



Rising
to the
CHALLENGE

DECADES AGO, FEW PEOPLE HAD HIGH EXPECTATIONS OF MENTALLY OR DEVELOPMENTALLY DISABLED CHILDREN. THESE KIDS WERE OFTEN KEPT AT HOME, AND GIVEN MINDLESS ACTIVITIES TO KEEP THEM BUSY AND QUIET. TODAY, THESE SPECIAL INDIVIDUALS ARE BEING GIVEN LIFE SKILLS AND A VOICE AS PART OF THE "SELF ADVOCACY" MOVEMENT

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"My brother-in-law Bentzy has Down syndrome," relates Shaindy. "As the youngest child in a large family, his house is always bustling, with married siblings and their children popping in and out. When I married Bentzy's brother, there were still many things Bentzy needed to learn how to deal with." He struggled with things like a break in his routine, a less structured environment, and people touching his things. "Even though Bentzy was a 21-year-old adult, he was being treated like one of the children," Shaindy recalls.

A year ago, however, a self-advocacy program was launched at Bentzy's school, a renowned special-education institution in Jerusalem called Seeach Sod. As the program progressed, the family saw dramatic changes in Bentzy's behavior. "For example, he now prepares everything for the different family members when they come to visit," says Shaindy, who is a special-education teacher and ad-

ministrator. "He straightens the rooms, makes the beds, and provides extra pillows and towels."

Not only do these actions make him feel capable, they also earn him the respect of the family, which in turn teaches him to respect himself more. Bentzy also knows a lot more about what he is — and isn't — capable of.

"He knows he's great with babies, but that he can't change diapers," Shaindy says. "He teaches the little ones not to hit, and tells them they have to share. He sets the table, cuts up the salad. He gets himself dressed now. These new behaviors endear him to his family and bring him a new level of independence. He feels great about himself."

What is perhaps most remarkable is that no one worked directly with Bentzy on these specific skills. "The changes," says Shaindy "are due to the way Bentzy sees himself. He's a person, he's capable, he contributes. The ability to do these things may have been there before, but the self-advocacy program brought out his potential."

Just because a person lacks verbal skills doesn't mean he lacks feelings and opinions. Nor does it mean he must remain unproductive or entirely dependent on others

THE SELF-ADVOCACY MOVEMENT

From a newborn's first moments, parents are attuned to every murmur. Does that cry mean she's hungry? Tired? Until children learn to speak, parents must master the art of deciphering sounds so they can best respond to their baby's needs. Once a child learns to communicate effectively, she gradually becomes more adept at stating her own desires and indicating her preferences. And as she matures, parents will gradually step back, serving less as a voice and more as a guide. After all, who can better speak for an individual than the individual herself?

Yet when a child has difficulty speaking for himself — as is often the case with special-needs people — parents continue to assume that role, sometimes indefinitely. But just because an individual finds it hard to express himself doesn't mean he still isn't the best candidate for the job. This is the philosophy behind self-advocacy, a concept that has become a growing movement.

Self-advocacy means that you're in charge of yourself, whether you're at home, in school, at the doctor's office, or out shopping. It's the ability to express your needs, interests, and feelings. It's knowing who you are — your skills, your strengths and weaknesses, your preferences and desires. It's choosing and being responsible for your decisions. It's knowing your rights and being able to speak up for them. It's setting goals for yourself and creating a plan to reach them. It's being independent in every way possible, and asking for help when you need it. Self-advocacy requires self-awareness, which is often sorely lacking in those with special needs.

Chaviva, a 12-year-old with moderate developmental delays, is a case in point. She used to float from person to person, activity to activity, place to place. She was a loner, more like an apathetic child than a preteen. In Seech Sod's self-advocacy program, Chaviva was encouraged to ask herself a fundamental question: "Who am I?"

She learned, for starters, that she was born in Shaare Zedek hospital. This discovery was an epiphany. For the first time, she realized that she had been born, and that her class-

mates, too, had been born. She was a *person*, and she was surrounded by other people. As her mother recounts, "It gave her both the ability and the desire to communicate with others. It connected her to people. She's not isolated any longer. She woke up to the world; she found herself."

TALK OF THE TOWN

It's common knowledge that historically, developmentally disabled individuals were often treated as subhuman. They were kept in dimly lit, overcrowded rooms, and subjected to forced institutionalization, isolation, malnutrition, exploitation, and abuse. We've certainly come a long way since then, in no small part due to the self-advocacy movement, which sprung from the civil rights movements of the 1960s.

It all began in Sweden, where mentally challenged young adults were encouraged to form their own recreational clubs. Toward the end of the '60s and into the '70s, club members created statements for themselves about how they wanted to be treated. By the early '70s, the idea had spread to England and Canada, followed by the United States.

Then came a pivotal moment in the self-advocacy movement: At a 1974 conference in Oregon, the participants grew dissatisfied, feeling that the assembly was run by professionals and didn't actually speak for the mentally challenged individuals it purported to represent. As a result, they formed a self-advocacy group called "People First," so named because they felt that their status as people was more important than their identity as disabled individuals. The idea mushroomed, and there are currently hundreds of self-advocacy groups around the world. More recently, the idea broadened to include younger children, as well as populations with other distinct needs, such as the hearing impaired and learning disabled.

Last year, the self-advocacy philosophy became the talk of the town in Israel when Seech Sod instituted

a self-advocacy program (*singur atzmi* in Hebrew), catching the attention and admiration of educators from across the country. Each class at the school engaged in a different yearlong project to instill self-knowledge and encourage decision making. The projects, displayed over the summer at an elaborate exhibit, varied by age and developmental ability.

David Yonaton's class, for instance, asked the age-old question, "What do you want to be when you grow up?" This question taps into a child's dreams for the future but also the essence of who he is — which means he has to *know* who he is. During the self-exploration stage, 12-year-old David realized he wanted to be a radio broadcaster. After a year of researching the profession, he actually sat at the controls in a state-of-the-art recording studio. A popular Jewish singer — David's favorite — was singing a song dedicated just to him while David pressed buttons and turned dials.

Shmuel, another boy in the class, wanted to be a policeman. He spent a day wearing a real policeman's hat while he entered the ammunition storage room, rode in a police car, toured the Russian compound, and saw firsthand what happens when someone dials 100, Israel's emergency police hotline.

The school's pet project had even greater repercussions than anticipated. Once a week, a class of nonverbal 17- to 21-year-old students managed an actual cafeteria in the school dining room, taking turns being the proprietors and patrons. Students prepared and packaged the refreshments. "Patrons" made selections with photographs of the foods they wanted, adding a photo of themselves to indicate whom the order was for. "Waiters" took the orders and brought out the prepared food. The program had a profound effect on everyone involved, with many students showing dramatic improvements in their behavior while in the cafeteria, regardless of the role they played that particular week. Seeach Sod is now thinking of ways to expand the program to include the entire school.

The success of the program underscores a central tenet of self-advocacy: Just because a person lacks verbal skills does *not* mean he lacks feelings and opinions. Nor does it mean he must remain unproductive or entirely dependent on others. "We would like all special education schools to learn

POWER TO THE PEOPLE

Most Western countries have enacted legislation regarding the ability of an individual with diminished mental capacities to make medical treatment decisions. Consequently, requests for assessments by primary care physicians is on the rise. In the US, where the laws are established by the states, the requirements include the ability of an individual to reach a decision, understand the information given, consider possible consequences of treatment or failure to treat, and rationally weigh information to arrive at a decision.

In the UK, several acts have been passed to not only recognize the importance of self-advocacy but also provide funding for it, such as the Mental Capacity Act 2005, and the Mental Health Act 2007.

Some countries are slower to make progress because of cultural issues. In Japan, for example, since the general culture does not emphasize independence or self-determination, these basic tenets of self-advocacy were slow to take root in that country.



Giving them a voice: Seeach Sod's self-advocacy exhibit

from this, and see it as an example, as something they can do," remarked Chaya, a representative for Chinuch Atzmai (Israel's chareidi public school system) after seeing the exhibit at Seeach Sod. "It *is* possible for schools to promote self-advocacy."

BARRIERS TO PROGRESS

Standing in the way of self-advocacy are people who don't recognize that developmentally disabled individuals have both the capacity and the right to speak for themselves. Social, educational, and family frameworks can also unintentionally limit a person's educational or employment opportunities, as well as his ability and drive to communicate his needs to others. Even well-meaning family members can have low expectations, which undermine efforts at self-advocacy and foster helplessness.

Take Esther, for example. She's the mother of 10-year-old Gili, who has moderate developmental disabilities. As a result of Seeach Sod's self-advocacy program, Esther began paying attention to her many interactions with her daughter. "I realized that all day long, I was making decisions for Gili. I told her what we were doing, where we were going, what she was wearing," Esther says. "I was treating her like a little kid."

One morning, Esther got up a little earlier than usual and asked Gili what she wanted to wear. Immediately, Gili went to the closet and chose a dress, not the usual school uniform. "This helped me understand that she doesn't particularly like her uniform," said Esther. "Then I asked her what she wants to eat. And she indicated she wanted a sandwich. That moment really opened my eyes. My daughter knew what she wanted! I had just never stopped to ask." Since then, Esther lets Gili choose her own clothes and what she wants to take to school for lunch. It doesn't matter that Gili asks for the same thing every day; the important thing is that Gili gets to choose.

"In the winter, when it was cold, I used to say, 'It's cold,' and hand her a coat. Now, I started to ask her if she wanted a coat or a sweater. If she chose a sweater and it was a very cold day, we'd go out on the porch together and talk about how cold it feels outside.

"I am respecting her in a whole new way," Esther shares. "As much as self-advocacy gave Gili, it gave *me* even more. It gave me faith in my daughter's independence. It made me see that she has so much potential — I just need to give her the opportunity to practice her skills, such as dressing herself. It changed my whole approach to parenting."

Another barrier to self-advocacy is refusal on the part of the caretaker to respect the individual's right to make choices that differ from his or her own. Yet "dignity of risk," as the term is coined, means a caretaker must respect an individual's choices, as long as those choices don't pose clear danger to himself or others. This is especially important because overprotection of people with disabilities often prevents them from learning to accept the consequences of their actions, and from learning from failure. "Dignity of risk" allows disabled individuals to test the limit of their capabilities, empowering them and enhancing their self-respect. The goal, ultimately, is to work *with* the individual, not *for* him.

The benefits of self-advocacy are multifold for those with special needs. There's the increased self-awareness and self-empowerment, but also the ability to prevent stressful or difficult situations. During a medical examination, for example, a person with cerebral palsy who has an overactive startle reflex can ask for gentler touch. Likewise, a person whose senses are easily overloaded by noise can ask that an interview take place in a quiet room rather than in a busy government office.

As special-education teacher Gita toured the Seeach Sod exhibition, she remarked, "Think back even 15 years ago. These kids just sat at home, at best entertained, often plopped down in front of a screen to be kept busy and out of the way. No one had any expectations. Today, these kids are being given life skills and a voice — a voice to be heard, and the ability to contribute. Their own estimation of themselves has risen dramatically. They are expected to learn and do — and they rise to the challenge." ■