

# A SUCCESSFUL LIFE IN THE COMMUNITY AFTER LONG-TERM INSTITUTIONALIZATION

Issue 4 • [Month] 2017

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In this newsletter, we are honored to be able to share **Hector Ramirez's** story.

## In Short

Hector Ramirez is a university professor, an advocate, and a respected figure in California's disability rights community. These achievements might surprise those who knew him during his childhood, which he spent institutionalized at a psychiatric hospital. Separated from his family and isolated from the outside world, Hector struggled to develop an appropriate sense of independence. For many years, he was treated as having significant limitations, and few who knew him expressed any meaningful expectations for his future. The opportunity to return to his family as an adolescent marked a momentous change in Hector's life, and he has continued to succeed in the community ever since.

## Life Before

Hector was diagnosed with childhood schizophrenia at a very young age. At age four, the state's child welfare agency removed him from his home, believing that his mother was not able to properly care for him. He was first placed in a group home, an experience that he remembers as extremely distressing. He did not cope well in that

setting because he missed his family so strongly. After only three months, he was moved to a psychiatric hospital, an even more restrictive and isolated placement. He would remain at the hospital for the next eight years. Hector's years at the hospital were largely unpleasant. Because he was so young when he was placed there, he did not fully understand why he had been institutionalized. Hector felt abandoned by his family, and he believed that he had been placed in the hospital as punishment for being himself. Being cut off from the outside world at such a young age prevented Hector from developing a realistic understanding of the world. He also felt that the hospital setting denied him a normal sense of dignity and self-determination, as he had few opportunities to make age-appropriate decisions about his daily life.

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His family visited when they could, but they were not able to come as often as Hector might have wished because, in his words, they “had to do what they had to do to survive” as they carried on their own lives in the outside world. They made sure to visit on birthdays and holidays, but even those visits felt structured and artificial.

The hospital also lacked a meaningful education program for its young residents. The staff seemed to focus more on behavior management than intellectual progress. Hector and his peers spent most of their time on hobbies and arts and crafts projects seemingly designed to keep the children busy and out of trouble. The hospital did not develop educational plans that were based on the individual strengths and needs of each child or that would prepare them for an independent adult life.

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## What Helped Hector

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During his time at the hospital, Hector was lucky to make a connection with one particular therapist who recognized his potential. She helped Hector to file a petition to be released from the hospital. Because of her advocacy, other people, including the judge at the conservatorship hearing, began to understand that Hector could speak for himself. Hector succeeded in his court petition and, at twelve years old, he moved out of the hospital and returned to his community.

Hector’s freshman year of high school was his first time attending a public school. The school initially placed him in a segregated special education class, then moved him to integrated but remedial courses. Over the next four years, Hector gradually overcame his educational deficits from his years in the

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For the first time, Hector had the opportunity to form relationships with his classmates who were not aware of his prior “special education” label. Hector enjoyed getting to know classmates from diverse backgrounds and feeling that he belonged in the school community. He took advantage of extracurricular offerings and joined the football team and the choir. Hector also spent a lot of time at the school library, which he found “amazing” compared to the limited resources available at the hospital.

After graduating from high school, Hector was excited to go on to college. Unfortunately, this first attempt at higher education was unsuccessful because Hector was still not fully aware of, or comfortable exerting, his legal rights. He did not understand the extent of the accommodations that might be available to him, and he resisted resuming “special education” services because of his negative associations with his experiences at the hospital. He dropped out of college, but reenrolled almost four years later.

Hector’s second attempt at college was successful. At a conference hosted by the disability advocacy organization RespectAbility, he had learned that the protections of the Americans with Disabilities Act were not limited to people

with physical disabilities but also extended to people like himself who had mental disabilities. Armed with this knowledge, he was able to request the reasonable accommodations he needed to succeed in his classes.

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The people who had known Hector as a child never expected him to graduate from college or pursue a challenging career. In fact, he says, most people who interacted with him and his fellow residents did not expect much at all from them, except to eventually land back in an institution. Hector was lucky to have a supportive family, including a mother who constantly encouraged him to advocate for himself.

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## **Hector's Life Today**

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Hector and his peers are also living longer than previous generations of people with mental disabilities did – and longer than anyone expected them to live when they were first diagnosed as children. Hector describes the experience of aging with a mental disability as a “new frontier” that presents new challenges. He has observed that older individuals with disabilities often face additional barriers to accessing services, and he fears that some individuals will return to an institutional setting because they are not able to access the services that should be available in the community. He is also concerned about the effects that budget cuts and policy changes could have on the

continued availability of mental health services. Hector has continued to advocate for people with disabilities and has served on the Los Angeles County Mental Health Commission. Today, Hector serves as a board member of Disability Rights California, the agency mandated by federal law to protect and advocate for the rights of Californians with disabilities.

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Still, the effects of his early years at the hospital continue to linger. Even now, at the age of forty-two, intrusive memories from the hospital occasionally wake Hector up in the middle of the night. His relationship with his family was also permanently altered. After a childhood of seeing his relatives only during defined visiting hours, Hector still finds it strange to spend unstructured time with his family just “hanging out.” Despite all of his personal and professional accomplishments, he – as well as his family members – continue to worry that everything could fall apart again. After the lack of autonomy he experienced as a child, Hector says, these fears will likely remain in the back of his mind for the rest of his life.