

for the person with Down syndrome and his or her family. What resources, programs, and services do they need to continue functioning actively in the community? Who should do the planning and provide the services? What is the role of siblings and other concerned individuals? All these questions need to be addressed.

Individuals with Down syndrome have every right to live in neighborhoods among people with whom they work and interact.

Relevant to all these issues is basic research into key questions about Down syndrome. Medical research into treatments for leukemia, respiratory problems, heart defects, and other illnesses that particularly affect people with Down syndrome must be continued. Behavioral research which looks at speech, language, memory, and motor coordination should expand. Social science research which focuses on employment, education, socialization, and living arrangements is essential. Advancing knowledge about these important issues will open up significant new possibilities for people with Down syndrome.

The 1990s will offer many exciting opportunities for people with Down syndrome. Pioneering parents will encounter new challenges as they strive to provide the widest possible choices for their children. As people with Down syndrome make strides toward achievement, professionals must continue to explore new options in delivery of services, education and training, and health care.

In the year 2000 we will look back at the 1990s as the time when people with Down syndrome moved forward to take on meaningful roles as teenagers and adults in our society.

Now is the time to do research and planning so that people with Down syndrome can branch out toward new directions in our society.

Aunt Jewell and Sammie

by Julie Heide

Good afternoon Principal Tompkins, ladies and gentlemen of the PTA, boys and girls. As the principal told you, I am Samantha Eckhardt. I am very pleased to return to Price Elementary School to receive this citizenship award and to tell you about my citizenship project. I attend Valley Middle School as a seventh grader. Middle school is pretty cool when you're in the seventh grade but sixth grade stinks. Well, anyway, back to my project. . .

It all started when I went to visit my Aunt Jewell last summer. Now here's a picture of her sitting next to where she gets her mail. Her box is number F-110. It's a shame she doesn't have number F-109 or 108 or something, because she can't reach number F-110 very well. She can get the key in but sometimes she can't reach all the mail if it's sitting at the back of the box.

She's not really my aunt. Technically she's my great aunt, because she was married to my father's uncle. She has my same last name, and she likes it when I call her Aunt Jewell. Aunt Jewell calls me Sam or Sammie, but not when my mom's around. My mom tells me I should like the name Samantha because of that girl who wrote to the president of the Soviet Union and got to fly over to Russia to meet some Russian kids. She says if I try really hard I'll have a chance to do something really important like that. Samantha is a beautiful, important name she says. I think they named me that because my dad had this thing for Elizabeth Montgomery. It's okay Mr. Tompkins, I'm getting to my project. I just wanted to point out that right from the beginning my Aunt Jewell and I got along because we knew what name to use to make the other one feel comfortable.

The first time I met Aunt Jewell I had rode my bike over to this retirement village where she'd just moved to. If you'd like to know it's called Happy

Valley, and all these old people live there. Aunt Jewell has a little apartment there. My mom sent me over there with a loaf of banana nut bread. I found Aunt Jewell's apartment okay and I pushed the buzzer. Nobody answered the door and I pushed it a few more times and I was getting ready to leave when the lady in the next apartment came out and asked me what I was doing. When I told her I was a relative she told me to go on in, that Jewell didn't hear well and was probably in the bathroom.

It seemed kinda strange to just walk in somebody's house but I did what that other lady said. Once I was inside I said, "Mrs. Eckhardt. I'm here to visit you. I'm Harry's girl, Samantha. I brought you

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some bread that my mom made." Well, Aunt Jewell heard me calling to her I guess and she came walking out of the bedroom pushing a wheelchair in front of her, leaning on the chair as she pushed it along. Her feet were all covered by these padded soft shoes, sort of like slippers only different. She walks really slow and careful. She picks her foot up pretty high and then she looks at where she should put it down again, and then she sets it down. She really concentrates, like she was walking on the moon or something. My dad says it's because she can't feel her feet anymore and if she doesn't put them down really careful that maybe she'll fall. Like when your foot or your whole leg falls asleep when you're watching TV and you get up to go to the bathroom and it feels like pins and needles. Aunt Jewell's hair is sort of light orange and gray, and it sticks out from

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her head like Yahoo Serious. She always waits too long to go for a new perm. That's what my mom says.

She walked into the room that day pushing her wheelchair and she was really smiling. She has a big smile that shows her teeth a lot. The teeth really stand out because of the holes where other teeth

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used to be. The doctor wanted to pull the rest of her teeth out that summer, but what was she supposed to do after they took out her teeth? They said she'd have to wait something like three weeks before she could get dentures. How'd you like to have no teeth for three weeks and not be able to eat anything and look like your face is all caved in? I said, "Don't do it, Aunt Jewell. Don't let 'em take your teeth."

They're always wanting to take something. The year before I knew Aunt Jewell her feet were giving her quite a bit of trouble. She had some big sores on them because she has poor circulation and she can't feel much. The doctor wanted to cut 'em off. I mean he wanted to cut them right off! How's she supposed to get around without any feet? Aunt Jewell, she told the doctor she wanted to try to do something to heal the sores and he got really mad at her and said she was really being difficult and she should listen to him because he was the doctor. He said her feet were infected and if she wasn't careful she'd get gangrene and die. Aunt Jewell said well then she'd die with her feet on thank you, and she got a different doctor.

A lot of people don't much like taking care of old people. One time Aunt Jewell was staying in a nursing home while her feet healed up. The nurses kept giving her a laxative every day. She told them that she was having diarrhea and didn't need a laxative. They told her to take it anyway, that the doctor had ordered it and she shouldn't argue. They treated her like she didn't know anything! Aunt Jewell, she just started pretending to take that pill. She'd pretend to swallow the pill and then flush it down the toilet later. She was glad to get out of that place.

Sometimes when I go to visit Aunt Jewell she'll treat me to lunch at the Happy Valley dining room. My Aunt Jewell doesn't really cook. I think she fixes cold cereal for breakfast or toast or something, but her hands aren't very strong and her fingers don't have a lot of feeling. She worries about dropping things or burning herself, plus it's really hard to cook from a wheelchair 'cause you can't see what's going on. There's this meals-on-wheels program and they bring her her lunch, and then she saves part of it to eat at suppertime or she just eats some crackers.

The Happy Valley dining room is a cafeteria. Aunt Jewell's apartment is a long way from the dining room. She can get there through the halls without going outside or anything but it would take her about all day to get there because she goes so slow and careful. In a couple of the halls there are steep places and she has to turn her wheelchair around backwards and pull on the handrail while she scoots with her feet. It takes about an hour to get up one hill. When I visit I can push her in the chair.

Aunt Jewell likes to go through the food line, even though it's kind of crowded with her wheelchair and everything. I think she likes to pick out her own food from the steam table, and I don't blame her. I mean, sometimes food sounds pretty good until you see it and then you know you'd rather have something else. The serving people behind the steam table they're always in a big hurry. They say, "What would you like, Mrs. Eckhard?" They ask her that even when they can tell by just looking at her face she hasn't decided yet. They try to make her hurry.

And another thing: Aunt Jewell asks them for half-orders. If you want a half-order of one of the main dishes you just say, "Half-order, please," and they give you a smaller portion and stick a little party toothpick in it. Sometimes Aunt

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Jewell doesn't remember to say the half-order part until they've already put the food on the plate, and they just hate it

when they have to put some of the food back. They scrape it over the plate so that when she puts a roll or a piece of bread or something on the plate later it can't help but get mixed up with her main dish. I always wish my dad were there when we go through that cafeteria line; I don't think they'd be so nasty if he were there. He'd say to them, "I don't think Mrs. Eckhardt has decided just yet. Take your time, Aunt Jewell. We want you to really enjoy this meal." He always says kind of dopey things like that, but old people really like it. I think he helps them to feel relaxed.

So one time towards the end of summer I was over at Aunt Jewell's. The doorbell buzzed, but before Aunt Jewell could do anything the door opened. It seemed kinda weird. Why bother ringing the bell if you plan on opening the door immediately? The woman who delivers

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for meals-on-wheels walked right in with a styrofoam tray and set it down on the kitchen table. Aunt Jewell picked up her quad cane and started high-stepping over to the table. The meals-on-wheels woman looked over at me and then she looked back at Aunt Jewell — like she was trying to figure something out — and then her face turned all sour and she asked if Aunt Jewell was going to eat the meal now or put it in the refrigerator. She said something about how people who can manage to go out for lunch really shouldn't be receiving meals. The meals are for those who absolutely have no other way to get a hot meal. The whole conversation was really embarrassing. The woman made Aunt Jewell sound like a cheater.

Some grown-ups just seem like they want to blame old people for being old. And if you can't hear very good or get around good and if you're slow or something, they just act like you don't have any reason to be alive, or at least you ought to stay shut up at home so people don't have to look at you.

We had planned to go to the dining room for lunch that day, but Aunt Jewell didn't feel like it after the meals-on-wheels lady said those things. She was

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upset and she started crying. I took hold of her hand and I just sat there with her while she cried, and then after awhile I said, "Don't cry, Aunt Jewell." I was surprised to see her upset, because she acts so strong and cheerful and everything, but I guess I really shouldn't have been. I mean, you flip a pancake over: one side's done and the other one isn't, right?

She said, "Sammie, it's hell to be old. I can't walk, I can't hear, I hurt all the time. I'm just barely taking care of myself. And there's always someone trying to kick me down. They could buoy me up, but they seem to prefer to kick me down."

Buoy means to keep something floating, to keep it from drowning. Aunt Jewell meant that people could support her, but they don't. The post office guy knows Aunt Jewell can't reach F-110 because when I'm not around she has to ask him for help. He could give her a different box, but he doesn't. The cafeteria servers don't really have to be in a great big fat hurry and they know Aunt Jewell almost always asks for half-orders. They could be nicer to her and show more patience. They do the opposite. The Happy Valley people could fix their halls so they don't have steep places. Little things like that would be a big help to Aunt Jewell and a bunch of other people there.

When my social studies teacher Miss Elliott (she's standing up there at the back of the room in the red dress, if you want to know) assigned us to do a citizenship project, I thought about ol' Aunt Jewell and some of her friends and I decided to do a meals-on-wheels thing for Saturdays. We call it the Redline Express because I haul the food in my little brother's old red wagon. My mom and my dad and I, we fix a casserole and cut up some fruit and we keep it the right temperature in one of those big plastic insulated deals. For \$1.50 people can have casserole and fruit salad. I started out serving five or six people, but now I have around fifteen customers.

"Sammie, it's hell to be old. I can't walk, I can't hear, I hurt all the time. There's always someone trying to keep me down. They could buoy me up; they seem to prefer to kick me down."

Miss Elliott says my project is important because I saw where there was a real need and I created my service to fill the need. She says it's a shame how we try to cram people into programs instead of fitting the program to the person.

I learned that older people want to do things for themselves and to get out as much as they can — just like anyone else.

Now this is the part in my speech where I'm supposed to tell what I learned: I learned that older people want to do things for themselves and to get out as much as they possibly can - just like anyone else. And that some grown-ups, instead of figuring out ways to help older people to do for themselves and be a part of the world, seem to expect old people to just give up and stay home, to let people cut off their feet and yank out their teeth, and probably to just shrivel up and die. And I learned that once you figure out that isn't fair, there are lots of little simple things you can do to buoy people up.

I'm really glad I have an Aunt Jewell — for about a million reasons that I don't have time to tell you. I'm glad I can help when she needs a little help, and I hope that when I get old and maybe need some help with a few things, someone will help me.

Thank you for asking me to do this talk.

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