



## New Visions for Developmentally Disabled Young Adults

By Victoria Scott

For many, graduation is a time of glowing potential and wide horizons. Of beginnings.

But for young adults with cognitive disabilities (autism, Down syndrome, pervasive developmental disorder and the like) and their families, high school graduation may instead be an ending.

Peer networks disappear. Community support systems fail to materialize. And as doors close, these young people lose their capacity to dream and be productive.

"The issues are systemic and complex," says Kay Branz. "Only fools--mothers and families--would try to make it better."

Ms. Branz and Jane Doyle--both members and social entrepreneurs--have set themselves to the task. With their bold new venture, the Center for Independent Futures at 625 Madison St., they intend to expand post-secondary options for developmentally disabled youth.

Unimagined independent futures for parents and siblings may follow.

Ms. Doyle and Ms. Branz have copyrighted a name, Full Life Planning, for the Center's process of charting a course for young adults with disabilities. It amounts to creating "an intentional road map for a three dimensional life" for these young people, says Ms. Branz. "Beyond a job and apartment, it addresses isolation issues and the need for engagement within the community."

Ms. Doyle and Ms. Branz propose a brand new paradigm to supersede the "charitable model" that merely offers care and safekeeping for the disabled. Existing options typically "keep families at arms' length," says Ms. Doyle and "create a safety net" rather than "giving [the disabled] room to fail and succeed."

The two have incorporated their enterprise as a business, not a non-profit, to distance themselves from public funding and traditional notions of custodial care.

In their model, disabled individuals are instead "citizens with gifts for the workplace, the community, and the neighborhood," says Ms. Branz.

Like other citizens, they will continue learning and growing after graduation. Community supports, to be designed by families and individuals, will help these young adults move step by step to achieve their greatest potential.

But such a system "has to be created," she says. "It doesn't exist." She and Ms. Doyle, whose daughters first met in middle school special education classes at Martin Luther King Lab School, know firsthand.

"We have been living this," says Ms. Branz, who realized, "there is zero out there... It's going to have to be us."

Incorporated in December, 1999, the Center for Independent Futures is still in the startup phase. Ms. Branz brings a master's degree in business administration, and Ms. Doyle, a doctorate in special education and experience managing the program that transitioned special students at National Louis University from dorm to community.

Their "What Next?" consultations have begun helping families and individuals team up to identify achievable objectives and "get unstuck," says Ms. Branz. This summer they will pilot their Full Life Planning product with 16 to 21-year-olds.

But the centerpiece of Ms. Branz and Ms. Doyle's program is Community Living Options, an educationally-based model for independent living for young adults, ages 21 to early 30's, with mild to moderate cognitive disabilities.

Many want to try apartment living, like classmates with whom they have been mainstreamed. But because their experience has usually been limited in comparison, most need assistance.

"There is so little available in Illinois," says Ms. Doyle, who is in discussion with a Massachusetts group that has successfully pioneered communal living opportunities.

The Center for Independent Futures is holding a meeting for the public on June 12. They hope to identify six to eight families "who really want to work together to create a new living option," says Ms. Doyle, at a cost they hope will not exceed \$1500 a month.

They envision an apartment or condominium building with a live-in resident advisor "to pull together meetings and social events," she says. The Center, she says, "will facilitate the organization and provide a framework," including an array of education-focused support services (menu-planning, money management) available on a contract basis from trained providers.

The goal is to "get families planning for their child's future when they're still working," says Ms. Branz.

As for the new community model, Ms. Branz views it as "a place where quirks can be accommodated in an old-fashioned, networking experience." The benefits to the individual and society are reciprocal. She observes, "The more exclusive a community becomes, the less vibrant it will be."

### Paige's Story

Paige Doyle, 22-year-old daughter of cofounder of the Center for Independent Futures Jane Doyle, has successfully negotiated several transitions since leaving the special education program at Evanston Township High School. Apartment life and her job obviously give her great satisfaction.

But Paige's current well-being and future did not happen by chance.

"In order to support the hope and dreams Paige has for her life and to ensure her safety and successful future beyond our lifetime, we have had to intentionally plan and create personal networks

and put financial, legal, and living options into place,” says her mother.

Paige spent four years at Vincennes University, where she lived in a dorm and took classes in early childhood development, as well as special ed classes that she says “taught us how to handle ourselves as adults.” Since last August, Paige has been living in an Evanston apartment with a 33-year-old former student of her mother’s from the National Louis PACE program.

Living independently has been “good--it’s a challenge, but it’s good,”

says Paige with a ready laugh. She admits, “Cooking is a big deal” but names a list she learned to make at Center cooking classes.

She will soon resume a preschool teaching job she has had every summer since freshman year of high school. She has another job lined up for August.

Paige thinks it is especially “hard for people with disabilities to adjust to being by themselves.” After all, she says, “Someone’s been helping them all these years.” She says her roommate “helps guide me. We remind each other [of

things we need to do.]”

She counts on her family, whom she calls “very supportive.” She says she even calls her brother in California to say “I’m stuck” He answers, “This is what you need to do.”

Paige knows she is “more outgoing than some of my friends” and says, while some people find it embarrassing, she is “willing to go and ask for help... We may be a little slower,” she says of the disabled, “but we can comprehend.”