**PacRim Conference**

**Comments for housing panel**

**March 4, 2019**

**Sue Berk**

Two years ago Barbara Poole Street, Val O’Brien and I all moms with adult children with intellectual and developmental disabilities (IDD) started asking the question, “What will happen to our kids when we can no longer care for them?” We are in our 60’s and 70’s our kids are in their 30’s and 40’s.

We live in east Honolulu. The kids were raised there, attended schools there, attend church and enjoy neighborhood restaurants, beaches and walks. They know and enjoy their community and people in the community know them.

We began researching and meeting with a variety of people and organizations to understand the issue.

We took two views of the situation:

1. What does it take for a family to find a place for their adult child with IDD? What is available and what is being planned for the future and by whom?
2. What would it take to be a provider? Barb wants to establish her home near KCC as a DD Dom Home also known as Group home.

What we learned surprised and disappointed us. The first surprise was that typically an adult with IDD has to wait 10 years for a placement in a group home or apartment. And that placement would likely be 20 to 30 miles away from our home community in east Honolulu. We were further surprised and disappointed to learn that no one – not Dept. Of Health, not Dept. of Human Services, no non-profit agency is managing a plan for the future. There is no plan for the future.

Our vision of the future includes:

* **Choice** – our adult dependent children with IDD are able to choose who they live with and to live in their home community
* A **partnership** with colleges and universities where students who need practicum hours in social work, PT, OT, Nursing are linked to our residents.
* Homes or facilities that provide short term temporary **Respite** services in addition to permanent living arrangements
* A rich circle of **partners** (churches, businesses, community groups, colleges) who support the residents through friendship, activities and experiences to live fuller lives in their community.
* To strengthen and support the ***Caregiver*** role to a desired, rewarding career path with attractive pay.

You might be wondering how many people need placement. How soon? In what neighborhoods? No one really knows. There is no official statewide wait list that we are aware of. No one person or group has the responsibility to address the issue.

Wanting to try to size the issue Barb, Val and I developed a survey questionnaire, got permission from Special Olympics to distribute the survey to families and caregivers during the State Games in November. Our kids are all on the Mighty Ducks Special Olympics team.

We had a good response and found that:

67% of responders say they ***will*** need housing for the person they care for

71% of the families have made ***no*** future care plans (many don’t have a clue where to start)

94% wish to live in their home community

45% will need a place to live within 10 years

25% of that number will need a place to live within 5 years

We recognize that this is a biased sample. All are Special Olympics participants whose parents or caregivers are able to take them to practices and tournaments and keep them involved. A much larger number of adults with IDD are not represented here. A larger, official study would be appropriate. The DD Council says they plan to conduct a broader survey this year. We hope that happens.

What ***might*** the statewide need look like?

From the 2016 RISP statewide list, we found that there are **1811** adults living at home with family under Medicaid Waiver. If we apply the percentages we found in our survey to this number:

67% 1213 will need housing

45% of 1213 = 545 within 10 years

Of that 545 - 17% or 93 within 5 years

*(545 beds needed within 10 years. Three people to a home = 182 homes needed or a combination of homes & apartment to care for 545 people.)*

*(Another 668 needed in more than10 years)*

These are additions to what exists today. Again, no one appears to be planning for this.

We have been working to educate ourselves and to raise awareness of the shortage of homes. We’ve talked with Dept. of health, DHS, OCHA, Catholic Charities, Hawaii Community Foundation, Hawaii Housing Finance and Development Corporation (HHFDC) and Developers and housing advocates.

One big challenge we’ve faced is ***access*** to people and information in state DOH and DHS. Reaching people is difficult – we call, they take a message and promise a call back; don’t call back; a week later we call again, take a message will call back, no call back. It has taken over a month sometimes two to get a call back. Or it has taken a personal friend of mine who works for the state somewhere else to personally ask that I get a call back.

I mentioned that Barb Poole-Street wants to establish her home as a group home. Learning of this shortage was a confirmation that she should get started. Her journey has been bumpy. She has been working for two years to license her home.

Barb’s EXPERIENCE:

After attending the required classes (8 days class + cost $450), paying zoning fees ($150) and wading through requirements, submitting the proper paperwork, she submitted her building plan for review. Two and a half months went by. No word. She called was told it was incomplete and needed to resubmit answering one question about bedroom size. Resubmitted. No word. No acknowledgment. Called a month later was told to wait. They would call when complete. Waited one more month. Called given a phone number to call. Wrong number/disconnected. Given another number – finally spoke with someone but that person only handled restaurants. Again Called OCHA spoke to a woman who said that the guy that started her review had left. There was no one to review her submission. After some discussion the women ended saying, “oh, you don’t really need to answer that. That’s no longer needed”. Even though the requirement was on the checklist. Three months lost due to incomplete, inaccurate and unorganized information.

**If this is going to be fixed several things need to happen**:

1. Better understand the need. Survey families and Caregivers to identify what the scope of the issue is. Who needs a home? When will they need it? What neighborhoods should they be in?
2. Establish a transparent, accessible application system for people wanting to be providers. Make requirements clear. And keep them updated. Provide information on reimbursement schedules EXAMPLE: We had a great meeting with someone from DOH last year. She explained Medicaid waiver funding and policies. We asked about budgets, actual dollars, so that we knew how to budget for the home Barb was planning – she said they didn’t handle that, DHS did. So we asked who at DHS we should talk to. She didn’t’ know. Apparently the two organizations operate in separate silos.
3. Create an “Office of Housing for adults with IDD”. Give them ownership to solve the problem. Plan for, design, build or renovate a sufficient number of homes or apartments.
4. Establish a website with comprehensive and organized information like the one Multnomah County, Ore has. EXAMPLE: On a national state by state listing of Medicaid waiver services, Hawaii didn’t even provide an answer to the question “How do I become a provider?” Most states gave a phone number to call. Hawaii left it blank.
5. We need to raise awareness and urgency around the issue. It is a HIDDEN problem. It is not visible like homelessness because parents/families continue to provide care. But parents are aging and it is much healthier for a person to deal with transition to a group home while parents are healthy. Rather than dealing with a death or critically ill parent + moving out of the family home.
6. Create change with policy makers in the legislature as well as state agencies.
7. Educate and empower families to be involved.
8. Engage and collaborate with for-profit, not for profit organizations & government to facilitate change.

We want planned integration rather than forced segregation.

We’d like to see possibility thinking happen. Can we create something that doesn’t exist today? What about pocket neighborhoods? A small community within a residential neighborhood where – some percentage – say, 20% of the units are for adults with IDD, other units for Vets or seniors, and or students. Intentional communities.

Perhaps a pilot project that asks for a loosening of Medicaid Waiver rules which would allow for a living arrangement where more than 3 – perhaps as many as 10 or 15 people with IDD lived in a town home community or a building with a gym/café/art studio open to ***public*** membership or access that keeps a connection to a community. The 3 maximum residents allowed in a group home is a good thought – but is that doable in this housing market with limited land and current housing costs?

To solve this we’ll need a combination of group homes, individual apartments, perhaps 4 bedroom apartment suites, etc. Different neighborhoods need different solutions.

There are many challenges. But there is also GOOD news. Medicaid is now paying about $100 a day per resident in a group home. This is in addition to the Social Security payments the resident brings with them to the home. This is good information that is not made available to potential providers.

To solve this we will also need a sufficient number of caregivers. We should work on elevating the care giver role to a desired, rewarding career that pays a good wage. Caregivers are more and more important to life in Hawaii – our entire population is aging fast. Let’s make this rewarding career choice more attractive.

Success would mean:

A Place to live in a person’s home community.

Sustained funding.

Adequate staff.

A connection to community.

If we improve access to both stakeholders and information and improve efficiency we really could begin planning for and creating supported residential solutions whether they be apartments, homes or small neighborhoods for our adults with IDD.