FROM IPADD DISCUSSION ABOUT QUESTIONS PARENTS SHOULD THINK ABOUT PRIOR TO CILA PLACEMENT DECISION FOR THEIR CHILD

August 2013

Below is a list of questions that I received from my PASS Agency - PACT.  They are adapted from Service Coordination and The Arc of Maryland.  I found them very helpful.

1.  What is the Provider's mission?  Does it encompass the services and the intent you are seeking?

2.  Is the Provider certified, accredited or licensed and by whom?  How does the provider describe the standards of service the organization has adopted?

3.  How does the agency make sure people are treated with respect?

4.  Can friends and family visit anytime?  How much notice do family and friends have to give before a visit?

5.  How does the agency actively assist people to make choices?

6.  Does the agency encourage and support people to be active with self-advocacy groups?  How?

7.  How much say-so do people receiving services have in deciding and selecting the staff that works with them?

8.  How much say-so does the person receiving services have in deciding where he/she lives and with whom he/she lives?

9.  Do people have keys to their own home or apartment?

10.  How does the agency provide for privacy for the person?

11.  Can you supply me with a list of families who receive services from you so I can discuss your services with them?

12.  How many people with developmental disabilities and family members are on the board of directors?

13.  Does the agency have any written materials about the agency that we can take with us?

14.  How long has the agency been in business?

15.  Does the agency have a parent organization?  What role does it play?

16.  How can I obtain a copy of the most recent licensing survey?

17.  Is the agency accredited by any accrediting bodies?

18.  What kind of safety measures does the provider have to protect and assure treatment?

19.  Is the provider connected to other programs that your family member or friend might need such as day support or work programs?  How are they connected?

20.  What and how does the provider routinely report to families:  How often?

21.  How does the agency handle a person's finances?

22.  Ask the agency to describe the screening process it uses to hire staff.

23.  What training does the agency offer staff?

24.  How is direct service staff supervised?

25.  What is the turnover rate for direct service staff?  For administrative staff?

26.  What mechanism is used in supervision, evaulation and dismissal of staff?

27.  How can families and consumers reach different staff at all levels in an emergency outside office hours?

28.  What backup systems are in place for medical or behavior emergencies?

29.  What are the policies regarding medication and its administration?

30.  How are services individualized to meet individual needs?

31.  How many people have been discharged from the program in the last year?

32.  What procedure is used to discharge an individual?

33.  Why did the peole descharged from teh program leave?

34.  How many people discharged from the program moved to less supervised settings, or situations with fewer supports.

35.  How does the agency respond to life changes such as marriage, retirement, shift work, complications of aging, medical issues and so on?

36.  What recreational and social activities do people participate in?  How individualized, available, accessible and consistent are they?  How often do people participate in these activities?  What happens when individuals choose not to participate?

37.  What kind of transportation is available during the week?  On weekends?

38.  Does the agency have good relationships with neighbors and/or neighborhood associations where people live?  How are relationships nutured and maintained?

39.  How does the agency help people learn to be a part of their community?

Linda

I have more questions.

1. What training is given specifically for behavior crises?  Who receives
this training?

2. Are restraints ever used? What form of restraint? How often?  Are
records kept?  Where?  Who monitors the records?

3. Is isolation ever used for problem behaviors? This could include a
"calming room" or a "quiet room."  If so, how often?  For how long? What
records are kept?  Who9 has access to these records?

4. Who is included in conferences about difficult behaviors?  Are parents
included?  Is the consumer included?

5. Have you ever called the police because of a consumer's behavior?

That's all.  As you can tell, I've been hearing strange stories lately.

Jean Kulczyk

I would agree that it has a lot to do with the staff, staff on all levels.
I think all us parents should start making it a regular thing to ask questions to every agency we visit.

1) what is the staff to resident ratio?
2) Does that ratio fluctuate depending upon the need level of the residents in the house or is that a set number resident to staff?
3) what is the hierarchy of the staff. Direct support staff? House or site supervisor? Case managers and the # of houses on their individual case load? Other layers of supervisors (usually there are a couple above the site supervisor)? Behavior specialists who develop behavior plans for all individuals living together in the house- and their case load? Do they have monitors that come on a regular basis unannounced to check in on the house- how many times a week, daily? Nightly?
4) Who manages the calendar/schedule of engagement for activities? The schedule for outings-ASIDE FROM DAY PROGRAMING (evening & weekends).
5) is there a method of documentation or charting for these events and activities?
6) Insist that leisure/ social activities occur in the house, and that the residents are taken out into the community.
7) If you don't see this happening- insist that it does.
8) Be a visible and audible part of your adult child's life. Staff should recognize your voice when you call to ask how your child's day went. Make unannounced visits. Spend a little time on a frequent basis getting to know staff. Be pleasant, offer help and suggestions to staff. Make them aware of your wishes for your child. Help them plan activities for the house and for outings.
9) Ask when the house staff & residents have regular meetings and be there.
10) Do not sit back and accept staff and agencies that do the basic care and treat the home like an assembly line. This is what a group home in the community is supposed to be for- community living and integration, it's NOT an institution.

My son is living in a group home through Seguin services. He moved in in mid May. It is a lot of work on families IF they want things to be done right. Bad patterns are hard to break. Putting in the personal time and work before move in when the agency is getting to know your child and your family AND ON AN ONGOING BASIS after move in, FOR AS LONG AS YOU ARE ALIVE AND WELL will make all the difference in the world for ensure the best possible living conditions for your child. If you feel its all their job and do not stay visible and helpful likely your child life will not be as full.

Diane S