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# ✓ **HERE I AM!**

A lifebook kit  
for use with  
**Children with Developmental Disabilities**

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**Spaulding for Children**

in cooperation with  
**Michigan Dept. of Mental Health**

NATIONAL ADOPTION INFORMATION

CLEARINGHOUSE

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Susan Schroen

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# **Resource Manual**

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**a guide to accompany  
the "Here I Am" life book**

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# Instructions

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## INSTRUCTIONS

Most foster care and adoption workers who have a caseload of school-age children eventually find themselves taking glue and construction paper in hand to construct a lifebook. These "lifebooks" are very creative collaborations between the child and worker, and no two are ever alike. The "lifebook" process details a child's history and usually prepares the child for a move into adoption or a return home.

Children who have multiple handicaps or are mentally retarded are rarely asked to participate in such a process. The potential barriers are numerous. Workers, unfamiliar with mental retardation or physical impairments, are often reluctant to initiate conversations with multiply impaired children. Dealing with painful topics is even more intimidating. If the foster parents have said that a child does not remember previous placements or would not understand what "foster care" means, workers rarely question this assumption. Workers may not want to upset children and foster parents when there are few alternate placements. Still others believe that mentally retarded children need little preparation for a move and do not go through a grieving process.

Even when such attitudes are not a barrier, there are other problems in doing a lifebook with developmentally disabled children. Workers need ideas and help for translating concepts such as foster care into concrete terms that the child will understand. They also need encouragement for talking with children about handicapping conditions. Pictures of children in wheelchairs, especially minority children, are very difficult to find. Children in magazine pictures are almost never developmentally disabled nor do the families in these pictures ever appear to have problems.

### WHO CAN BENEFIT

*Here I Am!* was designed as a workbook for developmentally disabled children who are living away from their families. It can be used by social workers, therapists, foster parents, residential and mental health staff and adoptive parents to help understand why they are not living at home. It serves to engage children in the planning process that will affect their future. It also provides agencies with a tool for learning how children feel about themselves and sharing information about the handicapping conditions that are part of their lives.

This workbook, when used as part of a full lifebook process, will be most effective for mildly to moderately retarded children or children who are physically impaired and function between a pre-school and an adolescent developmental level. Children who function at an infant or toddler level can benefit from certain pieces of the process. For these children, a simple story about moving, complete with pictures, can be read over and over as a story book, emphasizing the feelings of a child who goes from one family to another. The process could be taped for a child with visual or severe physical impairments. A child who is physically impaired can also be involved in designing the lifebook by choosing pictures or directing the drawing of pictures. For all but the very youngest child, the lifebook is a **process** to be shared by child and adult. *Here I Am!* will require adaptations for every child. Suggestions for adapting the material to the child's skills and issues are made with each page. In most cases, the adaptations start at higher functioning levels and move to more concrete levels. In most cases, both the adult and child will come up with their own ideas for using pages or recording events. A lifebook process combines the skills and creativity of both the adult and child who put it together.

### THE PACKAGING

This lifebook is packaged in two separate pieces. The first, the Resource Manual, contains guidelines for using each section of the workbook and articles to help the worker or adult using the book understand more about developmental disabilities, preparation of children for moves or permanency planning. Because most people come to this process with knowledge and experience in some, but not all of these areas, we have selected those articles in each field which can enable people from a variety of backgrounds to work with developmentally disabled children around separation and attachment issues.

The second piece, printed on heavy paper, is the Child's Workbook. It is three-hole punched so that it can be inserted in a binder as each page is completed with the child. Pages may be completed in order or rearranged to fit the needs of the child and the style of the worker. There is an Options Section which contains topics that will be used with some, but not all children (such as sexual abuse and hospitalization), extra pages for multiple placements, and extra pictures to help illustrate the child's own story.

## THE DESIGN

The workbook, *Here I Am!*, is divided into eight sections as follows:

	Pages	
I.	Who Am I?	1-6
II.	Where I Live Now	7-10
III.	I Have Feelings	11-13
IV.	Places I Have Lived	14-18
V.	My Birth Family	19-26
VI.	Where Am I Going?	27-32
VII.	Optional Topics	33-34
VIII.	Optional Drawings	35-46

These sections may be used in order, or rearranged by the worker planning the process. Because there is so much variation in skill level, attention span and issues for each child, the worker will have to decide how many pages to cover in each work session. Advance planning is important to pull together materials and adapt the topics to the child's level of functioning and attention span.

The lifebook starts with an assessment/getting acquainted section called "Who Am I?" This provides an opportunity to assess the child's language skills and favorite modes of expression. For more detailed information on child assessment, see the companion piece to this volume, *The Value of Assessment in Placing the Developmentally Disabled Child*, as listed in the bibliography.

Section II details the child's perceptions of life in the current placement. Because there is so much discounting of developmentally disabled children's memories of the past, and because time is often a difficult concept for these children, we chose to start with the present. This also allows the adult and child to get comfortable in expressing feelings and understanding each other's use of language before exploring painful issues in the past.

As you move through Sections III-V, be prepared for the child to understand and remember more than expected and to be very interested in his or her history. Too often, no adult has talked with the child about birth family or reasons for leaving home. The respect accorded to a child in listening and sharing information about what has happened to him or her can result in the uncovering of a great deal of feelings and memories. Engaging the foster parents in this process is important. They can provide useful information and need to know what is happening in the sessions. Because children will be upset at times and act this out in the home, foster parents need to understand the rationale and be part of the process.

The final section, "Where Am I Going?", engages the child in the activity of planning for the future. It includes a piece on the difference between foster care and adoption (or return home) and provides an opportunity for both the child and adult to talk about plans they have for the future. A contract page is included for those children functioning on an upper elementary or higher level. This helps the child and social worker detail tasks that will be important in making the plan happen. Foster parents or residential staff can be very helpful here, as in earlier parts of the process, by contributing to and supporting the plan whenever possible. They may also enter into the contracting process. The final page, "This Is Home," can be used before or after a move to explain or celebrate the importance of settling into one place or one family. It is important for developmentally disabled children to know when they are "home". While we cannot make promises to children that we cannot keep, we can include them in the process of making and celebrating a commitment to become a family.

## SECTION 1 - WHO AM I?

### Pages 1-6

**Goals:** To build a relationship between the adult who is guiding the lifebook process and the child.

To assess the child's self identity.

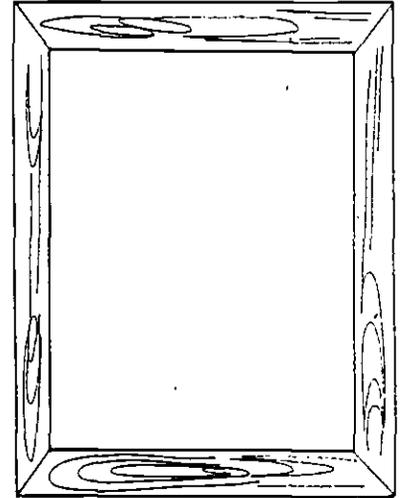
To identify the child's communication skills.

#### Activities:

##### Page 1 - THIS IS ME

The child draws himself, adding clothing, hair, and facial features. The emphasis is on the child's uniqueness. A child on a toddler level can be given a circle on a page and asked to add eyes, mouth and hair. Page 36 is included as an option for the child who might be reassured by having some help in drawing his or her body. As the child draws, you have the opportunity to build a relationship and learn how the child communicates.

##### This is me



Who am I?


I am \_\_\_\_ years old

##### Page 2 - WHO AM I?

The child chooses the picture that looks most like her. Page 2 gives you an opportunity to assess the child's awareness of his race, handicap and gender. Photographs or magazine pictures are useful when the age or race of the children pictured is inappropriate to the child doing the lifebook. Photographs are also helpful in this and following pages for the child who would respond better to a concrete photograph than to a symbolic drawing. Other pictures appear in the Options Section.

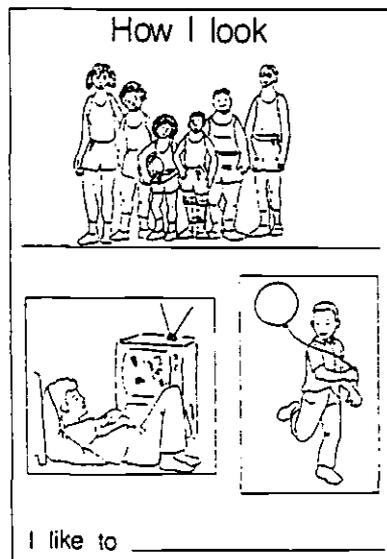
To assess the child's awareness of racial and gender difference, it is important to know whether the child: 1) recognizes differences between himself and others, 2) knows colors, 3) knows or can express the words or signs commonly used for these differences (girl, Black), and 4) identifies with people of the same race or gender. These developmental skills range from late infancy to roughly four years of age for the child with no disabilities. For the child whose experience is more limited because of physical, cognitive, language or environmental disabilities, these skills will

be delayed but generally follow the same sequence. A child who is placed with a family of a different race may show an awareness of race or of the differences in skin coloring long before he has the words to express this. This is as true for developmentally disabled children as for children who are not cognitively impaired.

In talking with a child about race, the adult can use crayons, photographs or a comparison of skin color as visual prompts. Children's picture or coloring books could also be helpful in this activity.

The child chooses the picture that he identifies with. He can also add himself in the picture. Pictures of children with adaptive equipment are available in the Options Section. A photograph of the child could be included here. As the child colors the picture, he can be asked how his body is different from the others pictured. You can point out that all bodies are special and different from each other.

The following illustrate how questions can be adapted for the cognitive and language skills of a child. As in all of the adaptations written for this lifebook, the initial questions are geared to the child with more sophisticated language skills and require a more complex response. The middle questions generally rely on a combination of verbal and visual cues. The latter questions depend heavily on visual cues for the child's understanding of the question and can be used with less verbal children.

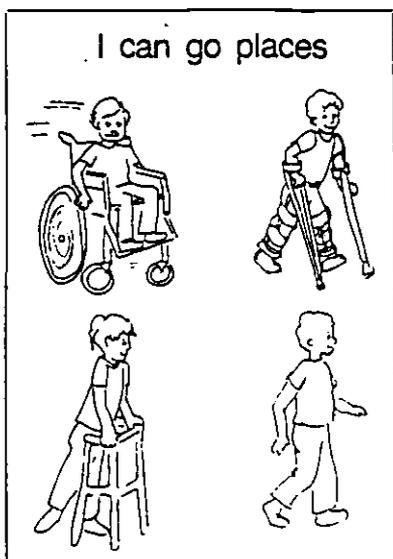


Sample questions

To learn what the child likes to do, he can be asked:

1. "Which of these boys is most like you?" "Why?" "What would you do if you could do anything you wanted?" (Note the use of open-ended "Wh" questions.)
2. "What are these boys doing?" (This question asks for a fairly concrete response.)  
 "Find the boy who is like you." (This requires a more complex thought process, but fewer expressive language skills. Pointing to both boys gives an extra visual cue.)  
 "Draw me a picture of you playing."
3. "Show me the boy who is watching T.V." (This direction gives the child a lot of verbal cues and requires only a pointing response.)

Magazine pictures of different activities shown one or two at a time, give the child an opportunity to make choices. Although the child may have few verbal skills, his receptive language may be higher. Therefore, you can put the child's non-verbal feedback (such as facial expressions, body movements, drawings, imitation) into words which acknowledge the child's contribution to the communication between you.



Page 4 - I CAN GO PLACES

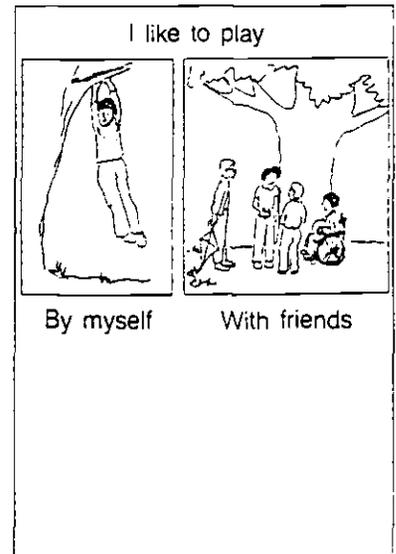
The child chooses a picture of a child who moves like he or she moves. If the child uses equipment to help with mobility, this is a good time to talk about the equipment, and how it works. It is a time to talk about what the child can do. You can also explore the child's feelings about having a disability or being different. See Options Section for other pictures.

## Page 5 - I LIKE TO PLAY

This page is used to explore the child's feelings about playing alone and with other children. It can also be used to discuss any problems or strengths that the child has in these areas.

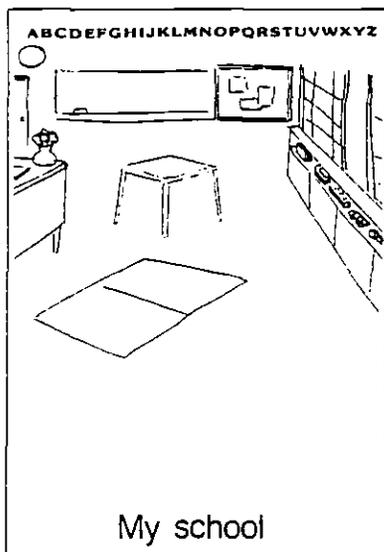
Sample questions:

1. "What are these children saying to each other?" "What is this boy thinking?"
2. "I can't tell if this boy is having a good time." "What is he doing?" "How do you think he is feeling right now?" "How would you feel if you were him?" (The response can be verbal, facial expressions or choosing between two or three facial expressions as pictured on Page 5.)
3. "Here you are playing." (The adult points to a child in the picture.) "I can't see your face. Can you show me how your face looks when you are playing like this?" "What do these other kids' faces look like?"
4. "Are you in this picture?" "Show me." (For a distractable child, one picture can be covered or put on a separate page.)



The space can be used to:

1. Draw, write, or use magazine pictures of activities the child likes to do.
2. Draw himself playing.
3. Draw or name his friends.



## Page 6 - MY SCHOOL

School issues relevant to this child can be discussed here, such as the child's relationship with teachers or peers, the child's behavior in school, activities that are enjoyed or not enjoyed.

Sample questions:

1. "If I came to your school, what would I see?" "What would you be doing?"
2. "Tell me what we need to put in here to make this look like your class."
3. "This is your school." "What is missing here?"
4. "What is your teacher's name?" "Let's put her in your school." (Have pictures cut out for the child to add to the picture.)

The discussion about school can be illustrated with drawings, pictures, faces with feelings (from Page 39), or examples of the child's work (i.e. numbers, letters or math problems).

## SECTION II - WHERE I LIVE NOW

### Pages 7-10

- Goals:** To identify the child's attachment to his present family and understanding of his relationship to them.  
To identify the activities and routines that are important to the child.  
To assess the child's ability to recall and communicate names.  
To record anecdotes and memories.

#### Activities:

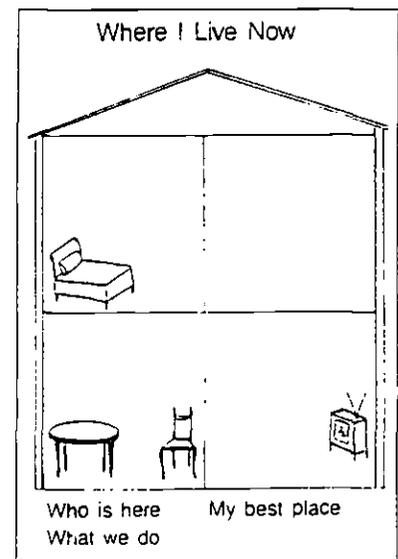
#### Page 7 - WHERE I LIVE NOW

The child makes the pictured house his current home by adding what is missing (people, pets, things). If the child does not like to or cannot draw, pictures can be cut out and pasted in. For a lower functioning child or one with more limited co-ordination, a separate sheet of paper can be used for each room significant to the child, and pasted together to fold into a larger house.

"Who is here?" "What we do" "My best place"

You can use the questions at the bottom of the page, asking where individual family members (including the child) like to be in the house and what they like to do. The child can draw or make faces to show feelings about activities and routines that happen throughout the house, (e.g. eating, sleeping, playing, taking a bath).

A younger or lower functioning child may need a three-dimensional doll house for this activity.



#### Page 8 - PEOPLE I LIVE WITH NOW

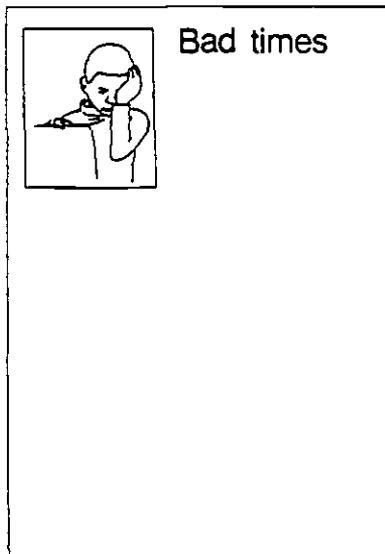
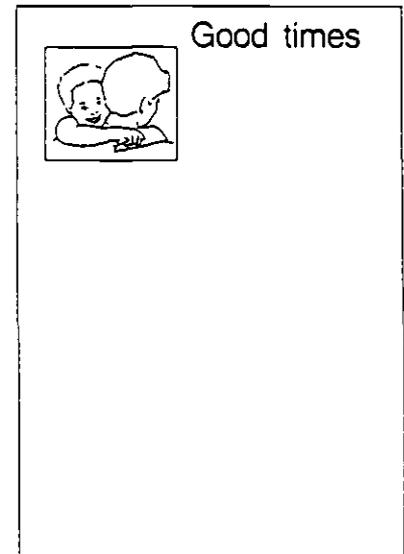
People I live with now

The child draws a picture of the foster family or constructs the family using pictures from Pages 40 and 41. Having pictures cut out in advance or mounted on cardboard is easier for children with motor co-ordination problems. The pictures can be cut out in squares for easier cutting. Pictures of family members can be used to re-create the child's arrival into the family, a fight between siblings or another child's arrival. This is a good time to explore attachments, jealousies or personality conflicts. It is a good time to identify names and terminology that the child uses to identify her relationships within the family (e.g. does she call the foster mother, "Mom", "Helen", or "my foster mother?")

## Page 9 - GOOD TIMES

The following pages allow you and the child to practice talking about memories and feelings that are more current and may be less painful than those related to the birth family. This is especially important for developmentally disabled children for whom past and present may be confused. It also allows you to determine the modes of communication which will be most comfortable to the child (describing, drawing, acting out, choosing pictures).

The picture can be used to prompt the child to talk about happy times in this family. These activities or anecdotes are recorded with the child's drawings, your writing, or both. You may want to prompt a non-verbal child by getting anecdotes from the foster parents or using magazine pictures to help the child remember family activities. Anecdotes can be written as stories, to be preserved and re-read by the next family. Pictures are available on Pages 40 and 41.



## Page 10 - BAD TIMES

The goal is to emphasize that there are good and bad times in all families and to make it safe for a child to talk about bad times. The tone should not be one of interrogation, but one of listening and picking up on the child's feelings and perception of events.

To help a child talk about bad times in the foster family:

Sample questions:

1. "What happened to this little boy?" "How does he feel?"
2. "Can you draw something that makes you sad?"
3. "What do people in your family do when they are mad?" "When they are sad?" "What do they look like?" "How do you look when you are mad?" "What do you do?"
4. Use a picture of an angry parent or child from Page 40 or 41 or describe an incident that happened in the current family. The child can draw a picture about the story or choose a face.
5. Use dolls or cut-outs to have the child show what happens when people in the family are having a bad day.

## SECTION III - I HAVE FEELINGS

### Pages 11-13

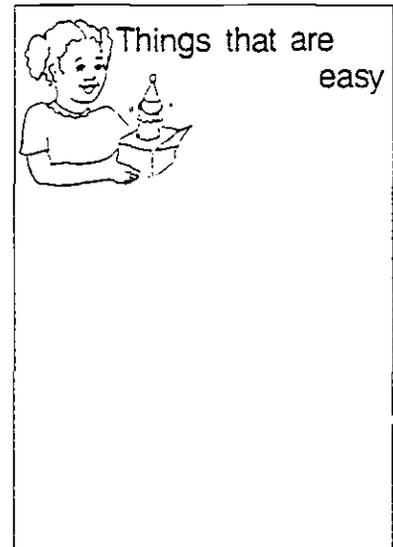
**NOTE:** This section examines the child's experiences and feelings about personal issues such as achievement, mental retardation, physical limitations and fears about moves or abandonment. Two additional topics are available in the Options Section (Pages 33 and 34). Foster parents and social workers often underestimate the developmentally disabled child's ability to remember people and events or to deal with information about handicapping conditions. The child must then make up his own explanations (e.g. for why she can't walk or had to be hospitalized) and gets little support. In this section, we recommend that you acknowledge both similarities and differences between this child and other children and not shy away from using labels and terms like "retardation" and "epilepsy". Children hear these terms and assume that they mean something bad, without knowing what they really mean. One goal of this section is to show that each of us has things we do well and things we don't do well. None of this diminishes our specialness. Another goal is to teach the child that he deserves to be respected and given credit for personal thoughts and feelings. Caregivers can be encouraged to provide support, and information and comfort when the child has unresolved issues.

**Goal:** To identify areas in which the child has misinformation about handicapping conditions.  
To provide basic factual information at a level that the child can utilize.

#### Activities:

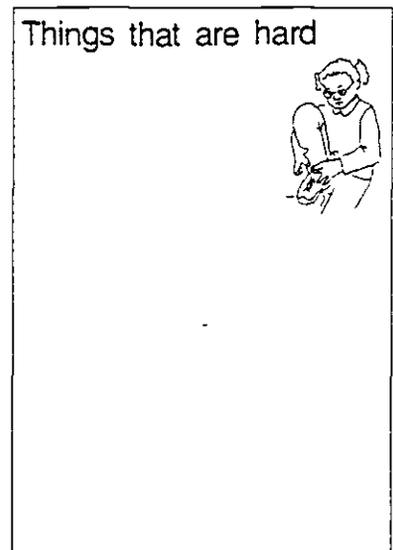
##### Page 11 - **THINGS THAT ARE EASY**

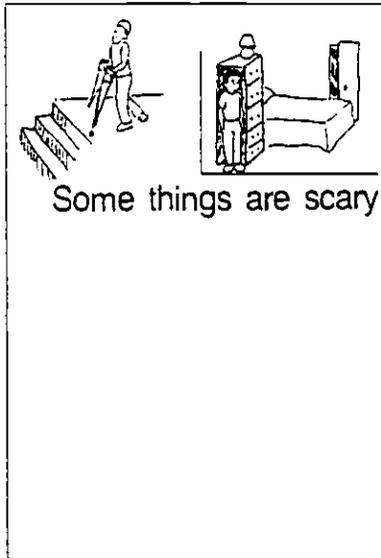
The picture may prompt the child to identify activities that are easy for her. Information from teachers and foster parents or worker's observations can also serve as prompts. The child draws or cuts out magazine pictures or makes a list of things that are easy for her. Use this page to reinforce that the child has **many** skills. A non-verbal child can show with his body what he can do or point to pictures of activities. Stickers can be used on both this and the next page to show pride in accomplishment and make the activity fun.



##### Page 12 - **THINGS THAT ARE HARD**

You may prompt with the existing picture or by sharing something that is hard for him or her to do. The child may make a list of things that are a **little** hard and a **lot** hard to do. Examples can show that each of us can do some things well and not do other things very well. There are reasons why we can't do some things. This allows you to talk about the child's mental retardation or physical impairments. If appropriate, ask if the child has heard the word "retarded" or anyone has ever called the child names. Follow-up on any fear or curiosity about this or any other "handicap" terms which may have been heard by the child. This can be a good time to find out what the child knows about his medical or handicapping conditions, and to give information (e.g. a simple definition of the disability, assurance that it is not catching and not a punishment for being bad). Sharing stories about other children or adults with the same medical condition can also be helpful. A disability is only one thing about a person. It is important to emphasize what the child **can** do. Stickers show pride in accomplishment. Books about role models or meeting other children and adults who can share their stories or serve as Big Brothers or Sisters are helpful in meeting this goal.





## Page 13 - SOME THINGS ARE SCARY

**Goal:** To explore the child's fears about being moved, abandoned or abused.  
To explore the child's fears about medical conditions (if appropriate).

### Activity:

These pictures show things that some children are afraid of. They can be used to prompt the child's own fears. The child can color pictures, show what he looks like when scared or add pictures of people who could help. A lower functioning child can be shown pictures and asked to choose the scary ones. The child can also be asked to show on his face how the child in the picture feels.

The child's fears can be reassured by any of these:

1. Having the child remember a similar fear that was comforted (i.e. fear of moving to this family).
2. Identifying a safe, comforting person to go to when he is scared.
3. If the child is afraid of moving, he can be given information about what will happen (keeping in mind a developmentally disabled child may have a limited concept of time.)
4. Acting out the scenario with dolls and showing the child how the doll receives comfort.
5. Asking the child to pick out a picture of how he looks when he is scared (see Page 39).

\*\*\*For a child who has been sexually abused or hospitalized, six optional pages are available (Pages 33, 34, 40, 41, 42, 43).

## SECTION IV - PLACES I HAVE LIVED

### Pages 14-18

**Goals:** To present an opportunity for the child to discuss previous placements and attachments.

**Activities:**

Page 14 - **BEFORE I CAME HERE, I LIVED IN ANOTHER PLACE**

Photographs of the previous homes or families, the child's drawings or a picture from Page 46 can be used as illustrations. The child can talk about or draw people who lived there. Obtain photographs from the previous families whenever possible. The child expresses feelings or shares information she remembers about family members, prompted as needed by information known to you.

Before I came here  
I lived in another place

Who lived with me?

Page 15 - **A LOT OF THINGS HAPPENED**

A lot of things happened



Some good

Some not so good



Some good — Anecdotes, activities or photographs from the case record or previous foster parents can be included with the child's memories. Former foster parents may be willing to write a letter, including things about the child that the family remembers. Pictures of families interacting are included on Pages 40 and 41 and can be used to illustrate the child's story.

Some bad — This section allows the child to share ideas about why she had to leave. You can, therefore, correct mistaken impressions. For a developmentally disabled child, this information will need to be repeated. Discuss the reasons for the child's move to clear up any misinformation. Be honest. The child can be told that adults are also good at some things and not good at others. The family (or agency) may have wanted the child to be with someone who could understand that child better or help him change. Perhaps the family did not know how to take care of a child who is slow to learn or had medical problems. The child

may have been unhappy and had fights at school and the family was not sure how to help him change. If so, you can talk about the parents getting so upset that they asked the agency to find another family. For a low functioning child you can tell the story of the child's placement using dolls and puppets.

Note: For significant placements, Pages 9 and 10 — Good Times and Bad Times can be used again for recording information and drawings.

## Page 16 - WHEN I HAD TO LEAVE

The child's memory of leaving and the accompanying feelings of loss, fear or anger are explored here. The child can be asked to tell, draw, or point out who is in the car, who is in the house and how each of them is feeling. The space can be used to tell the story, draw the people or have the child choose pictures from Page 39 and 40 to describe feelings. A low functioning child may understand better if the scene is made concrete by re-enactment with toy cars and doll houses (or using toy blocks for houses).

Further work may be needed to help the child separate (see *Helping Children When They Must Move* by Vera Fahlberg). The possibilities for further intervention are:

1. A personal visit or a letter from the family saying why the child can't go back and giving the child permission to attach to a new family.
2. Allowing the child time to grieve openly while being comforted by the current caregiver.
3. Creating a safe place for the child to express hurt and anger.
4. Visiting the old house or the gravesite of a deceased foster parent. If the family has moved or is deceased, a child may need proof that the family has moved. For a developmentally disabled child, it is important to be as concrete as possible. This may involve showing the child exactly what you want her to see and making sure that she understands why you are visiting this place.

When I had to leave



I felt

A rectangular box containing the title 'When I had to leave' at the top. Below the title are two simple line drawings: a house with a chimney and a car. Underneath the drawings is the text 'I felt' followed by a large blank space for writing or drawing.

Other places I have lived

A rectangular box with the title 'Other places I have lived' at the top and a large blank space below it for recording information.

## Page 17 - OTHER PLACES I HAVE LIVED

This page can be used to record other placements. Additional pages which can be copied as needed are Page 15, 16 and 46. Another concrete means of helping the higher functioning child understand the relative length of time in various placements is to draw a pictorial graph. Each placement is represented by a different amount of space and different color. This can help a child understand why he might have loved some families more than others.

## Page 18 - WHEN I HAD TO LEAVE

(Refer to Page 16 — "When I Had To Leave")

When I had to leave



I felt

A rectangular box containing the title 'When I had to leave' at the top. Below the title are two simple line drawings: a house with a chimney and a car. Underneath the drawings is the text 'I felt' followed by a large blank space for writing or drawing.

## SECTION V - MY BIRTH FAMILY

### Pages 19-26

**Goals:** To determine the child's memories and attachment to birth family.  
To fill in missing information about the family.  
To help the child understand the reasons for separation and know whether it will be possible to live with his birth family again.

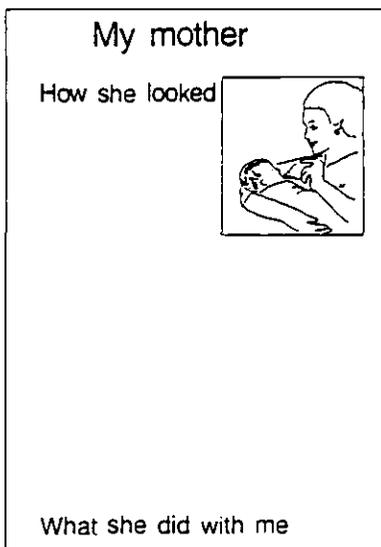
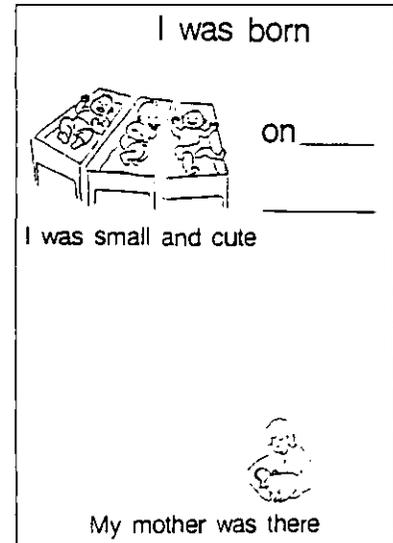
#### Activities:

##### Page 19 - I WAS BORN

Some children do not realize that they were ever babies, especially if they never see photos or hear stories about themselves or, if like many developmentally disabled children, they have trouble understanding the concept of time. This page allows you to record and celebrate the child's birth and introduce the topic of the child's mother.

Hospital birth records are available giving the information on the time of birth, weight and health of the child and length of time in the hospital. Sometimes the baby's footprint is available. If the birth was a difficult one, or the child had problems at birth, this page can document the special care given to help this baby grow stronger. Grandparents, relatives, or former foster parents are another source of information, as are family pictures and baptism records. The public library information desk can give you information about the weather or special events happening on that day. If no specific information is available, you can speculate about the baby's first few days and the importance of this event. A book about babies, written on the child's level, might also be helpful here to provide a way of talking about babies.

Ask the child to identify the woman in the picture.



##### Page 20 - MY MOTHER

The child colors the picture of the mother and can be asked any of the following:

1. What she looks like or was like (if the child was old enough to remember).
2. What mothers do for babies to take care of them.
3. To tell or show ways the mother looked like him (coloring, race, features).

The child can draw, describe or act out what babies and mothers do. If the mother never lived with the child or could not keep him, this discussion begins to prepare the child for a future discussion on why he could not live with her.

If the child does not remember his mother, previous foster parents may be able to describe his parents or send pictures. Grandparents or relatives are often willing to share pictures and provide information.

An adolescent may be ready to hear about his parent's ages or circumstances at the time of his birth and early childhood. The child may be able to empathize with parents being very young, or not knowing how to care for a child. You can help him speculate about things that his parents did with him, and ways they showed that they cared.

A child functioning on a pre-school level or one who has been in care for a long time may not know that he had a mother or father before his foster parents. Depending on the child's level of functioning, the adult can do any of the following:

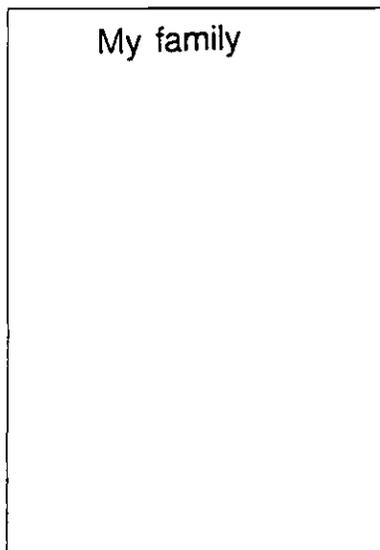
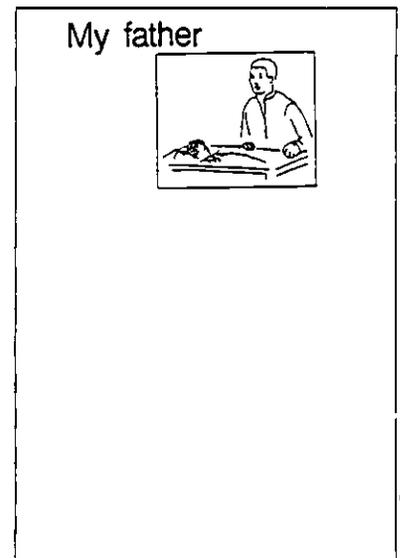
1. If the child understands the concept that numbers represent objects, he can be helped to name his first, second and third mothers, (i.e. Mama Sue).
2. The child may have possessions he brought from the birth family, which can be a concrete sign of their existence.
3. Using examples of babies the child knows, the child can be told that all babies have a mother and father, and then hear the story of his mother or father.
4. Help the foster parents tell the child the story about his arrival in their home and how his first mother and father could not take care of him.

### Page 21 - MY FATHER

If the child remembers her father's name, you can ask her what her father looked like or what they did together. If her father is unknown to her, the worker may want to tell a story about the child's father, giving as much information as appropriate about where he lived, how old he was, his relationship to the family and any attempts he made to care for the child. The story should be geared to the child's age and understanding level.

Sample activities:

1. Using the pictures from Page 40 and 41 or a photograph or a magazine picture, you can help the child reconstruct what her relationship with her father might have been.
2. Child draws her father's face and how he looked.
3. Child draws or shows how she feels when thinking about her father.
4. Child uses stickers to show her feelings about her father.



### Page 22 - MY FAMILY

The child reconstructs his birth family including extended family, by either:

1. Using photographs
2. Choosing pictures from Page 44 or 45
3. Making a family for a baby doll (or puppet) with other dolls or puppets

Discussion of family members can include:

1. Names
2. What they look like
3. What they did with the children
4. Child's feelings of anger or loss
5. Whether the child worries about family members

Page 23 - **GOOD TIMES**

Good times



A rectangular box containing the text "Good times" at the top left. Below the text is a small square illustration showing two children, a boy and a girl, smiling and hugging each other.

The child may remember good times and be able to share them. If not, you and the child together can talk about (or look at) pictures of things that make small children happy and decide which ones might have happened. It will help make the past more concrete for the child.

If the child does not remember being with the birth family, you may want to ask what makes little children happy. Help the child reconstruct the good times. Anecdotes can be obtained from relatives or previous foster families.

Pictures are available on Pages 40-45 to illustrate the child's story. Feelings as represented on Pages 39 and 41 or stickers can also be pasted on this page.

Page 24 - **BAD TIMES**

The child may not realize how helpless he was. To make this concrete show him how small a child of that age is compared to an adult. Real people, photographs and doll families could be used for this purpose.



Bad times

When I had to leave



I felt

A rectangular box containing the text "When I had to leave" at the top left. Below the text is a small illustration of a house with a car parked in front of it. Below the illustration is the text "I felt".

Page 25 - **WHEN I HAD TO LEAVE**

The child can be asked who is going away in the car and who is staying in the house. Discussion can include the reasons for the child's removal from the family, the child's feelings, subsequent contacts, the likelihood of a return home, and the child's worries about the family. This can be acted out with dolls, puppets or toy cars.

A higher-functioning child can draw or use pictures from the Options Section to tell the story, or draw a picture of what he worries about when he thinks about his family. The worker helps identify and validate any feelings of guilt, sadness or fear.

Where is my family now?



You may include any of the following:

1. Recent pictures of parents or siblings.
2. Information about the whereabouts of and status of siblings.
3. The likelihood of contact with relatives.
4. Magazine pictures to show how big siblings might be now.

Some developmentally disabled children may have trouble understanding that siblings have grown bigger or that their family may have changed over time. Actual visits with siblings or relatives supportive of the child and his placement would be very effective. You may be able to obtain current photographs. You will want to decide what is important for the child to know about his family, and how you can help him understand this message in the most concrete way possible.

## SECTION VI - WHERE AM I GOING?

### Pages 27-32

- Goals:** To establish why permanent families are important and distinguish between foster and adoptive, or foster and birth families.  
To describe the social worker's role in planning for the child.  
To help the child with fears about moving.  
To talk with the child about the permanency plan.

#### Activities:

#### Page 27 - WHEN I'M \_\_\_\_\_ I WANT TO

The goal of this page is to learn more about the child's hopes and dreams for the future, and incorporate them into the case planning. It also gives you an opportunity to identify the child's understanding about the impact of her disabilities on her future. This page is primarily intended for mildly to moderately impaired adolescents functioning at a late elementary school level, or above, though it may work with any child who has the ability to fantasize and understand that things change over time. It would be especially helpful for a child whose primary impairments are physical.

Before the session, choose an age in the child's future which you believe she will be able to picture in her mind. Write this in the space so that it reads as a full sentence (i.e. When I'm a teenager I want to...). Most developmentally disabled children and adolescents would be confused if they had to fill in the blank themselves.

It can become a game to fantasize about what the child would like to be doing, first at the age specified, and secondly, as an adult. Sample questions to use as prompts (and mixed in with both humor and seriousness):

1. When you are a teen-ager...
  - "What do you think you will do after school?"
  - "What will you do for fun?"
  - "What do you think you will worry about?"
2. When you are grown up...
  - "Where would you like to be living?"
  - "What kind of help do you think you might need?"
  - "Where would you go for fun?"
  - "Would you like to have a job?" "What would you like to do?"
  - "What do you think you have to do before you could get a job like that?"

When I'm _____ I want to . . .
When I'm grown-up, I think I will . . .

Page 28 - WHY DO I NEED A FAMILY?

This page is about families. There are some things that kids get from their families. The pictures representing love and food can help prompt the child to think of other reasons why children need families. The child names, points to or draws things that families do for kids. The child can draw her favorite food on the plates, or have you do it.

Some possibilities are: right and wrong (rules), holidays, vacations, church or synagogue, baths, clothes, houses, brothers and sisters, grandparents, help with schoolwork, being sick, tucked into bed.

Another option is to show the child a series of magazine pictures (of food, houses, etc.), helping her to pick out those things that mothers and fathers do for their children.

Why do I need a family?




Page 29 - MY NAME

Note: For a child functioning on a pre-school level this page would not be relevant. The important thing for a child on this level to know is that he will have someone to take care of him. It is important for us as adults, however, to strive for the continuity and permanence of that caregiver.

The child is asked to tell his own name and that of the current foster family. The child is then asked whether the names are the same, and why or why not. The worker helps the child understand the difference between a foster family and an adoptive family or between a foster family and a birth family. If adoption (or a return home) is a relevant topic for the child, it can be pointed out that when the child is adopted (or returns home), he has the things children need from a family as well as the same name. Using the picture of the 18th birthday party, you can talk about the importance of having a family when you are grown. It can be a game to have the child guess why someone might need a family even after they are as big as his mom or dad.

My name \_\_\_\_\_

I live with \_\_\_\_\_

Are the names the same? \_\_\_\_\_



Where will I be when I'm 18? \_\_\_\_\_

Page 30 - MY SOCIAL WORKER

Note: This page relates to the social worker's role in planning for the child's future. It can be used at any point in the process to: 1) explain your reason for moving the child, 2) bring up and discuss a child's fear of social workers, or 3) to begin to prepare the child for a move. The worker will need to decide for each child, when this session would be most useful.

If the lifebook is being done for assessment purposes, you may want to ask the child's interpretation of the suitcase picture, where she thinks the child is going, who is with the child, and how she thinks the child feels. You can use this opportunity to discuss the fact that social workers sometimes find new families for children. Discuss the child's experiences with moving (if needed) or the child's feelings about moving again. If the child is to be moved, reassure her that the worker will tell her about the family and let

My social worker




her meet the family before going with her suitcase. If the child is scared, you might remind her of feelings she had before coming here, and how she felt after getting used to being here. The worker can emphasize that it might take a long time to find the right family. Help foster parents support the plan with the child, whenever possible.

Alternatives:

1. If the child will not be moving soon, you may want to save this page until you are closer to a move, or you can explain that social workers make sure that children have families. The emphasis may be placed on the worker's role in getting to know the child so that the best decisions can be made.
2. If the child is to remain in her current placement, or return to birth family, you can use the pictures to talk about the social worker's role in these decisions.

### Page 31 - WHAT MY SOCIAL WORKER WILL DO

Note: This also would be inappropriate for a child who is working on a preschool level. It is especially useful for grade school and adolescents who should be involved as much as possible in the planning for their future.

This is a page to help the child while he or she waits to have a plan implemented. It sets up a contract between the worker and the child, helps clarify the plan and focuses on what the child can do to make waiting easier. Be as specific as possible. Don't make promises that you may not be able to keep or that are beyond your control (e.g. try to avoid saying "I will find you an adoptive family before school starts"). Together, you and the child can come up with things that can be done to help make it easier to wait, or that can help the child practice being part of a family.

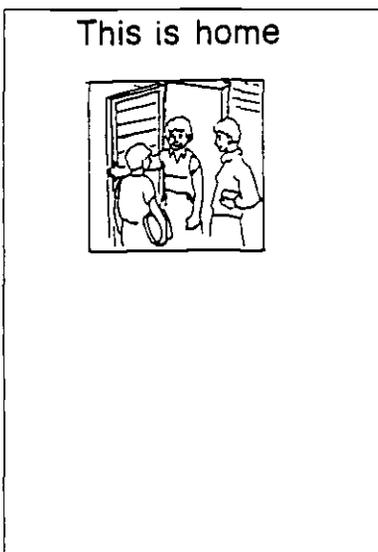
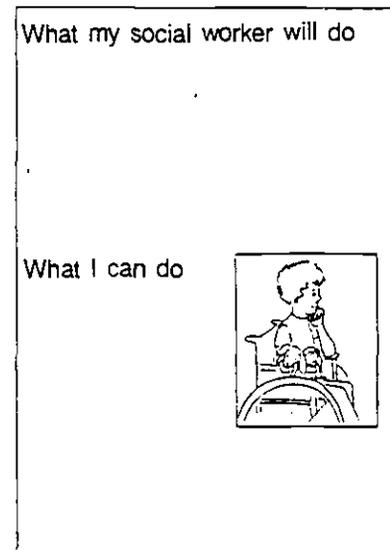
Examples:

**What my Social Worker will do:**

Look for a family to adopt John.  
Show John's picture in the paper.  
Try to find out where John's brother is.

**What I (the child) can do:**

Tell my foster parents I am scared or having bad dreams.  
Practice saying I am mad, instead of hitting people.  
Make a scrapbook of my pictures to take with me when I go.



### Page 32 - THIS IS HOME

This page describes for the child whether home will be 1) an adoptive family, 2) birth family, or 3) the current placement. It can be used prior to identifying the specific placement of choice or it can be saved until the decision is made and the child has been told. It could also be saved until the child has visited and is ready to move so that it becomes a celebration of going to a place that will be home. The child can color the picture or paste a photo over the picture.

When using the picture, you can ask the child:

- "What is the woman saying?"
- "How does the child feel?"
- "What is the child thinking?"

### Optional Activities:

1. If a family has not been identified, the child can draw what the next family might look like.
2. This page can also be used to prepare a child for a first meeting or visit. The child can tell what he thinks the woman should say to the child that would make the child feel less scared. This can help the worker give cues to the family about ways to help this child feel welcome and more relaxed. The worker can help the child think of what he could say to the family.
3. A "let's pretend" role play can work well here, with the worker being the child and the child playing the new parent. The worker can model things for the child to say and get an idea of what the child would like said to him. It is good practice for an anxious child.
4. Photographs can be used if a family has been identified. A welcoming letter from the new family can also be inserted here.
5. If the child is returning home, you can use the picture to explore the child's feelings about visits and re-unification, and to role play these visits.
6. The pictures of children with different feelings on Page 39-41 can be used to talk about how the child might feel.

Because a lifebook records a child's life story, it can be maintained as an on-going record. If the child moves to a new home, the new family can incorporate pictures of themselves into the child's book. Many adoptive families are asked to make a scrapbook to give to the child before visits begin. The child's book can be incorporated with the family book, or left in a place where the child has access. Foster or birth parents can also continue a child's lifebook, recording significant events or anecdotes and the child's feelings about these events. Adolescent children may want to keep up their own book, with help from adults in labeling pictures or organizing events. The process of recording the past and present can be on-going or it can end when the child begins the lifelong tasks of merging his or her own history with the family history. A lifebook is a very good place to begin.

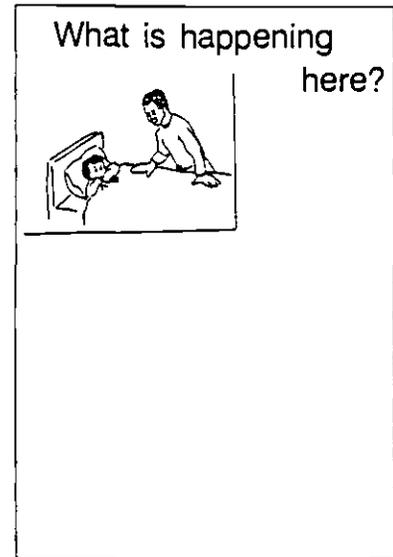
## SECTION VII - OPTIONAL TOPICS

### Pages 33-34

#### Page 33 - WHAT IS HAPPENING HERE?

This is an optional page which can have any of the following goals:

1. To help determine a child's awareness and reactions to having been sexually abused.
2. To assist in determining the need for referral or treatment for a child who may have been sexually abused.
3. To acknowledge and validate the child's experience and feelings.
4. To share information about the child's right to protect his or her body from being touched in ways that are invasive or abusive. Note: An alternate picture of a boy being held too tightly is included on Page 41. Many boys in foster care have also experienced some form of sexual abuse.
5. To help assess the child's vulnerability to sexual abuse, and to prompt the child to ask for help in the case of future abuse.



Note: A lifebook process is not an adequate substitute for treatment and therapy. Before treatment can be sought, however, the abuse must be acknowledged by significant adults in the child's life, including the social worker. For non-verbal children, it can be especially difficult to determine the likelihood, extent and perpetrator of sexual abuse. It is therefore easy to deny or discount the effects of sexual abuse on developmentally disabled children. Because it is an issue in birth, foster and adoptive families, we include this page to give workers some assistance in handling sexual abuse issues in as concrete and non-threatening a manner as possible. It is difficult enough to find therapists skilled or willing to work with developmentally disabled children. It is even harder to find someone who also is willing to provide therapeutic intervention around sexual abuse of a developmentally disabled child. Therefore, it often falls to the social worker to make an assessment of the impact on a child and to provide some intervention.

We have included an excerpt from "My Very Own Book About Me", written by the Rape Crisis Network of Lutheran Social Services of Washington. It is a children's workbook on preventing sexual abuse written for children ages 4-12. On Pages 42 and 43, we reprint two pages which show pictures of different kinds of touch. For the developmentally disabled child, this is another concrete way of talking with the child about the differences between touching that feels good and touching that does not feel good. See the enclosed bibliography for information on this workbook and other materials to help you, a family, a school social worker, or a therapist prepare an intervention plan for a child.

We also encourage social workers to put pressure on the child welfare and mental health systems to see that sexually abused developmentally disabled children are not denied the opportunity for treatment.

#### Activities:

Two pictures are presented which show a comfortable child and a frightened child. The child may be able to identify the feelings of the child in the second picture (using the faces from Page 39, if necessary). You might ask the child to help you figure out what this person is doing to make the child so scared. You can use the pictures of different kinds of touch on Pages 42 and 43 to prompt the child to identify kinds of touch that feels good and those that don't feel good. There are several good books available to read with the child. A particularly good one is *No More Secrets For Me*, by Oralee Wachter, as described in the bibliography.

If you have specific information about the sexual abuse which happened to this child, you may try sharing pieces of the information and asking the child to show which touching it was, how she felt or what happened next. You may need to be patient and ask the question in different ways. The child may not have names for what happened or feel safe in sharing the information, especial-

ly if a previous sharing of information led to the child's removal from a family. It may be more useful to teach the child how to say no to touching that doesn't feel good, than it is to find out exactly what happened.

The important things to say to the child are that:

1. Some kinds of touching feel good. Some kinds don't.
2. Her (his) body belongs to her and no one should touch her without her permission.
3. That sometimes adults have problems, but they are wrong to hurt children or touch children's private parts.
4. She might have liked some of the things that happened and not liked other things. That's ok.
5. Whatever happened was not the child's fault.
6. It's important to tell an adult if a person ever tries to touch her in any way she doesn't like.

**Options:**

1. The child can be prompted to talk about specific incidents if the worker shares pieces of known information and asks the child to tell what happened next. Be prepared to ask the questions in a variety of ways and give the child lots of time to answer.
2. For a lower functioning child, the worker can suggest that the child in the picture might have the same name as the child doing the lifebook. The worker can then ask the child to tell who the other person is in the picture and what he is doing.

**Page 34 - AT THE HOSPITAL**

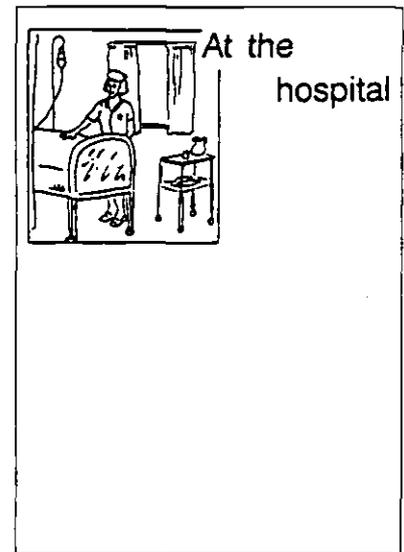
This page can be used in Section III, I Have Feelings, or can be used later to help document significant hospitalizations or losses experienced by the child.

**Goals:** To document a time when the child or a significant person was hospitalized and to record resulting feelings or significant life changes.  
To talk about the child's experiences with and feelings about a medical impairment.

**Activities:**

Prompt the child to talk about:

1. What *it is like* to go to the hospital.
2. Required medicines, physical therapy, physical assistance, or doctor visits. A verbal child may be asked who helps with these things and how hard or easy they are to do. The important thing is to be interested in the child and in his perceptions. Pictures from Pages 34, 41 and 46 can be used here.
3. His knowledge and worries about his health. For instance, it is common for a child to think that he will not have this handicap when he grows up. Some children might have a misconception that they might die from their medical problem, or that it is "catching". You will need to make your own judgements in responding to these questions. Whenever possible, help the child get access to accurate information and support for his questions about his body.
4. Illness or death of significant relatives or foster parents. This space can be used to document in writing and/or pictures the child's relationship to this person and the loss the child experienced. Remember to use concrete tools whenever possible, including a visit to the cemetery.



**SECTION VIII - OPTIONAL PICTURES**  
**Pages 35-46**

Additional drawings for use throughout the lifebook process are included in this section.



# **Annotated Bibliography**

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Annotated Bibliography

## B I B L I O G R A P H Y

### CHILD PREPARATION

Brown, Sara, "THE VALUE OF ASSESSMENT IN PLACING THE DEVELOPMENTALLY DISABLED CHILD, 1978, 120 pages. Shares some practical tools and techniques for those who are open to investigating all the permanency planning options for handicapped children. See more detailed information on the book under Permanency Planning in this bibliography. Available through Spaulding for Children, P.O. Box 337, Chelsea, MI 48118.

Fahlberg, Vera, "ATTACHMENT AND SEPARATION", part of the series Putting the Pieces Together, Michigan Department of Social Services, Lansing, MI, 1979, 64 pages. This is one of the best available description of separation and attachment issues as they affect children in placement. Issues addressed include: the development of attachment, assessing attachment, reactions to separation, identifying lack of attachment and promoting attachment. This workbook contains practical exercises and can be used by foster, adoptive and birth parents, as well as caseworkers, to educate themselves about the needs of the children in their care. Another volume, "The Child in Placement, Common Behavioral Problems" is also available in this series. Available through Spaulding for Children, P.O. Box 337, Chelsea, MI. 48118.

Fahlberg, Vera, "HELPING CHILDREN WHEN THEY MUST MOVE'", part of the series Putting the Pieces Together, Michigan Department of Social Services, Lansing, MI, 1979, 92 pages. Dr. Fahlberg provides assistance in planning for a wide variety of moves for children, including moves from hospital to foster care and long-distance moves. Available through Spaulding for Children, P.O. Box 337, Chelsea, MI 48118.

Jones, Martha, "PREPARING THE SCHOOL AGE CHILD FOR ADOPTION", Child Welfare, Volume LVIII, No. 1, January, 1979, 8 pages. Martha Jones has written an excellent introduction and overview of children's feelings as they separate from biological family. It includes good suggestions for meeting these needs as well as preparing prospective adoptive parents. This could be an excellent introduction for mental health case managers and others new to the adoption of older children.

Wheeler, Candace, "WHERE AM I GOING", 1978, 30 pages. This remains one of the best descriptions of the rationale, and techniques for preparing a lifebook with children in foster care. It gives ideas for describing family problems such as abuse or abandonment to children. Most examples are written for elementary school children, making this a good resource for work with developmentally disabled children functioning on this level. A very readable book, it is one of a series on adoption published by the Winking Owl Press. Available through the Winking Owl Press, 4315 Conifer Lane, Juneau, Alaska 99801.

Wimpfheimer, Shelly; Kendall, Jane; and Smith, Carol E., "DAILY LIVING SKILLS CHECKLIST FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES", taken from Reaching Out: A Resource Book for the Adoption of Children With Developmental Disabilities. An assessment tool to help child welfare workers determine and record the child's skills, activity level and general behavior. It can be used in helping caseworkers and prospective parents learn more about the children they will be working with. Not applicable to severely impaired children or children functioning on an infant level. Available through C.W.L.A., 67 Irving Place, New York, N.Y. 10003.

#### PERMANENCY PLANNING

Brown, Sara, "THE VALUE OF ASSESSMENT IN PLACING THE DEVELOPMENTALLY DISABLED CHILD", 1981, 120 pages. This manual for child welfare workers brings together information from the field of adoption on separation and attachment, and information on assessment and work with children with developmental disabilities. An assessment profile is included which Spaulding for Children uses to assess children for placement purposes. The last chapter provides specific information on preparing developmentally disabled children for placement and adapting the process to their language and cognitive skills. The reference bibliography includes materials on assessment, disabilities and preparation of children. This book will be especially useful to staff in increasing their skill and confidence in assessing and working with developmentally disabled children. "Here I Am" is written as a companion piece to this work. Available through Spaulding for Children, P.O. Box 337, Chelsea, MI 48118.

Bryce, Marvin E. and Lloyd, June, "ALTERNATIVES TO FOSTER CARE: PLANNING AND SUPERVISING THE HOME BASED FAMILY CENTERED PROGRAM", 1980, 194 pages. This booklet details demonstration programs in which the damage of out-of-home placement is minimized by a very creative and nurturing system of helpers providing almost daily help within the home. Family strengths and extended family are utilized rather than ignored. Administrative issues such as staffing and supervision patterns are covered in great detail. While this book is geared to working with families of neglected, abused or delinquent children, it has much to offer to the mental health system. The detail with which subjects such as recruitment and use of paraprofessional staff, and relationships between staff and families are presented would be helpful in making adaptations for the families of handicapped children. Distributed by National Clearinghouse for Home Based Services to Children and Their Families, School of Social Work, The University of Iowa.

Campbell, Margaret, Baker, Cynthia, LeBlanc, Linda, Phillips, Nancy, "REUNIFICATION OF CHILD WELFARE FAMILIES", A Source Book, New Orleans, Region II Child Welfare Training Center. This booklet is packed with content and well worth the price. Because its focus is on assessing and strengthening the family's support system, it is very adaptable to the families of developmentally disabled children. The material contains very specific guidelines

and tools to assist workers in making intake, assessment and placement decisions. There is a very helpful chapter on helping to reorganize the services offered to the family. Available through National Child Welfare Training Center, The University of Michigan, School of Social Work, Ann Arbor, MI 48104, 89 pages.

Downs, Susan and Taylor, Catherine, "CHILD WELFARE TRAINING, PERMANENT PLANNING IN FOSTER CARE; RESOURCES FOR TRAINING", 1980 DHHS Publication No. (OHDS) 81-30290 U.S. Department of Health and Human Services, Washington, D.C. 20201. This is the text book on Permanency Planning for children in foster care, developed at Portland State University. It is a compilation of articles, exercises, charts and text which take caseworkers step by step through the process of decision making, providing services to children and families and working with the legal system, especially around termination of parental rights. The material is clear, distinctly worded, and very comprehensive. Although it was written to deal with children in the child welfare system, the logic and framework for decision making can be applied to children in the mental health system.

Dunn, Linda, Editor, "ADOPTING CHILDREN WITH SPECIAL NEEDS, A SEQUEL", 1983, published by North American Council on Adoptable Children, 95 pages. Published seven years after the original, this collection of articles written by adoptive parents reflects the increase in placement of children with multiple disabilities, though it is not specifically geared to this type of special need. There are stories about ongoing contacts with foster parents, legal risk adoption and the pain and joy of parenting children with physical, educational and emotional disabilities. This is a must for prospective parents and new staff. It is available from the North American Council on Adoptable Children, 2001 S. Street, N.W., Suite 500, Washington, D.C. 20009.

Hughes, Ronald and Rycus, Judith, "CHILD WELFARE SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES", 1983, Child Welfare League of America, 64 pages. This booklet gives a very good introduction to the special needs of children with disabilities within the child welfare system. Written for child welfare staff, it defines and describes specific disabilities, explores common myths and details the kinds of services needed by these children and their families. Order from the Child Welfare League of America, 67 Irving Place, New York, N.Y. 10003.

Kravick, Patricia, "ADOPTING THE SPECIAL NEEDS CHILD", Colophon Press, Kensington, Maryland, 1976. In the Forward, the editor of this collection of personal experience articles by adoptive families and professionals gives its purpose: "This book is intended to serve as a rich resource of information, advice, and practical experience on the subject of adopting a child with special needs." The personal experiences, although they stress the positives and minimize the negatives, are invaluable for persons who are considering adopting a developmentally disabled child.

Martin, Vyonda and Griswold, Esther, "LOOK TO FAMILIES, A TRAINING CURRICULUM ON PERMANENCY PLANNING FOR CHILDREN WITH DISABILITIES", 1984, 229 pages. Though this is a training curriculum, it contains well written articles on fusing information from the fields of developmental disabilities and permanency planning. Much of the material focuses on work with biological family to prevent out-of-home placement. The curriculum also gives creative ideas for developing family ties for children who have lost them. Order from Family Builders by Adoption, 726 E. Sixteenth Ave., Suite 108, Denver, Colorado 80203.

Pawlowski, Wayne, "ADOLESCENTS IN NEED OF SPECIAL SERVICES", a training module in the series "Child Welfare Inservice Training Curriculum", P.D. Press, 1982, 272 pages. This training manual is filled with so many articles on adolescents with special needs that it would be worth purchasing for individual use. It has especially useful articles on the emotional impact of disabilities on the family and the child. Order from P.D. Press, Creative Associates, Inc., 3201 New Mexico Ave., Suite 270, Washington, D.C. 20016.

Smith, Carol E., et al, "REACHING OUT: A RESOURCE BOOK FOR THE ADOPTION OF CHILDREN WITH DEVELOPMENTAL DISABILITIES", C.W.L.A., 67 Irving Place, New York, N.Y. 10003. This material, is a compilation of training materials for workers and prospective adoptive parents. It focuses on the development of a genogram as an assessment tool to collect and discuss issues of importance to the prospective adoptive family. Also included is very basic information on handicapping conditions; advocacy groups and terminology used in the mental health system (e.g. normalization).

University of Georgia, "IN SERVICE TRAINING CURRICULUM FOR ADOPTION WORKERS IN THE PLACEMENT OF CHILDREN WITH SPECIAL NEEDS", obtain from Children's Bureau. A 50 hour curriculum on adoption. The units include 1) Introduction to Adoption of Special Needs Children, 2) Understanding Families, 3) Needs of Special Needs Children, 4) Preparing Children for Adoption, 5) Preparing Families for Adoption, 6) Moving Children into Families, 7) Legal Aspects of Adoption, 8) Post-Placement Services, and 9) Responding to Recruitment.

View, Virginia, "CHILDREN IN NEED OF SPECIAL SERVICES". One training module in the series "Child Welfare Inservice Training Curriculum, P.D. Press, 1982, 307 pages. This module is intended as a curriculum for a 15-hour training program. It contains particularly good information on child assessment and family intervention strategies. Order through P.D. Press, Creative Associates, Inc., 3201 New Mexico Ave., Suite 270, Washington, D.C. 20016.

## DEVELOPMENTAL DISABILITIES

Bardwell, Ann; Krieg, Fred J.; Olion, LaDella, "KNOWING THE CHILD WITH SPECIAL NEEDS: A PRIMER", Washington, D.C., Head Start Tech. Assistance and Management, 1973. This is a very helpful book written for "laymen" which defines and describes the major handicapping conditions such as mental retardation and cerebral palsy in easily understood terminology.

Belgum, David R., "WHAT CAN I DO ABOUT THE PART OF ME I DON'T LIKE?", Minneapolis, MN., Augsburg Publishing House, 1974. This book is written for adult readers who are themselves disabled. It gives insight into the development of a self image seen as "deviant". Anyone working with the developmentally disabled and their caregivers could benefit from the book as it provides ways of confronting feelings of rejection, abnormality, and inferiority; poses probing questions to provoke openness; and suggests ways of building on one's strengths. Includes listing of special organizations for the handicapped and a bibliography.

Bete Co., Inc., "EVERYONE IS SPECIAL", South Deerfield, Massachusetts 01373, 1983, 8 pages. This is a coloring book for early elementary children with the message that "Everyone is a little bit different. That's what makes everyone special." It includes pictures of children playing together, many of them with different abilities. This is a very simple up-beat book. The pictures are somewhat busy for developmentally disabled children. It is geared primarily to children who have not had much exposure to developmental disabilities.

Blacker, Jan, Editor, "SEVERELY HANDICAPPED YOUNG CHILDREN AND THEIR FAMILIES, RESEARCH IN REVIEW", 1984, Academic Press, Inc. This resource book provides a comprehensive view of current thinking and knowledge in this area. Though geared to professionals, it is written in an interesting narrative style. Research includes the outcomes of early intervention programs and of family decisions about placement.

Dickerson, Martha and Eastman, Michael, "TRAINING FOR PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES", Detroit, Wayne County Intermediate School District, 1982. Students Manual 56 pp. Instructor's Manual 126 pp. Produced for parents by an educator and a social worker who has also been a foster parent of handicapped adolescents, this is a very practical workbook. It is written in notebook form for parents to complete about their own children, rather than being a compilation of articles and exercises. Parents (both biological, foster and adoptive) are led to understand developmental disabilities, and to learn to create a safe and stimulating home environment. The course includes an assessment tool, the Adaptive Behavior Scale of the American Association of Mental Deficiency which allows a parent to assess his or her child's skills in independent functioning and social behavior. Intended for use in groups and structured in such a way that instructors can easily teach the class, it provides a very exciting way for parents to share their

experiences and improve their own and their children's skills.

Edwards, Jean and Dawson, David, "MY FRIEND DAVID", 1983, 125 pages. This booklet is excellent reading both for the person unfamiliar with those who are developmentally disabled and for the seasoned professional. Ms. Edwards assists David Dawson, an adult with Down's syndrome, in telling his story. A section of the book is in David's own handwriting. The remainder of the book provides information on Down's syndrome, available resources such as living and work options, and stories of other Down's syndrome people. This is a helpful book for parents. Ednick Communications, Inc., Box 3612, Portland, OR 97208.

Haskins, James, "WHO ARE THE HANDICAPPED", Garden City, N.Y., Doubleday and Co., Inc., 1978. An excellent introduction to the role that society's attitude plays in defining and propagating limitations on handicapped people. The book includes descriptions of the major disabilities (blindness, deafness, mental retardation, cerebral palsy, etc.) and is easily understood by the layperson.

Horrobing, J. Margaret and Rynkson, John E., "TO GIVE AN EDGE", 510 South 7th St., The Colwell Press, Inc., Minneapolis, MN., 55415. Although specifically written for parents giving birth to a Down's Syndrome child, this book is very helpful as it explains the syndrome and it's course, expectations of children, and day to day care and discipline.

Levine, Melvin D., Carey, Williams B., Crocker, Allen C., and Gross, Ruth T., "DEVELOPMENTAL BEHAVIORAL PEDIATRICS", Philadelphia, PA., W. B. Saunders Co., 1983. This is one of the few books coming from the medical field that attempts to look at the total child and describe how all the areas of development interrelate and influence each other. The book looks overwhelming. It is large and expensive, but it is well worth the money and the time spent to familiarize yourself with the contents. The book is well structured and specific topic areas are easy to find both in the Table of Contents and in the Index. It is helpful for gaining information on a specific disability, treatments and medications, and normal developmental stages. But the greatest value of the book is its sensitive, wholistic approach. This book will be used repeatedly by child welfare workers as a resource on medical, behavioral and educational issues. It is well worth the cost to an agency.

Mannelli, Robert P., Dell Orto, Arthur E., "THE PSYCHOLOGICAL AND SOCIAL IMPACT OF PHYSICAL DISABILITY", New York, Springer Publishing Co., 1977. Topics covered are: the psycho-social impact of a disability on society, the family and the handicapped person; attitudes toward the handicapped; sexuality and rights of the handicapped; and a variety of therapeutic models. Also included is a helpful bibliography and list of organizations.

Smith, David W. and Wilson, Ann C., "THE CHILD WITH DOWN'S SYNDROME", Philadelphia, PA., W.B. Saunders, 1973 (pb) Genetic,

physical and medical concerns are covered in detail. Daily life activities are described and illustrated. The final chapter is written by birth parents.

Sohol, Harriet Langsam, "MY BROTHER STEPHEN IS RETARDED", New York, Macmillan Publishing Co., 1977, 26 pages. Written by the parents of a mentally impaired child from the viewpoint of his twelve-year old sister, this book describes her fears and frustrations in having a retarded sibling. Complete with photographs, it could be useful in preparing the children in a family for the arrival or return of a handicapped child. Written in 1977, it focuses more on the negative aspects of living with a handicapped sibling and would need to be balanced with positives from another source.

Svoboda, William B., "LEARNING ABOUT EPILEPSY", Baltimore, University Park Press (pb) This book, written by a university professor of pediatrics and neurology, is a helpful manual for anyone who wants to know more about epilepsy and it's causes, treatment, and consequences. Chapters include definition, types of seizures, causes of behavior disturbances, medical and other types of management, and associated emotional behavioral and learning problems.

Turnbull, Ann and Rutherford, H., editors, "PARENTS SPEAK OUT; VIEWS FROM THE OTHER SIDE OF A TWO WAY MIRROR", 1978, Charles E. Merrill Publishing Co., p.b., 210 pages. This book, written by parents who are also professionals in the field of developmental disabilities, speaks to the strengths, needs and experiences of both groups. A very readable book, it argues for collaboration between parents and professionals and asks that professionals be willing to learn from parents.

Wicks-Nelson, Rita and Isreal, Allen G., "BEHAVIOR DISORDERS OF CHILDHOOD", Englewood Cliffs, N.J., Prentice Hall, Inc., 1984. This book is easy to read yet contains precise, detailed information regarding the various types of psycho-social (behavior) disorders of childhood. The book encompasses topics of eating, toileting and sleeping disorders, psychiatric disorders, hyperactivity, mental retardation, and conduct disorders. The concluding chapter discusses the issues of child rights and of the vulnerability of children. There is a helpful glossary and a large reference section.

Wikler, Lynn and Keenan, Maryanne P., editors, "DEVELOPMENTAL DISABILITIES, NO LONGER A PRIVATE TRAGEDY", 1983. This is the result of a collaboration between the National Association of Social Workers (NASW) and the American Association on Mental Deficiency (AAMD). It examines the role of social workers in working with clients with disabilities. It is especially helpful in learning about the stresses on families and on new ways of supporting families. The book also includes a great deal of information on working with adults with disabilities. Order from the National Association of Social Workers, 7981 Eastern Ave., Silver Springs, MD. 20910.

## ETHNIC COMPETENCY

Billingsley, Andrew and Giovannoni, Jeanne, "CHILDREN OF THE STORM: BLACK CHILDREN AND AMERICA'S CHILD WELFARE", New York Harcourt Brace, Inc., 1972, 236 pages. An excellent historical overview of the effects of racism on services to Black children in the United States, this book documents the exclusion and gradual admission of Black children into child welfare systems. The book describes social services and programs traditionally provided within the Black community, and proposes reforms in the American child welfare system. A fascinating book, it sensitizes staff to both systems and personal issues and problems in meeting the needs of the Black children in their care.

Dodson, Jualynne, "AN AFRO-CENTRIC TRAINING MANUAL: TOWARD A NON-DEFICIT PERSPECTIVE IN SERVICES TO CHILDREN AND FAMILIES", 1982, 163 pages, Knoxville, Tennessee, University of Tennessee, available through National Child Welfare Training Center, 1015 East Huron St., Ann Arbor, MI 48104. This manual contains the material necessary to teach a four-day educational workshop for social services staff. The content is exciting for those who have a deep knowledge of Afro-American culture, as well as those who are new to the culture. The conceptual framework can be used to study any culture from a non-deficit perspective, focusing on food, language, music, poetry and history. The National Child Welfare Training Center also has video-tapes of the workshop, as conducted by Jualynne Dodson, to be used as a resource to trainers. A series of seven video-tapes are available for sale through the National Child Welfare Training Center to use as a resource for conducting training in working with Afro-American families. They are: 1) Verbal and Non-Verbal Communication, 2) Strengths of Black Families, 3-5) Afro-American History, 6-7) Training for Trainers.

Sipp, Pat and Whaley, Mary, "PERMANENCY PLANNING: THE BLACK EXPERIENCE", a training curriculum, Chapel Hill, University of Tennessee, School of Social Work, 1983. This material is the result of a demonstration grant in which permanency planning resources were focused on the needs of minority children and families. It contains some of Jualynne Dodson's material on the non-deficit approach to assessing families and includes other articles and exercises on permanency planning. It is structured to be used by individuals or groups and is an excellent resource.

## SEX EDUCATION AND SEXUAL ABUSE

Gordon, Sol, "GIRLS ARE GIRLS AND BOYS ARE BOYS", New York, Ed-V-Press, 1979, 42 pages. An impressive soft-cover children's book, it could be used with children who function at elementary level through early adolescence. The writing is simple, but informative, and pictures are beautifully drawn and detailed. The children and adults are of many races and look like real people. The text and pictures attempt to break down sex-role stereotypes for children as well as provide basic information on bodies and sexuality. This book would be a worthwhile

investment for an adolescent, developmentally disabled child because the subjects covered are of great interest to adolescents and the book is simply written.

Stowell, Jo and Dietzel, Mary, "MY VERY OWN BOOK ABOUT ME", Lutheran Social Services of Washington, 1983, N. 1226 Howard, Spokane, Washington 99201. A Guide for Parents is available with the book. A Guide for Therapist and a Guide for Teachers is also available. This is a workbook for children which is intended to be a positive experience for the child and reduce the embarrassment often surrounding this subject for both adult and child. The workbook can be used for prevention and as a diagnostic tool and aid for the child who has experienced sexual assault. A very up-beat book, its theme is that children are all very special and have the right to say no to others who make them feel uncomfortable.

Wachter, Oralee, "NO MORE SECRETS FOR ME", Boston, Little, Brown and Co., 1983, (p.b.) Four beautifully written short stories about children who are faced with sexually abusive adolescents or adults and who turned to a trusted adult for help. The stories can serve as prompts for discussions on similar events that have happened to children and what they might do in the future. The book is versatile in presenting both boys and girls of various races, being confronted by babysitters, or adults known to them. It could be used with pre-schoolers through adolescents. Because of the large print, short, clear stories and illustrations of older children, it can be effective with older developmentally disabled children and adolescents. Each story is very believable and surprisingly non-threatening.

White, Laurie and Spencer, Steven, "TAKE CARE OF YOURSELF", A young person's guide to understanding, preventing and healing from the effects of child abuse, published by the authors and available through Stephen Spencer, 4340 Tamarac Trail, Harbor Springs, MI 49740, 1983, 34 pages. This is a beautifully produced story and workbook for later elementary and junior high children describing the dynamics of neglect and abuse and telling children what they can do to get help. It can be used as a coloring book as well as containing a great deal of information. This would be excellent to use with older developmentally disabled children to explain why they may have been abused and to teach them how to avoid future abusive situations.



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# Life story books

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## *Chris Lightbown*

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This article looks at some of the questions posed by those considering the use of life story books as a method of working with children in care. As a family placement worker I have been involved with many children who feel confused about why they are in care, why they have had so many moves of address, why they cannot return home. Their preoccupation with the past has hindered their perception of the present and their hopes and abilities to plan for the future. I began, therefore, to look at the past, present and future with children through a written account of their life story and encouraged other significant people in their lives, like residential workers and foster parents, to do the same. As a result, both I and my colleagues discovered that for some children this was a superb method for:

- a) helping a child examine and develop his self image;
- b) helping to develop the relationship between the child and key worker;
- c) helping natural parents to contribute something to their child, by giving information or sharing in the composition of the story;
- d) enabling potential substitute families to share in the story, as an aid to their understanding the child.

We also discovered the crucial point that the story had to be completely child-orientated. The child decided where it started, decided the speed of composition and decided whether or not the book should be shared with any-

one. This often meant that books were scruffy and 'higgledy-piggledy'. It also followed that the child could, at any time, decide to destroy his book.

Staff involved had to be completely sure of and at ease with the facts and, although some degree of encouragement proved appropriate when children resisted certain themes, this was all that could be allowed. Otherwise the role of the worker was to give information and act as sounding board and comforter.

### **Pertinent questions**

The pertinent questions to ask when approaching this kind of work are:

- Why should I be doing this?
- With which child should I do it?
- Which worker should take the main role?
- Where do I begin?
- What information and tools are needed?
- How do I deal with difficult themes?

For simplicity I will discuss these questions individually, illustrating them with reference to case studies. But, first a cautionary note: the reality of a child's life may involve many painful areas which he must face before he can come to terms with them and mature. To be involved in looking with a child at his life can cause contradictory and uncomfortable feelings in adults and this often leads to the worker finally being the one who is unable to examine the themes arising. The worker must have the confidence to enter into this depth of work if anything of value is to materialise. Support workers must understand this and give appropriate encouragement.

Furthermore, a child must have the basis of a trusting relationship with the worker before he can embark on so personal and confidential an experience. This calls for the time, commitment and involvement of the

worker. Not all life story books need to go to such depth, but all children in care could benefit from some form of practical account of their life experience, if only in the form of a photograph album. Nevertheless, for the child in real conflict who desperately needs help before he can grow, some degree of intensity is always involved.

Social workers and foster parents must decide where they stand in relation to embarking on this course of work, but just as crucially, social work managers must face the issues involved: the time and commitment demanded from staff need to be fully taken into account in the manning and support of child care services. In addition, if key workers are often to be foster parents, it is obvious that their selection and training processes must incorporate suitable preparation.

#### **Which child?**

Obviously the question of priorities comes in here. All children in care need some degree of help to sort themselves out. However, this method of work is particularly appropriate for those who need to be discussing plans for their future but who are unable to do so because they are preoccupied with the past.

Most of the children I have known who have been aided were exhibiting signs of obvious perplexity, had suffered several moves of placement since reception into care and, in view of my specialism, were being prepared for eventual substitute family placement. If a child is not ready for this method of work his overwhelming resistance will tell you so. Some children may prefer just to discuss their lives and keep photographs but not make a book.

#### **Which worker?**

I have found that a group discussion is the best method of identifying the worker to be directly involved with the child in story book compilation. A great deal depends on the intensity of the work to be entered into but the most appropriate choice, if possible, is the child's key worker. This is the person most likely to have a good working knowledge of the child and his trust. For this reason he or she is usually the residential worker,

foster parent or, occasionally, if the child has had many moves, the field social worker.

There are often difficulties: the key worker may lack the confidence or motivation to be involved in such a project, or may feel he or she lacks time. The group must base its decisions on a realistic analysis of any problems, including an appreciation of the fact that writing a life story can take a long time, perhaps over a year, and that during that time workers may change.

From my own experience I have found a variety of tasks associated with life story books.

#### *Jane*

A seven-year-old girl was removed from home and placed with foster parents on an assessment basis. She was very confused about what had happened to her. Although she had lived with her parents for some years, as a toddler she had also been in care and had lived in a number of short-stay foster homes. After an initial settling in period, her present foster mother began to piece together with Jane her life in story book form. It was a long process but little by little Jane began to see precisely where she had been.

My role in this situation had been encouraging the foster mother to undertake this method of work and then acting as her practical and emotional back-up. I was the information digger who wrote to Jane's previous foster homes asking for photographs and worked with her parents towards enabling them to provide her with life details. I was also the one with whom the foster mother could chew over the difficult details, on the basis that tackling some areas of a child's life requires two heads rather than one.

#### *Alice*

An eight-year-old girl was moved to a children's home for assessment following a foster placement breakdown. The situation concerning parental contact was difficult. Alice's problems were compounded by the fact that she was educationally slow and finding it extremely difficult to work out what was going on.

The child's housemother began to look

with Alice at her life story.

Initially she told her stories about a girl called Helen who, miraculously, was in a similar situation to Alice. These stories were written down and eventually a true life story also began to appear. Alice knew me very well, so it was decided that I should share the task of helping her write about her life. In view of the good relationship I had with the housemother this worked smoothly, with Alice knowing that either the housemother or I was available whenever she wanted to get down to business.

#### *David*

David was seven. His fostering placement had broken down and he had been moved to a children's home from which, eventually, I felt I might be able to place him for adoption. David knew me well and I had been with him when he had gone through some bad experiences. House staff at the home were frequently changing, so when he began to request a detailed account of his origins it was decided that I would be the appropriate person to help. In this situation it was house staff who provided me with consultative backup.

#### *Where do I begin?*

You begin with the child and the topic may be broached in a variety of ways. You may be playing together, or just sitting down discussing things and decide then to ask him how much he knows about himself, or wants to know; or he may lead the questioning. With David we were poking at stones in a brook when he suddenly asked what I knew about his mother, from whom he had been separated almost at birth. I had never met her and information on file was scant so I asked him if he would like me to find out as much as I could about her. David agreed with enthusiasm, so I further suggested that, in order to help him remember, we wrote down whatever we discovered. For the next year David and I spent regular sessions building this story, with the child doing most of the writing, putting things in his own words and glueing in photographs or drawings of himself or significant others. Sometimes a worker may sit down and help a child compile his

story in one or two sessions but caution must be taken. A child's attention span is limited and if he wants to write his own story, albeit with your help, he needs time to think things out. Some children request their social worker to present them with ready written accounts of their life and then that is acceptable.

David did need time to absorb the fascinating details I had discovered relating to his past and all the time we were discussing and writing about things he was working out how he felt in relation to it all. I contacted his earliest foster parents and we went to tea. They delighted him with anecdotes from his first Christmas when he tried to eat a glass bauble from the tree. They also told him what it had been like when he had first walked and talked. We visited the maternity hospital where David was born and the street where mum had lived and finally we found that he could look squarely at his life, including his present and also face all the bits that had hurt him. At last David was able to suggest that he would like a new family and when he moved to his adoptive home his new mum and dad continued to help him keep his story up to date.

Most of the children I have known and who have been introduced to the idea of a life story have preferred to tackle topics chronologically. A copy of their birth certificate and a photograph of the hospital where they were born have often been good starting points. Alternatively, some children have wanted to start from the present, or from the point of a particularly happy memory from their past. It is interesting and often significant to see where a child decides to begin.

#### *What information and other tools are needed?*

Information begins with the case file and this is where difficulties are first found. The information the child would find relevant is rarely there, a factor speaking reams about case recordings and our understanding as a profession of the needs of the children we serve. The narrative history is often scanty but, for the child who wants not only a wealth of factual detail about why and when he went here and there but also physical and

anecdotal details about his parents, grandparents and previous foster homes, case files are usually useless.

Detective work is the most time consuming aspect of life story books. Foster parents, residential workers or lost relatives may all need to be contacted before relevant background knowledge and old photographs are made available but although this aspect of the work can be hard and frustrating it is also exciting and rewarding.

Kenny was 13 but he knew next to nothing about his family background when I became his social worker. Meetings arranged to discuss this between himself, myself and his mother revealed a fascinating family tree. One of his grandparents had been Irish, one Italian and two English. Once this was known Kenny had a good time looking at maps and collecting things pertinent to his 'countries of origin': coins, newspapers and even a Dubliners' record. Kenny had been a child with a low, uninteresting image of himself so the effect that such a history had on him can be appreciated.

Sharing newly discovered, intimate facts about a life story draws people together and, if a child can share these details with those who care for him, or with a potential new family, new depths can be added to his relationships. Further, if valuable background information can be offered to the child by his natural parents, either directly or through the worker, new dimensions can be added to the casework element with mums and dads also. In preparing children for alternative family placement I have often been amazed by the role that the natural parent has been able to take in this process.

When David's mother was finally traced and asked if she would consent to his adoption she showed an initial resistance to this. She revealed that she was convinced that if she agreed to the adoption, he would inevitably regard her as the wicked woman who gave him away. I had taken David's half written life story with me to show her and once she had read it she was touched by the account he had related of his reason for being in care. He had written: 'I was born on 4 December 1969 in a hospital called Rustington in Barchester. My mother was called Ann Jones and she was 18 and a half years old

when I was born. When I was born my mummy found it very hard to look after me. She loved me very much but she was poorly and she did not have much money. She had no house and she did not love my daddy so they did not live together. Because of these things my mummy felt she could not look after me properly so she asked the social workers to look after me instead.'

David's mother was still unable to offer him a home and after reading this sympathetic but realistic account of his separation from her she seemed to be more able to face the possibility of him being adopted. Finally she became positively involved in supplying many other details for him to include in his story and by this means she was able to let David go.

Information like this may be the central tool in story book preparation but it is worth mentioning the other tools of the trade. Reference has already been made to time out for play and trips, but what about a departmental camera so that photographs may be taken of previous foster homes or of the street where a child lived? Add to this an actual 'scrapbook', pens and paper, glue and magazine cuttings (in the absence of photographs) and a pair of scissors for the basic equipment you need at hand when you work with children in this way.

#### **How do I deal with difficult themes?**

I have already mentioned that the greatest resistance people feel to embarking on a life story with children is fear of the pain it may involve. This is usually rationalised by the worker in terms of the great anxiety a child will feel if faced with the true facts of his situation. In one case I was introduced to, foster parents were afraid to mention the existence of a natural mother to a child despite the fact they knew he remembered her. They wanted to adopt him, so as a preliminary to this I encouraged them to piece a life story together with John. The ease with which he accepted rather uncomfortable reasons for his being in care, once the subject began to be tackled, astonished the family, and, at last, with great relief, they accepted that John had been able to face up to things far more easily than themselves. A sympathetic, simple and

realistic account always seems to prove best.

A colleague of mine once sweated out the prospect of dealing with a potentially extremely painful area with a child. Donald was thought to believe that his mother was dead, his foster parents had applied to adopt him and the need to explain that his mother was very much alive and willing to agree to his adoption could no longer be avoided. Mike was helping Donald to write his life story and suddenly the truth came out easily: to Mike's astonishment Donald's reaction was that he had suspected as much all along.

### Implications

In conclusion, the case examples referred to have involved children and parents who have been directly helped by the life story book method of work. The needs of the children cited differed, but they were all finally, if to varying extents, freed to grow towards a more positive understanding of themselves. These examples illustrate how we, as social workers, can begin to tackle the problems of confronting reality with the children in our care, enabling them to heal and move forwards; a task which we, as a profession, often seem disinclined to grapple with, not so much through lack of interest as, I would hazard to guess, through fear and doubt about our own potential.

Working with life story books is one viable method of working with children but it is essential to accept the level of time and commitment it necessitates. Social workers cannot, however, be expected to do this sort of work in a vacuum and an adequate framework is essential if this work method is to become feasible. This means appropriate supervision, support and management, involving the commitment of an entire department to this level of child care service. If local authorities are prepared to accept the heavy parental responsibilities vested in them these are the fundamental questions which must be asked:

Do social workers have the time and support necessary to enable them to embark on thorough methods of working with children?  
Are residential workers given the recognition, support and time due to their key worker role?

Are managers and supervisors aware of the emotional and practical implications of working with children?

Are members of social services committees equally aware of these implications and their responsibilities, and are they willing to act accordingly?

Can departments ensure that case recording is more appropriate and child-orientated?

Are foster and adoptive parents briefed on methods of working with children and is sound back-up available?

Are field and residential workers willing to face the implications of working with children?

### Helpful reading

D D Eikenberry, 'A story for Mary', in *Communicating with children* edited E Holgate, Longmans Papers on Social Work.

*Older children need love too*, ABABA, 35p.

*Planning for children in long term care*, ABABA, teacher's pack £5, student's pack £1.

*Working with children who are joining new families*, ABABA, course material £3, teacher's handbook 75p.

# Workshop by Claudia Jewett

## Separation, Grief, and Attachment in the Adoption Of Older Children

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**EDITOR'S NOTE:** *Claudia Jewett is the mother of 10 children, seven of whom are adopted. She is a consultant to 11 adoption agencies and an experienced and nationally-known therapist, dedicated to helping adopted children and their families. She is the author of *Adopting the Older Child*, an excellent guidebook for families undertaking this type of adoption.*

*Claudia was a well-received speaker at the NACAC convention in Houston last October. She also gave a workshop recently for PLAN (McMinnville, Oregon) families and social workers. At this workshop she discussed areas crucial to the adoption experience: 1) reasons children are separated from their bio families and how to help a child understand them; 2) how to assess a child's readiness for attachment; 3) the experience of loss and stages of grief, how to recognize where an adopted child is in this, and how to help him through it.*

*The following is a synopsis of Claudia's insights and observations in these areas. It was originally printed in two installments in "PLAN News" and is reprinted here with permission of PLAN.*

As we know, there are many reasons why children are separated from their bio parent(s): drug abuse, mental illness, incest, abandonment, illness, abuse, neglect, imprisonment, retardation, rape, death, poverty, unmarried parents, etc. Many of these circumstances fall outside of our life-experience, leaving us somewhat at a loss in explaining them. We need to develop skills (and comfortableness) in talking with children about them so that they will believe us, and so that we do not step on their loyalty to an absent parent or on their self-esteem. If we make a parent appear bad, we put a lid on a child's self-image.

Perhaps the most frequent reason given a child for their separation from their bio-mom is (oversimplified) "your mother loved you so much that she gave you away . . . because she wanted you to . . ." Something in this falls short. There is a piece missing. It is not entirely credible. If we want children to believe us we have to deal with the missing piece: granted that she loved me, what in her life kept her from keeping me?

In making separation understandable to children, Claudia suggests that we remember that children's thinking is concrete, while ours, as adults, is more abstract. Taken concretely, "Mother loved you so much she gave you away," might suggest you should never love anyone too much or you will be given away. In order to handle areas where we get befuddled she suggests the following:

- 1) We need to respect the birth-parent.
- 2) We can use the child's life experience to give him the key to understanding his bio mom and dad.
- 3) We need to look at what was the adult's reality in our child's bio family.
- 4) We need to put things honestly and compassionately.

For example, if we are dealing with abandonment and abuse, a basic factor in this behavior is frustration. Frustration can come because the parent experiences demands that are unfair (not fair because the parent wasn't adequately parented) or too harsh. These are many reasons for frustration, but if we experience this intensely enough, we tend to do one of two things: run or hit.

What is there in a child's experience that might help him to understand? Where has he experienced frustration? In school? What kinds of things have people asked him to do that were too harsh? Can he remember this and how he felt? We start with the child's experience because he believes that, and then we use this as the key to understanding his bio parent: "You know, I think that was what happened to your mom."

When a child's bio family experience has included incest he needs to know why grown-ups do that. This is partly because they are lonely and they need to feel close. What experience has the child had wanting closeness? But why did the child have to leave? Because we have rules about that. It is not good for children to be close in these ways and it interferes with their getting close in other ways.

If there is mental illness in a child's background, we can help him understand that life for their bio parent(s) was pretty scary. Most schizoid and psychotic parents are afraid, and most kids have the experience of being afraid of things "out there." Sometimes it's hard to know what is real, and kids have had experience with that, too. Experientially, they are often equipped to understand that their parents' life experience was one of confusion, so that sometimes, even in the daytime, things frightened them and they needed to go to a place where they felt safe.

If a parent is in the hospital, we need to use the concept of pain. All children understand a physical hurt and the need for care. If a parent is in a hospital or a prison, children need to understand that that was a place where they could not go with them. They need to know, "There is a special law written just for you, saying you are entitled to shelter, food, etc. and if your parents are away there needs to be another arrangement made for you. It is your turn (something children understand well) to receive these things, and you cannot wait until later."

In understanding the immature or retarded parents, the common denominator is learning, a very immediate experience in a child's world. With a very young bio parent, they can be helped to understand that their mom had not lived long enough to learn how to parent. With a retarded parent, they needed lots of practice to learn things, and they were not ready to take care of someone else.

Claudia suggests that we can help a child understand a birth parent's experience with rape as one in which one person wanted to be close in a way the other person didn't like. Children have had experience with this, for example, in being tickled. This may start out as being fun, but can turn into something they do not want, with an element of fear regarding the person, strong enough to overpower them against their wishes.

**The secret in giving children the key to understanding their parents' experience is to keep it simple and concrete.** If the child is not in touch with what was going on with his parent, his alternative is self-blame, making it difficult for him to grow and relate in another family to the full measure of his capacity.



## The Dilemma of Separation and Grief

We handle the impact of significant loss usually in stages, and Claudia labels them as five steps:

1. Denial
2. Sad
3. Mad
4. Despair
5. Detachment

Unless a child has had an opportunity to work through these various stages of feeling, frequently he may come into a family stuck in one or more of them. The family may then be involved in coping with problem behaviour, the cause of which is obscure, unless it is understood in terms of his grief experience.

## Denial

Denial is a way to numb out waves of shock and pain. If you don't believe the separation has happened, then you don't have to say goodbye. A child stuck in denial is afraid that he can't stand to do just that. Occasionally we hear of a child, seemingly at home in his adoptive family, unable, to his parents' surprise and dismay, to agree to finalization. When the family goes to court, it can be for the child a final goodbye that he cannot handle, unless enabled to move through that initial reaction to his earlier loss.

According to Claudia, one of the most common indications of a child stuck in denial is hyperactivity. Such a child shows you with his body what the problem is: Emotion. Better than medication is to deal with the issue bothering him, the assumption of blame for the separation. "It must have been my fault." Such children have problems focusing in school, avoid times of quietness and aloneness, and display resistance greater than normal to going to bed.

Claudia suggests with a bed time problem to comfort the child much as you might a new puppy:

- 1) with a soft radio (instead of a ticking clock)
- 2) using flannel sheets (instead of a hot water bottle)
- 3) with a night light (or flashlight available)
- 4) tucking them in very tightly
- 5) giving them a kiss to hold in their hand

## Sad and Mad

When a child has been overwhelmed by a separation, sometimes he doesn't know what to do with his grief, and becomes stuck in "sad". Frequently he is using all his energy holding the lid on his feelings, rather than moving through a resolution of them. The same thing may happen with anger. We may see a combination of symptoms. We can tell when a child may be stuck in one of these stages, if his behaviour when he is sad or mad is not normal for his age.

Since it is pretty hard business to keep a tight lid on feelings of grief or anger, children sometimes seek a rest and pick lesser issues that they can cry or fuss about. A child may create a frustrating situation that will release tears, or set up an experience that will make them feel alone. This, unfortunately, does not help to resolve or relieve the real issue.

Sometimes, on the other hand, rather than holding the lid on their feelings, children can seek a different ending to their story by being sad or mad long enough until people take them seriously. Another way of being stuck.

How do we help a child stuck in sad or mad? Claudia thinks of him as a pump needing a prime and the process as one of getting the feeling about the real issue up where it can be helped. Children that are stuck can not permit their bodies to let the feelings about it out. She helps children begin to do this in play. "I bet I can make a sadder (madder) face than you can!" After a bit of practice, she and the child move on to making a sad/mad sound. Permission to really feel sad is given.

If a child cannot find his feelings of sadness or anger, she wonders with them "where did that feeling go?" helping them to understand that sometimes it goes to a tight throat, to the tummy, or sometimes the feeling goes into movement.

In working with children who have repressed their grief in this fashion, she finds often real tears come, and this is the time for empathy, permission, and comfort: "You really do have something to be sad about." With children learning to express their anger about loss she gives them permission to put it in motion in ways that are okay: tearing, crushing, sometimes biting harmlessly.

Part of the problem is that we sometimes teach kids it is not safe to get mad, it's contagious. If you do, someone bigger will get mad at you! Children also unconsciously are afraid they will annihilate their parent with their anger or vice versa. Finding a safe way to express it can come, for example, in kicking boxes with your child.

Priming the pump can often be done through a third party. Claudia cites "Little House on the Prairie" as a beautiful source, observing that in almost every program Michael Landon cries. The children's book, "Charlotte's Web" is another super story to help children get in touch with their feelings about loss.

### **Despair**

Despair in a grown-up shows itself in depression, which in turn is evidenced in low energy. A common component is sickness, and in children, perhaps the most frequent symptom is food-laden behaviour: the enormous appetite, the hoarder. "The worst thing that could have happened to me has happened and it is never going to get better!" Claudia's suggestions for the gorgers are to give the second helping, but with the third to say "I will be your full," or "I don't think you need more food, you need a hug." A lot of children are unable to discern their bodily need.

The dilemma with the hoarder, the child that just takes but doesn't eat, is a little different. The underlying problem is his experience with parents who could not be trusted to give him what he needed. He can be helped through this with permission to take cans or boxes (things that will not spoil).

### **Detachment**

Detachment, the final stage, does not mean forgetting the loved person, but a disengagement from the pain of loss. In grown-ups, those acquainted with the dynamics of grief allow a year for recovery. Sometimes, Claudia observes, we give kids a week to 10 days. We have the need to see, in the happiness of a child, the confirmation of the correctness of our decision to adopt.

One of the loveliest moments of the workshop was Claudia's illustration of her work with detachment in children through candles. Placed before the child are whatever number of candles that may be needed to symbolize the significant parent figures in his life. The first, of course, his bio mother and father. He is then given a candle to hold and this is lit. The light of the candle stands for warmth and love. With his candle he lights the others in turn, but as he moves from the first to the second, the first candle remains lit, it does not go out. Nor, she explains, does the love that was expressed for him in that first relationship. It is still there, still a part of him, to hold and to cherish. And in turn, all the candles are lit, until all are aglow.



Credit: Adopting the Older Child, Harvard Common Press, 1978  
and  
Helping Children Cope With Separation and Loss, Harvard  
Common Press, 1982

## HELPING A PRE-VERBAL CHILD MOVE INTO ADOPTION

### Introduction

In this part of Section IV we discuss procedures for moving pre-verbal children into their adoptive homes. Many children aged one to three are placed for adoption. While moving these children is often viewed as an easier task than placing an older child, there are some serious concerns that must be attended to in work with the younger age group. Children age one to three are especially prone to having difficulties with separation from those to whom they are attached.

We strongly believe that it is easier to help the child and foster parents cope with the separation problems than to help the child's permanent family cope with the long-range effects of lack of attachment in the early years. However, this does mean that we must recognize the difficulties posed by separating a toddler and the person to whom he is attached, and do everything possible to minimize these problems.

In moving pre-verbal children, there is little margin for error in the way the move is handled. Workers and parents must pay close attention to detail -- particularly non-verbal detail. While the under-three child understands many more words than he can express, what he is really tuned into are the non-verbal signals. The attachment to the foster parents must be literally handed over to the adoptive parents; that means that there must be considerable contact between the two sets of parents. The ideal way that such a transfer occurs will be discussed in the rest of this part of Section IV.

### Initial Meetings

To start with we must remember that the child feels most secure on his home ground. Thus, most of the child's contacts with prospective parents, and certainly the initial contacts, should take place in the foster home and in the presence of his foster parents. Also the adoptive parents must understand that during the first contacts with the child, the interactions between them and the child must occur at the child's pacing.

If a child of this age is well attached to his foster parents, he may cling or hide a little when strangers enter the home. It is unlikely that he will immediately interact with them. It often works best if prospective adoptive parents just chat with the foster parents at first, almost ignoring the child. The child will sense that his foster parents feel comfortable and will begin to initiate interactions with the visitors. It is crucial that the child control the pacing of this encounter if he is to start to trust the prospective parents.

It is also wise for the adoptive parents to bring several toys to the visit. They will take these home, except for one cuddly type toy that they leave with the child. When the child first visits the adoptive home, he will have toys to play with that he became acquainted with

in the foster home. The non-verbal message in this is "things that are okay for you to play with in your foster home are okay for you to play with here."

We usually move pre-verbal children faster than we do children over three because of their poor sense of time. However, we must be careful not to move them too fast. Seven to ten days of visiting is usually about right for children of the toddler age with two to three days of contact being all that is usually necessary for the child four months of age or younger.

#### Pre-adoptive Visits

During the visiting period, the goal is to arrange for the most possible contact between the child and the new parents. The adoptive parents, especially the mother, should spend a lot of time in the foster home. The visits should occur at all times of the day. In part, this schedule allows the mother to learn the child's routine thoroughly. If the child is used to a crib, the adoptive parents should have one for the visits, even if it requires renting one. If the child is used to eating dinner at 5:30 and going to bed at 7:30, this is the routine that should be followed initially in the adoptive home, even if it is not convenient. As the first few weeks pass and the child feels more secure, than the changes in routine can be instituted gradually.

This type of extensive contact allows the child to receive the message from the foster mother that it is "okay" to like, to take from, and to get close to the adoptive mother. If careful attention is not paid to giving this message, the child may not accept affection from the adoptive parents; he may not mind them.

How can foster parents go about giving this message to the child? They can do it in the same way that most mothers unconsciously work at transferring attachment to other family members. In the midst of feeding the young toddler, the mother says something like "Oh, I need to check the cake in the oven, would you finish feeding him?" and hands the spoon to the adoptive mother. The message to the child is that the foster mother trusts the adoptive mother.

The foster mother needs to literally hand over all sorts of routine tasks to the adoptive parents during the visiting period. "would you please change him?" "Come help me tuck him in bed." "Give your new mommy a big hug and kiss, too."

Foster fathers and adoptive fathers have not had much of a role in the process just described. That is because it is usually the mother who cares for a toddler most of the time and is the person to whom the child is attached. However, if the foster father is an active caretaker for the child, he should be an active participant in the move. If he has a special relationship with the child, such as roughhousing with him, then these behaviors, too, should be actively transferred.

Interchanges like this help the child realize that something unusual is going on because this type of behavior is uncommon except among family members. The child's realization that things are different is essential; we want the child to know that something big and important is happening in his life. Adults tend to protect children in ways that in the long run prove to be harmful, such as by not wanting to upset the child prior to the move.

We once worked with a child who had been moved as a toddler from a foster home where she was strongly attached to an adoptive family at the end of one visit. Several years later when we asked her where she thought people got babies, she responded "anywhere they can." She was deeply afraid that someone -- anyone -- might come and take her away from her adoptive parents. She did not trust that the parents would be able to prevent this. After all, her previous parents had not prevented these people from coming, visiting with her, and the never taking her back to her foster home.

In general, it is more dangerous if the child perceives a move as someone coming and "taking" him, than if he perceives it as being "given" to someone else after much preparation and many interactions between the two sets of parents. If a child perceives a move as being taken away by relative strangers, he must live in a perpetual state of anxiety, fearing every knock at the door or every visit by acquaintances. If careful attention is paid to all details of the move, similar circumstances are not likely to recur in the child's life and trigger his extreme anxiety.

During the second or third visit in the foster home, we often have the foster mother suggest that the child go for an outing with the new parent -- either to a park, for an ice cream cone, or for some other short pleasurable outing. Even though this should be arranged in advance by worker, adoptive, and foster family, when it occurs it should be at the suggestion of the foster mother. This gives the child the message that "I trust these people; they will take good care of you, and they will bring you back home".

The visit following this one can include a visit to the new home, where the child can be re-introduced to the toys bought for the initial visit in the foster home and can become acquainted with the home. Prior to this visit, the adoptive parents should show the child pictures of the outside of the house, possibly a picture of his bedroom, and pictures of any family pets. If there are other children in the adoptive family, their pictures should be presented to the child at the first or second visit to their home.

For the pre-verbal child, overnight visits are not as important as they are for the older child. However, we like to include at least mealtime visits during the visits to the adoptive home and are not against an overnight visit.

### The Day of the Move

At the time of the final move, the adoptive parents should come to the foster home, and both mothers should participate in some of the last packing together. The preparation for the move and the packing must not be done secretly. The child must get the non-verbal message that this is a very special day; something unusual is happening today. The foster mother may well be tearful and that is fine. If she is attached to the child, she is going to be sad, as well as happy, about the child moving. This is nothing to be concerned about or covered up.

At the final moment of the move, the foster father may help the adoptive father load the car while the foster mother literally hands the child over to the adoptive mother at the doorway. This should not occur on visits; during those, the foster mother may get the child ready and encourage him to leave with the adoptive parents, but she should not pick him up and hand him over at the beginning of outings.

After kissing the child good-bye, the foster mother may cry, and the child may cry or cling to her. This should not be discouraged with sweet placations. Instead, the foster mother can say, "I'm going to miss you and you're going to miss us, but it's time to go now" and again literally hand the child over to the adoptive mother.

At the time of the move, the child should certainly take, not only his clothes, but also some special toys or bedding from the foster home to the adoptive home. Such transitional attachment objects are very helpful to children. Those who use them seem to be more, rather than less attached to parent figures.

### Post-placement Visits

From three to six weeks after the move, we try to arrange for the foster parents to visit the child. Again, this should take place on the child's homeground, which is now his adoptive home. It is very important that the foster parents' other children, whether they be birth, adoptive, or foster, be allowed to go on the visit, too. The other children in a foster home often worry about what has happened to foster children who lived with them. These concerns easily become intertwined with guilt feelings.

Most children in a foster family occasionally wish that the others weren't there. Then, they feel guilty when the child moves and they get to stay. If they see that the child is happy in his new home, and that things are going well for him, it dissipates their guilt feelings. It also helps alleviate the guilt feelings that many foster parents have for not adopting foster children who live with them.

This is asking a lot of foster parents. We recognize this. We asked a foster mother who had worked with us in the move of a pre-verbal toddler to an adoptive home to write about her feelings about being an active participant in the moving process.

## HELPING A CHILD MOVE BACK TO HIS BIOLOGICAL FAMILY

In most cases when children have been placed in foster care, the plan of first preference will be to return the child to his biological family. There are a number of factors to consider when doing this.

### Factors to consider in returning a child from foster care:

1. have the parents met the contractual agreements;
2. parents ability to admit that there is (or was) a problem and willingness to work toward change;
3. parents ability to ask for help;
4. stability in marriage, job, and/or living conditions has been attained;
5. parents have learned to make use of support systems;
6. parents have learned to trust someone;
7. child whose behavior was disruptive has attained new behavioral controls.

The child's reaction to returning to his birth family is going to be strongly influenced by the length of time he has been in foster care; by the kind of experience he has had in the foster home; and the number and nature of visits he has had with his birth family. If the child is pre-verbal, and has been separated for any significant period of time from his birth parents, procedures such as those outlined from moving the pre-verbal child into adoptive placement should be used.

To get in touch with the child's viewpoint, it is helpful to think in terms of what percentage of the child's life has been in placement. If no pre-placement visits have occurred, visits aimed at transferring parenting from the foster parents to the birth parents should be set up. If the child has had regular visits with his birth parents while in foster care, then only such final steps as giving the child permission to go and to get close to the birth parents need to be emphasized.

If the child is verbal, a discussion aimed at the child's level of understanding should take place. This discussion should outline the gains the child has made while in foster care as well as the gains and changes that have taken place in the family during this period. Ideally the caseworker, the child, the birth parents, and the foster parents would all participate in this discussion.

It is common for children in placement to express their feelings by behaving one way for one set of parents and in another way for the other set. This is not helpful to the child's adjustment in the long run. If the child has a discipline problem in the birth home but not in the foster home or if the child had behavior problems that subsided while he was in foster care, then the foster parents should be actively involved in helping with the move.

For some older children an open discussion with both sets of parents present may be enough. However, for other children another more lengthy process is helpful. This process might begin by having birth parents come to the foster home to observe the child's behaviors there. The foster parents might then begin to involve and support the birth parents in making demands on the child and in disciplining him. A final part of the process would include having the foster parents accompany the child on a visit to the birth home.

The child who usually behaves well in the foster home but not in the birth home is then caught in a dilemma. Should he behave in the way he usually does for the foster parent or should he behave in the way he usually does for the birth parent? If he chooses to behave badly, the foster parent can comment and give the child permission to do well for the birth parent. The foster parent can also help the birth parent get the desired behavior. If the child chooses to behave well, then both sets of parents can share their pleasure with the child.

We realize very clearly that many birth parents and foster parents do not want this kind of contact with each other. However, both sets of parents need to be helped to understand that lack of contact between them puts the child in the untenable position of having to choose one set of parents over the other. When this occurs, everyone loses because the child feels caught in a trap, acts out, and makes the move more difficult.

#### Ways to Help Kids Move

- Birth parents need to observe what techniques worked in the foster home.
- Birth parents need to try these techniques out in their own home.
- Foster parents need to give the child permission to do as well at home as he has done in foster care.
- Caseworker needs to support both the foster parents and the birth parents in the transfer process.
- In some cases, having the foster parent involved with the child and the birth parent after the move may be helpful.

When a child returns to the birth home he should have a Lifebook that contains the pictures and information compiled while he was in foster care. The birth parents are more likely to accept the Lifebook if they were involved in putting together the pre-placement information and if pictures of the birth family were obtained for the child while he was in foster care. A picture of the child and his birth parents should be taken on the day of the move home and it should be incorporated into the Lifebook.

At the time of a move back to the birth home old unresolved feelings and issues are likely to emerge, both for the child and for the parents. Whenever family composition is changed by adding or subtracting a family member, the entire family system will undergo stress. Such stress should be expected when a child returns home after any appreciable time away from the birth family. It does not mean that the placement is going to fail. It does mean that increased casework services must be provided when children are returned home to help families clear up misperceptions and resolve issues.

The courts must be sensitized to the needs of both families and children so that court orders allow time for pre-placement visits. No child should return to the birth home precipitously if he has been out of the home for a significant period of time.

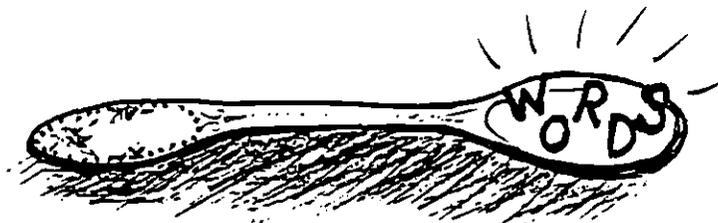
Credit: Attachment & Separation by Vera Fahlberg  
Contact Spaulding for Children, P.O. Box 337  
Chelsea, MI 48118

## Preparing a Non-verbal Child With Good Receptive Skills

During the lifebook preparation process, the worker can present factual information and attempt to encourage the child to interpret that information in light of his/her own memories, feelings, and perspectives. Using every means allows the child lots of avenues for expression.

Even a verbal child often finds it difficult to express negative or angry feelings in words! Often the worker must interpret facial and body language for the child.

The most difficult thing about preparing a non-verbal child who has good receptive language skills is that one is almost forced to put words in the child's mouth.



Your turn:

How might one avoid speaking for the child?

- by finding another communication mode
- by reading non-verbal cues
- by presenting interpretations with choices
- by asking lots of questions which can be answered by yes/no, pointing, or drawing behaviors
- all of the above

### 1) Finding another communication mode:

If the child uses a signing system or a complex gesture system, take some time to learn some of his words. This will not only enhance communication with him, but your rapport with him will be increased

as he begins to see that you feel he is important enough to learn his language. Some children may be able to draw, paint, or otherwise represent their feelings about their lives. You must be alert to every possible communication mode.

## 2) Reading non-verbal cues:

Some children who are severely physically impaired are unable to use a signing system. Yet their facial expression and body tone are very readable when one learns to look for those messages.

Mandy is a four-year-old, failure to thrive, severely cerebral palsied child. She has virtually no expressive language because of severe spasticity of her upper trunk and possibly other neurologic insufficiency. But Mandy has always been very expressive. She likes to be talked to, played with and held but not like an infant. She gets very *spastic* and frowns when she is treated like a younger child. Mandy's facial expressions are varied enough to reveal simple contentment, joy, surprise, fear, confusion, interest, anger, disgust, sadness and frustration. She also pouts quite well when things don't go her way. If one is willing to watch, Mandy can answer a number of questions around feelings, likes, dislikes, and frustrations with appropriate facial expressions.

As every good social worker knows, body language is very important in evaluating communication.



A child's position, body tone and physical proximity to you give many cues.



### Contact is revealing:

- \* avoidance may mean discomfort
- \* staring may reveal anger
- \* following probably reveals interest or curiosity
- \* quick eye movements may indicate distrust

Spasticity - abnormally high muscle tone (stiffness) which is seen as the child extends a joint. He may appear to be locked in an extended position. Children with brain damage and cerebral palsy are often spastic.

Gestures and facial expressions are communication tools. Learn to read them and allow the child some control over his situation by verbalizing them for him.

"It looks like you are quite upset over leaving your foster family, John. Am I right?"



"You look surprised that I know about your seizures! Has anyone ever talked to you about them?"



"When your birth parents gave you up for adoption, you were probably confused. I can tell by your face that you are still really angry about it. Let's talk about that more."



"Go ahead and cry. It's good that you can express your sadness about having to leave your family. It's not going to be easy, but there are some happy times ahead for you."



### 3) Presenting interpretations with choices:

When the child is not giving clear non-verbal body or facial cues or when you are unsure of their meaning, get him to interpret them by giving choices.

"I can't tell if you are mad or sad. Are you mad? Are you sad?"

"It's hard to know how you felt that day. I expect you were a little happy and a little sad. Were you happy that day? Were you sad that day? Or, a little of each?"

OR

How do you feel right now? Point to the right picture:



Sad



Mad

How did you feel when you moved that day? Point to the right picture:



4) Asking questions which can be answered with yes/no:

Yes/No -

Yes/no questions begin with words like "do, does, are, is, will, and can." They require a simple yes, no or appropriate head shake for an answer. They are the first questions children understand.

If a child doesn't seem to understand a question, using pictures in yes/no situations gives him extra clues as pictures resemble the object they represent. ("Do you have brown hair like this girl?") Words are less concrete as they bear no resemblance to the objects, people or activities they symbolize.

The use of "or" increases the demands of the respondent. He now has two or more choices from which to choose. "Is your hair black or brown?" (He can choose from two or more crayons.)

5) "Wh" pointing questions:

"Wh" questions (who, which, what, why, when, where) ask for a lot more information than simple yes/no questions. They require a specific choice be made among a number of options. If those choices can be replicated in some way (drawn - photographed - magazine pictures), the child can point to the choice in answer to a specific question.

Birth Family

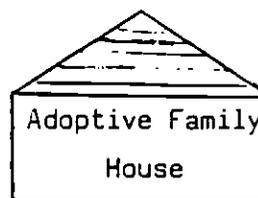
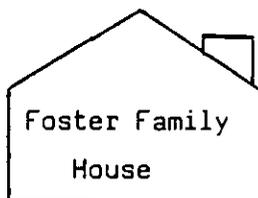
Foster Family

Adoptive Family

Which family is your birth family? Etc. (photos)



How did you feel that day?



Show me where you lived when you were five years old. (photos)



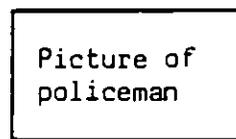
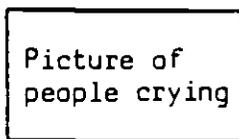
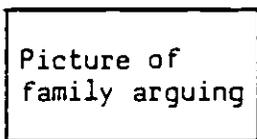
Who is your sister?

or Which one is Judy?



Count Fingers

How old were you when you left your birth family?



etc.

Why did you have to leave your birth family?

6) Drawing:

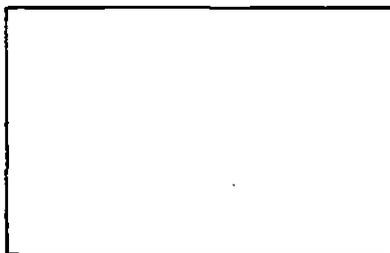
Some children with few verbal skills have artistic talents. They may be able to draw their feelings about their past if given a chance. Many can certainly draw pictures of their self-perceptions.

For those with more limited ability, provide some structure which they complete, having to add the critical dimensions.

- 1) How do you feel when we talk about these things? What does your mouth feel like?



Draw a picture of what you think your birth mother looked like.



### Acting

A child who is fairly bright may be able to "act-out" his feelings as an interpretation of what happened in the past. You must interpret as he is going along. It is tricky business not to obtrude with your own interpretation. It is helpful if you structure the context, such as, "What did you do when you left Mama Alice?" or "How did you feel when you left Papa Ray?"

### Concrete Preparation Ideas:

- \*Three-dimensional things are more concrete than two-dimensional.
- \*Video and audio tapes may be more concrete than static representations such as photos. (The action on the videotape lends life to the visual representation; voices from their past often bring forth humorous memories for a child.)
- \*Pictures are more concrete than drawings or sketches.
- \*Colored pictures are more concrete than black and white ones (real life is in color).
- \*Actions are more concrete than words
- \*Single, key words are more concrete than strings of words (i.e. "Momma Jane" is more concrete than "Jane, your foster mother").

CREDIT: The Importance of Assessment in Placing D.D. Children  
by Sara Brown, Spaulding for Children, P.O. Box 337,  
Chelsea, MI 48118

## Spaulding for Children

Success Factors In Moving Children  
From  
Residential Agencies To Adoption

- 1) The residential agency philosophy views adoption as a desirable alternative for all children without families and develops a program that flows from this conviction. Examples might be regular internal case reviews, inservice training for staff related to dealing with child's past, doing lifebooks, talking with children about family, moving to termination of rights when efforts to rehabilitate birth family fail, etc.
- 2) Residential staff are open with adoption staff in assessment stage of process about the child's strengths and weaknesses, needs and anticipated problem behaviors in family.
- 3) Residential agency staff are active participants in preparing a child for adoption. A variety of models might be used for preparation.
  - the adoption worker/residential worker team the process
  - the residential worker does the preparation with consultation
  - the adoption worker does the preparation with feedback given to residential staff and on modeling the process
- 4) Referrals are made to adoption staff at least three to four months before the termination of placement expected.
- 5) One person is designated from the residential agency to facilitate communication between agencies. This should be a person who has a meaningful relationship with the child and is in a position to communicate the child's needs and status to all residential staff who work with the child. This person has the power and/or influence to make decisions about the child's program.
- 6) When the adoption programming and residential programming goals and methods come into conflict, the adoption program takes precedence.
- 7) The residential facility delegates to the adoption agency the responsibility to select an appropriate family and to prepare the family for the adoption.
- 8) The preparation and moving process including timing of the move is centered on what the child needs to facilitate attachment and bonding to his/her new family. Both agencies have agreed on an appropriate individualized plan and both can be flexible throughout the visitation process to the child.

- 9) Persons who have significance to the child are involved in giving the child permission to move to his/her new family; usually this will be the child care staff.
- 10) Both agencies seek to reinforce the adoptive parents' role as new parents as early in the process as possible. For example, they should be involved in medical/school decisions etc. as soon as they are able to commit to proceed with the placement.
- 11) Conflicts between agency staffs are resolved as close to the line of direct service as possible.
- 12) The child's acting-out behaviors are seen as necessary during the preparation and visiting process. All staff who work with the child are attuned to the ambivalent feelings behind the behaviors and continue to support the child toward placement with his/her new family.
- 13) At least one person close to child on the residential agency staff is very committed to and advocating adoption for the child.

Credit: Judith K. McKenzie  
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## VISITING - ONE STEP IN THE PLACEMENT PROCESS

Taken from: "The Mechanics of Placement" by Kathryn S. Donley, Executive Director, New York Spaulding for Children, 22 West 27th Street, New York, NY 10001

The critical issue in this step is to use the visits for specific, understandable purposes and to learn as much as possible from the child and family after each visit.

The visiting plan can be a major source of conflict during placement. Agencies believe in them, workers are taught to provide them, families comply with them, and children usually survive them. But unless all parties understand what should be happening during visits, it is then futile. There are many reasons why visits are necessary, but most placement negotiations focus on only one--cushioning the child's separation. While that is one legitimate reason for visits to be planned, it is far from the major reason. When families hear it, they are usually willing to accept the idea at face value. After the first visit, this usually changes. ("He wants to stay... she doesn't want to go back... they haven't mentioned their old foster family once...") Once these messages, real or imagined, begin to flow, further visits become an uphill battle. Workers themselves have little grasp of why more visits are necessary. We need to examine the various reasons why visits are important in the placement process.

- 1) to display behavior described or predicted earlier when we presented information on the history and functioning of the child to the family; this is an early opportunity to verify presentation material, connect it to real behavior, and explore the origin of the behavior
- 2) to explain his placement during this, the child's first opportunity to explain who he is and why he is coming to a new family as he encounters other children, new neighbors, the new extended family; his explanation and that of his new family must be brief and truthful; visits offer the opportunity for him to grow comfortable with the explanation
- 3) to begin establishing ground rules since children come to new families with none of the verbal and non-verbal rules of the family available to them; they must learn these things or risk alienating individual members of the family; visits help begin this process, a bit at a time, but offer some relief too in that their return to the old placement gives them some breathing space and graphically demonstrates the difference between old and new ways.
- 4) to analyze responses the worker will need to know how the parties involved are responding to displayed behaviors and new ground rules; the intervals between visits provide time to explore responses of child and family by phone or personal contact; the visits themselves offer workers a fine chance to witness the responses in action
- 5) to adjust the interaction between child and family as there is no earlier opportunity in the placement to begin making necessary changes in the relationship between the participants, to weigh events and consequences, alter expectations, or review information received from actual observation or experience with child/parent interactions

- 6) to cushion the searation as it is important for the child to leave his former placement without a heavy burden of guilt or anxiety; visits help convince him the old family can survive his departure (mourn it, but survive it)
- 7) to assist the disengagement of the child; without help, the child can remain so connected to a previous nurturing figure (parent, relative, or foster parent) that he is unable to form an attachment to a new family; the worker can use the visits to assure the child it is possible to love and remember the previous nurturing figure and yet begin forming bonds with the new family
- 8) to begin making new attachments as each visit marks a shared experience between the child and the new family (including the pain of leaving the old and familiar, the pleasure of returning to the new family once again); the new bond is formed through feelings and experiences shared, expectations and interactions adjusted

Though we might agree on the various reasons just explored as valid arguments for visits to occur, they will be only as effective as the de-briefing efforts which follow each contact. Unless the child, the new family, and the worker understand that visits are designed with specific purposes in mind, they will go through the motions of a visiting sequence with few benefits realized and an opportunity lost to learn more about surviving the early adjustment period. During the visiting step, problem solving is demonstrated which sets the tone for the working relationship which lasts through the adjustment period and well into post placement. It seems reasonable that each visit should include a plan as to what should be attempted and a followup contact as to what occurred. One way to do that might be to develop and use a format similar to the one provided. (not included)

As the worker plans a visiting sequence, the relative age and ability of the child should be of paramount concern. Schoolage children need more visits than pre-school children. Pre-verbal and retarded children are often confused by frequent and abrupt changes in caretakers. Visits between such children and new families should be fewer in number with short intervals between contacts. Visits are usually best initiated in the previous placement setting if at all possible. When the child is familiar with new faces, smells, and touches, he will be able to risk visiting in a new setting without serious distress. Whatever the age or handicapping characteristics of the child, the worker's careful observation and judgment is necessary in determining when the visiting sequence has achieved its purposes and the child is ready to join the new family with an apparent degree of comfort.

Credit: "Visiting - One Step in the Placement Process" taken from The Mechanics of Placement

## HANDOUT

**THINGS TO REMEMBER REGARDING PHYSICALLY HANDICAPPED ADOLESCENTS**

- Adolescence is the time when handicaps take on a new meaning; issues that were "resolved" earlier get reactivated.
- Peer relationships take on new importance and dimension.
- How well individuals will handle the new issues in adolescence will depend to a large extent on how they have been treated and handled earlier.
- Between the ages of 12 and 14 it is imperative to clearly define the handicap with the adolescent:
  - Encourage health care and other involved personnel to define the handicap for the adolescent;
  - Give small bits and pieces of information at a time; don't overwhelm;
  - Be honest and complete;
  - Encourage questions;
  - Do not give false hope;
  - Deal with death honestly within the adolescent's capacity to handle the information;
  - Maximize the assumption of responsibility for self care.
- Give guidance regarding realistic vocational opportunities.
- Remember that handicapped adolescents will mature sexually:
  - Their need for education is great, be sure it is provided at an appropriate age level;
  - Recognize that they have the same physical needs and desires as the non-handicapped;
  - Realize that self control needs to be learned; inappropriate behavior won't go away by being ignored.
- Help parents and caregivers realize that handicapped adolescents are, or will be, sexual beings:
  - Help parents anticipate their fears and reactions to their adolescent's sexual development.

## HANDOUT

## THINGS TO REMEMBER REGARDING PHYSICALLY HANDICAPPED ADOLESCENTS (p.2)

- Common psycho-social adjustment problems include:
  - Denial;
  - Depression;
  - Helplessness (real and/or imagined);
  - Hopelessness;
  - Powerlessness and lack of control (real and/or imagined);
  - Poor or inadequate self image;
  - Shame;
  - Tendency to view self as handicapped first and as individual second;
  - Excessive self consciousness;
  - Lack of peer relationships;
  - Isolation (real and imagined);
  - Teasing;
  - Financial problems;
  - Lack of self control (real and manipulative);
  - Tendency to use the handicap to elicit sympathy, avoid responsibility, punish others and/or manipulate those around them;
  - Reluctance to grow up and assume whatever responsibility for self that is possible.

Credit: by Gwendolyn Murphy, Foster Care of the Developmentally Disabled: A Basic Course for Foster Parents and Foster Care Workers. Boston, MA: Boston University School of Social Work, 1975.

# Understanding the Past, Building the Future

By Rita Dushman Rich

When you give birth to a baby, you help to shape that baby's life from its very beginning. When you adopt an older child, you become the parent of a person whose life has already been molded by different hands—parents, guardians, caretakers before you. Their influence is as much a part of that child's life as anything you will provide.

When an older child becomes available for adoption, it is usually safe to assume her life has not been entirely happy. She may have known abuse or neglect or the uncertainty of foster care. It is easy for adoptive parents to assume the child wishes to forget about her past. But the past is as real to the child as anything her new parents can give her.

Tammy was nine-years old when we adopted her, but her life had been shaped by influences that began before her birth. Something happened in her mother's womb that changed the shape and features of her face—she was born with no nose, a misshapen mouth, and tiny, incompletely formed eyes that left her blind.

The doctors took the easy way out in dealing with her. She was labelled profoundly retarded and institutionalized. With the deprivations she suffered, it took several years for her to prove to those around her that her intelligence was perfectly normal.

To us, Tammy's life in the institution seemed intolerable. How could anyone bear such a limited existence? Although she had never been abused and her basic needs for food, shelter and medical care had been provided, she had no family to love her, no freedom to grow and develop. It was natural to imagine that her life in the institution was Purgatory and that adoption marked entrance into Paradise.

From Tammy's viewpoint, things looked different. She was excited about the adoption—Tammy has always approached any new situation with eagerness and curiosity—but she did not see it as a release from prison. To her, life in the institution was normal. She never questioned the rationale for being there. She knew nothing of things she was denied. It was her old home and she carried with her the same sentimental attachment most people felt for their homes.

In some ways the institution seemed to me like a rival for Tammy's affection. We wanted her to forget it, to love only us, but we knew we could not expect that to happen. We also knew that to belittle or demean the institution to Tammy would be like belittling a child's parents. The institution had helped shape the first nine years of Tammy's life. If we could not accept its contributions, were we truly accepting Tammy?

Tammy's blindness and physical abnormality were a part of her too, and we had to learn to accept them.

I have heard a parent say with pride, "I have never accepted my child's handicap." It is as if acceptance signifies acknowledgement that the child will never learn, will never progress, will always be a "victim" of her handicap.

It doesn't work that way. Accepting your child as she is, acknowledging her limitations as well as her strengths, and most of all letting her know that you accept her for what she is, is the only way to allow her to grow into the best person she can be.

Tammy first had to learn to accept herself. She was not born with the knowledge that she was different from the rest of the world and, unlike most blind children, she lacked interaction with normal people that would help her recognize her differences. In the world in which she lived she was surrounded by handicapped children, most of whom were far more severely handicapped than she. To Tammy, the world was made up of people who could not walk or talk or hear or see.

We had to help Tammy learn to accept her blindness and to understand that it is only one aspect of her being.

In the beginning, we were not really certain of how much understanding Tammy possessed. She would flip the pages of a children's book, making up a story as she went along and telling us that she was "reading." Was this denial, and a sign of refusing to accept her blindness, or was it the ordinary sort of pretending that young children

do? Certainly our other daughter Aviva had pretended to read books at an age when she had barely mastered the alphabet. I had not considered that a sign of maladjustment. Did Tammy's blindness alter the situation or was I being overly concerned?

I support it is impossible for a person, blind from birth, to ever fully understand what vision is. When Tammy told me that she could see her book, I was never sure if she was pretending in the normal make-believe way in which a child exercises her imagination, or if she was honestly trying to convince me she wasn't blind. Hardest to deal with was the possibility that she truly believed she was seeing it. She knew the book was there and that somehow or other there were words in it, and she did not understand that we could perceive it in more ways than she was able to. If you have never seen, how can you know what it is to know the world through vision?

We decided to treat Tammy's pretend reading as just that—pretend. She would sit and "read" to us from a book and I would say, "It's fun pretending to read, isn't it?" If it is just childish make-believe, I want her to know it's okay. If it is an attempt to convince me she can see, I want her to know I don't believe it.

The rules that govern vision seem so obvious to those of us who can see. We know we cannot see through walls or around corners, that we cannot see without light, that we have limits to distances we can see. A blind child does not have that understanding and has to be taught.

We talk to Tammy about what we see and try to make the connection between the visual knowledge we receive and the tactile or auditory knowledge she understands. When she puts on clothing with a raised pattern, I say, "I can see the stripes on your bathing suit; can you feel them?" She talks about the "bumps" on her seersucker dress, and I tell her that I can see them as stripes, some white and some blue.

Like most modern children, Tammy is fascinated by cars. She loves to ride in them and would occasionally make statements like, "When I'm sixteen, I'm going to get my driver's license." My husband Harry and I were concerned that people in the past had encouraged, or at best ignored, these dreams. We felt we had to tell Tammy the truth.

The thought of not being able to drive was a major blow for her. At last she denied her vision was that bad. With repeated explanations she came to accept the truth. Her concern became, "How will I go out to eat?"

Now was the time for practical advice. She would have to learn to use buses and taxis, we told her. I was able to provide her with the example of my parents, long-time city dwellers who do not own a car. They use buses and subways to get to work, restaurants, movies and friends' houses, and Tammy will have to learn to do the same.

We talk to Tammy about blind people we know or know about, to help her understand there are many avenues open for her in the future. Some careers may be out of the question—she will never be an airline pilot—but there are many fields in which blindness is not an impossible obstacle.

Tammy slowly began to acknowledge she has some special needs. We started hearing questions like, "Can blind people be teachers?" and "Can blind people be doctors?" Tammy's growing awareness of her differences was made clear to me the day she asked, "Can blind people have babies?" As we answer each question for her, she learns not only the ways in which she differs from other people, but more importantly, the things she has in common with them.

In teaching Tammy to accept her blindness we came to accept it too. In some ways the blindness has been easier to deal with than the deformity.

Our society places so much stress on the way people look; we can tolerate many differences in the way people act as long as they don't look too funny. The "funny looking" become our clowns or freaks or monsters. The handicapped person who is "normal" looking stands a much better chance of being accepted by the people around him than the deformed.

I can recall in my own childhood, hearing inspirational tales of Helen Keller and other handicapped people. Blindness took on a special aura for me; there was something fascinating about blind people.

As a teenager, I fantasized about my future family. I felt sure I could handle a blind or deaf or retarded child should I ever have one. But what about a deformed child?

I was still in my teens when the thalidomide babies made the news. Children with missing arms and legs, children with seal-like flippers—could anyone feel maternal toward "monsters" like these? It did not seem possible.

Now, here I was, adopting a child whom most people would regard as a freak. "She's cute," someone once said of Tammy, "if you're big on Star Trek." "The girl without a face" was a description given by one child. What were we letting ourselves in for?

With a child like Tammy, you always stand out in a crowd. People do double-takes—"Did I really see that?" People stare. Someone who cannot stand being conspicuous should certainly not adopt a visibly deformed child.

I may be taking credit for more psychic powers than I possess, but I feel that in most cases I can read the intent behind the response and act accordingly. A double-take is natural. But if that is all an onlooker does before moving on, I don't let it bother me at all.

Staring is a different matter. A prolonged stare can be very unnerving and uncomfortable. From children, I can tolerate it. No matter how parents try to instill manners in their children, they cannot cover every situation. How many parents would think of training their children in how to respond when they see a person who does not have a nose?

From adults, I expect better self-control. In general, I have not been disappointed. On only two or three occasions since we have had Tammy with us have any adults persisted in staring longer than a few seconds. On those occasions, I have taken pleasure in staring them down, watching them blush and avert their eyes as I stare unashamedly into their faces.

I admit I am thankful Tammy cannot see the stares. Of course, on occasion things are said to her by other children. The young children who have come up to Tammy and said, "Where's your nose?" or "What happened to you?" have asked their questions out of interest, not cruelty. We have taught Tammy to treat their questions as simple quests for information, as I assume they are, and to answer, "I was born this way." That answer is accepted without further questioning.

At one time, prior to adoption, Tammy was fitted with a prosthetic nose. It was a small piece of plastic shaped like a nose and glued to her face and supported by eyeglasses. It looked terrible, felt uncomfortable, and was quickly relegated to its carrying case. Shortly afterward, a curious little girl asked Tammy, "Where's your nose?" Tammy replied, "Up in my closet." There is nothing like simple honesty.

We have tried to teach Tammy that her handicap is simply a fact of life; it does not make her better or worse than anyone else. We continually show her we believe this to be true. We only hope the rest of the world will catch on.

Credit: "Understanding the Past, Building the Future" from Adopting Children With Special Needs: A Sequel  
Linda Dunn, Editor 1983, published by North American Council on Adoptable Children, Inc.

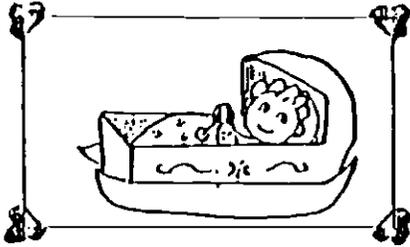
# A Story About MARIE

This story was written with a  
12-year-old, trainably mentally  
impaired girl during the Life-  
book process.

By:  
Sara Brown  
Spaulding for Children  
1966

## A STORY ABOUT MARIE

Everybody starts life as a baby. No matter who they are or what they grow up to be, they were once a baby just like you.



THIS IS A PICTURE OF YOU AS A BABY

Babies are alike in many ways:

- They are all soft and cuddly.
- They all need milk and clean diapers.
- They all need love.

Some babies look and act real different from other babies:

- They cry a lot.
- They don't move much.
- They are sick a lot.
- They don't smile.
- They look different.

You looked and acted different from other babies when you were young. Your mom and dad worried about you. They looked for doctors who could tell them why you looked and acted differently. Some doctors said they knew why. They said:

"Marie may not grow very tall, and she looks real different. She is mentally retarded."

This was all very hard for your birth parents. They did not know what mental retardation means. They were very sad and upset. They argued a lot. They took you to other doctors to be sure. You could see them worry and that made you upset. Sometimes you would run away and hide.

We know something your mom and dad did not know. We know that mental retardation is not a bad thing. We know retarded people can learn to do a lot of things. They are much the same as other people. Some things are harder to learn, but retarded people can learn them.

The doctors were partly right and partly wrong. Are you short? No. Do you look real different? No. Are you retarded? Yes, you are. We know you can do a lot of things. Name some things you can do:

- Write my name
- Learn to read
- Take care of myself
- Help in the kitchen
- Take care of babies
- Make a scrapbook
- Draw

MARIE

Some things are more difficult like:

- Riding a bike
- Swimming
- Reading

That's why you're in a special classroom.



Your birth parents did not know you could learn to do all these things. They could not understand your retardation so they went to a social worker for help. The social worker said: "We will find a family who can understand and help Marie."

It took a while to find that family. Sometimes you thought you would never have a family of your own. But now you do!

SOMETIMES YOU ARE HAPPY  
and  
SOMETIMES YOU ARE SAD

But it's nice to have a family who understands.



The Application of Permanency Planning to Developmental Disabilities

by Yvonda Martin

When discussing permanency planning, it is necessary to separate out children with developmental disabilities from other children. One of the primary reasons for a separate emphasis is that having a child with developmental disabilities in a family impacts the family dynamics in ways that cannot be compared to families whose membership does not include such a child. These families encounter, from the beginning, an increased level of financial, emotional, and physical stress.

Another reason for the separate emphasis lies with child welfare workers. Historically, they have had little experience or training in developmental disabilities. They often have no awareness of the complexity of needs that confront the families of these children, and therefore, cannot adequately address the issue of permanency planning. Additionally, child welfare workers begin working on the case only after the child has been placed in foster care. Permanent planning for children with developmental disabilities however, must begin before the child is placed if family ties are to be maintained.

Furthermore, child welfare workers unfamiliarity with developmental disabilities has also affected their attitude toward adoption for these children. Traditionally, case workers viewed healthy anglo infants as the only category of children desired by parents. Fortunately, those attitudes are changing and child welfare workers are now beginning to see children with developmental disabilities as "adoptable."

Finally, service providers in the field of developmental disabilities, rarely cite permanent family ties as a goal of their services. Only recently have professionals in this field begun to consider seriously the provision of supportive services to families to prevent their child from entering into substitute care. Professionals in the field have little or no awareness of the philosophy and practice of permanency planning and, as yet, have not incorporated it into their work with these children and their families. As with child welfare workers, developmental disabilities specialists have not considered adoption as a placement option for children who are placed out of the home.

Knowing such facts, permanency planning for these children clearly becomes an issue of concern, not just for the child welfare worker, but also for the wide range of service providers in the developmental disabilities field. These include teachers, social workers, casemanagers, advocates, and parents.

There are a number of factors which have contributed to the present attitudes and status regarding permanency planning for children with developmental disabilities. This country has a long history of institutionalizing individuals with developmental disabilities. Parents of these children are regularly counseled by professionals to place their children in institutions. Institutions are accepted by the general public as the appropriate "home" for these individuals. Recent efforts to deinstitutionalize residents at large state institutions have influenced attitudes and practices of service providers regarding out-of-home placement alternatives. However, little change has taken place in efforts to prevent placement. The unspoken message is that it is still acceptable to place a child with developmental disabilities out of the home.

Perhaps most importantly, the goal of permanent family ties for children with developmental disabilities has not been actively pursued by service delivery systems because of the nature of the child/family separation. When these children are placed out of the home, it is often at the parents' request. These voluntary placements usually result from an accumulation of family needs that are not addressed through the service delivery system. Often, everyday family stresses are exacerbated by the additional needs of the child. When the family asks for assistance, out-of-home placement for the child, rather than the provision of services to the family, is seen as a solution. Such placements are naturally painful to both the child and the family. The sensitive nature of these placements has contributed to the way professionals view, and subsequently, execute such placements. The assumption is made that if the biological family cannot function adequately with their child who is developmentally disabled, then no family can function with this child. The unspoken result of such thinking is that the child is judged as unable to participate in or undeserving of permanent family life. Consequently, conscious planning to ensure permanent family ties for the child does not become part of the services offered to families at the time of placement.

Hence, when a child with developmental disabilities is voluntarily placed out of the home, case workers and developmental disability workers often view institutional placement or group home placement as the goal. This curriculum advocates instead, that permanent family ties be the goal.

Credit: Reprinted from Look to Families; a Curriculum on Permanency Planning for Children with Developmental Disabilities, 1984

Unit 1: DIRECT SERVICES  
 Module 2: DECISION-MAKING

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DILEMMA OR DECISION: CRITERIA USED IN  
 PERMANENT PLANNING CASES

If there is one aspect of permanent planning casework which distinguishes it from more traditional activity in the area of foster care and adoption, it is probably the attention devoted to active decision-making about the best placement for the child, and the compression of decision-making points into a relatively short period of time. The necessity of making decisions may be forced by a crisis or sudden change in circumstances, or may result from a regularly scheduled judicial or agency review. Generally, the most difficult of these decisions address one of these questions:

- Should the child enter care?
- Should the child in care return home?
- Should release for adoption be pursued, either through a relinquishment or termination of parental rights?
- Which is the best adoptive family or other alternative permanent family for the child who cannot return home?

Most frequently, a decision around such questions is not simple or straightforward. Rather, as Kermit Wiltse pointed out in an address to the Third National Permanent Planning Conference, it is likely to be a dilemma -- a choice between alternatives, neither of which is entirely satisfactory.<sup>1</sup> Caseworkers and supervisors who frequently have to face such dilemmas often share this responsibility among themselves by making decisions as a group. They also examine the details of a case against several standards or criteria, each of which constitutes a slightly different way of looking at the situation. The remainder of this paper will examine three of these criteria. These are:

- minimum sufficient level;
- rights of the child vs. rights of the parents; and
- least detrimental alternative.

Minimum Sufficient Level

The "minimum sufficient level" of care necessary for a child's growth and development is a social standard, a minimum of parental behavior. Instances

where parenting falls below this standard justify state intervention. The following discussion, taken from Permanent Planning for Children in Foster Care: A Handbook for Social Workers, explains this concept and its application:

The minimum sufficient level is the point below which a home is inadequate for the care of a particular child. This standard implies that the child needs a certain amount of physical and emotional nurturing. Without it, the child is deprived of the care he needs to reach satisfactory adulthood.

Such a judgment is necessarily relative. There are no fixed criteria; whether or not a home falls below a minimum sufficient level must be decided by informed judgment, which evaluates a particular home as a suitable placement for the child who may return there. To some extent, the minimum sufficient level is set by local, current, community standards. Acceptable standards in one part of the country regarding, for instance, child supervision or corporal punishment, may not be acceptable in another.

A useful way to approach this judgment is to ask yourself, "If the child were returned home tomorrow, would I have concern for the child's welfare?" If so, try to identify the principal cause for concern. Would the child's nutrition, health and physical safety be neglected? Would he be left inadequately supervised for periods of time? Do you have reason to think he might be physically abused? Or could the child be emotionally neglected?

Note that the emphasis is on the care of a particular child. A child with emotional or physical handicaps may have extraordinary needs and require a different level of care than does a child without these handicaps. The age of the child may also enter into a determination of the level of care necessary. Workers with adolescents in their caseloads seek to evaluate the child's level of functioning, as well as that of the parent. A teenager who is largely able to care for himself may be able to return to a home considered marginal for a younger, more dependent child.

It is also important to realize that this standard is intended as a minimum, not an ideal. The courts and the agency do not have the right to require parents to meet some ideal in terms of child raising, but only to require that there be no real danger to the child. Attempts to restore a child to the family should not be confused with efforts to elevate the parental behavior to some level "far beyond that minimally necessary to secure a child's well being."<sup>2</sup> Wiltse points out that this standard may become increasingly useful as we are able to relate it to expanded scientific understanding of specific harms. As we learn more about the child's specific needs — in terms of nutrition, for example, we will be able to move away from indictments of parental behavior which are loaded with moral judgments.

### Rights of the Child vs. Rights of the Parents

The right of parents to raise their own children according to their own norms and customs has long been recognized. That children also have rights is an idea of more recent origin. Initially, these rights were stated in terms of the right to protection from specific harms — child labor laws and statutes prohibiting child abuse and neglect are examples. More recently, some have begun to claim that the child has rights beyond protection from harm — specifically the right to a continuity of relationship, to live with a family he can regard as his own. This claim raises questions about where the child's strongest attachments lie, whom he sees as his parents. The child's right to a permanent home, then, must be balanced with the parents' rights and wishes, and this information becomes important data in determining where the child should be placed.

### The Least Detrimental Alternative

Finally, and most in keeping with the notion of dilemma, the choices among those possible can be examined to determine which alternative will be the least detrimental to the child. Due consideration should be granted to the biological parents, and to foster parents, relatives, and others who may be involved, but the primary focus of the decision is to provide a good placement for the child. By recognizing that there is not one best plan for the child and everyone else involved, workers and supervisors can approach the decision realistically, and face it as the dilemma it is.

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HOME BASED CARE: DIRECTION FOR THE 80S

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PREPLACEMENT PREVENTION AND FAMILY REUNIFICATION  
DIRECTION FOR THE 80'S

More than a decade ago the Joint Commission on Mental Health of Children noted that this nation, which looks to the family to nurture its young, gives no real help with child rearing until a child is badly disturbed or disruptive to the community. The commission warned that the family cannot be allowed to withstand alone the enormous pressures of an increasingly technological world.<sup>1</sup> Long before the commission called our attention to the neglect of our primary social welfare institution, the family, others had pointed to the need to direct our resources not to the replacement of the family, but to its support and maintenance.<sup>2</sup> Perhaps the major impetus in this regard has come from the awareness that in order to protect children, we must protect their families.

Beginning with the St. Paul Family Centered Project in the 50's, home based family centered service programs began to emerge.<sup>3</sup> By 1970 researchers had raised profound issues about the extensive use of substitute care as a means of managing children.<sup>4</sup> During the 70's several important studies and surveys were publicized and politicized.<sup>5</sup> The public became the judge and the ensuing decade witnessed the development of numerous home based family centered service programs as alternatives to out of home placement.<sup>6</sup> These programs have reported relatively high service success rates at costs significantly lower than foster home and institutional care.<sup>7</sup> At the same time, the social and psychological risks of placement are avoided.

Fundamentals of the Home Based Family Centered Approach

Home based family centered service is sometimes erroneously equated with partial services which usually focus on an individual; casework with children who live at home, homemaker

services, day care, and other traditional partial services supportive to the family. These important programs are adequate for many families. Indeed, one or more may be a component of home based family centered service as described below. However these familiar services are often insufficient for many families whose problems are severe enough to prompt consideration for out-of-home placement.

The decision to place a family member outside his/her home is a monumental one which should be made only with the greatest of care and deliberation. Placement damages whatever continuity the child has experienced and introduces new emotional risks. The awesome responsibility for such decisions too often falls to those least qualified to decide and made without due regard for the power of family attachments:

Variations in HBFC programs reflect the objectives and needs of the community served. Variables include differing staffing patterns, intensity of service and staff availability, type and quantity of training and experience of staff, population served, and program objectives. The HBFC worker who is in the home most every day and whose unique position and relationship with the family is key, makes service coordination (usually more myth than reality) possible. Efficient and accurate assessment is possible and service is appropriate to needs.

Those programs which are appropriately utilized as alternatives to substitute care are characterized as follows:

1. A primary worker or case manager establishes and maintains a nurturing, supportive relationship with the family.
2. Small caseloads, staff availability and the utilization of a wide variety of helping options.
3. One or more associates serve as team members or provide backup for the daily worker and may meet regularly with the worker and the family.
4. Staff availability twenty-four hours a day, seven days a week, often serving as extended family.
5. The family home is the service setting, and includes

problem solving efforts in the family's ecological system. This may involve the school, police, employers, housing authorities, etc.

6. Service is as complete, comprehensive, and intensive as is necessary to effect problem resolution.
7. Maximum utilization of family resources, extended family, and community. Workers quickly discover and build on strengths in families, even the most problematic families.
8. Provision of help with any problem presented. If the team does not have the expertise or resources needed, it arranges for or creates them in order to stabilize and improve family functioning.
9. The parent remains in charge of his/her family, as educator, nurturer, and primary care provider. Parents are often given renewed relevance and participate in setting program priorities, planning, and decision making.

Home based family centered service programs reflect the principle that the first and greatest investment should be made in the care and treatment of children and their families in their own homes. Funds, personnel, and other resources are expended, not on one family member in placement, but on the family unit.

#### Advantages of Home Based Family Centered Service

It is estimated that the majority of children most in need of services are not reached by in-office approaches. HBFC care surmounts the professional distance barrier. The availability and consistency of the worker tend to overcome fear and mistrust. In-home workers gain firsthand experience with the realities of the family and its environment and struggles. Previously unknown problems of basic needs, family relationships and community pressures often emerge and errors in assessment tend to self-correct.

Families' strengths are most obvious in their own homes. Workers are able to utilize techniques which are realistically appropriate to needs. Many of the more effective educational

and therapy techniques, impossible to apply with once or twice a week contacts in the office, become applicable. The pattern in child welfare has been to move from minimal, once or twice a week contact, to total care (placement). The HBFC approach reverses this practice by filling the gap between minimal service and total takeover.

Parents often need more than a set of verbal directions about what they must do to continue caring for, or to get their child(ren) returned to their care. Learning styles differ! Not all learn by auditory instruction. And new patterns of behavior cannot realistically be expected to become permanent without practice. The HBFC program provides a planned, sequenced program which may include didactic teaching, modeling, coaching, counseling, rehearsing, encouraging, etc. The team focuses on the most pressing problem in the present context and attempts to make a difference for the family early in the program.

The HBFC approach provides the protective service worker and the judge with a more safe and comfortable option for many families. Immediate and intensive crisis intervention is extended. Close monitoring may prevent the placement reflex. If placement does become necessary it can include the family in the decision-making, planning, placement, and consideration for return, for permanent placement, or adoption. HBFCS minimizes the length of time spent in foster care and increases the chances for successful return home for children who have been in substitute care for an excessive period and have failed to adjust.<sup>8</sup>

#### Applications of HBFCS

HBFCS is the model of service most logical in efforts to reunify families. Special applications of HBFCS to family reunification include the following:

1. The accepting nurture and support which may be necessary for some parents to gain the hope and confidence to sustain effort and motivation in highly threatening circumstances.
2. The time, resources, and commitment necessary to initiate and support a therapeutic partnership between foster parents and biological parents when this is possible and appropriate.
3. The time and investment to facilitate, plan, and monitor increasingly frequent home visits by the child, leading up to reunification or alternative permanent plans.
4. When a child returns home from having been in substitute care, the adjustment period is crucial. The intensive nature of HBFCs provides for monitoring of difficulties and immediate intervention which facilitate adjustment.
5. HBFCs gives parents all the support and service necessary for them to resume care of their children.

HBFCs addresses the recent findings that over half of the children in foster home care received no services at home prior to placement.<sup>9</sup> The approach has proven effective with families at risk of out-of-home placement. These include the following:

1. Status offenders and minors adjudicated delinquent.
2. Both prevention and treatment of children at risk of abuse and neglect.
3. Multiproblem families.
4. Families of emotionally disturbed children or parents.
5. Families of adolescents in conflict with family and community.<sup>10</sup>

#### Implications for Minorities

Minority children and youth make up a percentage of those in substitute care disproportionate to their numbers in the general population. Blacks constitute about 13.6 percent of the total youth population but they account for thirty-six percent of those in placement.<sup>11</sup> Hispanic children are disproportionately represented in institutions for neglected and dependent children.<sup>12</sup> Asian-American families bring values unique to their culture which call for a HBFCs approach.

The cultural bias which has resulted in the placement of large numbers of children and youth from minority families has been particularly destructive for American Indian families. Twenty five percent of American Indian children are not living with their families and many of those are living in non-Indian homes with no access to their tribal homes and relationships.<sup>13</sup> HBFCs relates more realistically to the practical issues, needs and strengths of these families.

Traditional methods of service delivery have been ineffective for many minority families. Some HBFCs programs serve primarily minority families. The importance of culture in child development has too often been ignored. HBFCs programs recognize and build on the meaning and importance of biological, social, psychological, economic, and geographical components of relational systems.

#### Summary and Implications

High quality foster home and institutional care continues to be important as alternatives for many families. But a balanced child welfare system should include realistic options for families experiencing difficulty and the threat of placement of one or more members. We can give children the permanency of environment, continuity of relationships, and the security they need by giving them their families. Speaking at the First National Symposium on Home Based Family Centered Service in 1978, Gertrude Hoffman summarized the task before us:

The inherent integrity of the family as the primary care system must be at the core of any kind of social policy development, and there must be built-in safeguards against harm to that system. That we are dangerously close to aiding in the destruction of family life, because of archaic ideas about family responsibility, individual ability to be self-sustaining, and family relationships, gives rise to the question:

- 7 -

How do we strike down the barriers  
to comprehensive service delivery where  
and when they are needed.

Seasoned child welfare workers, professors and policy makers--many ask where HBFCS fits in the "continuity of care." To answer this question we must first ask and answer one which has been overlooked: Where does the family fit in the continuity of care? We must review our mission in the context of new knowledge. Professionals, policy makers, and the general public must scrutinize programs eager to bypass and replace the family. Activities which have earned us the dubious title of "child savers" must be reviewed. Programs which focus primarily on one family member at the expense of the rest of the family; those which revolve conveniently around a collective of professionals and one family member isolated from the family's daily reality; these traditional approaches which have often at best failed and at worst, have perpetrated damage, must be more closely monitored if we are to succeed in diverting scarce resources to the support, nurture, and maintenance of families.

Finally, the 1980 Adoption Assistance and Child Welfare Act (PL 96:272) may provide fiscal incentive for the continued development and expansion of the HBFCS approach. This remains to be seen, however, as there are indications that federal guidelines for states to qualify for new IVB funds may simply call for more of the traditional, partial, minimal, fragmented services to deeply troubled families who need far more. Any serious effort at preplacement prevention and family reunification must begin with the HBFCS approach as it has been developed during the past three decades.

The home based family centered model of service delivery to troubled children and their families offers public and private child welfare and family service agencies a farsighted, compelling challenge to move forward in the development and extension of effective, efficient and humane child welfare services.

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## ETHNIC CONSIDERATIONS IN PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

Because we live in a pluralistic society, composed of many ethnic and national groups, professionals providing services to families whose membership includes a child with developmental disabilities can expect to have some ethnic minority families on their case loads. Among the myriad skills a professional service provider needs, in order to work effectively with those families, is the skill of cultural awareness.

To be culturally aware is to recognize differences, from one group of people to another, in their values, beliefs, religion, language, kinship patterns, family structure, and sense of identity. Such differences must be taken into account when the service provider assesses the strengths and needs of a family; at the same time, these differences will be reflected in the manner in which the family responds both to the disability and to the outside agencies interacting with the family around the disability.

When building cultural awareness, it is helpful to think of the minority family in terms of a continuum, with life patterns ranging from very traditional (ethnically) to very anglicized, with many gradations in between the two extremes. By considering various cultural traits, the service provider will be able to see where the family falls on the continuum. Language, for example, can be an indicator of how acculturated the family is. What language is spoken in the home? Are family members bilingual? The degree of ethnic identity, i.e. how closely the family is aligned with traditional behavior patterns and beliefs, would be another sign of the family's acculturation.

Of course, certain generic social conditions must also be considered when assessing ethnic differences. These conditions cut across ethnic boundaries, and are applicable to all people in our society: regional differences, socioeconomic status, and rural or urban settings. A minority family living in a densely populated urban setting may have more in common with the people of that particular city than with a rural family from the same ethnic background. Similarly, economic constraints create comparable behavior patterns among families of vastly different cultural backgrounds.

Complicating the situation is the fact that our society is made up of one dominant majority group and many minority groups. There currently exists, between the majority group and the minority groups, feelings of misunderstanding, intolerance, suspicion, and anger. When a minority family interacts with a service provider of the majority group (whose role is defined by the authority of the dominant culture), or vice versa, both the family and the worker must deal with preconceived notions, past experiences, and cultural stereotyping of the group that each represents.

The three minority populations that service providers will

(statistically) work with most frequently are Black, Hispanic, and native American. Asian families may also be represented, depending on the region being served. Each of these populations has a unique culture; each culture has many distinct groups. Just as there are major differences between the life patterns of a Navajo family and a Sioux family, so are there cultural differences between a family from Mexico and a family from Puerto Rico.

Westerners are often unaware of the strong cultural differences between Asian groups. A service provider may have the opportunity to work with a Chinese, Korean, Vietnamese, Japanese, Laotian, Hmong, or Cambodian family, each of which comes from a different culture, with many sub-cultural variations. To establish an effective relationship with the family, the service provider should take the time to learn the cultural nuances of the family with whom he/she is working.

As a service provider works with an ethnic minority family to develop a permanent plan for a child with developmental disabilities, there are a number of factors of which he/she needs to have a clear understanding. The first is family structure. Whether the family is considering voluntary placement of the child, requires services to keep the child at home, or wishes to adopt a child with developmental disabilities, the structure of that family will play a major role in how well the permanent plan succeeds. (The following brief overviews of family structure are obviously superficial; a service provider working with a minority family is urged to learn all he/she can of the particular family structure system of which his/her client family is a part.)

Within the Black family, kinship ties are strong, and relatives are important. The concept of kinship is broadly extended beyond blood ties. Relatives and kin feel responsibility for each other, and share significant events. Children are raised within a milieu of kinship; child rearing responsibilities are shifted and shared between generations and kin. Supporting and supplementing the Black family is a broad system of social networks, with economic reciprocity used by lower-income families to stabilize their financial situation (Stack, 1974).

According to Padilla (1975), the Hispanic family, with its extended family structure, is a strong viable institution. His survey of three southern California towns supports generalizations about the Mexican American extended family having many relatives living nearby, visiting frequently, and helping each other in times of need. Services and goods are exchanged regularly by relatives; the extended family is a natural and ongoing support system. "Unattached" babies and children are often absorbed by the extended family; thus, the concept of adoption is considered foreign by many Hispanic families.

The native American family, too, is supported by an extended family structure. Designation of kin varies from tribe to tribe. Additional support for the native American family comes from the clan and tribal structure. In general, native American values are based on sharing,

cooperation, and group caring; the concept of "open adoption" has been practiced for many generations by the small communities of tribes.

Another factor that the worker needs to explore when working with an ethnic minority family is that of family roles, and how those roles function in the dominant cultural setting. For example, the person who acts as family spokesman will vary. Traditionally, the father in a Hispanic family is head of the household, the protector of wife and children, and the spokesman. Any planning and decision making must involve the father. In a Black family, however, the role of interacting with the institutions of the majority group is often assumed by the mother. In some extended family situations, outsiders may be referred to an elder of the family for information and decisions. The worker with cultural awareness will be sensitive to the roles of the family members, and how those roles mesh with the outside world.

Related to the above aspects of ethnic families is the factor of access to resources by the family. This is especially important when developing a family permanent plan for a child with developmental disabilities. Most minority families have, out of necessity, developed skills in functioning with less money than a middle class family considers necessary. Through their support networks of kin, through the practice of reciprocal exchange of goods, services and money, and through the establishing of goals and values that are not contingent upon large incomes, minority families have been creative in meeting the needs of their children.

The service provider will also want to examine with the family their personal and ethnic attitudes toward developmental disabilities. These attitudes will vary with the background of the family, and cannot safely be assumed or generalized by the worker. Rural versus urban experience, socio-economic experience, degree of acculturation to this culture, and previous cultural experiences are all factors that will color these attitudes. It should be kept in mind by the worker that attitudes toward developmental disabilities vary tremendously in the United States, even within the dominant culture, and one can never anticipate what attitudes a family will hold.

A discussion of permanency planning for children with developmental disabilities and ethnic minority families would not be complete without taking up the issue of cross-cultural placement. This is a difficult issue which confronts any agency dealing with out-of-home placement. According to Hegar and Rodriguez (1982:47), "While ethnic matching of child and family was once the norm, many agencies began to make cross-cultural placements in the 1960's, if not earlier. At that time, ethnic matching was viewed by some as akin to segregation and discrimination, things most social workers were reluctant to countenance. Foster and adoptive parents sometimes saw accepting a minority child as a way to help end racism."

Minority members, however, view cross-cultural placements as a racist practice, with implications that a child would be best served when raised

by a white family. They argue that minority children need ethnic identity and upbringing to prepare them to deal with societal racism. Current child placement theory acknowledges that placements of Black, native American, Hispanic, and Asian children, whether adoptive or foster care, should be within their own cultures. This means that agencies will have to revise their standards and definitions of viable families, and alter their recruitment and application practices to encourage minority families to participate in caring for out-of-home placements. Service providers need to be aware of state and federal laws that pertain to this issue. For example, the Indian Child Welfare Act of 1978 provides for tribal involvement when placing a native American child out-of-home.

In summary, a service provider working with an ethnic minority family in developing a permanent plan for a child with developmental disabilities needs to have the skill of cultural awareness. It should be remembered that there is diversity among the families within a culture, and assessment of a minority family requires recognizing the diversity as well as the cultural context from which the family operates.

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# *Shawntell and Tanya*

## A STORY OF FRIENDSHIP

by Jeffrey and Cindy Strully

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*We must all work towards  
having all children live,  
learn, and play together.*

---

*Parents of children with disabilities wonder whether their children can be participants in the everyday experiences of other children. Jeffrey and Cindy Strully portray their daughter's "special friendship." This friendship began as a part of a school's efforts to provide "mainstream" experience for all children.*

**T**his is a story of friendship between two girls who care about each other very much. The children view each other as important people, and see themselves as a part of one another's lives. What makes this story a little different is that one of the children has developmental special needs. We need to start realizing that children who are "typical" and those with special needs *do* want to share their lives in bonds of friendship with one another.

### **Shawntell**

Our daughter, Shawntell, is almost twelve years old. She is a beautiful young lady who enjoys

swimming, playing video games, watching movies, listening to records, watching television, and playing with her friends.

Shawntell also happens to be disabled. She has learned many new skills over the last few years. She is now able to walk for short distances with no external supports. Shawntell has a small vocabulary that includes, "yes," "no," "daddy," and "hi," and she also makes her needs known through body language.

For the last five years, Shawntell has attended the local, neighborhood elementary school. She has spent part of her time in a class for children with severe and profound challenges in learning. Shawntell has also spent part of the day with "normal" children learning skills that will help her to live and participate in the local community. Shawntell is a very friendly child who enjoys life and the people with whom she comes in contact.

Of course, Shawntell has her mom and dad who care about her and love her very much. She also has a brother and sister who feel the same way. In addition to her family, we hope that she has a circle of people who will be there to help her, love her, and assist her to participate in the community throughout her life. We hope that people will want to be involved with Shawntell because they care about her. We do not want professional human

service workers to be the only relationships that she has.

### Forming Friendships

It is sad to see people with or without developmental special needs who have no friends or family to care about them except those who are paid to perform that work. Have you ever thought about what your life would be like if the only people who would interact with you were paid to do so? I doubt if any of us would feel good about ourselves if that were the case. We want ordinary people to share their lives with Shawntell.

There are no easy answers or short-cuts to building friendships. It is hard work with many pitfalls, but there is nothing in this world that is more important. Just because someone has labeled Shawntell "severely mentally retarded" does not mean that we do not want the same things for her as any other parents. We want our daughter to experience the same joys and wonders that all children experience as they grow up—to go to parties, have friends, travel, learn new things, interact with all types of people and enjoy life to its fullest. Parents need to believe that friendships are something that are worth encouraging, working on, and striving to achieve. Though there is always the risk of rejection or that a relationship will end, trying to develop relationships is worth the risk.

*The future for these girls can include a continued relationship that will only blossom and grow as time goes by.*

Because Shawntell attended the neighborhood elementary school, rode the regular school bus, and participated in the local neighborhood activities, she met and started to become friends with a host of typical children.

Shawntell met Tanya two years ago at their school. They met as a result of Shawntell's teacher who has worked to integrate the children in her class into the regular education environment via a buddy program.

Children volunteer their time to work with Shawntell and the other kids in her class. They not only assist Shawntell and her classmates in learning new skills and competencies, but started to develop friendships—first in school and then later back in their neighborhoods. Over a few years, a number of children have started to form relationships with Shawntell outside of the school environment.

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### Tanya, a Close Friend

Tanya has become a close friend to Shawntell. We believe their story provides a vision on which to build a better community for all of us.

Tanya was ten years old and in fifth grade when she first met Shawntell. She is now twelve years old and has finished her first year in middle school. Tanya is a bright, articulate, attractive young lady who is interested in children (she babysits to earn money), animals (she wants to work with them when she finishes school), swimming, cute boys, parties, horseback riding, music, and a whole lot more. Tanya is a sensitive, caring person raised to respect and care about people.

Over the last two years, the girls have grown closer and closer. Their relationship, which started in the buddy program, has become just like any other good friendship between two girls. There has been a growing understanding and respect on both their parts as they learn more about each other. This has taken time and is a continuing process. The girls see each other often and enjoy their friendship. They do many things that are typical of children who are twelve years old—going to the movies, buying records, watching television, listening to music, and playing video games.

### Vacation Trip Together

When school let out this past year, my wife and I decided to take our family on a summer vacation to Hilton Head. We knew that Shawntell would want to take Tanya with her on vacation. Tanya was

really excited, not only to go on vacation, but to spend time with Shawntell. This was the very first time that the girls spent eight days and nights together in very close proximity.

The trip was great! The girls got along very well and enjoyed each other. They had fun swimming in the pool and ocean, and taking hikes on the beach at night. They even played miniature golf together where Tanya not only beat Shawntell, but her parents as well. We will never live that down. Friendship is sharing experiences together and making each other happy.

At a restaurant one evening, Shawntell and Tanya both located a young bus boy who they described as "real cute." Shawntell would follow him around watching his every move. She would get very excited at the sight of him coming around. Then Tanya joined in with Shawntell discussing their prospects of luring him. The two of them "talked" endlessly about this "cute guy."

Friendships are like that—sharing private moments that only you and your friend can really appreciate.

We invited Tanya on vacation with us because we knew that Shawntell would want her to come with us, and we knew that Tanya would enjoy being with Shawntell. Friends like to spend time with each other. Parents of children with developmental special needs can help facilitate these interactions. Because Shawntell does not communicate very well, we have to think about what she would really want, and then help to initiate that action.

### Messages for the Community

We need to work continually to enhance Shawntell's status and perceived value in the community. We do this by developing situations and activities that will increase the community's awareness of Shawntell and help others to see her as a member of the community.

One powerful message for the community is when a friend who is viewed as competent, valuable, and attractive is seen with Shawntell—walking down the street, going swimming, or going to the movies. Tanya can do something that her parents will never be able to do. She can say to the community, "This is my friend." How wonderful and beautiful that is. That message needs to be

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*Just because someone has labeled Shawntell "severely mentally retarded" does not mean that we do not want the same things for her as any other parents.*

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heard over and over again until it is a commonplace occurrence.

Shawntell needs to have a wide range of experiences that will enable her to live a full life in her community. In addition, if we are ever going to change people's behavior and attitudes, all our children need to learn from one another. This will never take place if we continue to separate, isolate, and prevent our children from being together. Perhaps it is not children who are scared of children with developmental special needs, but adults.

Many of us have never had the experience or opportunity to know a person who was perceived as different from us. However, our children can have these experiences. They can learn in the same schools, ride the same buses, go to the same parks, and enjoy life in a truly integrated community—if we give them the chance. We must all work towards having all children live, learn, and play together.

Tanya does not fully comprehend the significant influence she is making in the life of another person. More importantly, she is making a significant statement to the people of our community about the worth of another person—her friend, Shawntell. In her own way, she is making a contribution that is more important than all of the teaching that goes on in our school system and all

of the contributions that paid human service professionals could ever make.

Sometimes we wonder if Tanya thinks we are making too much of this relationship. Why do we write and talk about it? We have tried to explain that the relationship Tanya has with Shawntell should be a very commonplace occurrence that we all take for granted. Unfortunately, it is not. In many cases, children with developmental special needs have not had the opportunity to attend the local neighborhood school, live in the local community, and participate in community life. We believe that until all our children can learn together, our communities will not reach their fullest potential. So until that happens, Shawntell and Tanya's relationship will be viewed as something special—at least to us.

### What Does the Future Hold?

What does the future hold for Tanya and Shawntell? Tanya is twelve years old. Over the next few years, she will be involved in many new experiences that will probably change her life. She will become more involved with boys, school, parties, other friends, and many new dreams and exciting adventures.

We believe that Shawntell will continue to have a place in Tanya's life. We know that Tanya has a

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*Children are not brought into this life disliking others that are different.*

place in Shawntell's life. The future for these girls can include a continued relationship that will only blossom and grow as time goes by.

Double dating may be a possibility in the future for our daughter and her friend. Just because Shawntell has some learning challenges and may never be able to do exactly the same thing as everyone else does not mean that she should live a separate life. Surely, this would require acceptance, adaptation, and support in order for Shawntell to participate in such events, not only on her parents' part, but from her friends as well. It would also require a strong and open support on Tanya's part. She will need to be able to stand up to peer pressure and proclaim to her other friends that Shawntell is her friend and has a place among them. Whether this will happen, we cannot tell. We believe that it is possible.

But why shouldn't Shawntell be involved in these activities? Don't we want all our children to experience life to its fullest even if there are hard times, risks, and possible failures?

Although Shawntell risks rejection or ridicule, life without risk is not life at all. Until an individual experiences some of those risks and takes some chances, he or she will never experience life to its fullest.

#### **Children Are Caring**

We think Tanya is an exceptional child, unique and one of a kind. She has been brought up to care

about all people and to respect differences. She appreciates the unique gifts that each of us has to contribute to our communities.

Shawntell is also an exceptional child who is unique and one of a kind. However, is this not true of all our children? Each of them has his or her own unique qualities. This is the wonder and beauty of children. We would not want either Tanya or Shawntell to be anyone other than themselves.

There are a lot of children out there who, if supported, encouraged, and given the opportunity to interact with children with developmental special needs would do so. Until that is achieved, we will continue to perpetuate a separate mentality.

Children are not brought into this world disliking others that are different. They are not mean, nasty savages who are out to get your child because he or she is not exactly like them. Of course, there are some children—as there are some adults—who are not very nice to be around, but they are such a small group. The vast majority of children are caring, concerned people who, if given the right opportunities, would do the right thing.

#### **A Lesson For Adults**

The future is a scary and wonderful place, not only for Tanya and Shawntell, but for us. We will face the future with the firm belief that our daughter and her friend will make a difference in the way we care about and support one another. The girls have shown us more about what is important than all of the textbooks, professionals, research studies, and resources put together.

We believe that the girls have said to all of us, "You adults are really very silly, prejudiced, and narrow in what you think. We want to be friends. We don't understand why people make a big deal about two girls being friends. We accept each other for who we are and not for who others want us to be."

Tanya and Shawntell seem to understand and to know what is ultimately important. They know that people are people whether they can talk a mile a minute or not at all, or whether they have many competencies or very few. Their message is powerful and important for all of us. Maybe if we started treating all people the way these girls treat each other, our local community would be a better place for all of us. ■

Jeffrey and Cindy Strully live in Louisville Kentucky with their three children: Alex, Shawntell, and Sonia. They are both active in many community organizations—The Association for Persons with Severe Handicaps, the Council for Retarded Citizens, etc.

Credit: Reprinted with the permission of THE EXCEPTIONAL PARENT magazine, 605 Commonwealth Ave., Boston, MA 02215, September, 1984 issue.

THE EXCEPTIONAL PARENT magazine has served parents and professionals concerned with the care of children and adults with disabilities since 1971. Yearly subscriptions (eight issues) are available at \$16.00 for individuals and \$24.00 for organizations, schools and libraries.

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### The Child with Low Intelligence

The term *mentally retarded* usually refers to the child who is limited in his ability to learn and often behaves like a child much younger than himself. Mental retardation is defined as sub-average general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior.

In other words, mental retardation is impaired mental development beginning before, or during birth, or in a person's growth and developmental stages which makes social adjustment difficult for him:

There are many causes of mental retardation:

1. genetic
2. injury to the unborn child
3. complications during birth
4. poisons
5. brain damage
6. diseases of the nervous system
7. environmental deprivation

Environmental deprivation is said to account for 80 percent of the children with low intelligence. Environmental deprivation refers to the failure of the people and events that surround the child to meet that child's basic physical, emotional, and social needs. The child appears to lose his desire to grow and learn, thus retarding his development.

Not all children with low intelligence are the same. Over 85 percent of children with low intelligence can attain self-sufficiency as adults. Only about 1½ percent of children with low intelligence are profoundly disabled and require special training to obtain basic self-help skills, such as feeding or dressing.

Some common characteristics associated with children with low intelligence might be:

1. inability to follow directions that contain more than one or two steps.
2. lack of self-direction in play.
3. tendency to imitate rather than create.
4. inability to understand things not directly involved with at the time.
5. difficulty in paying attention.
6. inability to apply what is learned in one situation to any other situation. (lack of generalization)
7. difficulty finding differences and similarities in objects or events.
8. slower than most children in other developmental areas.
9. delayed in motor coordination.
10. unable to learn material without instruction.

Children with low intelligence have been classified for educational purposes as:

1. slow learners (I.Q. 80-90)
2. educable mentally retarded (I.Q. 50-79)
3. trainable mentally retarded (I.Q. 30-50)
4. totally dependent (I.Q. below 30-25)

Children classified as slow learners and educable mentally retarded are not usually recognized as delayed in intellectually functioning at the preschool level.

There is no sure way to find out how delayed any particular child is. The best way to see what a child can do is to let him try. When you know what he can do, then you can help him to the next step.

Children with low intelligence can benefit from normal school programs if the teachers are aware of their need for special help.

The goals of the program for the children with low intelligence include:

1. developing self-care and self-help skills
2. social competence - ability to get along with classmates
3. person adequacy - ability to feel good about himself

Children with low intelligence might need special materials necessary to improvise, adapt and adjust instructions to their rate of learning. Step by step teaching is essential as is matching the level of the task to the level of the child. Sudden changes in activities should be avoided. Using a multi-sensory approach, which stresses repetition, helps the child learn more easily. All children learn better when they feel that they are successful. Reinforcing good work should build the child's confidence and improve his learning skills.

#### The Child with Motor Disabilities

The child with motor disabilities, or a neurological impairment, is a child with a lack of complete development, or injury to the central nervous system. These children may have:

1. cerebral palsy
2. epilepsy
3. spina bifida
4. brain injury
5. orthopedic handicaps

Children with cerebral palsy make up the largest group of children with a physical disability. Cerebral palsy is a motor disability caused by damage to the brain. *Cerebral* refers to the brain, and *palsy* to lack of control over the muscles.

Types of cerebral palsy include:

1. spastic - causing stiff and difficult movement
2. athetoid - causing involuntary and uncontrolled movements
3. ataxic - causing balance and depth perception problems

Despite the apparent severity of the term, brain damage, all motor disabilities, including cerebral palsy, can range from slight to very severe. Some children may appear just slightly more clumsy than other children. Other children may have great difficulty learning such tasks as crawling, walking, reaching, chewing, or even moving their mouths and tongues for speech. Regardless of the extent of the disability, children with motor handicaps can still greatly benefit from a program in a normal school setting.

Causes of injury to the brain, nerves, or muscles of the central nervous system can be differentiated into three groups, depending upon when the damage occurs:

1. **Damage before birth:**
  - a. accidents
  - b. diseases to the mother
  - c. hereditary
  - d. drugs used by the mother
  - e. malnutrition of the mother
2. **Damage during birth:**
  - a. insufficient oxygen reaching the infant's brain (most frequent cause of cerebral palsy)
  - b. head injury
3. **Damage after birth:**
  - a. high fevers
  - b. disease
  - c. stroke
  - d. convulsion
  - e. accidents
  - f. burns
  - g. abuse

The child with a physical disability may need some guidance in adjusting to his handicap and finding ways to compensate for it. When a child is participating in an activity that he is unable to perform, find other activities for him to do. Give the child the chance to discover for himself what he CAN and CANNOT do. Attempt to adapt toys for him, if possible. For example; writing equipment can be made larger by wrapping crayons and brushes with layers of tape. Pencils can be pushed through rubber balls so that the child can hold the ball to write. Large size chalk is available for the child to use for blackboard work.

Selecting the appropriate toy for play can be very helpful. The child with poor balance can benefit from having something to push while he walks. If one hand is stronger than the other, direct him to activities that require the use of both hands. Minor modifications can make a tremendous difference.

## The Child with Neurological Impairments

Children with other neurological impairments usually require no special educational programming by the classroom teacher. Knowledge of the condition is helpful, as is knowledge of what to do if a medical emergency occurs in the classroom. For the purpose of being complete, the neurological conditions will be defined below:

### Epilepsy

When a child has a tendency to have seizures, he is said to have *epilepsy*. A seizure occurs when a group of brain cells becomes overactive and the well-ordered cooperation within the brain breaks down.

Epilepsy is the most common of all known neurological disorders. The majority of children with epilepsy are normal, healthy persons with average intelligence. The only way they differ from others is in the tendency to have seizures. There are essentially three types of seizures:

1. **Grand mal:** a series of contractions and relaxations of the muscles which usually lasts 2 to 3 minutes. (If a child experiences a grand mal seizure, the teacher should remain calm, ease the child to the floor, remove all furniture from the area to prevent injury to the child, allow the child to rest following the seizure, notify a nurse so the physician or parents may be informed; and, when the child is out of the room, explain to the other children what has happened.)
2. **Petit mal:** involves a momentary loss of consciousness and is observed as a nod of the head, blinking of the eyes, vacant stare, or loss of grasp and/or dropping objects. It is common in the younger child and disappears as the child becomes an adult.
3. **Jacksonian:** a type of focal seizure usually starting with jerking movements in the foot, hand, or one side of the face, progressing until it involves an entire side of the body. It is rarely observed in children.

### Spina Bifida

Spina Bifida is the most common defect causing disability in infancy and childhood.

It is a congenital condition in which body elements of the spine have not made a complete closure, leaving an opening in the neural tube.

Spina Bifida is frequently accompanied by hydrocephalus, which is an increase of cerebrospinal fluid in the cranial cavity causing pressure and enlargement of the size of the head.

### Minimal Cerebral Dysfunction

Minimal cerebral dysfunction is a term used for children with difficulty in learning, in which neurologists are unable to find definitive neurological signs of damage. Sometimes these children are referred to as *learning disabled*.

### Orthopedically Handicapped

A child with an orthopedic disability is one who has had a crippling impairment which interferes with the normal function of the bones, joints, or muscles. This category includes children born with handicaps and those who acquire a crippling condition later in life.

Children with neurological impairment, when grouped as a whole, may show greater tendency toward a personalized, introspective view of life. They are often very concerned about their disability and often need guidance and encouragement. There may be a need on the part of the teacher to encourage participation for these children. Some adaptation to the physical environment may be necessary to facilitate that participation.

### **The Child with Learning Disabilities**

The child with learning disabilities is a child with adequate abilities in intelligence, motor ability, vision, hearing, and emotional adjustment; but still shows evidence of deficiency in spoken and written language; including disorders in perception, listening, thinking, talking, reading, writing, spelling, or arithmetic. His disability may, or may not, have a specific reference to central nervous system dysfunction.

Children with learning disabilities do not appear able to learn in the usual ways. They are quite capable of learning, but special techniques must be employed to assist them.

**Characteristics of children with learning disabilities include:**

1. general clumsiness or awkwardness
2. inability to follow directions
3. short attention span
4. distractibility
5. hyperactivity
6. perseverance
7. marked motor disinhibition
8. distorted self-image
9. confusion in laterality
10. reversal problems
11. poor copying ability
12. inability to match shapes and colors
13. poor figure-ground discrimination
14. poor ocular motility and ocular control
15. poor fine motor control
16. poor gross motor control
17. poor rhythm and tapping skills
18. poor sequential memory
19. excellent memory in one modality, but not in other modalities
20. immature expressive language

Helping the child with learning disabilities requires a carefully performed diagnosis and prescriptive program. However, the following suggestions may prove helpful for general use by the preschool teacher.

1. use a multi-sensory approach
2. use the child's abilities; that is, teach through his strengths to his weaknesses
3. use step by step learning
4. give directions in small steps
5. reduce distractions
6. build confidence in all the tasks he performs.

### The Child with Language Disabilities

The ability to communicate is essential to a child's development. There are a variety of speech and language disorders. Speech is considered defective when its deviation from normal draws unfavorable attention to the speaker. Speech defects may take many forms ranging from complete inability to speak, to minor articulation defects. Speech defects may be the result of organic factors such as hearing losses, cleft palate, and cerebral dysfunction, or the cause could be emotional or environmental. Speech defects are often associated with other handicapping conditions.

Speech and language problems are classified into two types: The receptive problem is one in which the child does not receive correct information about sounds and language. An expressive problem is one in which the child cannot give information properly. Examples of expressive problems are:

1. Aphasia: inability to speak
2. poor formulation: inability to use and organize speech
3. poor articulation: inability to produce language sounds
4. poor vocabulary: knowing a limited amount of words
5. poor syntax: confused word order or non-use of certain parts of speech
6. fluency problems: disconnected speech, such as stuttering

A classroom teacher can detect signs of possible language problems in preschool children. Some signs might be:

1. the child is not talking by the age of two
2. the child does not use two or three-word sentences by the age of three
3. the child's speech is still difficult to understand after the age of three
4. the child omits either beginning sounds, or ends of words
5. the child is embarrassed by his speech
6. the volume of the speech is inappropriate: either too loud or too soft

The earlier the speech defect is detected, the easier the remediation will be. Some speech difficulties are not easily corrected. Children with serious speech and language problems should receive professional attention as soon as possible.

The best thing a preschool teacher can do for the child with a language difficulty is to provide him with as many normal language experiences as possible. A good model is essential to good language development.

### The Child with Emotional and Behavioral Disabilities

All children have some emotional problems from time to time. *No child's behavior is perfect* is probably a true statement. All children need some help in dealing with their feelings and abilities to cope in the school setting. Preschool is the first time most children are in a group setting. All children need some help in handling this new experience.

Emotional and behavioral disorders are present only when the behavior deviates from age-appropriate behavior, and significantly interferes with either the child's own growth and development, and/or the lives of the other children in the class.

Three types of behavioral disorders can be identified easily:

1. unsocialized aggressive child: defies all authority figures, cruel, malicious and assaultive, and has inadequate guilt feelings
2. socialized aggressive child: same characteristics as the unsocialized, except that he IS socialized within his peer group
3. over-inhibited child: shy, timid, withdrawn, seclusive, sensitive and submissive

There are a variety of strategies available to work with the child with an emotional and/or behavioral problem. Psychotherapy, behavior modification, psycho-educational approach (concerned with what the child does and why he does it), are just examples of a few.

If the problem is a severe emotional disturbance or behavioral problem, it may be best to call a professional who can help provide exact ideas in working with a child's specific problem.

The classroom teacher should be concerned with understanding how the child expresses his feelings. When is the child asking for help, security, or reassurance? Proper handling of feelings is one of the most difficult, but most important activities of the preschool teacher. A very important rule to remember is to be honest. Nothing ruins a child's trust more easily than knowing that he has been deceived. Children learn the behaviors they see and experience.

Credit: Knowing The Child With Special Needs. A Head Start Publication,  
U.S. Government Printing Office.

A Parent's Perspective on a Developmentally Disabled Child

by Jean Allord

The joy we experienced with the birth of our third child, a normal, healthy girl, was soon shattered. At the age of two months, our daughter, Angela, was bitten by a mosquito and contracted encephalitis. Although she survived this very critical illness, she was left with catastrophic brain damage. Today Angela is 18 years old. She cannot walk or talk. She cannot sit up. She cannot use her hands or care for herself in any way. She is also mentally retarded.

I think deep in the heart of every parent is the abiding fear that there could be something terribly wrong with their child. And, true to their apprehensions, this is the most devastating experience a parent can undergo. What does it mean to have a brain-damaged child in the family? First of all, it means a drastic major change in your daily life. It means waking up each morning to the knowledge that your child will be a baby the rest of her life and yours, that she will never get better, only heavier. It means having a job you never asked for and didn't want. It means doing therapy on your child for years on end, trying to find a school that will take her and then spending a good part of each day transporting her. It means buying special equipment and then finding someone to alter it. It means watching your child cry because she can't do what other children do. But, most of all, it means having your heart broken in such a way that it cannot be mended.

After realizing the overwhelming nature of Angela's handicaps, we strived to provide her with whatever she needed to grow and possibly improve. She became a vibrant, happy, loving addition to our family. Though she could not talk, she had a "total body response" to every member of the family, squirming and squealing her welcome whenever we came home. We enrolled her in a special pre-school and began therapy. She blossomed out socially, but showed no significant improvement physically. By the time she was five years old, I was winding down. Though the constant round of therapy, transportation, and tasks of her daily care were staggering, it was the emotional aspect of the situation that really put me down for the count. I became chronically saddened over the hopelessness and tragedy of it all. Just to hear the word, "Angela" was enough to bring me to tears. I harbored a secret wish that this would all be taken from me, yet I felt an incredible connection with this lovely child. Often my husband would play tumble with Angela on the floor, much to her delight. Yet, a few minutes later, I would walk into the room only to find him clutching her close to him, rocking back and forth, sobbing and sobbing - our rose half-bloomed, a song unsung - waiting for life's promise that would never come to be.

We were advised on several occasions to place Angela in the State Institution, and we did consider doing this. However, like most parents, we cherished our child and felt a deep sense of responsibility for her. We longed to provide her with a warm family atmosphere in which she could spend her childhood. So, with God's help, we struggled through. However, this was done at great cost to the other family members, especially me, the Mother. I was at the brink of a breakdown more than once. Angela and I were in direct competition with each other for getting our needs met. At times the stress was intolerable, mainly because Respite Care was not available then. It must be noted that those families who choose alternative living arrangements for their retarded child are equally devoted, and in deed, suffer intense, internal wounds surrounding this decision, regardless of external appearances. NO ONE GETS OFF FANCY-FREE!

During the seventeen years that Angela lived at home, we encountered many beautiful people along the way, some of them professionals. But, often we felt intimidated by them. We found that during any hospitalization, we would have to very vigilantly advocate for our retarded child or she would suffer needlessly. Mostly, the doctors, teachers, and social workers were just unaware of the impact ANY discussion of our child had on us. How I came to dread such words as "totally involved", "damaged", "poor prognosis". Once at a parent-teacher conference, I was braced for the usual grim report, but I wasn't ready for what happened. The teacher nonchalantly handed me a report from the therapist. It was a detailed summary of all of Angela's problems surrounding her mouth; her poor chewing and swallowing, her lack of speech, her drooling, her swollen gums, her tongue thrust. Of course, I already knew all of this, but just seeing it in black and white, an entire typewritten page, single spaced, listing all of her deficiencies was like a physical blow to me. And this dealt with only ONE part of her body! I thought, "My God, she's incredibly defective!" I didn't hear anything the teacher said after that, because I was trying so hard to hold back a torrent of tears. which were shed copiously on the way home.

In the early years of our dealing with professionals, especially the medical evaluation teams, I often felt as if we were specimens under a glass, to be scrutinized, measured, and judged; to have our every response reported on, and to have tabulations taken to see how we had "accepted" Angela's condition. It was a subtle tug of war - we withholding, defending; they proclaiming and dispensing from their safe, insulated throne. Never at any time, did I ever trust them enough to reveal my deepest anguish.

In the end, this combative stance was detrimental to all of us. As parents, we would not/could not utilize and

appropriate all the expertise and help available to us. As the patient, Angela needed to have everyone maximize for her to the fullest extent. And, as professionals, they never risked their own personal vulnerability, and thereby they missed truly sharing this most profound experience with families. Indeed, they often seemed blind to the beauty and meaning, the richness and value of these damaged children; the very heart of their chosen career!

Perhaps, someday we will be brought together by the children - those wonderful teachers of life! Perhaps then we can work in unity to cause the intolerable to be made tolerable, the unacceptable to be made acceptable and the impossible to be made possible.

Credit: Look to Families : A Training Curriculum on  
Permanency Planning (HHS#90DD0017/01) for Children  
with Developmental Disabilities

## CHILDHOOD AUTISM

By Grace Sandness

If you read about Neil in the CROSSROADS story, "Look at the Light", you have heard of a few of the symptoms of Childhood Autism. If you've read Son-Rise, that compelling true story of one family's experiences with their autistic birth child, Raun, you know of a few others. But both stories offer mere glimpses of an intriguing problem found quite frequently in children— including, quite naturally, those without families.

Childhood Autism is the name given to a group of behaviors which describe a specific psychotic condition of children; for reasons unknown, an autistic child shuts out the world - finding in it no meaning or relevance, no security, no food for the spirit. For reasons unknown he shuts out the very people who love and could help him. Because the reasons are unknown, autism can only be diagnosed by observing a child and cataloging what he does or does not do.

- 1) An autistic child may fail to respond to attempts to love, cuddle, or show him affection. He may actively resist such attempts. He may not seem to know or care if he is with people. He shows few 'normal' emotions - never seems to be excited or depressed, happy or sad, bewildered or confused - and doesn't seem affected by the moods of others.
- 2) The child shows a compulsive insistence that his environment remain unchanged. He may become upset or frightened if a piece of furniture is moved. He may line up toys or blocks in neat rows and patterns and insist they remain unchanged, or demand that only certain familiar words be used in given situations.
- 3) If you move directly in front of an autistic child and speak to him, he may appear to look right through you and act as though you're not there - as if he doesn't see or hear. Often parents of such children have incorrectly supposed them to be blind or deaf. But the way such a child reacts to sounds and sights varies greatly. While he may not 'startle' at a sudden loud noise, he may react to the barely audible crinkle of cellophane. The same child who appeared not to see you may spot a small piece of candy twenty feet away. This variability extends to the other senses, also. When he hurts himself he won't cry or seem to feel any pain.
- 4) Perhaps the most striking behavior which characterizes the autistic child consists of highly repetitive, self-stimulating acts such as rocking his body back and forth, twirling around, flapping his hands at the wrists, humming a set of notes over and over again, spinning objects, twirling pieces of string, etc. He may be incessantly preoccupied with acts like these for hours, days or weeks - seemingly finding security in the circular completeness they represent.
- 5) Autistic children are often self-destructive. They may bite themselves until they bleed, beat their heads against walls or furniture, or scratch or beat themselves until they cause severe bruises and even scars from their self-mutilation. Often this will be brought about by imposing some minor restriction - like being required to sit on a chair. Sometimes this aggression

Childhood Autism, #5, cont'd:

will be turned toward parents or teachers in kicking, biting, or other tantrum like behavior. Some children scream all night, tear down curtains, smear faces, throw flour around the kitchen, etc. Parents are often at a complete loss about how to cope with these outbursts.

- 6) Many autistic children are mute, with speech limited to uttering simple sounds. Sometimes what they say will be mere echoes of the words of others. If you ask, "What's your name?" the child will answer, "What's your name?", often exactly imitating your tone and inflection. Sometimes the repetition may occur hours, days, or even years later, when the child repeats T.V. commercials or bits of conversation he once heard.
- 7) An autistic child seldom learns any self-help skills, but must be fed, dressed, and toileted by others. He seldom 'plays' with toys, but puts them in his mouth or taps them repetitively with his fingers. He has no idea how to play with his peers, but drifts along in a world of his own. Common dangers mean nothing; he would easily run in front of a moving car if allowed to cross the street alone. Yet, in order to be classified as autistic, he must be of at least average intelligence and have normal motor development. (The above statement is inaccurate. The National Society for Autistic Children estimates that "60% of autistic children have measured I.Q.s below 50; 20% between 50-70, and 20% of 70 or more.")

Glimpses of average or above average intelligence are often seen in autistic children. Some are extremely clever in manipulating their parents, or at putting together and taking apart intricate mechanical objects. Others may have unusual memories - noticing minor changes in furniture arrangement or being able to sign entire songs or recite long strings of numbers. To see or read about these children is to be haunted by the feeling of real potential and bright minds in active bodies bound in a circular prison...of what?

Many children, like Neil, show behaviors which cause them to be labeled 'autistic'. But, though there were happenings in Neil's past that could be considered the cause of his autism, some children seem to be autistic from birth and remain so. In spite of loving parents, abundant attention, and apparent emotional security. Though many theories try to explain the cause of autism, none is accepted as adequate. Clinicians and therapists must deal only with the behaviors they can observe - both in the children whose progress has been followed from birth and in the children we might adopt, whose backgrounds may hide unknown traumas. In each case it is the child who must be helped to grow from where he is to where he needs to be, to learn that the world outside his circular prison is good and caring...and matters.

The one method proven successful with autistic children is behavior modification. Though behavioral scientists may prefer big words such as behavioral repertoires and stimulus functions, 'Behavior Mod' is quite simple - something even uneducated parents practice to some extent, simply because they've found it works.

Basically, behavior modification involves the use of rewards or punishment to strengthen wanted behavior and to weaken or eliminate undesirable behavior. In a therapy program - for autistic children, for example - this can become a complicated ongoing, and fairly lengthy process.

Childhood Autism, cont'd:

An autistic child usually has little adaptive behavior with which to function in society, simply because 'society' has no meaning for him. He lacks speech, play skills, and ways to interact with people 'out there'. By using reinforcers such as food, trinkets, etc., therapists can promote socially acceptable behavior and strengthen it when it occurs. Undesirable behaviors such as tantrums and self-stimulation can be weakened and sometimes eliminated by withholding reinforcers or apply punishers. When such a program is applied consistently, as it can be in a treatment facility, real progress can often be made. It's also possible that, by working closely with a therapist, a parent can use the same basic techniques with marked success. At least, in behavior modification we have a way to begin, a path to follow in helping the Neils and Rauns that may be part of our lives. (In addition to behavior modification, there are other approaches to working with autistic children. Spaulding suggests that you consult your local school program for autistic children to learn about other possibilities.)

Most metropolitan areas offer excellent programs for autistic and other emotionally disturbed children, programs which include the training and educating of parents. Usually children are bussed at those districts' expense. Information on such programs can be gathered by phoning your school district office or your county mental health center.

As those of us who have fought for 'special kids' now know, few situations are entirely without hope. In spite of the discouragement that is bound to come from trying to break through walls we cannot see, there will also be progress in which we can rejoice. Both are part of life.

Resources - Kaufman, Barry Neil, Son-Rise, Warner Books 1976  
Lovaas, O. Ivar, Young, Douglas B., and Creighton, D. Newcom, "Childhood Psychosis: Behavioral Treatment", Handbook of Treatment of Mental Disorders in Childhood and Adolescence, Prentice-Hall, 1978

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DOWN'S SYNDROME - MYTHS AND CHALLENGES

By Grace Sandness

Down's Syndrome (Mongolism) is the name given to a large group of characteristics found in persons born with an extra chromosome in their cells. Research has not yet uncovered the cause of this anomaly, though there are many theories. Of the three major types, 'nondisjunction', 'translocation', and 'mosaic', only the rare 'translocation' type has any familial or hereditary basis.

The physical characteristics of Down's Syndrome are many-over 50. They include facial features such as "somewhat slanted-appearing eyes, skin folds covering the inner corners of the eyes, a broad nasal bridge and .... a tendency to protrude the tongue. There are many other bodily characteristics including short stature, small head, stubby hands with inward curved little fingers, often a single crease across the palm, joints that are unusually flexible, and generally poor muscle tone ("floppiness"). Mental retardation is almost always present."

No child has all the possible features of Down's Syndrome. Any one of the features can be found singly in normal children. They can appear in a variety of combinations, none of which bears a direct relation to the degree of mental retardation present. It occurs in all races and happens about once in every 600 births. But the incidence of Down's births varies strikingly with the age of the mothers - from one in 1,500 for women under 30 to one in 50 for women 45 years old and over. The presence of Down's can usually be detected by examination at birth and verified by a blood test. It can sometimes be detected prenatally by examining the amniotic fluid.

The medical research on Down's is too extensive to be covered here. What must concern us more as child-conscious adults - as parents - are the Robbies, the Kevins, the Christophers who wait in the care of public and private agencies, whose needs are even greater than those of normal children but are less likely to be met, who desperately need the stimulation and support only a committed parent can give. For Down's children at best have extremely limited potential. To develop to their fullest they need more than normal kids, especially during the crucial infant and preschool years - more stimulation, more physical contact (cuddling, bathing, play), more opportunities and encouragement to learn.

But there are the myths to consider, the generalizations that must play their part in preventing Robbie from finding permanence.

1. "All Down's kids look alike." Wrong. Although certain common characteristics may be present, a single minute's glance through an exchange book and a look at winsome Robbie will refute that statement.
2. "Down's children are all uniformly slow in their development." Not necessarily. Although all are slow to develop, especially after the first two years of life, there is considerable variability in the ages at which different developmental 'milestones' (sitting alone, walking, etc) are reached. Language development shows the greatest variability. Some DS children will never talk; others may, by age four, be using three word sentences.

Down's Syndrome, Continued:

3. "All Down's kids have very low IQs." This is perhaps the most controversial 'myth' of all. Formerly it was assumed that these children would at best fall within the range of trainable retardation. Now people who work with educating Down's children are realizing that many of them do fall within the educable range. Often they can be taught to progress beyond what was formerly expected of Down's children. The use made of whatever potential they possess depends critically on the environment in which they develop and on the quality of time invested in them. Though no child can develop beyond his genetic potential, special care can make a great difference in the degree to which he uses his intelligence.
4. "Down's kids don't live very long, anyway." Partially true. Infant mortality rate is greater among Down's children since about forty percent have congenital heart defects. However, in many cases these can be managed through medical advances. Their congenital susceptibility to infection, particularly respiratory infection, can be counteracted by a growing list of antibiotics. Many children with Down's Syndrome will live nearly as long as other people do. It is the quality of that life that must be improved.
5. "Having a retarded child in the family is unfair to the other children." Is it? Studies show that children usually adjust to a retarded sibling with little stress if an effort is made to help them understand. Their activity and enthusiasm can be stimulating; learning to care for him and to understand his differentness can enrich their lives. Sheltering normal children from exposure to the 'real world' of the not-so-perfect can only limit their understanding and the depth of their caring.

The usual adjustment problem in a family with a Down's child will probably never arise if the child has been adopted. Misplaced guilt over having given birth to imperfection frequently drives birth parents to overindulge their 'special' child and to neglect or place too much responsibility upon his siblings. Even young children in such a family can wonder why they 'escaped' the damage or if they are 'immune'. They may wonder why they may wonder if their 'bad thoughts' about their Down's sibling may have caused his condition. They can worry about being 'different.' As teenagers they may be concerned about their own hereditary and its effect on their future as parents.

The fact of adoption can be a real blessing, both for the Down's child and for his adoptive family. It provides a guilt-free, burden-free framework within which the child, his parents and siblings can enjoy and appreciate each other. The family can willingly provide stimulation and opportunity for their 'special' child, enjoy his sunny individuality and take honest pride in his development. His siblings may even develop pride in being able to help that sibling who has some needs only they can meet.

But, if we adopt a Down's child, find him the special schooling he is entitled to (without cost) by federal law, help him develop self-care skills and acceptable social behavior, encourage within him a self-concept based on ability - not disability, give him security, stimulation and love... what of adulthood? Though we expect our normal young adults to leave us and take their places as contributing, productive citizens - what of this child? Will he always be with us - dependent on us?

Down's Syndrome, Continued:

Possibly. Yet, Dr. Horrobin believes that the stereotype of the martyred, work-worn woman trailed about by a sluggish, dull-faced, adult-size 'child' need not exist today. The National Association of Retarded Citizens is only one of a number of organizations concerned with encouraging maximum independence for Down's Syndrome and other mentally handicapped adults. In Minneapolis the Muriel Humphrey Residences provide group/independent living situations with varying amounts of training, counseling and supervision. Residents there share cooking and cleaning tasks and are prepared when possible to work in sheltered workshops and even in mildly competitive employment. Similar facilities are (or should be) available in most cities. In such settings peer group activities and friendships can contribute to a satisfying life away from Mother's apron strings.

But a child may not progress this far; if he does, funds may not be available to provide such 'luxuries.' Obviously parents of a Down's child must think of his future financial security. In this area adoptive parents are offered a subsidy from the state holding custody of their child. Such a monthly subsidy can provide for special education beyond that provided by law, summer camp, medical care for Down's-related problems, or be set aside to meet the child's future needs.

So, this can be their future. They remain a challenge to us, a source of honest satisfaction, and a chance to give of ourselves in love. Think about it.

Recommended Reading;

To Give an EDGE, by Margaret Horrobin and John Rynders. May be ordered from; The Cowell Press, Inc., 500 South 7th Street, Minneapolis, MN 55415 Cost: \$2.00

David, by Nancy Roberts

The Gift of Martha, by Claire Canning

A Child with Down's Syndrome, by Dr. David Smith; available at all book stores.

Your Down's Syndrome Child, by Dr. David Pitts, distributed by NARC.

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## ACTIVITIES TO INCREASE AWARENESS OF DEVELOPMENTAL DISABILITIES

1. Provide respite care for a child with developmental disabilities for an evening, a day or a weekend.
2. Visit a family whose membership includes a child with developmental disabilities and participate in that family's routine from after school to bedtime.
3. Arrange for yourself or all personnel in your office to simulate a specific disability for a day while continuing to perform your regular job duties.

For example:

- a) Borrow wheelchairs, crutches or walkers from a public health facility to simulate a disability which involves mobility.
  - b) Bind extremities with elastic material to simulate cerebral palsy.
  - c) Muffle hearing with ear plugs or cotton to simulate a hearing loss.
  - d) Wear very dark glasses or glasses which partially block your field of vision to simulate visual handicaps.
  - e) Refrain from verbal communication to simulate speech and language disabilities.
4. Spend at least a day visiting in a facility that serves children with developmental disabilities.
  5. Become an advocate for a child with developmental disabilities.
  6. Arrange to meet and spend time talking with an adult who is developmentally disabled.

Credit: Look To Families: A Training Curriculum on Permanency Planning for Children with Developmental Disabilities  
by Yvonda Martin

## REFERENCE

# DEVELOPMENTAL STAGES OF THE MENTALLY RETARDED CHILD\*

## STAGES OF DEVELOPMENT

Though the developmentally disabled person\*\* can be characterized by certain symptom patterns, it is difficult to describe a "typical" developmentally disabled child. No developmentally disabled child is exactly like any other developmentally disabled child. Each has his or her own inherited, constitutional, and cultural background, temperament, and personality. The developmentally disabled are impaired either mentally or physically, or both, but impairment may be very mild in one person or very severe and multiply handicapping in another. The child may or may not have an obvious physical disability.

The developmentally disabled child's developmental stages are slowed and dependency is prolonged. The child requires more time, energy, attention, patience, consistency, and responsiveness from foster parents during the stages of development. The child will need more sensory, motor, and environmental stimulation. The child will be penalized if foster parents are content to allow the child to remain immature rather than to develop his or her potential.

### INFANCY (Birth - 1 1/2)

#### Tasks to Accomplish<sup>1</sup>

Develop a sense of trust in himself/herself and other human beings.  
 Develop awareness of himself/herself as loved and therefore a lovable person, and one who is enjoyed and brings pleasure to others.  
 Develop the ability to delay gratification

#### Characteristics of the Developmentally Disabled

Early knowledge about the kind and degree of a child's developmental disability increases the chances for the development of the child's maximum mental and physical potential. Normalization should be the principle to follow. Foster parents may tend to set up a different set of expectations

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\*Adapted, permission pending, from Gwendolyn Murphy, Foster Care of the Developmentally Disabled: A Basic Course for Foster Parents and Foster Care Workers. Boston, MA: Boston University School of Social Work, 1975.

\*\*In this article the term "developmentally disabled" refers to a condition "closely related to mental retardation or that requires treatment similar to that required for mentally retarded individuals". The article was written prior to the expanded and current definition of the term developmental disability. It continues to have relevance for working with children who are mentally retarded.

## HANDOUT

## DEVELOPMENTAL STAGES OF THE MENTALLY RETARDED CHILD (p. 2)

for the developmentally disabled child. They may expect too much or too little from the child, or not know what to expect at all. Foster parents need to keep in mind that the child's chronological age may not correspond to the developmental age. Developmental stages follow a sequential pattern.

The self-concept, or the way the developmentally disabled view themselves, is greatly affected, or indeed determined, during the first phase of development by the attitudes of acceptance of the parents or parent substitutes. This sets the foundation for the child's future relatedness to others. The development of the relationship of the parental figure and the child is crucial during this stage. Failure or delay in establishing this bond of basic trust makes the child's development of other attachments more difficult and slows down emotional growth. There are some children who desire closeness and others who are not comfortable with it. Social stimulation of the child, however, is very important -- talking to, holding, cuddling, carrying, bouncing, rubbing. The Down's Syndrome child, for example, may develop at nearly normal rate during the first six months, during which time the parent-child bond can evolve naturally. The developmentally disabled child requires good physical care under the supervision of a pediatrician or the family doctor. Intervention and corrective measures during the child's early years are particularly important for improvement of the child's physical functioning.

TODDLER (1-1/2-3)2Tasks to accomplish:

- Develop self-control and self-esteem.
- Delay gratification (patience).
- Toilet training.
- Respond to discipline.

The child's progress continues to be slow during this period at a time when the normal child begins to do things on his/her own or autonomously. Retarded children who cannot achieve mastery of developmental tasks may not reach this stage until 3, 4 or 5 years of age. The toddler who has impaired muscular control, such as the cerebral palsied child, will have more difficulty in mastering this developmental stage. The child's motor skills may lag and he or she may need to be stimulated to explore the environment through crawling, rolling objects, touching, feeling. Experiences may be planned and structured for the child who needs special attention for developmental problems. The child may require special nursing care, treatment of physical defects, and physical therapy. Medical follow-up, special diet, medication, special aids, or surgery may be indicated.

Socialization may also lag, along with the developmental sequence. The developmentally disabled child who has an opportunity to meet other developmentally disabled children before beginning school will not think that he or she is the only one who is "different." If foster parents become too restrictive, the child may begin to experience a sense of failure. Foster parents have to allow adequate time in their schedules to feed, dress, and toilet the developmentally disabled child who may require more time than the normal child. The child will benefit from the development of a positive parent-child interaction. When the child senses the foster parent's impatience or tension,

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senses the foster parent's impatience or tension, the child may also become tense and anxious, slowing down the activity. If the child feels forced or pressured, a struggle between foster parent and child may begin. Foster parents may baby, overprotect, or overindulge the child. They may try to overcome or deny anger at the child's dependency, stubbornness, or negativistic behavior. Membership in associations related to various disabilities is very supportive to foster parents.

PRESCHOOL (3 - 6)

Tasks to accomplish:

Identify with his (or her) parents -- wish to become like them.  
Establish sexual identity -- his (or her) sense of being a boy or girl.  
Develop initiative.<sup>3</sup>

Characteristics of the Developmentally Disabled

If the two earlier stages have not been mastered, the child's development will lag and the child will remain immature. Assessment of the effects of the child's disabilities and remedial help are important. The child's identity is affected by the child's relationship with natural and foster parents, parental attitudes concerning the child, and their image of the child. When they view the child ambivalently as damaged or "special," or as both, it is likely that the image and behavior of the child will reflect the parental views. The child may identify with natural or foster parent who is depressed. The way in which the parental figures related to those around them is reflected back to the child and serves as a model for relationship.

The child, aware of being different from other children, may view himself or herself as awkward and clumsy. A poor self-regard and self-image, immaturity, and dependency will prevent the child from developing initiative and creativity. As with normal children, training in responsible sexual behavior begins during the developmentally disabled child's early years of development. The child should have a role in the foster family unit but should not be given special status. Day nursery care, specialized education, and playground experiences are of benefit in teaching the child basic academic and social skills, and in relieving foster parents of the total burden of care. Attention should be given to communication skills, especially if speech is affected. Dental care should be initiated.

SCHOOL AGE (6 - 12)

Tasks to accomplish:

Peer relationships are established.  
Ability to work and play.  
Accept and adjust to reality.<sup>4</sup>

Characteristics of the Developmentally Disabled

Developmentally disabled children want to be like other children. Because of social immaturity as well as physical problems, they may have difficulty in

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being accepted and in adjusting at school. The identity of the mentally retarded child has been further affected, because the educational system traditionally has placed less value on those of lower intelligence. Until recently, public school educational programs were designed to meet the needs of normal children. Labeling and segregating a child in the classroom diminished the developmentally disabled child's self-image. "...we cannot ignore the evidence that removing a handicapped child from the regular grades for special education probably contributes to his feelings of inferiority and problems of acceptance."<sup>5</sup>

Because the developmentally disabled lack social experience, they usually have fewer friends and are not likely to participate in peer activities. When they have difficulty competing, they tend to seek out younger companions. They may try to gain attention by naughtiness and clowning, partly to cover up intellectual slowness, inferiority, or hurt feelings about being left out. Other children who may be puzzled by their differences may tease or withdraw from them. Failures become more obvious during this period and dependence on foster parents increases. The child needs much support and reassurance about his or her assets. Foster parent-teacher communication is essential to promote the child's learning capacities and to prevent the child from becoming socially isolated, segregated, or a scapegoat. The child may learn socialization skills in an activity group.

## SPECIAL BEHAVIORAL CHARACTERISTICS

In order to understand the behavior of developmentally disabled children, it is helpful to know about some characteristics, found in some brain injured children, which cause such children to have difficulty in learning or to have disturbances in fixing their attention on the task they are doing. Brain injury may limit the capacity of some developmentally disabled children to comprehend what is the expected and reasonable thing to do in a given situation. Some of the "failures" of developmentally disabled children can be attributed to the limitations caused by brain damage. Inability of foster parents to recognize and respond to the communications and signals of the developmentally disabled can stem from a lack of understanding of the effects of brain damage on a child.

Short Attention Span

Some children with brain injury may find it difficult to concentrate attention upon a particular item or subject for an extended period of time. The child does not listen attentively; attention drifts; and the child does not understand communications. The child will shift from one activity to another in a relatively short period of time, giving an appearance of flightiness. Such a child is not likely to have a plan or purpose for his or her activity. The child may not be able to follow through on an activity. The child may give up because past experiences may have resulted in failures, or the task may be too hard or of little interest.

Distractability

Rather than keeping attention focused on a main idea, subject, theme, or goal, the child with brain injury may be very easily distracted by stimuli in

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the environment. Concentration can be quite easily diverted by extraneous matters or details which he or she sees, hears, or wants to touch. The child gets as involved in the unimportant as in the important. The environment should be free of overstimulating influences. The child needs help to learn to select what is most important, to disregard distractions, to discern the limits of a situation, and to practice making choices.

### Hyperactivity

Some developmentally disabled children may be overactive. The child seems compelled to be on-the-go or in motion most of the time. Activity may be constant and purposeless. The child needs structure, with limitations of distractions, stimuli, stress, and physical space. More supervision is required. Praise is important as the child often feels that he or she cannot do anything right. Special attention may be required if the child has a physical handicap. In hypoactivity, the opposite to hyperactivity, the developmentally disabled child is unresponsive to stimuli and inactive.

### Difficulty With Abstract Concepts

The child with brain damage may have difficulty in dealing with abstract concepts. Such a child needs concrete, specific, explicit information, directions, instruction, and help in order to understand and learn. The child may not recognize similarities in a number of different situations or items in relation to size, shape, color, distance. He or she has difficulty in applying concepts, thoughts, or ideas to specific situations. Counting, ordering, or grouping items may confuse the child.

### Difficulty in Making Transitions

Brain injury may cause some children to behave with a certain inflexibility. Changes may represent a threat to the child's security. Changes in time, tasks, persons, places, furniture can upset the child. Even simple changes may cause the child to become confused, disorganized, and irritable. Because of this pattern the child will respond best if he or she can depend on simple routines in the day-to-day activities. Such children will find it extremely difficult to make a transition from one activity to another. They should be alerted to transitions and to the next activity which is to occur. Telling the child, for instance, that it is almost time for a nap, lunch, bath, or playtime will prepare him or her for any impending change.

### Emotionality

The developmentally disabled child may have difficulty in controlling emotions. He or she may seem changeable or unstable, and behavior may be based on impulse. The child may react to stimuli with crying, laughter, or anger more readily or easily than a normal child. The manner and intensity of expressing emotions may be unsuitable to the situation which caused the reaction. The child may respond inappropriately with affectionate or aggressive behavior toward another. The child may talk at the wrong time or speak on impulse. On the other hand, when the child's emotions have been suppressed or dampened he or she may be extremely passive and unresponsive.

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Perseveration

Brain injury may cause some children to repeat continuously a response which is no longer appropriate to the situation. He or she may continue to repeat a word, statement, story, or an action when the stimulus for the response is no longer there or necessary. The child seems to be unable or unwilling to shift from the response or train of thought. It is possible that the child may wish to prolong a situation. On the other hand, it could indicate that the child is having difficulty dealing with stress or is threatened by fear of failure. Learning to recognize, understand, and break into the perseveration is important for those who are trying to relate to the child.

Catastrophic Reaction

The child reacts to a stressful or threatening situation with more anxiety and exaggerated response than the normal child, as if the situation were something of a catastrophe. He or she may become easily irritated or frustrated. The child may feel pressured and that too much is being demanded. The child may cry, scream, fight, kick, or bite. He or she may giggle or respond with silliness. The child may have difficulty reorganizing and beginning over after such a reaction.

<sup>1</sup>A Guide for Foster Parent Group Education. Chestnut Hill, MA: Boston College Graduate School of Social Work, 1967), pp. 34-35. (move this last No.1 to the end)

<sup>2</sup>Ibid., p. 35.

<sup>3</sup>Ibid., p. 36.

<sup>4</sup>Ibid., p. 37.

<sup>5</sup>Keith E. Beery, Models for Mainstreaming (San Rafael, Ca.: Dimensions Publishing Co., 1972), p. 30.

Credit: "Adolescents In Need of Special Attention," by Paevlowski, W., et al, Child Welfare Inservice Training Curriculum, Washington, D.C., Creative Associates, 1982

## CHRONIC SORROW REVISITED: Parent vs. Professional Depiction of the Adjustment of Parents of Mentally Retarded Children

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*In response to a questionnaire mailing, parents of mentally retarded children and social workers essentially agreed that such parents experience periodic crises during the child's development, rather than time-bound adjustment. Social workers tended to underestimate the impact on parents of later developmental periods. Clinical implications of the findings, which run counter to the prevalent professional view, are considered.*

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In the professional literature, there are two incompatible notions about the adjustment process of parents of retarded children—that parents work through their grief over time and that sorrow is chronic.

*Grief is time-bound.* The most prevalent view is that, basically, parents go through one predictable progression of adjustment to the situation of having a mentally retarded child. Most clinical studies have diagrammed the stages of grief in the order of shock, despair, guilt, withdrawal, acceptance, and finally "adjustment."<sup>10</sup> One popular medical school text described the main stages of parental acceptance as being shock, followed by denial; helping professionals, it maintained, should recognize

shock, denial, and guilt, and help the parents work through these feelings.<sup>7</sup> Another example of this attitude has been portrayed in a handbook on mental retardation for the primary physician, in which parents are said to

... usually go through three stages in adaptation: 1. emotional disorganization; 2. reintegration; and 3. mature adaptation, where parents . . . learn to live without undue stress.<sup>1</sup>

In a study that typifies much in the literature, the author<sup>5</sup> concluded:

The findings from the present study suggest that in cases where the behavior characteristic of grief persists beyond the initial two to three months, the grief process has become chronic because the internal process of decathexis of the lost child has not been carried through . . . A recommendation is then made for casework focusing on past fantasies, until the completion of decathexis.

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This recommendation is based on the assumption that the grief process can be concluded for the mother prior to her assuming the care of the baby.

*Chronic sorrow.* A minority of professionals have expressed disagreement with the view that the adjustment to having a mentally retarded child is time-bound. All would agree that, immediately after the diagnosis, parents go through a phase of grieving. This group would maintain, however, that even the best adjusted of parents may well find that, over time, there are numerous occasions on which the intense grieving feelings are re-evoked and experienced.

An astute and often reprinted article reflecting this minority view was written by Olshansky,<sup>9</sup> who presented a clinical picture of the repeated sadness experienced by parents of retarded children and argued that the wise practitioner would use this concept as a basis for intervention. More recently, Searl<sup>12</sup> argued that his own experience as the parent of a retarded child did not fit with the prevalent view of parental adjustment:

Parents of retarded people, the theorists tell us, learn to live with their children's handicaps. They go through stages of reaction, moving through shock, guilt and rejection to the promised land of acceptance and adjustment.

My own experience as the father of a retarded child did not fit this pattern. Instead, it convinced me that most people seriously misunderstand a parent's response to this situation. The standard view does not reflect the reality of parents' experience or lead to helpful conclusions.

Professionals could help parents more—and they would be more realistic—if they discarded their ideas about stages and progress. They could then begin to understand something about the deep, lasting changes that life with a retarded son or daughter brings to parents. And they could begin to see that the negative feelings—the shock, the guilt and the bitterness—never disappear but stay on as a part of the parents' emotional life.

Most parents, I believe, never fully resolve the complexity of feelings about their child's retardation. They don't "adjust to" or "accept" that fact, at least not in the way psychology books describe it . . .

In each case conventional assumptions about progressive stages toward acceptance did not seem to apply.

#### GOALS OF THE STUDY

It is critical—for both professionals and for parents of retarded children—to determine which of these two adjustment patterns best reflects the retarded children's parents' experiences. If the first view (of progressive stages toward a completed adjustment) is correct, professionals would: 1) facilitate the parents working through these stages, 2) discontinue services at the conclusion of the adjustment process, and 3) identify those parents who did not go through these stages as dysfunctional. On the other hand, if the minority view (that parents must expect to experience chronic sorrow) is correct, there are quite different clinical implications. As Olshansky<sup>9</sup> observed, professionals' perceptions of the parent will be different if they accept the idea that chronic sorrow is a natural rather than a neurotic reaction; *i.e.*, that sorrow is a natural response to a tragic fact. The recognition of the periodic crises a family of a retarded child may encounter over the life-span of their offspring would lead to the offering of a continuum of appropriate support services.

In order to determine which picture more accurately reflects parental experience, we conducted this study. We had three major concerns: 1) to determine how parents of mentally retarded children reported their adjustment process; 2) to specify the extent to which reported stress varied at designated points

over time, and 3) to examine whether practicing mental health professionals believe that parents experience time-bound grief or expect parents to experience chronic sorrow. Since social work as a profession has been very involved in providing support services to families of retarded persons, social workers seemed an appropriate group upon which to focus.

#### METHOD

##### *Subjects and Procedure*

The subjects included two groups—social work practitioners and parents of retarded children. Social workers (100) were randomly selected from a roster of names from Dane County Department of Social Services in Madison, Wisconsin. Thus they were included regardless of their position: *i.e.*, supervisor and social worker aides. Names of parents were obtained from client listings at the Diagnostic and Treatment Unit of the Waisman Center for Mental Retardation and Human Development. The clinic is a federally-funded center at the University of Wisconsin, which offers free evaluation services while training students who are pursuing professional degrees in the area of developmental disabilities. The first 100 parents of mentally retarded children who had received evaluation services in the years 1975–77 were selected.

Questionnaires, designed for this study, were mailed to subjects, along with self-addressed return envelopes. Only 16 of the parents responded to the first mailing; 31 questionnaires were returned with no forwarding address. Telephone contacts were then made with the remaining parents, to determine the reason for their lack of response. Many parents reported having

difficulty responding because of the evocative nature of the questions. The questionnaire asked that they graph their experiences, which was uncomfortable for some parents. Theorists have observed that the mildest empathetic probing of parents' feelings inevitably reactivates an intense but transient grief.<sup>3</sup> The subject of the questionnaire, chronic sorrow, may have re-stimulated the very feelings we were trying to define. Those who agreed to it by phone (38) were sent a second mailing. This effort produced 16 additional returns. Ultimately, there were completed questionnaires for 32 families.

The social workers returned 32 questionnaires after the first mailing. No effort was made to gain additional responses.

##### *Questionnaire*

The authors designed the questionnaire used in this study to examine parents' experiences of time-bound grief vs. chronic sorrow. The questionnaires sent to social workers and parents differed in only one respect: We asked social workers to depict their expectation of how *parents* adjust to having a retarded child. In contrast, we asked parents to indicate how they really felt. The questionnaire had three parts: a free-form graph for depicting the adjustment process, a structured graph, and a direct question (Do you experience chronic sorrow?). The contrasting notions of time-bound adjustment and chronic sorrow were explained to social workers and parents as follows:

We are interested in the feelings that parents of retarded children experience. Professionals have written about two differing patterns parents might experience in coping with the event of having a retarded child: one is that after the initial shock

and sadness wear off, one gets gradually adjusted and the pain decreases. The other thought is that the painful feelings never disappear and, in fact, reappear with other crises along the way of the child growing up . . .

The questionnaire showed sample graphs depicting these two processes, on which parents' feelings were charted over time, with "awful" as the low point and "just great" as the high point.

Based on what they (or their clients) had experienced, subjects were first asked to draw a free-form graph indicating the effect of time on their feelings. Visual inspection of these graphs enabled us to determine whether subjects' perceptions of parents' experiences seemed most similar to time-bound adjustment or chronic sorrow. In the second part of the questionnaire, subjects were asked to graph how they (or their clients) felt at ten specific developmental crisis points:

1) Diagnosis (official news of retardation from a specialist). 2) Child should have begun walking (12-15 months). 3) Child should have begun talking (24-30 months). 4) Younger brother or sister overtakes the retarded child's abilities. 5) Serious discussion of placement of retarded child outside the home (or actual placement). 6) Beginning of retarded child's attending public school, thus publicly labeled as different. 7) Management of a crisis (behavior problems, seizures, health problems, etc.) unique to the retarded child. 8) Onset of puberty (in which the body is clearly more developed than the mind). 9) Retarded child's 21st birthday, when adulthood and independence from parents are generally acknowledged. 10) Serious discussion about guardianship and care for retarded child when parents die.<sup>14</sup>

The structured graphs enabled us to construct two indices of social workers' and parents' perceptions of adjustment to a retarded child: 1) The *Total-Distress Measure*, consisting of sums of the ratings of how happy or sad parents were perceived to feel at each of the ten

crisis points. 2) *Parent Distress Early vs. Late in the Child's Development*, in which sums of ratings of parents' feelings at five early points (Points 1, 2, 3, 4, and 6) were contrasted with sums of ratings at three later points (Points 8, 9, and 10). (Point 5—serious discussion of placement—and Point 7—management of severe problems—could not be classified as specifically early or late in the child's development.) These contrasting measures were designed to tell whether social workers expected parents to experience time-bound adjustment (in which case they would see parents as being upset at the early points, far happier at the later ones) or chronic sorrow (parents rated as being upset early and late in their child's development).

*Direct question.* Finally, the questionnaire asked directly whether parents do in fact experience what Olshansky<sup>9</sup> termed "chronic sorrow." Polarized responses of "yes" or "no" were offered following a lengthy description of the concept:

In the field of mental retardation, there's a phrase that's often used to describe how parents of retarded children feel—"chronic sorrow." Things can be going along just fine, and suddenly out of the blue you might begin feeling sad again. Sometimes it may be little things that set off these feelings—those moments may be trimming the Christmas tree, hearing a special piece of music, seeing your child outside playing; or they may come at the big life changes, which bring back strong feelings of sadness—such as having your retarded child begin public school, or deciding about placement.

## RESULTS

The findings are presented paralleling the structure of the questionnaire: 1) the free-form adjustment graphs, 2) the structured developmental crises graphs, and 3) the direct question.

Table 1  
PARENT (N=32) AND SOCIAL WORKER (N=32) RESPONSES ON FREE-FORM AND  
STRUCTURED GRAPHS

DEVELOPMENTAL CRISIS POINTS	SOCIAL WORKERS	PARENTS	SD	F
Diagnosis	-4.08	-3.95	1.23	.17
Time for walking	-2.77	-1.33	2.06	7.81**
Time for talking	-2.80	-2.33	1.92	.98
Sibs surpass child	-2.53	-1.41	1.94	5.34*
Alternative placement	-2.88	-2.79	1.79	.04
Entry into school	-2.34	-.96	2.27	5.90*
Management crisis	-2.05	-2.52	1.86	1.00
Onset of puberty	-2.07	-2.02	1.38	.02
21st birthday	-2.03	-2.93	1.37	6.94*
Guardianship	-2.05	-1.64	1.62	1.03
SUMMARY MEASURES				
Type of Free-Form Graph	1.91	1.88	.32	.16
Structured Graph: Total Distress Index	-25.60	-21.89	11.30	1.73
Structured Graph: Distress Early vs. Late in Child's Development (Weighted)	-6.72	8.29	17.62	11.62**

\*  $p < .05$ ; \*\*  $p < .01$ .

#### Free-Form Graphs

First, parents and social workers were asked to indicate their adjustment in a free-form style on a graph. Three judges assigned each graph to one of four categories: 1) gradual smooth line of ascent, 2) bumpy line of ascent, 3) smooth line of feelings with no ascent, 4) bumpy line of no ascent. The latter two categories were considered to be depictions of chronic sorrow. In rating the 64 graphs, there were four disagreements; these were discussed, agreed upon, and included in the analysis.

Only one-fourth of the parents indicated that they had experienced time-bound grief, by free-form graphs judged to be in one of the first two categories. The rest of the parents, by far the majority, depicted a series of ups and downs with no general upward course. Parents' and social workers' free-form graphs did not differ in form ( $F = .16$ , 1; 62 *df.* NS). Evidently these profession-

als were sensitive to the fact that parents experience chronic sorrow.

#### Structured Graphs

In the second part of the questionnaire, parents (and social workers) were asked to indicate how they had felt at ten clearly demarcated developmental points in the child's life. We ran two planned comparisons (see Hays,<sup>4</sup> for a description of this procedure). First, we asked: "Do parents and social workers differ in their overall evaluations of how upsetting it is to have a retarded child?" The answer was "no." As shown in TABLE 1, overall, the social workers were quite accurate in their perceptions of parents' feelings. Social workers' and parents' ratings of their Total Distress index were virtually identical. (Main Effect  $F = 1.73$ , 1; 62 *df.* NS)

Secondly, we asked: "Did parents and social workers differ in their reports of how upsetting early vs. later experi-

ences were?" We expected that they would. We thought that both groups would accurately perceive how upsetting the early experiences were (diagnosis, walking, talking, the child's being surpassed by sibs and going off to school), but thought that social workers would markedly *underestimate* how upsetting continuing life crises were (the child's entering puberty, the 21st birthday, and guardianship). In brief, we expected that therapists would be expecting parents to experience only time-bound grief, while in fact parents were enduring chronic sorrow.

The findings indicated that the two groups did differ markedly (Interaction  $F$ s for early vs. late experiences—weighted equally = 11.62, 1; 62  $df$ ,  $p < .001$ ). Social workers tended to overestimate how upsetting the parents' early experiences were. They underestimated how upsetting the later experiences were.

Parents and professionals diverged within perceptions most significantly at four of the ten points. At three of these points, the social workers assumed parents would be more upset than they really were. These were: when the retarded child would normally have been expected to walk ( $F = 7.81$ ,  $p < .01$ ); when the younger normal sibling surpassed the retarded one in functioning ( $F = 5.34$ ,  $p < .05$ ); and when the retarded child entered school in a special class for exceptional children rather than a normal class ( $F = 5.90$ ,  $p < .05$ ). In contrast, the social workers markedly underestimated how upsetting the child's 21st birthday was to parents ( $F = 6.94$ ,  $p < .01$ ).

Social workers were most accurate at estimating stress reported by the parents at three of the ten points: time of

diagnosis, time of placement (or serious discussion of placement) of the retarded dependent, and time of puberty. These periods were acknowledged by both groups as being painful.

#### *Direct Question*

Social psychologists often argue that, if you want to know something, the best way to find out is simply to ask. In this case that seems to be true. In response to the question, 63% of the parents and 65% of the social workers said yes, these parents do experience chronic sorrow.

#### DISCUSSION

The results of this study support the minority of professionals' view about the adjustment of parents of mentally retarded children. That is, chronic sorrow rather than time-bound adjustment characterizes their experience. Both in the request to draw a graph depicting their feelings and in response to a direct question, most of the parents indicated that there were various periods of stress and sadness over time.

They did not, however, indicate that the sorrow was continuous. Instead, it seems that it is a periodic phenomenon. In the free-form graphs the parents drew peaks and valleys of their adjustment. There were no graphs by parents showing a flat, total, and unchanging sorrow (although there were several such by social workers). The structured graphs assumed the periodicity of grieving. A list of potential crises was presented to the parents, based on the first author's theoretical formulation.<sup>14</sup> Each point related to a developmental stage of the affected child. The child's deviance from normal performance at these stages was considered to precipitate a period of stress for a family. The parental responses to this part of the ques-

tionnaire showed no decrease in the intensity of the emotions experienced with the passage of time. Instead, the level of intensity seems to be a function of the particular developmental stage, as well as of the individual coping strengths of the family.

Several problems may limit the use of the findings of this small study. The sample of parents upon which these findings are based is a nonrandom one with a possible bias. The names of the parent subjects were obtained from clinic records. This may skew the results toward encountering troubles over time when contrasted with all parents of mentally retarded children, because the access to this part of the population of parents is relatively easy. To check this problem we reviewed the results of a pilot study. A small group of eight parents from a parent organization, who volunteered to be involved in another project,<sup>13</sup> had been asked to also respond to this questionnaire. This group was less likely to be biased towards difficulties. Their responses were, however, similar to those of this study (*i.e.*, six of the eight drew graphs of chronic sorrow rather than time-bound adjustment.)

A second concern about the sample is the low number of respondents among parents who were contacted for the study. Although none of the pilot study subjects raised objections to the questionnaire, many of the total sample who were reached by phone indicated ways in which the questionnaire had made them uncomfortable. Our guess about the meaning of this is that our sample was a) coping better than the nonrespondents, b) able to distance themselves sufficiently from their own adjustment process to respond with perspective, and c) neither intimidated nor

alienated by the request to graph their feelings.

The request for graphing of feelings may itself have limited the number of respondents; graphing may have seemed an unnatural reporting of affective information, thereby limiting the validity of the findings. The direct question, "Do you experience chronic sorrow?" was considered to be a measure of internal consistency on individual parents' responses, which could help to dilute this concern. Indeed, those who graphed chronic sorrow, also said that they experienced chronic sorrow. Another internal measure of the validity of the responses were the many comments elaborating on topics of the questionnaire. Typical comments included the following:

Perhaps disappointing would be a better word than sorrow. I firmly believe we did have many peaks and valleys. There is sadness, but many joyous and funny moments too.

When I first realized my son was lagging I felt very guilty and wondered if I had somehow caused it. Then I began to tell myself that I'm too inept to cope with a retarded child, all the while I was coping with him.

I find each new crisis or situation has to be dealt with and I always pray our family has enough strength and courage to work through it. So far we have been able to keep the pace but it isn't easy.

#### *Clinical Implications*

Our findings suggest, first of all, that chronic sorrow does not seem to be an abnormal response; rather, it is a normal reaction to an abnormal situation. To treat it as such entails allowing for periodic grieving, and perceiving that as a strength in coping. At those moments, when the child's abnormality is exaggerated in the parent's perception by the child's deviance from normal developmental milestones, it is especially

likely that the initial feelings of confusion and disappointment will be rekindled. Secondly, a continuum of services over the life span of the mentally retarded person should be provided. These should be adapted to the predictable developmental crises of families of retarded children pinpointed in this study. Finally, these periods may be primarily characterized by needs for information on management. These would differ according to each stage. Creative and energetic outreach programs offering support and information might prevent or alleviate the difficulties that ordinarily plague these families.

To some professionals who have worked extensively with families of mentally retarded children these recommendations may seem self-evident. However, they are based on data that has not been obvious to the majority of professionals who write about parents. Nor were the findings self-evident to the social workers surveyed in this study. In general, the social workers correctly estimated the overall degree to which the parents experienced distress. They agreed with the characterization of periodic upheavals and responded affirmatively to the direct question about chronic sorrow at approximately the same rate as the parents. This was more accurate than the literature would lead one to expect. However, in examining social workers' perceptions of responses over time, there was a significant underestimation of the intensity of the parents' difficulties in the later stages. Social workers and other professionals have primarily worked with parents of younger retarded children. This is partly a function of early institutionalization.

With the advent of deinstitutionaliza-

tion and the increase in school and community programs, there is a greater likelihood that the mentally retarded person will remain in the community. The findings of this study are particularly relevant to clinical practitioners as they plan programs for and work with families of older retarded persons.

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## SEX EDUCATION FOR NEGLECTED YOUTH:

Retarded, Handicapped, Emotionally Disturbed and Learning Disabled

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A few small extremist groups have mounted the most successful attack on American public education that modern times have witnessed. We have been an audience to the remarkable phenomenon of dozens of state legislatures and hundreds of boards of education forbidding or abandoning what was in most cases (at best) carefully conservative sex education programs. And who suffers the most? The handicapped child (such as the deaf, blind, crippled and neurologically impaired) -- often cut off from "the consensual validation of ideas from peers and teachers,"<sup>1</sup> the mentally retarded child, the dyslexic and the non-readers for whatever reason and perhaps the largest group -- the so-called disadvantaged or poverty youth. Handicapped children with the same emotions and sexual drives as their "normal" counterparts but with less knowledge, as well as the disadvantaged youth with all their "experience," are by far the most vulnerable segment of our youth population with regard to sexual exploitation and pathology.

Parents seem to operate on the false assumption that the less an exceptional child knows about sex, the less likely he will be irresponsible sexually. Educators seem to operate on the assumption that they have enough trouble teaching reading; why get into "sensitive" issues? And yet, these youth experience the same physical and emotional changes that "normal" children do, as well as the anxiety which often accompanies adolescence. Thus, exceptional children must cope with all the emotional conflicts of their normal teenage counterparts in addition to those produced by their handicaps. According to Dr. Jean L. Bloom:

... control of sex impulses and the need for sex role identification create anxieties (even) in normal adolescents ... The combination of anxieties from the various sources could be at a high enough level to interfere with the learning and growth processes.<sup>2</sup>

The John Birch Society and the Christian Crusaders make no assumptions. Their arrogance has led to enormous success. Already, Congress and state legislatures have placed or may place legal restrictions on sex education in the public schools. Local school boards face the same situation.

The isolated among our handicapped cannot afford to be naive about sex. The retarded and their families must be prepared early for making decisions about such matters as contraception and voluntary sterilization. It is a ludicrous experience to read currently available material about sex education for retarded children which focuses on cleanliness, morality and good health habits. As Medora S. Bass states:

Today 95 percent of the retarded are living in the community, and they are often the most difficult to reach with birth control services and sex education programs. Many of the teenage retarded are dropping out of school, pregnant ... Society expects the retarded to adopt socially acceptable behavior and to control their sexual impulses, yet society offers them almost no training to handle sex in a responsible manner. Few schools have family life-sex education for the special class student and it is particularly difficult for parents of the retarded to tell their children about "the facts of life."<sup>3</sup>

## SEX EDUCATION FOR NEGLECTED YOUTH CONTINUED

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As for disadvantaged youth who tend to have sexual experiences early in their adolescence, we are finding out with grim statistics that it is precisely this large segment of our population that know the least about conception, contraception and the dangers of venereal disease.

The question is not whether we should have sex education for the handicapped, but whether we consider "educational" the information received from sexploiting popular media, pornography, myths from "gutter" discussions, graffiti in our public school bathrooms, and premature and sometimes involuntary sexual experiments. Exceptional youth must be taught about conception, contraception and venereal disease. They must be able to discuss premarital sexuality in the context of mature decision-making and moral dilemmas. They must learn that it is wrong to risk premarital pregnancy, wrong to risk getting venereal disease and wrong to have sexual relations for exploitation purposes. They must form a system of values so that they can make decisions of a moral nature. They must know that masturbation can be healthy, but that at times it can be inappropriate.

Genetic counseling and voluntary sterilization must certainly be discussed among older exceptional (especially retarded) youth and their parents. In this area, I strongly agree with the position taken by two eminent authorities, Laidlow and Bass:

Voluntary sterilization can and does contribute to mental health; by helping to keep the population increase in line with developing resources; by reducing the anxiety caused by fear of unwanted pregnancies; by preventing children from being born to irresponsible parents with resultant neglect and social ills; by allowing the retarded to marry and lead more normal lives; by preventing some hereditary abnormalities. All this can be accomplished without unfavorable psychological effects and with a high ratio of satisfaction.<sup>4</sup>

Special education has a special responsibility to include sex in its curriculum. Now is the time to be counted among those who are opposed to "control" of public education by extremists as well as by some religious denominations with particular and idiosyncratic notions about sexuality. People are entitled to practice their own religious beliefs but have no right to interfere with public discussions about these beliefs, especially when it involves something as necessary and long overdue as sex education for the handicapped or disadvantaged child.

#### Mental Retardation and Sexuality

Professionals are gradually being forced to recognize what almost everybody knows - the so-called mentally retarded are not exceptional in their sexual impulses. Whereas, in the past, we "all" joined everybody else in a crusade against these impulses, a very small group of pioneers are saying to all of us - that the mentally retarded are human beings entitled to expression of impulses as we all are. Like the rest of us, they are entitled to be sex educated in a manner that does not make the presumption that only containment of sexual impulses is valid.

## SEX EDUCATION FOR NEGLECTED YOUTH CONTINUED

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In all likelihood, what "we" (the so-called normal) have most in common with the mentally retarded are hang-ups, guilt and fantasies about and/or desires for sexual expression. Yet, the vulnerability of the mentally retarded makes the case for sex education even more compelling than for most people.

We need to consider that some of the best education is done by "unqualified" people. I have not noticed that teachers, nurses, doctors are, in general, especially good sex educators. We have overstated the importance of expertise when what counts is attitude and good will. The problem is with a society, or a school, or an institution that permits its employees to operate in terms of their own levels of prejudice or ignorance. For example, in several hospitals in New York State, nurses are wearing buttons which read "Abortion is Murder" and are harassing women who come to these hospitals for abortions. Clearly, the hospital administration is responsible for permitting such behavior.

In an institution for the mentally retarded where I recently addressed the staff about sex education, aides and nurses were invited to submit questions in advance of my presentation. The majority of the questions could be summarized as follows: How can we stop masturbation? A considerable amount of staff energy was devoted to curb the masturbators. When this institution was composed of only male residents, much of the available energy was spent in punishing or curbing homosexual behavior; but now with females added as residents, the main thrust is against any expression of heterosexuality. Administrators, school and others blame the staff. Staff is everywhere said to be conservative, yet it is the administrators who are to blame because of their role in selection of staff. There are also numerous examples of staff who are "fired" because they do not maintain the traditions of conservatism that staff are traditionally supposed to maintain.

The fact is that the retarded (and, in many respects, normals) do not need to know many facts about sex. The information that needs to be imparted can be given in a few minutes (repeated at different levels and times).

At the risk of demoralizing "the staff" of any institution in this country, let me suggest that this is what we need to communicate:

- 1) Masturbation is a normal expression of sex no matter how frequently it is done and at what age. It becomes a compulsive, punitive, self-destructive behavior largely as a result of guilt, suppression and punishment.
- 2) All direct sexual behavior involving the genitals should be in privacy. Recognizing that institutions for the retarded are not built or developed to ensure privacy, the definition of what constitutes privacy in an institution must be very liberal. Bathrooms, one's own bed, the bushes, basements are private domains.
- 3) Anytime a physically mature girl and a boy have sexual relations, they risk pregnancy.
- 4) Unless they are clear about wanting to have a baby and the responsibility that goes with child-rearing, both the male and female should use birth control.
- 5) Until you are, say 18, society feels you should not have intercourse. After this, you decide for yourself - providing you use birth control.

## SEX EDUCATION FOR NEGLECTED YOUTH CONTINUED

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- 6) Adults should not be permitted to use children sexually.
- 7) The only way to discourage homosexuality is to risk heterosexuality.
- 8) In the final analysis, sexual behavior between consenting adults (regardless of mental age) and whether it is homo or hetero, should be no one else's business - providing there is little risk of bringing an unwanted child into this world.

The following additional factors need to be considered: 1) We need greater acceptance of abortion as a safe, legal, moral alternative to bringing an unwanted child into this world. 2) Voluntary sterilization can be a desirable protection for some retarded individuals who can function perfectly well in a marriage if there are no children.

What is needed for people who work with "exceptional" youth is for them to begin to show some honesty, courage and integrity in facing squarely the issues of human sexuality. And right now we should spread the word that 1) staff should not condition girls of any age to believe that every woman wants and must have babies to be "normal"; 2) masturbation is all right; and 3) sex is enjoyable (however, use protection).

If we provided the above information, we would be doing almost all the sex educating that we need.<sup>5</sup>

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Incest: the family affairSEXUAL ABUSE: THE THINGS TO LOOK FOR

(This article was abstracted from the Urban and Rural Systems Associates, RUSA, Contract to Develop Child Abuse and Neglect Materials.)

## FROM THE CHILD:

1. Regressive behavior--molested children (especially young children) may withdraw into fantasy worlds. Sometimes these children give the impression of being retarded when, in fact, they are not.
2. Delinquent or aggressive behavior--molested children (especially pre-teen and teen) often act out their anger and hostility on others.
3. Sexual promiscuity--the sexually molested girl or boy may be sexually promiscuous, and their behavior may become very apparent not only to the school, but to the entire neighborhood.
4. Confiding in someone--a molested girl may confide in a special friend or teacher. These confidences may not take the form of direct information about being molested, but may involve such statements as "I'm afraid to go home tonight," "I want to come and live with you," or "I want to go and live in a foster hom."
5. Poor peer relationships--molested children (if molestation has occurred over a long period of time) may not have social skills or are too emotionally disturbed to form peer relationships. The parent(s) has a vested interest in keeping them emotionally isolated. The child may have such a poor self image (the bad me concept) that it overshadows his whole existence.
6. Prostitution--the middle-to-older, molested teenager may turn to prostitution.
7. Extremely protective parent--in incestuous relationships, the parent involved may become exceedingly jealous of the child, often refusing him/her any social contact. The parent is afraid the child will tell, but even more afraid of losing the child to others. A father, for example, may pick up his teenager daughter at school every day, and become furious if he sees her talking to anyone.

8. Unwillingness to participate in physical recreational activities— young children who have been highly sexually stimulated or forced to have sexual intercourse with an adult, may find it painful to set in their chairs in school, or to play games which require a good deal of movement.

9. Runaways—teenagers who have been molested sometimes resort to escape and run away from the home.

10. Drugs—teenagers who have been molested may resort to escape through the use of drugs.

11. Confession--the child who has been molested may seek to report the offense. A number of incest cases where a teenager reports may be fictitious, but a thorough investigation should be made to determine the validity of the statement.

#### AT THE DOCTOR'S:

1. Bruises in external genitalia, vagina, or anal regions.
2. Bleeding from external genitalia, vagina, or anal regions.
3. Swollen or red cervix, vulva, or perineum.
4. Positive tests for either spermatozoa, pregnancy, or venereal disease.

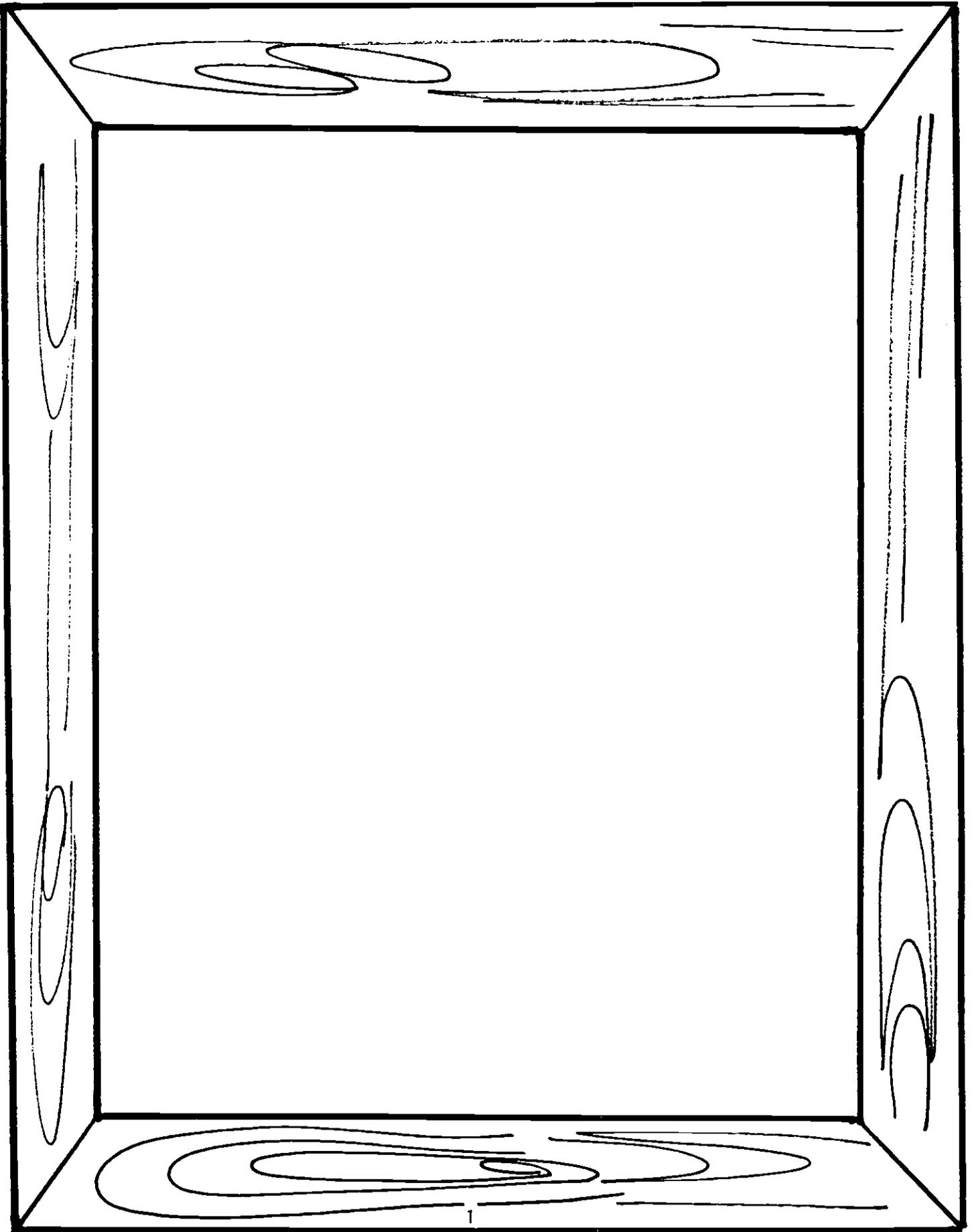
#### IN THE HOME:

1. Prolonged absence of one parent from the home.
2. Loss of one parent through death or divorce.
3. Gross overcrowding in home—insufficient sleeping space.
4. Physical proximity.
5. Alcoholism.
6. Family members lack normal social and emotional contacts outside of the family.
7. Isolation—created by the remoteness of home to other homes (in rural areas.)

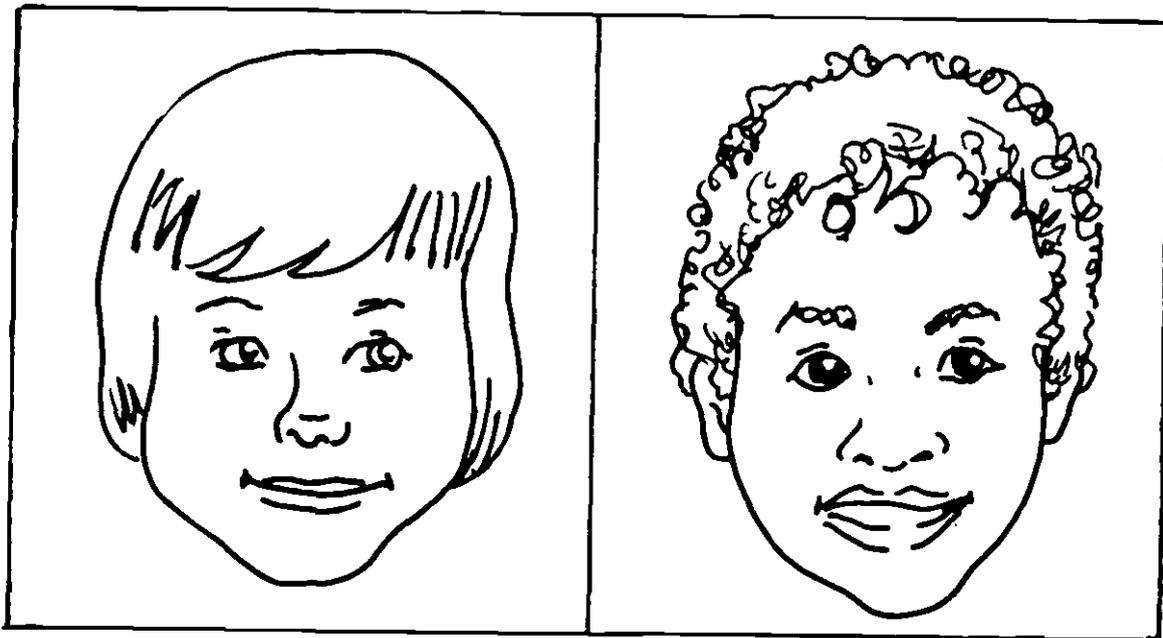
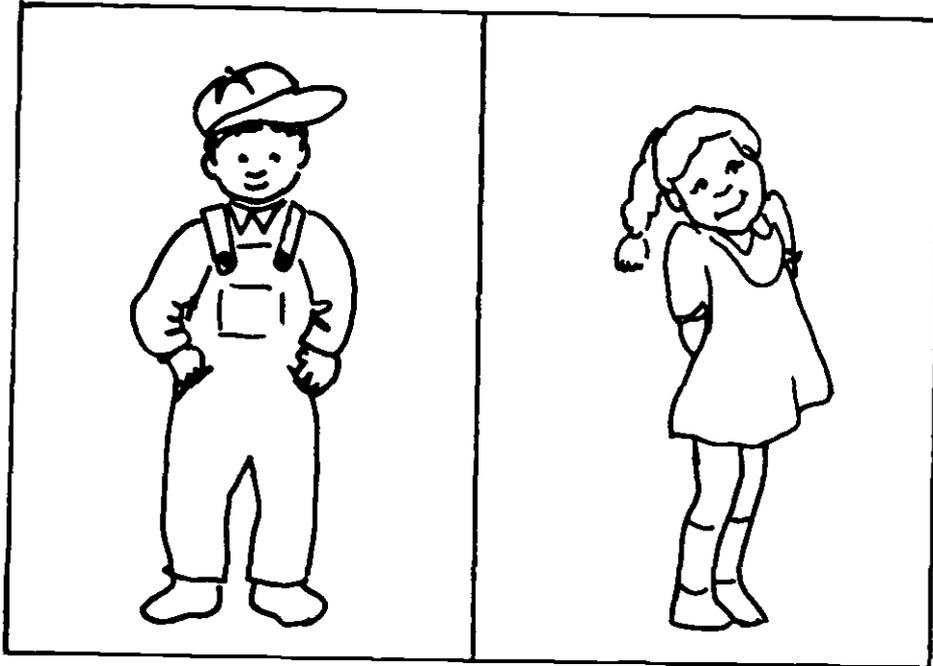


# Child's Workbook

This is me

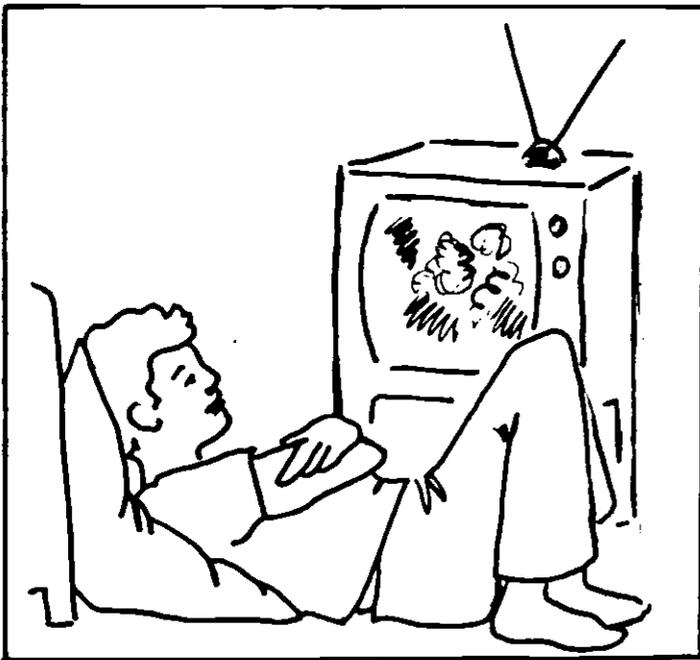


# Who am I?



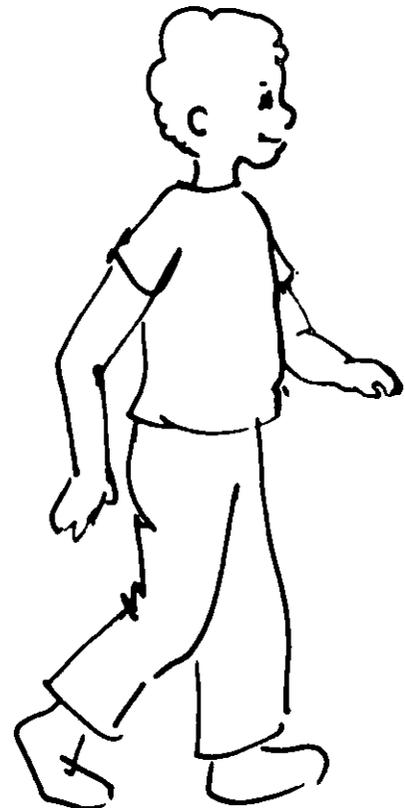
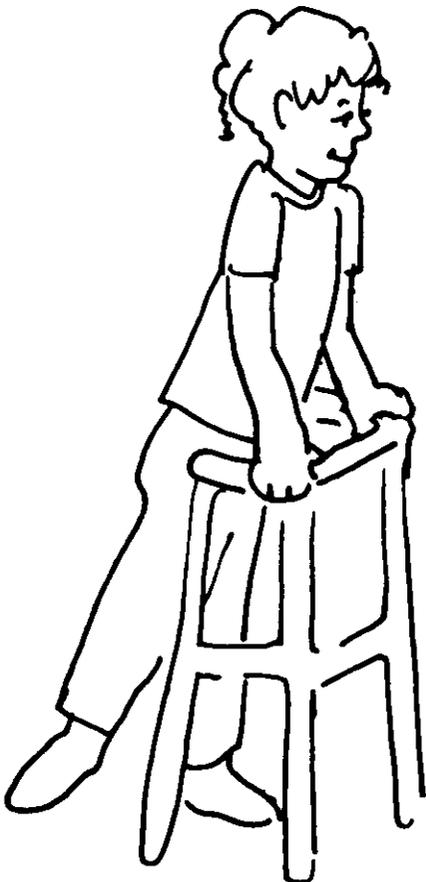
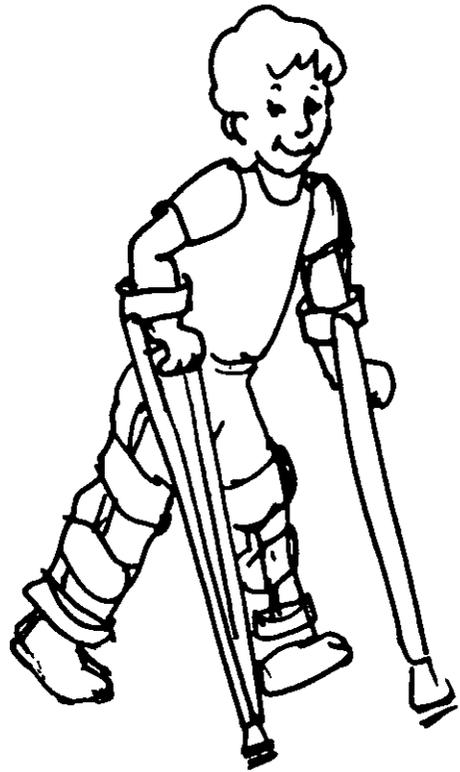
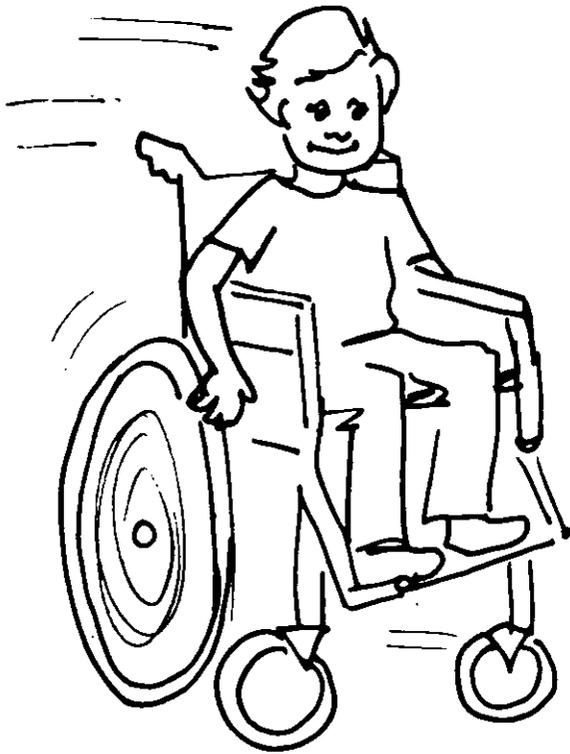
I am \_\_\_\_\_ years old

# How I look

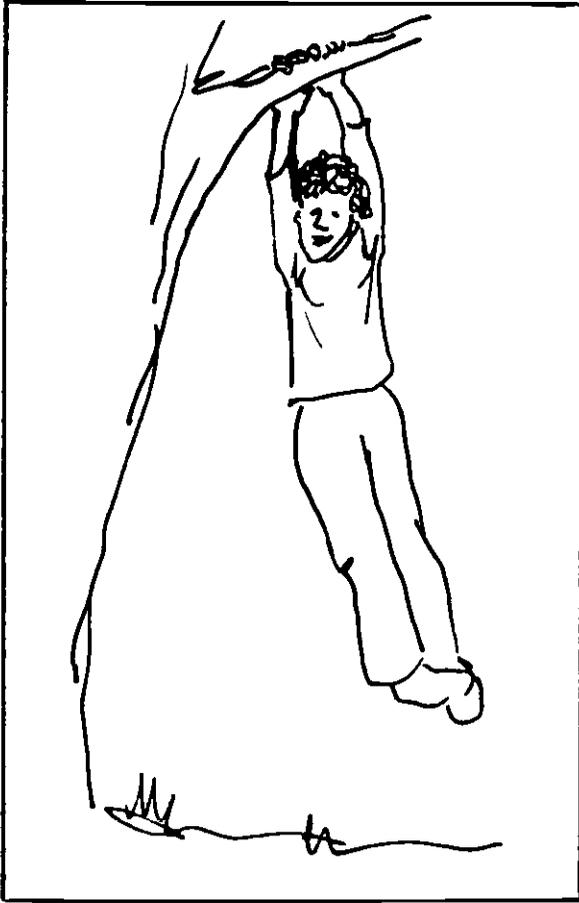


I like to \_\_\_\_\_

# I can go places



# I like to play

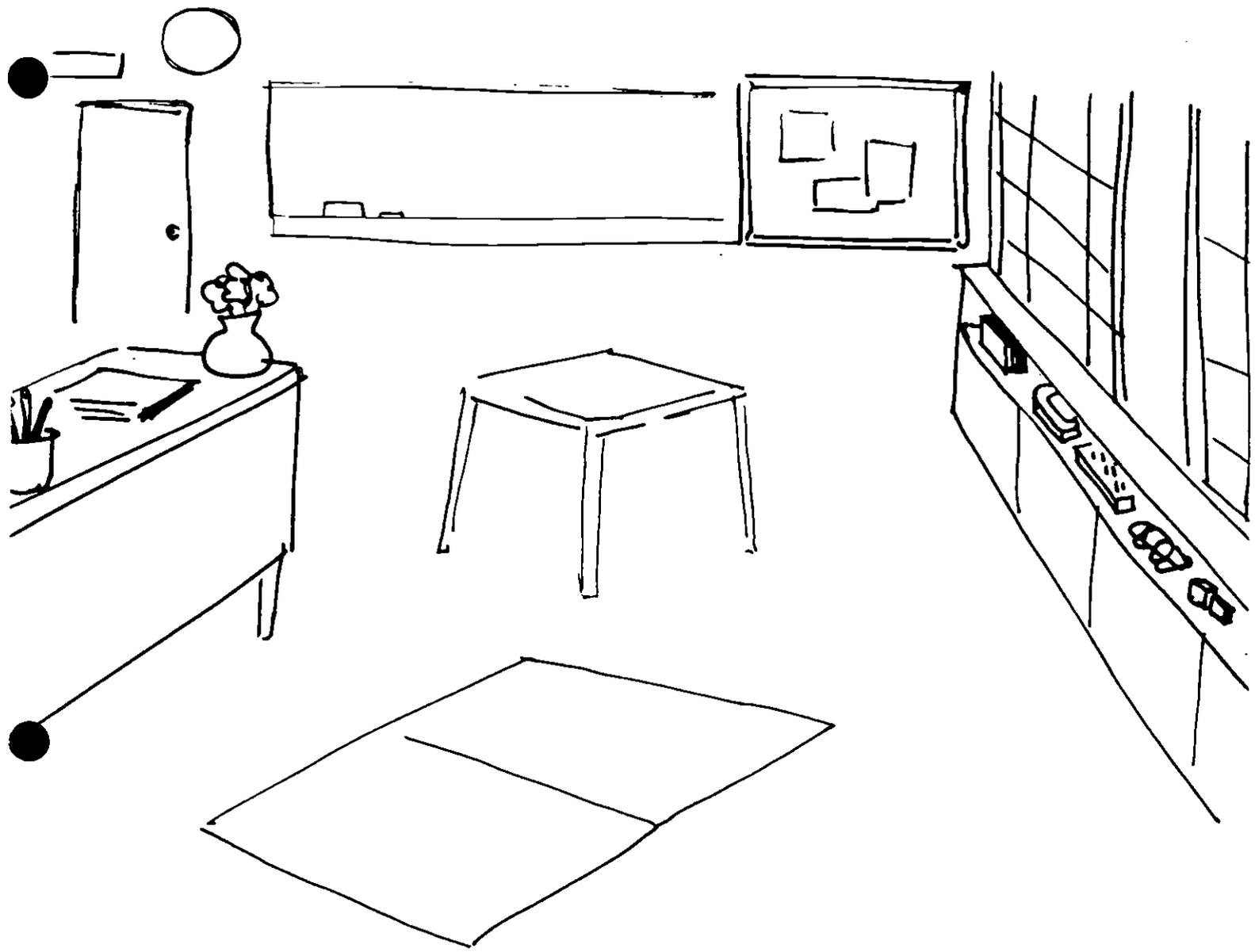


By myself



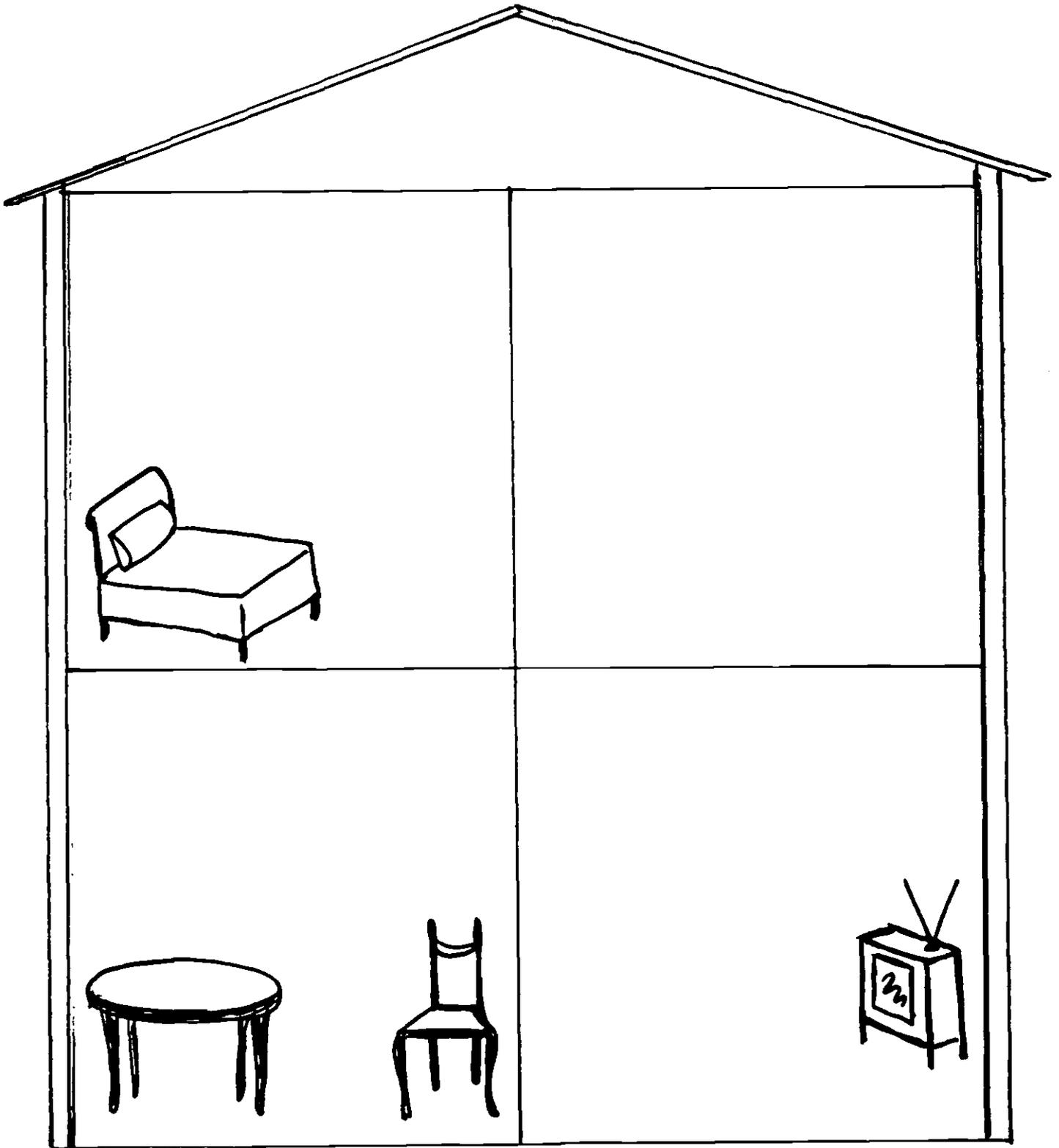
With friends

ABCDEFGHIJKLMNOPQRSTUVWXYZ



My school

# Where I Live Now

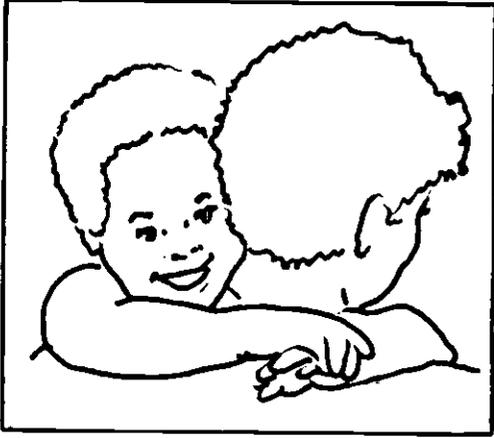


Who is here.  
What we do.

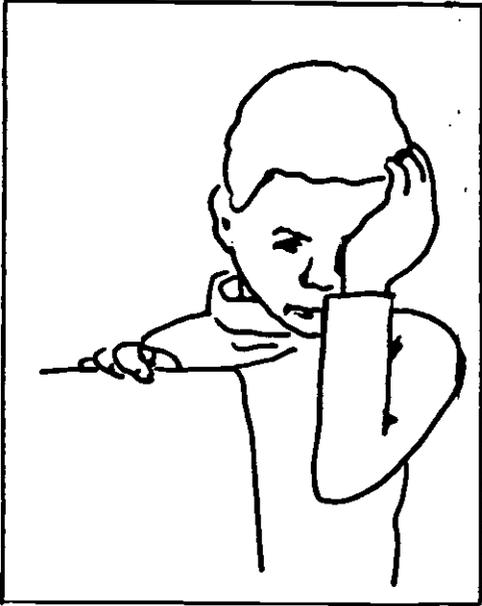
My best place

● People I live with now

# Good times



# Bad times

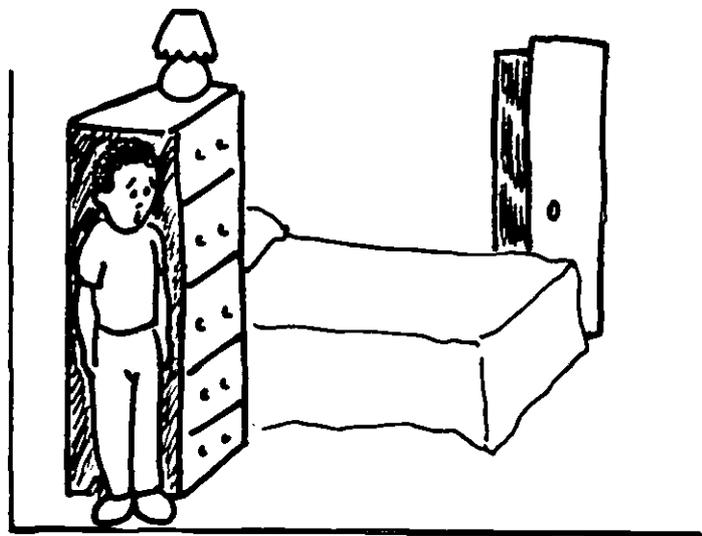
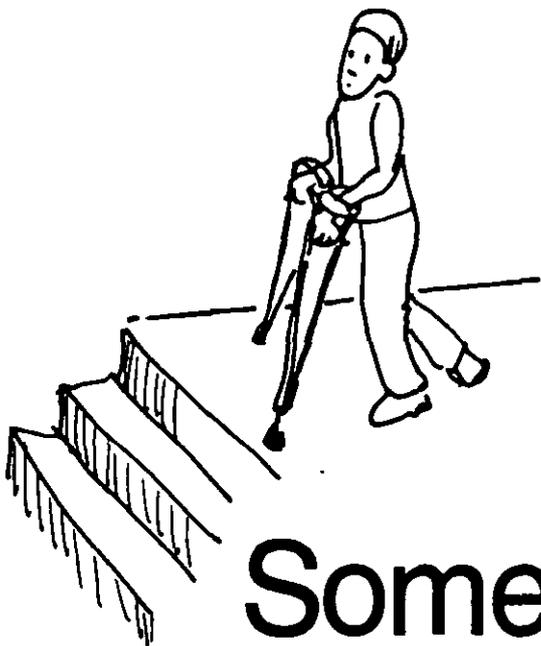


- **Things that are easy**



# ● Things that are hard





**Some things are scary**

Before I came here

I lived in another place

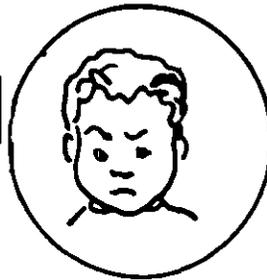
Who lived with me?

● A lot of things happened

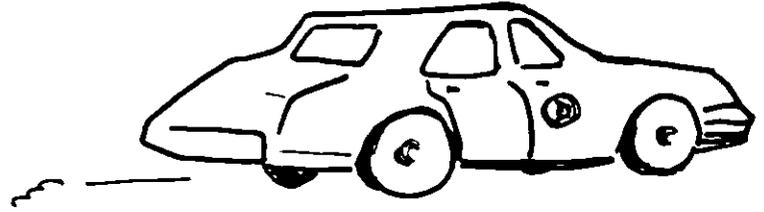
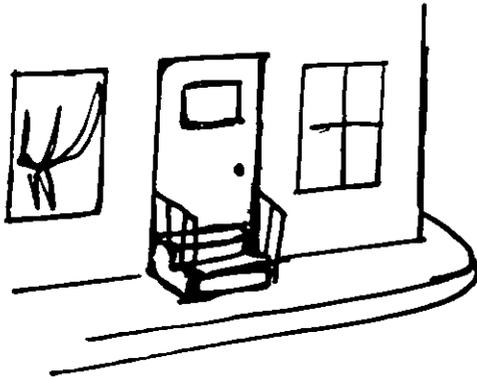


Some good

●  
Some not so good



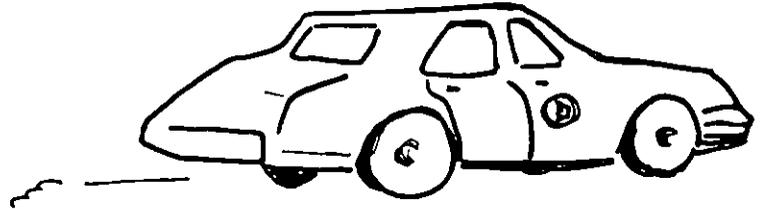
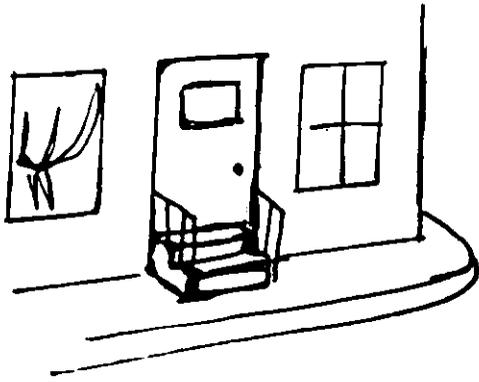
When I had to leave



I felt

● Other places I have lived

When I had to leave



I felt

I was born



on \_\_\_\_\_  
\_\_\_\_\_

I was small and cute



My mother was there

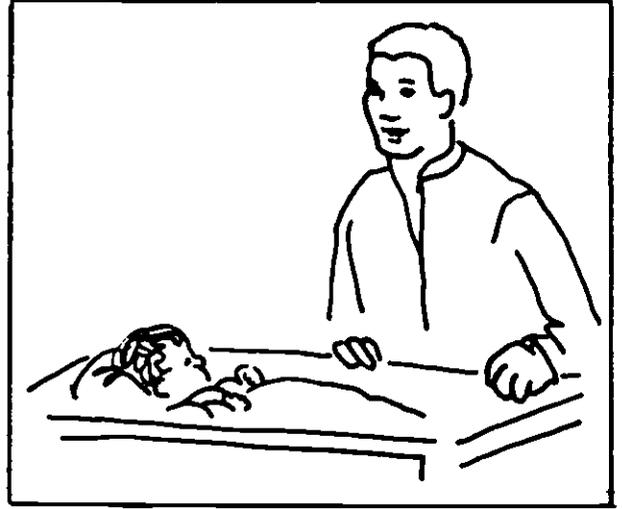
# My mother

How she looked



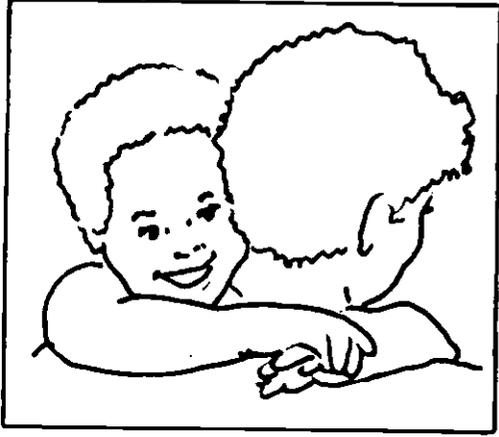
What she did with me

# My father

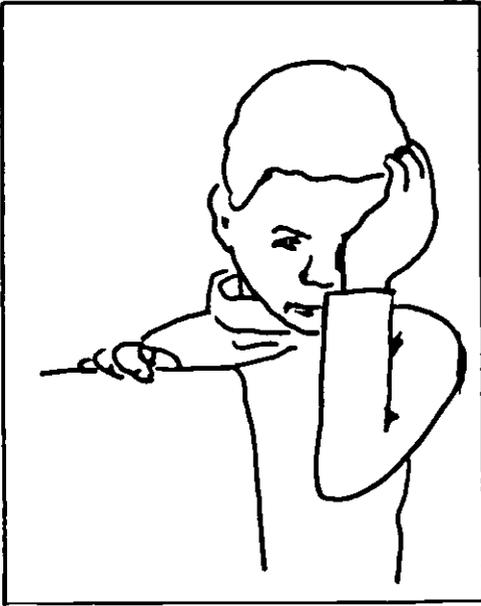


# My family

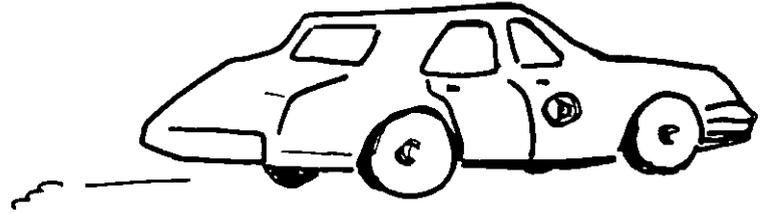
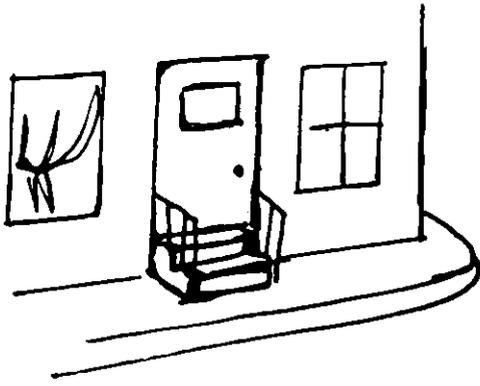
# Good times



# Bad times

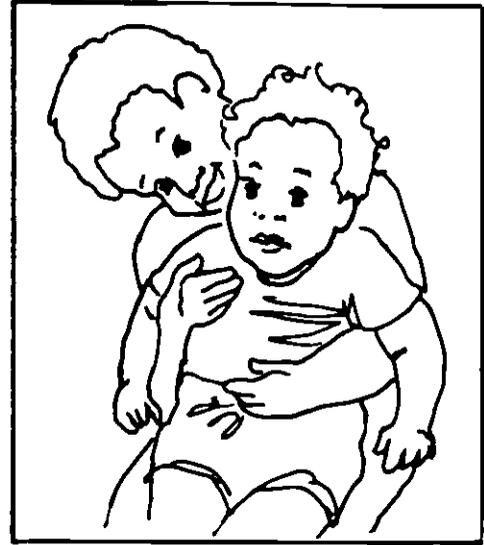


When I had to leave



I felt

Where is my family now?

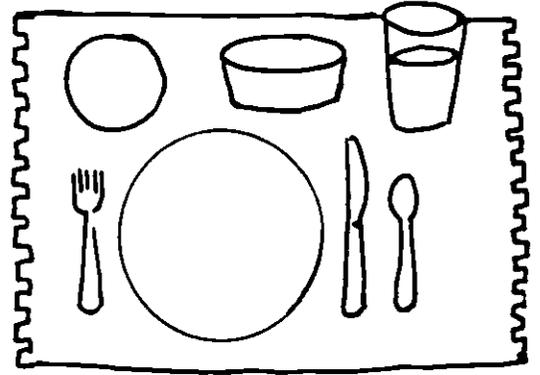


● When I'm \_\_\_\_\_ I want to. . . .

● When I'm grown-up, I think I will. . . .

●

# Why do I need a family?



●

---

My name

● I live with

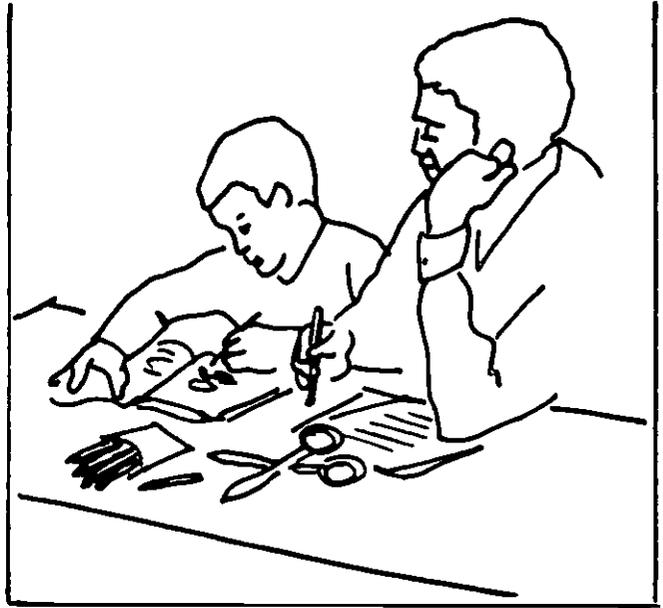
Are the names the same? \_\_\_\_\_



●

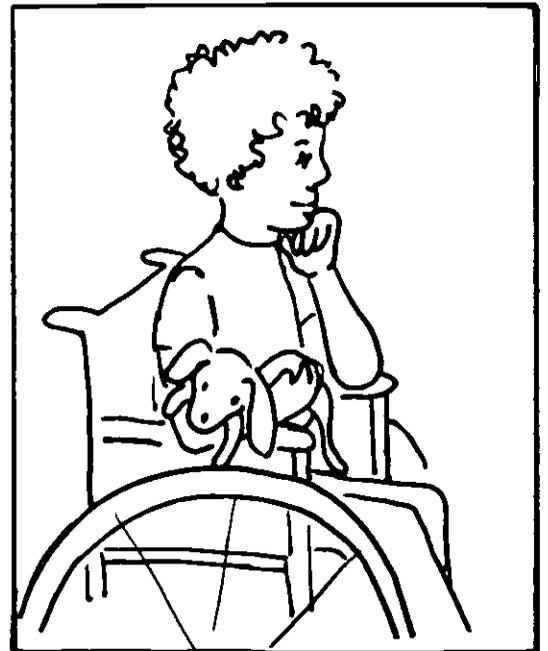
Where will I be when I'm 18?

# My social worker



- What my social worker will do

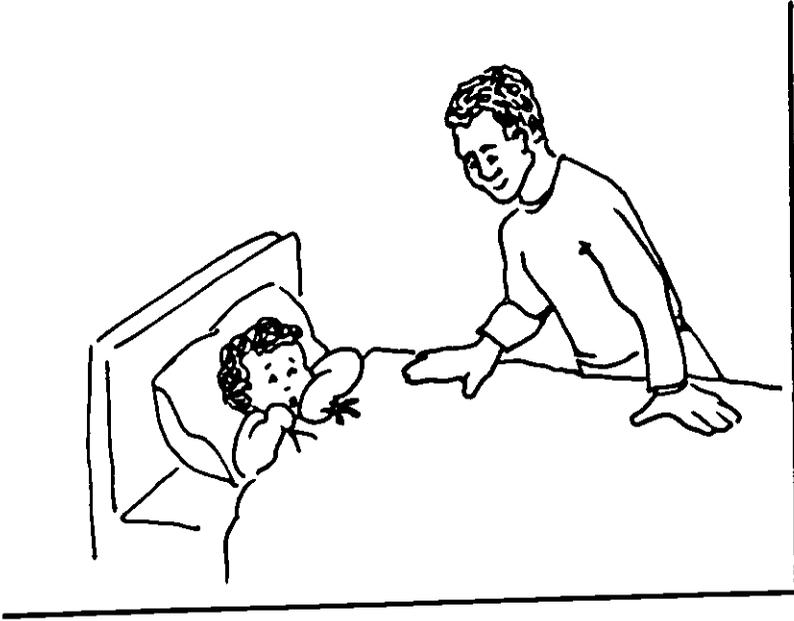
- What I can do



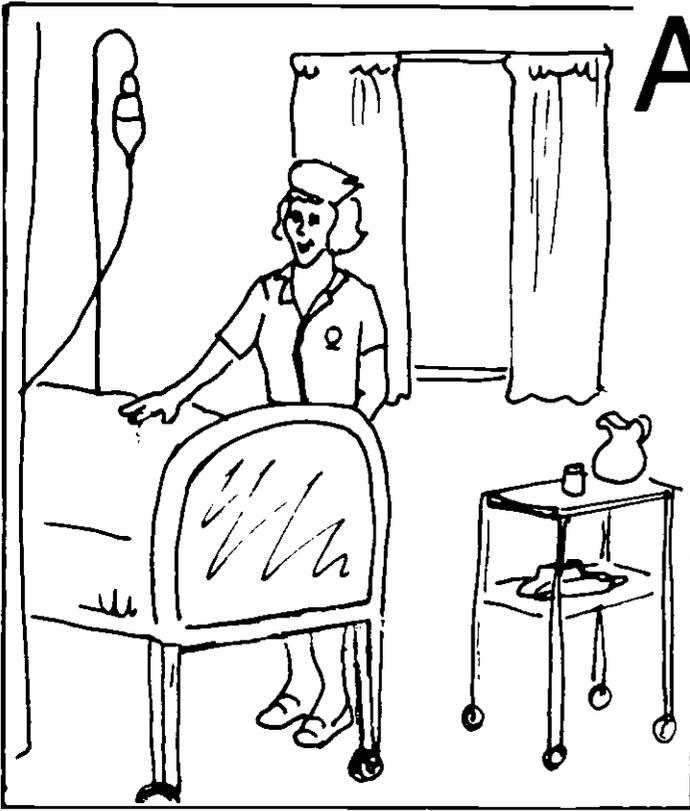
# This is home



What is happening here?



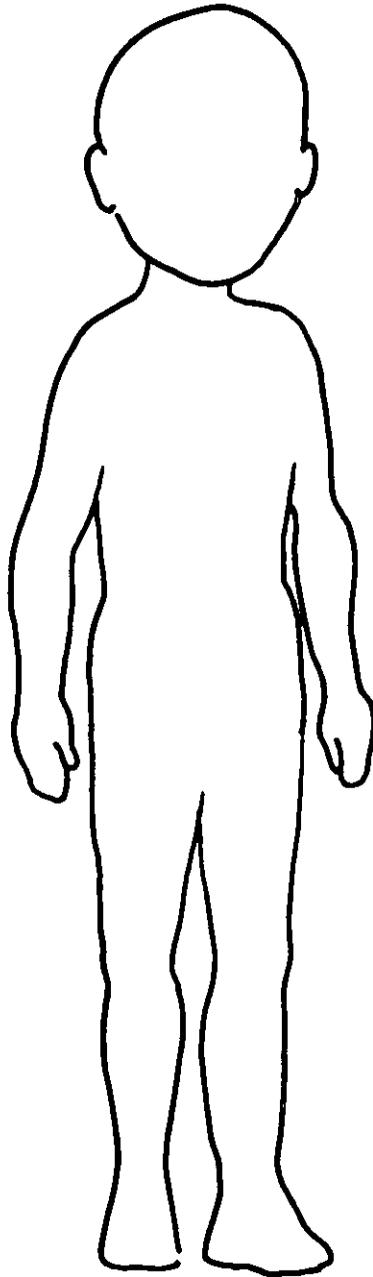
# At the hospital

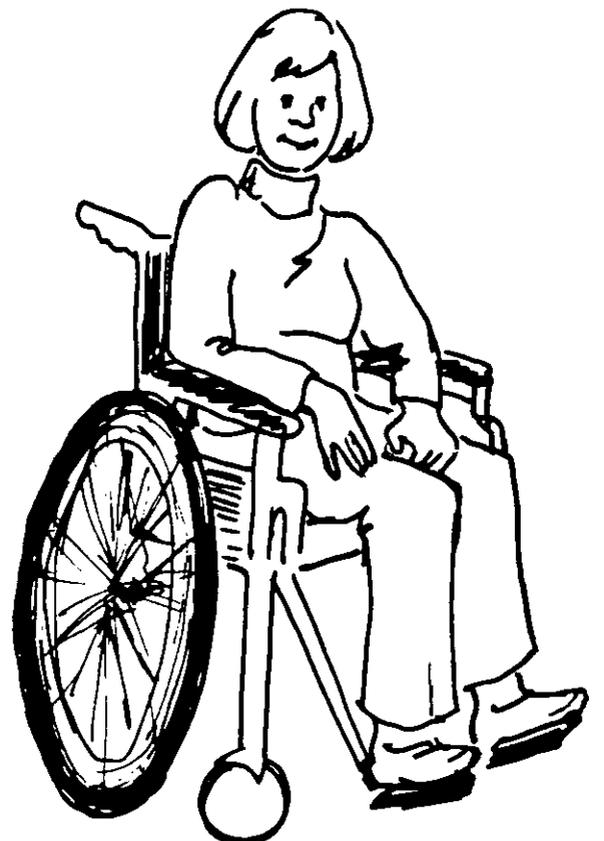


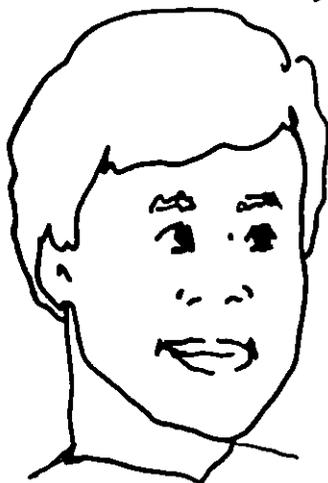
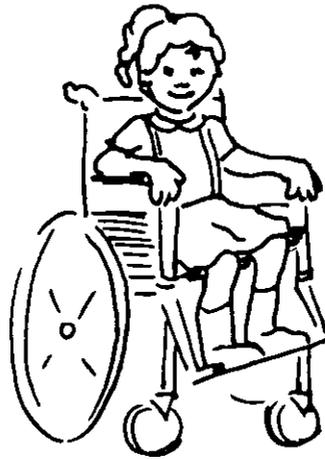
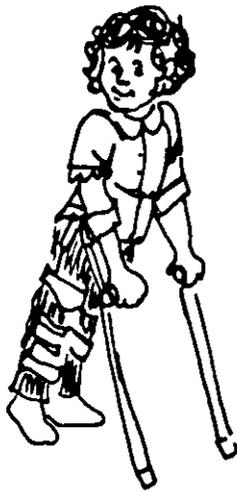


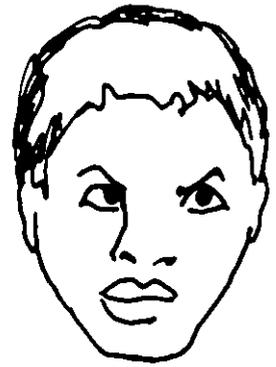
# Optional Pages

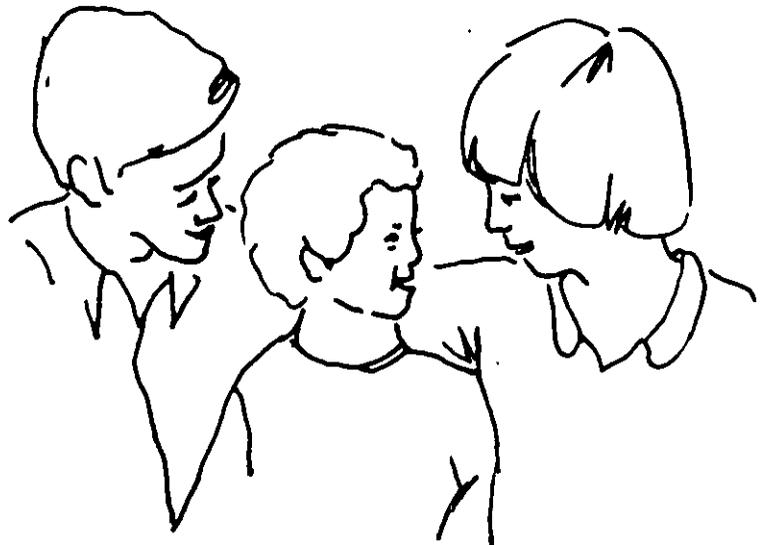
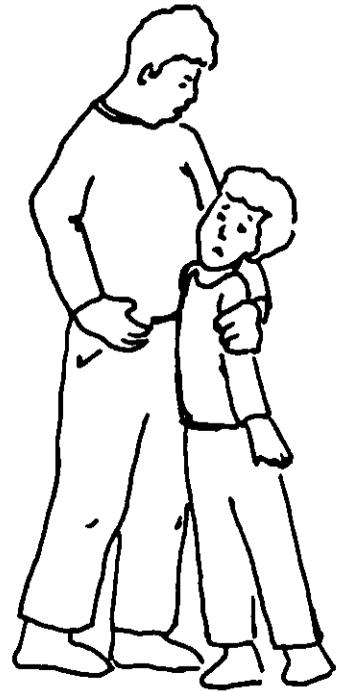
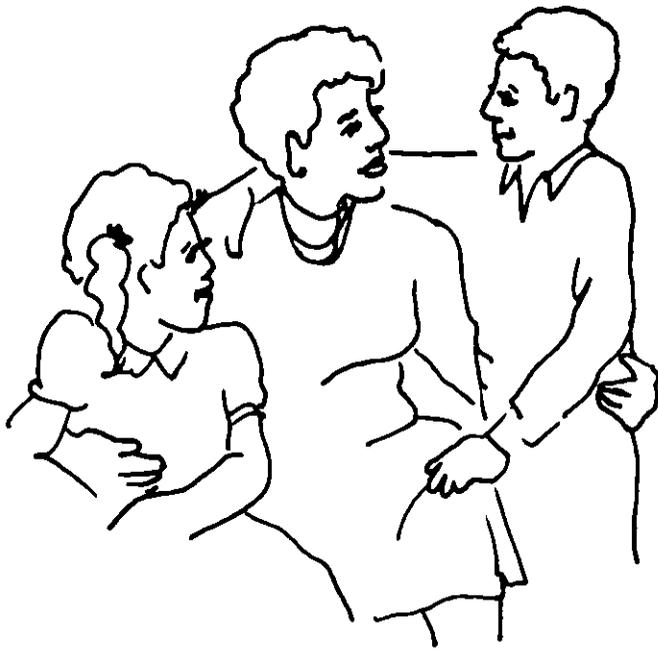
This is me

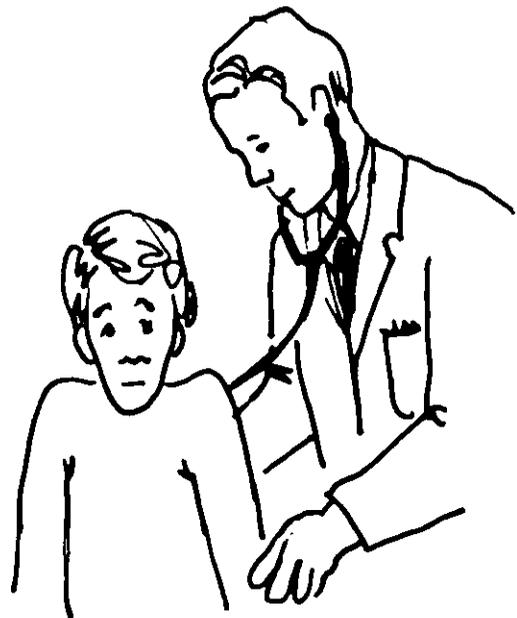
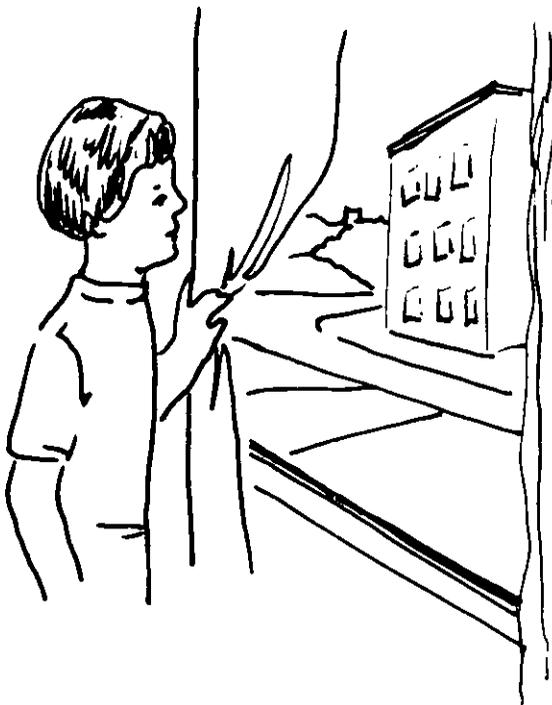
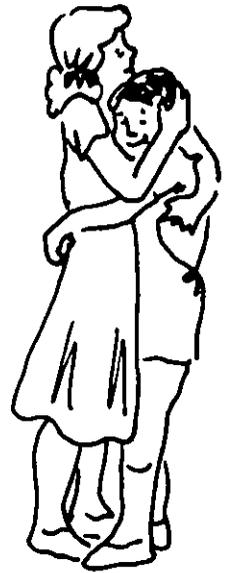
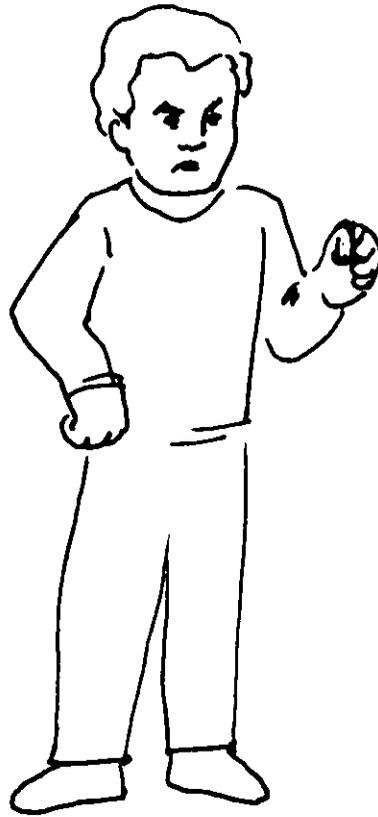






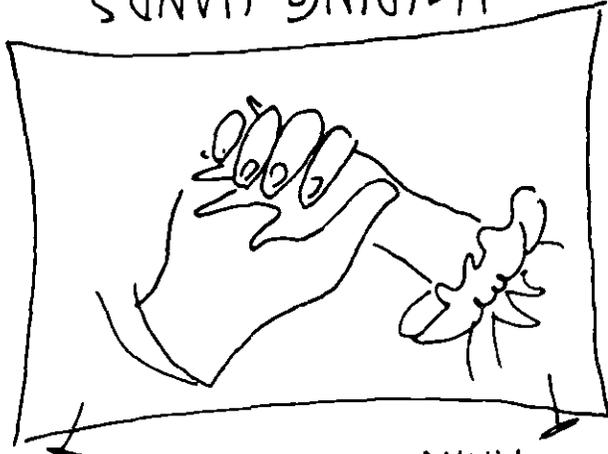






HERE ARE SOME KINDS OF TOUCH

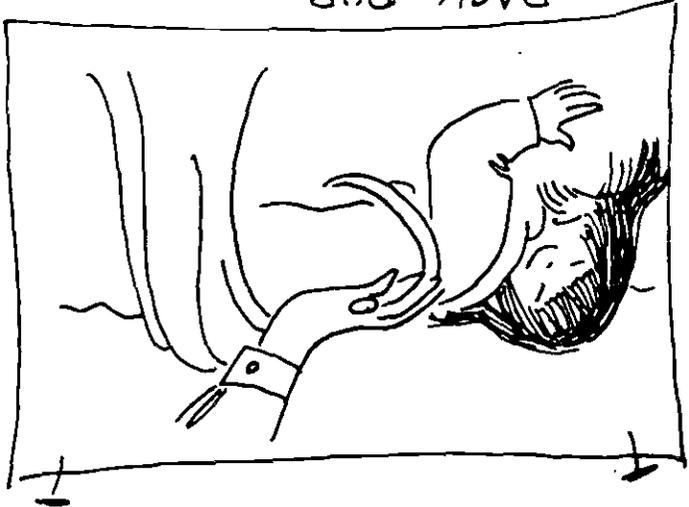
HOLDING HANDS



HAIR BRUSHED . . .



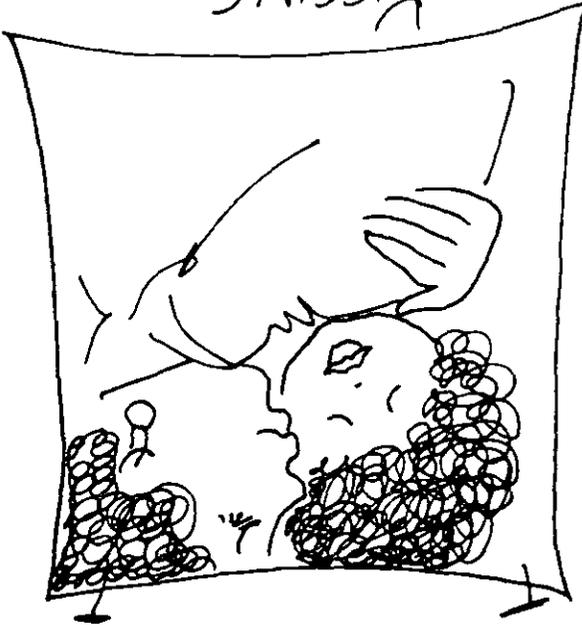
BACK RUB . . .



SNUGGLING . . .

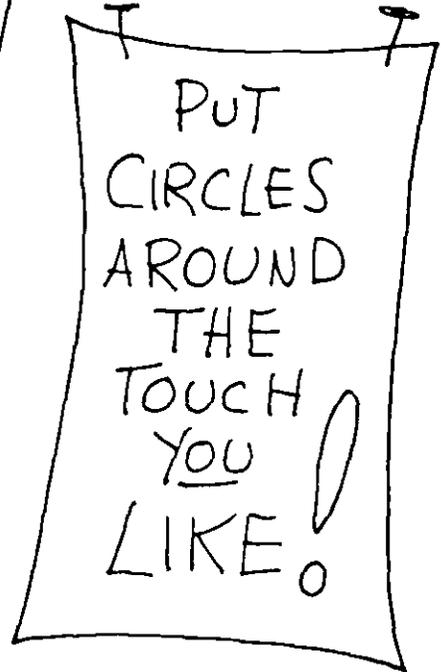


KISSING . . .

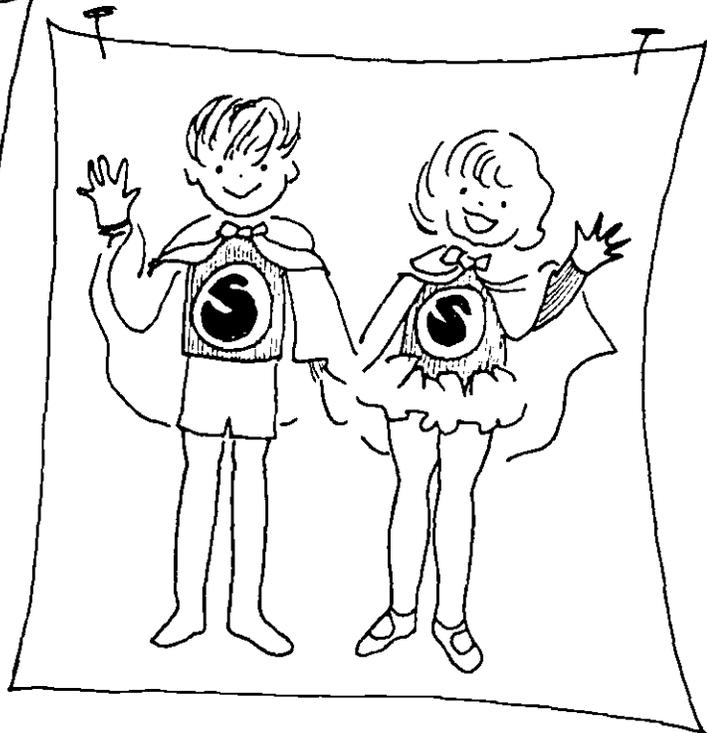




TICKLING



BEING CLOSE  
WITH A FRIEND...



ALL KIDS ARE SUPERKIDS

