

INTENTIONAL COMMUNITIES

For Adults with Fragile X Syndrome



Carolyn Ybarra, PhD

Housing Crisis (California)

Statistics

- 225,000 people in California with DD
- 73% live with parents
- 9% live in their own homes with SLS or ILS

Trends

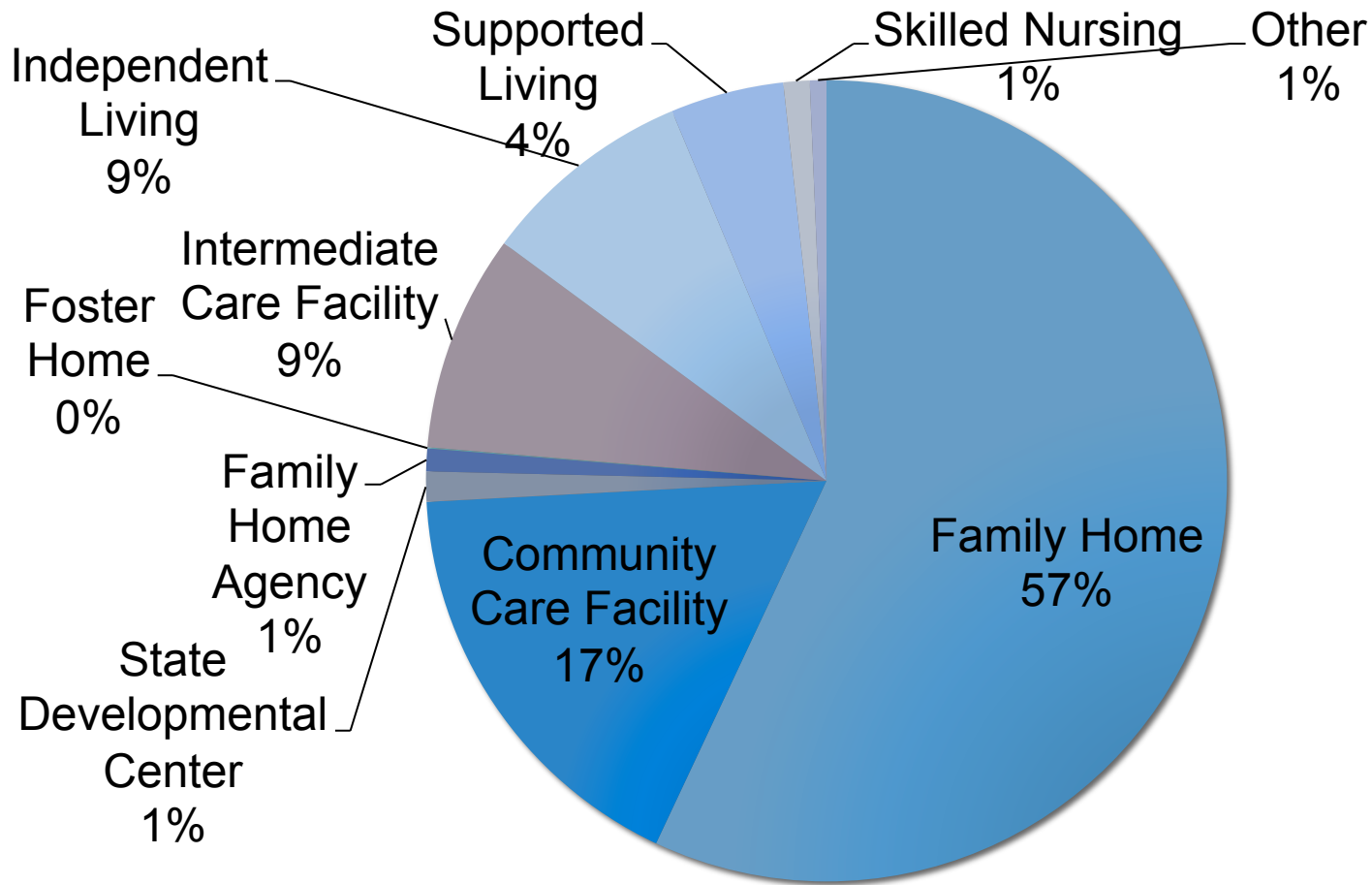
- Low Income
- High cost of housing
- Young population with disabilities
- Increase in prevalence of autism (5,700 in 1994 to 27,000 in 2004)

Orange County, California

- Regional Center of Orange County (RCOC)
- <http://www.rcocdd.com/housing/housing-faqs/>
- Where are The Real Adults with Disabilities of Orange County living as of 2012?



Adult Housing in RCOC Area - 2012



Current Foci for Housing

De-institutionalization

- Olmsted decision
 - services & housing in integrated settings
 - Independent living emphasized

Autism

- Dramatic increase in numbers draws attention and resources
- Sensory issues demand a different approach

Existing Housing Options

- Living with Family
- Institutional Homes
- “Family” Home Model
- Group Homes
- Group housing or apartments requiring high annual payments
- Affordable apartments/houses with housing waivers
- Parent initiatives



Parent Initiatives



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Parents create housing alternative for disabled adult children

January 23, 2013 | By Bonnie Miller Rubin, Chicago Tribune reporter

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Baruch and Joyce Schur were out of options. They couldn't find anywhere for their physically and intellectually disabled 26-year-old son to live, at least nowhere that met their criteria or didn't have a yearslong waiting list.

The 55-year-old couple made plans to move out of the state. Uprooting themselves from their native Chicago, leaving friends and a family [business](#), was the only way to give Josh a home — not an institution — that offered independence, a kosher kitchen and a sense of community before his parents



Jacob Mosbacher, 25, is excited to show his mom, Joan Katz,

- Apartment or house bought or rented by parents
- Apartment or house bought or rented by a group of parents
- Independent Living Services centrally coordinated
- Rural House or Farm
- Intentional Community

Intentional Communities

Structure

- Typically requires non-profit status
- Requires coordination with city and/or county
- Majority are farm/ranch communities
- Structure and size must be coordinated with support organizations.
- Community integration must be well thought out

Major Issues

- Type of home affects funding.
- Land /housing cost and fundraising are major issues
- Ongoing issues include staffing and continuity



Resources

Agricultural
Communities for Adults
with Autism
<http://ac-aa.org/>

FRED Conference
fredconference.org

National Down Syndrome
Society Housing Options
[http://www.ndss.org/
Resources/Transition-and-
Beyond/Housing-Options/](http://www.ndss.org/Resources/Transition-and-Beyond/Housing-Options/)

NFXF
[http://www.fragilex.org/
treatment-intervention/adults-
life-planning/community-
living/](http://www.fragilex.org/treatment-intervention/adults-life-planning/community-living/)

The ARC
[http://www.thearc.org/
page.aspx?pid=2588](http://www.thearc.org/page.aspx?pid=2588)