

Example Scenario – Marcy

Consumer Name: Marcy

Dx's: Down Syndrome, mild cognitive impairment, and dysphasia

Family/Supports: Parents live 15 minutes away and visit at least once a week. 1 brother and 2 sisters live out of state but talk on the phone with Marcy at least once a week.

Age: 56

Language: English

Income: Supplemental Security Income

Home Setting: Intellectual/Developmental Disability Adult Foster Home

Social History: Marcy was diagnosed with Down Syndrome at birth. She lived at home where her parents were her primary caregivers until the age of 44 when her parent's health began to decline. Marcy has been in the same DD home for the last 12 years. Marcy and the providers have a close bond and the family hopes to maintain this placement indefinitely.

Last month Marcy had to have surgery to remove a tumor in the upper right-hand side of her chest. Unfortunately, during the surgery, they discovered additional tumors that had spread into the area around her shoulder which they removed at that time. At this time the doctors believe the surgery was successful and that Marcy will not need additional treatment such as radiation or chemotherapy. They do plan on monitoring her closely over the next year for any changes in condition.

Marcy came back to the home and is struggling with compromised range of motion and pain in her shoulder. Her independence is very important to her and she is struggling to feed herself using her right hand due to the pain and lacks coordination to successfully use her left hand. Marcy also loves to draw and is frustrated that it is difficult and painful for her right now.

While the family and provider are relieved that Marcy does not need additional treatment for the cancer now – it has brought up a lot of questions about Marcy's care and future.

Presenting Issue:

After being home for a week Marcy developed MRSA (Methicillin Resistant Staphylococcus Aureas) and was sent to the hospital. She needs to be discharged to ICF level of care in a nursing facility for IV antibiotics.

Currently her placement is funded through Developmental Disabilities program, which does not cover ICF level of care in a Nursing Facility. as it is considered an institutional setting. The hospital has called the local APD office for ICF authorization and left a message on the screening line requesting an assessment. The social worker from the hospital describes the consumer's care needs as follows:

- Six weeks of IV antibiotics
- Hands on assistance with dressing upper part of her body every time
- Hands on assistance with bathing her upper body and washing hair.
- Special diet preparation every meal
- Monitoring for aspiration
- Hands on assistance with eating when her arm tires and hurts which occurs about half way through each meal

The team should discuss the situation, the following questions and what their office's resources and responsibilities are to assist on this case. Take time to connect with the representatives from Access Technology, Inc and Public Utilities Commission about potential items that could benefit Marcy.

How does ICF get authorized? What actions do the local Medicaid and IDD offices need to take? What needs to happen to set up payment to the Nursing Facility?

The DD home has agreed to re-admit Marcy once IV antibiotics are complete. As Marcy nears the end of her stay at the NF the provider calls ADRC to find out more about any cancer support resources. He takes the opportunity to ask about any organizations or programs that may be able to help the family with figuring out what she may need in order to be prepared at her end of life or if her parents, who are also her legal guardians, die before Marcy. What resources may the ADRC help connect the provider and family to for support?

The provider had no time to research or obtain any assistive devices to help with the complications in her right arm before going back to the hospital. Who can help the provider and Marcy identify and obtain the assistive devices she needs once back in the home to be successful and enjoy the same quality of life prior to the surgery? Which agency helps her transition back to the DD home? What steps need to be taken to reinstate DD payment once Marcy returns home?

Are there any other community resources your team is aware of that could help this family?