

AADD Professional Conference - Parents sharing Session 5/23 (Thursday) 12-1pm
NYU Langone Health Medical Center Farkas Auditorium
AFDN Parents: Su Wen Kwan & Nyuk Siem Yap

Su Wen Kwan:

I am from Brooklyn. My husband and I have two daughters – 24 and 16. My younger daughter were born with Carpenter’s Syndrome, which is a condition characterized by the premature fusion of certain skull bones (craniosynostosis 顱縫早閉症), abnormalities of the fingers and toes, and other developmental problems. At 1-year old, she was only 10 lbs.

In the first 9-months after birth, I was so perplexed and questioned how my daughter survived. No social service unit or provider gave me any information for services. Physicians, nurses and hospital professionals seemed not knowing the resources nor mentioned to me about Early Intervention (EI) or OPWDD. I ran around everywhere spending a lot of time asking and searching. Finally, a social worker at NYU hospital mentioned EI to me, but I had to do the application on my own. My daughter started receiving EI services at 9-months old.

Then, I had to struggle again for more than a year searching and applying OPWDD services for her. She was approved for OPWDD Care at Home Waiver Program (now Health Home Care) at 2 years old. Due to her medical and physical condition, she also received Medicaid funded services under the NYC Care at Home Program. For all the 16 years, I commit my whole life to care and search for the best services for my daughter.

Many AFDN parents have similar or worse experiences. We took many years to learn about a government agency call OPWDD. And, we took many years to navigate the complicated system to enter appropriate programs and receiver services for our children with special needs.

One of our board members – her son was diagnosed autism at 3, learned about OPWDD from a parent of his son’s classmate (white American) at 7, approved eligibility at 9, started getting services at 10. This also reflected the assessment and application process is prolonged and complicated. In our immigrant community, many parents lack English skills and this makes the situation more insufferable.

Another example: OPWDD are well known in DOE D75. However, children with IEP in other School Districts, where professionals including social workers, psychologist, special teachers as well as parents rarely heard about OPWDD. It is not necessary to be a District 75 student in order to receive OPWDD services. The non-D75 school children with IEP may be eligible for OPWDD services.

I, personally, and AFDN parents hope that OPWDD would outreach to hospitals (children health), DOE School Districts and community health clinics. More social service and healthcare providers learn about OPWDD and the assessment process, they know where to refer children with developmental disabilities and special needs for assessment and services.

On the other hand, I hope the Chinese healthcare community can do something. AFDN parents hoped that the professional medical groups such as CAIPA can take a more proactive and leading role to inform their member pediatricians by – for example - developing standard assessment protocol administered at different stage of developmental milestones, advocating for universal assessment for all children, distributing resources and referral guides of EI, OPWDD and other related programs.

Nyuk Siem Yap:

I am from Queens. My husband and I have two sons – age 21 and 18. They both were diagnosed ASD at 3 years old. They started receiving OPWDD services at 5 years old. They attended special education programs under School District 75.

My older son is transitioning out of the public-school system this year. I am still figuring out where I can send him this fall. He has been in several intake interviews for Day Habilitation program, which is a funded OPWDD programs; however, he had not been accepted due to behavior challenges.

As a matter of fact, I am not the only parent encountering such difficulties. Many aging out young adults with behavior challenges are not accepted to any Day Habilitation on-site programs. As I know, OPWDD has limited numbers of site-based Day Hab programs, which individuals with challenged behaviors belong to.

There are no answers to parents whose children are over 21, who are not able to enter the job market and do not know where to go. Many of our parents have no choice to keep them at home doing nothing. And, parents are tied up by intensive personal caring. We have no personal life. My children's life is my life. The people most needed site-based day habitation services have no service. Spaces only give to well-behaved inds.

Other than Day Hab, there are several different types of OPWDD funded services. However, not many people including frontline workers or professionals know each type of services. And, there are not enough support to help parents learn and use the services effectively. And, there are very limited vacancies for those services.

Many children of AFDN parents (particularly monolingual Chinese parents) eligible for OPWDD services may not benefit from these programs due to language barriers. Most needed programs among Chinese parents are IRA (Individualized Residential Alternative), Holiday Respite, Site-based Day Hab and Community Hab programs. We worried that where our children go and who take care of them after we pass away.

In our community, many new immigrant parents do not speak English, no knowledge of the service delivery system and available resources. Information of system is very confused. They are very difficult for parents and caregivers to understand, particularly for those non-English readers and speakers.

All different service units which include early intervention, special education (CPSE for preschool and turning 5 and CSE for IEP) and OPWDD require a unique set of assessment, before application can be submitted and eligibilities for services are determined.

Parents do not know where to get different types of assessments. They have no knowledge re: those agencies. Parents are forced to be passive. Or, they had to run around crazily to search and schedule assessments, particularly bilingual assessments, which are not always accessible.

It is unbearable for parents when there are long waiting lists for their children to get evaluated and long waiting time to get approval for services. And, once the application gets approved, the child may not obtain the services that meet their education and developmental needs.

Monolingual Chinese parents encounter problems receiving services from main stream agencies and providers.

Other than the difficulties Su and I experienced, AFDN parents had reported to us many different difficulties in navigating the service delivery system, we do not have enough time to share everything today. We put them in writing. We hope that you will understand more about our difficulties and support us to advocate for positive change of the service delivery system.

1. Problems with cultural and linguistic competence -
 - a. Gaps in communications between caregivers and front-line workers or professionals
 - i. Culturally sensitive (more than ethnic cultural differences and Chinese-English translation)
 - ii. I/DD community and caregiver culture and languages, especially specific terminologies.)
 - b. Poor verbal translation services used by government agencies due to translators not having knowledge re: I/DD community.
 - c. Lost in translation occurs in many brochures and booklets published by OPWDD and other government agencies, including Department of Education. Many parents have difficulties understanding or misunderstanding meanings of the translated materials. Some contents are out of context in terms of cultural meanings.
2. Quality assurance of service delivery and support – lack of I/DD related knowledge and resources causes frontline workers and professionals in social service, school and healthcare setting to make incorrect assessment of child’s condition and delayed opportunity for early intervention and OPWDD services – professionals lack of knowledge about OPWDD, not making timely referrals. Or, we hope professionals and frontline workers to provide info for parents, let parents decide if they want to apply for OPWDD eligibility for funded services.
3. Quality of individual case managers and care coordinators are not consistent. Manpower turnover rate is very high in agencies serving the I/DD community. One knows something. The other knows nothing. One of AFDN parents experienced a situation. After an original worker started an application for service for her child, she left the agency. The new worker did not have enough knowledge about available services and procedures to follow up. Another example, some frontline workers do not know children with developmental disabilities have straight Medicaid coverage. They kept asking parents for the managed care insurance card.

There are not enough trainings to new or concurrent workers. AFDN parents hoped that agencies should provide quality in-service and culturally sensitive practice trainings to staff members and develop policies to assure the consistency of the quality of service delivery.

4. There are very limited Asian population-based service agencies and providers. Monolingual parents have no choice to get services from these already overloaded and case flooding agencies due to poor English proficiency. They remain passive in the endless waiting state. They do not know the progress and status of applications. Even though the workers work very hard, they receive very low pay and keep high caseloads. They do not have time to obtain trainings to upgrade their knowledge re: I/DD related resource and services.

Some parents use main stream service providers, if they speak a little or fluent English. We have non-English speaking parents attempted to obtain service from main stream providers. A parent was immediately rejected because she did not speak English. Some parents expressed that their children were being rejected to the program because they were not able to manage interviews due to poor English proficiency. We hope that providers will be able to sense cultural differences and implement cultural competence practice.

5. And, also during program transitional periods, e.g. MSC to CCO, parents still do not get care coordinator one year after transition. Some cases are pending over 2 years. We understand that Care Coordination Organizations have difficulties to hire enough workers. Case management tasks absorbed by family support workers who has a high caseload. They have to help parents. So, they have to take extra responsibilities.

6. Self-direction program – caregiver or parent coordinates service for one’s own child. The program has existed for long time, but was not well known to the Asian community in the past. There are increasing Chinese parents enrolled into the program, but non-English speaking parents have problems fully utilizing the benefits of the program. They need a lot of support in locating services and managing the billing system, which is not always available. Moreover, there are inadequacy of quality assurance on broker and support services. The application takes very long processing time before it gets approved.