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## Access to Services for New Americans with Intellectual and Developmental Disabilities: Building Capacity Through the Ramirez June Initiative


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## Access to Services for New Americans with Intellectual and Developmental Disabilities: Building Capacity Through the Ramirez June Initiative

### Cover Page Footnote

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# Access to Services for New Americans with Intellectual and Developmental Disabilities: Building Capacity Through the Ramirez June Initiative

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## Plain Language Summary

*“New Americans” are individuals born outside of the United States (U.S.) who now live in the U.S., and their families. There are about 4.4 million new Americans in New York State. New Americans make up almost a quarter of New York’s population. New Americans with intellectual and developmental disabilities (IDD) face barriers in accessing services. Disability services in New York include care management, employment, housing services, and more. Resources and information about IDD services are often not translated into other languages. There is limited outreach to inform new Americans about available services. New Americans with IDD may face barriers based on language or immigration status. IDD services usually lack adequate interpretation or document translation for new Americans. New Americans also reported facing long wait times. These barriers have led to challenges in access to IDD services for new Americans. Two New York agencies partnered to address this issue. The two agencies are the Developmental Disabilities Planning Council (DDPC) and the Office for New Americans (ONA). They created a navigator program called the Ramirez June Initiative. The Initiative is named after two new American families who shared their stories. This program helps new Americans know more about disability services through outreach. The Ramirez June Initiative helps new Americans with IDD better access critical resources. We recommend other states adopt this model in their efforts to help new Americans with IDD.*

## Abstract

*New Americans with intellectual and developmental disabilities (IDD) are a significantly underserved community in New York State (NY) facing complex barriers accessing IDD services and fully integrating into their communities. New American communities lack*

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*connections with IDD service systems and struggle to find culturally and linguistically accessible information about disability services and resources. New Americans may be fearful of engaging with service providers, especially if they lack lawful immigration status and are undocumented. In acknowledgement of these barriers, NY implemented an initiative to create a navigator model that is the first of its kind in the nation. The initiative is named the Ramirez June Initiative (Initiative), which was created in 2019 to build capacity at the local and state level to better serve new Americans with IDD. In this article, we outline the background, context, and key components of this navigator model. By providing a comprehensive and detailed overview of the Initiative, we hope to support the model's replication across the nation, while considering local strengths and needs.*

### **Disparities for New Americans with IDD in New York**

New York (NY) has a culturally and linguistically diverse population, with a high number of new Americans demonstrating the need for intellectual and developmental disabilities (IDD) services that are culturally and linguistically competent. Culturally and linguistically competent services are those that are

*...provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program. (Developmental Disabilities Assistance and Bill of Rights Act of 2000 [DD Act], § 15002(7), 2000).*

This definition provides a comprehensive conceptual framework for designing services that are culturally competent by its attention to multiple facets of culture, including language, beliefs, attitudes, and behaviors. It also points to the need to assess the effectiveness of service provision based upon actual engagement and participation in services. We use this definition because of its emphasis on systemic practices that result in tangible outcomes for people with IDD and their families.

NY defines a “new American” as “an individual born abroad and their children, irrespective of immigration status” (Scott, 2021). The term “new American” can refer to immigrants, refugees, asylees, visa holders, and undocumented individuals. In NY, there are 4.4 million new Americans (American Immigration Council, 2020). NY is also home to approximately 835,000 undocumented individuals (Migration Policy Institute, 2022). Most new American families are “mixed status,” which means different family members have different immigration statuses. Most children in mixed status families, about 90%, are U.S. citizens (Fortuny et al., 2010). Some new Americans have limited English proficiency (LEP), which means they have difficulty, speaking, reading, and writing English. In NY, there are 2.5 million individuals with LEP (Zong & Batalova, 2015), and an estimated 5.7 million individuals speak a language other than English at home (Zeigler & Camarota, 2019). Given the large community of new Americans in NY, ensuring that public services are responsive to their needs is of utmost importance to the well-being of these families.

Overall, New Americans face barriers when accessing health care services. Existing research reports racial, ethnic, and immigration-related disparities in health, healthcare, and access to services and resources (Bogenschutz, 2014; Goode et al., 2014). A disparity, in general, is defined as a noticeable and significant difference (Merriam-Webster, n.d.). While Horner-Johnson et al. (2014) point out that there are long recognized disparities in health and health care by racial and ethnic group, they note that less research has been done to understand disparities in health care at the intersection of disability, race, and ethnicity. Across issue areas and new American communities, including with IDD, there has been limited focus and resources dedicated to finding solutions to ameliorate these disparities. Research on intersectional disparities is a vital resource for policymakers and state agencies because it often signals the need for public action or systemic change. Thus, given the aforementioned research limitations, the complex barriers that prevent new Americans with LEP and IDD from accessing services are not well understood, and therefore, not adequately addressed by public policy or initiatives.

The NY Developmental Disabilities Planning Council's (DDPC) awareness of the disparities faced by new Americans increased while conducting research for its 2017-2021 State Plan. As a result of a 2016 federal requirement that State Councils address disparities,<sup>1</sup> and increased interest by the Council, the DDPC made a substantial effort to ensure that underserved<sup>2</sup> communities were represented in outreach efforts. During the research phase, the DDPC conducted 12 Focus Groups across NY in partnership with multicultural organizations that serve underserved communities to get more diverse input. In the DDPC's focus groups with people who spoke Spanish, Mandarin, Cantonese, and Fujianese, the issues of limited language access and culturally competent services were a prominent theme, highlighting the need for focused work in this area. Language access played a defining role in the level and quality of information focus group participants received about services and supports for people with IDD. Focus group participants shared stories of Individualized Education Plans (IEPs) not being translated, waiting hours for an interpreter, and being provided with an interpreter whose interpretation quality was so low they could not be sure they were receiving accurate information. It was clear from these focus groups that new Americans faced significant disparities when interfacing with IDD services.

Additionally, the DDPC began to identify other organizations with strong connections to underserved communities who were identifying the same issues, including the NY Office for New Americans (ONA). ONA is housed within the NY Department of State (DOS) and is the first state-level immigrant assistance office of its kind created by statute in the U.S. ONA assists new Americans through a statewide network of community-based organizations (CBOs), which

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<sup>1</sup> Starting in 2016, each State DD Council was asked to include a Targeted Disparity Goal or Objective in their 2017-2021 State Plan.

<sup>2</sup> The DD Act (2000) defines unserved and underserved communities as "populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life" (§ 15002(32)).

provide direct support to multilingual new American communities. Partnering with CBOs, or organizations that have standing trust and experience with new American communities, is widely recognized as an effective practice for engaging culturally and linguistically diverse communities (U.S. Department of Health and Human Services [HHS] Office of Minority Health [OMH], 2013). Since its creation in 2012, ONA has assisted over 450,000 of the 4.4 million new Americans living in NY. The scope of free services offered through ONA's statewide network of providers includes legal services, English language learning, civic and community engagement, workforce development, and support for health and well-being, which encompasses the Ramirez June Initiative.

In the context of limited research at the intersection of disability, race, and ethnicity as highlighted by Horner-Johnson et al. (2014), both the DDPC and ONA knew additional research was needed to gain a better understanding of the issues facing new Americans with IDD. The DDPC and ONA co-developed a needs assessment and distributed it to ONA's network of CBOs that are in direct contact with the new American community. The aim of the survey was to determine if new Americans with IDD and their families utilized ONA resources and if ONA staff could identify the major needs and barriers of new Americans with IDD. Of the 27 ONA network organizations surveyed, a total of 15 ONA responded to the survey and identified the following major barriers: lack of awareness among providers and new Americans about IDD services, lack of culturally competent IDD services, inadequate access to language translation or interpretation services, lack of connections to the IDD service delivery system, difficulty accessing disability assessments and obtaining an IDD diagnosis for new Americans, lack of overall understanding of IDD, challenges accessing disability accommodations in the immigration system, and ineligibility for disability-related benefits due to immigration status.

The many substantive challenges highlighted by the DDPC-ONA needs assessment reinforced the necessity for a targeted approach to connect new Americans with IDD services and to elevate the unmet needs of new Americans across NY agencies. Staff from the DDPC and ONA met to analyze the needs assessment results, brainstorm potential solutions, and better define the roles of each agency in a collaborative grant initiative. Together the DDPC and ONA were able to input their knowledge, research, and expertise about building programs to support people with IDD and new Americans across NY. The Ramirez June Initiative's research and development process was shared with members of the DDPC's Cultural Competency Workgroup, which includes new American families who helped to shape the Initiative based on their lived experience.

As a result of the demonstrated need, the DDPC Council voted to fund the Ramirez June Initiative through ONA. Once a commitment was established by both agencies, the agencies developed a set of primary objectives that included directly connecting multilingual new Americans with IDD and their families with information; building the capacity of the ONA network to support new Americans with IDD; and elevating the needs of new Americans, at a local, state, and national level, to inform systemic change. Research on existing navigator models that address healthcare disparities informed the creation of the Ramirez June Initiative.

## Navigator Model as a Strategy to Address Disparities

Since the 1990s, navigation models have been developed in healthcare to reduce barriers and address the health and social issues related to the management of complex cancer needs, for example (Carter et al., 2018). Individual navigators or teams of navigators help patients, their families, and caregivers navigate the complex and fragmented healthcare system. Navigators help people to access services that can improve their social determinants of their health (SDOH) meaning the conditions that impact one's health status, functioning and quality of life, which can include services to support housing, hunger alleviation, employment, and reduce financial hardships (Carter et al., 2018; Schaffer et al., 2018; U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion, n.d.). The functions and roles of navigators have evolved to also include support for individuals with disabilities and care for the elderly who may have limited access to services because of systemic barriers (Donovan et al., 2018). Originally, navigator programs were based in hospitals, community-based organizations including health centers, and government organizations (Wells et al., 2018).

Subsequently, new kinds of navigation programs have emerged. For instance, navigators in the Family or Community Navigation Programs meet with families and communities where they live and support them to access services related to IDD, mental health, chronic illness, or other services to support their SDOH (Llano et al., 2021; Schaffer et al., 2018). In addition to linking clients with resources, navigators advocate for expanded access to services (Wells et al., 2018). Navigators recommend improved organizational practices and advocate for systemic change outside of the service sector, and report and speak out against disparities, barriers, and discrimination (Schaffer et al., 2018). The success of navigation programs relies on the interpersonal skills of navigators, which help to build their connections and networks with other navigators and service providers (Schaffer et al., 2018). Research has also demonstrated that cross-agency collaboration is important for better serving people with IDD. Day et al. (2021) note that to meet the needs of people with IDD, collaboration among service providers, CBOs, and government agencies, is needed to create a system of "collective efficacy." Collaboration was, therefore, included as a key component of the Ramirez June Initiative model.

## Ramirez June Initiative Model

The Ramirez June Initiative model builds on prior navigator models but adds unique components informed by feedback from NY's new American communities and the lived experiences of the Ramírez family and the family of June Lum. The language, cultural, and systemic barriers faced by the Ramírez family and June Lum are experienced by many new American families. For example, June Lum shared with the DDPC's Cultural Competency Workgroup that it took her years to access IDD services for her children. When June expressed concerns about her child's development to her pediatrician, she did not receive information about the early identification of disabilities and was not connected to the Early Intervention Program in time for her son to receive services from the program. The Ramírez family was also not informed about their rights to access services for their young son with cerebral palsy for

years.

The Ramirez June Initiative is a grant funded by the DDPC and led by ONA that created a new full-time role based at ONA for a Developmental Disabilities (DD) Navigator who leads the Ramirez June Initiative. Like other navigation models, the DD Navigator conducts outreach, organizes trainings, and advocates for systemic change. The DD Navigator is based in a NY government agency that has a direct connection to new American communities through a statewide network of CBOs. The DD Navigator is partnered with other state agencies and initiatives to elevate recognition of the disparities faced by new Americans with IDD and their families and to build its expertise in all the areas that intersect with the promotion of the well-being of the community. Promoting equitable access to IDD services, the Ramirez June Initiative shares its findings and offers technical assistance at the local, state, and national levels.

To create a system of collective efficacy and improve understanding of immigrants' access to disability services in NY, the Initiative has engaged with cross-system partners with varying focuses to support the different needs of new Americans with IDD. In the first year of the Initiative, the NY Office for People with Developmental Disabilities (OPWDD), signed on as a strategic partner. OPWDD is the state agency responsible for coordinating services for people with IDD in NY. OPWDD committed to regular meetings with the Initiative, offering staff resources at informational events, helping connect the DD navigator with relevant OPWDD staff, and reviewing informational resources. Collaboration between ONA and the OPWDD network also included a series of Community Conversations. These regional meetings connected staff at ONA's CBOs with IDD service providers and facilitated discussions that explored the needs of local new American communities. The Initiative created a comprehensive Resource Guide based on input from seven different state agencies. The Resource Guide, entitled *Accessing Services for New Americans with IDD in NYS*, was shared with the 96 attendees and the larger ONA network of over 85 CBOs.

Throughout its implementation, the Initiative has partnered with other national and NY-based partners. In 2019, the Initiative joined the NY Community of Practice in Cultural and Linguistic Competence in Developmental Disabilities (CoP) team, a collaborative group in NY working to advance cultural and linguistic competence. The NY CoP team includes representatives from eight organizations, including the DD Network, which receives ongoing technical assistance from Georgetown's National Center for Cultural Competence (NCCC). Through bimonthly meetings and trainings from NCCC, the NY CoP has helped to contribute ideas, disseminate information, and bolster the Initiative.

The Initiative has also collaborated with the NY Interagency Task Force on Human Trafficking to provide training to the ONA network staff on awareness and prevention of human trafficking of new Americans with IDD, given the fact that new Americans with IDD have also been targets for human trafficking (State of New York Interagency Task Force on Human Trafficking [ITF], 2020, 2021). Additionally, while OPWDD is a large and significant provider of IDD services in NY, multiple other agencies have a role in IDD services and have supported the Initiative. Early childhood initiatives such as *NY Acts* promotes the early identification of disabilities using



resources from the CDC’s “Learn the Signs. Act Early.” Interagency collaborations have supported the DD Navigator and the ONA network to have a stronger sense of the disability resources available in NY and to identify a network of support to assist ONA’s network of CBOs and new Americans communities to overcome challenges accessing disability resources and services.

The DD Navigator provides technical assistance to both immigrant and disability service providers to increase their capacity to service new Americans with IDD, a key component to ensure wider spread impact. For instance, the DD Navigator connects immigrant service providers with information about disability services. In turn, the DD Navigator connects disability service providers with information about new American communities including the languages they speak and the barriers they face. Communication with service providers is key to ensuring that new Americans with IDD have improved experiences in the ONA network as well as with disability service systems.

The DD Navigator has offered case support for new American youth with IDD with complex behavioral and health needs through the NY Council on Children and Families (CCF) Interagency Resolution Unit. Guidance was given to service providers on how immigration status affects eligibility for services. In general, undocumented individuals with IDD have increased barriers accessing vital services given their ineligibility for many publicly funded programs. The DD Navigator has connected disability service providers with ONA’s network of free immigration attorneys to support undocumented individuals with IDD and their families to understand what actions they can take to gain an immigration status, access immigration-related accommodations, and remain in the U.S. Their immigration status is a key step in gaining access to more comprehensive services in NY.

To communicate directly with multilingual new American communities and individuals with IDD, the Ramirez June Initiative dedicates a substantial portion of its grant budget to language access and accessibility services. The Initiative leverages its cross-system network of partners and stakeholders to bring service providers to meet with new American communities and share information about vital disability services. The DD navigator and Initiative partners have met virtually and in-person across the state and connected with new American communities that speak a variety of languages, including Deaf new Americans who use Nepali Sign Language.

The Initiative directly supported new Americans with IDD who have faced challenges accessing services and who have been kept waiting years. The Initiative has identified disparate access to disability assessments, which are needed to be eligible for disability services, as a key barrier that increases wait times for new Americans. Individuals with LEP and communication-related disabilities struggled to find assessment providers who can meet their language needs. The COVID-19 pandemic only exacerbated these challenges. The ONA Ramirez June Initiative has elevated these issues to other state agencies to assist and evaluate systemic change.

## Outcomes and Successes

The Initiative has measured outcomes and successes primarily via surveying participants, tracking systemic policy changes, and cataloguing direct feedback from participants. In 2022, the Initiative's collaboration was recognized in OPWDD's draft strategic plan for 2023-2027, which states that OPWDD's new Office of Diversity, Equity, and Inclusion (DEI) will examine policies and practices and build off the work of the Ramirez June Initiative. This was a significant step in formalizing the partnership that has been in place via practice for the last 3 years, ensuring sustainability of the collaboration for an additional 5 years. Additionally, the inclusion of the Initiative in OPWDD's strategic plan signals a long-term commitment and recognition of the success of the Initiative to advance DEI objectives in NY.

Despite the limitations posed by COVID-19, the DD Navigator still carried out substantial outreach across NY. During the first 3 years of the Initiative, the DD Navigator conducted 75 outreach events engaging people with IDD, their family members, and professionals in the IDD and immigration field. Events provided language interpretation, including American Sign Language (ASL) and closed captioning. After the events, participants completed virtual or paper satisfaction surveys in multiple languages, including English, Spanish, Simplified Chinese, Pashto, Burmese, Ukrainian, Karen, and Arabic. In the post-event surveys, a total of 609 respondents, including 459 professionals, 134 family members and caregivers of individuals with IDD, and 16 individuals with IDD, reported their demographic data, satisfaction with the event, and the impact the Initiative had on their ability to advocate for themselves or support new Americans with IDD. Participants reported high levels of satisfaction with the Initiative, more specifically, 98% of professionals, 99% of family members, and 94% of individuals with IDD reported they were satisfied with Initiative activities. Because of their participation in the Initiative, 100% of individuals with IDD reported that they feel better able to say what they want; and 93% of professionals, family members, and caregivers said that they feel better able to support individuals with IDD. Most respondents were professionals because a primary aim of the grant is to build the capacity of professionals in the field to better serve new Americans with IDD. The DD Navigator also received feedback directly from families assisted through the Initiative. One Chinese American mother with LEP who was assisted in accessing services for her son through OPWDD shared,

*My son's community Habilitation, Day Habilitation, and Respite service have been approved, thank you again for your help! I appreciate it from the bottom of my heart! My son wouldn't be the same without you.*

Additionally, the Initiative created unique resources for IDD professionals, as well as new American families. For example, informed by the challenges June Lum faced accessing early intervention services for her son, the Initiative created *Voyage*, a multilingual resource book, to help new American families learn the early signs of disabilities. *Voyage* was translated into 10 languages including the top six non-English languages in NYS and an additional four languages in response to recent flows of migrants including Dari, Pashto, Ukrainian, and Arabic. The books include recommended ages for autism screenings, developmental screenings, well-child visits, and other resources to help families. The Initiative and its partners have distributed 3,495 copies

of *Voyage* to over 160 recipients including pediatric practices, childcare providers, and CBOs. In partnership with the NYS Act Early Ambassador to the CDC, the DD Navigator has hosted multilingual workshops to share information about the early identification of disabilities with new American parents and immigration service providers. One Spanish-speaking mother who attended a DD Navigator workshop shared the following through an interpreter:

*I try to go to all the workshops I really like them...I would like to tell you I really like and appreciate the information and help.*

While systemic change is slow, the Ramirez June Initiative has made progress to improve access to services for new Americans.

In April 2021, the Initiative presented at the Georgetown NCCC's Transformation Forum as part of the NY CoP. Aside from NY, nine other state and territory CoP teams participated as well. The presentation was an opportunity to share about the disparities faced by new Americans with IDD, to highlight the Ramirez June Initiative, and to engage other states in a discussion about how to advance this model in other states. It was among the first steps in getting a wider, national audience to encourage the advancement and sustainability of this work.

### Conclusion

For new Americans to have equitable access to IDD services, both on-the-ground enhanced support through interagency collaboration, as well as support from leadership of the IDD services system is vital. Systemic barriers have prevented new Americans with IDD and their families from having equitable access to services, but the resilience of new Americans and the collaboration of cross-system Ramirez June Initiative partners have driven change and expanded access. An important success of this program has been directing cross-system time, energy, and attention to this cohort of the new American community. The Ramirez June Initiative has built the foundation to ensure their needs are included in other advocacy and capacity building efforts.

The Initiative has raised awareness for the impact of federal immigration policies on new Americans with IDD. The Initiative has made sure public comments ONA provided on federal or state immigration regulations, include an evaluation of any impact to new Americans with IDD population.<sup>3d</sup> Three years after its implementation, the Ramirez June Initiative has expanded the capacity of ONA's network of CBOs to support new Americans. The Initiative has learned directly from new American communities and has elevated the needs of this community at the local, state, and national level, beyond DDPC and ONA's initial expectations. Given the success of this

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<sup>3</sup> This includes ONA public comments on the U.S. Department of State's (USDOS) interim final rule (IFR) regarding "Visas: Ineligibility Based on Public Charge Grounds" published in the Federal Register on October 11, 2019 (84 FR 54996); the U.S. Department of Justice (USDOJ) and the U.S. Department of Homeland Security's (USDHS) Notice of Proposed Rulemaking relating to "Procedures for Asylum and Withholding of Removal; Credible Fear and Reasonable Fear Review" published in the Federal Register on June 15, 2020 (85 FR 36264); the U.S. Department of Homeland Security's (USDHS) Advanced Notice of Proposed Rulemaking relating to the "Public Charge Ground of Inadmissibility" published in the Federal Register on August 23, 2021 (86 FR 47025).

model in NY, we recommend that other states adopt the model in their efforts to help new Americans access IDD services.

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