

**HIGH QUALITY
LIVING OPTIONS FOR
YOUNG ADULTS
WITH MODERATE TO
SEVERE AUTISM**

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WHO
ARE WE
TALKING
ABOUT?

MODERATE TO SEVERE AUTISM

- ◉ **Proposed DSM-5 Severity Level Descriptors**
- ◉ **Level 2**
- ◉ **Requiring Substantial Support**
 - Marked deficits in v/nv social communication
 - Social impairments apparent even with supports in place
 - Limited initiation of social interactions
 - Reduced or limited response to social overtures from others
 - RRBs and/or fixed interests are frequent and noticeable to a lay person; interfere with functioning in multiple contexts
 - Distress when RRBs interrupted; difficult to redirect from fixed interests

MODERATE TO SEVERE AUTISM

- ⦿ **Proposed DSM-5 Severity Level Descriptors**
- ⦿ **Level 3**
- ⦿ **Requiring *Very Substantial Support***
 - Severe deficits in v/nv social communication severely affects global functioning
 - Very limited initiation of social interactions
 - Minimal response to social overtures from others
 - RRBs markedly interfere with functioning in ALL areas
 - Marked distress when RRBs and routines are interrupted
 - Very difficult to redirect from fixed interests; returns to RRBs and fixed interests quickly after interruption

MODERATE TO SEVERE AUTISM

- ◉ **Additional Challenging Behaviors**
- ◉ Aggression - at times extreme
- ◉ Self-injurious behaviors

WHAT SHOULD
LIVING
ENVIRONMENTS
ADDRESS?

KEY BEHAVIORAL CHALLENGES THAT LIMIT COMMUNITY INTERFACE

- ◎ **Peter Gerhardt, Ed.D.**

- ◎ “There are few skill excesses or deficits that the community-at-large cannot be taught to accept or tolerate.”

- ◎ They are:

- Extreme aggression/self-injury
- Inappropriate eating/mealtime behavior
- Inappropriate toileting/restroom use
- Inappropriate sexual behavior
- Poor hygiene

LIMITED VALUE FUNCTIONAL SKILLS

- Often at the expense of addressing these key challenges, programs focus on teaching easier to produce skills which are functional in less severe populations, but have little effect on quality of life for people with moderate to severe Autism:
 - Sorting, collating, assembling
 - School-based activities vs. Community-based activities
 - Nonfunctional academics (horse vs. zebra) [Peter Gerhardt]

QUALITY

OF

LIFE

QUALITY OF LIFE

- ⦿ A Definition
- ⦿ A major study by the Centre for Health Promotion of the University of Toronto, published in 1997, defined Quality of Life as:
- ⦿ **“...the degree to which a person enjoys the important possibilities of his or her life.”**

QUALITY OF LIFE FOR THOSE WITH MODERATE TO SEVERE AUTISM

- Nonverbal people with higher QOL were associated with:
 - having an occupational activity of some kind
 - not having marked behavior problems
 - having leisure activities in community
 - having community access
 - being more independent
 - making own decisions
 - having opportunities available from which decisions can be made
 - having practical support from other people
 - having emotional support from other people

WHAT SHOULD LIVING ENVIRONMENTS ADDRESS - REVIEW

- ⦿ Key Behavioral Challenges That Limit Community Involvement
- ⦿ Quality of Life
- ⦿ Self-determination
- ⦿ Community Education

THE PROUST QUESTIONNAIRE

The Interactive Proust Questionnaire | Vanity Fair - Windows Internet Explorer

http://www.vanityfair.com/culture/features/proust-questionnaire

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Kindergarten at CHIME Los Angeles Unified School ...

Gimme Shelter: Housing for A... The Interactive Proust Q...

0/20 QUESTIONS ANSWERED

10

10. When and where were you happiest?

11. If you could change one thing about yourself what would it be?

12. If you could change one thing about your family what would it be

◀ PREVIOUS QUESTION | NEXT QUESTION ▶

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THE PROUST QUESTIONNAIRE

- ◉ #10: When and where were you happiest?
- ◉ 47 year old man with Autism who was playfully answering the Proust Questionnaire with a housing program staff member at The Help Group's Project Six Adult Residential Program answered:
- ◉ **“Three years ago when I came to live here.”**
- ◉ That's a testament to **QUALITY OF LIFE.**

OTHER COMPONENTS OF QUALITY LIVING FOR THOSE WITH SEVERE AUTISM

- ◉ Emphasis on Self-determination
- ◉ Well-trained staff; Supervision by BCBAs
- ◉ Use of evidenced-based treatments such as ABA
- ◉ Recreational Opportunities
- ◉ Socialization Opportunities
- ◉ Support for Establishing Meaningful Relationships
- ◉ Community Education

LIVING OPTIONS

CALIFORNIA ADULT RESIDENTIAL OPTIONS

- ◉ Harbor Regional Center’s “It’s All About Options: Living Alternatives for Adults with Developmental Disabilities.”
 - http://www.harborrc.org/sitemanager/assets/pdfs/1_52_FF32EFC951D1B405707D2D833FE939E2.pdf

What Kinds Of Living Options Are Available?

Adults with a developmental disability have more living options to choose from now than ever before. Your relative can continue living in the family home. If he wants to live away from the family but doesn’t want to be on his own, he might want to try living in a licensed home. If he wants to be more on his own than is possible in a licensed home, however, he can choose to live with some supports in an apartment, a condo, or a house. He may live alone, or with one or more friends or roommates, or with a loved one. Let’s take a closer look at some of these options.

LIVING OPTIONS

- ◉ Stay at home

- ◉ Licensed homes
 - Community Care Licensed Group Homes (e.g. ARFs)
 - Department of Public Health Intermediate Care Facilities (i.e. ICFs)

- ◉ Supportive Living
 - Home Ownership for Personal Empowerment (HOPE)
 - <http://www.hope-homes.org/home>

THE HELP GROUP'S PROJECT SIX

- The Project Six Adult Residential Group Homes are classified as ICF-DD/H, which stands for “Intermediate Care Facilities for the Developmentally Disabled-Habilitative.”
- The homes are long-term care facilities, funded by Medical and are licensed independently by the California Department of Public Health.
- The homes provide a cozy, home-like environment with an emphasis on family involvement.
- Project Six is dedicated to improving the quality of life of adults with developmental disabilities through endorsing choices and protecting rights. We believe that every individual is entitled to the supports and structure necessary to help maximize potential. We are committed to a person-centered team approach which supports each resident in the achievement of self-worth and happiness.

PROJECT SIX PROGRAM ELEMENTS

- ◎ Project Six strives to improve the quality of life of our residents through fun, enriching activities while teaching skills which will help increase their independence.
- ◎ During the week, all residents participate in:
 - community school or adult day programs which meet their individual needs.
 - While in the group home, time is structured to allow each resident to practice the skills inherent to independence.
 - Staff members create fun ways for residents to gain critical knowledge and practice in meal preparation, medication administration, personal hygiene, and household chores.
 - Project Six contains a large social and recreational component. Residents participate in organized events with the other houses, such as BBQ's, dances, trips to the Pantages Theater, baseball games, Special Olympics, activities with community volunteers, etc. In addition, residents participate in weekly activities including visits to the movie theater, bowling alley, local museums, strawberry and cherry picking, shopping, beach, dinner-night out, Griffith Park and many community festivals.
- ◎ Central to the Project Six homes is the idea of active treatment. Direct care staff is trained to engage residents and to turn “free-time” into teachable moments. Every resident is working on individual goals which have been created by the interdisciplinary team to help him/her reach maximum potential. Activities within the home are designed to help residents practice the skills necessary to reach their goals.

TAKE HOME POINTS

- ◉ Quality Living Arrangements for Adults with Moderate to Severe Autism should all include:
 - ◉ Key Behavioral Challenges That Limit Community Involvement
 - ◉ Emphasis on Quality of Life
 - ◉ Respect for and development of Self-determination
 - ◉ Staff dedicated to Community Education