

DOCUMENT RESUME

ED 259 541

EC 180 277

AUTHOR Binkard, Betty
TITLE Disabled?...Yes Able?...Also, Yes. A Count Me In Project.
INSTITUTION PACER Center, Inc., Minneapolis, MN.
SPONS AGENCY Office of Special Education and Rehabilitative Services (ED), Washington, DC. Div. of Personnel Preparation.
PUB DATE Nov 83
NOTE 20p.; For related documents, see EC 180 278-279.
AVAILABLE FROM PACER Center, Inc., Parent Advocacy Coalition for Educational Rights, 4826 Chicago Ave. South, Minneapolis, MN 55417-1055 (\$1.50 single copy, \$1.00 per copy for quantity).
PUB TYPE Guides - Non-Classroom Use (055)
EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS Adjustment (to Environment); Adolescents; *Coping; Daily Living Skills; Deafness; *Disabilities; Emotional Disturbances; *Interpersonal Competence; Learning; Mental Retardation; Parent Child Relationship; Physical Disabilities; Prevention; Social Adjustment; Student Attitudes; Visual Impairments

ABSTRACT

Intended for adolescents, the booklet presents case studies of eight teenagers and their friends to illustrate views of ability and disability. Recounted experiences focus on attitudes and feelings of students with learning disabilities, epilepsy, spina bifida, visual impairments, mental retardation, deafness, and mental illness. Narratives center on such topics as coping with one's disability, stereotyping, personal independence, daily living skills instruction, total communication and communication devices, parent-child relationship, and suggestions for babysitting children with handicaps. A final section briefly describes prevention of handicaps. (CL)

 * Reproductions supplied by EDRS are the best that can be made *
 * from the original document. *

ED259541

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

- () This document has been reproduced as received from the person or organization originating it.
- () Minor changes have been made to improve reproduction quality.
- Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

DISABLED?

... YES

ABLE?

... also, YES

"PERMISSION TO REPRODUCE THIS
MATERIAL IN MICROFICHE ONLY
HAS BEEN GRANTED BY

Jacob Carter

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

The NATIONAL EASTER SEAL SOCIETY has provided funds for the printing and distribution of this handicap awareness booklet to selected secondary schools in the metropolitan Twin Cities area.

COUNT ME IN is a handicap awareness project of PACER Center, Inc. (Parent Advocacy Coalition for Educational Rights); 4701 Chicago Ave., Minneapolis, MN. 55407; (612) 827-2966, Voice & TTY.

This booklet was prepared by:

*Betty Binkard, author
Rianne Leaf and Polly Edmunds, COUNT ME IN coordinators
Paula Goldberg and Marge Goldberg, PACER co-directors
Deb Krupp, artist*

(c) Copyright, November, 1983, PACER Center, Inc. No part of this material may be reproduced without written permission from PACER Center, Inc., 4701 Chicago Ave., Minneapolis, MN. 55407, (612) 827-2966.

DISABLED? YES

ABLE? also, YES



Sometimes, like with the girl in the cartoon, it's hard to understand how a person with a handicap might look at the world and life with that handicap.

To make it easier, let's look at the stories of eight teenagers and their friends. They aren't real persons. But they could be. We've taken their stories from those told by hundreds of actual handicapped people. They'd like you to be able to look past their disability — and see the person behind it.

Shelly and Tom

"Having a good sense of humor," Shelly Vincent wrote in her theme book, "is one of the things I've learned is important for people who are learning disabled like I am. Like the time I got new jeans for Christmas and I read the label and called them Gloria Bandervilts and some of the other girls laughed every time I said it and I didn't know why.

"Then I heard an ad on T.V., and I figured out they were supposed to be called Gloria Vanderbilts, and I was so embarrassed."

"But I found out a long time ago that people with learning disabilities just can't go around being upset every time we make a goofy mistake, or we'd be upset a lot of the time. So now I just laugh too. Even though I don't always want to."

Shelly, a tall ninth grader with long brown hair and a good tennis player, would much rather be out on the courts tonight. But her weekly English theme is due tomorrow, and she's having a tough time with the assignment. Her teacher had said to write a paper on the biggest problem each student has faced in his or her life and what each person has done to handle it.

Tennis... at least "tennis" I can play and spell. Forget baseball, bowling, ping-pong, or badminton - 'coz they've got too many b, p, and d's. Those give me trouble.



"One of the hardest things, I think about having a learning disability is that sometimes it just doesn't seem to make sense. I'm good in math and science, and I can usually understand and remember the things the teachers talk about. . . well, I mean, unless they're talking about Einstein's theories or something far out like that. But when it comes to reading and spelling, I've always had trouble," Shelly continued.

Shelly's handicap, known as a learning disability, most often affects boys — for some reason we don't know yet. Most students who have this handicap are of average or above average intelligence. Like Shelly, they may do well in some of their classes. But they have special trouble with one or more of the things that our brains do when we read, spell, listen, write, or do math. Many students with learning disabilities would have even more difficulty with writing and spelling than Shelly does.

"I've always had to get extra help. . ." Shelly was writing when her little sister called up the stairs.

"Shelly, it's for you," Marcia screamed. "I think it's Tom. Are you guys getting married? This is about the 70th time he's called you this week."

Shelly groaned because she knew Marcia always yelled her dumb questions with the phone right in front of her mouth. Luckily, she's known Tom since they were both in third grade, and he has a little brother to pester him so he'd know Marcia wasn't really serious.

"Hi", came Tom's voice. "Maybe we should get married. We could run away across the state line and lie about our age. I mean, you're a pretty old looking 14."

"Get serious will you," Shelly told him. "That would really be class — us going down the highway on your bicycle."

"Well, O.K. I was just joking. But don't be so smart. I will have you know that I'm studying for my driver's exam right now. . . and that's drive. . . as in car, not bicycle."

"What?" Shelly snapped back. "You're studying for a driver's exam? But you have epilepsy! I didn't think you could drive."

"Well, you thought wrong. I do have to show that my medicine is working and that I haven't had a seizure for over a year before they'll give me a license. But I haven't had a seizure for a long time so I should be able to drive when I'm old enough, and I'm getting ready right now. What are you doing tonight? Oh, I know. You're in Smith's class and I'll bet you have that weekly theme due tomorrow. What's it about?" Tom asked.

"Oh, we have to write about the biggest problem each person has ever had and how we handled it. I'm writing about what it's like to have a learning disability. Tom, if you had to write the theme, you know, like what's the biggest problem you've had?"

"Keeping sticks and pencils and spoons out of my mouth!" he laughed.

"Huh?"

"Well, when I was in grade school, my seizures weren't under control yet. If I had one out in public, there'd always be somebody who'd run up and try to jam something between my teeth," he explained.

"Oh, yeah, I remember," Shelly laughed. "But they thought they were doing the right thing. They'd heard that old idea that a person having a seizure could swallow his tongue."

"Sure, I know that. But my mom had to spend a lot of time trying to explain to my teachers and other people that a person can't swallow his tongue since it's attached to the back of his mouth."

"I remember her coming to our first aid class one time," Shelly said, "and telling us what we should do. . . like getting things out of your way if you were having a seizure so you wouldn't hurt yourself on them. And placing something under your head so you'd be more comfortable, and then just staying with you and talking softly so you wouldn't get scared. After she told us that, it was easy because we weren't scared anymore. How long has it been since you've had a seizure anyway?"

"I really can't remember the last time. I think two years ago during Christmas vacation when I was doing too much stuff and forgot to take my medicine when I was supposed to," Tom recalled. "I'm really one of the luckiest ones. Ever since the doctors and my folks got my 'pill program' all worked out, I could almost forget I have epilepsy. Some kids still have problems even if they're on medication. But even they do better than they would if they didn't have the pills."

"Yeah," Shelly said. "I'm really glad for you. I wish there were an anti-learning disability pill."

"I know. You just have to keep working harder than a lot of kids do. And speaking of working, you'd better get back to that theme. They say Smith isn't kidding when she says she wants those papers in on time."

"Right, Tom. Seriously though, if you had to write this, what do you think your biggest problem is?"

Tom paused. "I don't know. It's hard to explain. I guess it's just when other people don't understand epilepsy. Maybe they see one seizure and they think — oh, that person is just totally out of it. They don't understand that it's just a temporary thing, and that the rest of the time you're O.K. I mean, having epilepsy is just one part of my life. The other things about me, like I'm good at hockey and all the girls are crazy about me. . ."

"Oh, really," Shelly interrupted, "girls — like in more than one — are crazy about you? Like, name some names."

"O.K. so maybe it was just one. And that was in fourth grade. But wait till I get my car. Anyway, what I was really trying to say was that there are a lot of things about me that are more important than the epilepsy bit."

Tom's handicap isn't quite as mysterious as Shelly's. We don't even know exactly what goes wrong in the brain to cause a learning disability. But with epilepsy, we know that the brain cells — usually for just a short time — send out unusual amounts of energy.

We don't know exactly why this happens. However, epilepsy may be linked to a head injury, a birth injury, or an infection of the brain. It's not something that can be "caught" by other people.

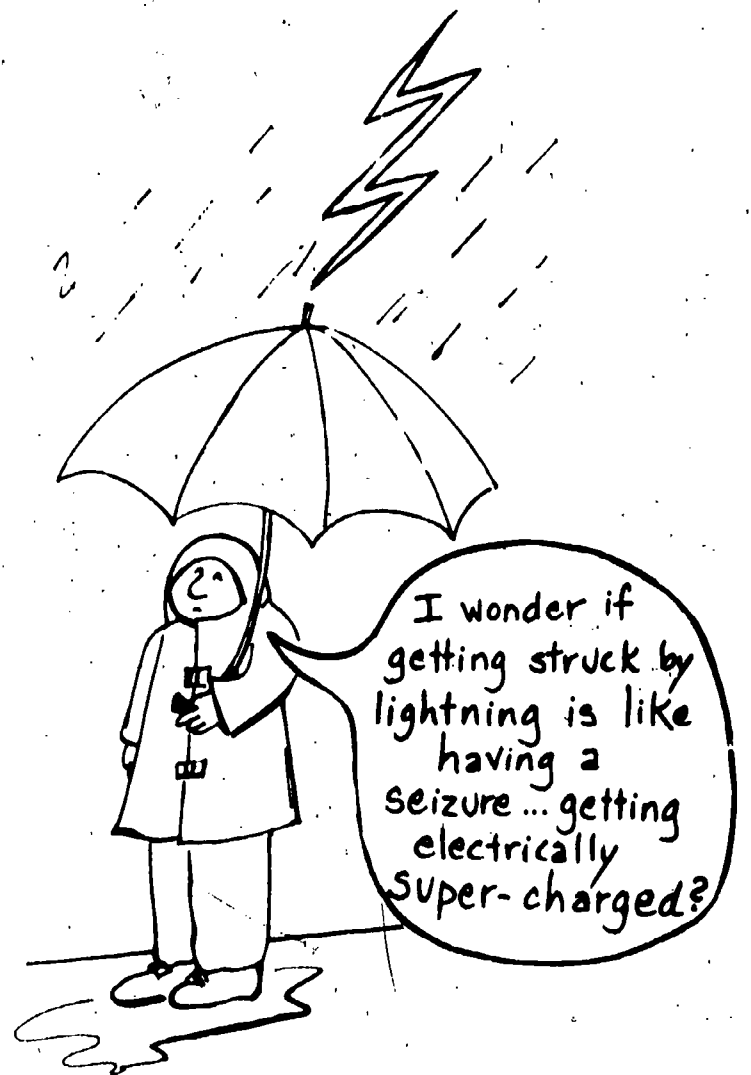
Shelly tries to make up for her handicap by working especially hard on her reading, spelling, and writing. She's had special help ever since her learning disability was discovered when she was in second grade. Where another person might have been able to recognize a word after just seeing it one time, Shelly's teachers had to go over the word again and again with her.

One teacher even cut new words out of sandpaper and then had Shelly trace the shape of each letter over and over. Somehow, if Shelly could "feel" the word, her brain was more likely to remember it and keep the letters in their right places. She's gone way past that stage now, but she'll always have to spend a lot of time finishing her reading assignments. And writing themes — well, it's always going to be more fun for her to play tennis.

Tom, on the other hand, overcomes his handicap by taking a medicine that usually prevents his brain from sending out those unusual bursts of energy that can cause seizures.

The kind of seizure he has is called "grand mal" or "tonic-clonic." With this form, the person loses consciousness and falls to the ground. His body will stiffen and then begin to jerk. The seizure might last from one to three minutes, and when the person "awakes", he's likely to be confused, tired, and have a headache.

A person who has "petit mal" or "absence" seizures would show few outward changes. He might lose consciousness but only for a very brief period (three to thirty seconds) and appear to have a blank stare. He wouldn't be able to see or hear anything during this time. Chances are, the seizure might be over so quickly that the people around him wouldn't even realize it had happened.



A third type of seizure is known as "psycho motor" or "complex partial." Persons with this type have different kinds of behavior during their seizures. They might stare at the same spot for quite awhile, walk around the room with no purpose, smack their lips, or say things that don't make sense.

Medications have been found to help control — but not cure — these three types of seizures.

Most people with epilepsy find that their handicap won't prevent them from having a job when they're adults — as long as bosses are willing to give them a chance. There are some limits — a person whose medicine doesn't always keep his seizures from happening wouldn't want to take a construction job on top of a high building for obvious reasons.

But with most jobs, an occasional seizure can be handled quite easily and quickly, and the person can still have an excellent work record.

Like Tom, Shely has a lot of hopes for her future, too, and decides to end her theme by describing them.

"I can't really say I've overcome my problem yet," she wrote, "because it's always going to be with me. I know I'm not dumb, and I want to go to college and maybe do something with math and computers. I suppose maybe I'll always have to spend more time on my homework than other kids do. But I've made a lot of progress since they found out I wasn't learning to read at all when I was down in second grade."

"I think of myself sometimes like that old story about the turtle and the rabbit. I will get across the finish line — though it may take me awhile. I just hope that when I try to get into college that they'll have tests where I can show what I really know and I won't flunk just because it takes me longer to do them. The End."

"Oh, Mom," she yelled down the steps, "will you get me up early tomorrow so we can go over this and check for spelling? Thanks."



Lionel, Becky, and Dan

"Hi, Lionel. How come you're here? You can't dance."

Lionel, interrupted while listening to the halfway decent band his class had found to play for the Thursday afternoon dance in the school cafeteria, turned in his wheelchair and saw Dan, his friend from biology lab.

"What'ya mean? I didn't know you had to be able to dance to come and listen," he challenged Dan.

"Well, you know. . . I mean, I know you black kids have natural rhythm, but I just thought. . . well, it doesn't seem like much fun to just have to sit and watch other people dance," Dan explained with some embarrassment.

"First of all, Dan, it doesn't seem like most of the people who come to these dances are much into dancing. I mean, the boys mostly stand on one side, faking they're brave and trying to get up nerve to maybe ask some girl. And the girls mostly stand on the other side, faking they're brave and giggling about who's going to be the first to get asked and what they'll do if the wrong person asks them," Lionel said. "And, second, what's with the stereotyping?"

"Huh? What's stereotyping?"

"It's what you're doing. It's like saying all black kids have rhythm. I mean, it just doesn't always apply. After all, I got kicked out of rhythm band in first grade because I couldn't keep time with the other kids, and I was always hitting that stupid tambourine in the wrong place," Lionel recalled.

"And then you figure I wouldn't want to come to a dance just because I can't dance myself. Well, I come because I like to listen to music," Lionel continued. "And not just to Stevie Wonder or the Supremes. I've probably got the best collection of Earl Scruggs stuff and the Foggy Mountain boys you'll ever hear."

"Who are they?" Dan looked puzzled.

"You mean, you were born and raised in Kentucky and you don't even know who the best bluegrass people are?" Lionel asked with a smile.

"Well, not everybody from Kentucky is into bluegrass you know. Besides, now who's making a stereotype? I happen to have the best collection of early Stones records of anybody in town," Dan retorted.

"O.K., I give. Enough stereotyping for both of us. Bring your Stones records over to my place some night. I really like their stuff. Hey, here comes Becky. She's looking great today. You're really lucky to be friends with a girl that sharp."

Though Lionel's physically disabled and Becky's blind and Dan doesn't have a handicap — well, except for his Kentucky drawl that the kids tease him about — they all three go to the same school. Several years ago, when they started kindergarten, many kids with handicaps were still required to go off to special schools. But laws that passed in the mid 1970's said that handicapped students should no longer be automatically isolated.

In Lionel's case, that meant being sure his school was "accessible," that he could get wherever he has to go with his wheelchair. Becky has worked with her "mobility" instructor from a class where she goes to learn special methods to get around in her home and the outside world. She's long since figured out how to find her way around the school building, using a white-tipped cane to help her locate her position and learn what lies ahead of her.

Her textbooks are in Braille, and she takes notes in class using a stylus, which is like a pen with a sharp point, and a slate, a kind of "punching board" where she "taps" in words. The words appear on paper as raised dots or Braille. She also uses a tape recorder a lot to remember what the teachers have said.

"Hi, Becky," Dan yelled over the crowd. "Over here. Hey, great sweater," he commented as she reached them. "Have you met Lionel yet? He thinks you're great."

"Thanks, blabbermouth," Lionel groaned. "Remind me to always tell you my deepest secrets so I can read all about them in the school newspaper. Anyway, Becky, it's nice to finally meet you. How'd you ever get hooked up with Mr. Hears-All-Tells-All here?"

"Oh," Becky recalled, laughing. "It was in algebra class last fall. He sat next to me and was just about ready to flunk out in a grand way. He said all those X's and Y's in the book made about as much sense as the Braille writing in my book. So I helped him out after school and now he's worked all the way up to getting D minuses instead of F's."

"Say, Lionel," Becky continued, "if it's not embarrassing, could I ask you . . . I've heard you and your wheelchair around school a lot. I've always wondered why you have to use it."

"No, that's O.K. I'd rather have people ask than just stare at me. I was born with what's called 'spina bifida.' It means there was a space left open in my lower back where the spine didn't close the way it should have. It messed up a lot of muscles and nerves like the ones my brain needs to send messages to my legs to move. Since my legs can't get messages. . . well, I can't walk," Lionel explained.

"Is. . . how'd you say it. . . 'spina bifida?' Is that something that's pretty common? Is that what's the problem for most people in wheelchairs?" Becky asked him.

"Well, for some people, but not for most," Lionel answered. "I've just been doing a term paper on physical disabilities for health class, and I found out a lot of people have to use wheelchairs because they have cerebral palsy. That's where something's wrong with the part of the brain that sends messages to a person's muscles, and it could mean the person has to use a chair."

"A lot of kids our age who use wheelchairs might have been in an accident, like on a motorcycle or diving into water that's not deep enough and hitting their heads, and they've injured their spinal cords."

"Then there are other reasons for a physical disability, too, where something goes wrong with a person's muscles or nerves. Doctors don't really understand why. A rare handicap, one that's inherited, is called 'brittle bone' disease. In that one, a person's bones break away too easily, maybe from just laughing hard or getting hugged. So he'd have to use a wheelchair to keep pressure off his bones."

"Hey, how'd we get into all this anyway?" Lionel asked with a grin. "Pretty heavy stuff for a school dance."

"Sure is," Dan commented. "How about we break away from here and all go over to my house. There are some steps to climb, but my dad and I can help lift your chair up there. You could hear my Stones' stuff tonight, and Becky can show off her cooking skills."



"You can cook, Becky? How'd you manage?" Lionel asked in surprise.

"I not only can cook," she explained. "I'm also learning how to measure and saw wood in shop class. My project is a bird house. I like to listen to bird songs, and, besides, the teacher says I'll know how to make some other furniture once I've finished the bird house."

"But back to cooking," Becky continued. "It's not that hard. In my home ec class, I get extra help from a teacher who's trained in ways blind people can do things to make up for the fact they can't see. Like cooking hamburgers. Did you know it's possible to tell when they're done by the way they feel? When they're ready, they don't squoosh down as much as when they're still too rare. I'm working with my mom now to put Braille labels on all the cans of food in the kitchen so I can tell them apart."

"Yeah, I suppose it'd be a bad deal if you had to open each one and taste it before you knew what was in the can. Say, I'm a lousy cook myself," Lionel told her. "Maybe you and I should plan on living together someday, and I wouldn't have to starve to death. Besides, that way at least we'd have one good pair of legs and one good set of eyes between us."

"Hey, watch it, friend. What if Becky and I are serious by then?" Dan interrupted.

"Besides, Lionel," Becky teased him, "Dan told me how you told the biology teacher you were totally allergic to all animals so you probably couldn't stand the guide dog I'm going to get as soon as I'm 18. That's when I can apply."

"Well, I just told the teacher that allergy thing because I hate cutting up defenseless frogs. I mean, what have they ever done to me? But I can see there might be a problem with Dan," Lionel admitted. "But how come you're learning all the cooking and carpentry stuff?"

Won't there always be somebody around to do things like that for you?"

"I sure hope not," Becky answered quickly. "I'm planning on being able to live by myself some day, or maybe with a roommate. Do you want to live with your mom and dad for the rest of your life?"

"No, I sure don't," Lionel agreed. "In fact, I've been thinking a lot about that lately, ever since I saw a new apartment building open up just over on Dalmont Street. It's got ramps and wide halls that a wheelchair can get through easily and wider bathrooms with bars you can use to pull yourself up, and now that they're making buses so I can use them, well, there's no reason I won't be able to be as independent as I want. Of course, some day I'm going to have a car with special hand controls. I'll be able to get in it by myself and drive it, too. Then — the sky's the limit. In fact, speaking of the sky, did you know there are even pilots who are paraplegics? That's people who have two disabled limbs."

"That's great!" Becky said. "Say, speaking of travel, did I tell you our family's going camping at Cape Cod over Easter vacation? They've got a long trail there that's marked so blind people can enjoy the park as much as everybody else. All the signs are printed in Braille, too, and they tell you about the things you can listen to in the park, like different bird calls, and stuff you might be smelling, like a patch of mushrooms, and even how to feel different things. . . like you can tell different trees apart by feeling their bark."

"Sounds fun. Think your folks will let me come along?" Dan questioned.

"Fat chance. They think we're together too much now," Becky told him.

"I know. I've heard all about it," Dan reminded her. "Let's the three of us depart from this scene and head for my place where Becky will demonstrate how 'squooshiness' can tell you when a hamburger's done."

Rich and Lisa

"O.K. Do you all have your shopping lists? As soon as you've all checked, we can get on the van," the teacher reminded the six students waiting on the sidewalk outside the school's van. The class was on its way to a neighborhood supermarket as a kind of field trip.

Rich and Lisa were standing at the back of the group, holding hands and busily talking to each other.

"Rich! Lisa!" The teacher spoke more sharply this time. "Do you have your lists? Come on, let's go."

"I never get to talk to you, Lisa," Rich complained.

"Yeah, but we'd better pay attention to her," Lisa responded. "Do you remember everything we learned about buying groceries?"

Rich and Lisa's class for mentally retarded students had spent the past month getting ready for today's trip to a supermarket.

"I know about the stuff we're supposed to buy. Like we have to get beans and peas and meat and stuff like that, and we can't get too much ice cream," Rich answered.

"Oh, that part's easy," Lisa told him. "The money part is what scares me."

"I know. But we're going to live by ourselves some day so we have to be able to take care of paying for things, the teacher said," Rich reminded her.

"I just hope I remember how the teacher showed us to count out our money and be sure we get the right change," Lisa worried.

Rich and Lisa are among the 125,000 children who are newly diagnosed each year in the United States as being mentally retarded. This means that they'll always find it more difficult to learn things. Some things that other kids "pick up" by themselves, like

how to deal with other people, may have to be taught carefully to these students.

Also, classes for students like Rich and Lisa will deal with the basic things people have to know to get along in the world outside a schoolhouse. That's why their class is making today's practice trip to the supermarket — to apply the things they've learned about budgeting money and planning meals.

Some of the causes of mental retardation are known though doctors don't know why it happens. For instance, one kind of retardation called Downs Syndrome occurs when the cells from parents that combine to make a baby have one extra chromosome.

Other kinds can occur if a mother doesn't eat right when she's pregnant or takes drugs or drinks too much alcohol. Still other children might become retarded after they're born if they aren't helped to grow, either mentally or emotionally.

Many retarded students can learn quite a lot and will be able to get jobs (probably working with quite a bit of supervision) and to live mostly by themselves (also, probably with some supervision.)

Others may be able to learn only to take care of their personal needs like being able to feed and clothe themselves.

Rich and Lisa are what's called "mildly" retarded students. They spend quite a bit of their school day with non-handicapped classmates. In addition to lunchtime, gym class, and homeroom with everybody else, Rich plays the bass drum in the school's marching band. Lisa is active in Pep Club and a class that just started for kids who want to learn about photography.

"Mom says if I do things right today and remember how much change I should get at the store, she'll let me go shopping by myself for a sweater next Saturday," Lisa told Rich as they got on the van.

"How much money are you earning at your job, anyway?" Rich asked her. Lisa spends each Saturday morning working as a special aide at a nursing home near her house.

"Well, it's not that much money. But I really like helping people and bringing them things. I like trying to cheer them up. Someday, I want to be a real aide in a hospital," Lisa said. "How much have you saved up?"

Rich has had a paper route for six months now. His dad went over the route with him every day for a week until he'd learned all the people who were supposed to get papers. Now he does the route alone. His mom still helps him with his records.

"I've got about \$37," Rich replied. "I'm going to use it for camp next year. My dad said if I get \$50, he'll pay the rest."

"You know, Lisa, it sure makes me mad. Some of my customers think that because I can't always think so fast, I'm real dumb about money. They think I can't count out change. They always want to do it. But I'm really good at making change."

"I know," Lisa told him. "I hate it when people think that just because I'm slow about learning some things that I can't do anything. Did you know I won the award for swimming the longest last year at my camp? And my boss at the nursing home says I'm the only aide who always remembers everybody's names and what kinds of magazines they like me to bring them. Do you know I've never missed one day of work? And I'm always on time. My boss says he wished he had more people like me to count on."

"I can't wait for when we're grown up and we can get married and live by ourselves. I don't want somebody else around, always telling us what to do," Rich commented.

"Yeah, that's going to be neat," Lisa agreed. "But you know our teacher said we'll probably always need another person who helps us keep track of stuff and makes sure we're watching our money and not buying stuff we



don't need and that we're going to the dentist when we're supposed to, and stuff like that."

"I know. But they won't be around all the time. I just want to come home from the store and have you bring me my slippers like in that movie we saw where the wife always did that."

"Hold on," Lisa interrupted. "I'm not going to bring you your slippers. I'll be too tired from my job at the hospital. I don't think wives do that anymore. What store are you going to work in?"

"Well, I sure like camp and all the stuff we do there. I want to work in a store that sells boats and skis and fishing poles. I talked to a man who runs a store like that. He said maybe someday I could work for him. I could help unpack things and move stuff around the store and keep it clean."

"Do you think we'll have enough money to live by ourselves?" Lisa asked.

"Sure," Rich replied. "And for some babies too."

"Rich, my mom and dad don't think it's a good idea for us to have babies," Lisa told him.

"Why not? I know how to change their pants. Mom makes me change my brother's sometimes. I know they have to have special milk, too."

"Yeah, I told them that. But they still don't like it. They think that we'll always need extra help just for ourselves and we shouldn't have a little baby to take care of, too," she explained. "Mom always says it's a big re. .re. . responsibility."

"Well, let's talk about it later. I just don't want to think about it now," Rich said. "Will you have to sit in that special pep club section at the game?"

"Students! Students! Quiet!" called the teacher from the front of the van. "Make sure now that you all have your lists ready when you go into the store. Remember where I told you things are."

"Be sure to count your money carefully when you're at the checkout line. O.K., is everybody ready? Let's go."

Rich and Lisa, nervous about doing everything right but happy that they had a chance to do things for themselves, slowly stepped out of the van.

Maria and Karen, Doug and Danya

"Hi, Maria. Where have you been all morning?" Karen signed to her friend as the girls met in the crowded hall outside the homeroom. "Did you call in sick to get out of that quiz in history?"

"No, I took that yuk thing last week so I could be gone today," Maria said with a speech sound that wasn't quite clear. Deaf since birth, she's a short pretty girl with shining black hair and eyes that cause envy among all her friends. "My mom took me downtown to try out for a dance group."

"But you can't hear music! How can you dance?" Karen asked her friend in surprise.

"Oh, this is a special dance group for deaf teens and adults. We can't hear music the way you can, but we can feel vibrations, and we all dance in time to those," Maria explained.

Maria is able to hear some sounds with the help of a hearing aid she wears. Although her speech sounds different, it can be understood. With her friends who've learned sign language so they can communicate better with her, she often uses a combination of both signing and speaking.

Years ago, she went to a special school program with other hearing impaired children to receive lots of help learning how to sign and to speak, something that's especially hard for people who've never been able to hear clearly the voices of others around them.

In grade school, Maria started going to classes in a regular school with children who weren't deaf. In classes like math and science, she had an interpreter who signed what the teacher was saying for her.

Now in her sophomore year, she attends a regular high school along with many other hearing impaired students. Help is available to them in a resource room if needed, and the school also has an excellent computer program for deaf students. Studying some subjects with a computer, they find, is a big help in addition to receiving instruction in a classroom with a human teacher.

Though Maria can read lips, lip reading, of course, works only when the speaker is facing her. Also, many words look just alike so lip reading isn't always reliable. Maria often finds she has to read her textbooks especially carefully to make up for not always being able to understand what a teacher said in class.





"That's really great you can dance," Karen told Maria. "I'm not very good myself even though I can hear all the music, not just vibrations. Sometimes I forget you're deaf, you do so many things. Remember when you first started school with us, and we were all worried because we thought you'd be too different?" Karen reminded her friend.

"Oh, yeah. I'll never forget how I felt that first day," Maria recalled. "Sort of like I was E.T. on a foreign planet, and I couldn't get home."

"I know. You looked terrified. We didn't know if we should try to talk to you or what. Then your aide explained that if we'd talk slowly and clearly and remember to face you, you could understand a lot of what we were saying. Of course, it took quite awhile for some of us to learn to understand what you were saying."

"Yeah, I was so glad when some of you started taking sign language classes so we could talk that way," Maria remembered.

"Then how come you still spend so much time on weekends going to parties with other deaf kids now that Sue and Aaron and Randi and I can all sign?"

"It's hard to explain," Maria said. "I guess when we're talking about group stuff, I just

still feel more comfortable when I'm around people who I know can all sign. When I'm with people who can hear, then I still feel different. But when I'm with people who are all deaf, then it's like sound just doesn't exist and we're all the same so I'm not different any more. Does that make sense?"

"Yeah, I guess I can understand where you're coming from. Oh, darn, there's the bell. Guess we'd better get going. Say, I've always wondered. How do you know when to start for classes and stuff when you can't hear the bells?" Karen asked.

"Oh, that's easy," Maria laughed. "I just watch everybody else and see that they're moving so I do, too. I always have to use my eyes to get signals. Like at our house. We've got it all set up with flashing lights. You've seen them. When the telephone rings, a light comes on so I know to answer it. I just say 'One moment, please', and I get someone else to talk. Or, if the caller has a TDD for their phone like I do, then I can take the call," Maria explained.

"What is a TDD anyway?"

"It means a 'telecommunication device for the deaf.' It's a special keyboard that's used with a phone. Both the person calling and the one answering have to have it. With it, you can 'type' messages back and forth.

"Like I 'see' what the person on the other end is saying, and then I type my message back to them, and it's written out on a strip of paper on their end," Maria said.

"Now," she continued, "I also have a portable TDD that I can carry with me and use to phone home. Oh, and you should see the new strobe light I've got for my alarm clock now. Mom was tired of having to shake me awake every morning. When the alarm goes off, this bright light like you wouldn't believe starts going off in my eyes. Very effective! Hey, we really had better get going. See you after school."

Walking into her homeroom, Karen sat down beside Doug, a tall junior she was thinking

about asking to go along on a Halloween hayride. So far, however, she hadn't quite got up enough nerve.

"Say, Doug, have you heard from your friend Danya lately? What's wrong with her anyway?" Karen asked.

"She had to go back to the hospital so she could get a lot of counseling and therapy," Doug replied. "Her mom says she has something called 'schizophrenia'."

"What's that? Is that like a split personality? Like Dr. Jekyll and Mr. Hyde?"

"Well, it's really not that dramatic. It's more like sometimes she just isn't connected to the real world like the rest of us are. She really gets withdrawn, and she says things over and over again that don't make too much sense," Doug explained. "My mom says when Danya gets in those moods, that she's 'out of touch' with reality."

"How can you stand to be her friend?" Karen wondered.

"Well, sometimes it's hard. When she's O.K., she's really a great person. Then when she gets sick, it's like the real Danya has gone away somewhere, and it's hard to recognize the person that's left."

"I used to get really mad at her," Doug continued, "and I'd tell her to straighten up and get her act together. But now I understand it's not something she can help."

"Well, isn't there some medicine they can give her?" Karen asked.

"There are medications that are used for grown ups — and for kids, too," Doug told her. "But it depends on the doctor's treatment plan. Mostly, I guess, she spends a lot of time talking with her counselors or doctors and having 'group therapy.' That's where kids with problems that are sort of alike get together with the doctor. I guess they try to get her to come back to 'reality'."

"Does she even know you're around when she's out of it?"

"I used to have my doubts," Doug said. "It seemed like she didn't even know her friends. But I went with her dad and mom to pick her up from the hospital one time, and when she was packing up, she had this box with all my letters saved up, and they looked like they'd been read about a thousand times. When she's having one of her good periods, she tells me that it's really important to her that I'm her friend. She says when she's sick, it's like there's kind of a wall between her and other people and she can't always break through the barrier. But she says she still counts on knowing that I'm there and I like her."

"Maybe I'd like to meet her when she comes home," Karen decided.

"Good. I think you'd like her. She's a good guitar player and she's written a lot of really good songs. They're kind of sad, but the things she says about feelings and life are the way I feel sometimes, too, when I'm in a blue mood, only I can't say it as well as she can," Doug told her.

"Speaking of guitars," Karen said after thinking quickly, "our class is going to hold a hayride, and we're going to have three kids playing country music, and I was wondering... well, maybe would you..."

"Students, this is the last time I want to remind you. You're supposed to be studying," the irritated teacher called from the front of the room.

"Oh, well, maybe tomorrow I'll get my chance to ask him," Karen thought as she picked up her biology notebook.



Shelly's Job

Shelly and her mom don't always agree on her school clothes. Mrs. Vincent thinks Shelly should wear the kind of blue jeans you can find on sale at discount stores. Shelly likes the kind her friends wear, the ones with a good label.

They worked out a deal last year. Shelly's mom chips in for what the plain jeans would cost. If Shelly wants the kind you see on T.V., she has to pay the extra herself.

So on a lot of Friday and Saturday nights, you can find Shelly babysitting. Her best paying job is across the street with the Johanson kids. Bill Johanson, who's six, is mentally retarded so it might seem like a good idea that Shelly is handicapped herself so she knows how to take care of him.

But she just smiles when asked about that.

"You can babysit for a handicapped kid *without* being handicapped yourself," she explains. "Of course, sometimes when Bill's been bawling for the last half hour, I wouldn't mind being deaf. Just kidding!

"Of course, there are some things you should know before you start besides the stuff you'd do with any kids like writing down a doctor's number and where the parents will be. If you're babysitting a kid who has a handicap, here are some things I think are important to find out:

1. If the child has epilepsy, how should you handle a seizure?
2. If the child can't communicate with you as another child would be able to, what special things should you do to understand what he or she might be trying to let you know? How can you get messages across to the child?
3. If a child has a physical handicap, are there special ways you should handle him such as when he eats or goes to the bathroom or to bed?

4. What types of games is she or he able to play? Are there any that might be dangerous and shouldn't be played?

5. Are there any special medicines the child needs to take?

6. Are there any specific things that the child shouldn't do because they might be dangerous to him or her?

7. If the child is deaf, remember he won't be able to hear you if you need to call to him or her suddenly to warn of a danger. Always be ready to run and grab the child before he or she tumbles downstairs or puts a hand on a hot stove, for instance.

"Finally, like I said before," Shelly concluded, "always be sure you have a number where you can reach the parents and a doctor's number to call in case there's an emergency."



When we can — prevent

Sometimes we know what's caused a handicap.

For instance, babies who have been shut off from getting enough oxygen when they were being born could develop cerebral palsy.

The babies of mothers who are sick with German measles while pregnant are frequently born with heart, brain, hearing, or vision defects.

However, even though we may know what a handicap is — for example, epilepsy is an unusual discharge of energy in the brain — we may not know why it happens.

And even when we know why certain handicaps occur, there may be nothing that anyone could have done to prevent them.

That means people with handicaps and their families have usually decided there's not much point in sitting around and trying to figure out what someone could have done differently several years before:

Instead, they think about how the person can best live with the handicap now that it's here. They look for ways he or she can get around the problems caused by the handicap. . . like vans with special equipment that a physically disabled person can drive or seeing eye dogs that help blind people move through the world. . . or learning sign language so a deaf person can communicate with other people.

Still, research has helped us learn quite a bit about things we *can* do to help prevent some handicaps from happening in the future. *

1. A poor diet for a mother during pregnancy can cause the developing baby to be "malnourished." This can lead to damage in his or her brain's development and stunted growth.

2. Chemical substances in the mother's blood during pregnancy, like drugs or alcohol, may have a harmful effect on the baby. For

instance, some tranquilizers, if taken during the early part of the pregnancy, can cause the baby to be born with missing limbs.

3. There are several diseases, such as chicken pox or German measles, that can cause defects in a baby if the mother has them while she's pregnant.

4. Finally, after a baby is born, unless he or she is fed properly, loved, and made to feel secure and taught the things needed to grow and develop, mental retardation or emotional problems can result.

When thinking about handicap prevention, the key is for the mother to go to a doctor as soon as she thinks she might be pregnant. She should be sure she is on a proper diet and avoid drugs and alcohol during the pregnancy. Getting all immunizations to prevent diseases during pregnancy is especially important.

If all medical advice is followed, there's less chance that handicaps will develop.

* *Young Children with Special Needs*, by Nancy Fallen with Jill McGovern, Charles E. Merrill Publishing Company, 1978.



PACER Center is funded by a grant from the Division of Personnel Preparation, Office of Special Education and Rehabilitation Services, U.S. Department of Education; foundations and corporation grants; and individual contributions. PACER is a coalition of 18 Minnesota disability organizations and is concerned with the education of children with all handicaps – mental, physical, emotional, and learning.

*PACER Center, Inc.
4701 Chicago Avenue
Minneapolis, Minnesota 55407
(612) 827-2966, Voice & TTY*