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## Ichthyosis: A Teacher's Manual

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**Ichthyosis  
A Teacher's Manual**

**By**

**Deborah Brewster Vilas**

**Advisor Sallie Sanborn, M.S., C.C.L.S.**

**Submitted in partial fulfillment of the requirements  
for the degree of Master of Science in Education  
Bank Street College of Education  
1992**

## ABSTRACT

Ichthyosis: A Teacher's Manual

by

Deborah Brewster Vilas

"Ichthyosis: A manual For Teachers" addresses the needs of children born with a rare, congenital skin disorder. Not unlike children with cancer, asthma or diabetes, children with ichthyosis have special needs regarding their physical comfort and safety in the educational setting. This manual addresses these needs along the developmental continuum. Using Erik Erikson's eight stages of man as a guideline, this manual addresses the physical, medical and psychosocial needs of the ichthyotic child from infancy through adolescence.

Included in this manual is an explanation of the disorder, it's symptoms and treatments. Practical tips for day care workers, teachers, school nurses and athletic coaches are given to aid them in creating a supportive atmosphere for the child. It is designed for use in tandem with parent/teacher conferences, as each child's situation is highly individualized. An annotated bibliography listing resources for children and teachers is included.

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## RATIONALE

For my Independent Study, I have chosen to write a manual for teachers. The purpose of the pamphlet will be to help teachers meet the needs of students with ichthyosis. Ichthyosis is a rare, incurable, congenital skin disorder that effects children both physically and psychosocially.

Pamphlets already exist which instruct teachers on how to assist children who may have asthma, AIDS, Chrones's disease, cancer, and a variety of other chronic or life-threatening diseases. However, to date, there is no such instructional material available for teachers who may be faced with the special needs of a child with ichthyosis. I have established the lack of original material by contacting the only existing formal support network for ichthyosis sufferers, a foundation by the name of F.I.R.S.T., the Foundation for Ichthyosis and Related Skin Types. F.I.R.S.T. is in the process of publishing a manual for the parents of children with ichthyosis, and hopes to publish the teacher's manual as a companion piece.

There has been a recent surge of interest in the support services offered by F.I.R.S.T., in response to an article which appeared in the Ann Landers' column in newspapers across the country. F.I.R.S.T. received over 10,000 inquiries regarding the article. I have spoken with the President and Executive Director of the Foundation, and they both believe that a manual for teachers is needed now more than ever. They

have agreed to publish and distribute the manual.

The manual will have classroom teachers as the intended audience, including preschool teachers and day care workers, elementary and high school teachers. In the manual, I address the developmental needs of various age groups, as the disease will effect children in unique ways at different stages of development. The manual will include information to assist school nursing staff and physical education teachers who will be faced with the unique limitations and physical/medical needs of the child. When a child enters the school system at any age, the parents will be able to give this document to the child's primary teacher, and the teacher will share the information with appropriate school personnel.

The expected date of publication by F.I.R.S.T. is early 1993.

## SUGGESTIONS FOR USE

The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) is a nonprofit corporation dedicated to helping individuals and families with genetic skin diseases collectively called the Ichthyoses. F.I.R.S.T. has agreed to publish "Ichthyosis: A Manual For Teachers". It will be distributed to all of the members of F.I.R.S.T. across the nation, reaching approximately 4,000 people.

For those members who have children in daycare or school, the manual is meant to be an introduction for their teachers to the special needs of the child with ichthyosis. The manual addresses the needs of children from infancy through adolescence. It is suggested that the parent(s) provide(s) the teacher with the manual in preparation for a parent/teacher conference. It is not meant to replace face to face interaction between families and teachers.

The manual is a tool that will assist the teacher in becoming familiar with the physical and psychosocial aspects of ichthyosis. Ichthyosis effects each child differently. Therefore, it is paramount that the parent(s) and teacher establish a rapport that will enable the individual child's needs to be communicated and addressed throughout the school year.

## ACKNOWLEDGEMENTS

This manual reflects the experiences, insights, hard work and good will of many people. I am grateful to them all. Specifically, the staff of F.I.R.S.T.: thank you for helping me get to know myself and my ichthyosis; Sallie Sanborn, M.S., C.C.L.S., for her guidance and editorial skills; Barbee O. Carleton, for providing me with a love for the written word, without which, there would be no manual; Jeff Krauss, my companion along my journey towards self love and truth; Eric Urevich, for his sound advice, and unfailing support and faith; My parents, Joyce and Skip Vilas, for their proactive response to my ichthyosis.

Most of all, I would like to extend my gratitude to the children with ichthyosis and their families, who participated in interviews, and provided me with more wonderful material than I could ever fit into one manual. You are all models of inspiration and resilience. You are the light.



## **I. Introduction**

This booklet has been prepared to assist you in meeting the needs of a special child in your classroom -- the child with ichthyosis. The booklet is designed to guide you in addressing the specific developmental, physical and psychosocial challenges of the student with ichthyosis. Whether the child is in pre-school, or in the elementary, junior high or high school setting, there are some general considerations that will aid you in making the school a more supportive environment for this student.

All children need opportunities to play together, be creative, develop self esteem, master new skills and express themselves. As a teacher, you address these needs daily. It is important to remember that the child with ichthyosis is above all, a child. Your acceptance, encouragement and appropriate interventions can make an enormous difference in the child's success in the schoolroom and on the playground. Never underestimate the positive effect you can have as the person on the front line -- the classroom teacher.

## II. What Is Ichthyosis?

When the student with ichthyosis joins your class, this might be the first time that you have ever heard of or seen the disorder. Unless you are informed by the child's parents, you may not be able to distinguish it from other skin related conditions.

According to The Foundation for Ichthyosis and Related Skin Types, "The Ichthyoses are a family of genetic skin disorders characterized by dry, thickened, scaling skin.... [T]here are at least twenty varieties of Ichthyosis, but the four main types are: Ichthyosis Vulgaris, Lamellar Ichthyosis, X-linked Ichthyosis, and Epidermolytic Hyperkeratosis. Some experts subdivide Lamellar Ichthyosis into two categories: True Lamellar and nonbullous Congenital Ichthyosiform Erythroderma (CIE)." (F.I.R.S.T., p.3.)

Normal skin is always in a state of equilibrium, with dead cells shedding from the surface at the same rate as new cells are being created in the epidermis. "Equilibrium is not maintained when Ichthyosis occurs, and cells build up in the stratum corneum. Ichthyosis can be visualized as a traffic jam of skin cells ... because the production of cells is too rapid or because the natural shedding process is slowed or inhibited, or both." (Ibid., pp. 5-6.)

This "traffic jam of skin cells" results in scaling, dry, taut skin. The condition is present from birth, and is not contagious. Most children present with redness, various

rashes, and blistering or severe cracking of the skin, which can bleed easily. Each child is different, and the symptoms can vary in their severity. Some children have parts of their bodies that appear extremely scaly, with dark, armor-like plates of skin covering them. Some children have heavy dandruff, which inhibits the growth of hair. Still others have to cope with hearing problems and odor problems caused by the build up of dead skin and bacteria. It is important to know that the scaling skin and odor problems are often beyond the control of the child, and do not reflect lack of personal hygiene or parental neglect. The most severely effected children may suffer from fine and gross motor impairment because of the tautness of their skin or bone involvement.

### III. How Is Ichthyosis Treated?

Treatment of ichthyosis depends on the severity of the disorder. Topical application of ointment, lotion or cream is the most common form of treatment. The main goal of topical treatment is to remove the dead cells from the skin's surface, and to moisten the new, tender skin underneath. Some ointments used may be prescriptions given by the child's physician, and others may be store bought or unique home remedies. The application of some lotions can burn and cause tremendous discomfort for the child. The frequency of application is usually dependent on the child's level of comfort, and can vary from weekly to multiple applications

throughout the day.

Children who have severe cases of ichthyosis are sometimes treated with oral medication. Antibiotics are prescribed for infections that may be harbored in the thick scaling skin, or for systemic infections. Retinoids, such as Accutane, have also provided some patients with dramatic symptom improvement. However, retinoids cause many side effects, ranging from mood swings and drowsiness to nausea and dryness of the mouth and eyes. Prolonged use can have toxic effects on the child's bones and internal organs. They can also cause birth defects in offspring. If a child in your classroom is being treated with retinoids, you should be aware of how the drug may effect the child's attentiveness and ability to concentrate. Patients using these drugs need to be monitored closely by their physician.

Children of all ages should be encouraged to be active participants in their own treatment. When the child takes on the responsibility of self care, he will develop a sense of independence, control, and competence, all of which will help him meet the normal developmental tasks of childhood.

#### **IV. Physical Comfort and Safety at School**

It is very difficult for a child to concentrate on learning when her skin is taut, cracked, sore or itchy. These symptoms can make simple activities such as holding a pencil, sitting or walking uncomfortable or even painful. Ichthyosis

can also affect the child's vision and eye control. Some children can not close their eyes because of the tautness of the skin. Therefore, your first task will be to ascertain the child's level of comfort and physical mobility. The child's parents are the best source of information at this point. They are the experts regarding the day to day care of their child. A conference should be conducted before the beginning of the school year. It should include the parents, the principal or administrator, the school nurse, and other staff members, such as the counselor or physical education teacher. If necessary, the child's physician should be involved as well. This will ensure a well integrated approach to the support of the child at school. One parent designed a letter of introduction for her son, explaining the disorder and its implications. The letter was distributed to all school personnel that would be interacting with her child, from the bus driver to the phys-ed teacher, all teachers and aides, as well as the parents of other school children. The letter encouraged them to answer children's questions about her son openly and positively. She found that this honest response to children's natural curiosity did a lot to prevent ostracizing and teasing of her son. Depending on the child's age and wishes, a classroom presentation may assist with the issue of peer understanding.

### Questions to Ask the Family

It is a good idea to meet with the child's family before the beginning of the school year, and to maintain good communication with them as the year progresses. Here are some suggested questions that will assist you in obtaining important information from the child's family:

1. Start with the positive. What are the child's interests and skills? What does she enjoy doing and what does she excel at?
2. How extensive is the child's current medical treatment?
3. What medical treatment must take place during school hours?
4. What are the side effects of this treatment? How can you best assist the child in coping with these side effects?
5. What considerations need to be made for the child that may be out of the normal realm of classroom/school rules? For example, does the child need special privileges for moving about the classroom to maintain physical comfort or leaving the classroom to drink water whenever she has the need? Children with Epidermolytic Hyperkeratosis (E.H.) find sitting on hard surfaces like classroom chairs painful. One such child brings a special set of cushions to school to help him sit comfortably. Are there dress codes that need to be addressed, that may be emotionally difficult for the child to cope with, such as a "no hat" policy if the child has hair loss or excessive

dandruff?

6. What are the child's (and family's) preferred way of handling questions or ridicule from peers and adults?
7. Do any changes need to be made in the school environment regarding temperature? One child with E.H. has the school air conditioning set for her comfort level. She overheats extremely easily, and goes into cardiac arrest if her body heat reaches a certain temperature. Another youngster's mother got a portable air conditioner donated to the school, which will follow her child from class to class throughout elementary school.
8. Can the child go outside in hot weather? If so, what precautions need to be taken? Does the child need sun block applied when out in the sun?
9. How does the child get to and from school? Are there any provisions that need to be made for transportation? One school was able to get funding to provide an air conditioned van to transport one child to school.

Once you have an initial understanding of the child's level of comfort and mobility, you can assist the child in maintaining a reasonable level of comfort. The key points to remember are:

- 1: Make sure the child has ready and discrete access to lotions and medications.

AND

- 2: Recognize the child's difficulty in regulating his body temperature.

### Topical and Oral Medication

A child with ichthyosis should be encouraged to keep a bottle of his moisturizing lotion in his cubby, desk or locker, where he has ready access to it. Preschoolers and young children may need a reminder from the teacher to apply the lotion after water play, sand play, messy artwork, or handwashing. However, most children know that they are more comfortable when they use their lotion, and only need the time and place to do it comfortably.

Some children have skin so fragile that it bleeds easily when rubbed or scraped. One mother of such a child sends a packet of polysporin to school daily in her daughter's knapsack. Her teacher knows to apply it in the case of scrapes.

If a young child must take medication at school, it should be dispensed by the school nurse. Older children should be encouraged to monitor their own medication when appropriate. As noted, teachers should be aware of possible side effects of medications that may effect the student's performance in the classroom, and what they can do to assist the child experiencing the side effects.



## Regulating Body Temperature

Most children with ichthyosis have difficulty regulating their body temperature. Scaling skin blocks sweat glands, making perspiration difficult or impossible. Coincidentally, these children also have difficulty keeping warm in cooler weather. They should be encouraged to keep an extra sweater or sweatshirt at school for this reason. Again, each child varies. Some children suffer heat stroke or cardiac arrest upon mild exertion, while others can be quite active if they take certain precautions.

In hot weather, or in the gym, the child **must** have easy access to drinking water. This is essential. Parents uniformly state that this is one of the most important aspects of keeping the child cool and properly hydrated. It often means extending privileges to the child that involve permission to leave the classroom or gym for water at any time without having to ask permission. The child should feel that teachers are her advocate in this regard, rather than an obstacle to her comfort and health.

Plant spritzers are a helpful way to keep kids cool. The children can carry them when engaging in outdoor activities. Regular spritzing keeps them relatively comfortable and enables them to participate in field trips or athletic activities. However, some children's heat problems are so acute, that they must wear a "cool suit." The cool suit was originally developed by NASA for use by astronauts. It

consists of a lightweight vest and cap, attached by tubing to a portable cooling system. The cooling system weighs about twenty-two pounds, and circulates cool water throughout the vest and cap. One child wears her cool suit everywhere, and with a little ingenuity, is able to roller blade, ride a bicycle and play baseball.

Because a child overheats easily, she can be labelled by uninformed teachers and classmates as slow, lazy, or a poor athlete. This child is at risk for developing poor self esteem, especially in the athletic arena, where the choosing of teams and the pressure of competition may leave her on the sidelines feeling rejected and unable to compete. One adult reflects back on his school days in gym class. "I just stopped trying after a while. It wasn't worth it, so I failed out." In this case, the insightful intervention or modeling of an understanding coach might have made all the difference.

Some children are severely physically handicapped by their ichthyosis. Because of the tautness of their skin, and involvement of their bones, they move in an awkward, robotic fashion. Stricture of the skin on the feet or blisters can make walking painful. It takes excellent communication and good judgement on the part of teachers and coaches to determine how much physical activity to expect of a child with ichthyosis. There are often "good" cycles when the child is more comfortable and able to push herself. There are also "bad" cycles where the child's mobility and comfort will be

more limited.

The true nature of team spirit was reflected recently when a young man with ichthyosis participated in and finished a twenty-six mile marathon. He was able to do this because a group of friends formed a water brigade, and doused him at every check point along the way to the finish line! One child won the annual physical education award at school because, as her mother states, "She **never** stops trying!" The goal of a caring professional should be to help the child find, set and respect her own limits and goals.

## **V. The Nurse's Office**

The school nurse is an important participant in the care of the child with ichthyosis. Because there are rules regulating how you administer medical care to students, a letter from the child's physician may be required when the care of a child with ichthyosis differs from the care of the typical child.

Some common differences involve the treatment of abrasions, cuts and blisters. Band-aids do not work well with ichthyotic skin. They either cannot adhere because of the lubricant on the skin, or they adhere too much, and cause further abrasion when removed. When bandaging is necessary, wrap the affected area in sterile, non-stick gauze and use surgical tape applied to the bandaging, rather than the skin. If the child in your care has Epidermolytic Hyperkeratosis (E.H.), consult with his physician for specific guidelines for treating blisters.

Due to the child's difficulty with regulating body temperature, a fever can be dangerous for the ichthyotic child. Please notify the parents immediately if the child develops a fever. Parents should also be notified immediately if there is a suspected infectious disease within the student population, such as chicken pox or measles. Some children with ichthyosis are more severely effected by the symptoms of these childhood diseases than others. These are the main concerns in the treatment of the ichthyotic child at school.

However, each child differs, and the parents and child's primary physician are the best sources of information. The more you know about the child and his specific needs, the more comfortable you will feel in administering nursing care.

## **VI. Developmental Challenges for Students with Ichthyosis** **Infancy Issues**

The developmental challenges of students do not exist in a vacuum. They exist in the context of how well the tasks of previous developmental stages were resolved. Therefore, it is important to review the issues that infants with ichthyosis face, in order to better understand the future challenges they will face as students in the classroom. Also, more and more infants are being enrolled in day care programs at earlier ages, so that the concerns of this age group need to be addressed.

According to Erik Erikson, a pioneer in the field of childhood development, the first stage of life is that of Trust vs. Mistrust. Infants in this stage respond very quickly to whether or not their basic needs are being met. If these needs are met, the child develops a sense of self as separate from the caregiver, trust in the predictability of care, and proceeds along the developmental continuum. If the infant's needs are not met, the child may suffer from symptoms ranging in magnitude from developmental delays to death.

For the infant born with ichthyosis, there are two

specific threats to the infant's developing sense of self and trust. The first threat is that of separation from the mother at birth, and the continued isolation if the infant is placed in a neonatal intensive care unit. This impacts strongly on the baby's need to bond with the mother and to receive consistent care from one caregiver. Efforts by medical staff to include parents in the daily care of the infant are paramount in promoting healthy attachment between the child and parents.

The second risk for the infant with ichthyosis is intrinsic to the delicate nature of the skin. The baby is born with skin that is raw and in many cases blistering and cracking like the skin of a burn victim. The infant's basic need for touch is now compromised by the pain he experiences when he is touched. Most infants develop a repertoire of comforting behaviors such as thumb sucking, rocking and vocalizing. The inability to comfort himself with these measures and the inability of the caregiver to alleviate pain form a basic challenge to the building of trust. How the infant adapts to the issues of separation and physical pain will have a strong impact on future development.

Day care workers caring for such infants need to be informed and comfortable with the level of physical care required. Infants with ichthyosis are often suffering chronic physical discomfort, and are difficult to soothe. Regular application of lotion throughout the day may be necessary to

keep the child's skin lubricated. Check with parents regarding special considerations when washing and diapering the infant.

Do not hesitate to engage the infant in activities that will stimulate development and provide distraction. Appeal to the infant's senses of touch, smell, vision and hearing by providing an interesting environment for the infant to interact with. Soft blankets or pieces of fabric, stuffed animals and sturdy rattles to grasp and hold will appeal to the child's sense of touch. Music, as well as the soothing use of your voice, may be comforting. Mirrors can be placed at the child's eye level, and mobiles overhead to engage the infant's attention. Through daily interaction with the infant, the caring professional will soon become attuned to deciphering and responding to the child's needs.

### Toddler and Preschooler Issues

According to Erikson, the next stage is that of Autonomy vs. Shame and Doubt. The primary task for a child at this stage is that of obtaining a sense of self-control without losing self-esteem. The child is now moving away from the parent, experimenting with control over her own body, and expressing independence. For the parent, the challenge lies in letting the child explore her environment, while not giving in to the urge to overprotect the child.

With day care and preschool programs, this is often the

first social experience the child has outside the family. Parents may be anxious about the reactions of other adults and children to their child's appearance. The challenge here is for parents and teachers to answer questions about the child with honesty and openness. Giving the child words to use when questioned about her skin is just as important. One parent shared that her daughter could say, "I have ichthyosis. It's a recessive genetic skin disorder," by the time she was two years old. This may sound precocious, but words were a valuable tool for this child's coping with the daily questions from the people around her. "If there is one piece of advice I can give others," says this mother, "It's talk, talk, talk." Giving a child words empowers her.

Teachers are powerful role models for young children. Your positive and open response to other children's questions and fears will set the tone for how children in your class deal with differences in general. Preschoolers need concrete, simple explanations. For example, "Johnny's skin is different than yours. He was born this way. You cannot 'catch' it by touching his skin or by being near him. Everybody has skin that looks different. How is your skin different from your friend's skin?" Children often gain self esteem by helping others. Teachers can encourage a community spirit by assigning daily helpers whose job it is to keep their classmate cool. They can bring water or call "time out" during physical activity when they see their friend getting



overheated. Books can be a positive tool for exploring how children feel about all kinds of differences. A list of suggested reading is included in the annotated bibliography of this manual.

Separation from parents and family is an issue for all toddlers and preschoolers. The child with ichthyosis may be more vulnerable to separation, due to either impaired body image or traumatization from hospital stays. Allowing the child to explore this issue through play and literature can assist in lessening anxiety. Games such as peek-a-boo, hide and go seek, and open ended dramatic play give children many opportunities to explore their feelings about separation.

#### Issues of the School Age Child

The Eriksonian stage of Industry vs. Inferiority best describes the issues of the elementary school age child. He is now "ready to apply himself to given skills and tasks" (Erikson, p. 259). The challenge of this stage is to nurture the child's sense of competency. On the other hand, the danger of this stage lies in the possibility of the child developing a sense of inadequacy or inferiority, which may in turn lead to low self esteem and apathy.

For the child with ichthyosis, this stage presents some unique and difficult challenges. He may do fine academically, but have difficulty socially or physically. Therefore, it is important that the child find something to excel at, both in

the academic and extracurricular realms. In this sense, teachers can be great catalysts. One second grade teacher discovered a child's aptitude for writing, and encouraged her expression through poetry and prose. That child is the author of this manual.

It is imperative that teachers have the same expectations for academic performance for the student with ichthyosis as they have for the whole class. Parents and children alike express the wish that the child with ichthyosis be treated no differently scholastically than any other student. "My daughter has a skin disorder, not brain damage," says one mom.

Expectations in the athletic arena, however, should vary with each case. Some children with ichthyosis can participate in sports and outdoor activities as long as they have ready access to water and can call "time out" when overheated. Others are more restricted. For these children, it may be helpful to assign other roles or tasks, such as assistant coach or score keeper. If the child cannot go outside at all, they can be involved in indoor projects, or given a special job in the school office. In every situation, the child should be encouraged to set and respect his own limits regarding physical exertion. Limitations imposed by others can inhibit the child from reaching his true potential.

School age children with ichthyosis are at risk for social isolation and teasing at the hands of their peers. This is often the most difficult obstacle for the child to

overcome. It is a true balancing act for teachers, to play a supportive role, without singling the child out, thereby causing further ostracism and ridicule. Class discussions about prejudice, cultural differences and friendship may address important issues without focussing on the child with Ichthyosis. Children need to learn early on that "different" does not mean better or worse. As with preschoolers, enlisting peers in the role of helper may also foster understanding and respect for the child with ichthyosis.

#### Issues for Junior High and High School Students

Identity vs. Role Confusion is the developmental task that Erikson delegates to adolescents. Rapid physical growth and change begin at puberty and continue throughout adolescence. Teens "are now primarily concerned with what they appear to be in the eyes of others as compared with what they feel they are..." (Erikson, p. 261). Teens are also faced with the challenge of drawing on their previously developed skills and interests, as they prepare for life as an independent adult. They are often caught in the pull between wanting to enjoy being a child, and aching for the freedom that they associate with being an adult. This stage can be summed up by three questions. Who am I? How do I fit in? And, what am I going to do with my life?

By now, the child with ichthyosis has probably mastered the physical management of her condition. She knows her

limitations, and is still discovering her aptitudes and interests. However, the newfound focus on self image can cause anxiety and self doubt to arise. As peers become more important in the eyes of the teen, the need for social acceptance becomes paramount.

Many teens feel isolated and misunderstood at this time. The teen with ichthyosis may be more vulnerable because of her awareness of being different in a very visible way. The pressures of dating bring concerns about physical attractiveness into the forefront. "Will anyone ask me out?" or, "Will I be turned down when I ask someone out?" are common concerns among teens. Entering a new junior high or high school also means leaving the safe confines of a school where most people know and accept the student. The teen is now faced with explaining her condition to many new people. It is a lot to cope with.

At this stage, the teacher is most supportive in the role of listener and mentor. If the student is lucky, she will have a positive, interactive relationship with a teacher or guidance counselor who can help her navigate the changes and challenges of adolescence. The task of the involved adult is to assist the student in finding the coping mechanisms and personal style that work best for her. Ready made answers and advice do not always apply to the individual child. Help the teen find her own answers, even if this means watching her stumble and make a few mistakes along the way. It is also

important for you to be an educator. Share information about the student's appearance, special needs, etc., with colleagues, substitutes, student teachers, and aides. The more information others have, the more everyone can work together to make the school a supportive environment for all students. Above all, your positive and open relationship with the teen can make a remarkable and lasting difference in her life. At a time when everything else is changing and uncertain, it is nice to have an understanding adult in your corner whom you can count on.

## **VII. Summary: Key Point Checklist**

### **1. START WITH THE POSITIVE!**

Every child has something unique to offer. Focus on what the child **can** do and what he enjoys doing.

### **2. RESPECT THE CHILD'S PHYSICAL LIMITATIONS.**

Create a supportive environment that allows the child to take self care measures without embarrassment or shame.

### **3. USE YOUR INGENUITY.**

When a child cannot participate in outdoor activities, help her find something meaningful and productive to do indoors.

### **4. DO NOT IMPOSE SCHOLASTIC LIMITATIONS ON THE CHILD.**

Ichthyosis is a physical disability, not a mental disability.

### **5. DIFFERENT IS NOT BAD!**

Teach this too all children. Answer their questions about all physical differences with openness and honesty.

### **6. DON'T BE OVERLY CONCERNED.**

One child described her teachers as worrying and hovering too much. In the child's own words, "Don't be afraid. Just let me be a normal kid!"

## Annotated Bibliography

### Books For PreSchool and Young Children

Alexander, Liza. **No Red Monsters Allowed.**  
Sesame Street/Golden Press, Western Publishing Company, Inc.,  
in conjunction with Children's Television Workshop, U.S.A.,  
1991.

Familiar Sesame Street characters find that red monsters can be as much fun to play with as blue monsters.

Carlson, Nancy. **I Like Me!**  
Puffin Books, 1988.

A little pig with great self esteem shows children how to be their own best friend.

Cole, Joanna. **Don't Call Me Names!**  
Random House, 1990.

Learning to cope with teasing from peers.

Quincey, Mary Beth. **Why Does That Man Have Such A Big Nose?**  
Parenting Press, Inc., 1986

"Different does not have to mean bad." This book fosters positive attitudes in children towards all kinds of people, by giving honest, positive answers to children's questions about others.

### Books For School Age Children

Estes, Eleanor. **The Hundred Dresses.**  
Voyager Books Harcourt Brace Jovanovich, Publishers, 1944.

This timeless classic addresses the issues of stigma at school. A young girl has ambivalent feelings when her popular friend teases an immigrant child.

Webster-Doyle, Terrence. **For Young People: Why Is Everybody Always Picking On Me: A Guide To Handling Bullies.**  
Atrium Society, 1991.

A practical and sensitive guide not just for the child being bullied, but for the bully as well.

### Books for Teachers

Featherstone, Helen. **A Difference In The Family.**  
Penguin Books, 1980.

How families cope with their feelings of fear, anger, guilt and loneliness, regarding a child with a disability. Plus tips for the professionals -- doctors, therapists and teachers.

Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.).  
**Ichthyosis: An Overview.**  
F.I.R.S.T., 1987

This booklet gives an explanation of the disease, its diagnosis, symptoms, treatment and psychosocial implications, in straightforward, readable format.

Matiella, Ana C. **Positively Different: Creating a Bias-Free Environment For Young Children.**  
Network Publications, ETR Associates, 1991.

Helpful suggestions for teachers, parents and other care providers of children to age ten.

### Other Resources for Teachers

Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.).  
P.O. Box 20921, Raleigh, NC 27619-0921/(800)545-3286. An international nonprofit organization dedicated to helping individuals and families with the genetic skin disorders collectively called the Ichthyoses. Inquiries, referrals. Free publications include: **Ichthyosis: An Overview;** **Ichthyosis: The Genetics of its Inheritance;** **Ichthyosis Focus: A Quarterly Newsletter.**

American Council on Education. **HEATH Resource Center.** One Dupont Circle, Ste. 800, Washington, DC 20036-1193/(800)544-3284, (202) 939-0320. Clearinghouse on education and training beyond high school for persons with disabilities. (a) Resource Directory. (b) List of 31 free publications, including: **How to Choose a College: Guide for the Student with a Disability;** **Financial Aid for Students with Disabilities;** **Young Adults with Learning and Other Disabilities: Guide for Selecting Postsecondary Transition Programs.**

National Information Center for Children and Youth with Disabilities (NICHCY). P.O. Box 1492, Washington, DC 20013/(703) 893-6061 or 1-800-999-5599. Funded through US Dept. of Education. Information on sources of assistance in states, rights of disabled children and their parents, appeal



procedures, advocacy. List of 43 free publications includes: Preschoolers with Handicaps; Education for Youth with Special Needs -- What Do the Laws Say?; Options After High School.

**US Department of Education.** Clearinghouse on Disability Information, Office of Special Education and Rehabilitative Services. Room 3132 Switzer Bldg., Washington, DC 20202-2524/(202) 732-1241 or -1723. Specializes in federal programs and legislation. Inquiries, referrals. (a) Summary of Existing Legislation Affecting Persons with Disabilities. (b) Pocket Guide to Federal Help for Individuals with Disabilities.

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