Beyond Access

Building an Equitable Developmental Disability System for New York's AAPI Families

Key Findings from the 2026 New York AAPI Special Needs Survey

Conducted by

Families Advocating for Individual Rights (FAIR)

with Dr. Xinwei Zhang

and Chinese-American Planning Council (CPC)

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Why This Matters

Asian American and Pacific Islander (AAPI) families remain one of the most underserved populations within New York's developmental disability system. While awareness of disability services has increased since FAIR's inaugural 2023 survey, many families continue to face barriers accessing timely, culturally responsive, and appropriate supports.

In 2023, when FAIR began advocating for the needs of AAPI families affected by intellectual and developmental disabilities (IDD), one challenge became immediately clear: **there was little to no community-specific data describing the experiences, barriers, and unmet needs of AAPI individuals with IDD and their families in New York.** Existing disability data rarely disaggregated AAPI populations, making it difficult to understand the unique challenges faced by immigrant families or to advocate effectively for policies and resources that reflected their lived experiences.

To address this gap, FAIR launched the **first New York AAPI Special Needs Survey** in 2023. This inaugural survey provided critical baseline data and helped elevate issues that had previously been largely absent from disability policy discussions.

Building on that foundation, the **2026 New York AAPI Special Needs Survey**, representing **345 participants**, provides one of the most comprehensive community-led assessments of AAPI families raising individuals with IDD in Downstate New York. By comparing findings over time, the survey not only measures progress but also identifies persistent barriers and emerging priorities that require policy attention.

This work demonstrates that **community-informed data collection is essential to equitable policymaking**. When historically underserved communities are missing from the data, they are also at risk of being overlooked in policy decisions, funding priorities, and program development. Continued investment in community-led research and disaggregated data collection will enable New York to better understand disparities, measure progress, and develop disability policies that reflect the experiences of all communities.

The 2026 New York AAPI Special Needs Survey

- **345 participants providing one of the most comprehensive snapshots of AAPI families affected by IDD in Downstate New York.**
- **85% of caregivers are foreign-born**, highlighting the importance of culturally responsive and multilingual services.
- **3 in 4 caregivers require interpreter services** when accessing disability-related support.
- **Only 45% survey respondents are satisfied** with the translation services they have received.
- **2 in 3 families experienced delays or barriers** accessing needed services in the past year.

- **Only 8% know exactly where to find disability services**, while **92% still need assistance navigating the system**.
- **1 in 2 caregivers screened positive for depression**, revealing a significant caregiver mental health crisis.
- **57% of caregivers report fair or poor health**.
- **51% of caregivers report poor or very poor quality of life**.
- **91% say caregiving affects their employment**, yet only **14% receive financial compensation** for providing care.
- **76% are concerned about the IDD individuals' transition to adulthood**.
- **More than 8 in 10 families worry about community inclusion and long-term supports.**
- **56% of families relied on a community organization for support in the past month.**

Key Findings/Issues Identified

Language Access Is More Than Translation

Language access is not just about providing an interpreter—it is about ensuring families can understand and use the information they receive. Although **76%** of caregivers require interpreter services, fewer than half (**44.6%**) are satisfied with the translation they have received. Half report difficulty requesting an interpreter, and **44%** experience long wait times. These barriers limit families' ability to understand eligibility requirements, navigate services, and make informed decisions, underscoring the need for both high-quality language services and culturally responsive communication.

Families Continue to Face Complex Service Systems

Although awareness of disability services has improved since 2023, families continue to experience lengthy wait times, fragmented systems, and complicated application processes. **Simply knowing services exist does not mean families can successfully access them and navigate through the systems.**

Caregiver Wellbeing Is a Public Policy Issue

The survey reveals that caregiving comes at a significant personal cost. High rates of depression, declining health, and employment disruption demonstrate that supporting family caregivers is an essential part of maintaining stable community-based care.

Families Are Planning for a Lifetime, Not Just Childhood

Caregivers consistently identified **adulthood**—not childhood—as their greatest concern. Families are seeking stronger pathways to employment, independence, community inclusion, and long-term supports beyond the school years.

Trusted Community Organizations Reduce Disparities

More than half (56%) of respondents accessed support from a community organization at least once in the past month. These organizations play a vital role in helping families overcome language barriers, navigate complex service systems, access available resources, and build supportive community connections. Trusted, culturally responsive community-based organizations are essential partners in ensuring equitable access to disability services, particularly for immigrant and multilingual families.

Recommendations

- **Ensure meaningful language access** by expanding timely interpreter services, providing qualitative multilingual information in plain language, and implementing culturally responsive communication standards across disability service systems.
- **Simplify access to services** by streamlining service enrollment, reducing administrative complexity, and improving transparency.
- **Invest in caregiver wellbeing** through mental health services, respite, and peer support.
- **Strengthen family economic stability** by expanding paid caregiving opportunities and workforce protections.
- **Expand transition and adult services** to promote employment, independence, and lifelong community inclusion.
- **Recognize community-based organizations as essential infrastructure** by increasing sustainable investment in multilingual outreach, navigation, education, and advocacy.
- **Strengthen community-informed data collection** to ensure future policy decisions reflect the experiences of underserved communities.

For more details about the survey please contact:

FAIR email: fair.cpc@gmail.com
Dr.Xinwei Zhang: xz3411@tc.columbia.edu
CPC Contact: sjoeng@cpc-nyc.org