program history and intent: Whom do we serve? NAMI Maine Family Respite serves families with children up to 17 years of age who have significant developmental delays (6 months or greater) in two or more areas of development, behavioral and/or emotional special needs, or developmental disabilities including mental retardation and autism.

The Respite Program began in 1987 as a grant from the federal government to meet the needs of families who had no natural family supports and were caring for children with demanding special needs, particularly in rural areas. Maine's success in developing a statewide service system that is family focused and responds to parent choices is a model for the country. Many other states have adopted aspects of the Maine Respite System.

The Nami Maine Family Respite Program determines eligibility based on guidelines established by DHHS

Funding for this program provided by the [Department of Health and Human Services](#)

The NAMI Maine Family Respite Process

Receiving NAMI Maine Family Respite Services is easy. The process is as follows:

1. **The referral:** Parents or professionals contact the NAMI Maine Family Respite Program for program information and applications. The NAMI Maine Family Respite Program Director determines if the family is eligible for Respite Care after the application process is completed. Each family receives an allocation of hours for the current fiscal year, per family not per child. The NAMI Maine Family Respite Program approves bills and issues payment to providers for services, eliminating out-of-pocket expense to families. NAMI Maine shares information with families about the NAMI Maine Family Respite Program and keeps family records. The NAMI Maine Family Programs also distribute registers of NAMI Maine Family Respite Certified providers to parents and tracks expenditures for respite. For a NAMI Maine Family application for Respite please go to: [Family Application](#)
2. **Provider** training: The NAMI Maine Family Respite program provides training for certification on its website in an on-line and self-study format.
3. **The coordinating process:** The NAMI Maine Family Respite Program provides families with a register of NAMI Maine certified respite providers. The parent contacts the provider, this is a family driven program, the family is encouraged to identify a provider. If the NAMI Certified provider meets the parent's approval, the parent may begin scheduling respite. The parent may discontinue services at any time. Parents may contact the NAMI Maine Family Respite Program Director with specific concerns about the quality of services. Parents may also choose to use a neighbor, friend or family member if they are NAMI Maine Family Respite Certified providers.

Delivering Family Friendly Services

(Concepts borrowed from Copernicus Projects, Kennedy Krieger Institute: Baltimore, MD)

1. **Respect family values** Children, regardless of the type or severity of their disabilities, belong with and do best with families. Accordingly, families should receive whatever support is necessary to care for their family members with disabilities at home. When working with families stay alert to the subtle ways in which you might expose and impose your own values on the family. Using a style that is comfortable for you and for the family you are with will help communicate the underlying truth of the fact that we are all people and must be treated as such to thrive in any relationship.
2. **Focus on whole family:** Family support must focus on the needs of the entire family. Each family and member in it has a set of experiences from within that system. Trusting their judgments, observations, and recommendations is a needed step. The system of care should be child-centered, with the needs of the child and family dictating the type and mix of services provided. Children with special needs will receive sensitive and responsive services without regard to race, religion, national origin, sex, sexual orientation, physical disability or other characteristics.
3. **Flexibility:** Family needs change over time and family support must be flexible and responsive to the unique needs and strengths of individual families. Personal history and perception shapes our expectations. To meet the needs of the families we work with we must begin with and work toward meeting their changing needs throughout our involvement.
4. **Integration:** Families should be supported to fully integrate their family members with disabilities into education, employment and social settings within their own communities. Support to families must build on social networks and other sources of support that exist in their communities. Family support is needed throughout the life spans of family members with disabilities.
5. **Family expertise:** Families should be recognized as experts regarding the needs of their members with disabilities. The family should be the primary decision-making unit regarding the support, services and opportunities it needs. Accordingly, families must be included in the planning and implementation of family support systems. Parents have been providing for the safety, growth, and wellbeing of their family long before providers got involved. This means they have a track record of making positive decisions and plans.

6. **People with disabilities have personal needs and preferences** to live, work, learn, grow, and to have relationships. People with disabilities have abilities, competencies, and aspirations, and should be supported to pursue desires and reach their fullest potential.
7. **Access to Services:** Children with special needs shall have access to a comprehensive array of services that address the child's physical, emotional, social, and educational needs. Children with special needs shall receive individualized services, guided by an individualized service plan, in accordance with the unique needs and potentials of each child and his/her family. Children with special needs shall receive services that are clinically appropriate with the emphasis on the home, school, primary health care and other natural settings, which are the least restrictive and most normal environment.

People First Language

People First Language is a very simple concept: People are human beings first before they are people with disabilities. It is essential that you look beyond the "labeling" of the child's disability and avoid creating or reinforcing negative stereotypes. When speaking it is important to remember that a person is always a person first.

Using terms like "retarded" or "handicapped" categorizes the individual as having only that characteristic and ignores many positive ones. Avoid conveying a status rather than a characteristic. For example, it is acceptable to say, "He has a learning disability," rather than "He is learning disabled." Always put the person before the disability in sentence construction.

Also remember:

- Focus on the person as an individual.
- Don't place unfair limitations on the person.
- Raise the self-esteem of the person with a disability, so the person can see past his/her own "label."
- Treat people with dignity and respect. Listen to that person. Show them that what they have to say is important.
- Provide the person with positive role models, by being one.
- Let the person make his or her own decisions or choices when possible.
- Let the person know that their goals are limitless. Empower them to shoot for the stars!

Examples of People First Language:

Say this:	Instead of saying:
Non-Ambulatory	Confined to a wheelchair
Needs support	Helpless
A child with cerebral palsy	Cerebral Palsied
A child with autism	Autistic
A child with ADHD	Hyperactive
Diagnosis	Disease

Victim - unless a person was injured in a plane, train, or automobile or is the target of a crime, then they are not victim.

Poor/Unfortunate - these words are very offensive; DON" T USE THEM!

Eligibility Requirements

Families are eligible for NAMI Maine Family Respite Services if they have a child who is birth up to seventeen years of age and has documentation of significant delays (6 months or greater) in two or more areas of development, or a documented emotional and/or behavioral disability, and is not eligible for respite services (such as foster care) through another agency.

The process of determining eligibility includes the completion of a NAMI Maine family application and income information. Current documentation of special need is necessary in the form of a doctor's evaluation, a developmental evaluation from a developmental clinic, an assessment from a qualified professional (LCSW, LCPC, PhD, MD, or pediatric neurologist) in developmental assessments. An evaluation is considered current if it is no more than (1) one-year old. Eligibility is reviewed at (3) three-year intervals unless waived by the NAMI Maine Program Director.

Children who are less than 6 months old can be determined temporarily eligible if there is evidence of significant delay. Similarly, children with conditions that are known to have a reasonable probability of resulting in substantial delays may also be found temporarily eligible. In both instances re-determination of eligibility will be required at age two. The NAMI Maine Family Respite Program

Director decides on eligibility and a letter of acceptance is sent to the family. This letter will state the allocation of hours for the fiscal year. The NAMI Maine Family Respite Program determines family eligibility based on guidelines established DHHS

The NAMI Maine Family Respite Program operates on the State's fiscal year, which begins July 1st of each year and ends on June 30th of each year. If a family uses their entire allotment prior to June 30th, no new respite is available until July 1st. Hours are divided quarterly with up to 72 hours being available every three months. Families are notified in writing *prior* to the start of each fiscal year regarding the number of hours available to them and about any changes to the NAMI Maine Family Respite program. Families are re-approved for NAMI Maine Family Respite from year to year based on a child's continuing special needs and available funding. It is not necessary to complete a new application yearly. Updated Fee Determination Forms will be required each year.

As mentioned previously, the NAMI Maine Family Respite Program divides the fiscal year into quarters (three months). The start and end of each quarter is given below:

1st Quarter	2nd Quarter	3rd Quarter	4th Quarter
July 1st - Sept.30th	Oct. 1st - Dec. 31st	Jan. 1st - Mar. 31st	Apr. 1st - June 30th

Beginning July 1, 2004, the Respite Program was required to implement a co-pay system based on a sliding fee scale. Each family eligible for NAMI Maine Family Respite must complete a Fee Determination Worksheet which is used to determine the amount of co-pay (a percentage of the total allocation a family qualifies for). Families should contact the NAMI Maine office about when co-pays are due.

Types and Uses of NAMI Maine Family Respite Care

NAMI Maine Family Respite funds allotted to families for respite equal a maximum of 288 hours per year or 72 hours per quarter. Parents and guardians may choose to use their quarterly respite evenly spaced out over the quarter or several hours in one month and very little the next. Care may be provided overnight or for periods longer than ten hours, but is paid at a maximum daily rate of 10 hours.

NAMI Maine Family Respite is intended to be a planned break for parents - pre-arranged with the NAMI Maine Family certified provider. NAMI Maine Certified providers should take time to get to know the children and families, and parents are encouraged to invest time in training their NAMI Maine certified providers about their child's specific needs before NAMI Maine respite occurs.

NAMI Maine Family Respite may be used for personal appointments, time with friends or family, or just time alone. NAMI Maine Family Respite cannot be used while parents are working as this is considered day care. (If it comes to the attention of the NAMI Maine Family Respite Program Director that respite is being used for this purpose, bills will not be approved for payment.) Some of the ways that families utilize respite are as follows:

1. In-Home NAMI Maine Family Respite:

In-home NAMI Maine Family Respite is offered in the home on a regular or on-call basis, usually as hourly respite, for short periods of time of ten hours or less. Family members may or may not be at home during this time.

Advantages of in-home NAMI Maine Family Respite include:

- You do not have to arrange transportation for the child or for any special equipment needed
- The child does not have to adjust to a new environment
- Other children in the family can be cared for at the same time (if mutually agreed upon with the respite provider. Parents are responsible for payment of siblings not covered by the program)

2. Out-of-Home NAMI Maine Family Respite:

Out-of-home NAMI Maine Family Respite can be provided in any setting outside the family's home. The kinds of out-of-home NAMI Maine Family Respite offered varies, and can take place in settings such as the providers' home, churches, day-care centers or in the child's community at parks or playgrounds.

Advantages of out-of-home NAMI Maine Family Respite include:

- Opportunities to interact with other children and adults
- When the child has out-of-home NAMI Maine Family Respite, family members can "take a break" but still be able to be at home

3. Overnight NAMI Maine Family Respite:

Overnight NAMI respite care may take place in either the child's home or a provider's home. However, a child cannot be cared for in a provider's home for a continuous period of more than 23 hours unless that provider has a Department of Human Services license. Periods of overnight care will be paid at a 10-hour maximum limit even though the child may receive care for longer than 10 hours.

Advantages of overnight NAMI Maine Family Respite include:

- the family can have an extended family break
- the child has an opportunity to experience a longer time away from his/her family

Connecting to Families

After completing the certification process, new providers are added to the NAMI NAMI Provider Register, and this information is distributed to families. Considerations a family may use when locating a NAMI certified provider may include needs of the child, type of respite requested, geographic limitations, and experience of the NAMI certified provider.

Families are in control of the selection process. They decide which NAMI certified providers they would like to meet, which they would like to use, and when they will use the service. The NAMI Maine Respite Program does provide oversight or supervision to certified providers, and is available to answer questions about the program.

It is important that you keep the NAMI Maine Respite Program informed of your availability so that information on the NAMI Maine Certified Provider Register given to families and case managers is current.

NAMI Maine certified respite providers should use the following steps when receiving a call from a family requesting respite services.

Step One: Phone Interview

When you receive a phone call from a new NAMI Maine family, have some questions ready to ask them, such as:

- What times and days do you need respite?
- Where do you live?
- Tell me about your child's diagnosis and behavior.

The parent or caregiver is likely to have many questions for you as well. Tell the parent or caregiver about your background in working with children with special needs. If you are not a good match for the family, simply say "I'm sorry, I'm not available." Remember, it is expected that you will always return telephone calls promptly and keep your commitments to children and families.

Step Two: Meet

If the family's needs match your availability, schedule a first meeting. Have questions that are important to you ready to ask, such as:

- Tell me more about your child's routine.
- Does your child have any allergies?
- What should I do in case of an emergency?
- What does your child like to do?

Step Three: Schedule the NAMI Maine first Respite **opportunity**.

Schedule a time for the NAMI Maine certified respite provider to care for the child for the first time. You may want to spend time with the child while the parent or caregiver supervises. Or you may have the parent or caregiver go on a short outing, such as to the grocery store, so that you and the child can get to know each other.

Guidelines and Expectations of NAMI Maine Respite Providers

Guidelines for NAMI Maine Certified Respite Providers

A successful and effective NAMI Maine Certified Respite Provider:

- Provides respite for at least one family.
- Acts in a professional manner when dealing with children and families.
- Respects the confidentiality of families and children at all times.
- Is reliable, exercising good judgment and gives children undivided attention.
- Returns phone calls promptly.
- Arrives on time to provide respite.
- Acts only as a NAMI Respite Provider, following parent's instructions and does not offer advice regarding school programs, therapies, or any aspect of the child's care.
- Contacts the NAMI Program Director with questions about the program including policy, procedures and billing.
- Promptly informs NAMI Respite Services of any changes in availability, address, phone number, or additional training documentation to be revised in the next register.
- Promptly informs NAMI Respite Services of additions to the household of anyone over 18 years, if respite care takes place in the provider's home.
- Always has a current Community CPR and Standard First Aid certification, and complies with certification requirements for maintaining certification and for re-certification.

NAMI Maine Certification Procedures:

The following is required to be considered for NAMI Maine certified provider:

- A NAMI Maine certified provider application
- two references,
- skills assessment
- DHHS, SBI, & DMV background checks,

- CPR, First Aid & BBP certification
- Completion of online training and exam OR Independent Certification (BHP, LCPC, etc.)
- NAMI Maine Orientation process

Participants with documented previous training and experience (certificates, CEU's, transcripts, or recommendations) may have a training module waived when the previous training meets or exceeds the level of NAMI Maine Respite training offered. Participants are required to submit documents of pertinent training to the NAMI Maine Program Director for consideration.

Certification: Individuals aged 18-79 are eligible for certification. NAMI Maine Certification will be offered to those individuals who successfully complete all training modules (unless attendance is waived) either in class, or using the on-line training, and have acceptable background checks and references.

Background Checks: Anyone applying for certification as a NAMI Maine certified respite provider must sign a release allowing the NAMI Maine Program Director to conduct checks with the Department of Human Services (for child abuse and neglect allegations). Background checks will also be conducted with the State Bureau of Identification (for a criminal record check) and the Bureau of Motor Vehicles, although these do not require the providers consent as they are public records. Specific conditions may be applied, or certification denied, to individuals whose background checks may prove detrimental. Any adult 18 years of age or older, living in the home of a potential NAMI Maine certified respite provider must also sign a release agreeing to all the background checks, if children will be cared for in the NAMI certified provider's home.

Felonies that will result in denial of certification include:

- Sexual Exploitation of Minors
- Kidnapping and Criminal Restraint
- Offenses Against the Family
- Robbery
- Arson and Other Property Destruction
- Prostitution and Public Indecency
- Criminal Use of Explosive and Related Crimes
- Weapons
- Drugs
- Abduction
- Cruelty to Animals
- Incest
- Manslaughter
- Murder
- Violation of Child Protection Act
- Rape and Carnal Knowledge
- Inhalation of Certain Vapors
- Treason

Background Check Guidelines

A. State Bureau of Identification

1. Any background check showing a Felony that is included in the above list will automatically result in denial of certification;
2. Any background check showing one or more other offenses (misdemeanors) within the last 10 years will require an additional statement of explanation from the potential provider;
3. Any background check showing more than two other offenses, even if older than 10 years, will require an additional statement of explanation from the potential provider;
4. Based on potential provider's statement of explanation, number of offenses, and age of offenses, certification will be based on NAMI's Program Director's discretion.
5. If subject is a housemate of potential provider, the NAMI Maine Respite Director may determine that the provider can be certified, but be restricted from providing NAMI Respite in his/her home.
6. Potential NAMI certified providers may appeal denial of certification in writing, and must then submit two letters of reference which address the past offenses and current suitability to care for children.

B. Department of Motor Vehicles

1. Any background check showing an OUI within the last three years will result in an automatic denial of certification;
2. Any background check showing three (3) or more speeding offenses within the last three (3) years will require an additional statement of explanation;
3. Any background check showing more than one accident within the last three (3) years will require an additional statement of explanation;
4. Based on subject's statement of explanation, certification will be at NAMI MAINE 's Program Director's discretion.
5. NAMI Maine's Director may determine that a NAMI certified provider can be certified, but is restricted from transporting children.
6. Subject may appeal the denial of certification in writing.

C. Department of Health and Human Services

1. Any background check showing a substantiated case of abuse or neglect will result in automatic denial of certification, unless a subject also submits a letter from the Department of Health and Human Services outlining his/her current suitability to care for children;
2. Based on statement of explanation, number of allegations, and age of reports, certification will be based on NAMI Maine's Director's discretion.
3. If subject is a housemate of potential provider, the NAMI Maine Director may determine that the provider can be certified, but is restricted from providing NAMI Respite in his/her home.
4. Subject may appeal denial of certification in writing.

D. DHHS Office of Inspector General

1. Any background check showing that the potential provider has engaged in fraud will result in a denial of certification.
2. Subject may appeal denial of certification in writing.

Reservation of Rights: The NAMI Maine Respite Program reserves the right to deny or revoke certification to individuals whose performance and/or personal behavior are inconsistent with those of agency expectations. The NAMI Maine Respite Program reserves the right to refuse to enter into or continue any and all relations with certified providers at any time.

Re-certification - The NAMI Maine Respite Provider certification is valid for two years. To be re-certified the following criteria must be met:

1. NAMI Maine certified providers must be actively providing care to at least one family and have at least one positive evaluation.
2. Nine hours of advanced training for continuing education is required each year, and may come from the NAMI Maine Respite Program or other venues providing services to children with special needs (ex. conference, employment, schools).
3. Current certification in CPR, First Aid & BBP.
4. Current satisfactory background checks.

NAMI Maine Program Expectations

NAMI Certified providers are per diem employees of NAMI Maine. As per diem employees they are not allowed to work over 29 hours per week.

Because NAMI Respite Providers are NAMI per diem employees, the reimbursement payment received reflects taxes deducted. Per diem employees of NAMI Respite are not allowed to work over 29 hours per week.

Confidentiality is imperative: You have a responsibility to the families to protect their privacy. All information given to NAMI certified respite providers is confidential. That means you cannot discuss anything regarding a child or his/her family with anyone else, except for the NAMI Maine Program personnel. When NAMI Maine certified providers are in a community setting they should not identify the child in their care as being part of the NAMI Maine Respite Program. NAMI certified providers cannot discuss specific information about families or children with other providers or other families with whom they are working. Breaches of confidentiality are a serious matter and may result in decertification.

HIPAA & Confidentiality

What is HIPAA? In 1996, Congress passed the Health Insurance Portability & Accountability Act, or HIPAA. In 2000, the Department of Health & Human Services issued final regulations under HIPAA establishing privacy standards for certain protected health information and final regulations became effective April 14, 2003.

What is Protected Health Information?

Protected Health Information (PHI) is health information created or received by a health care provider, health plan, other agencies; and includes written, electronic, or oral communication of individually identifiable health information which relates to the past, present, or future physical or mental condition of the consumer and can be used to identify the consumer.

How does HIPAA affect you?

As a NAMI Maine Respite Provider, you are expected to know, understand and comply with this federal regulation. You have a responsibility, both legally and ethically, to the families to protect their privacy. All information given to NAMI certified respite providers is confidential. This means you cannot discuss anything regarding a child or his/her family with anyone else, except for NAMI Maine Respite Care Services personnel. When NAMI certified providers are in a community setting they should not identify the child in their care as being part of NAMI MAINE Respite Care Services. Providers cannot discuss specific information about families or children with other providers, or other families with whom they are working, or the general public.

Exceptions as a Mandated Reporter

NAMI Maine Respite Providers are mandated reporters of suspected abuse and/or neglect of children. Abuse and/or Neglect can be defined as "a threat to a child's health or welfare by physical,

mental, or emotional injury or impairment, sexual abuse or exploitation, deprivation of essential needs or lack of protection from these, by a person responsible for the child". (Title 22 - Chapter 1071 of the Child and Family Services and Child Protection Act).

If a NAMI Maine Respite Provider suspects abuse and/or neglect of a child, they must take responsibility for calling the DHHS at 1-800-452-1999 with their concerns about the care and safety of a child

Violations of HIPAA & PHI

Violation of the regulations carries significant civil penalties, criminal fines, and even jail time. Civil penalties are \$100 per violation per person up to a maximum of \$25,000 per person per year per standard violation. Criminal penalties vary, but can include: up to a \$50,000 fine, 1 year in prison, or both, for inappropriate use of PHI; up to a \$100,000 fine, 5 years in prison, or both, for using PHI under false pretenses; or up to \$250,000 fine, 10 years in prison, or both, for the intent to sell or use PHI for commercial advantage, personal gain or malicious harm.

Mandatory Reporting: NAMI Maine Respite Providers are mandated reporters of suspected abuse and/or neglect of children. **Abuse and/or Neglect** can be defined as "a threat to a child's health or welfare by physical, mental or emotional injury or impairment, sexual abuse or exploitation, deprivation of essential needs or lack of protection from these, by a person responsible for the child" (Title 22 -Chapter 1071 of the Child and Family Services and Child Protection Act). If a Respite Provider suspects abuse and/or neglect of a child, they must take responsibility for calling DHHS directly with their concerns about the care and safety of the child.

NAMI Maine Allocation and Payment

NAMI Maine Respite Care has two basic levels of service. Each of the two levels reflects the amount of care needed by a child and is determined according to the following criteria:

- **Activities of Daily Living and Communication Needs:** Does the child function independently in this area or does he/she require minimal assistance? Is the child totally dependent?
- **Behavior:** Does the child have challenging behaviors or mild problems that the typical person could deal with, or does the child have behaviors that require a higher skill level of a provider?
- **Medical:** Does the child have good health or is he/she in need of a respite provider who is trained to meet the needs of children with moderate to severe medical needs?

Level I: Basic allocations are given to children with mild to moderate delays, stable conditions, mild behavioral issues and the presence of stabilizing medication. This level also includes children who exhibit moderate to severe needs in care, have seizure activity or atypical behaviors requiring behavior management skills. They may require frequent medication changes, which may not always stabilize the behavior. Therapeutic Crisis Intervention (TCI) or other behavioral intervention training is suggested for working with children who have emotional or behavioral diagnoses.

Level II: These children exhibit the highest needs, having severe medical, behavioral or emotional needs, which require a high level of skill from a provider. Children at this level can exhibit aggressive and/or assaultive behaviors. Behavioral intervention training is highly recommended.

NAMI Maine certified respite providers are reimbursed at the amounts listed below:

Level 1 child---\$10.50 per hour or \$105 maximum for a 10-hour day rate within 24 hours

Level 11 child--\$13.25 per hour or \$132.50 maximum for a 10-hour day rate within 24 hours

All NAMI Maine certified respite providers must have completed the application and orientation process.

The NAMI Maine Respite Program processes billing forms every two weeks, however *Providers must allow two full weeks (14 days) from the date the bill is received in the office for payment to arrive.*

Request for reimbursement *must be submitted in a timely manner.* Check with NAMI Maine Respite Program for requirements for billing.

	Quarters	Due no later than
1st	July 1 - September 30th	October 7th
2nd	October 1 - December 31st	January 7th
3rd	January 1 - March 31st	April 7th
4th	April 1 - June 30th	July 7th

NAMI respite billing forms received after the 7th will be paid from the next quarter's allocation if funding is available. Families can carry hours from one quarter to another except for the fourth quarter. Billing forms received after the close of the fiscal year (July 7th) will be returned unpaid.

Mileage will not be reimbursed; any mileage reimbursement will come from the family and at the federal rate of .44 cents per mile

Long-distance telephone calls are not reimbursable. Parents who request providers to take their child to activities that charge a fee (ex: amusement parks, movie theaters, museums) must be responsible for paying for the child. Parents must also negotiate payment for care of siblings who are not eligible for services through the NAMI Maine Respite Program. NAMI Maine certified respite providers may not care for more than four children in any one family at any time, nor can they care for children from different families at the same time.

NAMI Maine Workmans Compensation

NAMI Maine certified respite providers are covered under the NAMI Maine workman's compensation program, see the NAMI Maine Program Director as needed.

Module 2: COMMUNICATION

Language and Communication

Whenever you are in contact with another person you are sending them messages of one kind or another. It is impossible not to communicate. Usually you send both verbal messages and nonverbal messages. Language is an organized system of symbols that people use to communicate with each other. These symbols may be spoken, written or gestured. Many people view communication from a strictly verbal standpoint - that is, using words and sentences to convey thoughts, feelings, needs, and desires. Most of us depend largely upon "talking" or a verbal language system to communicate with others. However, in addition to our verbal abilities - or sometimes in place of - we utilize many non-verbal techniques or strategies to effectively relay our thoughts to others. Basic types of communication are nonverbal, verbal, and written.

Nonverbal communication includes communication through body movement, facial expression, posture, gestures, tone of voice, sounds, (such as laughing, crying, clearing the throat, etc.), touch, smell or dress. In infancy, non-verbal techniques are our primary means of communicating with others and include such things as eye contact, facial expressions, movement, body postures, etc. These techniques, in combination with early sound making, help us communicate effectively with our caregivers.

As the typical infant matures, non-verbal techniques are assimilated, and the infant gradually becomes more skilled at utilizing a verbal communication system. Throughout life, individuals continue to become more skilled verbally, constantly learning and engaging in complex verbal interactions with others.

In the infant and young child, there are critical periods during which the basis for all future verbal language development occurs. This development generally takes place between the ages of birth and three years; however, many extend somewhat beyond that for maturation of the speech sound (phonological) system. Please refer to the chart below for an overview of developmental milestones for communication.

Developmental Stages of Language

Expressive and Receptive charts by age groups:

By 6 months

EXPRESSIVE	RECEPTIVE
Vocalizes any sounds	Turns toward voice
Produces a range of vocalizations	Startles at loud sounds
Produces a variety of facial expressions	Can be comforted by caregiver's voice

By 12 months

EXPRESSIVE	RECEPTIVE
Babbles with variety of consonant-like sounds (ba-ba, ga-ga)	Ceases activity when told no
Takes turn vocalizing	Can participate in social games (peek-a-boo)
Imitates vocalizations or gestures	Consistently locates sources of sound in environment
Uses conventional gestures (*points) and vocalizations	Looks at or acts on objects mentioned or pointed to by adults
Communicates for behavioral regulation, social interaction, and joint attention	

By 18 months

EXPRESSIVE	RECEPTIVE
Produces a variety of sounds that may sound like words or short sentences	Responds to his / her name
Uses a variety of gestures and vocalization	Responds to names of objects within sight
Produces a few meaningful words to request objects, and direct attention	Responds to simple requests (come here, sit down, stand up)

By 24 months

EXPRESSIVE	RECEPTIVE
Uses at least 10 - 15 words	Responds consistently to many names of objects in immediate environment
Uses 2-word sentences meaningfully, including simple questions	Retrieves some objects out of sight upon request
Speech is present at least 50% intelligible	Responds to 2 step requests (get the ball, bounce it to caregiver)

By 36 months

EXPRESSIVE	RECEPTIVE
Produces sentences of 3 - 5 words	Responds to 'what', 'who', or 'where' questions
Talks about past and future events	Points to many different pictures in a book upon request
Ask questions using 'what', 'who', and 'where'	Responds to questions or comments about objects / events outside of immediate context to caregiver
Speech is greater than 75% intelligible, has vocabulary of 700 - 100 words	Shows interest in other persons conversation

When there are variations in a child's progression through the critical periods, typical development of communication can be compromised. The effect of these variations can range from very mild to severe and can impact on not only what is learned/expressed, but how this occurs as well. In most people who have developmental disabilities, there are factors that have influenced their transition through these critical periods. These may include prenatal and birth trauma, neurological factors such as cerebral palsy, biological factors such as Down's syndrome, or environmental factors.

It is your knowledge of the various modes of communication that will enhance your interactions with people who have developmental disabilities and will facilitate and broaden your communicative experiences.

Facilitating Effective Communication

General Principles: Communication develops best when we are actively engaged with people, objects, and activities in our environment. A language learning environment is rich with opportunities for both receiving and expressing information about our surroundings. Experiences which promote listening and observing form the basis for language comprehension and are equal in importance to those which promote expression - both verbal and non-verbal.

Language comprehension and expression may develop at different rates in different people. Some children's ability to understand what is said to them and to produce verbal/non-verbal language may be at the same level. Some children can understand much more than they can express verbally or non-verbally.

In learning to comprehend language, some children may utilize what they hear as a primary learning source. Others may learn best from a combination of sensory input, hearing, seeing, touching, etc. As a general rule, it is best to provide a language-rich environment that supports multi-sensory learning and multidimensional communication.

In supporting the development of expressive communication, particularly in persons with developmental disabilities, we must be aware of the non-verbal techniques that are utilized in effective communication. They may include:

- Eye contact
- Natural body language
- Changes in tone of voice, indicating pleasure, distress, or anger, etc.
- Facial expressions
- Body movements (posture, etc.)
- Simple gestures (pointing, reaching, waving)
- Behavioral changes (variations in daily patterns of eating, sleeping, etc; changes in mood, affect, temperament)
- Sign language
- Picture communication boards
- Computerized communication systems

Your skills in listening and observing are critical in three ways:

1. Validating the person's communication mode
2. Understanding and responding to the person's message
3. Facilitating and expanding the person's communicative experience

Tips for communicating with:

1. **PAY ATTENTION!!!** Look, listen; wait until the person is finished.
2. Encourage the person to initiate communication and to **meaningfully** indicate their needs, desires, thoughts, and ideas.
3. **TALK!!** Whether or not the person is verbal.
4. Speak clearly.
5. Use age-appropriate language.
6. Ask questions, open-ended ones, rather than those that require only a yes/no response.
7. Offer choices and options.
8. Talk "with" a person, not "at" them or "about" them.
9. If you don't understand what the person is trying to tell you, ask questions, ask them to repeat the message, clarify message, and ask them to "show" you if possible.
10. Accept a person's right to express feelings, even if they are not always positive - and be honest in sharing your feelings, both positive and negative. React to ideas, not to the person.

WHEN COMMUNICATING WITH YOUNG CHILDREN:

1. Keep it FUN!!
2. Keep it short and simple.
3. Speak slowly and clearly, repeat if necessary.
4. Be a good speech and language model.
5. Know what is reasonable to expect from a child.
6. Avoid pressuring the child to talk or "perform".
7. Follow the child's lead.
8. Label objects and people around the child, as well as activities occurring within the child's immediate environment.
9. Facilitate communication and play with peers.
10. Keep it relevant!

WHEN COMMUNICATING WITH PEOPLE WHO HAVE HEARING IMPAIRMENTS

1. Be sure to have the attention of the person you are speaking to before conversing.
2. Let your face be seen; do not stand in front of a window or light source when speaking; check to see if mustaches or beards are blocking a clear view of the mouth.
3. Keep your hands away from your face.
4. Avoid chewing gum, etc., while talking.
5. Speak clearly and not too fast.
6. Use a lot of facial and body expressions.
7. Use a normal tone of voice.
8. Be relatively close to the person when you are talking.
9. Don't assume that a person with hearing aids can hear you clearly or distinctly.
10. Avoid situations in which there is a lot of background noise.
11. Rephrase or repeat when necessary.
12. When assisted by an interpreter, always look at and talk to the person who is hearing impaired
-- NOT THE INTERPRETER.

WHEN COMMUNICATING WITH PEOPLE WHO HAVE VISUAL IMPAIRMENTS

1. Teach turn taking.
2. Use statements more than questions.
3. Sit face to face and encourage eye/face contact.
4. Label everything.
5. Be descriptive -- talk about details of objects, people, etc.
6. Allow time for listening and touching.
7. Identify yourself and what you are doing. Describe what is happening, what is going to happen next, etc.
8. Add auditory and tactile cues to play.

WHEN COMMUNICATING WITH PEOPLE WHO HAVE MOTOR IMPAIRMENTS

1. Offer choices.
2. Ensure proper body positioning for eye contact, vocalizing, optimal handling of toys, etc.
3. Always assume that the person understands what is being said.

4. Be a good observer! Look for even the slightest postural, vocal, or facial changes that may be communicative attempts.
5. Give extra support and guidance to facilitate exploration of the environment. Bring the environment to the child.
6. Allow enough time for the person to respond.

WHEN CARING FOR A PERSON WHO IS NON-VERBAL OR WHOSE COMMUNICATION SKILLS ARE DELAYED

1. Obtain information about the person's communication techniques -vocal, gesture, verbal, signs, picture boards, computerized systems.
2. Obtain information about the person's overall abilities - what is/is not reasonable to expect in terms of comprehension expression, behavior, etc.
3. Obtain information about how are they likely to respond in an unfamiliar setting.
4. Determine what environmental factors can be modified to promote positive interactions and effective communication (lighting, noise/activity level, etc.).
5. Discover what the person's particular interests, likes, dislikes are.
6. Obtain information about the person's routine.
7. Obtain information about how the person should be prepared for any change in routine.
8. Obtain information about what effect, if any, does the person's medication have on his ability to interact with others and to comprehend what is communicated to him/her.
9. Find out how the basic needs are communicated (hunger, pain, thirst, etc.)
10. Obtain information about what behavioral changes are likely to occur if the person is not able to communicate effectively or be understood by the caregiver.

Considering Grief when Communicating with Parents

When communicating with parents of children with special needs, it is important to consider the possibility that they are grieving. Loss and grief happen to us all, and working with children and families who are grieving can be difficult. These individuals are experiencing emotional pain and can be irritable or angry. Parents and other family members may have difficulty in trusting someone to care for their child.

Elizabeth Kubler-Ross is probably best known for her descriptions of how people grieve. She identified five stages of the grief process. These are:

Denial (this didn't happen to me!)
Anger (why did this happen to me?)
Bargaining (I promise I'll do better if...)
Depression (I just don't care anymore)
Acceptance

In the book, "**Living With An Empty Chair - a guide through grief.**" *Dr. Roberta Temes* describes three particular types of behavior exhibited by those who are grieving. These include:

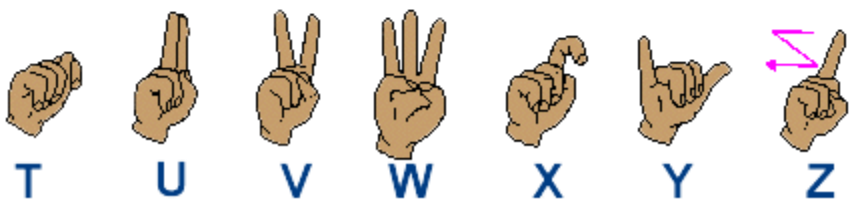
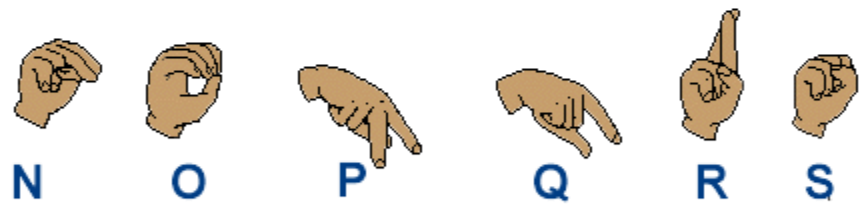
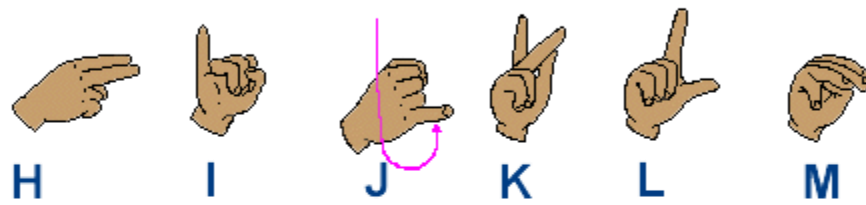
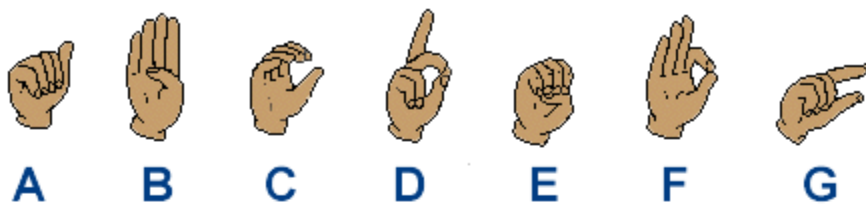
Numbness (functioning on auto-pilot and isolating socially)
Disorganization (intensely painful feelings of loss)
Reorganization (re-entry into a more 'normal' social life.)

Families who have children with special needs or people who experience trauma experience another kind of grief called "disenfranchised grief." This type of grief is not acknowledged openly, publicly mourned or socially supported. This type of grief is about the loss of potential development or the perceived loss of future. Each time a developmental step is not met for a child with special needs, the individual and the family repeat a cycle of grief. Over time everyone adjusts to the individual's current level of ability and a level of "normal" functioning continues for the family. The status quo is maintained until the next developmental step is not met and the individual and family again exhibit a grief reaction. Without help and support this can become a vicious cycle.

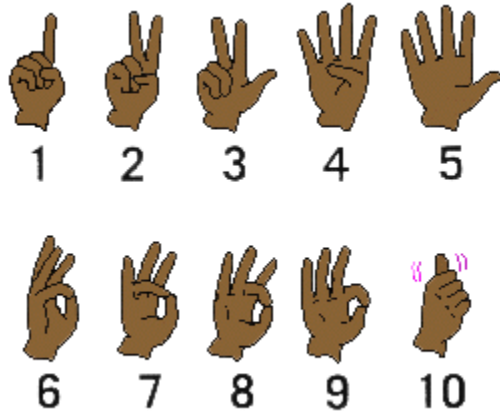
American Sign Language Chart

- American Manual Alphabet Chart
- Numbers from 1-10 Chart
- Resources/References for Communication Module

American Manual Alphabet Chart



Numbers from 1 - 10



RESOURCES

Parent Articles - Enhancing Parent Involvement in Language Learning
Edited by Margaret Schrader, Communication Skill Builders, 1988

Language Development in Exceptional Circumstances
Edited by Dorothy Bishop and Kay Mogford
Lawrence Erlbaum Associates, Publishers 1993

Children with Handicaps - A Medical Primer
By Mark L. Batshaw, MD and Yvonne M. Perrett
Paul H. Brooks, Publishers, 1981

Is Your Child's Speech Normal?
By Jon Eisenson
Addison-Wesley Publishing Co., 1977

The Development of the Infant and Young Child: Normal and Abnormal
By Ronald S. Illingworth
Churchill Livingstone Press, 1985

Handbook of Infant Mental Health
Edited by Charles H. Zeanah, Jr.
The Guilford Press, 1993

Developing Effective Communication for the Physically Handicapped Child
By Cassandra Faux, M.S.
Therapy Skill Builders, 1989

Handbook for the Care of Infants and Toddlers with Disabilities and Chronic Conditions
Developed by the First Start Program
Published by Learner Managed Design, Inc., 1991

Talk to Me: A Language Guide for Parents of Blind Children
The Blind Children's Center, Los Angeles, CA

Dancing Cheek to Cheek: Nurturing Beginning Social, Play and Language Interactions
The Blind Children's Center, Los Angeles, CA

Talking with Children, Inc. - Talking is Sharing (Video)
P.O. Box 839, Palmer, MA 01069

Module 3: CHILD DEVELOPMENT

Basic needs of children

The three basic needs of children, Acceptance, Love, and Warmth, are pretty simple.

Acceptance

- Let's take children as they are.
- Remember that every child has two sides:
- The Physical child - one you see and hear and
- The Emotional child - one who feels your words, looks, and actions.
- (Let's not live our dreams through our children.)

Love

- Caring for the emotional as well as the physical child.
- Bringing up a responsible child.
- Not spoiling a child.

Warmth

- Creating a comfortable atmosphere around you.
- Understanding.
- Communicating.

What to expect of young children

It is important to know the characteristic behavior for each age. Often parents are irritated by a child's behavior when he is only acting his age. This does not mean that misbehavior should be ignored, but it does help when you realize that the child will outgrow the behavior. Discipline needs to be in keeping with the child's age and abilities. Ask yourself -"Are my demands reasonable for him at his age?" "Do I expect too much?"

THE INFANT

I cry to get what I need and what I want. I am dependent on adults for my needs. I love to play with my food. I am growing rapidly. I get into everything. I sleep less as I grow. I learn by touching, tasting, smelling, seeing, and hearing.

THE TWO-YEAR-OLD

I can be negative (says "No" many times) and possessive ("That's mine"). I am often noisy. I try to get my own way. I have a short memory. I am curious and explore a lot. I often can't make up my mind. I can be poky (playing in food, dawdling). I can't sit still!

THE THREE-YEAR-OLD

I try to please and I can mind fairly well. I am learning to accept suggestions and I can be reasoned with. I am attentive when spoken to, especially when called by name. I can make a few choices. I can talk enough to be understood. I still don't know how to share.

THE FOUR-YEAR-OLD

I want friends. I ask many questions and tend to be bossy. I can brag and stretch the truth and I tattle frequently. I talk a lot. I am learning to take turns. I think I am very important. I enjoy playing with made-up words. And I may say words that shock you.

THE FIVE-YEAR-OLD

I am friendly with friends (usually) and parents. I am businesslike...I want to know and follow "the rules". I like to imitate grownups. I am dependable. I like praise. I like to feel important. I still tattle on others (if they're not playing fair!). I enjoy dressing up. I can give my name and address. I am serious and demanding.

THE SIX TO SEVEN-YEAR-OLD

I am very active; sitting still is hard for me. I like running, jumping, chasing and doing games. I can dress myself, but sometimes I dawdle. Small groups, with boys and girls, are fun at playtime. I like to wrestle, and have friendly fights. It seems one minute I'm "good" and the next I'm "not so good."

THE SEVEN TO EIGHT-YEAR-OLD

Slowly I'm getting taller. My friends and I all seem to have some habits like scratching or pulling ears. Jumping rope, hopscotch and jacks are favorite games. I like to dress like my friends and do what they do. Sometimes when my parents make me mad I wonder if I'm really their child. Sometimes I want to make something, but I can't make it work out like my idea. I can tell time. Often, I argue about what I'm expected to do. I am interested in how boys and girls are different.

THE EIGHT TO NINE-YEAR-OLD

I like doing things with my hands, but I can't always make them do exactly what I want. I am good on a bicycle and roller skates. I like to work on group, but sometimes it's hard to follow rules and wait

my turn. I know what's mine and what's yours. I like to know about what happened in the "olden days."

THE NINE TO TEN-YEAR-OLD

I take care of my own physical needs like baths and hair combing. I'm so busy I don't always get the rest and sleep I need. I'm not afraid to try things that people say are too dangerous. The "opposite sex" bugs me sometimes. I like to be part of "gangs" and clubs. Sometimes I get to visit my new friend who lives in a different neighborhood.

THE TEN TO ELEVEN-YEAR-OLD

A lot of girls I know are gaining weight. I enjoy working really hard to get better at climbing, running, and other things like that. Playing to see which team wins is neat. And it is fun to be on a team. Sometimes I need to be by myself. I put good things in secret hiding places. Once in a while I like to plan ahead. It's interesting to hear how other people feel about things-and to tell them how I feel.

THE ELEVEN TO TWELVE-YEAR-OLD

Everybody in my group likes a different game. I'll die if I don't get in that club soon. I enjoy doing things in school, my neighborhood, and church. Team games are my favorites. Sometimes people notice I'm a little shy. I'm beginning to be able to see where my writing and drawing needs to be improved. Earning money would help me be a little more independent.

THE ADOLESCENT

I am in a time of major physical and emotional change. I am experiencing stress, and creating it for others (unintentionally, for the most part). I may experience big changes over night or breeze through smoothly. I am trying to figure out who I am: I may experiment with new ideas and life-styles. I withdraw from time to time. I am moody and unpredictable. I am critical of family members, especially parents. I have short outbursts of anger, as I push for my independence. I have difficulty compromising-I know all the answers. I am restless, mixed up, self-critical. I will be forming a clear self-image, an identity of my own. I will need to share feelings and experiences with my friends. I am preoccupied with the opposite sex. I want to be treated like an adult. I have mixed feelings of joy about separating from home. I may not openly show it, but I need your love, your attention, and your understanding.

Caution: The exact time each child will reach each stage is highly unpredictable. What is predictable is that most teens do experience many of the feeling and behaviors described above.

Age and emotional development

Reference Chart for Development of Emotions by Age group:

Age	Development of Emotions
Infancy	Stable, well-balanced periods occur around 4, 16, 28, 40 and 52 weeks. Periods of imbalance occur often around 8, 20, 32, and 44 weeks.
18 months	Acts on impulse. Is insistent, demanding. Not much trouble with own emotions, but has trouble with other people's. Wants own demands met here and now. Not very adaptable or cuddly. Easily frustrated; attention span extremely short. Loves the outdoors and carriage/stroller rides.
21 months	More demanding and less adaptable. Dependent. Has strong needs and demands, but cannot communicate them. May resist being touched.
2 years	Less demanding. More adaptable. Tends to be quiet and calm. Willing to cuddle and accept affection.
2 ½ years	Great imbalance. Moves between extremes of aggression and withdrawal. Bossy, rigid, selfish, possessive, jealous. Likes sameness, repetition, predictability; changes are very hard, even minor ones; toys, etc. all have a "proper place."
3 years	Often time of emotional calm. May be happy, contented much of the time. Gets along well with others. Likes others and wants to please them.
3 ½ years	Difficult age. Is uncertain, unsettled, insecure, yet is stubborn, demanding -unwilling or unable to give in or adapt. Tends to be fearful, unhappy. Child's big emotional struggle 'is with his/her mother (she is the only worthy opponent); enjoys talking/conversation, time of great motor uncertainty and fluctuating fine motor capabilities. At this age, children are much better with almost anyone other than the principal caregiver.
4 years	Energetic, out-of-bounds. May go to extremes to test self against others. Often enjoys own impish, humorous ways. May be selfish, rough, impatient, loud. Loves adventure. Socially silly and larger-than-life manners may annoy adults.
5 years	Tends to be calm, quiet, well-balanced. Pulls in and usually tries only what he knows he can do, so is comfortably well-adjusted: Friendly, loving, appreciative. Wants to please and do the right things; wants and means to be good; not yet able to admit to wrongdoing and as much as he tries, does not always tell the truth.

5 ½ - 6 years	Highly emotional. Not in good balance. Loves one minute, hates the next. Much confusion and trouble between self and others. May demand, rebel, argue, fight. When in good mood, is cheerful, energetic, enthusiastic. Needs much praise, but behavior often merits criticism. This only makes behavior worse. Not able yet to tell the difference between mine and yours.
6 ½ years	Behavior quiets down for a few months. Usually relates strongly and warmly to adults close to them. Brief periods of being happy with themselves. Money is becoming of real interest both as an allowance and as a reward. Eager for more possessions.
7 years	Quiet, rather negative emotions. May be serious, self-absorbed, moody, worrisome, or suspicious. Very sensitive to others' emotions. May feel disliked by others and that they are critical or poking fun. Procrastinates, has a short memory, and is easily distracted; often completely tunes out the outside world.
8 years	Vigorous, dramatic, curious, impatient, demanding. Not as moody as 7, but still sensitive. Very demanding of: parents, especially mother; strongly influenced by her wishes and desires; wants time, attention, affection and approval; beginning to think abstractly: interested in and concerned about own possessions. Easily disappointed, if people don't behave as wished. Can be quite critical of others and self. Argumentative.
9 years	Quieter than at 8. Seems to be independent, responsible, dependable, cooperative. May sometimes be temperamental, but is basically reasonable. May be age of considerable rebellion against authority; tend to go to extremes; will take criticism fairly well if carefully phrased; great interest in fairness; group standards may be more important than parental standards. Demanding of others, but likely to be as critical of self as of others. Very involved with self and may not hear when spoken to. May appear absent-minded or indifferent. Shows anger at parents, but is also proud of them, is loyal to family, friends. May show concern for others.
10 years	Emotionally direct simple, clear-cut usually well-balanced, yet still childlike. Less anxious and demanding than at 9. Most often good natured and pleased with life, but may show sharp, violent temper. Can be very affectionate. Not a worrying age; yet a few earlier fears remain. Enjoys own humor; which may not be very funny to others. Happy age.

Child development

What is child development? Child development is a process every child goes through. This process involves learning and mastering skills like sitting, walking, talking, skipping, and tying shoes. Children learn these skills, called developmental milestones, during predictable time periods. Children develop skills in five main areas of development:

- **Cognitive Development:** This is the child's ability to learn and solve problems. For example, this includes a two-month-old baby learning to explore the environment with hands or eyes or a five-year-old learning how to do simple math problems.
- **Social and Emotional Development:** This is the child's ability to interact with others, including helping themselves and self-control. Examples of this type of development would include: a six-week-old baby smiling, a ten-month-old baby waving bye-bye, or a five-year-old boy knowing how to take turns in games at school.
- **Speech and Language Development:** This is the child's ability to both understand and use language. For example, this includes a 12-month-old baby saying his first words, a two-year-old naming parts of her body, or a five-year-old learning to say "feet" instead of "foots".
- **Fine Motor Skill Development:** This is the child's ability to use small muscles, specifically their hands and fingers, to pick up small objects, hold a spoon, turn pages in a book, or use a crayon to draw.
- **Gross Motor Skill Development:** This is the child's ability to use large muscles. For example, a six-month-old baby learns how to sit up with some support, a 12-month-old baby learns to pull up to a stand holding onto furniture, and a five-year-old learns to skip.

What is a developmental milestone?

A developmental milestone is a skill that a child acquires within a specific time frame. For instance, one developmental milestone is learning to walk. Most children learn this skill or developmental milestone between the ages of 9 and 15 months.

Milestones develop in a sequential fashion. This means that a child will need to develop some skills before he or she can develop new skills. For example, children must first learn to crawl and to pull up to a standing position before they are able to walk. Each milestone that a child acquires builds on the last milestone developed.

What are typical milestones, or skills, children learn at different ages?

We now know that our brains are not fully developed at birth. In fact, a baby's brain weighs about one quarter (1/4) of what an adult's brain weighs! The brain grows very rapidly during the first several years of life. During this time, a child is learning all sorts of new skills.

Because children usually acquire developmental milestones or skills during a specific time frame or "window", we can predict when most children will learn different skills. The pages below describe the types of skills children usually learn at different ages.

What if a child does not meet a developmental milestone?

Each child is an individual and may meet developmental milestones a little earlier or later than his peers. You may have heard people say things like, "he was walking before he turned 10 months, much earlier than his older brother" or "she didn't say much until she was about 2 years old and then she talked a blue streak!" This is because each child is unique and will develop at his or her own pace.

However, there are definitely blocks of time when most children will meet a milestone. For example, children learn to walk anytime between 9 and 15 months of age. So, if a child is 13 months of age and not yet walking, there is no need to worry if he is crawling and pulling to a stand. He has acquired the skills he needs to learn to walk and may begin walking soon. However, if you have a child 15 months of age who is not yet walking, it would be a good idea to talk with a child's pediatrician to make sure there aren't any medical or developmental problems since age 15 months is outside of the normal "window" or time frame in which children learn to walk.

In this section, we will provide you with some information about these "windows" or blocks of time when children usually develop a skill. We also will share with you some warning signs or "red flags" to watch for that may mean a child is not meeting developmental milestones.

However, whenever you have questions, do not hesitate to ask a professional like a child's doctor, nurse practitioner, or a trained child development or behavioral specialist. There are also several clinical specialists who are specifically trained in various areas of development who can be consulted. These include speech pathologists, occupational and physical therapists, developmental psychologists and audiologists.

How can I help a child meet these developmental milestones?

As parents and caregivers, we all want our children to succeed and be the best they can be. We know from research that two factors influence how a child succeeds and grows: genes and environment.

One of the factors that influence our child's development is their genetic makeup or "genes." Some people refer to this as "nature." Genes are the genetic material parents pass onto our children. Children are born with their "genes" in place. These genes act like a blueprint for what characteristics a child may have. For example, genes determine if a child will have blue eyes or brown eyes; they also determine if he will be left- or right-handed.

The other factor that influences child development is the environment. This includes experiences children have in their home, school and community environments. Some people refer to this as "nurture." The environment can either improve or harm a child's genetic blueprint. For example, malnourished children who live in third world countries may not reach their IQ potential because of the impact of their environment on their brain development.

We often think we need to run out and buy special toys, music and games to stimulate our child's development, but we have to remind ourselves that it is more important to provide the following, every-day activities you can do with a child to encourage brain development.

- Give a child lots of love and attention. No matter what a child's age, holding, hugging, and listening are important ways to show a child they matter.
- Interact with a child by talking, singing, playing, eating, and reading with a child. A child will grow up feeling special and important to you. You will also learn a lot about a child's interests and skills.

- Read, read, read. Research has shown that children who are read to by their parents and caregivers have a larger vocabulary than other children. Reading also provides children with new perspectives about the world we live in.
- Learn some simple care-giving skills for helping a child to learn how to behave. The most important care-giving skills are having consistent rules, rewarding behaviors you want to see a child do more of, and having consequences for behaviors you do not want a child to continue to do.
- Limit TV time and video time to no more than 1-2 hours of educational viewing per day.

Toddlers: 3 to 5 Years

At this age, a child believes that everything revolves around her. She is the center of her world. Her world is full of magic. Her imagination is working all the time. She is also learning to be a good companion to other children her age. Preschool, day care or playgroup provides a great opportunity for a child to learn appropriate social skills.

How a child eats:

- Make eating fun to avoid "food jags" and pickiness by preparing food in fun shapes or with different dipping sauces (e.g. cheese spreads, yogurt, etc.)
- A child is capable of helping with some meal preparation such as: pouring cold beverages, mixing, breaking eggs, mashing potatoes, and squeezing juice.
- Watch a child when he eats and avoid giving him foods that he might choke on. Examples include "hard to chew" food like steak, "small and round" food like hot dogs, grapes, peanuts, popcorn (hot dogs and grapes can be cut into strips), and "sticky" food like peanut butter (peanut butter can be mixed with plain yogurt to decrease stickiness).
- Children should stop sucking their thumb by 4 to 5 years. Thumb sucking beyond this age is strongly discouraged because it can cause dental problems, calluses, infections and social teasing. Ask a pediatrician or dentist about how you can help a child quit this habit.

How a child uses his hands (a child's fine motor skill development):

- A child will learn to hold his crayon better. Fat pencils and crayons help him to start drawing and pretend writing.
- A child will learn how to button his clothes and zip and unzip by himself.
- A child may offer to help with household chores. He may learn to pour liquid from a pitcher into a cup. Spilling at this age is normal though, so make sure your expectations are in line with what he can do.

How a child moves (a child's gross motor skill development):

- A child will learn to throw and catch a large ball.
- Hopping, climbing and skipping are activities that a child may love to practice.
- A child will learn to pedal a tricycle during this period. Make sure she wears a helmet.
- A child may be more prone to accidents because she may be more adventurous.
- Protect a child from falls by making sure play equipment is safe and supervising a child.

How a child communicates (a child's speech and language development):

- Asking "why" is a favorite activity for a child during this period. A child wants to know what causes the events around him.
- A child will learn to respond to the question "why" in his own fashion and may ask "Why?" over and over again.
- A child will learn to listen to the explanations of others with interest.
- A child's vocabulary continues to grow rapidly.
- A child is pronouncing words better, but may still leave out or substitute some sounds (especially "L" or "R").
- A child's imagination and his increased ability to remember the past make him an interesting storyteller.
- A child can recite familiar stories you have read. Reading is all about playing with words and sounds through rhymes, songs and stories.

How a child explores (a child's cognitive development):

- A child should be able to answer questions like "What do you do when you are sleepy or hungry?"
- A child will learn to know different shapes by name (circle, square, triangle) and colors (blue, red, yellow, green).
- A child will, by age 5, know how to tell a story with a beginning, middle, and end.
- By setting firm and consistent limits for a child, you will begin to teach a child the difference between right and wrong. He may still seem to "lie" on occasion, but he will believe this lie really is the truth.
- A child will have a difficult time knowing the difference between reality and fantasy during this period.
- A child will have a better understanding of the concepts of past, present and future by the end of this period.
- Playing pretend will ready a child for reading. If a rock can "be" an egg, then a group of letters can stand for a word.

How a child is growing emotionally (a child's social and emotional development):

- During this period, a child may develop new fears especially about unfamiliar sights and sounds.
- A child will learn to share with others, most of the time.
- A child will learn to follow simple rules in games like "hide and seek", but will always want to win and be first. Playing "fair" comes later.
- A child will enjoy playing make believe games.
- A child may be very easily influenced by what he watches on TV. He may try to act as if he were his favorite character. Supervise what he watches.
- Your support and guidance will help a child begin to gain control of his emotional, aggressive, and sexual impulses.
- You may notice that a child will approach other children and begin to play with them.
- Be aware that a normal part of a child's development during this period is sexual exploration of one's own body. A child will learn about what is appropriate from your messages to him.

Loving and playing with a child:

- Playing "house" will give a child opportunity to practice imitate your activities and to try different roles.
- Make outdoor playing time part of a child's daily routine. Visit playgrounds or parks and go for walks.
- A child's curiosity leads her into exciting new experiences and increases learning.
- Read to a child regularly, every day if you can.
- A child's interest and attention will be your guide as to what level story is "right" for him.
- Remember, some children may not be toilet trained until they are four years old.

Childhood: 5 to 7 Years

As a child begins school, each day becomes an adventure and a time of discovery. This period of childhood is the time each child begins to learn skills needed to become a self-sufficient person. Each child has his or her own personality that influences each step of learning and development. Physically, this is also a time of tremendous growth. A child will grow about 7 lbs. and 2 1/2 inches each year during this time. Muscular strength, coordination, and stamina increase, though a child may be somewhat clumsy at this time as his height and weight increase so rapidly.

How a child eats:

- A child is capable of measuring ingredients and using simple kitchen utensils such as an eggbeater, grater, and vegetable peeler. Practice basic skills until they are mastered before allowing a child to try advanced tasks. Make sure to carefully supervise activities in the kitchen.

- Watch a child when he eats and avoid giving him foods that he might choke on. Examples include "hard to chew" food like steak, "small and round" food like hot dogs, grapes, peanuts, popcorn (hot dogs and grapes can be cut into strips), and "sticky" food like peanut butter (peanut butter can be mixed with plain yogurt to decrease stickiness).
- A child may begin to lose her "baby" (primary) teeth around age 6. It is very important that a child see a dentist regularly to ensure the growth of healthy permanent teeth.

How a child uses his hands (a child's fine motor skill development):

- A child will learn how to use a pencil to make shapes (like a square) and then to make letters, words and sentences.
- A child will be drawing people, houses and trees with more detail than before (for example: at least 6 body parts when he draws a person).
- By age 7, a child will be able to tie his shoes (if given the opportunity to learn; with all the Velcro shoes and slip-ons around these days, it may happen later!).

How a child moves (a child's gross motor skill development):

- A child will be able to do a series of motions in a row in order to do a complicated motor activity like pumping herself on a swing, skipping, jumping rope, or swimming strokes.
- A child will develop more visual-motor coordination and be able to catch bounced or thrown balls more easily. The balls can be smaller now.
- A child will be able balance on one foot for 10 seconds.

How a child communicates (a child's speech and language development):

- A child will be able to recognize opposites, define objects by their use, and use relatively good sentence structure.
- By the time a child turns 7, she will be able to say "v", "j", "sh", "ch", "r", "l", "s", "th" and "str" sounds like in the words "victory", "judge", "shush", "child", "rabbit", "little", "six", "thirteenth", and "street"
- A child understands the rules of conversation and is able to talk and then listen.
- Be a good listener yourself and encourage stories.

How a child explores (a child's cognitive development):

- This is the time for learning the fundamentals of reading, writing, and basic math.
- A child is eager to learn and has a strong desire to please adults.
- Children at this age can be both cooperative and competitive. Both can promote learning.

- A child may focus on only one part of a situation. For example, a child of this age may believe that a tall, narrow bottle of soda contains more soda than a short, wide bottle with an equal amount because one is taller than the other.
- A child may believe that objects have feelings. For example, a child of this age might feel sorry for a car that has a lot of passengers in it.
- A child will understand the concept of today, tomorrow, and yesterday.
- A child will be able to follow two-step directions. For example, if you say to a child, "Go to the kitchen and get me a trash bag" they will be able to remember that direction.
- A child will know his full name, age and address.
- A child will be able to answer who, what, when, where, why questions.

How a child is growing emotionally (a child's social and emotional development):

- Developing self-esteem is a central issue at this age.
- A child is learning to use standards like grades or home runs to measure his performance.
- Home is still very important and is the foundation for a child to become independent.
- Increasing separation and independence from parents are healthy steps in a child's development, so going to grandma's or a friend's house is important.
- Children at this age tend to identify with parent of the same sex.
- A child is beginning to compare herself against other people's expectations.
- A child is becoming aware that she is one of many people in the world. Up to this time, most children are focused primarily on themselves. Sometimes, this makes a child seem less outgoing than before.
- A child may enjoy being with you and at home more at age 5 than she did at age 4. By age 8, a child will probably be more focused on his peers.
- A child is developing the social skills to make friends.
- A child is a wonderful mimic. He imitates both good and bad adult behavior.
- A child is able to communicate well with others without your help.
- How other children perceive a child will affect his self-image.

Loving and playing with a child:

- A child will love board games and other types of games at this age. Let yourself be a kid again and play with him!
- A child will start to be able to think about the world from someone else's perspective. Before age 5, she was pretty much focused on her view!
- During this time, a child will start to gravitate toward playing with children of her own sex.

- A child will become very interested in the difference between truth and lies. Be open and honest with a child. Praise a child appropriately, but remember to not overdo it. Children can see through false praise.
- A child often develops modesty around this time. Respect a child and his individuality.
- At the same time that a child develops modesty, he may also become more interested in his genitals and begin fondling them. This is a good time to calmly discuss sexual differences between boys and girls, acknowledge that masturbating "feels good", and then establish family rules about touching (where and when appropriate).
- Take time to listen. Take what a child tells you seriously.
- This is a good time to give a child responsibility within her ability.
- Read, read, read! Encourage a child to read at the level he is comfortable. Practice and success help a child love reading.
- Keep reading aloud. You can read the higher-level books a child is not quite ready to read by himself but will enjoy for the action and story line.

Middle Childhood: 7 to 12

When they start school, children enter "middle childhood" and remain there until they reach adolescence. This will help caregivers and other adults look at the general characteristics of children ages 7-12, consider special concerns of parents and caregivers, and give practical tips.

Between the ages of 7 and 12, the child's world expands outward from the family as relationships are formed with friends, teachers, coaches, caregivers, and others. Because their experiences are expanding, many factors can alter children's actions and impact how they learn to get along. Some situations can create stress and affect self-esteem. The middle childhood period is a time to prepare for adolescence.

Children develop at various rates. Some children in middle childhood seem very mature while others seem very immature. During this stage, behavior may depend on the child's mood, his or her experience with various types of people, or even what happened that day.

Parental concerns

Parents with children in middle childhood may begin to re-evaluate what kind of parent they have been up to this point. With children entering school, parents may be wondering if their child has what it takes to "make it" and succeed. Up to this point, children have always looked up to parents as the source of information, but now children judge parents more and label their actions differently. Parents struggle with how to support their children's independence while understanding the child's new connections with others (friends and teachers). With children's natural curiosity and expanding knowledge, parents often find children question them more, and they are asked to respond in greater detail to larger issues, such as why they must work overtime, why some people act unfairly, or even why there is war. Children continually struggle to understand new information that is difficult to

understand.

In middle childhood, children typically spend less time with their families and parents, and families spend less time in caretaking, reading, talking, teaching, and playing. Less monitoring and fewer verbal cues are needed, particularly for routine tasks (such as baths or brushing teeth).

As children get older, behavior can be managed with verbal reasoning, deprivation of privileges, appeals to child's sense of humor, or reminders of the consequences of his or her actions.

In addition to typical development, daily life challenges are normal. For example, most children will attend school. With school comes many transitions. Being afraid of new situations or feeling peer pressure are predictable stressors. Other stressors are not as predictable. Any disruption of what is considered normal for the child causes stress.

Developmental Aspects of Middle Childhood

Social and emotional development

- There are signs of growing independence. Children are becoming so "worldly" that they typically test their growing knowledge with back talk and rebellion.
- Common fears include the unknown, failure, death, family problems, and rejection.
- Friends may live in the same neighborhood and are most commonly the same sex.
- Children average five best friends and at least one "enemy," who often changes from day to day.
- Children act nurturing and commanding with younger children but follow and depend on older children.
- Children are beginning to see the point of view of others more clearly.
- Children define themselves in terms of their appearance, possessions, and activities.
- There are fewer angry outbursts and more ability to endure frustration while accepting delays in getting things they "want."
- Children often resolve conflict through peer judges who accept or reject their actions.
- Children are self-conscious and feel as if everyone notices even small differences (new haircut, facial hair, a hug in public from a parent).
- Tattling is a common way to attract adult attention in the early years of middle childhood.
- Inner control is being formed and practiced each time decisions are made.
- Around age 6-8, children may still be afraid of monsters and the dark. These are replaced later by fears of school or disaster and confusion over social relationships.
- To win, lead, or to be first is valued. Children try to be the boss and are unhappy if they lose.
- Children often are attached to adults (teacher, club leader, caregiver) other than their parents and will quote their new "hero" or try to please him or her to gain attention.
- Early in middle childhood, "good" and "bad" days are defined as what is approved or disapproved by the family.

- Children's feelings get hurt easily. There are mood swings, and children often don't know how to deal with failure.

Physical Development

- Growth is slower than in preschool years, but steady. Eating may fluctuate with activity level. Some children have growth spurts in the later stages of middle childhood.
- In the later stages of middle childhood, body changes (hips widen, breasts bud, pubic hair appears, testes develop) indicate approaching puberty.
- Children recognize that there are differences between boys and girls.
- Children find difficulty balancing high energy activities and quiet activities.
- Intense activity may bring tiredness. Children need around 10 hours of sleep each night.
- Muscle coordination and control are uneven and incomplete in the early stages, but children become almost as coordinated as adults by the end of middle childhood.
- Small muscles develop rapidly, making playing musical instruments, hammering, or building things more enjoyable.
- Baby teeth will come out and permanent ones will come in.
- Permanent teeth may come in before the mouth has fully grown, causing dental crowding.
- Eyes reach maturity in both size and function.
- The added strain of school work (smaller print, computers, intense writing) often creates eye-tension and leads some children to request eye examinations.

Mental Development

- Children can begin to think about their own behavior and see consequences for actions. In the early stages of concrete thinking, they can group things that belong together (for instance babies, fathers, mothers, aunts are all family members). As children near adolescence, they master sequencing and ordering, which are needed for math skills.
- Children begin to read and write early in middle childhood and should be skillful in reading and writing by the end of this stage.
- They can think through their actions and trace back events that happened to explain situations, such as why they were late to school.
- Children learn best if they are active while they are learning. For example, children will learn more effectively about traffic safety by moving cars, blocks, and toy figures rather than sitting and listening to an adult explain the rules.
- Six- to 8-year-olds can rarely sit for longer than 15-20 minutes for an activity. Attention span gets longer with age.

- Toward the beginning of middle childhood, children may begin projects but finish few. Allow them to explore new materials. Nearing adolescence, children will focus more on completion.
- Teachers set the conditions for social interactions to occur in schools. Understand that children need to experience various friendships while building esteem.
- Children can talk through problems to solve them. This requires more adult time and more sustained attention by children.
- Children can focus attention and take time to search for needed information.
- They can develop a plan to meet a goal.
- There is greater memory capability because many routines (brushing teeth, tying shoes, bathing, etc.) are automatic now.
- Child begins to build a self-image as a "worker." If encouraged, this is positive in later development of career choices.
- Many children want to find a way to earn money.

Moral Development

Moral development is more difficult to discuss in terms of developmental milestones. Moral development occurs over time through experience. Research implies that if a child knows what is right, he or she will do what is right. Even as adults, we know that there are often gray areas when it comes to making tough decisions about right and wrong. There are a lot of "it depends" responses depending on the particular situation.

Most adults agree that they should act in a caring manner and show others they care about them. People want to come into contact with others who will reinforce them for who they are. It is no different for children. To teach responsible and caring behaviors, adults must first model caring behaviors with young children as they do with other adults. While modeling, focus on talking with children.

This does not mean talking at children but discussing with them in an open-ended way. Work to create an air of learning and a common search for understanding, empathy, and appreciation. Dialogue can be playful, serious, imaginative, or goal oriented. It can also provide the opportunity to question why. This is the foundation for caring for others.

Next, practice caring for others. Adults need to find ways to increase the capacity to care. Adults generally spend time telling children what to do or teaching facts. There is little time to use the newly developed higher order thinking and to practice caring interactions and deeds.

The last step to complete the cycle of caring is confirmation. Confirmation is encouraging the best in others. A trusted adult who identifies something admirable and encourages the development of that trait can go a long way toward helping children find their place in this world. Love, caring, and positive relations play central roles in ethics and moral education.

Practical Advice for All Adults Working with Children in Middle Childhood

Social and emotional development

- Encourage non-competitive games, particularly toward the beginning of middle childhood, and help children set individual goals.
- Give children lots of positive attention and let them help define the rules.
- Talk about self-control and making good decisions. Talk about why it is important to be patient, share, and respect others' rights. Adults must pick battles carefully so there is limited nagging and maximized respect while children build confidence in their ability to make decisions.
- Teach them to learn from criticism. Ask "how could you do that differently next time?"
- Always be alert to the feelings associated with what children tell you.
- Give children positive feedback for successes.

Physical Development

- It is important to help children feel proud of who they are and what they can do. Avoid stereotyping girls into particular activities and boys into others. Let both genders choose from a range of activities.
- Encourage children to balance their activities between high energy and quiet activity. Children release tension through play. Children may be extremely active when tired. Encourage quiet reading, painting, puzzles, or board games before bedtime.
- Regular dental and physical check-ups are an important part of monitoring a child's growth and development. This allows parents to screen for potential problems. If a child accidentally loses a permanent tooth, finding the tooth and taking it and the child to the dentist may save the permanent tooth.

Mental Development

- Rapid mental growth creates many of the positive as well as negative interactions between children and adults during middle childhood. Some of the ways adults can help children continue to develop their thinking skills are:
- Adults can ask "what if..." or "how could we solve this" questions to help children develop problem-solving skills.
- Reading signs, making lists, and counting prices are all exercises to practice sequencing skills.
- Asking children if you can help them think about ways to talk with other children can provide limited guidance as they negotiate social relationships.

- Picking focused times to talk - without distractions - allows adults and children to converse and listen.
- Each stage in life is a time of growth. Middle childhood is a time to bridge dependence with approaching independence. The time of wonder and spontaneity is fading, replaced by feeling self-conscious and on guard. The new ways children act are ways they are exploring their future potential. Some behaviors will pass, but they must be experienced in order for the child to grow and be ready to face the stage of finding his or her identity during adolescence.

Television

A few cautions about TV: Too little physical activity can affect weight in children. Too many aggressive acts on TV can affect mood and actions, and children can begin to think that what they see on TV is the "norm." Limiting the amount of television watched and monitoring what is watched can help parents assure that the TV that is seen relates to their family's values.

Self-care

There is no magic age at which a child is ready to be left alone. Parents should consider carefully the child's willingness to be left alone, the child's day to day responsibility, the child's ability to anticipate and avoid unsafe situations.

Chores

Children want to feel useful and have a sense that they are contributing to the family. To help children learn household responsibilities, parents might allow children to choose from a list of chores. Paid chores should be in addition to what is generally expected. For example, brushing teeth, taking a bath, and keeping a room clean may be expected. Drying dishes, putting away folded clothes, or emptying trash cans may be chores that earn allowance and contribute to the family.

Money becomes more important since children now understand how it is valued in our society. Earning an allowance is a two-way agreement; children do agree upon work with little reminders in exchange for agreed upon money or goods. Charts with pictures to check-off chores help children remember what to do. The older children get, the more capable they are, but remember to choose age-appropriate duties.

Adolescence

Adolescence is a time of many transitions both for teens and their families. To ensure that teens and adults navigate these transitions successfully, it is important for both to understand what is happening to the teen physically, cognitively, and socially; how these transitions affect teens; what adults can do; and what support resources are available. As you read the following information, keep in mind that while all teens develop, they don't all follow the same timeline.

Physical Development: What Is It?

During the teen years, adolescents experience changes in their physical development at a rate of speed unparalleled since infancy.

Physical development includes:

- Rapid gains in height and weight. During a one-year growth spurt, boys and girls can gain an average of 4.1 inches and 3.5 inches in height respectively. This spurt typically occurs two years earlier for girls than for boys. Weight gain results from increased muscle development in boys and body fat in girls.
- Development of secondary sex characteristics. During puberty, changing hormonal levels play a role in activating the development of secondary sex characteristics. These include: (1) growth of pubic hair; (2) menarche (first menstrual period for girls) or penis growth (for boys); (3) voice changes (for boys); (4) growth of underarm hair; (5) facial hair growth (for boys); and (6) increased production of oil, increased sweat gland activity, and the beginning of acne.
- Continued brain development. Recent research suggests that teens' brains are not completely developed until late in adolescence. Specifically, studies suggest that the connections between neurons affecting emotional, physical and mental abilities are incomplete. This could explain why some teens seem to be inconsistent in controlling their emotions, impulses, and judgments.

How Do These Changes Affect Teens?

- Teens frequently sleep longer. Research suggests that teens actually need more sleep to allow their bodies to conduct the internal work required for such rapid growth. On average, teens need about 9 1/2 hours of sleep a night.
- Teens may be clumsier because of growth spurts. If it seems to you that teens' bodies are all arms and legs, then your perception is correct. During this phase of development, body parts don't all grow at the same rate. This can lead to clumsiness as the teen tries to cope with limbs that seem to have grown overnight. Teens can appear gangly and uncoordinated.
- Teenage girls may become overly sensitive about their weight. This concern arises because of the rapid weight gain associated with puberty. Sixty percent of adolescent girls report that they are trying to lose weight. A small percentage of adolescent girls (1-3%) become so obsessed with their weight that they develop severe eating disorders such as anorexia nervosa or bulimia. Anorexia nervosa refers to starvation; bulimia refers to binge eating and vomiting.
- Teens may be concerned because they are not physically developing at the same rate as their peers. Teens may be more developed than their peers ("early-maturers") or less developed than their peers ("late-maturers"). Being out of developmental "step" with peers is a concern to adolescents because most just want to fit in. Early maturation affects boys and girls differently. Research suggests that early maturing boys tend to be more popular with peers and hold more leadership positions. Adults often assume that early maturing boys are cognitively mature as well. This assumption can lead to false expectations about a young person's ability to take on increased

responsibility. Because of their physical appearance, early maturing girls are more likely to experience pressure to become involved in dating relationships with older boys before they are emotionally ready. Early maturing girls tend to suffer more from depression, eating disorders, and anxiety.

- Teens may feel awkward about demonstrating affection to the opposite sex parent. As they develop physically, teens are beginning to rethink their interactions with the opposite sex. An adolescent girl who used to hug and kiss her dad when he returned home from work may now shy away. A boy who used to kiss his mother good night may now wave to her on his way up the stairs.
- Teens may ask more direct questions about sex. At this stage, adolescents are trying to figure out their sexual values. Teens often equate intimacy with sex. Rather than exploring a deep emotional attachment first, teens tend to assume that if they engage in the physical act, the emotional attachment will follow. They may ask questions about how to abstain without becoming embarrassed or about how they will know when the time is right. They may also have specific questions about methods of birth control and protection from sexually transmitted diseases.

What Can You Do?

- Knowledge about what changes and behaviors during adolescence are normal can go a long way in helping both teens and adults manage the transition successfully. There are also some specific things adults can do to be supportive:
- Don't criticize or compare the teens to others. Teens are already acutely self-conscious about the way they look. They don't need you to point it out to them.
- Encourage teens to get enough sleep. Realize they may need an extra boost in getting out of bed for school. Try to be understanding when teens want to sleep until noon on Saturday.
- Encourage and model healthy eating habits. Keep plenty of nutritious foods in the house. Remember that teens need to take in more calories to fuel their growth. Monitor eating habits accordingly.
- Encourage and model physical activity. Exercise will help teens burn excess energy, strengthen developing muscles, and sleep better at night. It may also help teens become more comfortable in their changing bodies.
- Talk to parents about how to answer questions about sex. If you choose to have a discussion, make sure your answers are honest. Teens are in search of knowledge on this subject. If adults do not provide accurate information, teens are forced to rely on their peers or other potentially inaccurate sources. Unfortunately, such erroneous information is often to blame when teens make poor decisions.
- Be understanding of their need for physical space. Do not take it personally if a teen is not as physically affectionate as he or she was in the past. Do not force a teen to hug or kiss relatives or family friends. Maintain communication, but respect teens' need to withdraw.

- Be patient with excessive grooming habits. Teens often spend large amounts of time grooming themselves and obsessing over skin care products. Often, this behavior merely reflects teens' attempts to maintain some sense of control over their rapidly changing bodies.

Cognitive Development: What Is It?

Most adults recognize that teens have better thinking skills than younger youth. These advances in thinking can be divided into several areas:

- Developing advanced reasoning skills. Advanced reasoning skills include the ability to think about multiple options and possibilities. It includes a more logical thought process and the ability to think about things hypothetically. It involves asking and answering the question, "what if...?"
- Developing abstract thinking skills. Abstract thinking means thinking about things that cannot be seen, heard, or touched. Examples include things like faith, trust, beliefs and spirituality.
- Developing the ability to think about thinking in a process known as "meta-cognition." Meta-cognition allows individuals to think about how they feel and what they are thinking. It involves being able to think about how one is perceived by others. It can also be used to develop strategies, also known as mnemonic devices, for improving learning. Remembering the notes on the lines of a music staff (e, g, b, d, and f) through the phrase "every good boy does fine" is an example of such a mnemonic device.

How Do These Changes Affect Teens?

- Teens demonstrate a heightened level of self-consciousness. Teens tend to believe that everyone is as concerned with their thoughts and behaviors as they are. This leads teens to believe that they have an "imaginary audience" of people who are always watching them.
- Teens tend to believe that no one else has ever experienced similar feelings and emotions. They may become overly dramatic in describing things that are upsetting to them. They may say things like "You'll never understand," or "My life is ruined!"
- Teens tend to exhibit the "it can't happen to me" syndrome also known as a "personal fable." This belief causes teens to take unnecessary risks like drinking and driving ("I won't crash this car"), having unprotected sex ("I can't possibly get pregnant"), or smoking ("I can't possibly get cancer").
- Teens tend to become very cause-oriented. Their activism is related to the ability to think about abstract concepts. After reading about cruelty to animals a teen may become a vegetarian and a member of "People for the Ethical Treatment of Animals" (P.E.T.A.). Another teen may become active in "Green Peace" or "Save the Whales" campaigns.
- Teens tend to exhibit a "justice" orientation. They are quick to point out inconsistencies between adults' words and their actions. They have difficulty seeing shades of gray. They see little room for error.

What Can You Do?

- Don't take it personally when teens discount your experience. Try to empathize with and listen to their concerns.
- Get teens involved in discussing their behavioral rules and consequences. Teens should take a more active role in determining how they should behave. Their advanced reasoning skills make it easier for them to generate realistic consequences for their actions. Listen to their ideas!
- Provide opportunities for teens to participate in controlled risky behavior. Get teens involved in properly supervised extreme sports, such as parachuting, or rock climbing. Such activities will allow teens opportunities to play out their "it can't happen to me" mentality in an environment that won't be deadly if they fail.
- Provide opportunities for teens to get involved in community service. Teens want to become active in things that have deeper meaning. Suggest they volunteer at a homeless shelter, walk dogs for the animal shelter, or take meals to the elderly. Talk with them about their experiences.
- Talk to teens about their views and be open to discussing your own. Find out what they think about news stories on television or in the paper; ask them about their political and spiritual beliefs. Teens are already thinking about these things so give them a non-threatening forum for discussing them.
- Try to build a genuine relationship with your teen. Let them know what you were like as a teen. Talk to them about your mistakes and vulnerabilities. Try to understand their feelings and express yours so you can be understood.

Psycho-Social Development: What Is It?

There are five recognized psychosocial issues that teens deal with during their adolescent years. These include:

- **Establishing an identity.** This has been called one of the most important tasks of adolescents. The question of "who am I" is not one that teens think about at a conscious level. Instead, over the course of the adolescent years, teens begin to integrate the opinions of influential others (e.g. parents, other caring adults, friends, etc.) into their own likes and dislikes. The eventual outcome is people who have a clear sense of their values and beliefs, occupational goals, and relationship expectations. People with secure identities know where they fit (or where they don't want to fit) in their world.
- **Establishing autonomy.** Some people assume that autonomy refers to becoming completely independent from others. They equate it with teen "rebellion." Rather than severing relationships, however, establishing autonomy during the teen years really means becoming an independent and self-governing person within relationships. Autonomous teens have gained the ability to make and follow through with their own decisions, live by their own set of principles of right and wrong, and

have become less emotionally dependent on parents. Autonomy is a necessary achievement if the teen is to become self-sufficient in society.

- **Establishing intimacy.** Many people, including teens, equate intimacy with sex. In fact, intimacy and sex are not the same. Intimacy is usually first learned within the context of same-sex friendships, then utilized in romantic relationships. Intimacy refers to close relationships in which people are open, honest, caring and trusting. Friendships provide the first setting in which young people can practice their social skills with those who are their equals. It is with friends that teens learn how to begin, maintain, and terminate relationships, practice social skills, and become intimate.
- **Becoming comfortable with one's sexuality.** The teen years mark the first time that young people are both physically mature enough to reproduce and cognitively advanced enough to think about it. Given this, the teen years are the prime time for the development of sexuality. How teens are educated about and exposed to sexuality will largely determine whether or not they develop a healthy sexual identity. More than half of most high school students report being sexually active. Many experts agree that the mixed messages teens receive about sexuality contribute to problems such as teen pregnancy and sexually transmitted diseases.
- **Achievement.** Our society tends to foster and value attitudes of competition and success. Because of cognitive advances, the teen years are a time when young people can begin to see the relationship between their current abilities and plans and their future vocational aspirations. They need to figure out what their achievement preferences are-what they are currently good at and areas in which they are willing to strive for success.

How Do These Changes Affect Teens?

- Teens begin to spend more time with their friends than their families. It is within friendship groups that teens can develop and practice social skills. Teens are quick to point out to each other which behaviors are acceptable and which are not. It is important to remember that even though teens are spending increased amounts of time with their friends, they still tend to conform to parental ideals when it comes to decisions about values, education, and long-term plans.
- Teens may have more questions about sexuality. They may ask about adults' values and beliefs.
- Teens may begin to keep a journal. Part of achieving identity is thinking about one's thoughts and feelings. Teens often begin journaling as a way of working through how they feel.
- When they are in their rooms, teens may begin to lock their bedroom doors. Locking doors is a way to establish privacy. As long as teens continue to interact with the family, locked doors are usually nothing to worry about.
- Teens may become involved in multiple hobbies or clubs. In an attempt to find out what they are good at, teens may try many activities. Teens' interests also change quickly. Today they are into yoga, and tomorrow they are into soccer.

- Teens may become elusive about where they are going or with whom. When asked what they'll be doing for the evening, teens typically reply with "nothing" or "hanging out." When asked whom they'll be with, teens reply, "just some friends."
- Teens may become more argumentative. Teens may question adults' values and judgments. When teens don't get their way, they may say, "You just don't understand."
- Teens may not want to be seen with parents in public. They may make parents drop them off a block from their friends' houses or from school.
- Teens may begin to interact with parents as people. Even though they may not want to be seen with parents in public, teens may begin to view parents more as people. They may ask more questions about how a parent was when he or she was a teen. They may attempt to interact with adults more as equals.

What Can You Do?

- Encourage involvement in multiple groups or activities both within school and after-school. Realize that teens are trying to gain a sense of achievement—a sense of being uniquely good at something. Don't get frustrated if they frequently change their minds. At the same time, encourage them to stick with a project or activity long enough to establish some skills.
- Praise teens for their efforts as well as their abilities. This will help teens to stick with activities instead of giving up if they are not immediately successful.
- Help teens explore career goals and options. Take teens to work so they can see what adults do. Set up opportunities for them to "job shadow" others. Ask them questions about their future career goals. Remember that figuring out what they don't want to do is just as important as figuring out what they like!
- Give teens an opportunity to establish their behavioral guidelines and consequences. Their advanced cognitive skills coupled with their need for autonomy makes this a perfect time for them to provide suggestions and to demonstrate responsibility for their own behavior.
- Establish rituals to mark significant passages. Few rituals in our modern society mark the passage of teens to adulthood. Celebrate the teen's first driver's license and his or her ability to vote.
- Be aware of who your teens' friends are and what they are doing.
- Continue to provide a structured environment. Teens should be allowed to have more independence, but not enough to place them in jeopardy. Despite their complaints, teens rely on adults to provide them with the sense of safety and structure they need to deal effectively with all the psychosocial tasks of adolescents.

Gender Differences

Boys and girls face different challenges in our culture and may have different emotional needs during adolescence. Girls tend to have lower self-esteem than boys. Some girls may need help learning to express anger and to be more assertive. In contrast, boys may need to learn to be more cooperative and that it's okay to express emotions other than anger.

Cultural Differences

For many adolescents, this may be the first time that they consciously recognize their ethnic identity. Ethnic identity includes the shared values, traditions and practices of a cultural group. Feeling positive about one's ethnic identity is important to the self-esteem of an adolescent. This can be a difficult challenge for adolescents from minority cultures in the United States, given that they are often faced with negative stereotypes about their culture.

Behavioral Development

All of the developmental changes that adolescents experience prepares them to experiment with new behaviors. This experimentation results in risk-taking, which is a normal part of adolescent development. Engaging in risk-taking behavior helps adolescents to:

- Shape their identities.
- Try out their new decision-making skills.
- Develop realistic assessments of themselves.
- Gain peer acceptance and respect.

Unfortunately, some of the risks that adolescents pursue may pose a real threat to their health and well-being. These include motor vehicle accidents, pregnancy, alcohol and drug abuse, and cigarette smoking. Adolescents need guidance to channel the drive toward risk-taking behavior into less dangerous and more constructive pursuits.

First, adults who work with adolescents must be able to talk with them about the process of decision-making regarding sex, drugs, alcohol and other safety concerns. The goal is to help the adolescent weigh the dangers and benefits of a particular situation, consider his or her own strengths and weaknesses that may affect decision-making, and then make the best decisions possible.

Second, adults must be aware of positive pathways that teens might take to satisfy the need to take risks: becoming involved in a school play, learning to play a musical instrument, taking up a sport. A simple stretch beyond one's former capacities constitutes a risk and can satisfy many adolescents' need for risk taking.

Most adolescents will take risks. Eventually most will learn how to realistically assess risks and then will change their behavior accordingly. For others, risk-taking behavior may signal a problem that is a serious threat to their well-being. Signs that an adolescent's risk behaviors are beyond normal experimentation include behaviors that:

- Begin early, age 8 or 9.
- Are on-going rather than occasional.
- Occur in a social context with peers who engage in the same activity.

The areas of most concern for youth at risk of developing problem behaviors are:

- Drug and alcohol abuse.
- Pregnancy and sexually transmitted disease.
- School failure and dropping out.

- Crime, delinquency and violence.

There are several factors that can help prevent the development of problem behaviors in adolescents, even under adverse circumstances such as poverty:

- Stable, positive relationship with at least one caring adult.
- Religious and spiritual anchors.
- High, realistic academic expectations and adequate support.
- Positive family environment.
- Emotional intelligence and ability to cope with stress.

Unfortunately, these factors are not ones that an individual can create alone. A community must be able to offer the resources to build these elements into its structure. In order for this to happen, the needs of youth must be given priority.

Tips for Responding to Teenagers

- Keep in mind that it's normal for your teens to want to be independent from you. Try to look at their behaviors through that lens.
- Admit to yourself when you have overreacted. Go back to your teen. Admit that you overreacted. Apologize if that feels OK to you. Then sit down and begin a real conversation.
- Forgive yourself if you've responded negatively to a child. Many parents overreact out of fear or concern for their child's welfare. Remember it's always possible to recover from these incidents. Usually the first step is going to a child and apologizing. When the relationship has been repaired, you can move on with your teen to a more positive place.
- Build a support network around you. Parents who feel supported by friends, family members, clergy, or other trusted professionals, find it easier to deal with frustrating behavior from their teens.
- Find out why your teen is behaving in a particular way. Teens say they want parents to "walk a mile in their shoes" and to try to understand their point of view. Remember to listen as much as, or more than, you talk.
- Pick your battles. Give your teenagers privacy and allow them to make some of their own important decisions.
- Help your teen gain the skills s/he needs to live independently. That is one of your most challenging, but important jobs, as a parent.
- Think about how your responses to your teen's behavior will affect the closeness you share. Try to maintain a close connection with your teen. Remember that when teens feel connected to their parents, they are less likely to get involved in problem behaviors such as drug use or early sexual activity. (However, don't stop using a firm, fair and consistent set of household rules).

Developmental Tasks: Adolescents face the major task of creating stable identities and becoming complete and productive adults. They take on this task in small steps along the way as they adapt to the changes they experience.

Developmental Goal	Reaching the Goal: Facts and Tips
Achieve new level of closeness	Adolescents learn through experimentation to interact and trust with peers with others in more adult ways.
Gain independence from parents	Change is smoother if adolescents and their parents agree and develop new status within the family on some level of independence that increases over time. Example: Setting curfew times that increase as the adolescent matures and shows responsible behavior.
Develop a sense of personal identity.	New cognitive abilities give adolescents the chance to reflect on who they are and what makes them unique. Adults can help adolescents in this quest by: Engaging them with non-threatening questions, such as: Who do you admire? What do you like to do in your free time? What do you consider to be your strengths? What have you done in your life that you feel proud of? Casually showing rational decision-making strategies, such as discussing how someone you know defined a problem, generated options, anticipated outcomes, and made a decision. Discussing ethical and moral problems that are in the news.
Move toward autonomy in the larger world.	Adults can help them to gain insightful experience in the world by encouraging them to: Take on more responsibility in schoolwork and school-related activities. Get involved in community activities. Hold part-time or summer jobs. Develop future goals. Examine career/educational options.

Four Major Questions Facing Adolescents

The growth of one's intellect from concrete to abstract thinking makes adolescence an intense time of self-discovery. In their quest to define themselves and their relationship to the world, adolescents begin to ask themselves four basic abstract questions:

1. Who am I? (pertaining to his or her sexuality and social roles)

2. Am I normal? (Do I fit in with a certain crowd?)
3. Am I competent? (Am I good at something that is valued by peers and parents?)
4. Am I lovable and loving? (can someone besides Mom and Dad love me?)

Adults who work with adolescents need to recognize that these questions are quite central to the concerns of adolescents and should give them a chance to explore their own beliefs and find their own answers to these questions.

Four Major Questions Facing Adolescents - Guidelines for Adults

Who am I?

Give them the freedom to explore their world. Only then can adolescents begin to answer this question.

Am I normal?

Give them room to be like their peers. Fitting in with peers helps adolescents feel "normal." Monitor youth activities by using the four "W" questions:

1. Where are you going?
2. With whom are you going?
3. What are you doing?
4. When will you be home?

Am I competent?

- Assist adolescents with their problems and challenges but do not solve them.
- Ask questions instead of telling, such "What are some things you could do?"
- Guide but do not direct.

Am I lovable and loving?

Adolescents develop best when they have supportive families and community life that include:

- Warmth and mutual respect.
- Serious and lasting interest of parents and other adults.
- Adult attention to the changes they are experiencing.
- Clear standards regarding discipline and close supervision.
- Communication of high expectations for achievement and ethical behavior.
- Democratic ways of dealing with conflict

Module 4: DIAGNOSES

Defining Special Needs

Special needs can be in the area of mental, social, emotional, or physical development. Children's disabilities vary both in form and in degree of severity. They include, but are not limited to, physical disabilities such as cerebral palsy or muscular dystrophy; auditory or visual disabilities; health impairments (asthma, cystic fibrosis, AIDS); developmental disabilities (mental retardation, learning disabilities); emotional disabilities; and speech/language disabilities.

An individual may be diagnosed with more than one disability. For example, a child with Down syndrome may have mental retardation, speech difficulties, and heart problems. Depending on how broadly the definition is applied, between 10% and 20% of all children can be considered to have special needs. Over the last several years, great strides have been made in the field of developmental disabilities and special needs. Positive changes in the attitudes and practices of professionals, emphasis on family-focused intervention, and enhanced public awareness have all reinforced the fact that people with special needs are first and foremost people - with interests, desires, and expectations similar to those of typically developing peers.

The information in this Module is being provided in order to help you understand the special needs of the children receiving respite services. This information is not to be used to diagnose children - this is not the role of the respite care provider.

Many myths exist about people with disabilities. Through misinformation and/or prejudice, fears, and negative attitudes have developed. The following are common myths and misconceptions. Respite Providers need to be concerned with facts.

Myths vs. Facts

Myth 1: People with disabilities have lives totally different from that of most other people.

FACT: People with disabilities go to school, get married, work, have families, do laundry, grocery shop, laugh, cry, pay taxes, get angry, have prejudices, vote, plan and dream like anyone else.

Myth 2: People with disabilities always need help.

FACT: Many people with disabilities are very independent.

Myth 3: People with disabilities are more comfortable with being with "their own kind."

FACT: Years of grouping people with disabilities in separate schools and institutions have reinforced this misconception. Today more and more people with disabilities are living in mainstream.

Myth 4: No one should ever be curious and ask an individual about their disability.

FACT: Most people are endowed with a natural curiosity about other people. Asking questions helps to remove stigma and enhance understanding and acceptance. Society is just beginning to learn to treat people with disabilities in a normal, respectful manner.

Intellectual Disability

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

There are differing levels of Intellectual Disabilities: Most individuals with intellectual disabilities will fall into what used to be referred to as a mild range. IQ scores will generally fall between 50 and 70, and these individuals will usually reach a mental age of 8-12. They often can care for their own needs, attend school, and hold jobs. Individuals with a moderate ID usually reach a mental age of 5 - 8 years and require more intense educational and community supports. IQ scores will usually fall between 25 and 55. Individuals with a more severe ID, with a mental age of 2 -3 years, are often non-verbal or have minimal speech, require constant supervision, and have significant learning and self-care needs. IQ scores will fall between 20 and 40. Those with a profound ID are usually identified with a neurological condition. Individuals who have a profound ID have IQ scores below 20, and exhibit considerable impairment in sensory motor functioning during early childhood years.

The needs of a child with Intellectual Disabilities are individual and varied. Each child with Intellectual Disabilities will have his/her own strengths, needs, and learning style. Verbal directions should be given in simple, concrete terms, and repeated if necessary. Leave time for processing between repetitions. It may also be helpful to give visual cues and models or hand-overhand demonstrations. Developmental tasks should be divided into small steps and worked on one step at a time. Provide many opportunities for frequent successes and positive feedback. Behavioral techniques can be helpful for teaching and setting clear positive expectations and limits. It is important to involve a child with Intellectual Disabilities with typically developing peers to encourage language, imitation and learning, as well as social interaction and play.

Important: There are many possible causes of Intellectual Disabilities or any other condition. These possible causes are not important when working with children as a Respite Provider. Placing blame is not productive in the process of creating positive outcomes for children and families. It is important for Respite Providers to get information regarding the child's needs, abilities, and progress from the parents/guardians in order to provide exemplary care.

Intellectual functioning—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on.

One criterion to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.

Standardized tests can also determine limitations in **adaptive behavior**, which comprises three skill types:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.

- Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

On the basis of such many-sided evaluations, professionals can determine whether an individual has an intellectual disability and can tailor a support plan for each individual.

But in defining and assessing intellectual disability, the American Association on Intellectual and Developmental Disabilities (AAIDD) stresses that professionals must take additional factors into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave.

Finally, assessments must also assume that limitations in individuals often coexist with strengths, and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period.

For more information:

- Click here to [access the current AAIDD definition manual of intellectual disability](#).
- Click here to [read an FAQ on the AAIDD definition of intellectual disability](#).

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Down Syndrome

Down syndrome is sometimes referred to as Trisomy 21. The various physical and mental abnormalities associated with Down syndrome are caused by a genetic imbalance. Normally, every human cell contains 46 chromosomes. However, individual diagnosed with Down syndrome will have 47 chromosomes in each cell, with the exception of the sperm and ova. This disorder occurs in approximately one out of every 800-1,000 live births. Presently about 4,000 children per year will be born with Down syndrome in the United States. Parents of any age may have a child with Down Syndrome, however it is more common in children born to women over the age of thirty-five. Down syndrome results in physical and developmental features including:

- Poor muscle tone
- Slanting eyes with folds of skin at the inner corners (epicanthal folds)
- Hyper flexibility of joints (ex. "w" sitting)
- Short, broad hands with a single crease across the palm on one or both hands
- Broad feet with short toes
- Flat bridge of the nose
- Short, low-set ears
- Short neck

- Small head
- Small oral cavity, resulting in a protruding tongue
- Small stature
- Speckling of the iris (Brushfield Spots)
- Wide gap between the first and second toes
- Short, high-pitched cries in infancy
- Congenital heart disease
- Mental Retardation

The presence and degree of the aforementioned characteristics vary with each child. Many other features are associated with Down syndrome, and some of those listed above may be found in children without this condition.

With present medical and surgical intervention, and with improved educational opportunities, the prognosis for children with Down syndrome has improved dramatically. Many individuals now survive beyond the ages of 50 or 60. The most significant improvement in their physical and mental development has resulted from deinstitutionalization and from training in self-help and work skills.

Children with Down syndrome tend to be hypotonic, that is, to have low muscle tone at birth, making them floppy and poorly coordinated; this does improve with age, however. Overall growth is relatively slow, and final height is reached at around age 16. Girls may menstruate and be fertile, but males are usually infertile.

Mental retardation, which is invariably associated with this syndrome, becomes more evident as the child grows older and IQ and social maturity tests include more items calling for abstract reasoning. Performance on adaptive behavior tests usually improves. Serious health problems that may accompany Down syndromes are congenital heart disease and blockage in the small intestine (duodenal atresia). Because these children have a lowered resistance to infection, they frequently have respiratory infections, runny nose (chronic rhinitis), and conjunctivitis. Also common are eye problems, such as crossing (strabismus) or refractive error (e.g. farsightedness and nearsightedness), and mild-to-moderate hearing loss. Children with Down syndrome are 10 to 20 times more likely to develop acute leukemia.

Children who have Down syndrome have specific developmental/medical needs which Respite Providers should be aware of. An infant with Down syndrome may be difficult to handle because of decreased muscle tone (i.e. may feel like the infant is "slipping" through your arms). Wrapping the infant in a blanket may make holding him/her easier. Infants with Down syndrome should be fed slowly, with rest periods during feeding. This is especially important if the infant has congenital heart defect. The infant should be held with head slightly raised to prevent milk from flowing from the throat into the inner ear and solid food should be pushed towards the back of the infant's tongue. The filled spoon should be pressed down slightly on the infant's tongue to encourage lip closure and to facilitate food intake, and bits of solid food can be placed on one side of the mouth to encourage rotary movement and more mature chewing patterns. Many infants with Down syndrome need increased fiber and fluid in their diet as well. As Respite Providers, it is always important to check with parents on the individual child's nutritional needs.

Appropriate developmental stimulation of all children is important and especially for children with special needs, such as Down syndrome. Create a supportive learning/living environment that

stimulates all the senses. It will also be important to prevent over-stimulation. Encourage the child to initiate and to take turns. Give the child ample time to act and then respond positively to the child's attempt to engage you.

Obesity is another problem that can occur. Short stature is common and accentuates weight, as does the tendency for children with Down syndrome to be more passive observers rather than active participants. This issue can be addressed through well-balanced diet, exercise, and inclusion of children with Down syndrome in all aspects of community life.

Autism and Autism Spectrum Disorders

Autism is a neurological disorder causing lifelong developmental disabilities that usually appear during the first three years of life. It occurs in approximately 1 out of every 500 individuals (Center for Disease Control and Prevention, 1997). It is four times more likely to occur in boys than girls and crosses all racial, ethnic, and social boundaries. However, when girls are affected they are likely to be more seriously disabled and to have lower IQ scores.

As early as the late eighteenth century, medical texts described cases of children who did not speak, were extremely aloof, and who had unusual memory skills. It was not until 1943, however, that Leo Kanner, a psychiatrist at Johns Hopkins Hospital in Baltimore, first identified autism. He described the background and behavior of 11 children with very similar characteristics:

- Difficulty developing relationships with people
- Delayed speech acquisition and difficulty using speech once it is developed (echolalia, pedantic speech)
- Repetitive and stereotypical behavior (stimulating behaviors) such as rocking, waving fingers in front of face, twirling objects or flapping arms.
- Lack of imagination
- Good rote memory
- Obsessive insistence on sameness or routine
- Normal physical appearance
- Poor or no sense of safety to self
- Impaired sense of difference between private and public behavior

Kanner called this condition Early Infantile Autism, from the Greek word self (auto), because these children seemed locked inside themselves. The general diagnosis used today for this cluster of symptoms is **Autism** or **Autistic Spectrum Disorder**. This refers to impairments in social interaction, communication, and imaginative play prior to age three. Children will exhibit stereotyped behaviors, interests and activities.

Research is still needed to determine the cause of autism, but there appears to be several

possibilities, each with distinct neurological effects. Some cases of autism have been associated with untreated phenylketonuria (PKU), Rubella, Fragile X Syndrome, and chemical exposure during pregnancy. No known factors in the psychological environment of a child have been known to cause autism. It can occur by itself or in association with other disorders, such as, epilepsy, mental retardation, attention deficit disorder, oppositional defiant disorder, attention deficit hyperactivity disorder, and mood disorders.

Autism is a spectrum disorder. **Autism Spectrum Disorder** means that there are other diagnoses that are considered to be within the autistic "family", but have specific developmental, social, and/or behavioral characteristics that set them apart from the general diagnosis of Autistic Disorder. These diagnoses include:

Asperger's Syndrome - impairments in social interactions and the presence of restricted interests and activities. There are no clinically significant delays in language and testing in the average to above average range of intelligence.

Pervasive Developmental Disorder - Not Otherwise Specified - (PDD-NOS) - when the child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors, the diagnosis of PDD-NOS is given.

Rett's Disorder - a progressive disorder which to date has only occurred in girls. Periods of normal development occur, and then the loss of previously acquired skills. There is a loss of purposeful use of the hands replaced with repetitive hand movements. This disorder is usually evident between the ages of one and four.

Childhood Disintegrative Disorder - Normal development occurs for at least the first two years, with a significant loss of previously acquired skills thereafter.

Because there are no medical tests for autism, at present, the diagnosis must be based on observation of the child's behavior. An individual with autism will manifest behaviors in a variety of forms and degrees, but all will display some degree of impaired social relationships, difficulty in verbal and non-verbal communication, have difficulty with transitions, and have a restrictive repertoire of activities and interests in imaginative play. No two people with autism display the same characteristics.

A lack of social interaction is a hallmark of autism. People with autism often:

- Have difficulty making eye contact
- Are not demonstrative about their attachment to others
- Voluntarily spend an unusual amount of time alone
- Often develop a strong attachment to particular objects
- Have a high pain threshold and often do not seek comfort when hurt or upset
- Experience difficulty in perceiving the emotions of others
- Have few friends

Although most children do not begin to withdraw until around two years of age, parents usually pick up signs of problems in social development before that. When a child with autism does begin to withdraw from the outside world, they may begin to engage in self-stimulating behaviors described earlier. During the years between three and five, the isolation of the child with autism seems

especially severe and the delayed appearance or absence of language is an important factor that makes socialization difficult. The lack of appropriate emotional responsiveness is very distressing for families. Children with autism express joy, fear, anger, and other moods, but they are out of sync with social expectations. For instance, they may be completely miserable over a slight reprimand such as "put your shoes away" and completely ignore an important one such as "get out of the road".

After the age of five, there can be an improvement in social skills, especially in the more able child. However, learning to behave appropriately and interact with others is much harder for children with autism than it is for other children. There is a strong need to have consistency and a structured environment. Children with autism exhibit a greater potential for tantrums and other inappropriate behavior that restricts typical social interaction with peers. Play skills must be taught and social skills modeled.

Many children with autism seem to prefer to be alone and engage in unusual activities, such as playing with bits of string, spinning the wheels on a car over and over again, or walking the perimeter of the backyard repeatedly. Some children are compelled to "run" away from their house or yard, which poses a great safety concern. It is critical to know if a child is prone to slipping away so that the environment can be secured for safety.

As they enter adolescence, most youths with autism become more flexible in how they respond to their environment and show interest in people and the world around them. Some teenagers start to realize the difference between themselves and others, and this can be a source of frustration or even depression. Depression is particularly problematic for children with Asperger's syndrome.

Areas affected by autism:

1.Communication:

- Language develops slowly or not at all
- Uses words without attaching the usual meaning to them
- Communicates with gestures instead of words
- Short attention span

2.Social Interaction:

- Spends times alone rather than with others
- Shows little interest in making friends
- Less responsive to social cues such as eye contact or smiles

3.Sensory Impairment:

- Tactile defensiveness: Avoids letting others touch them, becomes distressed with hair washing or cutting, changing clothes, may not like getting hands or feet dirty
- Oral defensiveness: dislikes certain textures of food, tooth brushing or face washing

- Auditory defensiveness: certain noises are disturbing such as vacuum cleaners, fire alarms, or even rain hitting a roof. Some children may scream to block out the sounds
- Gravitational insecurities: fear of change in position or movement (ex. Going up or down stairs)
- Visual problems: sensitivity to light and visual distraction; may startle more easily and avoid eye contact

4.Play:

- Lack of spontaneous or imaginative play
- Does not imitate others' actions
- Does not initiate pretend games

5.Behaviors:

- May be overactive or very passive
- Throws tantrums for no apparent reason
- Perseverates (shows an obsessive interest in a single item, idea, activity or person)
- Lack of danger sense
- May show aggression to self or others
- Often has difficulty with changes in routine

While many children avoid direct eye contact, some have incredible peripheral vision and do not have to look at you to see you. Some children with autism can only tune into one sense at a time. For example, a child may be tuned into the auditory sense and focused on listening. That child would not seem to be paying attention to what is visual. However, children with autism are incredibly aware of what is going on around them despite giving the appearance of being indifferent or unaware.

Some children show a distinct lack of attachment to people. Some parents never hear their child call them Mom or Dad. Nevertheless, many children do show affection for their parents, as well as people who show respect for the child, have a calm manner, and show interest in the child's abilities.

Many children with autism appear to live a life of extreme isolation. Contributing to the isolation is the need that many children have for sameness. They may become very upset if objects in their environment are changed. Some children have the need for a very specific routine that must be adhered to. It is their insistence for sameness that gives the child with autism some control and sense of security in a bewildering and often frightening world. Structured activities and following routines helps these children get through the day. They know what to expect and that is essential for them in order to function. Often a written schedule of activities helps them make transitions from one activity to another. It is extremely important to prepare a child with autism for any change in routine in advance.

As mentioned previously, children with autism seem to have a limited range of play skills and interests. The younger child may be preoccupied with activities that provide sensory stimulation or

satisfaction such as flapping fingers in front of their eyes or sifting sand. Other children may develop an intense attachment to a particular and unusual object or group of objects that are collected and must be with them at all times. Some examples of these are bottle caps, soap bottles, a hair pick, a plastic shovel, or toothbrushes.

Children who have developed speech may have an intense fascination with a particular topic and spend great portions of the time collecting information on it. They can be quite persistent trying to discuss this information and can become quite repetitive. Children with autism have a broad range of language abilities ranging from no verbal communication to quite complex communication. Those children with limited or no speech can use other forms of communication including sign language, picture communication boards, computers, facilitated communication, or a combination of these. While there are many differences in the range of language impairments, one extreme form is called echolalia - echoing other people's language by constantly repeating a portion of what they hear. Some specialists believe that echolalia is repeated in an automatic manner without having communicative intent, while others think that children with Autism use it to get attention or as a way of participating, while others feel that it is a way of saying "I don't understand".

Children with autism often experience stereotypical behavior, self-injurious behavior, and aggression. Recent research has discovered that stereotypical behaviors are often an attempt by some individuals with autism to communicate boredom, are a way to regulate their own level of awareness, or as a release of tension. Children often engage in these behaviors when they are excited or over-stimulated, confused, or frustrated. Rocking behaviors are probably related to an underdeveloped vestibular system. These behaviors don't need to be changed unless they are interfering with what the child is doing. Some individuals with autism have self-injurious behaviors such as head banging, biting, or scratching. Though often harmless as an occasional symptom, it can become extremely damaging when done to excess. It is possible that pain sensitivity is reduced in certain people with autism. They simply do not feel pain the way others would. Be on the alert for serious harm that may require medical attention. Redirection can help, as can relaxation techniques, music, and deep pressure.

Aggressive behaviors are similar to self-injurious behaviors, but the behavior is directed toward others. Some children bite, shove, or hit. Find out what strategies are to be used if aggression occurs and be consistent in implementing them. Obviously, the best course of action is to know in advance what, if anything, triggers this behavior.

The severe communication disorder associated with autism results in confusion, frustration, and anxiety that can cause withdrawal or a variety of behavioral outbursts. The issues that greatly impact behaviors are limited understanding of the meaning of words. Children with autism are often "tuned out" or miss information that other children pick up. They may have trouble remembering the correct order of sequence of events, which makes it hard to understand that cause/effect relationships needed to predict and prepare for future events. Children with autism may not know how to ask for help or more information.

Stay calm and show interest in the child's abilities. Don't try too hard. Have a lot of patience, especially when there is a lack of communication skills or behaviors are present. Be consistent, and keep sensory stimulation to a minimum. Give simple and precise directions using words, gestures, pictures, or written words to help facilitate understanding. Give the child plenty of time to respond.

Children with autism can pose a variety of challenges. Successful interaction involves building trust through consistency, comfort, having their wants and needs understood and met. An environment that is structured and predictable, where routines are followed, and alone time is honored helps reduce stress.

Understanding Youth with Emotional and Behavior Difficulties

Of the estimated 7.5 million children under the age of 18 who have diagnosable psychological disorders, nearly half of these children are severely disabled by their mental health problems (U.S. Select Committee on Children, Youth and Families, 1991). In the State of Maine, 30,000 children and adolescents have mental health problems. An estimated 14,000 are diagnosed with a severe emotional disability (SED). As early as 1909, the White House Conference on Children expressed concern for the mental health of children and youth. National and state commissions and panels noted the shortages of community based services for children with severe emotional disabilities, the lack of coordination among child welfare, mental health, and other youth serving systems, and the increasing numbers of children in private psychiatric hospitals and residential treatment centers. As a result, national and state efforts have worked to improve mental health services through community-based programs such as Respite Care.

According to PL 94-142 (the federal law mandating educational services for all children with handicapping conditions), "seriously emotionally disturbed" is defined as a condition exhibiting one or more of the following characteristics over a long period of time, to a marked degree adversely affecting educational performance:

- An inability to learn which cannot be explained by intellectual, sensory, or health factors
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers
- Inappropriate types of behavior or feelings under normal circumstances
- A general pervasive mood of unhappiness or depression; or
- Personal or school problems

Children with severe emotional disabilities (SED) often arouse negative feelings and reactions from other children and adults. Because of their disruptive, impulsive and boisterous behavior, children with SED are often alienated and isolated from their classmates and playmates. They have usually experienced both academic and social failure, and most teachers find it difficult to work with these children. Children with SED carry the added burden of having a handicapping condition that is not visible. The stigma surrounding mental illness in our society means children with SED and their families experience shame, embarrassment and isolation from the rest of their communities.

In an effort to change the way mental health services have been provided to families and children, and to increase the partnership between families and providers, community-based services look at family strengths. Focusing on family strengths assumes that:

- Families of children with emotional and behavioral disabilities have strengths.
- Families are sources of wisdom and knowledge about their children and should be recognized as experts.
- Parents should be provided as much information as they want about their child's disability.

- Children with emotional and behavioral difficulties have strengths, deserve caring and respect.
- Diversity and individual differences are to be valued and celebrated.
- Children with emotional and behavioral difficulties need to live in their own homes and their own communities.
- The values, choices, and preferences of families should be respected.

One of the key elements of family strength-based community services is parent-provider collaboration. Instead of "we" and "they", providers and families become partners in the therapeutic process. Families have knowledge about what has happened to their child and they are the primary resource for the respite worker. From the very beginning of a working relationship, it is imperative that providers find ways to build a positive partnership with parents and their child. This means seeing parents as the experts, and engaging them as equal members of the team.

Respite providers can be active participants in creating this partnership. Workers should look at the resilience, flexibility, endurance and courage displayed by children with special needs and their families. Providers should provide accurate information and support. It is also very important to acknowledge the limits of our own knowledge about mental illness. Parents expect and appreciate honesty. If you don't know what to do, say so, directly and clearly.

The *Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV)* was first published by the American Psychiatric Association Committee on Nomenclature and Statistics in 1952 in order to establish an official psychiatric classification system, to assist clinicians in making accurate and appropriate diagnoses, as well as to collect statistical information on mental disorders. Since that time, The DSM has gone through a number of revisions, resulting in the DSM-IV, which was published in 1994 by the American Psychiatric Association. According to the DSM-IV the definition of a mental disorder is "a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g. a painful symptom), or disability (i.e., impairment in one of or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom" (p. xxi). The behavioral needs discussed in this module all contain specific criteria for diagnosis in the DSM-IV. ***Criteria in the DSM-IV should be used as guidelines by individuals trained and experienced in diagnosis and mental health issues.***

Attention Deficit (Hyperactivity) Disorder (ADD / ADHD)

Children with ADD or ADHD have difficulty sticking to tasks, sustaining attention, following through on instructions, chores or duties, organization and completing tasks work. Often the child fails to give adequate attention to work and makes careless mistakes. Children who are diagnosed with ADHD also have additional problems with impulsivity. In school, the child may talk out of turn, have trouble remaining seated, fidget, squirm or run. Because the child with ADHD displays many behaviors that other children find annoying and bothersome, making and maintaining friendships can be frustrating and difficult. This can lead to low self-esteem, low frustration tolerance, and temper tantrums. As children reach adolescence, impulsive and "acting-out" behaviors can become more serious. Approximately 3% - 7% of school age children are diagnosed with ADD/ADHD and the disorder is twice as frequent in boys as in girls. Children with ADD/ADHD are also more likely to have learning disabilities.

Conduct Disorder

The child diagnosed with conduct disorder shows a persistent pattern of conduct that repeatedly violates social rules and the basic rights of others. Low self-esteem, irritability, temper outbursts, and a low frustration tolerance are also present. It is estimated that as many as one in every ten children has conduct disorder, and is considered one of the most frequently seen mental disorders of adolescence (APA, 1998). Symptoms of conduct disorder include:

- Aggression towards people and/or animals
- Destruction of property/setting fires
- Deceitfulness or theft (e.g. breaking into homes, cars)
- Serious violations of rules (e.g. staying out all night, running away from home, truancy)
- Often starting fights/using weapons in fights
- Forcing sexual activity

Other problems such as hyperactivity, anxiety, depression and academic difficulties may also be present. Factors that can also influence the development of conduct disorder include:

- Inconsistent rules and harsh discipline
- Lack of supervision or guidance
- Frequent changes in caregivers
- Poverty
- Neglect
- Involvement with a delinquent peer group

While conduct disorder is one of the most difficult behavior disorders, symptoms can be lessened with psychotherapy and medication. Other interventions such as parent training, family therapy, training in problem-solving skills and community based services which focus on the child can also help.

Oppositional Defiant Disorder (ODD)

Children diagnosed with oppositional defiant disorder (ODD) display patterns of negativistic, hostile and defiant behavior. Often, this diagnosis occurs before a diagnosis of conduct disorder is given. ODD can begin when the child is of preschool age. Generally, the diagnosis of conduct disorder is given to an older child. Individuals diagnosed with ODD are argumentative with adults, become easily annoyed by others, defy rules and adult requests, and tend to blame others for difficulties. These children and youth also have low self-esteem, poor frustration tolerance, and school difficulties. They are at high risk for drug and alcohol abuse.

Depression

Depression is one of the most common psychiatric diagnoses given to children. It occurs in as many as one in every 33 children and one in eight adolescents. Children with this diagnosis tend to look sad, are not physically or verbally aggressive towards others, and are often at high risk for hurting themselves. They may appear anxious, immature, irritable or sad. They show a diminished interest or pleasure in all, or almost all school, family or social activities. Children and youth with depression may experience physical symptoms such as fatigue, stomachaches, headaches or insomnia. The child often expresses feelings of worthlessness, self-doubt and guilt.

The individual may have difficulty concentrating on schoolwork or other regular activities. For some children and youth, the intense feelings of worthlessness may lead to recurrent thoughts of death and suicide. Children and youth with more severe forms of depression may have attempted suicide or have a specific plan for committing suicide. Counseling and/or medication along with a well-developed plan of care are helpful in alleviating depressive episodes. Statistics show that with treatment, the majority of people (80%-90%) with depression show improvement.

Causes of depression include:

- Biochemistry - a deficiency in the chemicals serotonin and norepinephrine;
- Genetics - depression can be present in families. A family history of depression increases the chances of an individual developing depression;
- Personality - people who are easily overwhelmed by stress, have low self-esteem, or generally pessimistic appear to be more vulnerable to depressive disorders;
- Environmental factors - such as abuse, neglect, poverty and violence can increase the risk of depression in people who are already vulnerable.

Anxiety Disorders

Individuals diagnosed with an anxiety disorder experience an overwhelming sense of fear and dread that generally incapacitates them for a period of time. The feelings of anxiety and dread are often accompanied by physiological responses such as sweating, a "racing heart", and dizziness. Anxiety disorders are among the most common mental, emotional and behavioral problems that occur during childhood and adolescence.

In **phobic disorders**, children experience a fearful and/or anxious response to such events as: social situations, closed spaces, heights, or animals. In all instances, the extent of the anxiety and fear is disproportionate to the actual situation.

Children and youth diagnosed with **Post-Traumatic Stress Disorder** show symptoms of anxiety as a reaction to extreme stress and psychological and/or physical trauma that are beyond the range of normal human experience. Adolescents experience recurrent, intrusive, and distressing recollections of the trauma. In young children experiencing PTSD, repetitive play involving themes or aspects of the trauma is expressed. In very young children, loss of recently acquired developmental skills, for example, toilet training, may be considered equivalent to the "numbing" or non-responsiveness seen in adults diagnosed with PTSD.

Post-Traumatic Stress Disorder

"Our brains are sculpted by our early experience. Maltreatment is a chisel that shapes a brain to contend with strife, but at the cost of deep, enduring wounds." (Teicher, 2000, p.67)

Trauma is a sudden unexpected event outside the realm of typical human experience that overwhelms and creates feelings of helplessness, vulnerability, loss of safety and control in an individual. The **Merriam-Webster Collegiate Dictionary** defines trauma as "(a) an injury (as a wound) to living tissue caused by an extrinsic agent [surgical trauma]; (b) a disordered psychic or behavioral state resulting from mental or emotional stress or physical injury..."

Trauma information grew out of work in the 1980s with veterans of the Vietnam War. The medical profession realized that large numbers of the individuals returning from Vietnam were exhibiting the same symptoms - hyper-vigilance, hyper-arousal, depression, sleep and eating disorders, flashbacks and nightmares. This led to the establishment of the medical framework of trauma and the classification in the DSM-IV of Post-Traumatic Stress Disorder. PTSD is given as a diagnosis when a person is seen to have adopted pathological behaviors in order to cope with the traumatic event. These behaviors interfere with a person's daily functioning and can impact work and relationships.

A second trauma framework developed in the past 25 years is the Survival Theory. This theory looks at responses to traumatic events as adaptations; the ways in which individuals manage to cope with the event. Specific behaviors are manifested so that the person can adapt or cope with what has happened.

Trauma is laid down in the psyche in sensory/motor form. Sights, sounds, smells, feels and tastes of the trauma can be triggered and relived over and over again. Trauma results in changes to the central nervous system keeping people either very revved up or relaxed or both. Trauma is a highly individualized experience viewed through one's own unique set of resources. Each individual will find a way to make sense of the experience. For example, one person in a car accident may come away determining never to forget to wear a seatbelt again while another may decide never to drive again.

Children are more at risk to develop problems because they have less capacity to control their fight/flight or freeze/surrender responses to trauma. They have less capacity to use language or to analyze what is happening and may act impulsively or withdraw. Bessel van der Kolk, M.D. (1996) states that a child who has experienced a traumatic experience is focused on survival, not living. He notes that there are changes to the use of the right and left hemispheres of the brain which can result in difficulty in moving from feelings to using words to describe emotions. Factors that can impact how a child responds include whether the incident was a one-time event or continuous exposure (ex. a car vs. being in a war zone). The involvement of family as either victims or perpetrators is also an important factor in how the event will be perceived. The child's level of development can make a difference in the perception and response to trauma. Many developmental theorists suggest that a child's developmental process, at certain stages of development, can be interrupted by a traumatic event (Finkelhor, 1995).

Responses to trauma can be physical, cognitive, emotional and behavioral. Physical responses included changes to the central nervous system. Breathing can become more rapid and the heart rate can rise to 100 beats per minute or more as the fight or flight response engages. Individuals can develop sleep and eating disorders, or somatoform disorders such as chronic headaches, stomachaches or dizziness. They may experience panic or anxiety attacks. Cognitive responses can include lack of concentration or short attention spans. An individual may withdraw into fantasy. Children can appear to be daydreaming, and there can be a change in academic progress. Unwanted intrusive thoughts and images, called flashbacks, may interfere with thought processes, or they may be an avoidance of thoughts or feelings associated with the event. Traumatized individuals believe that safety is lost, that people cannot be trusted and that adults can hurt and betray you.

Emotionally people experience fear, depression, anger or irritability or extreme terror. They may feel guilty, shameful (especially in situations of abuse) and powerless. There is a sense of not belonging. Extreme emotional responses can lead to the development of abnormal states of consciousness such as dissociative disorders or multiple personality disorders. Other trauma related disorders can include Reactive Attachment Disorder, Adjustment Disorders, Mood Disorders, Acute Stress Disorder and Obsessive-Compulsive Disorder. Individuals may be diagnosed with

anxiety, depression or attention deficit disorders when the underlying cause is trauma and the PTSD diagnosis has been missed.

People respond to trauma with many different behaviors. Children or adolescents may exhibit age regression such as returning to thumb sucking or bedwetting. Others might revert to anti-social behavior towards peers or adults. Individuals may engage in self-destructive behaviors such as risk-taking, cutting, substance abuse, suicide attempts or ideation. Self-destructiveness is a powerful need to be self-punitive. Sexual abuse is often the trauma that has been the foundation for self-mutilating behavior. Responses will vary from child to child depending on the duration of the event, physical injury involved, disruption to basic care-giving, the degree to which the event is perceived to be life-threatening or the child's own genetic inheritance and temperament.

Loss and grief happen to us all, and working with children and families who are grieving can be difficult. These individuals are experiencing emotional pain and can be irritable or angry. Children may be emotionally withdrawn, difficult to motivate or may exhibit out of control behaviors because they do not know words to verbalize how they feel. Children may also be limited in their ability to attach to others emotionally. A child's grieving process can be unique because children often do not have the experience of dealing with the loss of someone on whom they have depended. As a result children may also have feelings of alarm and panic and react as though they are in physical danger. There may be regression in skills already learned such as suddenly not being able to dress independently or reverting to baby talk. Children may become more hyperactive in order to avoid thinking about what has happened to them.

It is important to create a safe environment when working with grieving children so that they can be encouraged to talk about their feelings. For children who are non-verbal or have limited verbal ability can be encouraged to use their bodies actively to "act out" their feelings of anger or frustration. Using art or music can also be mediums to help individuals express how they are feeling. Support should be constant and consistent as this will help to build a trust relationship and allow children to express their feelings openly. Maintaining a safe, consistent environment also helps to promote resiliency.

Resiliency is the capacity to bounce back from a loss or traumatic event; to withstand hardship and repair oneself. It is the universal capacity which allows an individual to prevent, minimize and overcome the damaging effects of adversity.

Respite providers can foster resiliency by encouraging independence, clarifying rules and expectations, communicating with the child around daily events and feelings, providing consistent rules and consequences and helping the child to recognize and express their own feelings. Remember that children rely on caregivers for help in structuring, organizing and understanding events that happen in their physical environment.

Creating a safe environment is of utmost importance when helping someone who has been traumatized. Safety strategies used are dependent on the developmental stage of the child and no physical intervention (such as MANDT, NAPPI, TCI or CPI) should ever be used to keep a child safe unless the person performing it has been trained. It is a Respite Provider's responsibility to understand the agency's policy on using physical intervention. Provider's should treat the family and child with unconditional positive regard, collaborate with the family on strategies for keeping the child safe and offer encouragement and hope. Help children put their feelings into words and to sort reality from fantasy. Giving children opportunities to use their bodies actively can help with self-regulation.

Being consistent and predictable in what is said and done can also help create safety for a traumatized individual. It is important to establish clear rules and expectations for time together and to follow-through on limits. Help the child understand the provider's role as a mandated reporter, but also explain about confidentiality. Offer opportunities for communication and listen to what the child is saying.

Finally, it is important to understand that working with people who have been traumatized can have a traumatizing effect on the worker. This is called vicarious trauma and it refers to the extended exposure to traumatic stories and images. Pearlman (1995) defines vicarious trauma as "the exposure to painful aspects of the client's experience, which leads to potential alteration of beliefs about self and world." Vicarious trauma affects all types of workers who help disaster and trauma victims. The symptoms are usually less severe than those of PTSD, but can affect the livelihoods and careers of those working with survivors. Vicarious trauma is often a cause for burnout in the social service field. Symptoms of vicarious trauma can include a sudden seriousness or cynicism, sadness, a decrease trust in one's own instincts, a loss of perspective and sense of humor and depression.

Vicarious trauma can be managed and transformed. First remember, that vicarious trauma is natural, so accept those responses as normal. Attend to emotional, physical and spiritual needs. Take time to enjoy activities that are replenishing, and create time to get away. To transform vicarious trauma meaning must be created. Bring meaning to daily activities of work and other activity by focusing attention on the sensory and emotional aspects of daily activities - even the mundane. Recognize and change negative beliefs and build a strong supportive network. Stay connected to others. Discuss problems with a supervisor or peer or seek therapy, if necessary.

Follow the **ABCs** of protecting against vicarious trauma. These are:

Awareness: Being attuned to one's needs, limits, emotions, and resources. Heed all levels of awareness and sources of information, cognitive, intuitive, and somatic. Practice mindfulness and acceptance.

Balance: Maintaining balance among work, play and rest. This balance allows attention to all aspects of oneself.

Connection: Connections to oneself, to others, and to something larger. Communication is part of connection and breaks the silence of unacknowledged pain. These connections offset isolation and increase validation and hope.

Sources:

About Trauma, David Baldwin's Trauma Information

Assessing VT II: Self Care, Trauma Research, Education and Training Institute, Inc. (TREATI)

The Behavioral Health Sciences Institute (BHSI) and the Department of Health and Human Services (DHHS) Behavioral Health Professional Curriculum, Module 4, Trauma.

The Body Keeps the Score: Memory and the evolving psychobiology of post-traumatic stress, Bessel van der Kolk, M.D.

The Victimization of Children: A Developmental Perspective, David Finkelhor, Ph.D.

Bi-Polar Disorder

Bi-Polar Disorder is often known as "manic depression." This disorder is characterized by the extreme changes in mood, energy and behavior. In the manic phase of Bi-Polar disorder, an individual will experience feelings of euphoria. They will feel as though they are on top of the world, or feel they are experiencing a happiness that nothing can change. The individual may have grandiose delusions, imagining they have special connections to leaders, celebrities or God. They

feel invincible, as though nothing can stand in the way of what they want to accomplish.

Other symptoms of the manic phase of Bi-Polar Disorder include:

- Hyperactivity - inability to relax or sit still;
- Excessively risky behavior;
- Uncontrollable racing thoughts/rapid speech;
- Less need for sleep;
- Sudden irritability or rage.

Symptoms of the depressed phase are:

- Intense sadness or despair;
- No interest in activities once enjoyed;
- Loss of energy, fatigue;
- Sleep difficulties;
- Changes in appetite;
- Difficulty concentrating;
- Constant thoughts of death or suicide.

Research indicates that many children diagnosed with Bi-Polar disorder also carry a diagnosis of ADHD, OCD (Obsessive-Compulsive Disorder) and ODD. The American Academy of Child and Adolescent Psychiatry reports that up to one-third of the 3.4 million children with depression in the United States may actually be experiencing the early onset of Bi-Polar disorder. * Bi-Polar disorder can run in families, and it is estimated that there is a genetic cause. As many as 90% of individuals with Bi-Polar Disorder have a family history of depression or Bi-Polar Disorder, a rate that is 10-20 times higher than the general population.

*Information obtained from "About Early-Onset Bi-Polar Disorder" www.bpkids.org/printing/about.htm

Obsessive-Compulsive Disorder

Obsessions are persistent ideas, thoughts, or images that are experienced as intrusive and inappropriate and cause anxiety or distress. Common obsessions include thoughts about contamination (ex. Being contaminated with a disease by shaking hands), the need to have or do things in a particular order, doubts (ex. repeatedly returning to the house to make sure the door has been locked), aggressive impulses, or sexual imagery.

Compulsions are the repetitive behaviors or mental acts that help the person to reduce or prevent the anxiety produced by the obsessions. Common compulsions are repeated hand washing, checking off lists, counting, repeating words silently or out loud and establishing routines for tasks (such as counting to 10 five times before locking a door).

The diagnosis of Obsessive-Compulsive behavior is given when the following are present:

- Thoughts that are recurrent and persistent even when the individual attempts to ignore them;
- Intentional, repetitive activities or behaviors are compulsively enacted by the person;
- Obsessions and compulsions are sufficiently severe and time consuming to interfere with social, school and family functioning.

Impaired Thought Processes

Individuals with impaired thought processes experience auditory hallucinations, visual hallucinations, and intrusive thoughts. Mental health professionals commonly refer to this behavior as "psychotic". The term psychotic describes a broad range of behaviors that indicate that the individual is not "in touch with reality". In other words, the person is not able to accurately perceive what he or she is seeing, hearing or thinking, leading to incorrect assumptions about the world. Schizophrenia is primarily a disorder of young adulthood, however, the symptoms for schizophrenia often begin during adolescence.

Tourette syndrome

(This is a reprint from the newsletter of the Maine Parent Federation)

Tourette syndrome (TS) is a neurological movement disorder which begins between the ages of two and sixteen and lasts for life. Rapid repetitive movements of the body, often called "tics", are characteristic of Tourette's syndrome. Such movements can include rapid eye blinking, shoulder shrugging, head jerking, and facial twitching.

Involuntary vocalizations, repeated sniffing, throat clearing, coughing, grunting, barking, shrieking, echolalia (repeating other people's words), palilalia (repeating own words), stuttering and coprolalia (utterance of inappropriate or obscene words) are often observed. These symptoms are often confused as abnormal behavior or "nervous habits". Individuals with TS rarely have all the symptoms, but may develop several over a long period of time.

Researchers believe that Tourette syndrome is caused by chemical imbalance in the brain. Studies have shown a chemical abnormality in the basal ganglia of the brain. Stimulants such as Ritalin, Cylert and Dexedrine, which speed up the central nervous system, can worsen TS. Symptoms also worsen during puberty. Tourette' syndrome symptoms sometimes stabilize somewhat during adulthood. A few individuals learn to control TS symptoms while in public, but once they are in a more relaxed situation, the symptoms frequently emerge more explosively.

Children with Tourette syndrome often have difficulties in school. It is estimated that 60% of children with TS have learning disabilities, such as Attention Deficit Disorder, and should be referred to special education for an education evaluation. After an evaluation is completed an Individual Education Plan is developed to meet the child's needs.

There is no cure for Tourette syndrome, although several drugs, such as Haldol, Catapres, Prolexin, and Clonopin can reduce the symptoms in some cases. Unless the symptoms interfere with a person's life, medication should not be used. Individuals often seek psychological counseling to build coping skills and to deal with society's reaction to this disorder.

Researchers are still working to find a cure. Genetic studies are being done to help determine how it is transmitted from one generation to the next, as 50% - 70% of the cases appear to be hereditary.

Learning Disabilities

Linda M. Levine, M.Ed.

Sheila's story

Sheila's parents had been worried about her for a long time. At 4 years old Sheila seemed bright, but she had trouble remembering things. Sheila was always in motion. She never sat down long enough to watch a favorite TV show. She had a hard time catching a ball and was always tripping over her feet. Sheila seemed to hear her parents, but couldn't always follow directions. She confused up and down, front and back, squares and circles. When she started school, she continued to have problems. When Sheila was tested she was found to have learning disabilities.

What are learning disabilities?

Learning disabilities include problems such as short attention span, poor memory and delayed language development. Children with learning disabilities have difficulty learning even though they have NORMAL intelligence. They are not "slow." But they do learn differently. An individual may have one or many learning disabilities. Some children with learning disabilities do well in a regular classroom with extra help from a special teacher. Others with more serious problems need a special classroom.

What to look for in children.

1. BEHAVIOR problems:
2. Poor MEMORY:
3. SPEECH or LANGUAGE problems:
4. Poor COORDINATION:
5. SOCIAL problems:
6. Problems with SCHOOLWORK:

What causes learning disabilities?

Almost everything we know about learning disabilities has been discovered in the past 20 years. Researchers know that many more boys than girls have learning disabilities. Some learning disabilities run in families. The cause of learning disabilities is still unknown. But physical problems, emotional problems, hearing or seeing problems are not the MAIN cause of learning disabilities.

Tips for working with children with learning disabilities:

1. Be honest. Your child can tell that something is wrong. Explain the child's learning disability and ways to help. Don't promise a quick "cure." But do tell your child that many people have succeeded in careers despite learning disabilities.
2. Accept your child's unique strengths and weaknesses. Help other family members understand.
3. Help your child organize activities and schoolwork. Help plan ahead. Today is good. Next week is too far away.
4. Give short-term jobs, one at a time. Use clear, short sentences to give directions.

5. Reduce distractions.
6. Keep pressure off. Give praise for small accomplishments.
7. Tell your child the behavior you expect and the consequences of behavior.
8. Really listen. Misbehavior is often a "help me" signal.

Epilepsy/Seizures

Epilepsy refers to a chronic medical condition (sometimes called a seizure disorder) caused by temporary changes to the electrical functioning of the brain. Epilepsy is characterized by sudden seizures, muscle convulsions, and partial or total loss of consciousness. Both "epilepsy" and "seizure disorder" mean the same thing; that the normal flow of electricity to the brain has been interrupted and there will be an underlying tendency to experience seizures. However, the diagnosis of epilepsy means that seizures happen more than once and that there is no known treatable cause. Most people are diagnosed with epilepsy before the age of 25. At least 50% of all cases begin in childhood. In 70% of all cases, there is no known cause. Possible causes include lack of oxygen during or following birth, poor development of the brain before birth, head injury, tumors, high fevers or severe brain infections such as meningitis or encephalitis. There is evidence of genetic factors and research is going on to find the genetic roots of epilepsy*.

There are seven types of seizures: Generalized Tonic Clonic (grand mal), Absence seizures (petit mal), Complex Partial Seizures (psychomotor or temporal lobe), Simple Partial Seizures (Jacksonian), Atonic (drop attacks), Myoclonic Seizures, and Status Epilepticus. Common behavioral characteristics as they relate to epilepsy include drowsiness, fatigue, embarrassment, changes in emotion, and alteration of perception.

1. Generalized Tonic Clonic (grand mal):

The Generalized Tonic Clonic is usually known as a grand mal seizure. This type of seizure is the least common form of epilepsy but probably the most frightening. An individual experiencing a grand mal seizure may cry out, fall, and experience a temporary loss of consciousness and muscular movements ranging from the twitching of eyelids to shaking of the entire body. These seizures usually last from one to three minutes. Breathing may be shallow or temporarily suspended, the skin may turn bluish and there can be a loss of bladder and/or bowel control. One feature of a grand mal seizure that sometimes differentiates it from other seizures is the presence of an "aura." An aura is an internal warning to an individual that a seizure is imminent. This involves an individual experiencing a particular taste, sound, feeling or vision prior to the seizure.

*The Epilepsy Foundation provided information about the causes of this disorder (www.efa.org).

2. Absence Seizures (petit mal):

In contrast to the Generalized Tonic Clonic or grand mal seizure, the Absence or petit mal seizure may be characterized by a momentary loss of contact with the environment or the stoppage of activity. This may take the form of fluttering of eyelids, a blank stare, chewing movements of the mouth, or the twitching of a limb. This type of seizure lasts for only a few seconds and can occur in

succession within a short period of time. Usually, the individual returns to full awareness once the seizure has stopped. In most instances the person does not realize that a seizure is occurring.

3. Complex Partial Seizures (psychomotor or temporal lobe):

This form of epilepsy usually begins with a blank stare, followed by chewing, or a random activity such as smacking of the lips, rubbing of hands, or picking of clothes. The individual may seem dazed, unresponsive, and unaware of their surroundings. They may run, appear afraid, struggle, or flail out at attempts to restrain them. Once the pattern of this seizure has been set within the brain, it will usually occur the same way with each seizure. These seizures may last a few minutes or several hours. Individuals may maintain consciousness but still engage in an activity such as the clothes picking, or chewing. Time will be distorted, the individual will not be aware of their surroundings, and will have no memory of what happened during the seizure.

4. Simple Partial Seizure (Jacksonian):

The Jacksonian form of epilepsy is similar to the grand mal seizure except that the person usually does not lose consciousness. This seizure is characterized by jerking movements that start in one part of the body and progress to the other side of the body resulting in a convulsive seizure. The individual experiences a distorted environment and may see or hear things that are not there. They may have unexplained sadness, fear, anger or joy. Some individuals may experience odd smells or nausea.

5. Atonic Seizures (drop attacks):

A person experiencing this type of seizure will suddenly collapse and fall. Within a few seconds the individual recovers, regains consciousness, and can resume normal activity.

6. Myclonic Seizures:

Myclonic seizures are evidenced by sudden, brief massive muscle jerks. This type of seizure can be very mild and only affect part of the body or strong enough to involve the whole body and cause the individual to fall to the floor.

7. Stasis Epilepticus:

This type of seizure continues for an extended period of time. The individual does not regain consciousness. Because this seizure is so severe, immediate medical attention is required.

CARING FOR A CHILD WITH A SEIZURE DISORDER

Some things such as strobe lights and/or loud, sudden noises can precipitate a seizure. Therefore, it is important to adapt the environment as necessary. Special dietary practices are sometimes used in conjunction with anti-convulsion drugs. In the majority of cases, epilepsy is controllable and people with this disorder live very normal lives.

When caring for a child who has an epilepsy/seizure disorder, it is important to follow procedures outlined by the parent/guardian. Make sure you understand the individual's seizure pattern. Seizures are usually not harmful unless they are very prolonged or recur in rapid succession (such as the status epilepticus type). If breathing is frequently irregular, ceases, or the person does not regain consciousness within a couple of minutes medical assistance should be sought immediately. It is important to keep the individual on his or her side to prevent food from getting into the lungs should vomiting occur. It is not necessary to place anything in the mouth, as the tongue cannot be swallowed. Do not restrain movement, but remove hard objects in the area to prevent injury. Place a blanket or pillow under the head and loosen tight, restrictive clothing from around the neck. Assure

the person by talking calmly and quietly to them during the seizure. Do not give medications or liquids during or immediately after the seizure.

If a child has a seizure while swimming, contact EMS and the parents / guardian immediately. Concerns include aspiration of water into the child's lungs.

If the child has no history of seizures or is not diagnosed with epilepsy and a seizure happens, seek medical help immediately and then contact the parent or guardian.

Respite providers should keep a record of seizures that describe:

1. What part of the body the seizure started in.
2. How long the seizure lasted. Try to check a clock or watch for accuracy.
3. What occurred after the seizure stopped? Was the individual sleepy or disoriented? If the person slept, how long did they sleep?
4. Whether or not medical assistance was necessary.

Spina Bifida

Spina Bifida is a term used for a variety of conditions in which there is a defect of closure in the bony part of the spinal cord. In fetal growth, the two halves of the spinal cord develop and fuse in the midline. This closure begins at the middle and proceeds toward the head and feet, like a double zipper, until the tube is open at either end. Spina Bifida occurs when the spinal tube either fails to close or is blown open by pressure. Spina Bifida may exhibit a protrusion of the nerve fibers and other contents into a sack outside the spine. The nerves to the lower limbs and internal organs, particularly the bladder and kidneys, below the defect may be cut off, causing paralysis and lack of function. Most people with Spina Bifida use colostomies and ileostomies. Various abnormalities of the skeletal system, such as clubfoot, dislocated hips, and un-segmented vertebrae, as well as anomalies of the heart, bowel, or brain, may also be present. Individuals with Spina Bifida also have latex allergies, so it is important that latex products (such as protective gloves) are not used.

Sometimes during the birth process, excess fluid is not adequately absorbed in the brain or scar tissue does not allow the fluid to circulate evenly, and hydrocephalus results. The head becomes enlarged as a result of the fluid buildup. This excess fluid puts too much pressure on brain cells and they are destroyed. Hydrocephalus is a frequent complication of Spina Bifida and can cause mental retardation. Fortunately, modern surgical methods have been developed, and tubes (shunts) with special valves can be inserted to drain off excess fluid. Once the shunts are inserted, hydrocephalus can be prevented, and brain damage minimized.

Children with Spina Bifida have high mortality rates, although improvements in health care have lowered the death rate considerably. Orthopedic care usually begins at birth, and although normal function of lower limbs is not always possible, an individual is often able to get around with crutches and braces.

Cerebral Palsy

Cerebral Palsy is a developmental disability resulting from damage to the brain that may occur before, during, or after birth. Cerebral Palsy is characterized by the loss of control over voluntary muscles in the body, and affects such as activities as sitting, standing, grasping, and eating. Cerebral Palsy is characterized by shaking movements called tremors; or rigid, slow, and stiff contraction of muscles. Joints may also become fixed in abnormal positions. A short frustration tolerance is a behavioral manifestation of this disorder. Approximately 25% to 50% of all people with Cerebral Palsy will experience learning difficulties. About 50% will also experience seizures. There are four types of Cerebral Palsy. They are: Spastic, Athetoid, Ataxic and Mixed.

It is important to remember that a wide range of functioning exists in all types of CP, and that limited functioning may affect one part of the body more than others. CP can also co-exist with other conditions such as Mental Retardation and Epilepsy. Caring for an individual with CP requires training in proper positioning, lifting, carrying, and handling. There may be a need for adaptive equipment such as wheelchairs, walkers, adapted brushes, combs, eating utensils, and the removal of architectural barriers. The use of language boards or picture exchange systems can facilitate communication.

Individuals with CP have needs related to their unique development, motor, and sensory difficulties. Common difficulties associated with CP include delayed motor skills, abnormal motor movement, tactile sensitivities (which result in their not liking to be "cuddled" easily), and some learning disabilities. It is important for respite providers to discuss the unique needs of each person with parents/guardians. Specific routines, positioning, feeding, educational, and general care techniques should be discussed fully. In general, be aware of facilitating motor development by encouraging sitting, crawling, and walking at appropriate stages and with a supportive therapy plan. Provide incentives for the individual to move and explore.

When interacting with a person with CP, talk slowly in a conversational pattern. Allow adequate time for a response and learn each person's unique communication signals. Always inform the individual about what you are going to do before you do it, and use objects and pictures to reinforce communication if necessary. Be sensitive to physical fatigue that can aggravate symptoms and always use appropriate lifting, transporting, and safety precautions.

Fetal Alcohol Syndrome / Fetal Alcohol Effect

Fetal Alcohol Syndrome (FAS) is a result of the effect of alcohol on the brain and other developing organs of the fetus, which causes the physical and mental abnormalities that characterize this disorder. The major characteristics of FAS include both prenatal and postnatal growth deficiency, delay of gross and fine motor development (often associated with mental retardation), and congenital malformations, some of which result in a characteristic facial appearance. Individuals with Fetal Alcohol Effect (FAE) have less dramatic physical abnormalities, but share many of the same behavioral and psychosocial characteristics of those persons born with FAS. FAS is a direct result from exposure of the fetus to alcohol during pregnancy, and is presently the leading cause of mental retardation in the United States. The developing fetus absorbs alcohol at the same concentration as the mother during pregnancy. However, the fetal blood alcohol level remains much higher than the mother's for a longer period of time. It is unknown how much alcohol it takes to cause FAS or FAE.

Incidence rates for FAS vary, ranging from 1.9 to 9.8 cases per thousand live births. It has been estimated that between 44% of all women who drink heavily will have a child with FAS. Of the other 56%, some will have FAE, minor learning disabilities and/or behavioral difficulties. Most children with FAS are not identified until later infancy or childhood. Many are never identified.

Children with FAS are usually small at birth and continue to grow poorly. In addition, they often have delays in motor and mental development and may exhibit behavior problems such as hyperactivity. Physical, cognitive, and social abnormalities associated with this syndrome include:

- Small head, eyes and mouth, as well as droopy eyelids
- A wide space between the nose and upper lip, a thin upper lip
- Occasionally a cleft palate
- Congenital heart disease
- An exaggerated startle response
- Poor wake and sleep patterns
- Hyperactivity, distractibility and attention deficits;
- Temper tantrums
- Impulsiveness
- Lying and stealing behaviors
- Poor social skills
- Poor abstracting skills
- Processing problems including input, memory, integration, and output of information.

Children with FAS / FAE do best with a highly consistent routine. The same activities should occur at

the same time each day. When the routine is changed, preparing the child as much as possible in advance will ease transitions. Activity-based learning is important. Use all the senses (touching, movement, seeing, hearing, smelling) to stimulate learning. The use of pictures, music, and kinesthetic activities has been known to enhance learning for children with FAS / FAE.

Module 5: ENGAGING A CHILD

General Guidelines

The following are some suggestions for working with children and adolescents. Children with physical and emotional disabilities have activities that are identified as appropriate. It is imperative that you discuss all activities with parents and get approval from them before you start the activity. While providing respite care to a child, your main goal is to keep the child safe and happy. You may choose activities that have therapeutic or educational value, or you may choose to simply have fun! Remember, the program is designed to give the parent or care-giver a break to relax and recharge. A parent or caregiver will be relaxed if he or she knows that their child is safe, happy, and doing something worthwhile. Consider the following goals:

Provide activities which:

- are age-appropriate (see Age Appropriate Activities section below);
- are parent/guardian approved and meet their desires;
- focus on ability rather than disability;
- are fun and enjoyable for the child;
- build on the child's skills, and,
- give necessary direction and assistance.

Facilitate leisure, play, and recreation by:

- providing opportunities for creativity and discovery;
- allowing the child freedom to initiate activities and make choices;
- sharing in the experience/activity with the child;
- giving the child time to explore, create, learn at their own pace;
- providing encouragement and positive reinforcement (e.g. verbal praise).

Do not take play or recreational activities away from a child as punishment. You may offer an activity as incentive for desired behavior (as soon as you..., we can...). See the Module on Positive Behavior Supports for more information on this. Do not try to force an interest in play. Focus on doing the activity rather than achieving an end product.

Promote:

- a balanced, healthy leisure lifestyle;
- active and passive activities;
- indoor and outdoor activities;
- time alone and with others;
- activities that promote fitness.

Children of all ages respond best to:

- an enthusiastic approach and a playful attitude;
- patience;
- structure;
- a mix of active and passive activity, and
- allowing time to process learning.

Be Safe, Always:

- Use non-toxic materials (e.g., glue, paints, markers, plants); consult label.
- Be sure equipment/supplies are in good working condition
- Be sure equipment and supplies fit the child's size (e.g. height/weight) and functioning (emotional, cognitive, physical, social).
- Use equipment/supplies as designed.
- Wear appropriate clothing and protective gear.
- Use sun protection when outdoors - sunscreen, hat.
- Be sure that the child is well supervised and does not get into any cupboards with detergents, oils, paints, etc.
- Be aware of the potential for accidents involving crawlers. Child proof your home and remove potentially dangerous objects.

NEVER: Give a baby or toddler anything smaller than his/her fist size to prevent swallowing or choking. Use the "toilet tube" method (use the inside of a toilet paper role to judge the size of an object. It is too small if it fits into the tube). **NEVER:** Take your eyes from a child who is in or near water or using an appliance.

Find out what interests the child.

Listen carefully to what the parent or caregiver tells you about his/her child. If the parent or caregiver does not offer the information, please feel free to ask questions about what the child enjoys. Plan your time together based on your knowledge of what the child enjoys, in addition to

what is necessary to meet the child's needs (meals, naps, etc.) For example, if the child enjoys sports, plan some time to play tee-ball in the backyard. If the child loves to color, have a craft activity ready for after lunch. Routines may be important for some children, so be sure to find out from the parent or caregiver what the child's normal routine looks like, and try to follow their schedule. Consult with the child's parent/guardian about the child's interests and the parent or guardian's desires.

Have parent/guardian identify:

- 10 things "My child loves to do for play/leisure/recreation/fun."
- The child's favorite activities during the time you will be with him/her. (e.g., Right before bed the child likes to have a book read to him/her, the child likes to go outdoors in the late morning.)
- Child's dislikes (e.g., TV shows, toys, textures, noise, people, animals).
- Dominant hand (i.e., which hand primarily uses to write, throw ball, or manipulate objects);
- Positioning and/or movement for different activities (e.g., crawls to play tag, sits in beanbag chair when reading, uses two hands to hold paint brush);
- Endurance (e.g., can only walk 1/2 block before needs to sit down, active play time 10 minutes).
- Ability level (e.g., can swim laps in the pool, can't figure money although likes to pay for self when goes out);
- Behavior when bored, tired, excited, scared, etc.
- What the child is not allowed to do (e.g., ride bicycle off property, paint, use the computer, be up after certain time, go outside without having eaten full lunch).
- What leisure/play/recreation equipment/supplies do the child and family have that you and the child can use?

Ask the child:

- 10 things "I'd like to do for fun."
- 10 things "I'd like to do with you."
- 10 things "I'd love to try doing for fun."

Observe the child in play and leisure and try a variety of activities with him/her.

Watch for:

- attention span (How long does he play/stay with an activity or toy?)
- what s/he seems to enjoy/not enjoy
- how enjoyment is indicated
- physical skills (e.g., sitting balance, standing balance, mobility, endurance, strength, use of different body parts), and
- social and communication skills.

Share your interests with the child.

You may also incorporate your own interests and skills when building a relationship with a child. For example, if you love to garden, have the child help you choose flowers and teach him or her to plant a garden. If you love cars, bring books about cars with you to share with the child, or bring the child to an auto show. Your enthusiasm may inspire a new interest for the child and make your time together more enjoyable for both of you. Be sure to share your ideas and plans with the child's parent or caregiver first.

Go on outings.

Outings are often a wonderful way to spend a day of respite. To find local activities, try looking in the "What's Going On" sections of local newspapers and magazines. Schools are often a good resource for local kid's activities. Some ideas of community outings that are appropriate for children are:

- Parks (Picnics)
- Playgrounds
- Beaches
- Museums
- YMCA
- Community Centers
- Zoos
- Planetariums
- Movie theaters
- Libraries
- Bowling alleys

Be sure to discuss the specifics of the outing with the parent or caregiver before you bring the child on an outing. Parent and caregivers may have specific instructions regarding water safety, appropriate movies, etc.

Also be sure to discuss in advance how outings will be paid for. You may offer to pay for admission and mileage, or the parent may offer to pay. You may decide to split the costs of activities.

Stay in. Can't go out? Whether it's because of the cost of activities or the weather outside, sometimes outings are not an option. Some ideas of ways to spend the day indoors with a child are:

- Craft activities (coloring, scrapbooking, etc.)
- Baking
- Reading together
- Renting movies
- Acting in your own play (pretend play)
- Listen to music (dance!)

- Board games
- Card games
- Write journals or cards
- Help with homework

Again, be sure to discuss your ideas and plans with parent or caregiver first. Some parents may have specific instructions about what foods you can bake, what books the child likes to read, etc.

Age Appropriate Activities

Listed by age group: **3 - 6 Months:**

- Cradle, gym, squeeze, playpen toys
- Use a mirror and ask the baby "Who's that?"
- Imitation games
- Sounds of music
- Change in voice
- Bath time

6 - 18 Months:

- Games of drop and throw
- Bounce chair
- Nesting toys
- Games: Peek-a-Boo, Hide and Seek
- Feeding fun (easy to eat finger food)
- Water play (use wash cloth puppets, sponges of different shapes and colors, bubbles to blow)
- Bath time play (floating toys, sponges, washcloth puppets)
- Kitchen play

Ages 18 Months-4

- Experiment with clay and color
- Paints and do handprints
- Play with water and forms
- Wiggle
- Play follow the leader
- Dance

- Play hide-and-seek.
- Let the child "help" -- at the store, preparing dinner.

Ages 5-7

- Bake and frost cut out cookies
- Fly a kite on a windy day
- Go on a walk and collect interesting rocks, leaves or other items
- Feed the ducks at the park
- Make a present for someone special
- Play UNO, Crazy 8s, or Old Maid
- Play badminton or croquet
- Go for a walk and find interesting places to practice "balancing"
- Have a peanut butter and jelly sandwich picnic
- Visit a pet store and decide which is the oddest pet
- Cloud watch on a bright summer day

Ages 8-10

- Start a scrapbook with a page for pictures of favorite things
- Go on a camera scavenger hunt to find odd objects to photograph
- Make greeting, get well, or holiday cards for special people
- Make a bug cage and catch lightning bugs together
- Visit the zoo at feeding time
- Read a selected book out loud and tape record it
- Play miniature golf or go bowling
- Play Monopoly, Life, Sorry, or hangman
- Go on a field trip to the museum - focus on one exhibit and discuss it
- Go for a bike ride
- Make a lemonade or a hot cocoa stand - learn basic business principles
- Got to the library together
- Participate in seasonal activities - go apple picking, carve a pumpkin, make a snowman, go puddle jumping, paint Easter eggs

Ages 11-13

- Watch a TV program and identify negative stereotypes
- Look up your state on the Internet: what is the major industry?
- Build and paint a bird house - watch for occupants
- Rent rollerblades and learn to skate, safely

- Make a list of people you admire - look them upon the Internet
- Take a long ride on public transportation to the end of the line
- Visit the SPCA and offer to walk the dogs
- Mow the lawn or wash the car together
- Play computer and video games together
- Participate in a community service activity to show your Little the importance of giving back
- Plan or plant a garden or visit a community garden and offer to help

Ages 14-16

- Research what happened on the day and year each of you was born
- Figure out how to program your VCR
- Visit the fish market, meat market or other place where food is not prepackaged
- Check out the classified advertisements and discuss what each job requires in terms of education and experience
- Go out for dinner at an ethnic restaurant - who else is eating there? What is your favorite dish?
- Explore a new radio station together - discuss ads and target audience
- Plan and shop for ingredients to cook dinner together
- Go to a concert featuring a favorite performer
- Try mastering something difficult: juggling, cooking a soufflé, water color painting
- Watch a professional or semi-professional sporting event
- Talk about what's in today's newspaper
- Buy ten shares of stock in an inexpensive company the child will recognize and watch it make or lose money

Adolescents and Teens

For teens, listen carefully to what they tell you about their interests, and let them suggest activities. An adolescent may want to share his/her favorite music with you, or create a collage of photographs of friends. A teen may want to show you his/her skateboarding skills, or his/her expertise with a certain computer program. Let the teen take the lead, so long as the activity is appropriate and permitted by the parent or caregiver.

Adapting / Modifying Activities

In many situations you will find that adaptations must be made to allow a child with a developmental disability to fully participate in a recreation or leisure activity. The general idea is to make only those adaptations that are necessary to facilitate participation.

Finding that balance between challenge and frustration is the key. For example, it will not be challenging for the child who wants to learn to ride a bike to be pushed in a wagon. On the other hand, if the child lacks the physical skills necessary to ride a bike, some adaptations will have to be made. There are four areas of adaptations that we will explore in this section: compensatory techniques, adapted equipment, method, and rules.

Compensatory techniques:

Think about ways that a person can compensate for a lack of skill or ability in recreation and leisure. Have you ever had your hands full and carried your car keys in your mouth? A child who is unable to use one or both hands may be able to perform a task using his or her mouth. When one body part doesn't function completely, the child may use that body part as a functional assist. For example, try picking up a large playground ball with just one hand. You will find that you can pick the ball up by assisting with your foot, your chest, and your chin. The child with impaired vision or hearing may need you to provide them with additional cues or physical contact to perform a task. Blind skiers use sighted guides to call out position and direction so that they may ski safely. People with impaired mobility may perform skills that are usually done standing up, while seated in a chair, such as bowling.

Adapted Equipment:

There are many kinds of adapted equipment available, ranging from expensive complicated pieces of equipment to the very simple and inexpensive. Adapted recreation and leisure equipment can be found in catalogs, some sporting goods stores, and at a few recreational areas/facilities. One handed fishing rods, pool cue supports, one handed knitting and embroidery aids, playing card holders and shufflers, large print books and cards, books on cassette tape, mouth sticks, batting tees, bowling ball ramps, and quick release bowling balls are just some of the equipment that is available. There are a few easy and inexpensive things that you can adapt yourself. For children with limited grip strength, it is often helpful to build up the handle of a piece of equipment. By using tape or foam tubing, you can enlarge the grip on a tennis racquet, ping pong paddle, baseball bat, golf club, paint brush, and writing or eating utensils. Velcro strapping can be used to help secure equipment to a child. Playing card holders can be made by cutting slots in a tissue box, to help the child with limited grip strength or arm function. You can make a mouth stick by taping a pencil, brush, crayon, or marker to a chopstick. Page turning is made easy by simply using the eraser on the end of a pencil. For the child with impaired reaction time and coordination, use large objects. For example, use balloons, large playground balls, or beach balls for throwing, catching, and kicking. There is a terrific non-skid material called "Dycem" that can be used to keep coloring books from sliding around on the table, secure a wood project when sanding, and facilitate holding just about anything. It can be cut into strips or shapes and affixed to materials; it is very helpful to persons with tremors or limited hand or arm function.

Method:

By changing the way a skill or activity is performed; a child can have the opportunity to participate. Usually ice-skating is done with regular ice skates or even double runner skates. By pushing a folding chair around on the ice, a child with impaired balance may be able to skate. In many schools and leagues, the batting tee is used to help teach batting skills. Basketball can be played from a wheelchair? If a child cannot throw a ball with one hand, try using two hands. Think about simple

changes like using an overhead or underhand toss, trying the activity while seated, or using a different kind of ball, bat, glove, or racquet.

Rules:

One of the simplest adaptations you can make is to change the rules of the game. Change the scoring, the size of the playing field, the distance between bases, and the hoop height. Allow more chances at bat, eliminate strikeouts, allow more than one bounce of the ball for tennis or ping-pong, and give an extra turn. Encourage participation for the sake of enjoying the game. There are many non-traditional games and activities where there is no winner or loser. Remember that participation in any activity is for fun, to learn and demonstrate a new skill, to build self-esteem, and to learn how to play with others.

Module 6: POSITIVE BEHAVIOR SUPPORTS

What's my care-giving style?

Caregiving styles fall roughly into three categories. Do you recognize your style?

Authoritarian

- Do you find yourself saying to your kids, "Do it because I said so"?
- Are you constantly telling your kids what to do to keep them in line, and keep in control?
- Do you think, "If I don't control the kids, the kids will not be able to control themselves"?

Authoritarian caregivers want to maintain control. But when the control is all in the hands of a caregiver, children don't learn to think for themselves, to trust themselves, or learn how to exercise personal responsibility and self-control.

Permissive

- Do you want your kids to view you as nice caregivers-as friends?
- Do you have difficulty setting and maintaining limits and expectations, providing structure, and enforcing rules?

Permissive caregivers send the basic message, "Do as you want, sweetheart, as long as you're happy" Children of permissive caregivers have difficulty taking "no" for an answer, saying "no" to themselves, and taking anyone else's feelings or needs into consideration. Often, they're rejected by other children.

Respectful

- Do you balance kindness with firmness?
- Do you require mutual respect between you and the children?
- Do you take the time to listen and understand how the children feel?
- Do you work together with children to solve problems?
- Do you balance your own needs with the child's needs?

The children of respectful caregivers learn to think, "What are my needs?", "What are my caregivers' needs?", and "What can we work out so that everybody's needs are met?" Children raised with this type of approach learn how to discipline themselves.

Learning how to be good caregivers and teachers

Children come into this world helpless and unable to thrive without us. Our job is to love and nurture them and to teach them how to live.

Discipline means "to teach and train." We need to be good disciplinarians, to acquire skills that will accomplish the goal we set for ourselves - that of helping the child learn to control and set standards for himself. There are several ways we can "make" children behave. One is by using force. Another is by using fear. Still another is by punishment. Unfortunately, these three methods imply that the caregiver is superior and should overpower the child. Rather than leading to a child with inner control, they make the child angry, resentful, fearful and dependent upon force.

There is another way to discipline children. Though it may not appear to get the immediate results we might like, it is safer, more natural and humanistic. It is based on the assumption that children are by nature good, fair, and honest and ultimately capable of responding to that which is good, fair and honest within us. This method is to treat the child with respect. It is treating the child as if he is as important a human being as you are. It is treating him with the same respect with which you wish for him to treat others, you, and himself.

How can we treat children with respect?

We can treat our children with respect by using discipline techniques that teach them self-control and responsibility.

How to Build The Child's Self-Esteem:

- Show children that you like them by smiling at them, hugging them and speaking to them in a positive way.
- Read out loud together.
- Use positive reinforcement to encourage responsible behavior.
- Help them to learn responsibility by requiring them to complete tasks.
- Set aside a time each day to spend with each child individually.
- Help children to develop organizational skills by providing space for toys, books, schoolwork, etc.
- Help them to discover their own special gifts by letting them develop an interest in activities such as sports, music, dance, drama, etc.
- Encourage their independence.

Discipline Techniques that Work:

- Following through with what you say
- Being consistent
- Modeling, appropriate behavior
- Being firm yet kind/fair
- Clearly stating expectations before child has engaged in undesirable act
- Giving a child a choice only when you intend to accept that choice
- Making the child feel worthwhile, liked and successful
- Rewarding positive behavior and ignoring negative behavior (except when dangerous, destructive, or embarrassing)
- Removing child from the situation
- Providing consequence for misbehavior immediately after undesirable act is performed
- Providing when/then statements: "When you have...then you may..."
- Shaping non-existent behaviors
- Providing if /then statements: "If you have...then you may..."
- Abuse it/lose it
- Redirecting misbehavior

Discipline Techniques that Often Backfire:

- Spanking (The Respite Program does not condone, nor will it tolerate, any physical punishment of a child)
- Embarrassing
- Humiliating
- Taking away favored things
- Punishing psychologically
- Engaging in power struggles
- Rewarding misbehavior
- Giving in to undue commands
- Allowing child to manipulate adult
- Saying what you don't mean
- Expecting child to read your mind
- Allowing dangerous, destructive, embarrassing behavior to continue
- Repeating commands
- Pleading, begging
- Ordering
- Nagging

- Labeling
- Arguing
- Threatening
- Being vague
- Fussing
- Being inconsistent
- Losing your cool
- Making child feel guilty
- Assuming they "know better"

Basic behavior management

Think about helping a child learn about finger paint. Let's imagine these children had never seen finger paint before. Hardly any caregiver would ever think of just putting out lots of paint in front of this group of young children without some guidance.

A top-notch caregiver might talk about finger paint, show the children its consistency, and probably demonstrate how to use it on paper. The caregiver probably would give the children a few cautions about not throwing or slopping the paint or not dumping the entire jar of paint on the paper. No caregiver would simply put out the open finger paint jars and go do something else. She would watch carefully, making appropriate and encouraging comments about what the children are doing.

Every one of you, if you were in this situation, would be patient, and would not yell if the child accidentally dropped some paint on the floor. You'd calmly tell the child to get a paper towel and wipe it up. You would realize the child is learning, and that the child is a beginner in this business of using finger paints.

Helping a child learn what is acceptable behavior is much like helping a child learn about finger painting. It takes patience, it takes repeating, and it takes firmness. In our example, if the child deliberately turns the jar upside-down and dumps the paint onto the floor, you would talk with the child and probably end the finger painting activity. But you would do it calmly, and you would understand that the child is not ready, at least today, to do finger painting.

So it is with behavior. The one big difference is that behavior is occurring all the time. Unlike finger painting, you can't tell the children, "Now we are going to behave!" Why? Because they are behaving all the time. You meet new situations all the time. So do they. They don't always know or remember how to act. Because you are an adult, you developed some skills that will enable you to deal with most of the situations you run into. Remember, children are beginners. They don't have much experience. Most situations children face are new.

Many caregivers come to the pediatrician or other family physician with complaints about their children's behavior. These complaints are particularly common during toddlerhood, when children begin to assert themselves and their wills. Basic behavior management is most useful when started at this time. It becomes increasingly more difficult and less successful as children age. The following guidelines can assist caregivers who are motivated to make changes in their children's behavior.

Changing a child's behavior is an adult's work

It is important for caregivers to understand that managing behavior will require a significant amount

of work on their part. They must be willing to make changes and spend time and energy. To do it occasionally, to start then stop or to give in too quickly is a waste of their time and confusing to the child. However, energy invested now will reap benefits for years to come.

Keep it simple, keep it quick, keep it coming

Caregivers should begin with reasonable expectations for their child, considering his or her age, developmental level and any health concerns particular to the child. Caregivers must be precise about what they want the child to do. "Listen better" is the most common request, but it is vague at best. Children usually listen to what a caregiver says, but choose to disobey. "When mom says stop, you stop," is much clearer to the child. He or she knows exactly what is expected. The more simple and specific the request, the more likely the child will comply.

Pick the right place to start

Once caregivers have identified the behaviors they want to change, they must choose which one to work on first. Chances for success are increased if caregivers work on one behavior at a time. Start with a behavior the child can change, but not the one that is the most common. Choosing a behavior that happens every day but not many times a day offers a better opportunity to reward good behavior and provide consequences for undesirable behavior. When a child is successful, he or she is more motivated to continue working.

Provide immediate feedback

Responses to behaviors, both positive and negative, must occur quickly. Children have short attention spans and their memories still are developing. For young children (age 4 and younger), waiting seven days (while they collect enough stars or stickers or "good days") is not effective. They need more frequent acknowledgement of their efforts. They also require more reminders of what they are trying to change. Several times a day a caregiver can say, "Remember you are working on not hitting." Preventing an undesirable behavior is better than having to provide a consequence after it has occurred. If a child has trouble every time he and his brother play with cars on the floor, saying, "Remember, you are working on not hitting," may help the child to find another way to manage the difficulty. Suggesting another way to handle the situation is even better.

Increase the chances for success

Avoiding situations where the child is likely to have trouble is another basic element. If the child cannot manage being in the grocery store without crying for a candy bar, he or she is not ready for the store. If a chocoholic mother is dieting, a good spouse does not bring home a chocolate cake and set it on the table in plain sight. As much as possible, caregivers must assist their children in the same way by reducing circumstances in which their children are likely to fail.

Be prepared to be consistent

Consistency is the most important part of managing behavior. If a caregiver gives a time-out for hitting sometimes but not every time, the child often will think it is worth a try. If the child doesn't know for sure, he or she doesn't know change is necessary. Keep in mind that children don't wait to challenge until their caregivers are well rested, full of energy and have all the time in the world. Children challenge when their caregivers are tired, preoccupied, sick, pressured, on the phone, with company, in the car, in the store, in the restaurant. Being prepared to leave the shopping cart in the middle of the aisle and remove the child from the store is difficult, but this sends a strong message that changing this behavior is so important that the caregiver is willing to forego something he or she wants in order to achieve it.

When good, simple, quick, consistent attempts to change behavior fail, it may be time for professional help. If caregivers are struggling with serious behavior problems on a daily basis and tips like these don't help, pediatricians and other primary care physicians can assist by referring families to pediatric behavior management specialists

Child behavior: What caregivers can do to change their child's behavior

What is normal behavior for a child?

Normal behavior in children depends on the child's age, personality, and physical and emotional development. A child's behavior may be a problem if it doesn't match the expectations of the family or if it is disruptive.

Normal or "good" behavior is usually determined by whether it's socially, culturally and developmentally appropriate. Knowing what to expect from the child at each age will help you decide whether his or her behavior is normal.

What can I do to change a child's behavior?

Children tend to continue a behavior when it is rewarded and stop a behavior when it is ignored. Consistency in your reaction to a behavior is important because rewarding and punishing the same behavior at different times confuses the child. When the child's behavior is a problem, you have 3 choices:

- Decide that the behavior is not a problem because it's appropriate to the child's age and stage of development.
- Attempt to stop the behavior, either by ignoring it or by punishing it.
- Introduce a new behavior that you prefer and reinforce it by rewarding the child.

How do I stop misbehavior?

The best way to stop unwanted behavior is to ignore it. This way works best over a period of time. When you want the behavior to stop immediately, you can use the time-out method.

How do I use the time-out method?

Decide ahead of time the behaviors that will result in a time-out--usually tantrums, or aggressive or dangerous behavior. Choose a time-out place that is uninteresting for the child and not frightening, such as a chair, corner or playpen. When you're away from home, consider using a car or a nearby seating area as a time-out place.

When the unacceptable behavior occurs, tell the child the behavior is unacceptable and give a warning that you will put him or her in time-out if the behavior doesn't stop. Remain calm and don't look angry. If the child goes on misbehaving, calmly take him or her to the time-out area.

If possible, keep track of how long the child's been in time-out. Set a timer so the child will know when time-out is over. Time-out should be brief--generally 1 minute for each year of age--and should begin immediately after reaching the time-out place or after the child calms down. You should stay within sight or earshot of the child, but don't talk to him or her. If the child leaves the time-out area, gently return him or her to the area and consider resetting the timer. When the time-out is over, let the child leave the time-out place. Don't discuss the bad behavior, but look for ways to reward and reinforce good behavior later on.

How do I encourage a new, desired behavior?

One way to encourage good behavior is to use a reward system. This works best in children over 2 years of age. It can take up to 2 months to work. Being patient and keeping a diary of behavior can be helpful to caregivers.

Choose 1 to 2 behaviors you would like to change (such as bedtime habits, tooth brushing or picking up toys). Choose a reward the child would enjoy. Examples of good rewards are an extra bedtime story, delaying bedtime by half an hour, a preferred snack or, for older children, earning points toward a special toy, a privilege or a small amount of money.

Explain the desired behavior and the reward to the child. For example, "If you get into your pajamas and brush your teeth before this TV show is over, you can stay up a half hour later." Request the behavior only one time. If the child does what you ask, give the reward. You can help the child if necessary but don't get too involved. Because any attention from caregivers, even negative attention, is so rewarding to children, they may prefer to have caregiver attention instead of a reward at first. Transition statements, such as, "In 5 minutes, play time will be over," are helpful when you are teaching the child new behaviors.

This system helps you avoid power struggles with the child. However, the child is not punished if he or she chooses not to behave as you ask; he or she simply does not get the reward.

What are some good ways to reward a child?

- **Beat the Clock** (good method for a dawdling child) Ask the child to do a task. Set a timer. If the task is done before the timer rings, the child gets a reward. To decide the amount of time to give the child, figure out the child's "best time" to do that task and add 5 minutes.
- **The Good Behavior Game** (good for teaching a new behavior) Write a short list of good behaviors on a chart and mark the chart with a star each time you see the good behavior. After the child has earned a small number of stars (depending on the child's age), give him or her a reward.
- **Good Marks/Bad Marks** (best method for difficult, highly active children) In a short time (about an hour) put a mark on a chart or on the child's hand each time you see him or her performing a good behavior. For example, if you see the child playing quietly, solving a problem without fighting, picking up toys or reading a book, you would mark the chart. After a certain number of marks, give the child a reward. You can also make negative marks each time a bad behavior occurs. If you do this, only give the child a reward if there are more positive marks than negative marks.
- **Developing Quiet Time** (often useful when you're making supper) Ask the child to play quietly alone or with a sibling for a short time (maybe 30 minutes). Check on the child frequently (every 2 to 5 minutes, depending on the child's age) and give a reward or a token for each few minutes they were quiet or playing well. Gradually increase the intervals (go from checking the child's behavior every 2 to 5 minutes to checking every 30 minutes), but continue to give rewards for each time period the child was quiet or played well.

What else can I do to help a child behave well?

Make a short list of important rules and go over them with the child. Avoid power struggles, no-win situations and extremes. When you think you've overreacted, it's better to use common sense to solve the problem, even if you have to be inconsistent with your reward or punishment method.

Avoid doing this often as it may confuse the child.

Accept the child's basic personality, whether it's shy, social, talkative or active. Basic personality can be changed a little, but not very much. Try to avoid situations that can make the child cranky, such as becoming overly stimulated, tired or bored. Don't criticize the child in front of other people. Describe the child's behavior as bad, but don't label the child as bad. Praise the child often when he or she deserves it. Children want and need attention from their caregivers.

Develop little routines and rituals, especially at bedtimes and meal times. Provide transition remarks (such as "In 5 minutes, we'll be eating dinner."). Allow the child choices whenever possible. For example, you can ask, "Do you want to wear your red pajamas or your blue pajamas to bed tonight?"

As children get older, they may enjoy becoming involved in household rule making. Don't debate the rules at the time of misbehavior, but invite the child to participate in rule making at another time.

Children who learn that bad behavior is not tolerated, and that good behavior is rewarded are learning skills that will last them a lifetime.

Why shouldn't I use physical punishment?

Caregivers may choose to use physical punishment (such as spanking) to stop undesirable behavior. The biggest drawback to this method is that although the punishment stops the bad behavior for a while, it doesn't teach the child to change his or her behavior. Disciplining the child is really just teaching him or her to choose good behaviors. If the child doesn't know a good behavior, he or she is likely to return to the bad behavior. Physical punishment becomes less effective with time and can cause the child to behave aggressively. It can also be carried too far -- into child abuse. Other methods of punishment are preferred and should be used whenever possible.

It is **NEVER** acceptable for a respite provider to use physical punishment. This constitutes abuse and will be reported to the Department of Human Services.

How to listen so kids get heard

Create an atmosphere where kids feel they can talk freely.

- Make the time to listen.
- Accept the child's thoughts and feelings.

Listen.

- Look at the child.
- Pay attention.
- Show that you are interested. Respond with a word, a sound, or a nod.

Get the facts.

- Ask questions if there's something you don't understand.
- Repeat in your own words what the child says to be sure you really understand.

Respect feelings.

- Pay attention to feelings. Acknowledge and reflect the child's feelings.
- Give feelings a name. By identifying the child's feelings, you free the child to begin to work things out.

Remember not to:

- Interrupt.
- Bombard the child with questions. It can put any child on the defensive.
- Make up your mind before the child finishes speaking.

Possible causes of challenging behavior

Any discussion around “What can we do?” needs to start with: “What exactly is happening?” and “Why is it happening?”

Some Possible Causes of Behavior:

- Pain or illness
- Sensory/tactile needs
- Avoidance/escape of demands
- Rewards/desired activities or possessions
- Attention
- Control over others or environment
- Medication/side effect
- Communication (can't/won't express verbally)
- Fear
- Revenge
- Self-regulation of physical/emotional status
- Internal process (hallucination/trauma)
- Play
- Imitation of observed behavior
- Seizure activity
- Loneliness

- Physiological need (hunger, sleep)
- Habit/routine
- Affection
- Diet

On consequences

A consequence is what results when a rule is broken. For example; your son leaves the hammer in the rain-he loses the privilege to use it the next time. If there is no consequence following a broken rule, the child learns that rules can be broken and therefore don't need to be followed.

If the consequence is not attached to the child's behavior, it is not really a consequence. It is a punishment. For example; your son leaves the hammer in the rain-he loses TV for a week. (Losing TV has nothing to do with the hammer.)

Children learn a very important lesson by having consequences attached to their behavior. They learn that they can begin to take responsibility for their actions and that what happens to them is under their control.

Consequences are most effective when caregivers follow these simple guidelines:

Whenever possible, be sure the child understands ahead of time that certain behaviors will carry a consequence.

Before imposing a consequence, give the child a chance to correct his behavior.

The consequence should be related to the broken rule.

The consequence should guide the child in making a better choice the next time.

Rules and Expectations

Children need and want clear limits or boundaries, even though they may sometimes fight against them. Rules, expectations, and limits provide structure, but they need to be specific because when kids don't clearly understand what's expected of them, it can lead to conflict.

Setting family rules:

- Keep rules simple and easy to understand.
- Keep the number of family rules low.
- Repeat the rules often.

Establish what happens when rules are broken.

- Have "Do" rules as well as "Don't" rules.
- Change the rules as kids change and grow.

Expect that all members of the family respect and follow the rules. Make sure the rules are ones that really matter. For example:

- Treat everyone respectfully.
- Listen to each other
- No name-calling or put-downs.
- Absolutely no hitting, punching or slapping.
- Everyone puts away their personal property.
- No yelling.
- Ask yourself some questions before you ask the child to do anything.
- Is what I'm asking a child to do reasonable?
- Is it something a child can do by himself or does he need a helping hand?
- Can my expectation be clearly stated?
- Have I given a child a chance to voice his feelings or wishes?

Helping a child become independent

Growing up and becoming independent is one of the most important jobs of childhood. As children learn to do more for themselves, they become more confident, they feel good about themselves, and they are more able to relate better with other children.

Caregivers can help children in their attempts to become more able to do things for themselves. Here are a few hints you can use to help the children become more independent:

1. Avoid doing things for the child that he/she can do.
2. Allow extra time when possible for the child to do things for him/herself - like dressing and undressing.
3. Encourage the child to try doing things he/she has not yet tried. Don't interrupt if they are trying to do something. If you see they are getting frustrated ask if they need help and assist them in getting that job done. Don't take over the job. Then say, "Look, you did it!"
4. Also, don't expect their attempts to be perfect. Expect that there may be wrinkles in the bed they just made.
5. Put shelves and drawers at the child's level so he/she can put away toys, books, and clothes.
6. Put cereal, milk, juice, and other foods into small, unbreakable, easy-to-handle containers so the child can serve him/herself.
7. Even if you have to walk slowly, let the child walk whenever possible rather than be carried.
8. Avoid answering questions "for" the child. Let him/her answer when ready.

9. Child-proof your house so the child can explore safely.
10. Let the child make choices whenever possible - like which cereal to eat or which shirt to wear.
11. Above all, notice when the child tries to do something by themselves, say, "Good job," "You're really trying," or "looks like you're growing up."

GIVE CHILDREN CHOICES

Give a choice if possible. When children are given choices, they learn their opinions matter and they learn how to make decisions. For example: "You can play in the yard away from the road or you can go in the house." OR "Would you like to drink your milk in the red cup or the blue one?"

Sometimes you cannot offer a choice. Describe the action that the child must take. For example: "It is time to get ready for school now."

REMEMBER: Enforce the rule until the child learns it.

HOW TO KEEP YOUR COOL

The way you handle your feelings of anger influences the way children handle theirs. Do not put children down verbally.

Talk about your feelings

Describe the action that upsets you. Be clear that it was the act that upset you, not the child. For example: "Messy rooms do not make me happy."

If you do lose your temper with a child:

- Do not act out of anger.
- Get yourself under control first.
- Take deep breaths.
- Count to ten.
- Drink a glass of water.
- Call a friend, relative or a local help-line.
- Children will act the way they see you act. Do whatever it takes to help you calm down.
- REMEMBER: Never shake, spank, or slap a child.

BEHAVIORS TO AVOID

Nagging

- For example: "If I've told you once, I've told you a thousand times! "

Lecturing

- For example: "When I was your age, I was not allowed to..."

Name calling

- For example: "You're impossible! You are such baby sometimes!"

Put-downs

- For example: "What is the matter with you? Can't you ever do anything right?"

REMEMBER: It is just as easy to say something positive, as it is to say something negative.

HELPFUL IDEAS

Safety: Childproof your home to keep the child safe and protect your valuables when your toddler starts crawling or walking.

- Give safe toys to play with before the child gets into something that is off limits.
- Take the toddler away from the situation to avoid trouble. Get the child interested in something else.

REMEMBER: Toddlers do not understand the word "no."

Bedtime:

- Follow a routine.
- Read a short story.
- Talk quietly.
- Make bedtime a pleasant, calm experience.
- Be firm when it is time for the child to go to sleep.

Chores:

Children learn to accept responsibility by having their own chores to do. As they grow older, children can gradually take more responsibility for helping out.

- Show young children how to do chores.
- Stay and help.
- Make doing chores a game if you want.
- It is not necessary to do it all for them.

REMEMBER: Children like to be helpful!

Toilet Training:

Toilet training is difficult. Children must first learn to control muscles that worked without notice before. Most children cannot control these muscles until around age two.

- Encourage the child's desire to be like caregivers, older brothers or sisters.
- Expect slow progress and mistakes.
- Do not punish for mistakes.
- Praise successes.

- Deal with mistakes in a matter-of-fact way. For example: "You wet your pants, let's get some dry pants for you."

New Situations

- Children may feel fear or be uncomfortable in a new situation.
- If children are old enough, prepare them ahead of time to know what to expect.
- Give the child extra attention.
- If the child acts out, you may take him/her away from the situation. Stay with the child

Temper Tantrums

A temper tantrum comes from the children feeling a strong need or fear and feeling they have no way to satisfy it. They have not learned another way to express frustration.

- Do not try to reason with a child in the middle of a tantrum.
- Describe the behavior to the child: "You have that break something, throw something feeling". This tells the child you understand.
- Show children a positive way out of the situation. They may need to sit down or go to their room to calm down. Stay with a very young or very upset child.
- Get toddlers interested in a toy or stuffed animal.

REMEMBER: "Giving-in" teaches children they can get their own way by throwing a tantrum. Teach children to use words to express frustration, such as: "I feel mad, sad or upset."

Sibling Rivalry

Feelings of jealousy and competition between brothers and sisters are normal.

- Step in if one child is hurting another.
- Ignore tattling and minor disagreements when you can.
- Praise children when they get along well.
- Give each child time alone with you.
- Pick activities for them to do away from each other.
- Respect the child's need for privacy.
- Not all prized possessions have to be shared.
- REMEMBER: All children want and need their caregivers' attention.

Homework

Learning how to do homework can start at an early age. When children begin to get homework:

- Give a quiet space to work.
- Help pick a study time.
- Supervise when necessary to help the child learn how to study. The child will need less supervision as he/she learns study habits.
- Develop a system of rewards for acceptable work and consequences for unacceptable work for children and teens who have trouble getting motivated. The consequences should relate directly to study performance. For example: Loss of TV or telephone privileges during the school week. Rewards could be keeping these privileges.
- Praise effort. Setting unreasonably high goals discourages effort.
- Never do children's homework for them.

What to do in the Grocery Store to Help a Child Behave:

- Give child a responsibility (Match coupons with the labels)
- Ignore inappropriate behavior unless it is dangerous, destructive or embarrassing to you or a bother to others
- Remove child to a private place to discuss misbehavior
- Praise another child's appropriate behavior
- Play a game with the child (Let's count all the tennis shoes we see on people's feet)
- Discuss rules before entering store
- Bring a nutritious snack for child to eat during the shopping
- Bring a storybook for child to look at
- Select a secret word or signal that you can both use to get the attention of the other
- Don't let the child out of your sight
- Reinforce appropriate behavior
- Bring a favorite toy, blanket, etc. to help make him/her feel secure
- Don't bring children to the store if they are tired or hungry
- Role play at home how to act at the grocery store
- Give child something of yours to play with -- keys, pocket book, etc.
- Tend to unacceptable behavior as soon as it occurs
- Wear comfortable shoes and clothes to the grocery store (both caregiver and child)
- As the child is able, let him comparative shop for you
- Take an older child to help you
- Let child know it is a privilege to go shopping with you

Positive Ways to Encourage Children's Growth

- Show children you like them.
- Provide a model for intellectual curiosity.
- Reward responsible behavior and tasks you ask them to complete.
- Require the child to complete certain tasks starting at an early age.
- Set aside time each day to give the child your undivided attention.
- Encourage organization at an early age.
- Help the child discover his natural gifts.
- Work with the child's teacher.
- Encourage the child's growing independence & autonomy (ability to become self-reliant)

We can treat our children with respect by letting them solve their own problems.

Six Step Problem Solving Technique

1. State the problem.
2. Brainstorm the alternatives.
3. Select one possible solution.
4. Implement a solution.
5. Reassess the plan.
6. Start over, if unsuccessful.

REMEMBER: It is normal to sometimes feel frustrated. Talk to others about problems and experiences. Talking helps you to cope with tough situations.

The toolbox

The Nuts and Bolts of a Good Plan is Teaching the New Skill...

- Replace problem behavior with a new skill
- Intentionally teach throughout the day
 - Children learn through multiple opportunities
 - Teaching is easier when the child is not engaging in challenging behavior
- Choose teaching strategies that match:
 - Child's level
 - Caregiver's style

- The activity or situation
- Children with problem behavior have a skill delay in language, social, behavioral, and/or emotional development-So we need to teach them the skills they need

Weigh Your Options

Be Thoughtful About Preventions

Prevention Strategies can soften triggers or make the problem behavior irrelevant

- Anticipate and cue
- Prompt/cue children
- State clear and simple expectations
- Provide predictability
- Signal or warn
- Use "first-then" statements
- Use proximity
- Offer choices
- Encourage/praise
- Embed preference
- Adjust length of activity
- Modify materials
- Use timers
- Model
- Allow for flexibility

Say What You Want to See, Not What You Saw

- Give children clear expectations
- When redirecting let children know what you want to see
 - Say, "Walk" instead of "Don't run"
 - Say, "Feet on floor" instead of "Stop climbing"
 - Say, "Quiet voice" instead of "No yelling" (and model what a quiet voice would sound like)

Don't Get Backed Up, Take the Plunge!

- Follow non-preferred tasks with preferred tasks
- Use "First-Then statements" (combine statement with visual if child needs visual support)
 - "First clean up, then go outside"
 - "First lay down, then hold bear"

- "First say help, then I'll help you"

Roll with It, Sometimes Activities Can Perk Children's Interest or They Simply Flop...

- Read the child's cues
- Extend activities that the child is actively engaged in
- Move on to a new activity when an activity just doesn't work
- Ask the child what he/she wants to do
- Choice is a powerful teaching tool
- Follow the child's lead

Don't Throw in the Monkey Wrench, Stay Positive...

- Challenging behavior is challenging...
- Remind yourself you can support this child
- Teaching is your strength, this is a skill learning issue

Paint the Picture, a Visual Can Speak a Thousand Words...

- Photograph schedules give children a clear sense of time and expectations within a routine
- Mini schedules allow for predictability with individual activities within the daily schedule
- Activity task sequences represent steps within an activity
- Visual cues can be used to communicate clear expectations

Keep a Level Head, Teach the "Turtle Technique"

- Model remaining calm
- Teach children how to control feelings and calm down
- Recognize your feeling(s)
- Think "stop"
- Go inside your "shell" and take 3 deep breaths
- Come out when calm and think of a "solution"
- Prepare children for possible disappointment/change
- Recognize and comment when children stay calm
- Involve families: teach the "Turtle Technique"

Don't Just Blow the Whistle, Coach Children to Think of a Solution...

- Remind children that for most problems there is a "solution" or a way to make it better...
- Cue them to: Stop! What's the problem-Think of a possible solution- What might happen-Give it a try...
- Assist children in problem solving, what could be done:
 - Get a teacher
 - Ask nicely
 - Ignore
 - Play
 - Say, "Please stop."
 - Say, "Please."
 - Share
 - Trade
 - Wait and take turns

Look at the Right Angle, Use the Child's Point of View...

- Get down on the child's level
- Place visual supports within the child's reach and view
- Room arrangement should work for the child and help prevent problem behavior
- Try to look through the lens of the child

Support Children So They Can Measure up, Feel Good, and Make Friends...

- Teach skills that lead to friendships
 - Sharing, giving compliments, turn-taking, helping others, organizing play (Let's statements: "let's build", "let's play tag")
- Provide toys/activities that promote cooperation
- Give attention and time to children who engage in friendship
- Model and role play friendship skills

Shine the Light on Angles, Talk with the Family

- Family members are the child's primary teacher
- Collaborate
- Be aware of and sensitive about family traditions and culture
- If needed, allow the child to bring a comfort item from home (fade over time)

Don't Let the Work Load Bring You Down, Ask for Help...

- Collaboration Works
- Surround yourself with individuals who are supportive and positive
- Share tasks with team members (family members and educational staff)

Give Children Tools

- Teach children "Feeling Vocabulary"
- Help children understand and label their own feelings and feelings of others
- Teach throughout the day
 - In play, with stories, incidentally, through special activities
- Teach feeling words by pairing the word with a picture or photograph
- Teach/model what to do with a feeling "Boy, am I mad. I need to take 3 deep breaths and calm down."

Avoid:	Say/Model:	Remember to add:
Don't run!	Walk	Way to go!
	Use walking fee	I like how you're walking
	Stay with me	Thanks for walking!
	Hold my hand	
Stop climbing!	Keep your feet on the floor	Wow!
		You have both feet on the floor!
Don't touch!	Keep your hands down	You are such a good listener
	Look with your eyes	you are looking with hands down
No yelling!	Use a calm voice	[In a low voice] Now I can

	Use an inside voice	listen, you are using a calm voice
Stop whining!	Use a calm voice	Now I can hear you; that is
	Talk like a big boy/girl	so much better
	Tell me with your words what's wrong	
Don't stand on that!	Sit on the chair	I like the way you are sitting!
		Wow, you're sitting up tall!
Don't hit!	Hands down	You are using your words!
	Hands are for playing	Good for you!
	Use your words**	You're playing nicely!
No coloring on the wall!	Color on the paper	Look at what you've colored!
		Pretty picture!
Don't throw your toys!	Play with the toys	You're playing nicely
		I really like to watch you play!
Stop playing with your food!	Food goes on the spoon and then in your mouth	Great! You're using your spoon
	Say "all done" when finished	What nice manners, you said "all done;" you can go play now

Don't play in the water	Wash your hands	Thanks for washing your hands! I can tell they are really clean!
No biting!	We only bite food	You're upset, I understand. Use your words if you're upset**
Don't spit!	Spit goes in toilet/grass	Good using your words!
	Use your words**	Thanks for using your words!

** (Give child appropriate words to use to express emotion)

A caregiver's guide to understanding temperament

How often have you heard a child described as “easy” or “difficult” or “shy until you get to know her?”

These casual labels all refer to characteristics of temperament, those traits that influence how the child reacts in various situations. Researchers have described nine temperament traits which individually, or in combination, affect how well the child fits in at school, with peers, and even at home. Temperament influences how teachers, peers, and family relate to her, as well as how she relates to them. The child's temperament directly affects how she approaches her school work and chores at home.

When a child's natural behavior doesn't fit with what is expected, social, family, or academic problems may arise. For a child with an identified learning disability (LD) or behavior issues, her particular temperament may help her achieve success more easily or it may compound her difficulties.

Behaviors for each temperament trait described below fall along a continuum. Responses toward either the high or low end - while still completely normal - may be cause for concern.

Effects on the child

Extremes on each continuum of traits are not likely to guarantee success or failure in all situations; somewhere in the middle gives the child flexibility to adjust to a variety of conditions and expectations at school, at home, and in the community. Consider that some combinations of traits can be more troublesome or more beneficial in school than others. High persistence can help the distractible student stay on task, whereas high distractibility combined with high activity and low persistence are strongly correlated to academic problems and bear a striking resemblance to the

characteristics of Attention-Deficit/Hyperactivity Disorder (AD/HD).

Understanding the behavior traits of the child with LD or AD/HD helps you predict how she is likely to react in various situations. Are those traits liable to enhance her performance or cause additional problems for her? For example, auditory processing difficulties may be aggravated by low sensitivity; memory problems may be intensified by high distractibility. High persistence and low distractibility, on the other hand, tend to benefit most kids - with or without LD or AD/HD.

Tips for Managing the Extremes

Here are some tips for helping the child modify the traits that might be problematic for her.

Activity Level

For the child with very high energy:

- Heed the signals that indicate it's time for the child to blow off steam, and find a way to let her do so.
- Incorporate some active time during the day. Walk to school instead of driving, or stop at the park on the way to go grocery shopping.
- Avoid using confinement as a method of discipline.

For the child with very low energy:

- Allow enough time for tasks and activities.
- Use a timer to set a goal for when a chore should be finished.
- Reward the child for sticking with a project and completing it in a timely fashion.

Sensitivity

For the child who shows high sensitivity:

- Acknowledge the child's feelings and provide ways for her to make herself more comfortable.
- Layer clothes to allow for adjustments on days that are too warm or too cold.
- Avoid over-stimulation, e.g., loud music, strobe lights, noisy groups of people.

For the child who shows low sensitivity:

- Help her notice external cues by pointing out sounds in the environment, odors, and changes in the colors of stoplights.
- Explain interpersonal cues, such as facial expressions, body language, personal space.

Regularity

For the child who demonstrates high predictability:

- Provide advance warning of changes in routine.
- Help her learn to handle changes now to develop flexibility as she gets older.

For the child who shows low predictability:

- Create routines, even if they seem odd. Ask her to sit down with the family for dinner even if she's not hungry or go to bed at a regular time even if she's not sleepy.
- Reward successes, such as turning in a paper on time.

Approach/Withdrawal

For the child who approaches new situations easily:

- Provide firm rules and close supervision. This child is curious!
- Teach her to use reasonable caution with new people or in new situations.

For the child who withdraws:

- Allow time to adjust to new situations; let her set the pace.
- Quietly encourage her, without pushing, to try new activities and make new friends.

Adaptability

For the child who is slow to adapt:

- Give plenty of warning about transitions.
- Role play or practice expected behaviors before going into new situations.
- Acknowledge the stress she feels in new situations and encourage her to talk about it.

For the child who adapts too easily:

- Teach her to make her own decisions rather than just go along with her peer group.
- Encourage her to find out all she can about an activity before signing up and committing her time.

Mood

For the child who tends to be negative:

- Try to ignore her general negative mood, but tune in to real distress.
- Encourage her to recognize and talk about the things that make her happy.
- Act as a role model for positive social interactions.

For the child who's always positive:

- Be sensitive to subtle signs of unhappiness that she may be bottling up inside.
- Teach appropriate ways to express feelings of sadness, anger, fear, and frustration.

Intensity

For the child who is less responsive:

- Don't equate a lack of intensity with lack of feelings.
- Watch and listen carefully to pick up more subtle clues to problems.

For the child who is overly responsive:

- Teach her to control her emotional responses through anger management, self-talk, or calming strategies.

Persistence

For the child who shows low persistence:

- Break tasks into small steps, and acknowledge small successes.
- Try timed work periods followed by short breaks.
- Reward her for sustained effort and finished assignments.

For the child who is overly persistent:

- Provide lots of warning before transitions.
- Remind him that it's not always possible to be perfect.

Distractibility

For the child who is highly distractible:

- Reduce external distractions as much as possible.
- Keep instructions short.
- Use a special cue - gesture or word - to remind her to get back on task.

For the child who shows low distractibility:

- Cue her when it's time to move on to something new, e.g., say her name or touch her arm.
- Set a timer to remind her when to move on to the next task or activity.

Appreciate Your Whole Child

No matter what the child's temperament, show respect and understanding; let her know you accept her the way she is. Her temperament traits combine to make her the very unique and special individual she is.

Remember that some traits seen as challenging in kids are valued later. The extremely open and approaching child becomes an adventurous and exploring adult who makes new discoveries. And the child with high energy and persistence could become the next Olympic gold medal winner!

TIPS:

1. It will get worse before it gets better. Expect escalation of the inappropriate behavior.
2. Set the limits and be consistent upfront. You are building a relationship.
3. 95% of the behavior change comes from the adult.
4. Remain emotionally detached during behavioral incidences, especially with adult attention seeking children.
5. Refrain from engaging in conversations with the child that contain rationalizations and explanations of expectations. Teach and practice expected behavior in advance and warnings become unnecessary.

Understanding behavioral intervention

What is "Functional Assessment of Behavior"?

1. Observe the child in different settings across time. There are several ways to collect the data (frequency, duration, etc.). An effective method is through the use of an A-B-C chart.

2. Gather information from familiar adults (and maybe the child) through interviews and behavior checklists.
3. Define the behaviors concretely.
4. Document the environmental factors and setting events that reliably predict the behavior.
5. Record the antecedent triggers or cues that indicate an inappropriate behavior will happen.
"What would make the behavior happen?"
6. Identify the maintaining consequences that continue to allow the behavior to happen in this environment (i.e., reinforces the behavior).
7. Develop a hypothesis (educated guess) about the function of the behavior.

Example: Barry pulls a peer's hair because he wants the teacher's attention. The behavior is reinforced because the teacher takes Barry aside, puts him on her lap, and talks about his behavior.

How do "Behavior Improvement Plans" work?

1. The goal is to teach a child how to get his/her needs and wants met while demonstrating socially appropriate behavior.
2. Determine the Desired Behavior: "What do you want him to do instead?"
3. Decide on an acceptable Replacement Behavior.
4. Teach and practice the new skills. You will have to meet the child "where he is."
5. Maintain use of the new behavior by eliminating the success of the old, inappropriate behavior (it cannot meet the same need anymore).
6. Set up the environment for success. Match academic expectations to the child's skills. Provide social supports as needed.
7. Provide pre-corrects (advanced reminders) and redirection (prompts) as needed.
8. Reinforce use of the new behavior and fade as possible. You may need to use tangibles, but they should always be paired with verbal identification of appropriate behavior. Fade to only verbal cues and/or a smile or thumbs up.
9. Collect data on changed behavior and adapt the plan as indicated.

Module 7: PROVIDING SAFE AND EFFECTIVE CARE

Meeting Basic Needs

As a Respite Care Provider, one of your responsibilities will be attending to the basic needs of individuals with developmental disabilities. Activities such as eating, dressing, bathing and toileting can present special problems.

Performing activities of daily living involves a variety of sensory, motor and cognitive skills. Acquisition of basic self-care skills is an important part of the socialization process. As the development approach teaches, independent mastery of these activities generally proceeds in an orderly and predictable manner. Typically, a person gradually assumes more and more of an active role in self-care, as the caretaker assumes a more passive role. If you understand what an individual is able to do by him/herself, you will be able to help facilitate independence and the acquisition of new skills rather than frustrate the person by demanding either too much or too little. Often skills are in a transitional phase, which means that the person is still in the process of learning to utilize a new skill efficiently. It may be necessary to provide additional time and/or opportunities to complete tasks. It is also important to praise all efforts to help foster self-esteem and perseverance.

This section will discuss six important areas:

1. **Positioning** - general rules for handling and positioning during a variety of activities;
2. **Eating** - problems in eating; adaptive equipment
3. **Body Mechanics** - mechanics of lifting, carrying and transferring; using a wheelchair;
4. **Dressing** - dependent and independent dressing skills; use of braces
5. **Bathing** - use of adaptive equipment
6. **Toilet Care** - assisting with toileting; use of adaptive materials; scheduling.

1. Positioning:

Many children are unable to move from one place to another independently. The physical manifestations of their condition may include weakness, paralysis or poor coordination due to a lack of voluntary control over muscles or difficulty in maintaining equilibrium. Invariably there is some type of abnormal muscle tone. Increased muscle tone is referred to as "hypertonic," and the individual may exhibit "spasticity" in various muscle groupings. Decreased muscle tone is known as "hypotonic," and muscles may appear "floppy." When muscle tone fluctuates from hypotonic to normal it is known as "athetoid."

Normal coordinated movement is based to a large extent on reflexes. Reflexes are classically

viewed as predictable motor responses that follow specific sensory input. A person who has central nervous system damage may exhibit reflexes in an exaggerated form, and be unable to move out of abnormal postural patterns without assistance. Proper handling and positioning techniques is important in order to maximize comfort level and the ability to interact with the environment.

Contracture occurs when a joint cannot move through its full range because muscle on either side has shortened at a resting state. Contractures can be prevented if the person's body is kept in correct alignment when resting, and daily exercise and moving of the limbs through the normal range is followed. It is important to move and re-position an individual with physical disabilities often so as to provide various types of motor stimulation and to decrease the possibility of pressure sores and joint fixation.

Proper Positioning:

- Always have the individual in a symmetrical position (both sides of the body look the same.)
- Have hips and knees and feet at least at a 90-degree angle.
- Flex the head and roll the shoulders forward. Flex the hips and knees up to help break up excessive muscle tone.
- Use safety straps and shoulder harness as necessary. Make sure the straps are not too tight and interfering with breathing.
- Use only the necessary adaptive side and back supports on a wheelchair.

2. Eating:

In many families socialization takes place around the dinner table. It is important that the individual with special needs be encouraged to participate with other members of the household to the fullest extent. Information pertaining to eating should be discussed with the parent/guardian. It is imperative that you be informed of food allergies, reactions to medications, type and texture of food and frequency of meals. Positioning is also important when assisting an individual with eating or when attempting to feed someone. Pay attention to the following:

- **Body positioning:** relax the individual and place him/her in the desired position. An ideal position for eating is upright sitting so the head is aligned with the body. Avoid feeding an individual who is lying down. Consult with the family in special circumstances. Proper positioning during eating will help relax excessive muscle tone and/or help strengthen muscle if the tone is low. When positioning an infant or child in a high chair make sure:
 - The trunk is erect - you may have to place side rolls next to the body to keep the trunk straight. You can make side rolls from rolled-up towels. Be careful not to crowd the child with too many rolls.
 - Hips are next to back of chair - secure the chair's seat belt around the hips to keep them in place. You may need to place a non-skid surface on the seat of the chair to prevent sliding out of the seat. (Non-skid bathtub decals can work).

- Knees are bent over the edge of the chair - If the individual is too far back in the chair you may need to add a back support to bring him/her forward. Do not bring the individual too far forward to prevent falling out of the chair.
- Feet are placed on footrest - Avoid dangling the person's feet. You may need to build up the footrest with books or cardboard. Feet should be flat on the footrest so that the angle between ankles and feet is 90 degrees, and between knees and legs is 90 degrees. Toes should not be pointed up or down.
- Head is erect or slightly bent forward - Do not permit the head to tilt backwards when feeding. You may have to provide support behind the head, under the curve, to give needed control. Watch that the head does not lean to the side. Do not allow the head to "flop" forward or backward. The head should be held in the middle, looking straight at you.
- Arms are on top of tray - Arms should not be under tray or out to the side.

When an individual is seated in wheelchair or a "travel chair" be sure to:

- Watch for a straight trunk, head in the middle position, feet secure and hands on top of the tray.
- Place the chair in the most upright position that can be tolerated by the individual.

For individuals seated at a table in a regular chair make sure that feet are supported. You may need to place a footstool under the table for the feet. Keep the hips positioned next to the back of the chair and maintain upright posture. A towel or large sheet can be used as a seat belt to prevent slumping forward. The individual may need to lean the elbows on the table for support, but whenever possible hands should be placed on top of the table, not dangled at the side.

As much as possible follow the normal eating routine of the family (e.g. time of day, preparation, routines). Maintain a pleasant mealtime atmosphere. Speak quietly and calmly. Eliminate excess noise and distractions. If the individual cannot see the food, use voice and touch cues. Describe what you will be feeding him/her, or what is being served for them to eat. Individuals with hearing impairments should be able to see the food at all times, however continue to talk to the person. Signing or picture communication can also be used to help the person understand what they will be eating.

Many individuals experience oral sensitivity to food texture, taste and temperature. They may be uncomfortable with utensils being placed in the mouth. Always check with parents/guardians about the best way of assisting with eating when these issues are present. Avoid startling the person and keep your voice calm and reassuring.

Some individuals will have difficulty with chewing and swallowing. They may engage in frequent coughing or choking when eating. Watch the person and allow him/her to cough without patting on the back as long as he/she is able to cough. If you see that he/she is gasping for air begin procedures for clearing an obstructed airway.

The inability to keep food or liquids inside the mouth may be the result of an inability to keep the mouth closed. You may provide assistance by placing a finger or thumb at the jaw joint with your middle finger or thumb under the chin. Use the other free finger to push up on the lower lip.

Some people exhibit an inability to swallow smoothly or have a tendency to bite down hard on a utensil. With your forefinger, press the jaw joint to release the jaw. Never use plastic or breakable utensils when feeding an individual where this problem is present.

Feeding equipment:

Spoons should fit the size of the mouth. Spoons with built-up handles allow individuals to hold the spoon better. Flatter bowls make the removal of food easier, and a higher rim on plates allows the scooping of food against the edge. Dividers in infant plates help to keep foods separate. Using insulated plates can keep food temperatures constant. Foam pads, clay substitute, non-skid plates or a suction cup placed under the plate will assist an individual with self-feeding while keeping the plate in place.

3. Body Mechanics:

When lifting, transferring or carrying a person who is physically disabled it is very important that you observe the following principles of body mechanics. Practicing them will help to prevent possible strain or injury to your lower back, and insure a safe lift for the individual.

The term "handling" refers to methods for holding or lifting a person with developmental disabilities. Always prepare for what is going to happen. Tell the person what you are going to do, use a gesture or a familiar signal so that the individual understands. Allow the individual to assist in moving as much as he/she is able, and as long as it does not require excessive effort or strain. Handle the person slowly and securely. Maintain the same posture on both sides of the body, with good body alignment. Handle at the shoulders, hips and through the trunk - not by the arms or legs.

Lifting:

Plan the move/lift.

Make sure you have ample room for good footing and the path is clear for carrying.

Stand so you do not have to twist as you lift.

Lift by straightening the legs is a steady upward thrust and, at the same time move the back to a vertical position.

The person's weight should be kept as close to you as possible

Keep your back straight, not arched.

Change direction by stepping around and turning the whole body.

Lower in a slow and even manner, bending your legs.

Although some individuals who use wheelchairs may have sufficient arm strength and coordination to transfer in and out of their chair independently, many will need assistance. Always ask the parents/guardians to show you the method used for their child. An additional issue to consider is that often respite care may take place in the home of the provider.

It is important to think about ways in which you can make your home more accessible, such as removing floor rugs from central pathways, rearranging moveable furniture or making minor adaptations to entry or foyers (such as wooden ramps over extra steps).When transferring individuals into or out of wheelchairs, always remember to:

Transfers:

Make sure the chair is locked when taking a person out of it or putting him/her into it.

Pull wheelchairs backwards up steps, curbs, etc.

Adjust the height of the foot pedals so that the person is sitting at a 90 degree angle at the hip and

knee unless he/she is in a "Posture 90" chair.

Place one arm around the person and under his/her arm at the armpit. Place your other arm under the person's knees. OR

Face the person in the chair, secure a hold under each arm, lift out of the chair making sure you have put up the foot pedals or moved them out of the way.

Moving from Bed to Wheelchair:

Place the chair at a close angle to the bed.

Move the person to the edge of the bed, moving upper trunk first, then the legs, one at a time.

Remember to bend from the knees, not from the waist.

Position yourself near the person's head and trunk.

Slide one arm under the person's upper trunk (under the arms) and raise to a sitting position.

Place your other arm in a cradle position under the person's hips. Straighten your knees, lift and hold the person close to your body.

Turn one half circle to face the chair and lower the person into it while bending your knees.

From Wheelchair to Bed:

Place the chair at an angle close to the bed.

Face the person, assume a slight squatting position (knees bent), place one foot in front of the other and encircle the person at the waist or upper chest.

Shift your weight onto your back foot, straighten the knees, and lift the person out of the chair.

Swing one-half circle, and sit the person on the bed.

Place the legs on the bed and move him/her to the center of the bed.

4. Dressing:

For most people undressing is easier than dressing. It is important for you to understand how much independent dressing an individual may do and how much assistance will be needed. In order for an individual to dress independently he/she needs to be able to maintain a sitting balance and have adequate trunk control so that arm motions will not affect balance. The individual must be able to move the arms purposefully in a desired direction to reach necessary garments, and to lift up in order to remove slacks, pants, etc. Grasping and releasing article of clothing requires finger dexterity, as does shoe lacing, tying and buttoning.

Some individuals may find it easier to dress while sitting on a floor, in a chair, on the bed, lying down or in a kneeling position. When assisting with dressing, do not try to stretch the limbs too quickly.

Talk in a calm, soft voice and guide the individual through the clothing. If braces must be used always have the parent show you the correct procedure for taking them on and off.

5. Bathing:

It is important to provide a comfortable and safe position for bathing. If a person is unable to sit in a tub independently, a special bathtub seat with suction cups and a seat belt can be used. An inflatable "doughnut" tube may also provide sufficient support. Bathtubs and showers should have slip-resistant strip to prevent falling.

Bathing is a good time to inspect the person's skin for pressure areas. These areas will develop in individuals with sensory and motor problems as a result of remaining in one position for too long. Skin breakdown can be a serious problem if it is not cared for immediately. Should you notice any early warning signs, such as reddened areas on the person's skin, notify the parent/guardian

immediately. Be sure to position the individual in positions which relieve pressure on the affected area and move frequently to minimize additional injury.

6. Toilet Care:

Toileting is the most personal activity of daily living that may require assistance. In order to protect the person's self-esteem, it is very important that toileting issues be handled in a positive and supportive manner. Some of the individuals you will assist will be in the process of learning to toilet themselves. You may be asked to maintain a toileting program. Make sure that parent/guardian has thoroughly explained all steps of this program and how it is to be documented. Schedules may be strict, ranging from attempts to toilet every few minutes to various times throughout the day. Make sure you adhere to any toileting schedule that is in place.

Catheters or urine collection devices may be worn either internally or externally. A catheter is a tube-like medical appliance which is surgically inserted into the bladder to help drain urine. Urine drains into a container which may be attached to the individual's leg or a wheelchair. Tubes on these devices can become obstructed. It is important to check the tube to make sure it is draining from time to time, especially after a major change in positioning has been made.

It is always necessary to wear protective gloves when assisting individuals with toileting or when emptying and cleaning catheter containers.

The information outlined in this module is meant to be an overview, and may need to be supplemented by another source. The parent/guardian should always be asked for information and direction before any assistance is attempted in areas of daily living.

Back Safety

YOUR BACK / THE SPINE

Purpose

- Your back maintains you in a stable upright position
- Your back helps you to be mobile

Why is your back vulnerable to injury?

- We continually place constant stress on it
- Because we are weight bearing
- We are constantly changing our posture

This is why you must use your back properly and keep your spine strong and flexible.

The working parts of the spine

- Vertebrae (the bones)
- Discs (the cushions that separate the bones)
- Joints (the pivot areas)
- Ligaments (they hold the spine together)
- Muscles (provide the movement)
- Nerves (the monitoring system)

LIFTING

Before you lift:

- Check the object
- Is the load packed right?
- Is the load easy to grip?
- Is the load easy to reach?
- Test the weight of the object
- Clear a pathway
- Stretch before you lift
- Ask for help if needed

RISK FACTORS FOR BACK PAIN OR INJURY

Factors we have no control over:

- Heredity
- Structure and anatomy
- Age
- Time of Day
- Height

Factors we have some control over:

- Occupation
- Level of fitness
- Factors we have the most control over:
 - Smoking
 - Nutrition
 - Weight
 - Lifestyle (active or sedentary)
 - Stress/anxiety
 - Posture

- Proper body mechanics and lifting techniques

ANATOMY OF THE SPINE

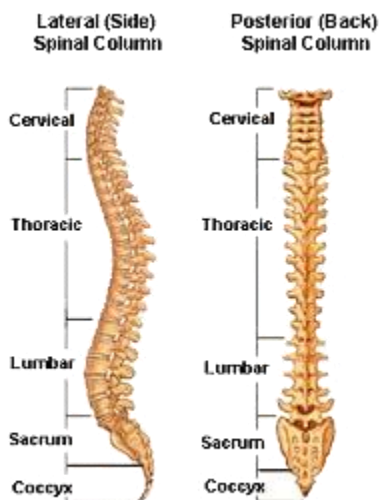
A Healthy back is a flexible, strong, and pain-free. Its chief functions are to support your upper body, protect your spinal cord, allow flexibility, and provide a point of attachment for your muscles and ligaments. The spine is composed of many bones (vertebrae) which form three curves in the back to provide our backs with flexibility and shock absorption.

Cervical Region: The neck is made up of 7 vertebrae which has an inward curve or cervical lordosis.

Thoracic Region: the mid-back is made up of 12 vertebrae with 12 ribs attached. This region has an outward curve or Thoracic kyphosis.

Lumbar Region: The low back is made up of 5 vertebrae and has an inward curve or lumbar lordosis.

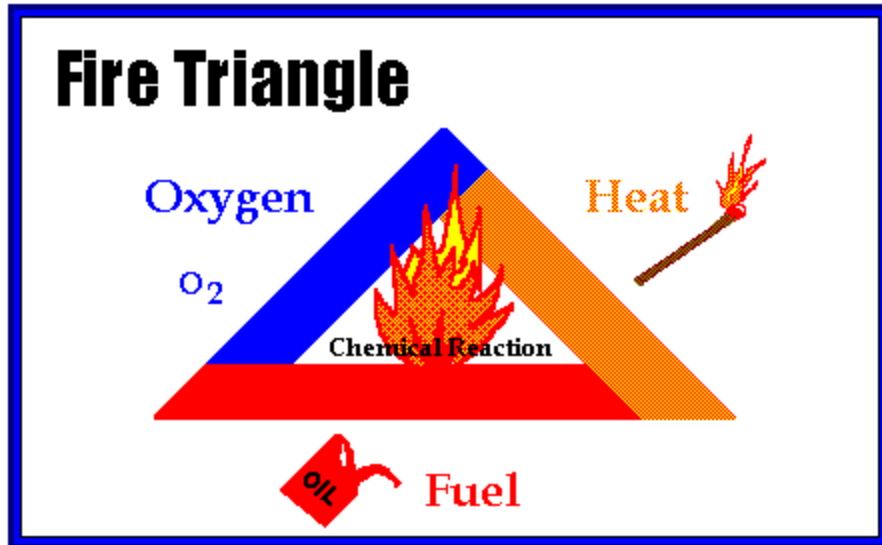
Sacrum: The sacrum is a solid mass of bone or 5 fused vertebrae.



Fire Safety

Three elements that must be present for a fire to occur:

- Oxygen (more properly, an oxidizing agent)
- Fuel (a reducing agent)
- Heat



Three types of fires:

A - Ordinary combustibles such as wood, paper, cloth, rubber, etc.

B - Flammable liquids or gases like cooking oil, paint, gasoline, etc.

C - Electrical items such as appliances, panel boxes, cords, etc.

EVACUATION PLANS

What is the purpose of an evacuation plan?

- Ensure that people in the home/workplace know what to do if there is a fire
- Ensure that the home/workplace can be safely evacuated

Evacuate immediately!

- Call 911 from a safe location (post emergency numbers)
- Have two means of escape (again have emergency numbers posted at these escape routes)
- Meet at the assembly place
- Practice fire drill (monthly is suggested)
- Know your role in a fire emergency
- Consumers first! (For Certified Respite Providers this would mean the children in your care)

FIRE EXTINGUISHERS

P-A-S-S Procedure

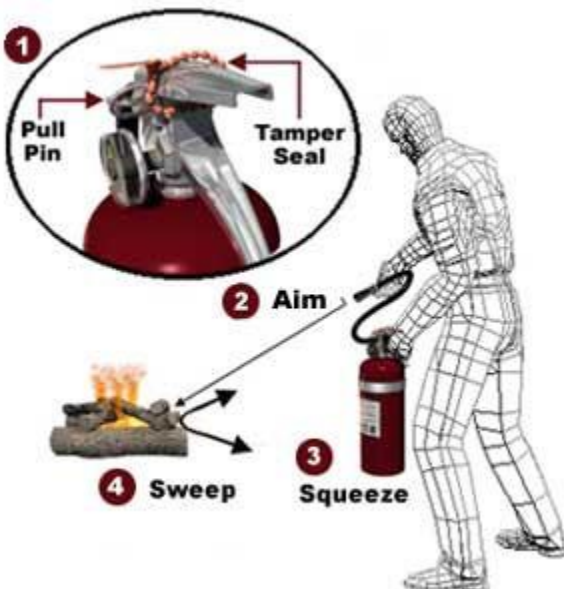
Keep your back to an exit and stand 6-8 feet away from the fire. Follow the four step P-A-S-S procedure (see the steps below). If the fire does not begin to go out immediately, leave the area at once.

PULL the pin: this unlocks the operating lever and allows you to discharge the extinguisher (some extinguishers may have other lever-release mechanisms)

AIM low: Point the extinguisher nozzle (or hose) at the base of the fire

SQUEEZE the lever above the handle: this discharges the extinguisher agent, releasing the lever will stop the discharge (some extinguishers may have a button instead of a lever)

SWEEP from side to side: moving carefully toward the fire, keep the extinguisher aimed at the base of the fire and sweep back and forth until the flames appear to be out



Blood Borne Pathogens

How do infections occur?

In order for an infection to occur, the following must be present:

- A pathogen (germ)
- A large amount of the pathogen (germ)
- A susceptible person (host)
- An entry site (where the germ gets in)

How do infections enter the body?

There are several ways that an infection can enter the body. They are:

Direct: when a person comes in direct contact with another person's blood or body fluids (this is the greatest risk of all). Example: Blood in an open wound.

Indirect: indirectly coming in contact with blood or body fluids like a contaminated surface or linen.

Airborne: the infection is spread through the air. Example: Coughing or sneezing.

Vector borne: when infection comes from animal or insect bites. Example: Rabies from a dog bite.

What do you do when you have been exposed to substances that could be infectious or disease bearing?

- Clean the exposed area thoroughly with anti-bacterial soap and water. If an open wound has been exposed clean it as well and attempt to make it bleed. If the eyes have been exposed flush the eyes.
- Secure the scene if there is a concern about it being safe. If the area needs to be cleaned use universal precautions when doing so.
- If a child has been injured or exposed to infectious material contact the parents immediately. Once the situation is under control the Respite Program should be notified as well.

REMEMBER THOROUGH AND CONSISTENT HANDWASHING IS ONE OF THE BEST WAYS TO PREVENT THE SPREAD OF INFECTION