

The Sacramento Bee

11/12/10

FAMILY & HEALTH



Deron Schmidt looks down from atop the trampoline in his front yard. He became the south Sacramento home's owner in August.

Deron's dream

After frustrating experiences with group homes for her son, Joan Schmidt helped create a place that helps mentally disabled people build independent lives

By David Barton Bee Staff Writer

It may not look like much, this tiny house set behind a low cyclone fence in a low-income Sacramento neighborhood south of City College, but it is a dream home.

It was a dream without a dreamer. Or so some thought.

For years, this home was hidden inside the mind of a man who, for most of his life, wasn't acknowledged even to have a mind worth noticing, let alone dreams worth pursuing.

And yet, as Deron Schmidt, the home's owner, wanders the grassy lot on a sunny November morning, there is a palpable sense of contentment. He is in near-constant motion, from his bedroom to the kitchen to the trampoline in the front yard.

The contentment is there in his relaxed but energetic demeanor, in his soft, dark eyes. Or is it?

To look into Deron's eyes is as much to wonder as to know. Even those closest to him have a tenuous connection with his inner world, even as they see his life improve as they pursue their stilted, but fruitful, dialogue with him.

Schmidt, 29, is autistic. Like many with this poorly understood developmental disability, he has never spoken a word, and until the past few years, he was prone to violent outbursts that made him difficult to handle, even to house.

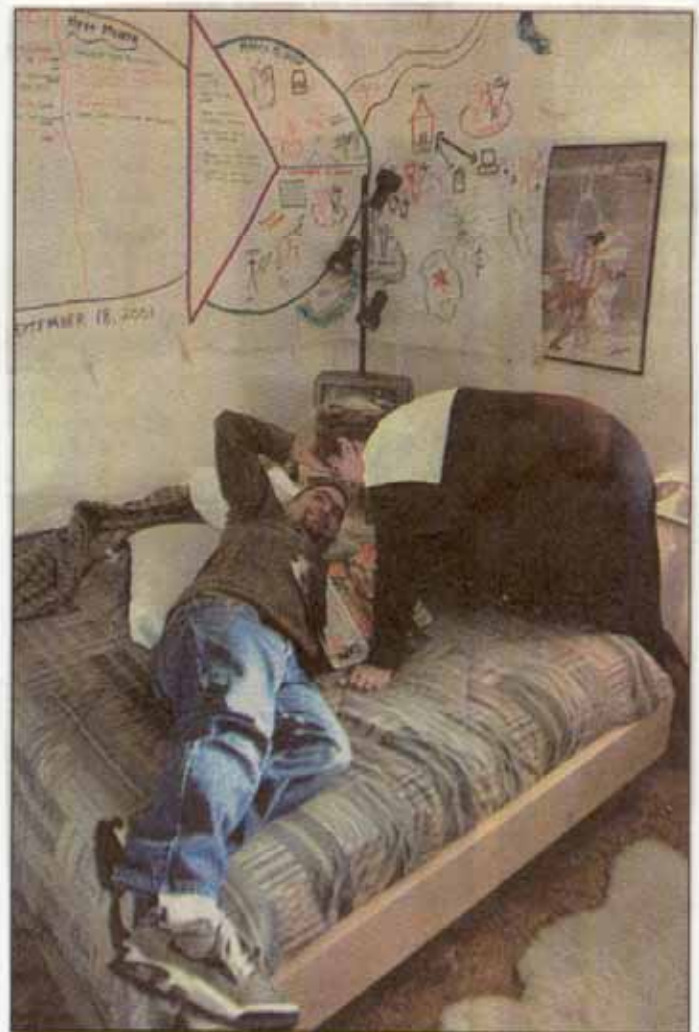
"About 10 years ago, he was getting pretty violent," says his mother, Joan Schmidt. "We couldn't have him at home, and at

► DREAM, page E5



Joseph Sampalo, who spends eight hours a day with Deron, lends a hand outside Sampalo's apartment complex.

Sacramento Bee photographs by Anne Chadwick Williams



Kathi Campbell, a friend of the Schmidt family and the co-founder of Creative Living Options, says goodbye to Deron during a visit this month.

Dream: 'Facilitated communication' puts him in touch

► CONTINUED FROM E1

the group home, they were afraid he'd hurt somebody. I could see that the only remaining option for him was Sonoma State (a developmental center that is the hospital-like home for those who are unable to cope in private or group homes). I'd visited hospitals, and that just wasn't an option for us. So I said, 'What if we took the same money to maintain someone in a hospital and set him up in a supported, independent-living situation?'"

Behind Joan's thinking was the notion that Deron's outbursts were based on something real: frustration and anger that he had no control over his life.

"I don't know about you, but my worst nightmare would be to have my mother in charge of what I wore and did every day," says Joan, a robust mother of four adults whose lifelong work as a trainer and organizer in various business capacities, as well as her role raising an autistic son, has made her an appealing combination of authority and diplomacy, of kindness and resolve.

"Everyone is entitled to their decisions and choices," she says. "Everyone has an idea of what they want. When you see people who are very developmentally disabled, I think much of that glazed look is just that they've shut down because they aren't a part of what's going on."

"But when people get a chance to make their own choices, we see them come alive and wake up, because we ask them what they want to do and where they want to go."

With that in mind, Joan and her friend Kathi Campbell, who is also the mother of an autistic adult, have formed a nonprofit company, Creative Living Options, that aims to give people like Deron a chance to live their own lives.

Launched in March, the company is already serving four individuals — not including Deron, for whom his mother is what is called a "parent vendor" — and has a long waiting list. It is one of a dozen or so such agencies in the state Department of Developmental Services' Alta California area, which covers 10 Northern California counties, including Sacramento County.

Julia Mullen is the manager of the community development branch of DDS, which has an annual budget of \$2.1 billion to serve some 170,000 people in California with serious developmental disabilities.

Of those 170,000 people, she says, 67 percent live at home with a parent, even through adulthood, and 16 percent live in licensed care facilities (or



Sacramento Bee/Anne Chadwick Williams

Deron Schmidt, left, gets help with a workout from Joseph Sampaio, one of his roommate/helpers.

group homes). Only 9 percent live in their own homes. The other 8 percent live in state hospitals or skilled nursing facilities.

But, she says, "Supported independent living is the fastest-growing living arrangement in the developmental disabilities service system. It's because our society has come to a greater appreciation of the fact that people with developmental disabilities are citizens, too, and that inclusion in the community is important for them and for the community at large."

"We all grow from their presence."

Deron moved into the community, into his own apartment, 10 years ago and became a homeowner in August of this year. He still needs around-the-clock assistance, but what has changed is his behavior and, those close to him believe, his sense of having his own life.

In the past few years, his violent outbursts have decreased from hundreds in a day to a few, if any, per month.

But since Deron doesn't speak, how did his mother know he even wanted his own home?

"He told us," she says.

The key to talking to Deron has been "facilitated communication," by which a question is asked and the answer is given by the disabled person using a keyboard.

"When we sat down with Deron, we asked, what does he like?" she says.

"He likes to go for walks, he likes jewelry, he has a great appreciation for art, and so you start building his life and how to make the supports. He doesn't like crowded places, so let's not put him in a place with a lot of people. It's just as you and I would do it: How do you want to structure your life?"

But facilitated communication is a controversial approach. Because many autistic people have poor motor control and therefore cannot type, their hands must be held in some fashion by a "facilitator." And this has led to accusations that it is the facilitator, not the autistic person, who is responding.

But Mark Grassinger, Deron's friend of 12 years and the house manager for his home, has no doubt about the usefulness of facilitated communication. The proof, he says, is in Deron's life.

"He was so aggressive and unhappy when we met," says Grassinger. "He had no voice, and through facilitated communication, we were able to find a voice, and through that he was able to start living."

"I understand the skepticism (about facilitated communication), I really do," says Grassinger, 37. "Society has taught us that if you don't speak the same as everyone else, you must not be all there. Speech is the communication people are willing to accept as a sign of intellect. And Deron has never formally learned to read, though he reads magazines all the time."

"But I know that FC works with Deron, because when Deron makes choices, they are sound choices," he says. He offers a couple of examples.

"When we go out to breakfast, and he types out what he wants, and then he demolishes it, he's made the choice he wanted," he says. "When he picks out a pair of shoes in the morning, he'll keep them on, whereas if they're the ones I choose, he'll take them off."

"I can tell by his actions that he is happy with his choices. The validation of his expression is truth enough for me."

Grassinger has been with Deron for 12 years, and the trust that they've

FAMILY & HEALTH

developed is the key to not just the facilitated communication but to Deron's sense of being an individual, and an adult.

But adult responsibilities can chafe as much as they liberate. "When we start doing things for him, he loses the desire and the ability to do things for himself," says Grassinger, who directs the household and keeps Deron on track. "So he needs to take responsibility for himself, and he does. He gets himself up now. He shaves, showers, he's fully included in his life - and he has self-esteem now, he derives great pleasure from being able to accomplish things.

"I treat Deron as I treat anyone else," he adds. "In many ways, I don't treat him any differently from my other friends. I don't let my other friends hit me, and I don't let him. It's like, 'Dude, if you want to hang, this is the way it is. Don't hit me.' And he gets that.

"If I went in and said, 'I'm just here to take care of him, love and nurture him,' Deron wouldn't have gotten where he is today."

And since Deron has 24-hour assistance, he has three roommate/helpers, each on an eight-hour shift, led by Grassinger. One is Joseph Sampaio, who, during his eight hours daily with Deron, takes him to his apartment complex to do some light weight training.

"He feels better if he looks well," says Sampaio. "He doesn't like to do it at times, but he feels good about himself."

Another helper is Gabe Jimenez, who has a relationship with Deron that's quite different from Grassinger's, Sampaio's or Joan Schmidt's.

Jimenez is a stocky, muscular man who, when not with Deron or his own family, is a professional wrestler known as Big Ugly. And part of his unique contribution to Deron's life is the way he avoids the common caregiver's trap of treating the charges like children. Jimenez doesn't buy that.

"He's a man, even though he's got a disability," Jimenez, 28, says as he and Deron make a fifth walking lap around the track at Hughes Stadium, where Deron works out three days a week. "He wants to be in control, but he also wants things done for him. So he has to learn that being in control means work."

And Jimenez is not a hugger or a hand-holder. He prefers instead to indulge Deron's predilection for giving high-fives, figuring that if Deron's going to become a part of society, he has to observe its social constraints.

"The general public doesn't want some 29-year-old man to walk up to

them and give them a hug," says Jimenez. "Same way it's not OK for him to walk up to someone when they're eating and take food off their plate."

But while Deron is learning the most basic social rules and undertaking the mastery of activities most people don't even think about, he is also teaching those around him.

"Deron has been one of my greatest supports and continues to be," says Grassinger. "I see the struggles and challenges that he has, and it puts my own trivial problems into perspective. I derive great strength from Deron.

"And Deron has shown me that I have this ability to work with people with disabilities," he says. "You can go your whole life without knowing what you're going to do, and Deron has shown me what I have to do."

To that end, Grassinger has undertaken a social-work degree at Sacramento City College. As for Joan Schmidt, knowing that Deron is on his way to his own life has freed her to help those who may not know about their options to choose supported living.

"My thing isn't Deron now," she says. "I don't worry about what will happen to him if I drive off a cliff tomorrow. I want my kids to live to the highest sense of their desires rather than just keep them safe at home in bed. With someone with developmental disabilities, it doesn't always happen that they ever get to grow up.

"And everyone deserves the chance to grow up and have his own life."

Deron agrees. Sitting down on the day before Thanksgiving to talk through his keyboard, he's not in as sunny a mood as he was the previous week. Some of the head-slapping behavior that was once the norm has returned, and his responses to questions are punctuated by yelps and cries and the random head movements that are a common feature of autism.

And yet he recognizes a visitor and, unprompted, types "Yim glad bto see you."

Asked how he likes his new house, he types, "it feelsright."

Writing like this, with Mark holding his wavering arm, is always difficult for Deron, but it his link with a world that otherwise would have no idea who he really is inside.

So, despite his pained expression and struggle to control his head and arms, he volunteers a closing comment.

"I have becomen real happy since i have received help yliving on myu own."

□ □ □

The Bee's David Barton can be reached at (916) 321-1075 or dbarton@sacbee.com.