SPECIALIZED FAMILY CARE
Provider Training

Category:	**Pre-Service Training**
Title:	**Overview of the Specialized Family Care Program**
Materials:	*Pre-Service Training Document*
Goal:	Applicant understands the Specialized Family Care Program and the requirements to become a Specialized Family Care Provider
Credit Hours	3 Hours
Date Developed:	July 2014
Developed by:	SFC Program

This skill-building instruction has been approved for Specialized Family Care Provider training by:

8/29/2016

Specialized Family Care Program Manager **Date**

Carol Brewster 08-29-2016

Content Reviewed by: Carol Brewster, FBCS **Date**

Training Objectives:

- Specialized Family Care Provider can describe Specialized Family Care
- Specialized Family Care Provider knows the requirements to become a Specialized Family Care Provider
- Specialized Family Care Provider knows the roles/responsibilities of Specialized Family Care Providers
- Specialized Family Care Provider has a basic understanding of developmental disabilities
- Specialized Family Care Provider knows the confidentiality requirements of the SFC Program
- Specialized Family care Provider understands role of a mandated reporter

Training Procedures:

- Specialized Family Care Provider initiated self-study
- Test completed by Specialized Family Care Provider
- Review of test responses by Family Based Care Specialist and Specialized Family Care Provider

I certify that I have completed all the materials associated with this training module. I feel that I have a basic understanding of the material completed.

Specialized Family Care Provider **Start Time** **End Time** **Date**

Reviewed by: _____
Family Based Care Specialist **Date**

This Program is funded by the WV Department of Health & Human Resources, Bureau for Children & Families and administered by the Center for Excellence in Disabilities, West Virginia University.

WEST VIRGINIA UNIVERSITY
CENTER FOR EXCELLENCE DISABILITIES

OVERVIEW OF THE SPECIALIZED FAMILY CARE PROGRAM

INTRODUCTION

Thank you for your interest in the Specialized Family Care Program of WVU Center for Excellence in Disabilities. We hope that upon review of this information you will choose to consider your qualifications and ability to become certified as a full time home provider **or** respite care provider for an individual with an intellectual and/or developmental disability.

This document is divided into the following sections to familiarize potential applicants with the SFC Program and to answer questions regarding certification and expectations of Specialized Family Care Providers:

TYPES OF SUBSTITUTE CARE
HISTORY AND BACKGROUND OF THE SFC PROGRAM
QUALIFICATIONS/QUALITIES OF SFC HOMES AND FAMILIES
STANDARDS FOR SFC HOME APPROVAL
ROLES/RESPONSIBILITIES OF SFC PROVIDERS
OVERVIEW OF DEVELOPMENTAL DISABILIITIES
LEGAL ISSUES
FINANCIAL/PAYMENT

This Program is funded by the WV Department of Health & Human Resources, Bureau for Children & Families and administered by the Center for Excellence in Disabilities, West Virginia University.

You may see terms and abbreviations throughout this document which are new to you. An explanation of these is:

ID/DD Refers to intellectual disability/developmental disability

FBCS Family Based Care Specialist. The professional person from the SFC Program, who recruits, trains and guides the potential applicant in becoming certified as a Specialized Family Care Provider. The FBCS monitors the home, providing support to the person in placement and the SFCP.

PIP Person in Placement. Refers to the individual (child or adult) who is residing in the home of a Specialized Family Care Provider.

SFC Specialized Family Care. SFC is a placement option for an individual, child or adult, who has an intellectual and/or development disability and meets financial criteria. The individual resides with a family who has been certified to provide in home care.

SFCP Specialized Family Care Provider. An individual who is certified to provide full time **or** respite care in his/her home to a person with an intellectual/developmental disability.

TYPES OF SUBSTITUTE CARE

The information provided in this pre-service training focuses on Specialized Family Care. The following information, however, is provided to applicants to provide explanation of the other types of family care. The following definitions describe the variety of care and adoptive placements which might be considered as an option for a child or adult.

Adoption: "A legal process in which all rights and responsibilities are transferred to an individual or couple who has agreed to assume them. Adoption is permanent and grants a child full membership into the new family as if he/she were born into it. Adoption terminates all rights and responsibilities of the biological parents." (National Council for Adoption)

Open Adoption: An adoption in which there are degrees of ongoing communication and/or contact between the birth family and the adoptive family.

Subsidized Adoption: A form of adoption which allows the provision of short term or ongoing financial and medical assistance for an individual who has special needs.

Adult Family Care: Services provided by families willing to provide care to adults who need some assistance with daily living skills, who may or may not have disabilities.

Foster Family Care: Services provided by any person not related to the individual who has been approved to provide care in an out-of-home living situation when no suitable relative placement is available.

Legal Guardianship: A formal decision by a judge that suspends a parent(s) custody of the child and gives an adult/agency authority to provide for the child's needs and make decisions in regard to those needs. In the case of an adult needing care, a formal decision may be made by a judge to grant guardianship to an adult/agency to provide for necessary care and needs.

Permanent Foster Family Care: A permanent, court sanctioned, foster family living arrangement for the individual who cannot return to his biological family.

Specialized Family Care (SFC): Services provided by persons who are primarily willing to provide care within their own home to individuals, of any age, who have intellectual/ developmental disabilities.

Specialized Family care Adoption: This alternative should be considered for any individual who has been in an SFC home and has established roots and connections with the family. SFC families who wish to pursue this permanent option must meet specified criteria, undergoing an adoptive home study.

HISTORY, BACKGROUND & EXPLANATION OF THE SFC PROGRAM

In 1978, a federal civil rights action, *Medley eta/. v. Ginsberg eta/.* was filed against the state departments of health and welfare, community mental health centers and the state superintendent of schools in West Virginia. The plaintiff was a 17 year old girl who was intellectually disabled (Macel Medley) and who had been unnecessarily institutionalized because of a lack of community services. In 1979, the case evolved into a class action suit. In October 1981, as a result of this law suit, the State Departments of Health, Education and Human Services, and Shawnee Hills Mental Health/Retardation Center gained the court's approval to work together to develop a statewide program of community based services. The resulting court decree made it possible for young people living in state institutions to move out of state facilities and into communities throughout the state. The Specialized Family Care Program was designed to meet this need.

There were more than 400 Medley Class Members (youth with intellectual disabilities and/or developmental disabilities who were school age when the lawsuit was filed) living in West Virginia state institutions. When the lawsuit began in 1978, there were 232 children under age 18 residing in state institutions. Today there are no children residing in state institutions. Children with intellectual/developmental disabilities are now placed in Specialized Family Care Homes. The WV Specialized Family Care Program is essentially a WVDHHR foster care program funded and administered by the Bureau of Children & Families, Division of Children and Adults.

The Specialized Family Care (SFC) program supports individuals, both children and adults, with intellectual/developmental disabilities in homes, neighborhoods and communities. SFC providers are trained and certified to become a foster family for the individual, receiving monies to support the individual in placement and paid for their services.

Referrals for placement of an individual with ID/DD in an SFC home come from sources such as family members, WV Department of Health & Human Resources, behavioral health centers, medical facilities and other interested persons. Individuals referred to the SFC Program must have a funding source of Title XIX waiver, personal care or private pay funding.

SFC PROVIDER QUALIFICATIONS

A variety of "families" are eligible for consideration as SFC Providers. This can include singles, married couples, same sex couples, or cohabitating individuals. (It is desirable that the SFC family include two adults.) Each home is evaluated on an individual basis. Couples in which both parents are employed outside the home shall not be excluded from consideration for approval, however when alternate care outside the home is needed, these arrangements must be evaluated and approved. Individuals undergo a process to become certified to become SFC Providers. Applicants complete the certification process, completing an application, gathering verification documents and completing training materials provided to them. Some of the requirements for initial home approval include:

At least 21 years & not older than 65 years at time of application

- US citizen and a resident of WV
- State and Federal Criminal investigation checks on everyone in home over age 18
- WVDHHR Child Protection reference check on all adults in the home
- Home which can meet space, safety, water, fire and sanitation standards
- Access to necessary services, medical, educational, recreational, etc. in the community
- Financial stability without dependence on SFC program monies
- Good physical and mental health, verified by medical examinations, on each person in home, including immunization records on any children in the home.
- Complete required pre-service training modules, including an additional 27 hour course, PRIDE, which is offered by WVDHHR for a provider who wishes to care for children
- First Aid and CPR certifications which are kept current
- Six references
- Reliable transportation, accepting responsibility to transport person in placement. Verification of driver's license, vehicle registration & insurance required.
- Willingness to participate in the home study process, including interviews, completing required written materials and providing required verifications
- Willingness to limit care to no more than two individuals with special needs

Homes are certified for a one year period of time. Re-certifications are completed annually. Requirements for recertification include:

- Cooperation with monthly home visits by the FBCS, if providing full time care, and 4 times yearly if providing respite care.
- Ability to maintain up to date verification documents
- Completion of 24 hours of annual on-going training, which can be provided in the home setting

QUALITIES OF SFC PROVIDERS

Providing care for an individual with intellectual disabilities and/or developmental disabilities can be an extremely demanding and entails much responsibility. Desirable attributes of Providers who can undertake and perform the responsibilities required for caring for an individual include:

- Patience, sincerity and genuine interest
- Nurturing and possess good caregiving skills
- Evidence of good family life and total family involvement
- Willingness to accept the person in placement as a family member
- Responsible, stable, mature
- Emotional stability
- Flexibility and ability to modify expectations, attitudes and behavior in relation to the person in placement
- Willing to seek and accept professional assistance when needed
- Ability to carry out person in placement's treatment plan
- Willingness to learn new skills

STANDARDS FOR THE SFC HOME

Physical standards of the home shall be a degree of comfort sufficient to ensure the well-being of the family and shall have adequate space to accommodate all household members including a person in placement (PIP). Compliance with home/safety standards is the responsibility of the SFC Provider. Homes are inspected monthly by Family Based Care Specialists for full-time placements and quarterly for families who provide respite. Homes are recertified annually. Standards for the home include:

Home & Housekeeping Standards

- Home must be maintained in a clean, hazard free and orderly manner, both inside and out. There shall be no unnecessary clutter which could be a safety concern.
- PIP cannot be housed in unapproved rooms or detached buildings.

Telephone:

- SFCP's must have a working telephone in the home at all times.

Sleeping Arrangements:

- No more than two PIPs, including the SFCP's own family, may share a bedroom.
- All PIPs sharing a bedroom shall be of the same sex.
- Each person is to have his/her own bed. Infants are to be placed in a crib.
- Adults placed in a home shall not share a bedroom with a child. Folding cots, roll-away beds and recliners are not allowed. Double decker or bunk beds are discouraged.
- PIP's bedroom shall generally be on the main floor of the home.
- Fire safety ladders may be used if PIP is capable of using them.
- Space must be provided in the bedroom for PIP's personal possessions and a reasonable degree of privacy. Closet space must be available.
- Each room in which a PIP sleeps must have a window in the room that can be accessed as an emergency exit and an interior door leading to the rest of the home. Half doors are not permitted.
- Bedroom of a PIP with a physical disability shall be within easy access of a responsible person who is approved to provide care when needed.
- Attic or basement bedrooms must meet the same standards as all bedrooms in the home.

Bathrooms:

- Must have windows and/or fans for ventilation.
- Shall be easily accessible and equipped to meet needs of PIP.
- Must be clean and free from odors and in good working order.
- Must have doors for privacy.

Home Safety Environment:

- Prospective SFC home will be inspected by the FBCS during certification and annually thereafter.
- Use of mobile homes is limited to those manufactured after 1976.
- Homes must have screens on all windows when opened and have at least two exits that can be used for emergency.
- An attached garage must be separated from house by a tight fitting door which is kept closed.
- Furniture, carpets and accessories shall be sanitary, in good condition, comfortable and free from odors.
- Heat sources such as fireplaces, furnaces, stoves, radiators, water heaters, and other heaters must have safeguards including thermostatic controls, automatic shut off valves, vents and screens that are functioning. Ventless gas heaters need to be vented using a cracked window or door according to owner manuals.
- Walls, ceilings and floors must be protected from heating and cooking equipment by sufficient clearance or noncombustible insulation.
- Ashes from burning coal or wood must be kept in a metal container clear of wood floors and walls.
- Extension cords must be used properly.
- Electrical circuits must be protected by a maximum 20 amp fuse or circuit breaker.
- Chemicals and flammable materials must be stored in unbreakable, clearly labeled containers out of reach of the PIP.

- Firearms must be properly stored in locked containers inaccessible to PIP.
- Residence must have appropriate supply of water, including hot water.
- Drinking water supplied by means other than a municipal water supply must be evaluated and approved safe by local Dept./Division of Health or by independent facility capable of making distinctions. This shall occur initially and annually thereafter.
- Liquid waste must be disposed in sanitary manner into public sewage system or into a system which meets standards of the Department/Division of Health.
- Garbage and trash shall be collected and disposed in compliance with established standards.
- All pets shall have proof of current vaccination/certification which is required by WV Code. A sickly or vicious animal must be confined in an area inaccessible to PIP. All PIPs must be carefully supervised when handling or caring for an animal.

Fire Safety:

- There shall be a self-contained battery operated smoke alarm near the entrance to each bedroom in the home.
- There shall be smoke alarms located near all cooking areas and home heating sources.
- There shall be a carbon monoxide detector near the top of the basement stairs or near the heating source.
- There must be a fully charged portable 5 lb. ABC fire extinguisher in each home located near cooking and heating units. A home diagram must be made identifying rooms and occupants that reflects a fire escape plan, escape route and an outside meeting place.
- There must be a written and diagramed evacuation plan posted in case of fire.
- There shall be a fire drill or "walk through" of the evacuation plan with each PIP within 24 hours of placement and monthly thereafter.
- Concerns about fire safety in the home may require the SFCP to arrange for an inspection by a member of the local fire department.

ROLES & RESPONSIBILITIES OF SFC PROVIDERS

ROLES & RESPONSIBILITIES TO THE PERSON IN PLACEMENT

Food & Nutrition:

- Provide at least 3 nutritionally balanced meals per day with no more than a 14 hour span between the evening and breakfast meals. Between meal snacks that adhere to any special diets as prescribed by a licensed physician are to be available to PIP.
- Cost of liquid supplements for adults prescribed by a licensed physician is included in the cost of the monthly room and board payments. If cost of supplements is more than half the cost of the monthly payment, then the FBCS may assist the SFCP in accessing other available resources.
- Food preferences of PIP shall be taken into consideration, without sacrificing good nutrition.
- PIP shall eat meals with the family and encouraged to assist in meal preparation if possible.
- Adults in SFC homes may be eligible for foods stamps and may access this resource.

- Foods shall be prepared, served and stored under sanitary conditions.
- Refrigerators shall be in good working order.

Care & Welfare Standards:

- PIP shall be suitably dressed at all times and given assistance, when needed, in maintaining good body hygiene and grooming.
- PIP shall be provided soap, shampoo, clean towels, wash cloths, individual mouthwash cups & toothbrushes and other personal items as needed.
- PIP shall not be denied right to rest periods, but shall be encouraged to use other areas of the home and to take part in social activities.
- PIP shall not be denied right to privacy, however, monitored 24 hours a day in accordance with needs.
- PIP's correspondence shall not be opened except as authorized by PIP or legal guardian.
- PIP shall not be housed in unapproved rooms or in detached buildings or trailers.
- Special equipment, such as wheelchairs or walkers, shall be available if needed.
- Assistance in laundry or minor repair of clothing shall be given when necessary. Replacement of the initial supply of clothing shall be made when necessary.
- PIP shall be provided with opportunity for participation in religious services of his/her choice. In case of a child, the biological parents' choice shall be taken into consideration at time of placement.
- Opportunities for personal and private counseling shall be provided as desired by PIP.
- SFCP, their families and visitors will not smoke in the SFC home while PIPs and individuals receiving respite are present.

Education:

- SFCPs shall participate in the development of an IEP for school aged PIPs.
- Home schooling is not an option.

Discipline and Supervision:

- Punishment of a physical nature, including hitting on the body in any manner, or any punishment that subjects PIP to verbal abuse, ridicule, or intimidation is strictly prohibited.
- Threats of removal from the home, humiliating words or acts, screaming at the PIP in anger, verbal abuse, derogatory remarks about the individual or his/her biological family, keeping an individual out of school or day programming, denying meals or food, closing or locking an individual in a closet, shed, room or inside or outside of the home or fondling or any form of sexual abuse is not acceptable.
- Simple understandable rules shall be established by the SFCP. These rules shall set forth specific expectations for behavior and reward appropriate behavior.
- Discipline shall be related to the developmental stage of the PIP and within the PIP's abilities to comply.
- The PIP shall be given a time out for a short period of time, if necessary, to help him/her gain control.
- Behavior problems shall be treated individually and privately. If there is an assessment of a PIPs pattern of unacceptable behavior, the SFCP should be involved and cooperate

in carrying out the specific positive behavior support plan for the PIP after they have been trained on the plan.

- Positive behavior support should be used when treating behavior problems.
- Denial of mail, phone calls and/or visits with family members will not be used as a disciplinary measure.
- SFCPs are not to use or permit the use of any form of physical restraint unless they have been trained by a certified trainer and have been certified by the trainer as having required knowledge and skills to use this technique. This crisis intervention method is used only as a last resort.
- Each PIP shall be supervised at all times unless otherwise specified on their Individual Program Plan.
- SFCP will not allow children under the age of 12 years to operate an All-terrain vehicle.
- SFCP will assure that PIPs, age 12 years and older, do not operate All-terrain vehicles without a certificate of completion of a vehicle rider awareness course as offered or approved by the Commissioner of Motor Vehicles. During operation of the vehicle protective gear must be worn and the activity closely supervised by an adult.

Medical Care & First Aid:

- PIP shall be under supervision of a licensed physician.
- SFCP shall be responsible for obtaining medical care from a licensed physician in case PIP encounters an accident, acute illness or emergency medical situation.
- Ensure that PIP will have, at a minimum, a routine yearly physical examination, bi annual dental visits, yearly eye examinations as well as any specialty services as ordered.
- Keep an ongoing record of the entire PIP's medical treatment.
- Children under age of 21 are required to be screened by Early Periodic Screening, Diagnosis & Treatment Services (EPSDT/WV HEALTH CHECK) within72 hours of placement and at scheduled intervals during their stay. SFCPs are required to use this program for physical examinations for children under age 21.
- Responsible for transporting or arranging transportation to medical appointments for the PIP.
- All sickness and accidents causing injury to the PIP must promptly be reported to the Service Coordinator, FBC Specialist, the person's guardian or Health Care Surrogate and Medley Advocate (if assigned to the PIP).
- SFCP shall give PIP prescribed medications and any over the counter medications only with a physician's or dentist's prescription or authorization and shall dispense only the exact dosage of medication prescribed.
- All medications in the home, either prescription or over the counter, must be stored in places inaccessible to the PIP. This may entail use of a locked box.
- Medications must have child-proof caps.
- Prescription medications shall be in original containers which are labeled with the individual's name, prescription number and directions for dosage.
- Pillboxes are not approved for storage of medications.
- Medication Administration training must be completed by all adults in the home who may administer medication.

- SFCPs are expected to use universal precautions when dealing with any spill of blood or other bodily fluid. *Universal Precautions* training is to be reviewed annually.
- CPR and First Aid certifications must be kept up to date.
- First Aid supplies are to be available and stored in a place easily accessible to adults in the home.
- PIP shall not require a degree of care beyond the skill level of the SFCP unless necessary and reliable assistance can be obtained from outside sources.

Transportation/Car Safety:

- Every driver who transports PIP shall provide for the protection by properly placing, maintaining & securing individual and themselves in safest manner applicable to federal motor safety standards.
- Safest place for individual 12 years old and under is in the backseat.
- Infants up to 20 pounds and up to 1year should ride in a rear facing child seat in the back seat of the vehicle. Child should never ride in front seat.
- Children over 20 pounds and at least 1year should ride in a car seat in the back seat that faces the front of the vehicle.
- Older children over age of 8 years should ride in the back seat in a booster seat that meets Federal Vehicle Safety Standards. If individual is at least 4 feet, 9 inches tall, they may be secured in the vehicle with the *car's* safety belt system.
- PIPs who use wheelchairs shall be properly secured using the approved method for their PIP.
- Smoking inside a vehicle is prohibited.
- SFCP, spouse or significant other shall provide copies of current driver's licenses, automobile registrations and insurance cards.

Financial:

- When the PIP or SFC family chooses to dine out in the community, the meal shall be the responsibility of the SFCP as payment has already been received for 3 meals per day through the room and board payment.
- Cost of liquid nutritional supplements for adults prescribed by a licensed physician are included in the cost of the monthly room and board payments, unless cost is more than half the cost of the monthly room and board payment, in which case other resources may be available.
- An allowance shall be provided for the PIPs discretionary spending at a rate set by the treatment team.
- There shall be no demands that PIP's allowance money be spent on family activities initiated by SFCPs.
- PIP shall not be expected to spend personal allowance money for items covered by room and board payment, such as meals, shampoo, soap, etc. and on items the PIP cannot take with them when they leave the home.
- PIP's personal funds should not be spent on items used in common areas such as television for the common living area or washer and dryer that service entire family.
- Issues regarding funding for PIP are discussed and resolved by the treatment team and legal guardian.

If Representative Payee:

- PIP must have separate checking account set up for the person and allow FBCS to review the records monthly.
- Monies must be spent in reasonable and ethical fashion, allowing enough money in account for medical copays, without allowing total in account to exceed $2,000.
- All monies of the PIP are to be spent in a manner that directly benefits him/her. Any items purchased must be removable so they can be taken with PIP if he/she moves.
- SFCP may not take a fee from beneficiary's funds for their services as payee.

Confidentiality:

- All written and verbal personal information and documentation about a PIP and his/her family are to be treated in a confidential manner.
- SFCPs who are not legal guardians do not have the right to sign consents for the PIP to be photographed for publication in print or the electronic media. This is the responsibility of the legal guardian.

ROLES & RESPONSIBILITIES TO PERSON IN PLACEMENT'S FAMILY:

- SFCP should engage in cooperative interaction to encourage a positive relationship between the PIP and the biological family when this has been recommended by PIPs treatment team. This may include the sharing of progress updates and responding to questions and concerns.
- SFCP shall participate in the development of a visitation plan to allow PIPs and their family members, as well as former foster providers and friends, to visit and communicate in accordance with the plan.

ROLES & RESPONSIBILITIES TO THE AGENCY:

- SFCPs must be present for all scheduled home visits or cancel the appointment with good reason in a timely enough manner so that the visit can be rescheduled. Failure to keep scheduled appointments or continually cancelling home visits without good reason may result in closure of the SFC home and removal of the individual.
- SFCPs shall participate in required training. Training includes maintaining current CPR and First Aid certifications. Annual review of the EPSDT and OSHA training is required. A total of 24 hours of approved training is required annually and is provided through training materials brought to the home or SFCP may choose training provided by other agencies.
- SPCP musts notify the FBCS in a timely manner of all scheduled treatment team meetings for PIPs.
- SFCPs shall attend and participate in all treatment team meetings by informing the team members of any changes in the individual's status, including but not limited to any critical incidents or accidents.
- SFCP will inform team members of any emergency situations and share information about the problems regarding the PIP as well as any progress the PIP has made.
- SFCP shall notify the FBCS of any major changes in the household such as change of address, contact information, members in the home, employment, etc.

- SPFP shall notify the FBCS of any contact with the criminal justice system.
- SFCP is to comply with re-certification requirements, maintaining a file of updated documents, as they become available, to expedite the recertification process.

OVERVIEW OF DEVELOPMENTAL DISABILITIES

SFC Providers care for individuals who have a developmental disability. Developmental disabilities are a group of conditions which:

- Involve mental and/or physical impairment
- Has symptoms which present before the age of 22 years
- Are likely to continue indefinitely

Developmental disabilities result in functional limitations in three or more of the following areas:

- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency

Causes & Risk Factors

Developmental disabilities may be caused by a mix of factors. Some of these factors include:

- Genetics- Many conditions may be passed from one generation to the next. Chromosomal and metabolic disorders result in changes in brain structure and are attributable to genetic factors. (Example: Down syndrome)
- Environmental- Factors such as malnutrition, head trauma, child abuse, or infection may be factors which can result in a developmental disability.
- Prenatal- Problems can occur before birth which can interfere with the development of the brain and organ systems. Maternal disease conditions which may be a risk factor are:
    - Chronic renal disease
    - Diabetes
    - Toxemia
    - RH incompatibility
    - Poor nutrition

  Direct harm can also occur to the fetus due to:
    - Infection (Rubella, Syphilis, AIDS)
    - Radiation
    - Drugs and chemicals

- Perinatal- Problems occurring around the time of labor and delivery may interfere with the proper transport of oxygen and other nutrients to the brain. (Example: Cerebral Palsy) Factors which may cause this are:
    - Prematurity (less than 37 weeks)
    - Postmature
    - Low birth weight (less than 4.5 lbs)
    - High birth weight (greater than 10 lbs.)
    - Prolonged or severely irregular contractions that interfere with blood flow for the baby
    - Position in birth canal (other than head first)
    - Multiple births
    - Analgesia & Anesthesia (drugs)
- Postnatal (after birth) conditions:
    - Infections/illnesses such as meningitis, encephalitis, influenza, tumors
    - Accidents
    - Child Abuse
    - Drugs & chemicals (i.e., lead poisoning, being born drug addicted)
    - Malnutrition

TYPES OF DEVELOPMENTAL DISABILITIES

There are over 200 kinds of developmental disabilities, although this document focuses only on some of the more common ones typically seen in individuals who are served by the SFC program.

Intellectual Disability

A person diagnosed with an intellectual disability has an IQ below 70 (100 is considered average.) There are significant limitations in three or more skill areas. The condition is present by age 22. There are three ranges of intellectual disability: mild, moderate, severe. Individuals with a mild intellectual disability make up about 80% of all persons with an intellectual disability, with their abilities being just below the low end of normal range. Persons with a mild intellectual disability can and do learn in the academic world, but at a slower rate.

Individuals with moderate intellectual disability often show delayed behavioral development (such as sitting up, walking, talking) as well as deficits in intellectual behavior. Individuals diagnosed as in the moderate range can learn, although most of their academic training may focus on vocational or job related skills as well as personal, social and self-help skills.

Individuals with severe and profound intellectual disability often have other disabilities such as visual or hearing impairments, cerebral palsy, epilepsy (seizures), or serious orthopedic difficulties. These individuals may require much assistance and extensive training to care for their basic needs.

Autism Spectrum Disorder

There are different forms of autism. Autism is not a single disorder, but a range of closely related disorders with shared symptoms. The overlap among different forms of autism and the wide variation in symptoms has led to the term autism spectrum disorder. Terms which identify various disorders on this spectrum include autism, Asperger's syndrome, pervasive developmental disorder, Rhett syndrome and childhood disintegrative disorder. Symptoms include social, sensory and behavior problems. Social skills difficulty may include unusual or inappropriate body language, gestures or facial expressions (avoiding eye contact or using facial expressions that don't match what is being said). Behavior includes being rigid and obsessive in behaviors, activities or interests. Sensory problems include emotional difficulties and uneven cognitive abilities.

Down Syndrome

Down syndrome is a common type of intellectual disability. This condition is caused by the presence of extra genetic material and causes both physical differences and intellectual disability. Intellectual ability in an individual with Down syndrome may range from near normal to profound, although usually in the mild to moderate range. Physical differences include slanted eyes, a small nose, a short heavy build and heart abnormalities.

Fetal Alcohol Syndrome

Fetal alcohol syndrome (FAS) involves mild to severe mental and physical damage to the fetus caused by the mother's use of alcohol during pregnancy. Children with FAS are small at birth and have slow growth rate throughout their development. Certain facial features are characteristic of FAS. There is damage to the central nervous system that may be in the form of intellectual and developmental disabilities, seizures, vision and hearing problems, heart defects, and other physical and behavioral problems.

Orthopedic Disabilities

Orthopedic disability refers to a physical condition that causes problems with gross motor and fine motor capabilities. Orthopedic disabilities are usually quite visible because of the presence of aids such as wheelchairs, crutches, walkers, or by uncontrolled or unusual movement. Examples of orthopedic disabilities include cerebral palsy, muscular dystrophy and spinal cord injury. Cerebral palsy is the disorder which is most commonly seen in individuals served by the SFC program. Cerebral palsy is caused by problems during the birth process. Injury occurs to the portion of the brain which controls voluntary movement and muscle activity. Two types of cerebral palsy are spastic cerebral palsy, which causes tight muscles that move very stiffly and with great effort, and athetoid cerebral palsy which causes excessive, uncontrolled and involuntary movement. Persons with cerebral palsy often have other problems such as speech impairments or seizures.

Seizures (Epilepsy)

Seizures are a disorder of the central nervous system. Seizures occur when there is a temporary increase in the electoral impulses in the brain. This causes the brain to lose control over consciousness and unconsciousness and over various parts of the body. Seizures can be

caused by an injury to the brain by an accident, illness, lack of oxygen or can accompany other disabilities such as cerebral palsy or intellectual disability. Not all persons who have seizures, however, have developmental disabilities, as onset may occur at any age. General types of seizures are:

- Petit mal: More common in children than adults. These seizures consist of brief periods of unawareness with few other signs. Typically, the person stares blankly. Petit mal seizures in children are often mistaken for daydreaming.
- Jacksonian: Characterized by uncontrollable movements like shaking and jerking. The activity is typically confined to one area of the body (e.g., to one side of the body). The person does not lose consciousness, but simply cannot control the activity.
- Psychomotor seizure: Characterized by seemingly erratic behavior. The person stops what he/she is doing, stares blankly, and then engages in some purposeful behavior (e.g. lip smacking, buttoning and unbuttoning). The person cannot control this activity. The seizure duration is about 1-2 minutes and is followed by a return to normal consciousness.
- Grand mal: This is the most common type of seizure, characterized by convulsive movement (stiffening and jerking of the body) and loss of consciousness. The person typically falls to the floor and the seizure continues, usually for 2-5 minutes. Breathing may be shallow, excessive saliva may accumulate and bladder control may be lost.

LEGAL ISSUES

Confidentiality:

SFC Providers are required to provide confidential information about themselves to the Center for Excellence in Disabilities and other agencies in order to be certified and paid for the work which they do. This information includes birth dates, address, social security number, family background, health information, etc. This information is required to be kept confidential by the professionals who serve the SFC family and only shared with other professionals who have a need to know. SFC applicants are provided with a copy of "Notice of Privacy Practices". This document addresses your medical information, called Protected Health Information (PHI) and describes how it is protected.

SFCP are required to protect the confidentiality of the PIP. Medical and other personal information about the person should not be shared with others who do not have a need to know.

Mandatory Reporting

Upon certification as an SFC Provider you become a **"Mandated Reporter".** This is defined as a "person in any helping field, including foster care/Specialized Family Care, who **must** report any abuse/neglect." As a mandated reporter, you do not have to witness abuse/neglect occurring. If you suspect abuse/neglect you have the responsibility to report the allegation. The report can be made on an anonymous basis. Reports are made to the local DHHR office or by calling the hotline at any time at 1-800-352-6513.

Definitions for abuse and neglect are as follows:

- Abuse -Infliction or threat to inflict physical pain or injury or imprisonment
- Neglect- Failure to provide the necessities of life with the intent to coerce or physically harm and the unlawful expenditure or willful dissipation of the funds or other assets owned or paid to or for.
- Abused Child- A child whose health and welfare are harmed, or threatened by a parent, guardian, or custodian who knowingly or intentionally inflects, attempts to inflict, or knowingly allows another person to inflict physical injury, or substantial mental or emotional injury upon the child or another child in the home, or sexual abuse or sexual exploitation. Physical injury may include excessive corporal punishment.
- Child Abuse & Neglect- Physical injury, substantial mental or emotional injury, sexual abuse, sexual exploitation, or neglect treatment or maltreatment of a child by a parent, guardian, or custodian who is responsible for the child's welfare under circumstances which harm, or threaten the health and welfare of the child.
- Sexual Abuse- Sexual intercourse, sexual intrusion, sexual contact or sexual exploitation .
- Incapacitated Adult- Person who by reason of physical, mental or other infirmity is unable to independently carry on the daily activities of life necessary to sustaining life and reasonable health.

The SFC Provider or family could also be subject to an allegation of abuse/neglect. If this should occur, an official investigation will be conducted. Although this can be a stressful experience, this is not uncommon in the foster care setting. The investigation would be conducted by the Department of Health and Human Resources. Child Protective Services (CPS) investigates abuse and neglect for children under the age of 18 years in the home environment. Adult Protective Services (APS) investigates reports of adults (over the age of 18 years) who live in their own homes, Specialized Family Care homes or other settings. Institutional Investigative Unit (IIU) also investigates abuse and neglect in SFC Homes. At the conclusion of the investigation the Person in Placement (PIP) will or will not be removed from your home depending on the outcome and findings of the investigation. Reports of suspected abuse and neglect may be shared by the protective services worker with the Family Based Care Specialist and the PIP's service coordinator. Outcome from an investigation could include a corrective action plan developed by the FBCS, protective services worker, service coordinator and SFC Provider, to criminal charges being pursued, to closing the home and the PIP being removed.

At initial approval and yearly thereafter, SFC Providers and spouses review and sign a Discipline Policy Form.

Corrective Action

Corrective action plans may also be written by the FBCS in cooperation with the PIP's service coordinator, SFC provider, and PIP's guardian to address deficiencies found in an SFC home which may not have warranted an abuse/neglect referral, but is required to maintain SFC Program standards. Such plans specify the necessary corrective action and time frames for

accomplishment. The SFC Provider is notified immediately of any deficiency and receives a copy of the corrective action plan within three days of its completion and, along with team members, sign the plan indicating willingness to participate in the plan.

In the event an SFC Provider fails to properly implement the corrective action plan within the specified time frame, the PIP can be moved and the home may be closed by the FBC Specialist.

Grievance Process and Fair Haring

The Department of Health & Human Resources and social services agencies have a grievance process to ensure that problems are identified and resolved and decisions are in compliance with policies. SFC Providers (and potential Providers) who have questions/concerns about a decision my contact the FBCS or the SFC Program Manager.

The sponsoring agency of the PIP is not liable for any damages to the SFC Home or injuries to the family that may be caused by persons placed in the home through the SFC Program.

FINANCIAL

SFC Providers receive payment for the services which they provide to the PIP in their home. The two major funding sources are Personal Care and Title XIX Medicaid Waiver. Private funding is also a source for financial reimbursement. Personal Care reimburses for the personal care services provided to an individual as determined by a Nursing Plan of Care which is signed by a physician. The amount of monthly reimbursement for the SFCP is determined by the PIP's treatment (IPP) team. The amount of reimbursement varies. Providers also receive monthly room and board payments. (Current rate is $16 per day for adults and $20 per day for children.) The room and board payments assist in providing for necessities such as food, clothing, personal hygiene items, recreation, etc.