

MEET: MARISA NIWA



PITTSBURGH, PA

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MARISA NIWA: MARISA: THE NEED FOR
COORDINATED COMPLEX CARE



Marisa is an adult with Down syndrome who has built a life reflecting her interests, abilities, and values. She works part-time at a local grocery store, where she has been for 24 years, and enjoys greeting customers while contributing to her community's daily rhythm.

Outside of work she enjoys participating in Special Olympics activities like golf and bocce, and also volunteers at a neighborhood food pantry, helping deliver groceries to those in need. These connections give her purpose, independence, and a sense of belonging.

Her mother, Nancy, plays a key role in Marisa's life. She helps coordinate medical appointments, ensures Marisa's various doctors understand her history, and encourages healthy habits like regular exercise and balanced meals. Staff at her group home also support her by maintaining routines and assisting when new health challenges arise.

Marisa's health needs are fairly complex and require consistent, thoughtful coordination. She has Down syndrome, which means she sometimes deals with related health concerns like hearing impairments, heart issues that require a cardiologist's care, and occasional respiratory infections. In addition, orthopedic challenges can arise over time, so regular check-ins with an orthopedist are also necessary. Each of these conditions demands attention from different specialists, and the key to Marisa's well-being is making sure all of these doctors are aware of her full medical history and current situation.

However, simply having multiple specialists isn't enough if they don't know how to engage with Marisa effectively. Some doctors have rushed appointments or have failed to explain what they're doing and why. When that happens, Marisa may feel anxious or confused. On the other hand, when a physician takes the time to listen, speak clearly, and maybe even review her records beforehand, the difference is immediate. Marisa feels understood and respected. This encourages her to trust the healthcare process, follow through with recommendations, and return for periodic check-ups.



At times, Nancy and Marisa have encountered doctors who don't seem fully prepared or interested in working with adults who have Down syndrome. Those moments highlight a real need in the health system: more training and resources to help providers understand how to communicate, schedule adequate time, and customize their approach for patients with intellectual and developmental disabilities. Even simple adjustments like offering a quieter exam room or using more direct, step-by-step explanations can help Marisa feel at ease.

Marisa and her mother, Nancy, want a health system that genuinely treats people with disabilities as full, valued individuals who work, play, volunteer, and contribute to their communities. They hope for clinics and hospitals where doctors take the time to get to know their patients, not just their conditions. This might mean scheduling longer appointments for those who need more explanation or being patient when someone asks to hear things more than once.

They'd also like to see better communication among specialists, so each doctor knows Marisa's complete health picture. When professionals work together by sharing notes, discussing cases, and making decisions as a team, Marisa's care improves and she feels safer and more understood.

In addition, Nancy believes that including people with disabilities in research and clinical trials would lead to better treatments down the line. When individuals like Marisa help shape what's studied and why, the results are more likely to meet their real needs. She also emphasizes the need to preserve Medicaid and Medicare because they are crucial for people with disabilities to access the care they deserve, when needed.

Above all, Marisa and Nancy want healthcare providers, policymakers, and the community at large to remember that good health is about more than just treating symptoms. It's about building trust, listening closely, and respecting each person's way of understanding the world. By doing so, the health system can support not only Marisa's physical well-being but also her sense of dignity, independence, and belonging.