

## Slide 2



Slide 3

#### BIOGRAPHY

 Charmaine Fitzig, RN, Dr.PH, Retired Associate Professor, City University of N.Y. (CUNY), York College worked in both service and academia. Conducted several workshops on Advocacy for Head Start programs.



Founded and worked with a self-help advocacy parents group in local community called PIN (Parents Information Network) Lifelong advocate

for children with special needs.

## LEARNING OBJECTIVES

At the end of the presentation the participants will be able to:
Understand the Americans with Disabilities Act (ADA 1990).
Define the role of advocacy.
List at least two (2) specific activities parents, nurses and teachers can implement to be effective advocates for children who are physically disabled.

### Slide 5



Slide 6

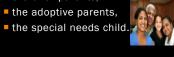
### THE EXTENT OF THE PROBLEM

 About 52.1 million or 18% of the American Population are disabled,

...and within that population it is estimated that 17% of U.S children are born with disabilities that result in development delays.

### DIAGNOSIS

When the diagnosis of a special needs child is made, the health care team immediately has three clients or patients to consider...
the birth parents,



## Slide 8



## THE EXTENT OF THE PROBLEM

 Whether the diagnosis of a disability is made at birth or later, the process and actions needed to respond to the crisis is the same. Before I continue, I need to share some definitions with you:

Slide 9

## ADVOCACY

 Is the action of speaking or writing on behalf of someone else and using persuasion in support of another.

#### CRISIS

Is a state of acute emotional upset in which one's usual problem solving ability fails; occurs in response to an identifiable traumatic event, e.g., accident, victimization, death of a loved one, or the diagnosis of a special needs child.

## Slide 11



### DISABILITY

 Is a physical or mental impairment that substantially limits one or more of the major life activities of an individual.

Slide 12

## SPECIAL NEEDS CHILD

 For the physically disabled: a child who needs assistive devices in order to perform life activities.
 For the mentally disabled: a child who needs assistance to function at the highest level of potential.

#### **ASSESSMENT OF STRENGTHS**

One of the first activities the health care team completes is an assessment of the family members. This includes the strengths and needs of each family member.
The strengths of the bonds between the parents and the identification of the specific needs of the child involved.

### Slide 14



# ASSESSMENT OF STRENGTHS

Although each special needs child is unique in terms of services needed, there are a number of actions that are common to all.
The health care team assists the family in assigning specific activities to each family member and one member is designated as the coordinator. [Give examples]

Slide 15

#### QUICK TIPS FOR THE ADVOCATE

 Keeping records is important. A large calendar with space for noting medical and other appointments by date is an absolute must.

 If private transportation is used for travel to appointments the mileage is necessary. If public transportation is used, keep a record of carfares. Lunch or supper costs, companion or parent accompanying disabled child is deductible on income tax.

### QUICK TIPS FOR THE ADVOCATE

 Books or other reference materials for the education of the child or the parent are also deductible.

 Records of all medication with co pay costs, including over the counter medicines are critical and last but not least, is a thorough knowledge of the legislation that defines the Americans with Disabilities Act (ADA) of 1990.

Slide 17

## REFERENCES

 Day, L. (2006) Welcome to your crisis. New York, Little Brown and Co.



Hoff, L.A., Bonnie J. Hallisey and Miracle Hoff (2009), People in crisis. (6th ed.), New York, Rutledge