



**Be All That You Can Be:
Caring for the Child with Down Syndrome**

A Training Curriculum

Developed by:

**SUN Home Health Services, Inc.
Sharon Auker, RN, MSN**

**For the
Pennsylvania Child Welfare
Training Program**

**University of Pittsburgh
School of Social Work
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316 & 936: Be All That Can Be: Caring for a Child with Down Syndrome

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316 & 936: Be All That Can Be: Caring for a Child with Down Syndrome

An Overview of the Curriculum

Rationale

The care and encouragement of a child with Down Syndrome sets the course for ensuring a meaningful and active future for the child. Empowered with an understanding of the problems and potentials of this group of children, the caregiver can confidently deal with the daily concerns and needs of the child with Down Syndrome and guide the child toward a lifetime of fulfillment.

Learning Objectives

Upon completion of the training session, participants will be able to:

- Describe the cause and diagnosis of Down Syndrome
- Explain the characteristic growth and development of the child with Down Syndrome
- Identify common health concerns and interventions
- Describe the role of the caregiver in maximizing the potential of the child

Competency to be Addressed in Curriculum

316-1. The Child Welfare Professional knows health and medical conditions which can affect the well being of children and families or which can contribute to or result from child abuse/neglect.

Workshop Training Time

3 hours

Target Audiences

Child Welfare Professionals, Family Preservation Workers, Foster Caregivers, and Adoptive Parents.

Expectations of Trainer

This curriculum has been developed to be delivered by a trainer knowledgeable in the medical, developmental, and psychosocial needs of the Down Syndrome population, have an awareness of community resources available to meet the needs of this diagnostic group, and have experience with disease management in the home setting. The trainer should have a strong medical background and have a minimum of a Bachelor's Degree. The trainer should have some knowledge in child welfare practice, specifically in direct services to children and families. The trainer should have considerable experience in training workshops and should possess excellent group facilitation skills. The trainer must have knowledge and experience in diversity awareness so that special attention can be afforded to the provision of culturally congruent healthcare.

Equipment Needed

Specific materials needed to conduct the training are listed for each section of the curriculum. All sections require overhead projector and flip chart.

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Agenda for a Half-Day Curriculum on Be All That Can Be: Caring for a Child with Down Syndrome

- 0.5 Hours INTRODUCTION AND OPENING ACTIVITIES
- Section I
0.5 Hours ALL ABOUT DOWN SYNDROME
- A. Who has Down Syndrome
 - B. What causes Down Syndrome
 - C. Diagnosis and characteristic features
- Section II
0.5 Hours GROWTH AND DEVELOPMENT
- A. Mental age
 - B. Social skills and concerns
 - C. Education and training
 - D. Employment possibilities
- Section III
0.5 Hours HEALTH CONCERNS
- A. Common physical problems
 - B. Screening and prevention
 - C. Diet, weight control, and activity needs
- Section IV
0.5 Hours LIVING WELL
- A. Importance of caring environment
 - B. Home care or institutional care
 - C. Maximizing potential
- 0.5 Hours EVALUATION AND CLOSURE
- A. Transfer of Learning

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Dear Trainer –

The caseworkers, family preservation workers, foster parents, and adoptive parents that attend your training have accepted the challenge of caring for children with Down Syndrome. Their ability to meet this challenge can be greatly enhanced by this training you are about to present.

Best wishes as you teach “Be All that You Can Be: Caring for the Child with Down Syndrome”.

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Preface

Managing the care of a child with Down Syndrome cannot be accomplished by one individual. The interdisciplinary philosophy of care must be reinforced. Please be advised that information regarding Down Syndrome is subject to change as advancements are made. Workers and caregivers should strive to remain updated on new information to assist the child with Down Syndrome in leading an active life.

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Incorporating Transfer of Learning Into This Curriculum

A major component of this training session is the incorporation of a mechanism to promote transfer or learning from the secure training environment to the varied environment of a child living with Down Syndrome.

In order for this training to have an effect on caregiver/caseworker practice, the participants must use this newly acquired knowledge in their daily interactions with the involved child. At the conclusion of this curriculum, you will facilitate an activity to promote this transfer of learning.

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INTRODUCTION AND OPENING ACTIVITIES

Rationale: Participant interaction and group trust promote a positive environment for learning. Because each training audience may contain a blend of foster parents, adoptive parents, and caseworkers, it is important for the trainer to provide an opening activity that will reduce stress caused by this diversity and to encourage active involvement in the training experience.

Learning Objectives: Participants will be able to:
Familiarize themselves with other participants.
Describe the course and expectations for learning.

Time: 0.5 Hours

Methods: Presentation by trainer. Group activity and discussion.

Materials: Name tags
Name tents (large index cards or heavy stock paper)
Markers
Overhead #1 – Agenda & Learning Objectives

Activities: Activity #1 – Name tag mixer
Activity #2 – Name tents

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Trainer Notes

INTRODUCTION AND OPENING ACTIVITIES

Trainer Note: Place name tent materials and markers on each participants' table prior to the start of training. Have self-stick name tags made prior to session with each participant's name already written

Activity #1 – Name Tag Mixer

Step 1 – As participants arrive, check off his/her name on the roster but present him or her with a different person's name tag. Explain that they should find the person to whom that name tag belongs. When they find the person to whom the name tag belongs, they should introduce themselves and ask where that person lives and why they came to the training today. Participants should be told to remember this information because they will need it later.

Step 2 – After everyone has received their own name tag, the group should be seated. Each participant should then be called on to introduce the person whose name tag they delivered. Instruct them to tell everyone the person's name and why they came to the training.

Activity #2 – Name Tents

Although participants are already wearing their self-stick name tag, the tent is required to assist trainer in an easy-to-read recognition of participants. Instruct participants to fold the large index card in half to form a tent. Ask them to write their first name in large letters in the center of the tent. Have them also note, under their name, whether they are caseworkers, foster parents, adoptive parents, or other classification.

Next –

- Introduce trainer and welcome participants to the training.
- Review specifics of Competency-Based Training
 - 15-minute rule
 - Sign-in sheet
 - Evaluation form completion and submission
 - Availability of continuing education units
 - Review “housekeeping rules” pertaining to specific training

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Trainer Notes

site.

Trainer Note: Use Overhead #1 here. “Agenda, Learning Objectives, and Competency”

- Review Agenda, Learning Objectives, and Competency.

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Who Has Down Syndrome?

Down Syndrome is the most common serious disability at birth. The condition was named after Dr. Langdon Down, an English physician who provided the first clinical description of it 125 years ago. Down Syndrome is also known as Trisomy 21.

One in 1,000 births in the United States results in Down Syndrome. That is more than 4,000 each year. At any given time, there are about 350,000 people in the US affected by Down Syndrome. The incidence of Down Syndrome is about equal between boys and girls. It is also represented among every race.

One in three children to women with Down Syndrome will also have the condition. Men with Down Syndrome are thought to be infertile. Only one case of a man with this condition fathering a child has ever been documented. Although parents of any age may have a child with Down Syndrome, the incidence is higher for women over 35. In fact, for women over 40, the chance is 1 in 100. It has been recently discovered that the age of the father also effects the chances of having a child with Down Syndrome, especially if the father is older than 50 years.

Down Syndrome is often identified in cases of miscarriage. However, parents do not cause Down Syndrome; nothing they did before or during pregnancy caused it. Down Syndrome is determined right at the moment of conception.

Each child with Down Syndrome is unique. Each has its own personality, talents, attitudes, and thoughts. People with Down Syndrome are people first!!!

What Causes Down Syndrome?

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Trainer Note: Use Overhead #4 here.
“Chromosomes”

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The human body is made up of cells. Each cell has a center called a nucleus. This is where genes are stored. These genes contain the codes that determine our inherited characteristics.

Genes are grouped along rod-like structures called chromosomes. Each cell normally contains 23 pairs of chromosomes, half of which are inherited from each parent.

When a baby is born with Down Syndrome they have an extra chromosome on the 21st pair. Their total number of chromosomes is 47 instead of 46. This additional chromosome is not defective, just extra.

Because 95% of all cases of Down Syndrome occur because there are 3 chromosomes on the 21st pair, the condition is often referred to as Trisomy 21.

Diagnosis and Characteristic Features

The diagnosis of Down Syndrome can sometimes be determined before the baby is born. An ultrasound, which is a way of taking pictures of the unborn child using sound waves, may show shorter leg bones and extra neck folds. Fluid can be extracted from the mother's womb and studied to identify the extra chromosome.

If the diagnosis of Down Syndrome is not made before the birth, the newborn's appearance will often alert healthcare personnel to the condition. There are many physical characteristics that lead to the suspicion of Down Syndrome. Some of these physical features are also found in the general population of people who do not have Down Syndrome. Therefore, once Down Syndrome is suspected, a blood study will be done to confirm the diagnosis. Some infants with Down Syndrome may only have a few of the

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distinguishing traits; others may have many of them.

The common physical features found in children with Down Syndrome include:

1. Low Muscle Tone – Called “hypotonia”. This means that the muscles are too relaxed and feel “floppy”. This can effect the baby’s movement, strength, and development. This hypotonia will impact the child’s development of motor skills like rolling over, crawling, standing, and walking. This lack of muscle tone may also effect feeding. Sucking a bottle, and later chewing and swallowing solid food, may be difficult. Early intervention by a qualified physical therapist will help greatly. However, the child’s muscle tone will always be somewhat lower than that of other children.
2. Nose – The child’s face may appear a little broader and the bridge of the nose somewhat flatter than usual. The nose may appear smaller.
3. Eyes – The child’s eyes may appear to slant upwards. The eyes may also have small folds of skin at the inner corners. There may be tiny light spots in the colored portion of the eye. These spots do not effect the child’s vision. (Brush Field’s Spots)
4. Mouth – The mouth may be a bit smaller and the roof of the mouth more shallow. This fact, along with the decreased muscle tone, makes it more difficult for these children to keep their tongue inside their mouths. Their tongues, however, are no larger than that of the average person.
5. Teeth – The teeth may come in later than those of other children. They may come in in a random order and be misplaced, smaller, or shaped differently.
6. Hands and Feet – Hands are often short and broad. The little finger may curve in slightly. Often these children have just one palm crease instead of the usual multiple creases. There may be a gap between the first and second toes with a deep crease on the sole of the foot at this gap.

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7. Skin – The child with Down Syndrome often has quite fair and very sensitive skin.
8. Hair – The hair is typically very thin and quite soft. It may also be sparse.
9. Chest –The chest may be shaped differently from individuals.
10. Neck – The child’s neck may appear wide due to the increased number of skin folds.
11. Joints – Children with Down Syndrome have an excessive ability to extend joints. Their flexibility is exaggerated.

Group Activity

GROWTH AND DEVELOPMENT

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Rationale: It is important to have a general knowledge regarding the mental and social development of the child with Down Syndrome so that the caregiver can recognize areas of concern and can realize the capabilities of the child. Many persons do not realize the potential for growth that the person with Down Syndrome possesses.

Learning Objectives: Participants will be able to:
Describe the wide range of mental abilities of this group.
List primary social skills to be encouraged in this population.
Explain the educational opportunities available to the child with Down Syndrome.
Discuss possible employment opportunities for the future.

Time: 0.5 Hours

Methods: Presentation by trainer. Group discussion.

Materials: Overhead #7 – No one can predict . . .
Overhead #8 – Children with Down Syndrome . . .
Overhead #9 – Public Laws 94-142 and 99-457
Overhead #10 – Special Education Team
Overhead #11 – Tips to Encourage Learning
Overhead #12 – Employment Possibilities.
Handout #1 – What are you thinking?

Activities: Activity #3 – Critical Thinking Exercise “What are you thinking?”

GROWTH AND DEVELOPMENT

Trainer Note: Use Overhead #7 here. “No one can predict . . .”

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Mental Development

No one can predict how intelligent any baby will be or what the child will achieve as it grows. Although all children with Down Syndrome have some level of mental retardation, no one can tell when they are small what they will be capable of learning. The mental retardation of these children is usually mild to moderate, not severe; and they are filled with possibilities and talents and strengths. Children with Down Syndrome learn to sit, walk, play, toilet train, and do other childhood skills just as other children do. It just takes longer in most cases. By age 16, most children with Down Syndrome are at a level of that of another child between the age of 6 and 10 years, but are more capable because of their years of experience.

Children with Down Syndrome benefit greatly from stimulating, caring environments and early intervention programs. The Early Intervention Programs in each county can help with testing of: mental development, hearing, and vision. This group can recommend special programs to meet the needs of the individual child.

Along the way, especially when the child is school age, the child's progress can be measured. Those who are trained to do the testing will look not only at the child's mental abilities, but also at developmental tasks and social functioning. Remember intelligence is not a static thing and will increase with good care and education. The caregivers should be aware of the variations in ranges of age for developmental achievement. A helpful guide can be the Developmental Milestones and Skills Table for Children with Down Syndrome.

Social Skills and Concerns

Children with Down Syndrome are usually happy and relate well to others. Like all children, though, they do experience temper

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surges and must be corrected.

Most people with Down Syndrome will not ever be able to live alone without the support of other adults. However, they will grow independent in many functions and seek out companionship beyond the family.

Children with Down Syndrome should be encouraged to make friends and join in activities. They are generally glad to be with others and will cooperate quite well. Typically, the child with Down Syndrome finds excitement and wonder in simple daily experiences. When other children and adults become acquainted with the child with Down Syndrome, the affected child is usually well accepted and loved. The child with Down Syndrome has much to offer and can greatly enhance the family, the school, and the community.

Education and Training

As described before, each area of the state has a government funded early intervention program. Every child with Down Syndrome should be evaluated by this program. Recommended early interventions should be pursued such as infant stimulation programs and physical therapy as indicated.

According to Public Laws 94-142 and 99-457, up to age 21 every child with a disability must receive free and appropriate education in the least restrictive environment. This means that the child will be taught in a regular classroom or in a setting as much like a regular classroom as possible.

It was believed, until recent years, that only separate classes were effective for teaching children with mental retardation. Today, however, both parents and teachers generally agree that these children should have the opportunity to participate in some regular classroom activities. Most children with Down

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Syndrome now spend a portion of their school day with a special education teacher and a portion in the regular classroom participating in subjects such as art, music, and story time.

The level of skill that any given child will achieve in reading, writing, and arithmetic depends on his or her ability and the care and encouragement received from teachers and caregivers. Two essential areas of focus in the early years are language development and social skills.

The parent or guardian of a child is, by law, a member of the Special Education Team that plans the child's education. The team will meet to create an Individual Education Plan (IEP) for the child. Caregivers should be present at that meeting and give their input. The caregiver is a very valuable asset to the team, giving insight into the unique needs of the individual child and ensuring that the child receives an appropriate education.

A new IEP will be created for the child every year. This is a good opportunity to evaluate how well the plan is working and what changes should be made. It might be a good idea to meet with the teacher or the education team every few months.

Some basic tips for encouraging learning in the child with Down Syndrome:

- Use concrete materials that are interesting, age-appropriate, and relevant to the student.
- Present information and instructions in small, sequential steps and review each step frequently.
- Provide prompt and consistent feedback.
- Teach tasks and skills that these children can apply outside the educational setting.

Much of the most important learning occurs in the home when there are dedicated, caring adults available to work with the

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child. Children with Down Syndrome can learn simple tasks and can progress from easy jobs to more complex skills. Tasks should be broken down into easy steps and instructions reviewed often. Words and gestures of approval for effort are important.

Employment Possibilities

Work-related programs for students with disabilities are available in high schools. These programs are aimed at helping the student function more independently.

Sheltered Workshops are usually run by organizations for the disabled or mentally retarded. Generally, sheltered workshops contract with businesses to do some necessary, but relatively simple, tasks such as putting parts together, attaching labels, or packaging items. After being trained, the individuals usually stay on and get paid to work in this environment.

Supported Employment is another option. Some businesses will offer jobs to adults with Down Syndrome, especially if there is a supporting agency sponsoring the individual.

People with Down Syndrome can become productive, contributing adults at home, as well as in the community.

Activity #3 – Critical Thinking Exercise – “What Are You Thinking?”

Have participants discuss the questions with each other. Stress that their feelings are all acceptable and that support and assistance is available.

Reconvene after about 5-10 minutes and ask for volunteers to give answers to the questions.

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HEALTH CONCERNS

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Rationale: Information regarding health concerns common to children with Down Syndrome will allow the caregiver to identify treatable conditions early and secure the appropriate care for the child. Prevention of some complications is also possible if caregivers are aware of high risk areas of health issues.

Learning Objectives: Participants will be able to:
List the most common physical abnormalities frequently found in this population.
Explain the importance of early screening and treatment of health concerns.
Give reasons for good dietary management and encouragement of physical activity for these children.

Time: 0.5 Hours

Methods: Presentation by trainer.

Materials: Overhead #13 – Health Concerns
Overhead #14 – It is imperative that children . . .
Overhead #15 – These children can learn . . .

Activities: None

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HEALTH CONCERNS

Trainer Note: Use Overhead #14 here. “Health Concerns”

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Children with Down Syndrome are at increased risk for certain health problems. Among these problems are:

1. Congenital Heart Defects – One third of these children have this problem. The defects occur because certain parts of the heart do not develop normally before the child is born. These structural abnormalities:
 - Effect how blood flows through the heart.
 - May decrease the volume of blood or decrease the oxygen supply to the body.
 - May cause the heart to overwork.
 - May necessitate surgery during infancy or as the child grows.
2. Increased Number of Infections – The child with Down Syndrome must be watched carefully because they often have:
 - More colds and stuffy noses.
 - Increased number of ear infections.
 - More fevers.
3. Decreased Thyroid Function - This must be detected early and treated because:
 - This condition can be very serious but is easily treatable.
 - If left untreated, will effect the child's growth and development.
4. Vision Problems – Many children with Down Syndrome:
 - Have crossed eyes.
 - Need to be treated by an eye specialist.
 - Require eye surgery at some point.
5. Hearing Difficulty – This is a concern for children with Down Syndrome because:
 - Thick fluid builds up behind ear drum.
 - Tubes may be required.
 - A hearing aid may be necessary.
 - It can effect learning.
 - Alert teachers that it may be helpful for this child to be seated near to the speaker during class.
6. Loose Joints – Found in many of these children and:
 - Are due to poor muscle tone.
 - Limp muscle tone may give “rag doll” appearance and, as a

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result, holding and cuddling infant may be difficult.

- Encourage caregiver to wrap infant securely in blanket (swaddle) before picking up to promote security and warmth.
- Usually improve by age 10.
- Good posture should be encouraged.
- Child should not sleep or sit with legs twisted in or out.
- Are often present between the 1st and 2nd bones in the neck and can be dangerous. In these instances, strenuous activities and sports may be limited. An x-ray is needed and surgery may be required. (Atlantoaxial instability)

7. Compromised Immune System – A concern because:

- It does not fight off germs well.
- Regular blood tests are needed.
- It increases the chance of Leukemia (Leukemia is 15 times more likely but can usually be successfully treated.)

8. Digestive Track Obstruction – This causes:

- Difficulty swallowing, digesting, or eliminating food.
- A need for surgical treatment.
- The large protruding tongue can interfere with feeding. The tongue thrust is not a refusal to eat but is a physiologic response. Use a small, long, straight handled spoon to push food toward the back and side of mouth.

It is imperative that children with Down Syndrome receive excellent medical care. A pediatrician who deals frequently with this population will be careful to screen and treat early the common health concerns of these children. Caregivers must be alert to changes in behavior or stamina. Most of the health concerns mentioned can be successfully treated, if caught early.

Children with Down Syndrome have a tendency to become overweight as they grow. It is important to supervise their eating and encourage appropriate activity to avoid related social and health problems. These children can learn about healthy food choices and normal-sized portions. They should be taught these

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concepts at a young age.

Network to other community organizations for additional assistance for the child with Down Syndrome.

National Down Syndrome Congress
160 Chantilly Drive, Suite 250
Atlanta, GA 30324
1-800-232-6372
<http://www.carol.net/-nnsc>

National Down Syndrome Society
666 Broadway, 8th Floor
New York, NY 10012-2317
1-800-221-4602
<http://www.pcsltd.com/ndds/>

LIVING WELL

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Rationale: Realizing the impact of the home environment will give caregivers a sense of their importance in the child's development. Many misconceptions exist regarding the capabilities of this group. When caregivers can see the strengths and potential of children with Down Syndrome, they will be better equipped to provide the opportunities necessary for growth.

Learning Objectives: Participants will be able to:
Describe the elements needed in a home environment to maximize the growth potential of this group.
List the benefits of home care versus institutional care for these children.

Time: 0.5 Hours

Methods: Presentation by trainer. Small group activity and discussion.

Materials: Overhead #16 – In a caring, supportive environment . . .
Overhead #17 – Children with Down Syndrome need and appreciate . . .
Overhead #18 – Supported Living and Small Group Homes
Flipchart (or chalkboard)

Activities: Activity #4 – Critical Thinking Exercise “What Does It Take?”

LIVING WELL

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Caring Environment

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The care of a young child with Down Syndrome may seem overwhelming. It is normal for caregivers to wonder if they can handle the responsibility and challenge of this job. The needs of these children are much like the needs of all children, however. They need to be fed, dressed, and bathed. These children also need lots of love and affection. They respond well to cuddling, smiling, and adult attention, and soon learn to return the affection. In a caring, supportive environment, children with this condition will progress and develop warm, caring personalities of their own. Children with Down Syndrome deserve, as do all children, respect, supervision, and wise guidance.

Home Care or Institutional Care

Study after study has shown that community living enables people with disabilities to live happier, healthier lives. Children with Down Syndrome need and appreciate a sense of home and community, and thrive in this setting. Although at times institutional care may seem to be the only viable option, life in any institution has many serious limiting consequences for individuals. Today there is a movement to keep mentally challenged children and adults integrated into the community. With proper assistance and a nurturing support system, this is possible and is the best choice.

People with Down Syndrome do become adults and deserve to be treated as such. There are independent living options available to these community members. Community living arrangements allow these individuals to live much the same way

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that other people live. The degree of intervention needed to help them live in the community varies according to their abilities. Some live in their own homes or apartments in what is known as a “supported living” situation. These folks may live alone or choose to have a housemate. Usually a partnership is formed between the individuals living in the home, their families, and other professionals. As much control as possible is given to these individuals to make their own lifestyle choices. Quite often they simply need assistance with decision making and securing needed services. This type of “supported living” situation works best for those whose mental capacities are stronger.

“Small group homes” are also available and government subsidized for adults with Down Syndrome. Usually six or fewer individuals live in these homes with 24-hour staff support. Other community living arrangements can be accessed for adults with Down Syndrome. The Mental Health and Mental Retardation (MHMR) in each area can give details and assist with planning.

These independent living arrangements are government funded, but actually save taxpayer money. In 1996, the yearly cost for a person in a community setting was around \$24,700, as compared to \$92,000 for those in state-run institutions.

Individuals with Down Syndrome age rapidly and are subject to premature senility. Families and caregivers should be assisted during the childhood years to make appropriate plans for as much independent living as possible during young adulthood and for support/assistive care when their child ages. Many children with Down Syndrome outlive their parents. Over a 80% survive to age 30 years and beyond.

Activity #4 – Critical Thinking Exercise “What Does It Take?”

Ask participants to break up into their previous work groups of 2-3 persons. Have them brainstorm and make a list of things needed by all children to bring out the best in them as individuals. Give about 5 minutes for this exercise, then reconvene and ask for one person from each group to share their list. Make a composite list of these items on a flipchart (or chalkboard).

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Make the point that these elements are the same for children with Down Syndrome, and they are obviously already experts. Congratulate them and stress that there is no substitute for the care of well-informed, loving adults.

**EVALUATION AND CLOSURE
TRANSFER OF LEARNING**

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Rationale: This section is designed to reinforce participants' transfer of learning and to allow participants the opportunity to evaluate the presentation.

Learning objectives: Participants will:
Complete and submit the program evaluation form.

Time: 0.25 Hours

Methods: Presentation by trainer. Group discussion.

Materials: Handout #2 – What Have I Learned
Evaluation Forms

Activities: Complete and discuss “What Have I Learned”
Complete Evaluation Forms

EVALUATION AND CLOSURE

Trainer Notes

Transfer of Learning

Trainer Note: The following exercise will allow you to recap this session and give the participants the ability to formalize their knowledge. Distribute Handout #2 “What Have I Learned?” Have participants take about 10 minutes to complete the handout and then

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Evaluation

Before closing the training session, all participants must complete and return the evaluation forms to assist in future curriculum planning. Allow approximately 10 minutes for this activity.

Closure

Children with Down Syndrome are complete, whole, and wonderful little people and deserve the best that life has to offer. You can make all the difference in how fulfilling and productive their lives become. The ironic part of being part of the care team for these children is that you will receive far more than you give. Just remember that much help and support is available to you as you meet the daily challenges of caregiving.

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