



TRANSITIONING TO A GROUP HOME IN THE COMMUNITY

By Rosemary Bellaire



Background

- Our son Rob diagnosed with an inoperable brain tumor at age 5.
- Radiation took care of the tumor, but . . .
- Caused significant brain damage, in motor skills, short-term memory and executive functioning skills.
- He has 18 diagnoses.

Background cont'd

- Rob went to school with a 1:1 aid, graduated from H.S. and attended the ELSA Program at Elmhurst College.
- Rob lived at home for 29 years.
- Selected from PUNS in 2013 and moved into a CILA in 2015.
- Had to choose between CILA or Home-Based Services.
- We chose CILA.

Transitioning to CILA

- Difficult decision.
- Many considerations.
- Requires time & effort.
- Must find one that is suitable.

Service Coordination Agency

- You need to get your son or daughter on the PUNS list. NOW!
- Must go through a Service Coordination Agency.
- Does screening & leg work.
- DayOne PACT is the agency in DuPage County.
- “Your concern is valid in regards to finding a CILA that has the services and supports to appropriately care for your son.”

Extensive Process

- Significant information is needed:
 - Medical History
 - Diagnoses
 - Current medicines
 - Immunizations
 - List of doctors
 - Other detail information

Process cont'd

- Lengthy interview with SCA service coordinator.
- Psychological testing.
- Transition Service Plan/Person Centered Plan.
- Extensive packet of information sent to many agencies.
- Visits to numerous agencies to find the right one.

Process cont'd

- We also visited several Intermediate Care Facilities (ICFs).
- “Institution-like.”
- Old; some poorly maintained.
- Son not a fit with most residents.

Rob needs an accessible house

- Our son uses a large power wheelchair.
- Service Coordination Agency did not know who had accessible houses.
- Needle in a haystack.
- No new CILAs were being built. State not funding.
- Many agencies had no accessible homes.

What we found in visits

- Some CILAs were crowded.
- In poor condition.
- In questionable neighborhoods.
- Not truly accessible.
- Residents not a fit with our son.

What we encountered after visits

- Most agencies rejected our son.
 - No vacancies.
 - No accessible home.
 - “Couldn’t handle his needs.”
- Another issue is medical needs.
 - At most, a nurse visits a CILA once or twice a week.
 - Parent involvement is critical.

Finally found a CILA

- Nice house.
- Very accessible.
- But, 75 mile round trip.
- We can't understate difficulty of being far away.
- Day Program not a good fit.

18 months later

- Moved to another CILA 9 miles from us.
- New house in nice neighborhood.
- Good Day Program.
 - Other clients a better fit.
- However

We were surprised . . .

- CILA opened with less than full staffing.
- State's rate of under \$10/hr is a REAL problem.
- Continues to be a problem at \$10/hr.
- Quality of care has suffered.

Low pay rate=Problem for all agencies.

- Difficult jobs, with heavy responsibility.
- Very difficult to find caregivers.
- Can't compete with retail, fast food, Amazon, etc. wages.
- Inexperienced caregivers. Can't hire experienced caregivers.
- Difficult to enforce standards or give consequences.
- High turnover.

Day Program spillover

- Finding employees also a problem.
- Leaving to take higher paying jobs.
- Shortage of employees means-
 - Clients don't get to go out in the community every day.
 - Sometimes are stuck in the CILA all day.

Most CILAs are not set up to handle:

- Clients with extensive medical needs.
- Adults with CP who are non-verbal, but understand everything.
- These clients also present challenges for Day Programs.

What we learned

- Finding a good home will take time.
- After move-in, being sure it works takes even more time.
- Be prepared to stay involved.
- Visit often.
- Keep communication lines open.
- And . . .

It is an adjustment for all.

- You have to help your son or daughter adapt to new environment.
- Cannot expect it to be the same as the family home.
- Your son or daughter needs to learn how to work with caregivers:
 - If verbal, they need to speak up about their needs and wants.
 - They should not be intimidated by any caregiver.

A few parting words

- It is a difficult decision.
- But, what will happen after the parents are not around?
- It is a huge burden to wholly place on siblings.
- Some would say it is best to plan ahead and avoid having your son or daughter face grieving when the last parent dies and then face a move out of the family home at the same time.