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Home Sweet Home???: Fixing Group Homes for Human Beings Who Have Special Needs

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INTRODUCTION

When I was five years old, doctors who evaluated me for my autism told my parents to put me in an institution for the rest of my life. The doctors saw no hope; they just saw me as something to be warehoused. My parents did put me in an institution, which was college. My lifelong pursuit to help others with special needs to be treated with dignity began when I went with a Christmas Carol choir to sing Carols at a state hospital ("institution"). I saw patients strapped to chairs; they were lethargic, drooling, and no staff were in the rooms to attend to them. Instead of singing, I had to fight back tears of sadness. I asked my mom, "Is this what doctors wanted you to put me in?" No person with special needs should have to live like that.

But my scholarly writing pursuit began on a drive home from a Special Olympics state softball tournament when some of my teammates who live in various residential group homes shared horror stories of their group home living situations. I realized that many residential group homes are not much better than the hospitals. Many special needs individuals are being treated inhumanely; more often than not, the licensing agencies that are supposed to be checking the places where the special needs individuals live do not find anything (because the custodians tend to hide the mess before inspection). Tragically, some group homes in my birth city of San Diego confine their residents and never allow those human beings to experience life outside of fences. Some of those facilities have staff who beat or neglect the people they are supposed to care for. Oftentimes, no one is standing for the residents.

In my lifelong fight for others with special needs, I have learned that the difference between being just another advocate and being a hero is the willingness to stand alone. A hero has to be willing to stand against an adverse larger group, or in some cases, a really powerful

antagonist who demands that the hero yieldingly shake his hand. When I am trying to convince the movers and shakers to be a part of the solution to help people with special needs, I have to be able to subdue them with kindness. One thing I have learned in law school and outside is if I can be collaborative and the most respectful person (but NOT kiss-ass) in the meeting, I can be the most influential. By showing respect, I can help others with special needs to get respect and dignity.

In writing this paper, the desire is to shine a light on residential care for the developmentally disabled, and call upon my readers to take action. But to do that, we have to understand history so we do not repeat mistakes; we must comprehend the things that are happening and how these influence each other so we can tailor solutions that meet the interrelated problems. This paper will cover the background about how group homes first came to exist in the 1950s and the institutional problems they were trying to fix. Then, the background will reveal the problems that creating group homes has not fixed. Next, the background covers the types of group homes and the requirements that group homes are supposed to meet. After the background section, the analysis will go into the main interrelated problems that include resident/staff relationships, lack of oversight and staff training, and the lack of state funding for group homes. Finally, I'll propose some solutions for the main problems.

To succeed in achieving quality of life for individuals with special needs who live in group homes, we must invest in and oversee the group homes more vigorously. We must also ensure group homes have competent staff who treat residents with respect, and that group homes have enough staff and other resources to meet residents' needs.

DEFINITIONS

Disability refers to "[a] physical or mental impairment that substantially limits one or more of the major life activities for such an individual."[1] "Disabled" addresses a diverse group of individuals, including people who have hearing, visual, cognitive, emotional, or other impairments.[2] I did not like the definition the author gave because the definition had the word "disabilities" in it.

"Qualified" individual means a disabled individual with high independent living skills who could live independently in supportive housing.[3]

Deinstitutionalization refers to the movement beginning in the mid-1950s to remove developmentally disabled individuals from state psychiatric institutions and place them into licensed group homes that could serve their needs better.[4]

Transinstitutionalization is a term for the failure of some group homes to be better than the state psychiatric institutions.[5]

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[1] Riley, Glenna, *The Pursuit of Integrated Living: The Fair Housing Act as a Sword for Mentally Disabled Adults Residing in Group Homes*, 45 Columbia Journal of Law and Social Problems 177, 181 (2011); *see also Glossary of HUD Terms, U.S. Dep't of Hous. & Urban Dev.*, http://www.disabled-world.com/disability/statistics/census-figures.php.

[2] *See id.*, *supra* note 1, at 181; *see also* Rehab. Research & Training Ctr. On Disability Statistics & Demographics, Annual Disability Statistics Compendium: 2010, 1 (2010), *available at* http://www.disabilitycompendium.org/Compendium2010.pdf; *see also* U.S. Dep't of Hous. & Urban Dev., Office of Policy Dev. & Research, Discrimination Against Persons with Disabilities: Barriers at Every Step 53 (2005) [hereinafter Barriers], *available at* http://www.huduser.org/Publications/pdf/DDS_Barriers.pdf.

[3] Americans with Disabilities Act, 42 U.S.C. §12132 (2006).

[4] *See* Riley, *supra* note 1, at 178; *see also* E. Fuller Torrey, Out of the Shadows 8, 85 (1997).

[5] *See id.*, *supra* note 1, at 185; *see also* Ira A. Burhim & Jennifer Mathis, *The Olmstead Decision at Ten: Directions to Future Advocacy*, 43 Clearinghouse Rev. 386, 391, (2009).

Supportive Housing is a kind of housing alternative with apartment housing units scattered throughout communities that allow residents to get help with living skills such as "cooking shopping, budgeting, medication management and making appointments."[6]

San Diego Regional Center is a "diagnostic, counseling and service coordination center for developmentally disabled persons and their families."[7]

Family Home Agency (FHA) is a private nonprofit company that the San Diego Regional Center vendors; the FHA oversees and "approves family homes which offers the opportunity for up to two adult individuals with developmental disabilities per home to reside with a family and share in the interaction and responsibilities of being a family" and to participate in the community.[8]

Special needs is another term for developmental disabilities.

BACKGROUND

A. Deinstitutionalization Movement…or was it Transinstitutionalization?

In the mid-1950s, the public recognized a vulnerable population was suffering segregation. Up to that point, developmentally disabled individuals were being warehoused permanently in state psychiatric institutions because of "negative social stigma toward such

[6] *See id., supra* note 1, at 186; *see also Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 304 (E.D.N.Y. 2009).
[7] 17 CCR § 56002.
[8] State of California Department of Developmental Services, Family Home Agency, (last visited Jul. 17, 2014), http://www.dds.gov/LivingArrang/FHA.cfm

individuals."[9] Because of who they were, people with disabilities were separated from society; that is one of the worst forms of discrimination. In 1955, the government sector began the "deinstitutionalization movement" and formed community-based housing so that developmentally disabled people would not have to live in psychiatric institutions separate from society.[10] Because the public sector could not operate all of such housing itself, "many states licensed private group homes in an effort to provide more humane treatment."[11] The purpose of having several group homes spread out through the community was to allow people with special needs to have greater scope of contact with the community.[12] It appeared the government was finally accomplishing something good for such a vulnerable population by helping people with developmental disabilities to find living environments more suited to their individual needs. At least that was the intention.

But many private group homes did not progress above the level of the psychiatric facilities preceding them.[13] Developmentally disabled individuals continued to be separated from society.[14] Even though the public had a desire to include people with special needs in society, the reformers forgot to put policies in place to prevent private group homes from being as inhumane as the state psychiatric institutions.[15] Politicians viewed the deinstitutionalization movement as a chance to cut public spending on state institutions, and they did not think about installing viable alternatives or how to oversee them.[16] States have adopted several different alternatives, such as

[9] Riley, *supra* note 1, at 182; *see also* Meghan K. Moore, Note, *Piecing the Puzzle Together: Post*-Olmstead *Community-Based Alternatives for Homeless People with Severe Mental Illness*, 16 Geo. J. on Poverty L. & Pol'y 249, 251 (2009).
[10] *See id.*, *supra* note 1, at 178.
[11] *See id.*, *supra* note 1, at 178; *see also* Arlene S. Kanter, *A Home of One's Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Disabilities*, 43 Am. U.I. Rev. 925, 928-929 (1994).
[12] *See id.*, *supra* note 1, at 202.
[13] *See id.*, *supra* note 1, at 178; Kanter, *supra* note 11, at 930-32.
[14] *See id.*, *supra* note 1, at 178; *see also Disability Advocates*, *supra* note 6, at 298-99.
[15] *See id.*, *supra* note 1, at 183; *see also* Torrey, *supra* note 4, at 85.
[16] *See id.*, *supra* note 1, at 183.

"licensing private group homes."[17] Group homes are permanent living areas where residents with disabilities are supposed to receive quality services. Some group homes provide sufficient housing, but many others operate under horrible conditions.[18] Because the sub-standard group homes are operated in a regimented manner, the residents living in them do not get individual choice; they are told when they HAVE to eat, bathe, and take medications.[19] In the sub-standard group homes, the residents are confined in a segregated area, and they do not get to socialize with others outside of the homes.[20]

Discrimination, abuse, and separation of people with special needs have not ended yet. John Talbott of the American Psychiatric Association coined a term for deinstitutionalization's shortcomings. He called it "transinstitutionalization", and said deinstitutionalization just moved "the chronic mentally ill patient…from a single lousy institution to multiple wretched ones."[21]

In 1990, the Federal Government tried to mandate that people with disabilities be allowed to integrate into the community. It enacted the Americans with Disabilities Act, which says "[n]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[22] The public entity is not allowed to institutionalize disabled individuals who are able to get treatment in the community.[23]

A glimmer of hope emerged in New York in a case called *Disability Advocates v. Paterson*. In that case, an advocacy organization challenged New York's housing policies as

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[17] *See id.*, *supra* note 1, at 184; *see also* Kanter, *supra* note 11, at 932.
[18] *See id.*, *supra* note 1, at 184; *see generally* Clifford J. Levy, *For Mentally Ill, Death, and Misery*¸ N.Y. Times, Apr. 28, 2002.
[19] *See id.*, *supra* note 1, at 184-185; *see also Disability Advocates*, *supra* note 6, at 298.
[20] *See id.*, *supra* note 1, at 185; *see also* Kanter, *supra*, note 11, at 392.
[21] *See id.*, *supra* note 1, at 186; *see also* Torrey, *supra* note 4, at 88 (quoting J.A. Talbott, Deinstitutionalization: Avoiding the Disasters of the Past, 30 Hosp. & Comm. Psych. 621, 621-24 (1979).
[22] *See id.*, *supra* note 1, at 188; 42 U.S.C. § 12132 (2006).
[23] *See id.*, *supra* note 1, at 189; *see also* Olmstead v. L.C. *ex rel*. Zimring, 527 U.S. 581 (1999).

unlawful against the Americans with Disabilities Act (ADA) for discriminating against mentally disabled adults. The court ordered New York to end such discrimination by ensuring that the group home adult residents can live in a more integrated environment like supportive housing.[24] Even though New York is a different state, and the case dealt with moving qualified individuals into supportive housing, that story represents the push toward having people with special needs being allowed to participate in the community. It represents the progress that can be possible for developmentally disabled individuals in San Diego, if people in San Diego would go beyond mere advocacy and act. We in San Diego need to do more to help individuals with special needs be a part of society. This paper will not concentrate in depth on supportive housing but instead on group homes. From 1955 to 1994, the number of state-institutionalized persons dropped to an eighth of the number before the movement.[25] But have the lives of those in group homes improved eight-fold? It does not appear that they have.

B. Types of group homes

There are two types of group homes.[26] These are Community Care Licensing (CCL) group homes and Intermediate Care Facility ("ICF") homes. The category of ICF homes designated for developmentally disabled individuals is Intermediate Care Facility Developmentally Disabled Habilitative ("ICFDDH").[27] CCL homes are funded by the San Diego Regional Center.[28] They have four levels of classifications based on levels of residents' needs

[24] *See id.*, *supra* note 1, at 179; *see also* Disability Advocates v. Paterson, No. 03-3209, 2010 U.S. Dist. LEXIS 17949, at 20 (E.D.N.Y. Mar. 1. 2010).
[25] *See id.*, *supra* note 1, at 183-184; *see also* Torrey, *supra* note 4, at 8 ("In 1955, there were 558,239 severely mentally ill patients in the nation's public psychiatric hospitals. In 1994, this number had been reduced by 486,620 patients, to 71,619….").
[26] Interview with Nancy Dow, Area Board XIII, in San Diego, Cal. (Jun. 16, 2014).
[27] *See id.*, *supra* note 26.
[28] *See id.*, *supra* note 26.

and care necessary to meet them.[29] The level also affects what minimum standards are required of a group home. Level 1 is the class of group homes with residents who just require board and care and do not need much other help.[30] They have self-help skills and do not have behavior issues.[31] "Their meals are prepared for them, but they can come and go as they please."[32] In Level 1 and 2 CCL homes, the residents are in charge of deciding when to go to the doctor.[33] In Level 2 homes, residents receive incidental training, they have some self-care skills, and have no serious behavior issues.[34] In Level 3 homes, residents have limited self-help abilities, and/or some physical mobility hindrances, and/or harmful or disruptive behavior issues.[35] In Level 3 and 4 homes, the staff are responsible for scheduling residents' doctor appointments, and the homes must also have designated doctors and nurses.[36] But the residents usually have Medicare or Medi-cal, and the selection of medical professionals is limited to those who accept such healthcare plans.[37] Level 4 homes have residents with the most intense needs, and this class of group homes has its own subdivisions depending on the severity of disabilities and how much staff is needed to handle the needs.[38]

Without going deep into the types of ICFDDH homes, these homes are funded through Medi-Cal and have different requirements than CCLs.[39] Types of ICFDDH homes have different acronyms identifying them as having basic nursing components, having large residential

[29] *See Community Care Facilities*, State of California Department of Developmental Services, (last updated October 23, 2007), http://www.dds.ca.gov/LivingArrang/CCF.htm
[30] *See id.*, *supra* note 26; *see also Community Care Facilities*, *supra* note 29.
[31] *See Community Care Facilities*, *supra* note 29.
[32] Interview with Nancy Dow, *supra* note 26.
[33] *See id.*, *supra* note 26.
[34] *See Community Care Facilities*, *supra* note 29.
[35] *See id.*, *supra* note 29.
[36] Interview with Nancy Dow, *supra* note 26.
[37] *See id.*, *supra* note 26; *see also Community Care Facilities*, *supra* note 29.
[38] *See id.*, *supra* note 26; *see also Community Care Facilities*, *supra* note 29.
[39] *See id.*, *supra* note 26.

facilities, or having more nursing needs.[40] To get into ICFDDH homes, residents have to have deficits in either self-care or behavior, or both.[41] Sometimes ICFDDH homes have about fifteen residents, but others have four. The ICFDDH homes that have about four residents ("diversion homes") are for individuals who have either come out of "developmental centers" and have intense needs, or are at risk of going into "developmental centers."[42] I believe "developmental centers" means state psychiatric hospitals.

C. Standards of group homes in San Diego

Group homes all have standards to abide by when caring for residents. Requirements for group homes depends on the type or level. ICFDDH homes have to meet the same regulations as nursing homes, violation of which can lead to financial consequences.[43] CCL homes have different standards to follow; CCLs that have violations found in inspections receive citations.[44]

Each resident in a group home should also have an Individualized Program Plan (IPP), which is a plan tailored to the individual with developmental disabilities.[45] In making an IPP, the people involved include the San Diego Regional Center client, the client's family members, SDRC staff, and anyone else who the client asks to be there to advocate.[46] The caretakers in the group home are supposed to have residents develop living skills (such as doing chores or cleaning up plates) and social skills, which would help those residents perform according to their

[40] *See id.*, *supra* note 26.
[41] *See id.*, *supra* note 26.
[42] *See id.*, *supra* note 26.
[43] *See id.*, *supra* note 26.
[44] *See id.*, *supra* note 26.
[45] *See id.*, *supra* note 26; *see also Services for Adults*, San Diego Regional Center, State of California Department of Developmental Services, (last visited July 17, 2014), http://sdrc.org/services
[46] *See Services for Adults*, San Diego Regional Center, State of California Department of Developmental Services, (last visited July 17, 2014), http://sdrc.org/services-for-adults

own IPPs.[47] A great group home is one that helps residents develop job skills through "pre-vocational" activities instead of just "babysitting" residents.[48]

For ICFDDH homes, one of the licensing requirements I find most important is "active treatment." The activities that are aimed toward helping residents medically and behaviorally constitute "active treatment."[49] Individual residents should receive fifty-six hours a week of staff members' efforts in helping them with medical needs and behavioral development.[50] Because active treatment appears to call for one-on-one attention by staff members toward the residents, it does not include activities that occur in a day program.[51] Active treatment can include nursing treatment such as repositioning a resident in a wheelchair or providing behavior treatment.[52] The main focus is for staff members to help residents develop health and wellbeing. To make sure ICFDDH homes are meeting residents' needs, licensing inspectors go in about once a year and do "surveys" that can take up to a week.[53] Here, surveys mean the inspectors observe the homes, visit the day programs, talk to the staff, look at active treatment, check nutrition, evaluate staffing patterns, etc.[54]

For CCL homes, one of the critical requirements is an adequate resident-to-staff ratio. Here it means CCL homes must have at least one staff member for every three residents.[55] Each CCL home has six residents.[56]

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[47] Interview with Nancy Dow, *supra* note 26.
[48] Interview with Martha Morrissey, Executive Director, Promising Futures, Inc., in El Cajon, Cal. (Jun. 23, 2014).
[49] *See id.*, *supra* note 26.
[50] *See id.*, *supra* note 26.
[51] *See id.*, *supra* note 26.
[52] *See id.*, *supra* note 26.
[53] *See id.*, *supra* note 26.
[54] *See id.*, *supra* note 26.
[55] Interview with Martha Morrissey, *supra* note 48; *see also* 22 CCR §85065.5.
[56] *See id.*, *supra* note 48; Interview with Mark Sanchez, in El Cajon, Cal. (June 28, 2014).

Also, group homes' managing agencies are required to provide staff with training in three areas: CPR, first-aid, and Crisis Prevention (CPI) training.[57] CPI is especially important for Level 4i CCL homes because residents in those homes tend to have the most severe behavioral issues.[58] CPI offers training in seminars, workshops, certification programs, and on-site sessions.[59] The purpose of CPI is to train staff to diffuse conflicts without any crises becoming more dangerous.[60]

Along with requirements that California imposes for ICFDDH homes or CCL homes, the group homes add their own regulations. Private homes "appoint their own directors, control their own finances, hire and fire their own employees, and develop their own treatment programs."[61]

Physical or recreational activities opportunities vary between group homes. Ideally, a lot of exercise is built into the schedule.[62] Some group homes have stationary bikes and treadmills.[63] I visited an El Cajon group home called Promising Futures, Inc. so I could see what a group home looks like; I also interviewed Martha Morrissey, the executive director at Promising Futures, Inc. After my interview at Promising Futures, Inc., I saw an exercise room in the building with a treadmill and a stationary bike. During my interview at Promising Futures, Inc. Martha showed me a January 2014 chart of one of the three Promising Futures group homes. Every Sunday, they go to church and they participate in a breakfast outside of the group home. Every weekday there is something different. Because a group home is supposed to function like a home, good group homes allow residents to have a meeting so they can vote on activities they

[57] *See* Interview with Mark Sanchez, *supra* note 56.
[58] *See* Interview with Mark Sanchez, *supra* note 56.
[59] *See Nonviolent Crisis intervention: a CPI specialized offering*, cpi, 2, (reprinted 2012).
[60] *See id.*, *supra* note 59, at 1.
[61] Dept. of Health & Human Services v. Chater, 163 F.3d, 1129, 1131 (9th Cir. 1998).
[62] Interview with Nancy Dow, *supra* note 26.
[63] *See id.*, *supra* note 26; *see also* Interview with Martha Morrissey, *supra* note 48.

want to do and places they want to go.[64] This voting process is especially important because staff members have to take residents in groups to maintain adequate supervision.

In group homes, whether a resident participates in activities in the community should only depend on that individual's behavior. During the interview at Promising Futures, Inc., Martha told me that residents get into the community if they are good, and that on Fridays and Saturdays, residents who could get through the week without any behavioral outbursts got to go to the county fair.[65] She also told me about a "points-outing" reward system, in which residents collect good behavior points and use them on things like going to a nice restaurant.[66]

Even though group homes have regulations and statutory requirements to meet, these standards are not always being met. The reasons for this come in a mixed bag of inter-related problems. These issues include resident-staff dynamics, lack of oversight and staff training, and lack of financial resources for group homes.

ANALYSIS

A. PROBLEMS:

1. Resident-staff dynamics

a. Imbalance of resident-to-staff ratios

It really matters how much staff the group homes have. Group homes need to have enough staff members so they can meet the resident-to-staff ratio requirements and so they can give individual attention to meet residents' needs better.

[64] Interview with Martha Morrissey, *supra* note 48.
[65] *See id.*, *supra* note 48.
[66] *See id.*, *supra* note 48.

It is also important for group homes to have more staff members so the employees can monitor each other and their interactions with the residents. In my interview with Martha, she emphasized two things: gender and numbers of staff. A group home should never leave a male staff member alone with female residents; a female employee should always be present when there are female residents.[67] This rule's purpose is to prevent sexual assaults by the staff on the residents. The same kind of rule might apply for female staff members and male residents. Also, higher numbers of staff helps decrease the risk of improper employee conduct because they would be in position to monitor each other.[68] Generally, there is power in numbers.

One problem that may impact the ability to maintain staff numbers is turnover. A major factor and concern for employees has to do with wages. This will be discussed in the third analysis problems point, which addresses the lack of financial resources for group homes.

Another influence that may not be as common but still important is termination. I agree that quality control is important, and that the employees who engage in repeated misconduct or who make errors a lot need to be fired. But, we should not fire staff too quickly for honest one-off mistakes. Taking an opportunity to retrain employees who make infrequent mistakes is less costly than trying to find and train new employees.[69] As long as the infrequent mistakes do not pose a threat to residents' health or wellbeing, employees should not be terminated quickly. The times in which firing is appropriate include existence of high gravity of danger to the residents, injury to residents, or repeated errors.

One other variable affecting the resident-to-staff ratio is whether the staff members show up for their shifts. Group home employees operate in shifts. If some staff do not come to the

[67] *See id.*, *supra* note 48; *see also* Interview with Mark Sanchez, *supra* note 56.
[68] *See id.*, *supra* note 48.
[69] Interview with Mark Sanchez, *supra* note 56.

group homes for their shifts, that makes it more difficult for group homes to meet the staff gender and numbers requirements.[70]

The people who suffer the most from low numbers of staff members are the residents. If there are not enough staff to go out, this limits the extent of activities that residents can engage in within the community.[71] Instead of being able to satisfy all residents' activity desires, group homes would end up sending one group of residents who go out and another group that stays at the home, and the activities might not be everyone's first choice.[72] Or if the employee numbers are very low, the residents may likely not get out at all. Some group homes with low staff numbers and/or lack of transportation only take residents out into the community once a year.[73]

b. Staff treatment (or mistreatment) of residents

From the interview with Martha Morrissey, I could infer the biggest difference between Promising Futures, Inc. and many other group homes is staff treatment of residents. Few group homes concentrate on making positive relations between staff and residents. She devoted a lot of time to talking about having staff who enjoy working at Promising Futures group homes, and why she decided to manage group homes. She did not like the way other group homes were operating, so she has been managing group homes for twenty-eight years since.[74] She told me she only retains staff members who enjoy working at the group homes and are available at least five days a week;[75] she has fired people who did not measure up.[76] Even though how quickly staff members who are underperforming should be let go is debatable, the focus on having staff

[70] *See* Interview with Mark Sanchez, *supra* note 56.
[71] Interview with Nancy Dow, *supra* note 26.
[72] *See id.*, *supra* note 26.
[73] *See* Interview with Mark Sanchez, *supra* note 56
[74] Interview with Martha Morrissey, *supra* note 48.
[75] *See id.*, *supra* note 48.
[76] *See id.*, *supra* note 48.

members who put the residents' interests first is a compelling one. This is also likely why Promising Futures, Inc. has staff train twelve hours per month instead of just the federally mandated twelve hours per year.[77] To be able to meet the residents' needs, staff members need to devote themselves.

Healthcare is another area in which many group homes and their employees fall short. For one, many group homes either are slow to make medical appointments or do not make them at all. Even CCL Level 3 and 4 homes tend to be deficient in this area. In one story, a resident's visiting physician had ordered twice for the resident to get treatment.[78] For almost seven months, that resident's "caretakers" at Casa Real did not acquire the proper medication for the resident.[79] An inspector who visited the home noted that the licensee repeatedly failed to make appointments for the resident whose eye was having trouble, and because of that, the resident lost an eye.[80] Casa Real did not make a correction plan.[81] The article that posted this story also listed other ones. Even though the stories were about assisted living homes, the healthcare problems also occur in group homes for people with developmental disabilities. The previous agencies that Martha has dealt with – either as an employee or as an advocate for her daughter – have had sub-standard health care for residents.[82] Martha's daughter's grooming needs were not being met by the group home she was living in; her hair would sometimes be mangled and unwashed, or the shampoo would not be completely rinsed out.[83] Because she also has a seizure disorder, Martha's daughter was prescribed seizure medication.[84] One day, after taking her

[77] *See id.*, *supra* note 48.
[78] *See* Schoch, Deborah & McDonald, Jeff, *Medical Errors Plague Care Homes*, U-T San Diego, 4, (Dec. 17, 2013), http://centerforhealthreporting.org/article/medical-errors-plague-care-homes
[79] *See id.*, *supra* note 78.
[80] *See id.*, *supra* note 78.
[81] *See id.*, *supra* note 78.
[82] Interview with Martha Morrissey, *supra* note 48.
[83] *See id.*, *supra* note 48.
[84] *See id.*, *supra* note 48.

medication, she threw up in the shower, and the group home employees did not give her new medication; she had a seizure.[85] Martha filed a formal grievance with the licensing agency about the group home that her daughter was in. Martha ended up pulling her daughter out of that group home.[86] As Mark Sanchez – an interviewee who has managed group homes and now runs a family home under a family home agency – told me, the residents are fine, but the staff members in group homes tend to be the problem.[87]

2. Lack of oversight and staff training

Staff treatment (or mistreatment) of residents happens because of a lack of oversight and because training is either deficient or non-existent. Poor oversight by employees or lack of training for employees is what leads to most of the injuries or deaths in California assisted living homes,[88] and probably in group homes too.

a. Who do you believe?

Oversight by managers of employees tends to be deficient because staff members may think the managers have to believe the employees instead of residents.[89] In other words, employees may think that they are more credible because they are in position of power. A fellow Special Olympics athlete, Randy Smith, told me about a previous group home in which he had stayed. In that home, his roommate kept stealing from him, and Randy eventually caught him stealing.[90] Randy talked to the group home manager, but the manager did nothing.[91] Even though

[85] *See id., supra* note 48.
[86] *See id., supra* note 48.
[87] Interview with Mark Sanchez, *supra* note 56.
[88] *See* Schoch, *supra* note 78, at 5.
[89] Interview with Mark Sanchez, *supra* note 56.
[90] Interview with Randy Smith, Special Olympics athlete, in El Cajon, Cal. (Jul. 12, 2014).
[91] *See id., supra* note 90.

Randy's roommate was the one stealing, the employees and manager were the bigger problem because they allowed the thefts to continue by failing to act. The staff members and manager in that group home decided to put their own convenience ahead of residents' wellbeing.

The bias favoring staff members is a problem, especially when the residents involved in disputed events are nonverbal, because nonverbal residents are less able to share their side of what happened. This is one way in which bad employees cover up their own misconduct; they target people who cannot advocate for themselves.

b. Cover-up

Much misconduct goes unnoticed because many group homes do not report abuses or errors.[92] Dropping medication is an example of a medical error. Martha told me that Community Care Licensing said Promising Futures, Inc. is the only group home agency in San Diego that reports medical errors.[93] If that is true, that is clearly a catastrophic healthcare problem because most group homes are putting their own public appearances ahead of residents' safety. Analogously, medical errors are common in assisted living homes for seniors. In those homes, "at least 80 times in recent years, employees at San Diego County assisted living homes overlooked serious medical issues, gave the wrong medication or otherwise failed to properly care for vulnerable seniors."[94] In September, reporters from news companies revealed 27 deaths from injuries and neglect at the assisted living homes.[95] This problem is not exclusive to assisted living homes. Family members of the residents are often not told when employees make errors.[96]

[92] Interview with Martha Morrissey, *supra* note 48.
[93] *See id.*, *supra* note 48.
[94] *See* Schoch, *supra* note 78, at 1.
[95] *See id.*, *supra* note 78.
[96] *See id.*, *supra* note 78, at 2.

The California Department of Social Services (CDSS) – the parent organization of Community Care Licensing – stashes the findings away and forgets about them.[97] CDSS does not publicize its findings.[98] Family members often do not find out about a home's long history of violations and deficiencies until much later.[99] Another aggravating part of cover-up is that fines are inadequate to shape behavior. If a resident dies in an assisted living home or a group home due to an error, the home just gets cited for a violation and fined a maximum of $150.[100] If deficient group homes see an opportunity to profit from their lackluster care for residents, they are going to do so.

Here is another instance of cover-up; Martha told me some group homes do not send their residents to Promising Future Inc.'s day program because they know that Promising Futures, Inc. will report things about the other group homes.[101] This is disturbing because the deficient group homes are hiding dirty laundry and depriving residents of opportunities to be in the community.

c. Tragic consequences of turning a blind eye

Offenders benefit from the lack of enforcement. I do not know to what extent background checks are done on residential care staff members. But I do know that physical abuse, neglect, medical errors, and even death resulting from these, have been happening in a lot of group homes. In Connecticut in 2004-2010, state officials noted that seventy-six developmentally disabled group home residents died because of cited "abuse, neglect, or medical errors."[102] Most

[97] *See id,. supra* note 78.
[98] *See id., supra* note 78, at 3.
[99] *See id., supra* note 78, at 2.
[100] *See id., supra* note 78.
[101] Interview with Martha Morrissey, *supra* note 48.
[102] *See* Diament, Michelle, *Senator Seeks Federal Probe Of Group Homes*, Disability Scoop, 1, (Mar. 6, 2013), http://www.disabilityscoop.com/2013/03/06/senator-seeks-federal-probe-of-group-homes/17441/print/

of those deceased individuals were residing in privately-run group homes.[103] Similar cases emerged recently in "Virginia, New Hampshire, Massachusetts, Louisiana, and Texas."[104] In looking at such stories, Senator Chris Murphy of Connecticut started pushing for a federal investigation of private group homes for the developmentally disabled nationwide.[105] Although other advocates have suggested Murphy also look at "state-run facilities and family settings",[106] the article makes clear that "too many…bad actors"[107] throughout the country are mistreating developmentally disabled human beings.

d. Training process needs to be better

The training process is very deficient. What often happens with the training meetings – if the group home agencies even conduct those – is the meetings are held, but the quality of the training is lackluster.[108] Staff usually do not get the training needed to operate in group homes, they just get certificates.[109] Even if group home employees ask for follow-up training sessions, the agencies typically just do not follow up; group home employees have to get training from external classes.[110] Even though it costs a lot of money to train group home employees, the group home agencies are supposed to be holding the training sessions and making sure the quality of training complies with regulations.[111] Another benefit of having group home agencies provide quality training sessions is the group home employees can put the training into context more easily. This leads to another point about the quality of the training sessions. In some meetings,

[103] *See id.*, *supra* note 102.
[104] *See id.*, *supra* note 102.
[105] *See id.*, *supra* note 102.
[106] *See id.*, *supra* note 102.
[107] *See id.*, *supra* note 102.
[108] *See* Interview with Mark Sanchez, *supra* note 56.
[109] *See id.*, *supra* note 56.
[110] *See id.*, *supra* note 56.
[111] *See id.*, *supra* note 56.

the instructor is just lecturing the students about a cookie-cutter format instead of providing an interactive learning experience.[112] If the training sessions would be interactive, then the trainees would learn more than just twenty percent of the material.[113] Interactive learning would also help trainees learn how to interact with the group home residents.

Because many developmentally disabled residents do not have much verbal communication skills, they struggle to advocate for themselves. They have to rely on others speaking for them to meet their needs. As a person with autism who had no verbal language until age seven, I had to trust other people to speak for me. My parents and teachers developed communication strategies so they could understand what I would try to tell them. This helped me to feel like I had some control over my own life, and to keep me from feeling isolated. I also have some Special Olympics teammates who do not speak verbally; my coaches and I have communication strategies with them so we can decipher what they want, have them understand what we would like them to do, and help them develop their abilities individually. Education can happen when the teachers and aides tailor teaching methods to the individuals, and the people involved develop trust. That is why it is especially critical that staff members caring for developmentally disabled individuals learn how to learn what the residents' needs are and understand the importance of trust. The solutions section will cover some ideas for improving the training process more in depth.

3. Lack of financial resources for group homes

The financial constraints on group homes are getting tighter, making it more difficult for the homes to meet their residents' needs. For one, the government did not think thoroughly about

[112] *See id., supra* note 56.
[113] *See id., supra* note 56.

the consequences of raising wages and salaries.[114] While minimum wage may increase and food is becoming more expensive, the financial support from governmental agencies to group homes has not increased for years.[115] This makes it harder to retain staff and maintain an acceptable resident-to-staff ratio. Promising Futures group homes try not to "skimp on food."[116] Another thing that many group homes struggle with is securing transportation. As if acquiring vehicles was not already hard, buying auto insurance and finding qualified drivers are very difficult tasks.[117] Auto insurance can be expensive. Finding drivers for the vans is even tougher. Drivers for group homes have to be at least twenty-six years old and have no traffic tickets.[118] The availability of qualified drivers is low.[119] Not having drivers to drive the vans severely limits group home residents' access to the community.

A lot of times, Promising Futures, Inc. spends more than the company takes in because it is trying to maintain excellent care for the residents. I do not know how the shortfall is being met, or if it is. But group homes and their residents need more help. Instead, a hefty amount of funding has been going to the state psychiatric hospitals, several of which have been shoddy. Martha claimed the state institutions have twelve residents for every one staff member.[120] This would make individualized care virtually impossible. Even though a different article reported that each resident in California's major board-and-care state institutions outside of San Diego has roughly 2.5 staff,[121] this does not mean the residents are getting developmental care. "Some patients have spent decades in the [institutions], from childhood to death. Some cannot form

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[114] Interview with Martha Morrissey, *supra* note 48.
[115] *See id.*, *supra* note 48.
[116] *See id.*, *supra* note 48.
[117] *See* Interview with Mark Sanchez, *supra* note 56.
[118] *See id.*, *supra* note 56.
[119] *See id.*, *supra* note 56.
[120] *See* Interview with Martha Morrissey, *supra* note 48.
[121] *See* Gabrielson, Ryan, *Sloppy Investigations leave abuse of disabled unsolved*, California Watch, 1 (Feb. 23, 2012), http://californiawatch.org/print14971

words and have IQ scores in the single digits."[122] Abuse cases also increased by forty-three percent in the 2008-2010 period, and unexplained injuries cases also jumped eight percent in that same period.[123] Such problems also continued to rise in 2012, even though hundreds of developmentally disabled individuals were moved from the institutions to group homes.[124] These cases included "unexplained injuries [such as] deep cuts on the head; a fractured pelvis; a broken jaw; [broken] ribs; shins and wrists; bruises and tears to male genitalia; and burns on the skin the size and shape of a cigarette butt."[125] Even more disturbing, in 2012, California set its budget to allocate $577 million in the fiscal year to run the five board-and-care institutions (in Los Angeles, Riverside, Orange County, Tulare, and Sonoma), or about $320,000 per patient.[126] Also disgustingly, most of the abuses and "unexplained injuries" go unnoticed or unpunished because Office of Protective Services (OPS) investigators are slow to start investigating, and institutions staff hide the evidence by the time the investigators show up.[127] In April 2010, a janitor in the Canyon Springs Developmental Center in Riverside sexually abused a female patient.[128] OPS investigators visited the center but did not arrest anyone; state regulators also visited the center and cited the center for sexual abuse.[129] In December 2010, public health officials fined the center $800 for the sexual abuse.[130] That is the only penalty the center got for the sexual abuse. This means the female human being was deprived of real protection. The lackluster care for the patients and the grossly high budget means California decided to pay $577 million just to imprison developmentally disabled individuals and deprive them of protection.

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[122] See *id.*, *supra* note 121.
[123] See *id.*, *supra* note 121, at 2.
[124] See *id.*, *supra* note 121.
[125] See *id.*, *supra* note 121.
[126] See *id.*, *supra* note 121, at 1.
[127] See *id.*, *supra* note 121.
[128] See *id.*, *supra* note 121, at 4.
[129] See *id.*, *supra* note 121.
[130] See *id.*, *supra* note 121.

Also startlingly, staff members in state institutions make $16 per hour – double in wages than the group home staff members who are not on salary – and the living conditions for special needs individuals in the hospitals are worse.[131] Even though higher wages may be an incentive for people to keep working at the places, this does not guarantee the quality of the work is going to improve. Five other state hospitals for developmentally disabled people were inspected; because they had violations, they lost state funding.[132] Four million dollars in four months were wasted on state institutions that ended up getting inspected and then decertified.[133] To make matters worse, the state institution administrators have been making too much money in salaries; $500,000 each to be exact.[134] Some significant residuals have been lining the pockets of administrators who are not doing enough to improve patients' wellbeing. Some of that money should have been spent on paying for hospital staff to get better training to meet residents' needs.

In summary, we are focusing too much on keeping big sinking ships afloat, and not enough on preparing smaller rescue vessels that could *potentially* save the passengers. Smaller vessels would mean the group homes, and Family Home Agencies (FHAs) – another alternative worth mentioning in the solutions section.

B. SOLUTIONS:

I am not saying group homes are perfect compared to state psychiatric institutions; many group homes are sub-standard. But there are two things the government should do simultaneously to make sure the money for group homes is well spent. First, the government

[131] Interview with Martha Morrissey, *supra* note 48.
[132] See *id.*, *supra* note 48.
[133] See *id.*, *supra* note 48.
[134] See *id.*, *supra* note 48.

must improve oversight of group homes and of staff training. Second, the government must increase financial resources for the group homes.

1. Improve oversight of group homes and of staff training

This approach is critical because it considers the quality of the services. Without checking the quality, increasing financial resources would be practically useless. Earlier this year in San Diego, county officials started an effort to reform elder care for assisted living center residents.[135] The approach that officials took this year with elder care should serve as a useful guide for improving adult residential care for individuals with developmental disabilities. The approach includes "increasing oversight staff, focusing prosecutions and partnering to offer more site-specific information for consumers."[136] This means capacity for oversight would be greater, victimized residents would have real protection, and consumers and their families would be able to learn more about the sites. All of these are critical for consumers' safety and wellbeing.

Regarding oversight and information about homes, county supervisors started working with the Better Business Bureau (BBB) to "make a rating system for assisted living homes so families will have more confidence in the decisions they make for their elderly relatives."[137] A rating system for group homes that house people with developmental disabilities would be enormously helpful because families looking for a group home have a difficult time finding one to trust with their loved ones' lives.

As for criminal prosecutions, District Attorney Bonnie Dumanis began a project to focus on "prosecuting crimes inside assisted living homes – neglect and abuse incidents that regularly

[135] McDonald, Jeff, *County Approves Care-Home Reforms, Center for Health Reporting*, 1, (Mar. 12, 2014), http://centerforhealthreporting.org/article/county-approves-care-home-reforms
[136] *See id., supra* note 135, at 1.
[137] *See id., supra* note 135, at 1.

go unpunished by state investigators."[138] The state police agency in charge of investigating crimes in assisted living homes had "not made an arrest since 2004."[139] This means for at least ten years, residents in assisted living homes or group homes had not had any real protection against neglect, abuse, or medication errors.

On the state civil investigation side, county supervisors voted for the Residential Care Facilities for the Elderly (RCFE) Reform Act of 2014.[140] It is a set of bills that would increase the maximum for violations fines, mandate more-frequent homes inspections, make state investigators respond to complaints about homes faster, and "require licensees to buy liability insurance."[141] The state would attend to the residents more quickly; the boost in fines and the purchase of liability insurance would help discourage group homes from violating the residents. Even though these bills were written for assisted living care, the key set of hearings were scheduled for February, and the budget and update for the BBB rating system are due at the end of 2014,[142] I am confident the methods in the bills would be well-suited for adult residential care for people with special needs.

Another useful method to improve care for people with special needs is to improve the training. Along with having group home agencies provide training sessions and ensure that trainees are actually getting the basic requirements in the meetings, trainees should take classes in subjects such as special education and disabilities. This would help trainees to learn about various kinds of disabilities, and how to connect with people who have special needs. This is not preaching a systematic set of stages; one size does not fit all. The mission of the classes would be

[138] *See id.*, *supra* note 135, at 1.
[139] *See id.*, *supra* note 135, at 1.
[140] *See id.*, *supra* note 135, at 2.
[141] *See id.*, *supra* note 135, at 2.
[142] *See id.*, *supra* note 135, at 2.

to emphasize to trainees that the trainees need to develop trust with the individual residents and to form individualized communication strategies that are tailored to the residents. Having more group home employees who work with residents individually on communication and other social skills helps people with special needs to have dignity.

2. Increasing financial resources for group homes

In this approach, one of the methods is to allocate more money to the group homes instead of state institutions. Even though the sub-standard care for the patients in institutions would likely suffer even more in the short term, reallocating funds to group homes would help group homes to hire and train more staff and to purchase more vehicles to take residents into the community. Group home companies with additional trained staff can open more group home locations and accept more residents, including those who have been living in state institutions.

3. Family Home Agency option

An alternative solution instead of group homes would be to allocate more money to family home agencies. Family homes can accommodate up to two individuals with special needs. This means the ratio of homeowners to people with special needs is 1-2 or 1-1; it is easier for family homes to meet residents' individual needs.[143] This also means caretakers have less paperwork to do, and they keep weekly time logs instead of daily logs.[144] In addition, licensing requirements and regulations are more lenient for family homes than group homes.[145] But family homes still meet basics, like having insurance, a fire extinguisher, first-aid, and certification.[146]

[143] *See* Interview with Mark Sanchez, *supra* note 56.
[144] *See id.*, *supra* note 56.
[145] *See id.*, *supra* note 56.
[146] *See id.*, *supra* note 56.

With greater ratios and less restrictions, family home caretakers can devote more time to developing residents' self-care skills and behavioral skills, and help them to become higher-functioning. Behavioral development includes forming communication strategies, maintaining proper dining etiquette, doing chores, and acquiring job skills.[147] Speaking of job skills, family home residents are allowed a certain amount of hours to get out into the community on their own, and some residents are employed.[148] This is the ultimate skill development because people with special needs learn independence. Family home residents are also allowed up to 2-4 hours alone at the homes.[149] Part of learning responsibility is understanding that there are consequences for bad behavior. Here, if a resident misbehaves – at a job or at home or elsewhere – the family home caretakers just will not drive the residents out into the community.[150] Individuals with special needs are still free to find other ways to get into the community, such as riding a bus.[151] This means family home caretakers can refuse to drive the residents for misbehaving without taking away access into the community. The residents in Mark Sanchez's family home are following the house rules better because they are recognizing the importance of maintaining trustworthy relationships as part of independent living.[152] If residents show trustworthy behavior, the caretakers reciprocate trustworthiness by accommodating the residents' societal needs.

In group homes or family homes, trust between residents and caretakers is the key to guaranteeing that people with special needs have dignified lives.

[147] *See id.*, *supra* note 56.
[148] *See id.*, *supra* note 56.
[149] *See id.*, *supra* note 56.
[150] *See id.*, *supra* note 56.
[151] *See id.*, *supra* note 56.
[152] *See id.*, *supra* note 56.

CONCLUSION

To achieve quality of life for people with special needs living in group homes, we must devote more to group homes and watch the homes more closely. We must raise the numbers of staff and resources for group homes, and train staff more thoroughly, so residents will have their needs met and receive respect. Accomplishing these things will allow the deinstitutionalization movement to be the liberating venture it should have been for special needs human beings trying to get out of state psychiatric hospital imprisonment. Although these tasks will be a hard challenge, pursuing this mission courageously will help people with special needs to integrate into society and to live dignified lives.