

## Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

### Latina Family Caregivers in Rural Areas Turn to Their Community to Support Young Adults with Disabilities in Transition

*A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).*

Families play an important role in helping young adults with disabilities achieve their goals after transitioning out of high school. However, some family caregivers may face difficulties partnering with their child's educators or accessing community resources to help their children with the transition process. In particular, Latino family caregivers may face additional barriers to involvement in their children's transition planning, such as language barriers, racial discrimination, distrust, and cultural values that may differ from those of their children's educators. Families living in rural areas may face further challenges such as a lack of community employers offering jobs for young adults, or a lack of qualified special-education staff. In a recent NIDILRR-funded study, researchers interviewed Latina immigrants in a rural town who were family members of young adults with disabilities. The researchers wanted to find out what factors helped or hindered the caregiver's involvement in their children's transition planning.

Researchers who conducted the study, [Assessing Family Employment Awareness Training](#), interviewed 13 Latina family caregivers (12 mothers and 1 aunt) of young adults with disabilities ages 14-24. The participants were all first-generation immigrants who lived in a small town in the midwestern United States. More than half of them were single mothers, and two-thirds were living at or below the federal poverty level. The researchers interviewed each participant up to 3 times over a 20-month period to learn about their experience assisting their child's transition process, including their interactions with school personnel, community resource staff, and employers. In the second and third interviews, the researchers reviewed themes from the first interview and the participants were invited to expand or update any information or events related to those themes. The interviews were conducted in Spanish, with an interpreter who was a trusted staff member at the local Parent Training and Information (PTI) center.

The researchers identified several common themes in the participants' experiences, as listed below:

- Importance of family: Several of the participants described their families as tight knit. The participants described having strong, trusting, and supportive family relationships. They described the high value and importance of their role as caregivers to their children, as well as to aging parents or extended family members. However, they also described how extended family caregiving responsibilities could sometimes made it difficult to attend transition planning meetings. Some of the participants also explained that their young adult children, both with and without disabilities, chose to live at home after graduation as part

of their strong family unit. However, they still empowered their children to gain independence by teaching them to care for themselves and participate in household chores.

- **Strained school relationships:** Many of the participants believed that school personnel mistreated their children, such as by punishing them excessively or failing to provide needed supports. Some of the participants felt that racial discrimination played a role, as did a lack of qualified teachers. Some of the participants also reported that their children were bullied or excluded by their classmates. Only one of the participants described having a positive relationship with her child's educators. She explained that she was more proactive in consistently demanding what her child needed to succeed, while also offering a willingness to collaborate with her child's team.
- **Language and citizenship challenges:** Several of the participants said that they did not have reliable access to materials in Spanish that they needed to participate fully in their children's transition planning. For example, interpreters were not always available during team meetings, and Spanish translations of documents were sometimes unavailable or inadequate. The participants also described being reluctant to seek community resources for their children for fear of having their citizenship questioned, being arrested, or being deported. Even the participants who were legal US citizens or residents feared that community providers might not believe that they or their children had a legal status to live and work in the US. One participant described being repeatedly harassed for her "papers" by an employee of a community service organization.
- **Importance of Latino community connections:** Because of their negative experiences with schools, community providers, and government authorities, the participants said that they received most information about resources for their children by word-of-mouth recommendations from other Latino community members. While the Latino community offered benefits and supports to the participants, sometimes information about community resources was inaccurate or incomplete.

The authors noted that Latino immigrant families of young adults with disabilities may face unique challenges that can limit their children's prospects for employment and community participation after high school. This may be especially true for Latino families living in rural communities, where interpreter services and highly qualified educators may be in short supply. Educators and service providers can support these families by providing culturally responsive services. This includes working to build trust with families, providing access to Spanish-language materials and resources, working to help families to overcome discrimination, and understanding Latino cultural values, such as *familismo* (importance of family unity) and a different meaning of independence from that of western society. School and agency personnel should also consider building

strong partnerships with local Latino community leaders to enhance trust and collaboration with Latino families.

[To Learn More](#)

Earlier results from this study were discussed in [Hispanic Young Adults with Disabilities and Their Families May Face Challenges Transitioning from School to Work](#)

[Parents Taking Action](#) is an innovative program designed to teach Latino parents of children with autism spectrum disorders (ASD) about ASD and ways to support their children.

The Rehabilitation Research and Training Center on Learning and Working During the Transition to Adulthood (Transitions ACR) has [factsheets and guides for young people with mental health disabilities and their parents in Spanish](#).

The [Center for Parent Information and Resources has a Spanish-language guide](#) for parents of children with disabilities (age 3 to 21), describing the legal, service, and community supports available to them and their children.

[To Learn More About this Study](#)

Francis, G.L., Gross, J.M.S., Lavin, C.E., Velazquez, L.A.C., & Sheets, N. (2020) [Facing double jeopardy: The transition experiences of Latina family caregivers of young adults with disabilities living in a rural community](#). Rural Special Education Quarterly (RSEQ), Volume 39(1), 17-34. This article is available from the NARIC collection under Accession Number J83231 and in full text from the publisher.

---

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at [www.naric.com](http://www.naric.com) or call 800/346-2742 to speak to an information specialist.

NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.