

What Do We Know, What Have We Learned, and Where Do We Go from Here to Help CLD Families and Youth with Disabilities in the Transition Process?

Taisha Mubano, an African American woman in her late 40s, ran into Jemilla Franklin, an old friend, after not having seen her for years. Jemilla asked, "How's your son Jonas doing these days? He's probably graduated high school by now."

"Yes indeed," said Taisha, "and he's doing alright. Thanks for asking."

"That's great to hear," said Jemilla, "I know how many years you struggled trying to get services for him. His autism was a real challenge for you and your family."

Taisha replied, "You know, we finally got some good help for Jonas when he started high school. For the first time, I felt the special education teachers listened to what we had to say and truly tried to help us. And it made a big difference!"

"Really," said Jemilla. "What did they do?"

Taisha said, "Well, when Jonas turned 16, they met with us in our home one night with Jonas there, too; put a big piece of paper up on the wall; and asked us a lot of questions about our hopes, fears, dreams, and goals for Jonas's future. Everybody had a chance to talk, including Jonas, and it just felt good. We really thought they cared about him and wanted to help him be successful in school and in the future."

Jemilla replied, skeptically, "Talk is talk. They always make promises, give you hope but my experience is that they don't deliver."

"Well, nobody is perfect, but the school really made an effort to follow through on what they said they were going to do. Jonas was given a one-to-one aide to work with him in his general education classes, they had a Best Buddies program to help him make friends, and he got a lot of tutoring and assistance with his classes in high school. They helped him get a job at our neighborhood Target store, and the manager there liked him so much that he hired him full time after Jonas graduated high school. He works there about 30 hours a week. And they helped us connect with services that would help Jonas as an adult."

"That's fantastic!" said Jemilla. "Where's he living now?"

"He lives with us," replied Taisha, "but his Regional Center counselor is helping him look for a supported living situation in the neighborhood."

"What's that?" asked Jemilla.

"It's semi-independent living, like a group home. Other adults with disabilities live there and staff help care for their needs. We think it's great that Jonas can live nearby but be a bit more independent," said Taisha.

"How does he get to work?" asked Jemilla.

"He takes the bus. They taught him how to use the bus when he was in high school," replied Taisha.

"Wow, that's terrific! Sounds like things actually got taken care of. Well, you give Jonas a big hug from me. It was great to see you," said Jemilla.

The story of Taisha Mubano, a happy and satisfied mother of a young adult with autism, illustrates numerous recommended practices in culturally responsive transition planning presented throughout this book. The purpose of this chapter is to synthesize and review this information and to offer some additional transition resources for CLD families and youth with disabilities. The chapter focuses on answering the following questions:

- 1. What do we know about the transition experiences of CLD families and youth with disabilities?
- 2. What have we learned about how to support CLD families of youth with disabilities during the transition years?
- 3. Where do we go from here? How do we infuse research-validated transition practices and recommendations for working with CLD families and youth with disabilities into public schools and transition service agencies?

WHAT DO WE KNOW ABOUT THE TRANSITION EXPERIENCES OF CLD FAMILIES AND YOUTH WITH DISABILITIES?

Making the transition from school to adult life is challenging for all youth with disabilities, but even more so for those from CLD backgrounds. CLD youth with disabilities and their families experience problems with the transition to adult life beyond disability alone. Chapters 1 and 2 provided an extensive review of the literature on this topic. This research has revealed important things regarding CLD families of youth with disabilities who are involved in the transition planning process and the school and transition personnel who interact with them.

The research has found that many school and transition personnel

- 1. Do not possess critical knowledge and skills related to the multiple dimensions of cultural and linguistic diversity
- 2. Do not respect CLD parents and youth with disabilities involved in the transition process
- 3. Do not acknowledge the hopes and dreams for the future held by CLD families and youth with disabilities

4. Do not engage in culturally responsive collaboration with CLD families and youth with disabilities in a way that makes them feel valued, listened to, and accepted during the transition planning process

Research on CLD families and youth with disabilities has found that many of them

- 1. Lack knowledge of the legal requirements for transition and a clear understanding of their role and function in IEP/ITP meetings
- 2. Experience racial and cultural stereotypes as well as biases from school professionals, which leads them to not actively participate in IEP/ITP meetings
- 3. Lack proficiency in English and face immigration issues and fears that affect their active participation in IEP/ITP meetings
- 4. Possess a different set of norms and cultural expectations for their child's adult future, which leads them to view transition differently than school and transition personnel

In summary, as presented in the first two chapters of this book, CLD youth with disabilities experience serious problems in the transition process beyond those experienced by youth with disabilities in the general population. Fortunately, an emerging body of literature focusing on this unique population has provided recommendations for how to address this problem.

WHAT HAVE WE LEARNED ABOUT HOW TO SUPPORT CLD FAMILIES OF YOUTH WITH DISABILITIES DURING THE TRANSITION YEARS?

A number of highly effective practices have been recommended to promote more positive transition experiences for CLD families and youth with disabilities. These recommendations apply to two specific groups: 1) school transition professionals and 2) CLD parents and youth with disabilities. Suggestions for transition professionals include the following:

- 1. Transition professionals need to be competent in culturally responsive collaboration and communication practices that facilitate their ability to effectively engage in skilled dialogue with CLD families and youth with disabilities.
- 2. School districts and transition service agencies need to assess the quality of knowledge and skills of personnel who collaborate with CLD families and youth with disabilities in transition planning using the instrument presented in the Chapter 2 appendix or a similar instrument.
- 3. School districts and transition service agencies need to provide cultural competence training to personnel who lack quality knowledge and skills for engaging in culturally responsive collaboration with CLD families and youth with disabilities involved in transition planning.
- 4. Special education and transition service personnel need to conduct transition planning with CLD families and youth with disabilities in informal environments, such as the home, instead of in the school or other public settings.
- 5. Transition professionals should use culturally responsive techniques such as PCP and family-centered approaches to collaborate with CLD families and youth with disabilities.

Here's what we've learned about helping CLD families and youth with disabilities in the transition process.

- 1. CLD parents who know their rights and responsibilities in formulating transition goals for their child and other aspects of special education law and practice are more active in IEP and ITP meetings in the public schools and are better able to advocate for their children with disabilities. Therefore, CLD parents and youth with disabilities need to increase their knowledge and skills in these areas.
- 2. Training is available throughout the United States to promote the knowledge and skills of CLD families and youth with disabilities with respect to not only the transition planning process but all aspects of special education and special education law. Chapter 2 presented resources for such training, and experts should encourage CLD families of youth with disabilities to access these resources and receive this training.
- 3. Parent support groups, mentors, and community liaisons benefit CLD parents of youth with disabilities by helping them understand special education law, the special education system in the public schools, and their role in the transition planning process. CLD families and youth with disabilities need to seek out existing resources such as these or create similar ones in their school districts or communities.
- 4. The use of bilingual and bicultural interpreters who are well trained and knowledgeable in special education law and practice benefits families who do not speak English. CLD parents should request that schools provide these types of interpreters to them throughout the transition planning process.

Interview with Irene Martinez, M.S.W., Director of Fiesta Educativa

I conducted an interview with Irene Martinez, M.S.W., who is the Director of Fiesta Educativa, a parent support organization for CLD parents of youth with disabilities in Los Angeles, California (www.fiestaeducativa.org). Many of the questions I asked her were related to the recommended practices just discussed.

What cultures are represented in the CLD population for your service region?

We work with families from East Los Angeles and the San Gabriel Valley. These are primarily Latino and Chinese families.

What challenges have you seen CLD families of youth with disabilities face in the transition planning process?

Many of our Latino families are monolingual Spanish-speaking recent immigrants. They have different levels of acculturation. Some of them are from low-SES backgrounds and are struggling to live day to day. They don't plan ahead. They need prompting. Sometimes the schools don't initiate with these parents, and the parents don't think about transition planning.

Some of the sons or daughters of these families graduate at 18 or 22 years of age and just stay at home. If the families decide to keep them at home, it's for safety and security, not because they want to hide them. The families we've worked with are generally

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open to resources and services offered. Undocumented status is not a problem; we don't ask them about their immigration status.

What things have you tried and implemented to improve the quality of collaboration with CLD families of youth with disabilities in the transition planning process? What has been successful and what has not?

We have tried to provide more training to parents to get them to start transition planning earlier. We've tried to raise consciousness in them. We have conducted one-to-one workshops. We get referrals from Regional Centers and family resource centers, and from the media where we have done advertising. We have developed good working relationships with a number of school districts in our region, but we're limited by resources. We have written and obtained grants, but there are large pockets of underserved CLD families we have not been able to get to.

We're using a home-based family education model. A small group of parents get together in a host parent's home. It's a family driven and family centered environment that is interactive. We provide speakers and trainers who answer specific questions the families ask. This is one of the most effective models for helping CLD families and youth with disabilities during transition.

We have a professional advisory council. We have a statewide grant that was funded. And we have received foundation funding that led to a contract with three counties to work with Regional Centers. Regional and statewide conferences are another way we have been able to successfully network with CLD parents of youth with disabilities and find resources.

We have a grant from the J.P. Morgan Foundation which we used to form a school district partnership. We met with the school district director of special education initially; the key was to get principals to buy in. We found three schools and sold the idea to the principals. Parent community representative liaisons became involved in the partnership as well. We designed curriculum, workshops, and more formal professionally oriented training. We conducted the workshops in the morning when kids are in school. We sent mail outs, made fliers, and made telephone calls to families to get them to attend. There are six modules, some of which include training on transition, IEPs, and behavior. Parents are required to attend all six modules and earn a certificate of completion at the end. We are hoping to add a middle school to the partnership next year.

What do you recommend as best practices for collaborating with CLD families of youth with disabilities in the transition planning process?

Help the parents work with the school so there is not a broken relationship. Help parents be more interactive and facilitate a positive relationship with the school. Parents need to work with the resources they are entitled to for their child who is transition age.

What do the CLD families and youth with disabilities with whom you have worked want and need when it comes to planning the future for their child?

Parents of youth with developmental disabilities need employment development services for their child. They haven't thought about their child working. We need to help them to see their adult children differently; they are fearful of their child going to work.

We provide them with training to help with job development so they can see that they can have control. We try to encourage a strong family component in our training rather than focus on self-advocacy and self-determination. They need to take responsibility for their child and obtain more knowledge of how to work with the IEP team and educational system. They need to learn how the system works, such as the role of Regional Centers and the Department of Rehabilitation in the transition of their child.

What advice and support do you offer to transition professionals who interact with the CLD families and youth with disabilities with whom you work?

Latino families may not be proactive. They need to be informed and encouraged to seek out education opportunities. When they are given this opportunity, they do respond. Offer them training, resources, and opportunities.

What do you think are key strategies to promote leadership and improved services for CLD families of youth with disabilities in your community?

Work with schools. Work with school districts and on-site administrators. Work with local parent council representatives. The family-based home host parent program promotes leadership in these parents. You need to develop parent leadership. Raise consciousness, attend councils and advisory panels, and increase CLD parent involvement in leadership. Help parents to become advocates for their child and promote regional system change and to have influence on public policies.

In this interview, Irene Martinez reinforces many of the practices recommended in the literature for schools to help CLD families of youth with disabilities become more knowledgeable and capable with regard to the transition planning process. The question that remains is where do we go from here? How do we make this happen?

WHERE DO WE GO FROM HERE?

How do we infuse research-validated transition practices and recommendations for working with CLD families and youth with disabilities into public schools and transition service agencies? This is perhaps the biggest challenge that must be faced. Translating research into practice can be a difficult process and often becomes derailed by poor public policy, ineffective implementation of recommended practices, or competing educational or school initiatives. However, there are a number of ways to put into practice the information that has been presented and discussed in this book:

- 1. Use the leadership strategies presented in Chapter 4 to develop leaders in school special education and transition service agency personnel working with CLD families and youth with disabilities involved in the transition process. Promote similar leadership development in CLD parents of youth with disabilities whose children either have reached adulthood or are transition age. These parents can serve in an advisory capacity to schools or transition service agencies (see the interview with Irene Martinez for some specific suggestions).
- 2. Select and implement the organizational change strategies discussed in Chapter 4 that would work best with the stakeholders and constituents in the local schools or region.

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Implement and evaluate the effectiveness of these strategies for promoting organizational change and improved outcomes for CLD families and youth with disabilities in the transition process.

- 3. Provide training where training is needed to transition professionals as well as CLD families and youth with disabilities. Use the recommended training format and content presented in Chapter 2 as well as the approaches mentioned by Irene Martinez.
- 4. Develop resources such as CLD parent support groups, mentors, and community liaisons to help CLD families in the transition process. Contact existing groups and programs that provide these services for recommendations on how to initiate them in the local schools or region (see the list of additional recommended resources for CLD families of youth with disabilities in the For Further Information section).
- 5. Pursue continuing knowledge, education, and professional growth on this topic to maintain currency in the field. Share this information with others on a consistent and ongoing basis.
- 6. Seek external funding from nonprofit organizations, grants, and foundations to promote program development and improved practice in this area.
- 7. Attend local, state, and national conferences to gain further information, resources, and training on this topic and to network with others who have similar interests in this area.
- 8. Keep your eye on the ball; remain passionate and committed to the process and recognize that change occurs slowly and often requires up to 5–7 years to be fully implemented. Don't give up!

SUMMARY

Everyone deserves an equal opportunity to experience a quality adult life, including individuals with disabilities. CLD families and youth with disabilities involved in the transition process face additional challenges, but professionals can support them effectively through culturally responsive collaboration. This book has included guidance on this collaboration, as well as considerations for making legal and effective transition documents (ITPs and SOPs) for CLD youth with disabilities. Yet beyond the direct practices involved with individual families, improvement in support for CLD families of youth with disabilities requires changes at an organizational level. Thus, this book has presented information on how to promote leadership in special education and transition service agency personnel who interact with CLD families and youth with disabilities in the transition process. Experts can use these strategies to improve the schools and agencies in which special education and transition service personnel work.

I wrote this book not only for school and transition service agency personnel but also for CLD families and youth with disabilities involved in the transition process. I wanted to give these individuals a voice by presenting their words, feelings, and experiences related to the transition process. I have presented information and resources aimed at empowering these individuals to better advocate for themselves in the transition process. Moreover, I have attempted to show them how to assume leadership in schools and communities that will result in better and more culturally responsive transition services for other CLD families and youth with disabilities in the future.

The case studies, interviews, resources, and references presented here are not an exhaustive compilation of the research on this subject. However, they represent a solid review of the literature and a balanced presentation of practical and theoretical information about the transition process for CLD youth with disabilities. I invite further research, writing, professional presentations, and professional growth on this topic and hope that this book will inspire others to pursue these directions in the future.

How fortunate Americans are to live in a country that believes in and is committed to providing equal opportunity for all individuals, including those with disabilities. I have dedicated a significant portion of my professional career in education to improving the transition outcomes of youth with disabilities. My hope is that this book will make an additional contribution to this effort, particularly for those youth with disabilities who come from CLD backgrounds.

FOR FURTHER INFORMATION

Transition Resources for CLD Families of Youth with Disabilities

The Arc of the United States

http://www.thearc.org

The Arc is the world's largest community-based organization of and for people with intellectual and developmental disabilities. It provides an array of services and support for families and individuals and includes more than 140,000 members affiliated through more than 730 state and local chapters across the nation. The Arc is devoted to promoting and improving supports and services for all people with intellectual and developmental disabilities.

Council for Exceptional Children (CEC)

http://www.cec.sped.org

CEC is the largest international professional organization dedicated to improving the educational success of individuals with disabilities and/or gifts and talents. CEC advocates for appropriate governmental policies, sets professional standards, provides professional development, advocates for individuals with exceptionalities, and helps professionals obtain the conditions and resources necessary for effective professional practice.

CEC Division on Career Development and Transition (DCDT)

http://www.dcdt.org

A subdivision of CEC, DCDT focuses on career development and transition for youth with disabilities. DCDT publishes the journal *Career Development for Exceptional Individuals*, sponsors state subdivisions, and offers state and national conferences on career development and transition for youth with disabilities.

Department of Vocational Rehabilitation (DVR)

(Check the Internet to find a DVR in your area.)

The mission of the DVR is to provide services and advocacy to assist people with disabilities to live independently, obtain employment, and enjoy equality in the communities in which they

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live and work. The DVR works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living, and equality for individuals with disabilities.

Directory of Independent Living Centers Nationwide

http://www.virtualcil.net/cils

This site provides a map of the United States with links to centers for independent living that provide services in the areas of advocacy, independent living skills training, information and referral, and peer counseling.

Family Village

http://www.familyvillage.wisc.edu

The Family Village web site brings together thousands of online resources in an organized, easyto-use directory. The centerpiece of Family Village is the library, in which children and adults with disabilities, their families, and their friends and allies can find information on more than 300 diagnoses.

Family Voices

http://www.familyvoices.org

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through their national network, they provide families with the tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

National Association for Parents of Children with Visual Impairments (NAPVI)

http://www.spedex.com/napvi/

NAPVI is a nonprofit organization of, by, and for parents committed to providing support to the parents of children who have visual impairments. This national organization enables parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities. NAPVI provides leadership, support, and training to assist parents in helping their children reach their potential.

National Coalition for Parent Involvement in Education (NCPIE)

http://www.ncpie.org

The mission of NCPIE is to advocate for the involvement of parents and families in their children's education and to foster relationships among home, school, and community to enhance the education of all young people.

National Council on Independent Living (NCIL)

http://www.ncil.org

As a membership organization, NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

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National Down Syndrome Congress (NDSC)

http://www.ndsccenter.org

The mission of the NDSC is to provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome. The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome. It is the purpose of the NDSC to create a national climate in which all people recognize and embrace the value and dignity of people with Down syndrome.

National Federation of Families for Children's Mental Health

http://www.ffcmh.org

This national family run organization provides advocacy at the national level for the rights of children and youth with emotional, behavioral, and mental health challenges and their families; provides leadership and technical assistance to a nationwide network of family-run organizations; and collaborates with family-run and other child-serving organizations to transform mental health care in America.

National Secondary Transition Technical Assistance Center

http://www.nsttac.org

This center provides support and information to states, local education agencies, practitioners, researchers, parents, and students regarding effective transition education that can enhance postschool outcomes for youth with disabilities.

National Youth Leadership Network (NYLN)

http://nyln.org

NYLN provides a national voice for young leaders with disabilities and offers resources and speakers on a variety of disability-related topics.

PACER Center

http://www.pacer.org

The mission of the PACER Center (Parent Advocacy Coalition for Educational Rights) is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents.

Social Security Administration (SSA)

The SSA operates the federally funded program that provides benefits for people of any age who are unable to work because of a severe mental or physical disability. There are several programs for people with disabilities, including Social Security Disability Insurance, Supplemental Security Income, Plan to Achieve Self-Support, Medicaid, and Medicare. For further information, contact your local SSA office or go to http://www.socialsecurity.gov

Technical Assistance ALLIANCE for Parent Centers

http://www.taalliance.org

The ALLIANCE is an innovative partnership of one national and six regional parent technical assistance centers, each funded by the U.S. Department of Education's Office of Special

Education Programs (OSEP). These seven projects compose a unified technical assistance system for the purpose of developing, assisting, and coordinating the more than 100 Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) established under IDEA. The national and regional parent technical assistance centers work to strengthen the connections to the larger OSEP Technical Assistance and Dissemination Network and fortify partnerships between Parent Centers and education systems at local, state, and national levels.

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