

# **Sara's Story**

## **Individual Transitioning from an ICF/DD**

### **Case Study: Individual with developmental disability transitioning from ICD/DD**

Sara is a forty-year-old female, who was admitted to the public ICF/DD, Pinecrest Supports and Services Center (formerly Pinecrest State School), at the age of 9. Until that time, she lived at home with her family. Sara's parents were not aware that she had a developmental disability until Sara was about 1 year old. At that time, her parents began to note that she was not developing as her other siblings had. Sara did not walk or speak until the age of 3. Before moving to Pinecrest, Sara had not received any form of formal education. Her family felt that she could acquire some "training" at Pinecrest that they could not provide to her at home. Sara was diagnosed with Mental Retardation and Autistic Disorder, and even though Sara communicates verbally and ambulates independently, she is not capable of fully communicating all of her desires or needs. The majority of communication from Sara consists of her singing a variety of songs and indicating food preferences.

Sara's family lived near Pinecrest, and following her move to the facility, they remained active in her life. Her mother was her legally authorized representative through the years, but other family members, including siblings and a niece, assumed varying levels of responsibility/contact as her mother's health declined. All family members remained fairly active in Sara's life, visiting her during holidays and other special occasions. They also took her home for weekend visits and to participate in family functions.

Sara's family involvement included them attending her annual staffing for review and approval of her Support Plan. During this process, the Facility Treatment Team was able to give their professional input on Sara's overall quality of life throughout the past year. Sara and her family voiced their concerns in regards to her health and well-being from the past year, too. Throughout the year, it was noted by staff that Sara had not been eating her meals regularly and had lost a little weight. Her mom and sister explained to the Facility Treatment Team that whenever Sara comes home to visit, she eats heartily and enjoys eating at buffet-style restaurants. As a resolution to her losing weight and not eating the meals from the cafeteria, the Team dietician and physician suggested Sara be provided vouchers for the Pinecrest canteen and bakery. Sara could use the vouchers in lieu of eating the meals from the cafeteria. The canteen sells candy, chips, soft drinks, and a variety of easy to prepare items such as hamburgers, sandwiches, and fried chicken. The Pinecrest bakery has wonderful breads and pastries. During the months following the review of her Plan of Care, the dietician noted that Sara was once again within her recommended weight range.

A main focus of the person-centered planning was the "Living-Setting" portion of her plan. The facility Treatment Team, along with Sara and her family, discussed the best place for Sara to receive services. They talked about whether it was best for Sara to remain at Pinecrest or if she would benefit from being served in the community. The "Living-Setting" discussion included the Facility Treatment Team's input, Sara's feelings on alternate placement, and her family's wishes regarding alternate placement. The

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group also discussed what community supports Sara might need if she were to transition. This was necessary to give Sara and her family a picture of what community living might be like. It also helped keep the Team's documentation updated and ready should Sara transition in the coming months.

Following Sara's annual staffing, the facility Treatment Team met with Sara and her family quarterly. Throughout the years, Sara and her family were offered educational opportunities regarding alternate placement options. They visited various housing options (apartments, houses, and community homes) and attended local and regional provider fairs. While visiting alternate placement options, familiar staff observed Sara for her responses to the different settings to make a determination of what she preferred. For many years, Sara's family remained opposed to the idea of transition to the community; however, through the various educational opportunities offered by Pinecrest and the OCDD Regional Office, they better understood community transition and the steps involved in Sara's moving to a community-based living option.

One day, the Transition Services department at Pinecrest was contacted by Sara's mother and sister. They had recently attended a community education forum offered by the OCDD Regional Office, in partnership with a local provider in Pineville. They had visited some homes of waiver participants using Shared Living Services options available through the Residential Options Waiver. They were pleased with what they viewed and became interested in services that could be extended to Sara if she used a Residential Options Waiver (ROW). Sara's family indicated that they had viewed other community-based options offered by the New Opportunities Waiver (NOW) in the past but were especially impressed by the service package that OCDD was offering in the ROW, a new waiver for people with developmental disabilities. They requested that Pinecrest begin the discovery process for Sara to transition to a living option in the ROW. When questioned as to why they felt this was best for Sara now, they reported that in their opinion, Sara would be offered more opportunities to engage in activities she enjoyed, such as eating out, shopping, and vacationing, than she would if she were to remain at Pinecrest. They also felt that she deserved the right to have a home life as close to "normal" as is possible given her diagnosis of Mental Retardation and Autistic Disorder. They were not sure in the past that a setting existed that would meet Sara's needs and also seem like home, but the Shared Living Services option seemed like a fit.

Sara's family sat down with the Pinecrest Facility Treatment Team to discuss the selection of the ROW versus the NOW. With Sara's diagnosis of Autism, Sara's family and Pinecrest staff felt Sara's life could be improved by her living in a smaller setting. Sara enjoyed opportunities to go out in the community but did not like to go in large groups or with unfamiliar people. As a result of limited resources, most trips she participated in at Pinecrest were with large groups; however, Sara seemed to enjoy herself more when only out with a friend or two. This made Sara more comfortable and likely to engage and interact with others, rather than shy away. For this reason,

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Sara's family felt her participating in a living option that offered supports to only a small number of people and where she could share supports with preferred friends would be great for her social development and quality of life. Sara was mostly independent in her daily living skills, so her family thought that Sara's sharing supports with others in the Shared Living Service would also encourage her to use and retain her daily living skills. Sara's family did not believe that Sara would be happy with one-to-one supports at home alone, since she seemed to do best with a mix of privacy and interpersonal time with peers. While more people are beginning to share supports in NOW, Sara's family had not seen many examples of people sharing using NOW. They liked the Shared Living model in ROW and also were drawn to the larger menu of professional services in ROW. They believed Sara may need some professional services, specifically psychological services and a dietician, to ensure her success at home based on her Autism diagnosis and past struggles with diet. A dietician is not available in NOW.

During a conference call, Pinecrest Transition Services staff told Sara's mother and sister about the Money Follows the Person (MFP) Rebalancing Demonstration, better known as the My Place opportunity. My Place would help Sara to access a ROW opportunity immediately. Her family was informed that services under the ROW began on day 1 of the transition process, pending all certifications and necessary paperwork. Pinecrest Transition Services staff set up a meeting to present the informed consent materials to Sara and her mother that week. Though Sara's mother agreed to her participation in My Place, she was curious as to how Sara's services would be impacted at the end of her My Place opportunity. Transition staff informed Sara's mom that Sara's services would continue after the 365 day demonstration period for as long as Sara remained eligible for the waiver.

Pinecrest Transition Services staff and the MFP Transition/Quality Coordinator for persons transitioning from ICFS/DD met with Sara's mother, sister, and other family members. They explained the transition opportunities of the Residential Options Waiver and the My Place (Demonstration) support to Sara and her family. They explained that it would take them working together with Pinecrest and new community-based providers they would choose to make Sara's transition smooth, safe, and successful. After the informed consent materials for both My Place and ROW were signed, Pinecrest submitted paperwork to the OCDD My Place Program Manager to begin Sara's transition. Pinecrest was already engaged in a planned downsizing initiative approved by OCDD Central Office, so the facility was working to reduce the number of beds filled and overall capacity. Sara's moving to an individualized living option through My Place fit right in with the planned downsizing initiative.

Following the initial paperwork, Sara's mother and sister chose a Support Coordination agency, and the agency assigned a Support Coordinator to Sara. The Support Coordinator provided Sara's mom and sister with a list of providers in their region. Pinecrest worked with the Support Coordinator to arrange for Sara and her family to

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meet a number of providers. Sara's mother and sister also made visits to the different types of living options offered in the waiver including: Shared Living, Host Home, Companion Care, and Community Living Supports (apartment settings). OCDD Regional Office staff were also notified of the family's request and served in a support role to assist the family with locating places to visit. The visits would give them an idea of what living options were available in the Pineville area. Sara's family wanted her to live nearby, so they could continue to see her often.

At first, this seemed like a lot of time and effort to Sara's mother and sister, but staff members at Pinecrest and the OCDD Regional Office were firm that actually seeing different living options would help in the discussions that had to take place during Sara's person-centered planning process. This would also assist in the selection of a provider for Sara's residential services setting.

Sara's Transition Support Team was led by her Support Coordinator and initially included members of the Pinecrest Facility Treatment Team, as well as Sara, her mother, and her sister. The Support Coordinator first asked the family what they envisioned for Sara over the next year, five years, and ten years and completed a Personal Outcomes Assessment for Sara. Then, they talked about what supports and services they thought would be needed to implement the family's vision for Sara and what supports they knew from professional evaluations would be needed to insure Sara's health and safety in a community setting. All of this information was then used to begin to develop Sara's support plan for community living.

After reviewing her facility Plan of Care, the Support Coordinator also discussed Sara's need for 24-hour care. The group was in agreement that Sara needed 24-hour care and talked about which living setting would best meet Sara's needs for 24-hour care. A Host Home opportunity or Shared Living option seemed to be the best fit for Sara. Sara had a third choice in choosing to move home with her mom, but her mom's health served as a barrier. Due to advanced age and the inability to ambulate far without assistance of a walker, Sara's mom was not physically able to care for Sara and offer the supervision and active lifestyle Sara wanted.

The Support Coordinator assisted Sara and her family to select a provider based upon Sara's support needs and their previous visits. Members of Sara's Transition Support Team, including a direct support worker from Pinecrest who knew her well, accompanied Sara to visit persons supported by the family's choice provider. They paid close attention to her overt facial expressions, as well as behaviors she displayed during the visits because Sara communicated best through these mechanisms.

Sara seemed especially pleased during her visit to a particular residence where participants were using Shared Living Services. The house was located in the Piney Meadows subdivision. The two ladies who lived there welcomed Sara and the Transition Support Team members to their home. One of the ladies, Angel, recognized Sara. They knew each other from their participation in the local People First chapter.

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Angel took Sara on a tour of the home which included an empty bedroom that might be Sara's. The bedroom was just vacated by Emily, who moved into her own apartment using Community Living Supports in ROW. Angel then showed Sara the garden in the back yard. Sara began singing and dancing in the yard among the spring flowers. Sara went back inside and motioned for the direct support worker from Pinecrest who knew her well to go outside to touch them. Once inside, Sara began moving room-to-room singing and pointing at different objects. During visits to other homes of participants using Shared Living and also some Host homes, Sara would smile and look around with prompting, but she never initiated exploration.

Sara's mother and sister were contacted by Sara's Support Coordinator regarding the home in Piney Meadows subdivision, and they discussed Sara's initial response. Her mother and sister were pleased and were quick to schedule a visit. After their visit, they felt that it was a beautiful home with warm staff and housemates with whom Sara would have a lot in common. Sara's mom consented to Sara transitioning to share supports with the ladies living in Piney Meadows. The Support Coordinator contacted the chosen provider agency about Sara's choice. The provider agency discussed Sara's decision with the two ladies living in the home, and the two were excited to welcome Sara into their household. The agency supervisor and staff working at the home were then included in the transition planning process.

From that point on, Pinecrest staff and Sara's mother and sister began taking Sara to visit the home in Piney Meadows subdivision so that she could continue to make friends with the two ladies who lived there. As new housemates, they worked out details about routines and how they would share space and expenses. Sara even stayed overnight and visited on weekends to ensure that the home would be a good fit. She also spent this time meeting with her housemates' families and her soon-to-be neighbors. During the visits, Sara worked with her family to choose a color scheme for her bedroom and started to decorate the room in her favorite colors of red, blue, and yellow. Over the years, Sara had shown an interest in flowers, so a floral theme was chosen for her bedroom. She really enjoyed picking out a bedspread with bright spring flowers on it.

The home and community-based services agency (HCBS) responsible for providing the services Sara would need while living the home in Piney Meadows subdivision started attending Sara's Team meetings. Sara's mother and sister participated in the meetings, also. They all worked together to develop a plan of care that would reflect Sara's goals and preferences as well as keep her healthy and safe. With Sara's needs for supports identified, providers of community-based medical supports, therapies, and day habilitation were located. These providers were included in the Transition Support Team meetings.

The team worked hands-on with support staff from the home in Piney Meadows subdivision to teach the HCBS staff about Sara's support needs. The transition planning was a partnership involving Sara and her family, her Support Coordinator,

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and her current ICF/DD provider working to transition Sara to her new community-based providers, who would offer Sara services after her move. Throughout the process, Sara's new community-based residential provider assisted in negotiating support arrangements that were agreeable to all three ladies who would share the home.

Before Sara moved, her certification for Medicaid and state developmental disability services were verified, including Sara's qualification for ICF/DD level of care. Sara, her mom, and her sister talked to OCDD staff about Sara's quality of life. Her mom and sister were contacted by a contractor who was administering the "Quality of Life" survey for the My Place program. They agreed to meet one morning about two weeks before Sara's projected move date at 10:45 a.m., to complete the interview.

It took about 60 days to complete Sara's move to her new home. The majority of the transition process during this time was dedicated to ensuring Sara's adjustments to her new home, her new bedroom, and her new housemates and staff. Due to Sara's diagnosis of Autism, this was an important part of the transition process to ensure Sara's quality of life and a successful transition. Sara's support staff at the home in Piney Meadows subdivision were excited about Sara coming to live there and were quick to learn about her needs and preferences. Sara also had to visit her community-based primary care physician before moving to ensure continuity of medical care. She was a bit unsure of the unfamiliar medical office setting at first, but Sara came around quickly when the nurse offered her a chocolate candy and a warm smile.

Sara's ROW services began the day of her move into the new shared living setting. During the first 365 days of her waiver, Sara also participated in the My Place program. Every quarter, Sara's Support Team met to discuss her progress on her support plan goals. Her Support Coordinator evaluated her current living setting, documented that Sara was receiving the services in her Plan of Care, and evaluated whether any new services were needed.

During follow-up visits and phone contacts made in the first six months after the move, Pinecrest staff noted Sara's continued pleasure with her new home. Sara was very happy living in the smaller, individualized setting. Sara clearly enjoyed being around her housemates. She learned to help out with chores and to keep her bedroom and bathroom neat. She had numerous opportunities to participate in preferred community activities including: shopping at the Alexandria Mall with her new housemates, going out to eat with friends at Piccadilly Cafeteria and Fire Mountain and becoming a member of the choir in a local church. While living at Pinecrest, Sara showed great interest in attending local parades and festivals in the area. She continued doing so by attending the Colfax Pecan Festival and taking a trip to Natchitoches during the Christmas holiday to tour the Festival of Lights and watch the fireworks display and laser show. Perhaps Sara's best experience came when she and her two housemates took a mini-vacation to New Orleans. They visited the Audubon Zoo and watched a few of the smaller Mardi Gras parades Uptown.

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About 90 days before her first anniversary in the home in Piney Meadows subdivision, Sara's Support Coordinator did a Personal Outcomes Assessment and made sure that all of Sara's assessment information was up-to-date for the Support Team to complete the upcoming annual planning meeting. Her Support Coordinator determined no new services were required and that existing services should continue. The Support Team agreed, so there were no changes to Sara's second year excepting her updated Personal Outcomes Assessment and updated goals section. Sara's mother and sister agreed with the changes that were suggested in Sara's second year plan of care. On day 366 of Sara's stay in the new home, the My Place program ended and Sara continued her ROW waiver without even realizing anything had changed.

At the end of the first and second year, Sara and her family again participated in the Quality Life Survey that was part of the agreement when she moved using My Place. Each survey required about half an hour to answer the questions about how Sara enjoyed her life in the community. It was reported by Sara and her family that she continues to get along with her housemates and enjoys her new active lifestyle. Her family continues to visit her, and they are very pleased with their decision to support Sara's transition through the My Place program. It has allowed Sara more freedom to do what she enjoys, and it has aided her in seeking out her own identity by trying new things and making independent choices. They feel that the move was ultimately the best decision because Sara is the happiest they have seen her in years. With all the singing she is doing these days, her mom and sister jest that she should try out for American Idol!