

Lived Experiences in Mental Health

Part of the Mental Health Educational Toolkit available at <https://apstarc.acl.gov/toolkits>.

Introduction

Two interviews were conducted with adult daughters of mothers with mental health issues. Both interviewees were caregivers for their mothers as they aged. Their experiences were provided with the assurance of confidentiality therefore, they are referred to as “Alice” and “Betty”.

Alice and Betty were asked questions and their responses were recorded below. The responses and terms used by Alice and Betty are their words and not those of the author.

It is important for readers to understand that the information shared and gathered is offered as an opportunity to understand the lived experiences of family members and their interactions (or not) with APS. Suggestions they have to offer for APS staff working with people with mental health disorders may help APS programs with their interactions with clients and family, as well as maltreatment prevention efforts, and community education efforts.

Alice knew at a very young age that something was different about her mom. Frequent hospitalizations, long absences from home, physical abuse, drunkenness were common occurrences. Fast forward to her mom at 90 years of age living at home and in need of support. Mom had at least one mental health diagnosis (bipolar disorder) and other medical health issues. She frequently reported to law enforcement and adult protective services that she was being physically abused and financially exploited by the daughter that lived nearby (Alice’s sister).

Betty also knew at a very young age that her mom was not like everyone else’s parent. They moved often to different towns and states and it was not uncommon to live in their car or homeless shelters. Betty’s earliest memory of watching over her mom was at the age of 12 when they moved to a new place and she went to the local sheriff to explain her mom’s behavior. She begged the sheriff that if she called them to please not to put her mom in jail but to take her to the hospital. Since the early 1970’s her mom lived in state hospitals/institutions, state group homes, homeless shelters, low-income group homes, assisted living facilities, and skilled nursing homes. Her mom’s diagnoses included bipolar disorder, later in life dementia, and other medical problems. Betty didn’t know until this interview about adult protective services.

Are you familiar with the APS program? If so, describe your experience with APS.

Alice – Yes, we know the local APS staff. Mom would often report to APS and law enforcement that my sister was abusing her. APS was not able to help us mostly because mom would not accept any help. I was thankful that APS confirmed with the “law” that my mom was not being abused by my sister. My sister got the brunt of her craziness because she lived next door to her.

Betty – No, I have never heard of APS. How that is even possible when my mom lived in two different states and bounced around between shelters, state hospitals and all types of care homes is beyond me. I had the most interactions with law enforcement, Medicaid staff, and facility administrators. I think

that if families are desperate and knew of APS, they would call for help. I would rather have called APS than law enforcement on some occasions.

People sometimes are fearful of people with a mental health problem. Is this really a concern?

Alice – My mom was mean as hell and very paranoid. She kept guns and ammunition throughout the house. Later in life she would strike out with her cane or walker. She was more apt to hurt family than a stranger. Still, I think it would be good to ask a caller (e.g., reporter to APS) if they know if the person has guns, weapons, and if they are in an agitated state. With my mom it would be best for two people to go out together because if someone went to visit her alone, she would probably later claim that they had raped or molested her.

Betty – My mom while living in facilities and taking her meds daily was pretty chill. You could approach her and have a pretty good conversation most days. She exaggerated and lied a lot, so it was hard for me and others to figure out what was true or not. If I were to call APS, I might tell them that it would be best to send a man. My mom liked men more than women. Also, I'd suggest that they visit a couple of times, if possible, to hear the story again. If she is consistent with the details, there is a good chance that she is mostly telling the truth.

Do you have any insight into body language and suggestions around such?

Alice – When my mom was acting-out her eyes would be wide open, and you could see more of the white in her eyes. If she would not look at you that was not a good sign. Stand or sit far enough away that you can dodge any item she might throw.

Betty – When my mom was agitated you could see more of the white part of her eyes above the irises. If she was speaking quietly and slower watch out. Always be near a door so that you leave as quickly as possible. The CNAs in nursing homes are not trained and knowledgeable about mental health problems. It would help if they were trained better. I hate to tell you but some of the CNAs have gotten smacked by my mom.

What about self-neglecting behaviors?

Alice - Yes, my mom was her own worst enemy. The best thing she ever did for herself was to quit drinking. I still do not know why she quit drinking. She shopped around with different doctors to get new and different prescriptions. Funny because she was not consistent with taking any medications.

Betty – Whenever my mom did have a place of her own it was nasty – beyond comprehension. She was a hoarder of anything and everything. She would not bathe. I was labeled as a “feral child” and rarely stayed at home with her. Why should I have? As an adult in my mid 20-30s I was not attentive to my mom. Yeah, I would occasionally go to her home and attempt to clean the kitchen and would bring her food but that was about all. She was much better off living in some type of group home. All the facilities’ staff had a horrible time getting her to bathe. She was evicted often. Once word got out most of the other facilities did not want her.

What advice do you have for getting to know someone?

Alice – It would have taken several visits over a period of time for my mom to trust you. If you told my mom that you would like to come back to visit next Monday at 2:00 p.m., then you better be there and be on time. If not, you may never earn

her trust. If it's possible to include family in discussions with her that might help. It was better to visit in the afternoon rather than morning. We lived in a rural community and everyone knew my mom was crazy. Talk to others to find out as much information as you can. As they say, "In our family we don't hide crazy we put them on the front porch".

Betty – I would like to speak about getting to know the family caregiver. If folks (doctors, administrators, nurses, social workers) would have spent more time listening to me they would have learned more about my mom. My mom called law enforcement to the facilities all the time. The facility administrators would get so upset. Mom worked as support staff for law enforcement in her early years; she loved them (LE). So really, it's not so much something that the facility has done wrong but my mom wanting to see cute (male) LE officers. In fact, your best chance of getting her to do something was to say the sheriff said for her to accept help.

Anything else that you would like to share?

Alice – I don't pretend to have ever loved her. She was abusive to all six of us. Four of us ran away from home as youngsters. Only two graduated from high school while living with other relatives. I am very proud that all of us got a GED, higher education or technical skills, and have had good jobs and families. It sure as hell wasn't because of anything she did - maybe it was even in spite of her.

Betty – My mom was smart, creative, and could at times be a lovely person. I am thankful that as an adult child I could see that side of her and occasionally have good visits. She had one brother who probably appreciated this side of her also. The rest of the family - not so much.

Interviewer: Maria Greene, APS TARC Team Member

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