



Isolating or Innovative? Self-Advocates Discuss Life in Intentional Communities

Self-Advocate Panel:

Sloan Meek, North Street Neighborhood (NC)
Tamsin Kearns, Sweetwater Spectrum (CA)
Cameron Mack, The Arc Jacksonville Village (FL)
Oliver Lowe, The Arc Jacksonville Village (FL)
Julia Burns, Down Home Ranch (TX)
Daniel Marin, Down Home Ranch (TX)

Moderator:

Desiree Kameka,
Madison House
Autism Foundation (MD)

Defining 'Intentional Community'

Wikipedia: “An *intentional community* is a planned residential community designed from the start to have a high degree of social cohesion and teamwork. The members of an *intentional community* typically hold a common social, political, religious, or spiritual vision and often follow an alternative lifestyle.”



www.IC.org: An “intentional community” is a group of people who have chosen to live together with a common purpose, working cooperatively to create a lifestyle that reflects their shared core values. The people may live together on a piece of rural land, in a suburban home, or in an urban neighborhood, and they may share a single residence or live in a cluster of dwellings.

This definition spans a wide variety of groups, including (but not limited to) communes, student cooperatives, land co-ops, cohousing groups, monasteries and ashrams, and farming collectives. Although quite diverse in philosophy and lifestyle, each of these groups places a high priority on fostering a sense of community—a feeling of belonging and mutual support that is increasingly hard to find in mainstream Western society.



Presentation Overview

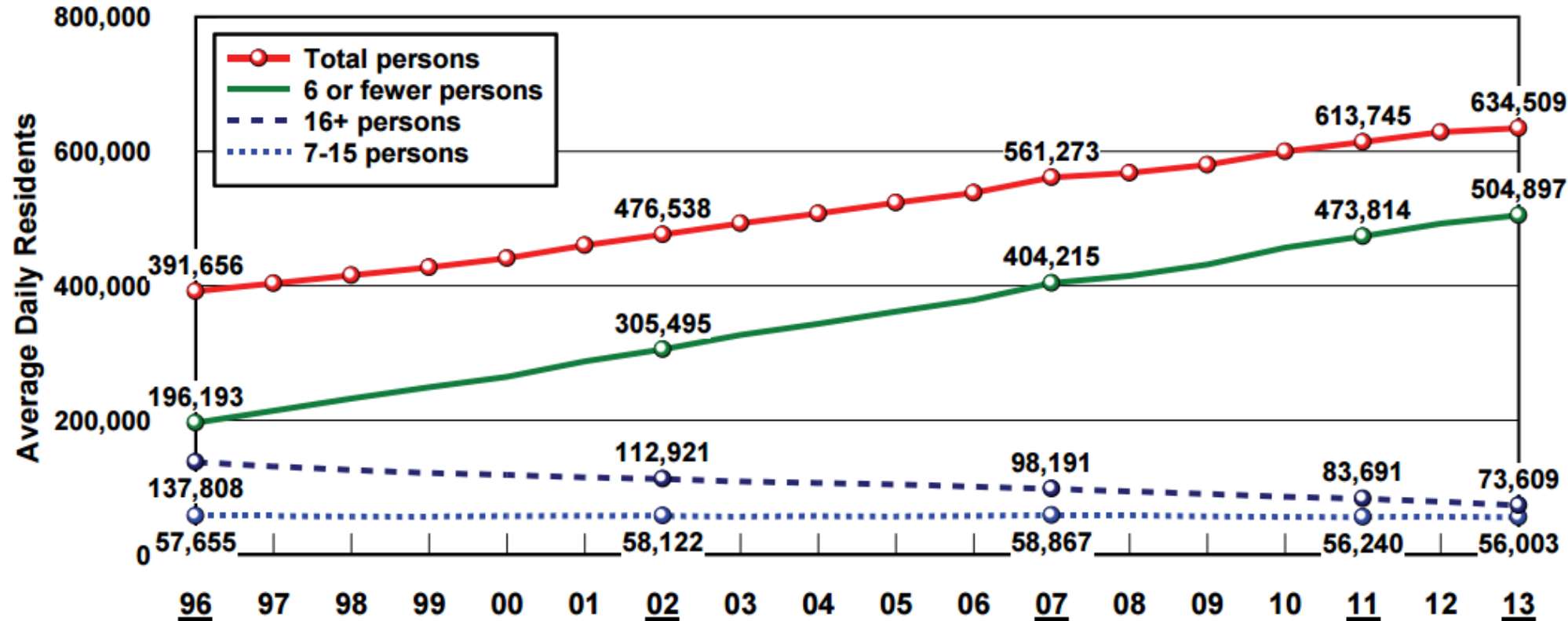
- Glimpse at Housing & Support Crisis
- Advocates Discuss Life at:
 - Northstreet Neighborhood
 - Sweetwater Spectrum
 - The Arc Village
 - Down Home Ranch
- Q & A



○ Q & A

Can growth of residential supports meet demand?

Less than 250,000 have been given supports to move out of their family home into any other setting in the past 17 years...



*Almost 1,000,000 individuals with I/DD are living with caregivers over the age of 60.
What will happen to this population?*



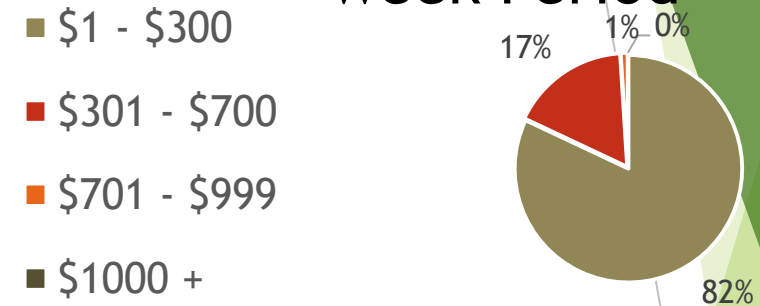
Can Individuals With I/DD Afford Housing?

Source: Priced Out 2014 Report



**NATIONAL
CORE
INDICATORS**
NASDDDS & HSRI

Amount of Community Gross Wages Earned During Two-week Period

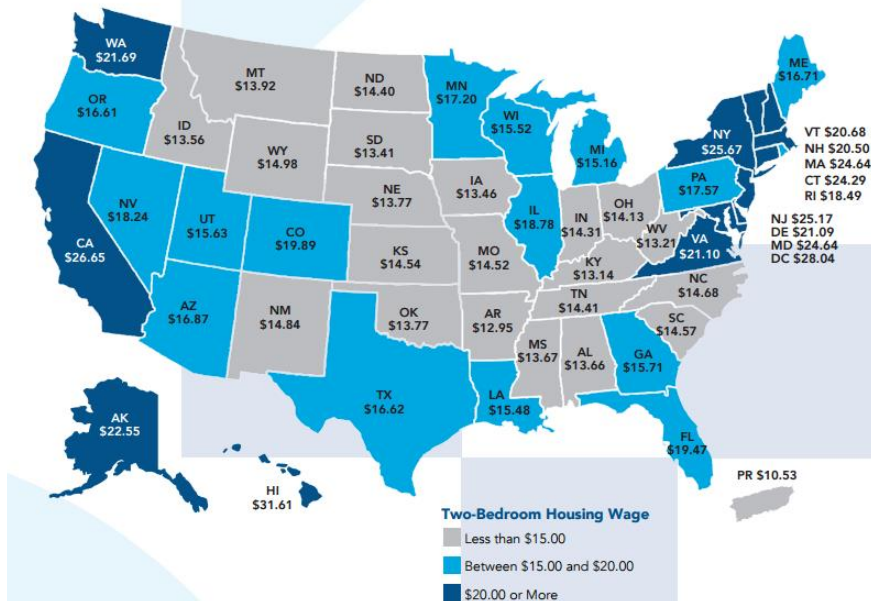


A renter earning the federal minimum wage needs to work 90 hours per week to afford a one-bedroom rental home.

The average monthly rent for a basic one-bedroom apartment is **\$780**

That is **104%** of my
monthly income

WAGES NEEDED TO AFFORD RENT ACROSS THE U.S.



**IN 2015,
THE
2-BEDROOM
NATIONAL
HOUSING WAGE IS**

\$19.35

An American household must earn at least **\$19.35 an hour** to afford a modest, two-bedroom apartment without spending **more than 30% of income on rent**. This wage varies from state to state.

Is Abuse Still Happening?

“The bottom line is that abuse is prevalent and pervasive, it happens in many ways, and it happens repeatedly to victims with all types of disabilities.”

Reasons for not reporting:

58%
believed
nothing
would
happen

38% had
been
threatened
or were
afraid

33% did
not know
how or
where to
report

63% of adults
with I/DD have
been victims
of abuse

34%
sexually
abused

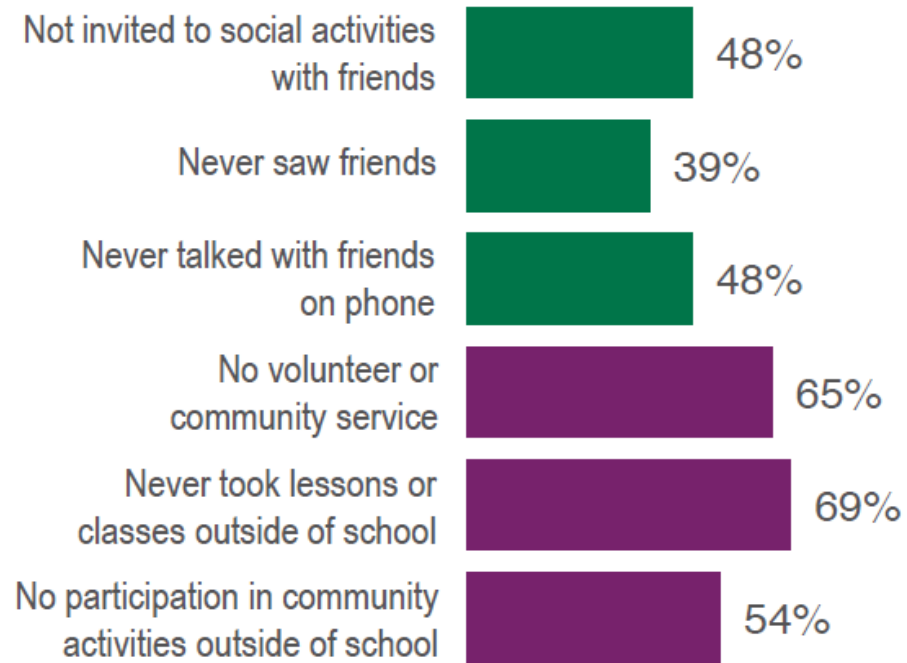
40% more
than 10x

Only 54%
reported
the abuse

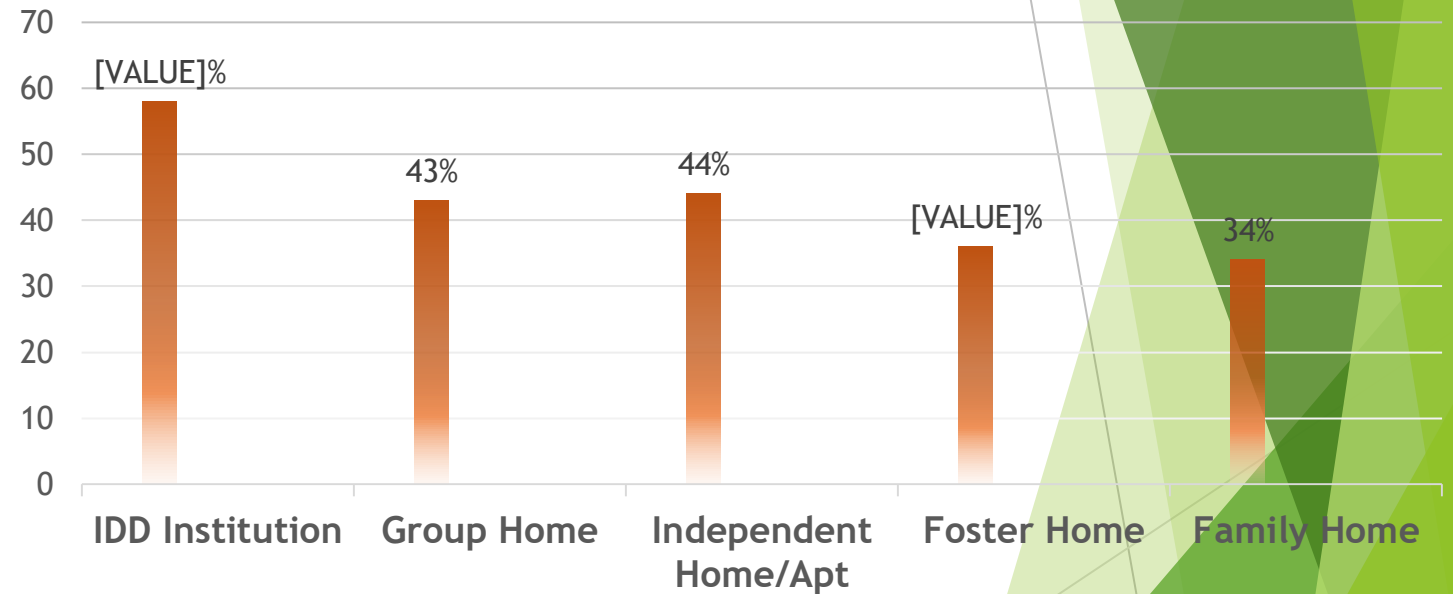
Source: Report on the
2012 National Survey
on Abuse of People with Disabilities
www.disability-abuse.com

Do Citizens with I/DD Feel Valued? Part of Community?

Rates of **no community participation** in the past year were higher than rates of **no social interaction**.



INDV. WITH I/DD WHO 'SOMETIMES' OR 'OFTEN' FEEL LONELY BY SETTING (2013-2014)

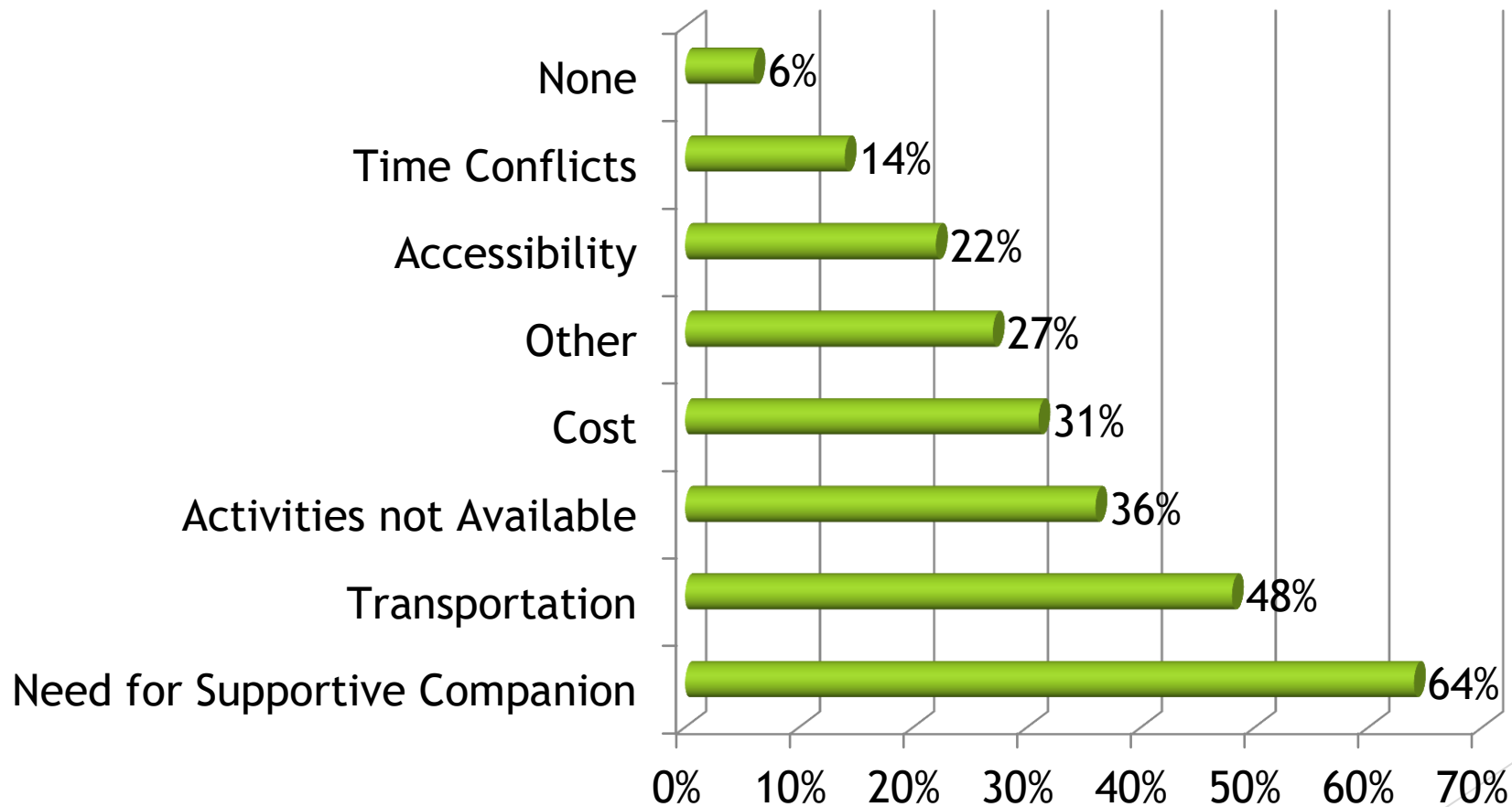


“Loneliness and the feeling of being unwanted is the most terrible poverty.”
—Mother Teresa



What are the barriers to accessing their community?

According to the 2008 UM-NSU CARD survey, these were the specific obstacles to community participation:



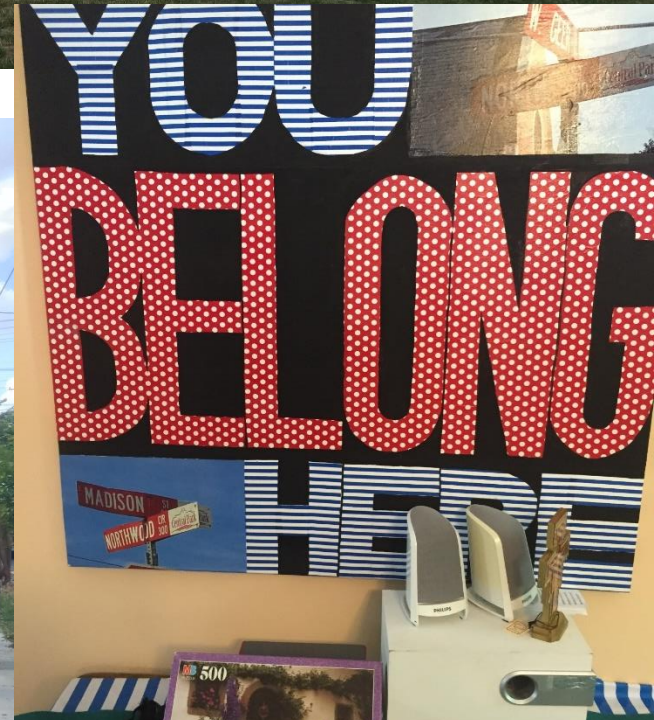
North Street Neighborhood (Durham, NC)

- ▶ Families from a local ministry partnered with a developer to create their own neurodiverse neighborhood
- ▶ Each of the 17 homes looks similar on the outside, but inside every one is unique to the desire of the home owner.
- ▶ Residents choose their model of service delivery that works best for them: host family home, 2 friendship houses, only natural supports



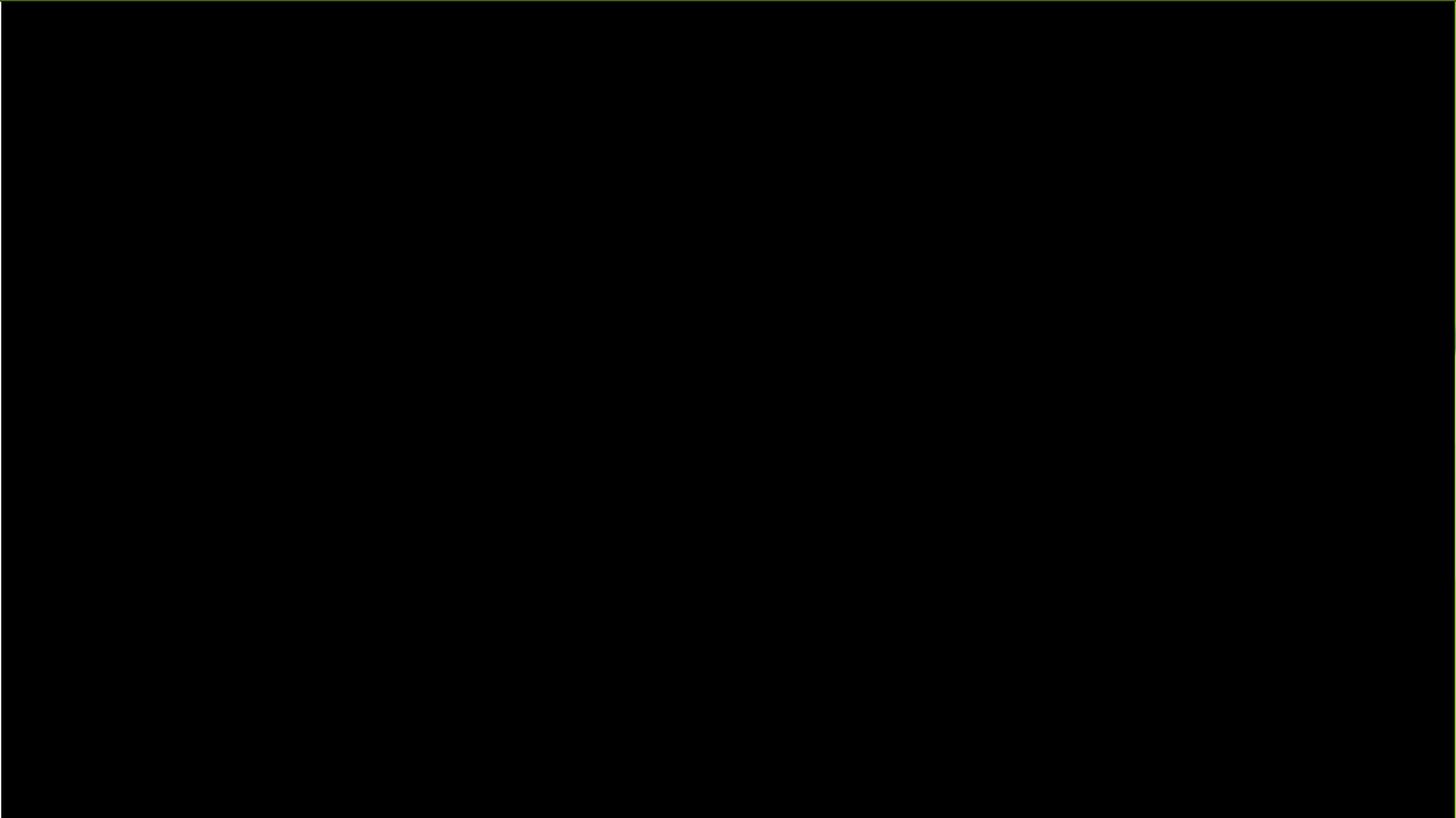
North Street Neighborhood (Durham, NC)

- ▶ Some units owned by a family offers potential future income
- ▶ Ripples of relational community extend into greater community through community garden and half court



North Street Neighborhood (Durham, NC)







North Street Community

Durham, NC

<http://northstreetneighborhood.weebly.com/>



2009 Nation's Triathlon
Washington D.C.



My girl Janie



Picnic
Taco
Night
with
some of
my North
Street
buddies



Reality Ministries is a community-based non-profit that offers a variety of opportunities for participants to work, play, learn and grow together.

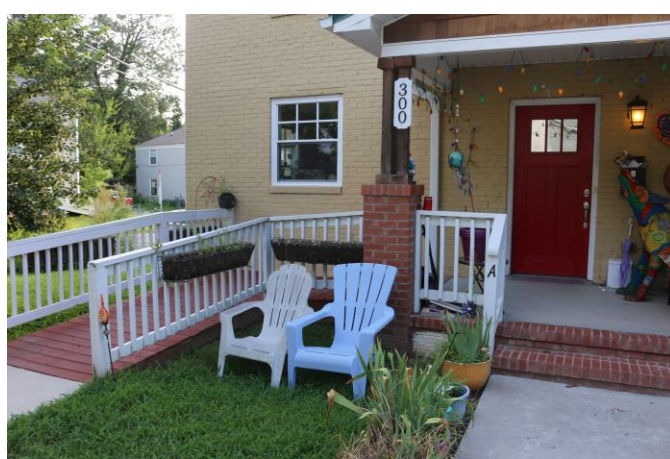
www.realityministriesinc.org

Last week at Reality Ministries Summer Camp we visited Fort Macon State Park in Morehead City, NC.

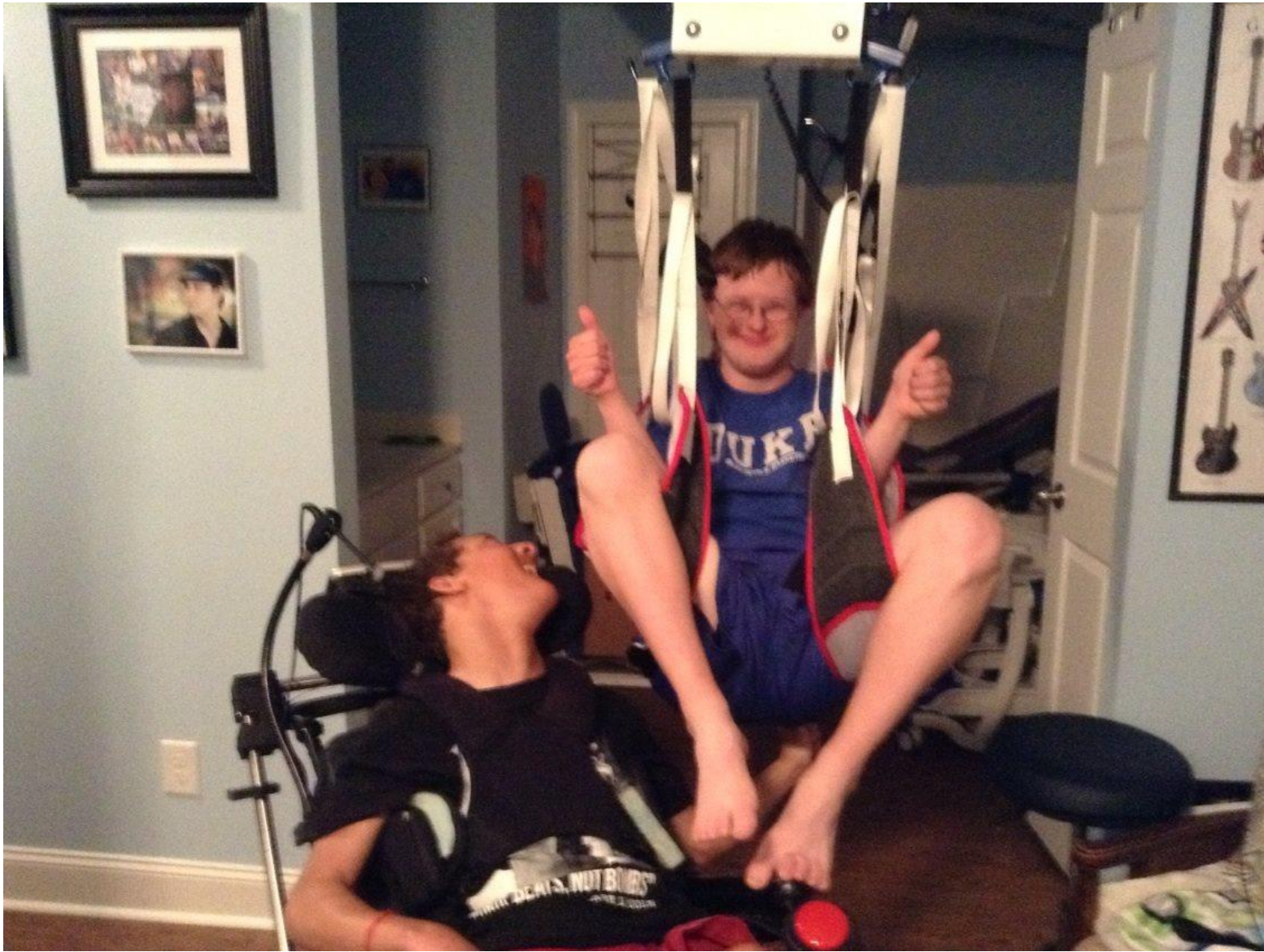


Singing with
friends in front
of my house.





The Ramps of North Street



My best friend, and neighbor, Alex and I goofing off in my room. He likes my lift.



Support and Celebration



Celebrating
a North
Street
Wedding



Cheering Tom
for reaching
5 Million
Steps!



North Street shares the same neighborhood as Durham's Downtown Social District

A Very Merry Motorco
'COMMUNITY CAROL EXTRAVAGANZA'
HOSTED BY SLOAN MEEK

DEC
10

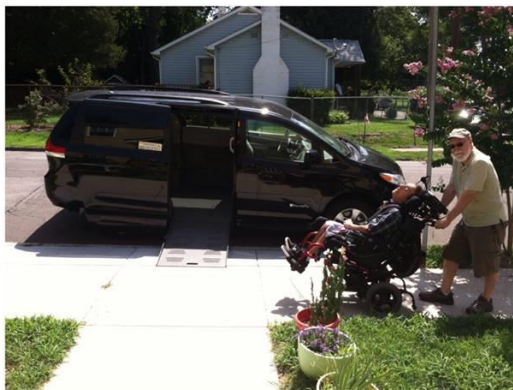


7:30
PM

FEATURING LOOK HOMEWARD,
THE PINKERTON RAID, AND MANY MORE!



My birthday party was listed in *The Independent* as one of Durham's **Best Bet** Events.



North Street Neighborhood

Durham, NC



northstreetneighborhood.weebly.com

built around people with disabilities



Sweetwater Spectrum (Sonoma, CA)



- Privately developed community started by families who are now creating a social enterprises for more work opportunities
- 4 homes plus amenities in the middle of Sonoma, CA



SITE PLAN

1 WELCOME BUILDING 2 PARKING 3 HOUSE 4 STORMWATER TREATMENT BIO-SWALE 5 COMMUNITY CENTER 6 THE COMMONS: PLAZA & LAWN
7 THERAPY POOL & SPAS 8 ORCHARD 9 TRASH 10 STORAGE BUILDING 11 IRRIGATION WELL 12 GREENHOUSE 13 ORGANIC FARM 14 FIRE ACCESS ROAD

Sweetwater Spectrum (Sonoma, CA)

Design features:

- island kitchen with lots of counter space
- office space for staff
- private wings for rooms/noise
- nooks
- storage for less clutter



Supported Living: A Personal Perspective

By Tamsin Kearns

- Life at a Group Home
- Finding a New Option
- Life at Sweetwater Spectrum
- A Life of Choice



Life at my group home...

- ▶ People with mix of disabilities - high to low functioning
 - ▶ 7 females in a three bedroom house
 - ▶ 3 or 4 assigned to a room
 - ▶ 1 bathroom
-
- ▶ After 2 years, moved to an apartment with one roommate



Life with little choice...

- ▶ Scheduled meal times with predetermined monthly menu
- ▶ Mandatory dining with staff for first 4 months
- ▶ Curfew: in bedroom at 9pm
- ▶ Permission to have visitors
- ▶ No dating first 4 months



Life with little choice...

- Mandatory schedule:
 - volunteering once a week at food bank
 - life skill classes: 4 days a week for 1 - 2 hours
 - weekends outings - hiking, bowling, site seeing
- No community support with activities
- No access to fitness options



Bad & Good of My Group Home

Bad

- ▶ Too controlling with few choices
- ▶ Schedules that didn't work
- ▶ Preselected roommates = roommate issues!
- ▶ High staff turnover
- ▶ No choice in staff selection
- ▶ Not enough support while living in the apartment



Good

- ▶ Life skills
- ▶ Band class
- ▶ Not living at home
- ▶ Made good friends
- ▶ Learned about who I am and what I like

Finding a New Option...

Sweetwater Spectrum

1. Tour with Executive Director
2. Make application with parents
3. Meet with existing housemates and families who make the new roommate selections
4. Once accepted, provide evidence of a service provider
5. Sign yearly rental lease

Moved in October of 2014!



So, what is Sweetwater Spectrum?

- ▶ A supported living rental community for 16 adults with autism
 - ▶ A non profit 501(c)(3) formed by parents & associates
 - ▶ Located in the heart of Sonoma, California
 - ▶ Opened in January of 2013



Sweetwater Spectrum

Our Mission

*To provide adults with autism innovative, community-based,
long-term housing that offers individuals choice and
challenges*

each resident to reach his or her highest potential.

Sweetwater Spectrum Amenities

- 3.5 acres
- 4 houses
- Community building with a library, exercise room
- Pool/hot tubs
- ½ acre garden and green house



Sweetwater offers...



Pool and hot tub time



Greenhouse and gardening skills



Chickens!



Life skills classes



Community Room for activities and holiday gatherings

Exercise options



Sweetwater offers choice...

- ▶ On-site enrichment activities such as life skills training, gardening, art/music, exercise, and a variety of social events
- ▶ Community integration through events, volunteering and work opportunities
- ▶ Choice of supported living services



Creating a home life with choices...

- ▶ Choice of my own bedroom
- ▶ Creating house rules
- ▶ Choice of new roommates
- ▶ Choice of daily schedule/hours
- ▶ Choice of what you eat and when
- ▶ Choice of activities



More choices!

- ▶ Decorate your room as you like
- ▶ Choice of individual support staff
- ▶ Choice of planning and attending activities
- ▶ Choice of who attends
 - house meetings
- ▶ Create own goals
- ▶ Support with reaching
 - IPP benchmarks



My choice to pursue...

- ▶ Volunteering at local elementary schools with reading and behavior management
- ▶ Opportunities to advocate for autism - radio, speaking engagements
- ▶ Working with other children with disabilities
- ▶ Working at the farm stand



My accomplishments through choice...

- ▶ Planning social activities
- ▶ Creating an emergency plan
- ▶ CPR, First Aid and AED training
- ▶ Job skill training
- ▶ Building my resume
- ▶ Attending Santa Rosa Junior College

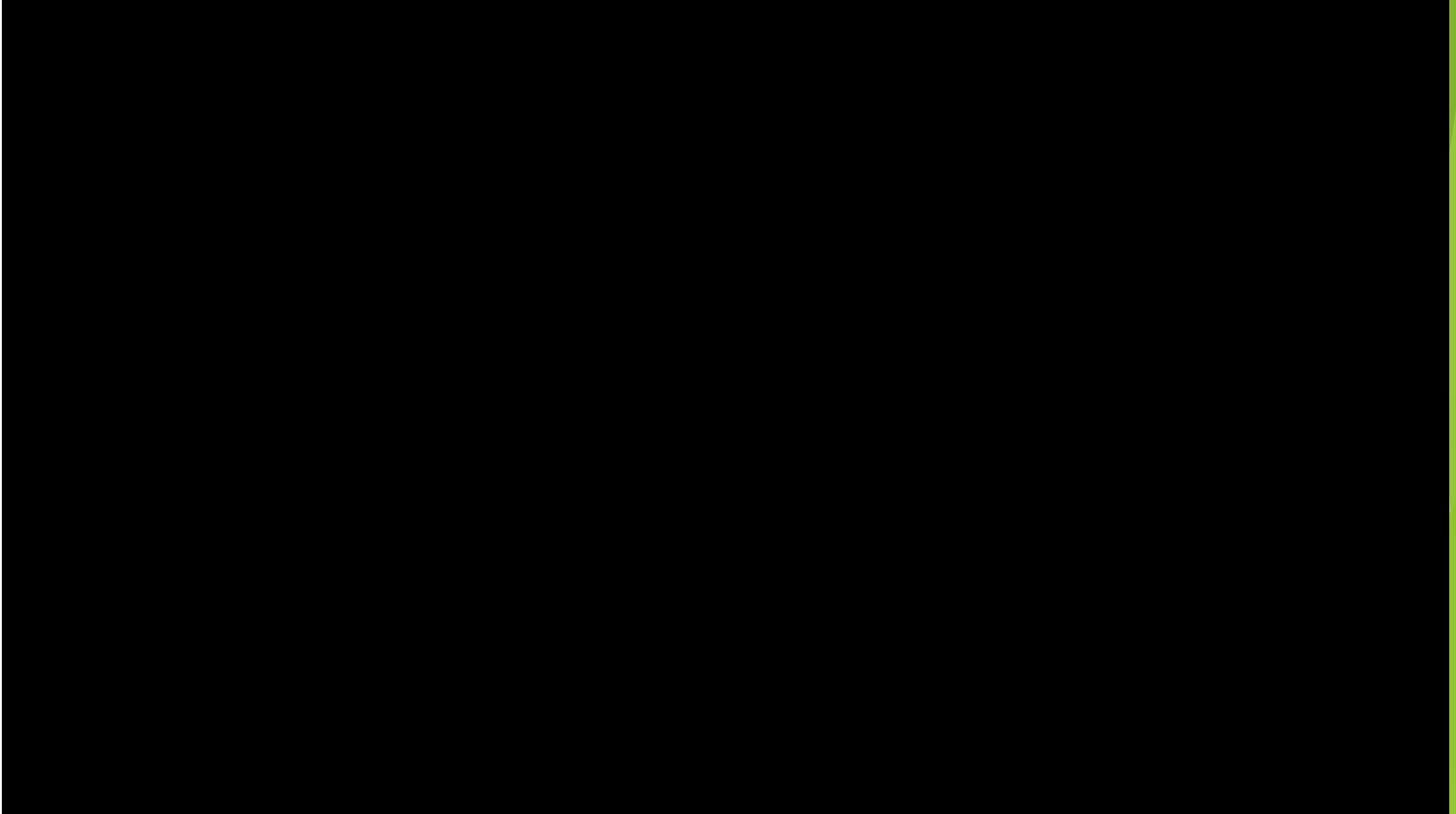


Sweetwater has given me...



... a life with purpose through choice.

The Arc Jacksonville Village





95 apartments | 121 residents | 80% set aside



The Arc Jacksonville Village (Jacksonville, FL)

The Arc Jacksonville Village utilizes the following avenues to minimize costs to residents:

- Natural supports
- Community partnerships
- Faith-based organizations
- Volunteers
- Civic groups
- College mentors
- AmeriCorps



	1-Bed (low)	1-Bed	2-Bed	2-Bed Shared
Rent	\$250	\$525	\$700	\$350
Utilities	\$125	\$125	\$175	\$88
Food	\$350	\$350	\$350	\$350
Personal	\$200	\$200	\$200	\$200
Total	\$925	\$1,200	\$1,425	\$988

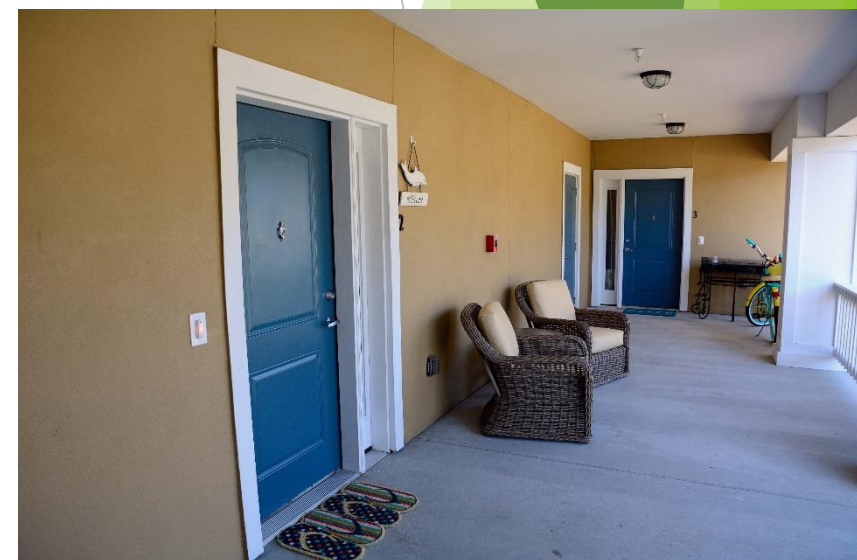
The Arc Jacksonville Village



Amenities:

- Community Center
- Snack bar
- Pool and hot tub
- Computer lab
- Movie room
- Dining Hall
- Energy-efficient appliances
- Emergency call device in each unit





Down Home Ranch (Elgin, TX)



- 37 Ranchers with I/DD and 30 families / staff live on the 410 acre ranch
- Micro homes, independent living homes, ICF homes with neurotypical RA's on the ranch
- HCBS-funded homes are off-ranch (not by choice)





Tom gets
a home of
his own.



Bringing
in the
hay.



Dave harvests
hydroponic
tomatoes.



Cypress Pond and barn.



Cabins, cottages, tiny houses, big
homes, ponds and pools, fishing
and kayaking and 410 acres to
roam.

Peggy Sue and Charlotte

Down Home Ranch

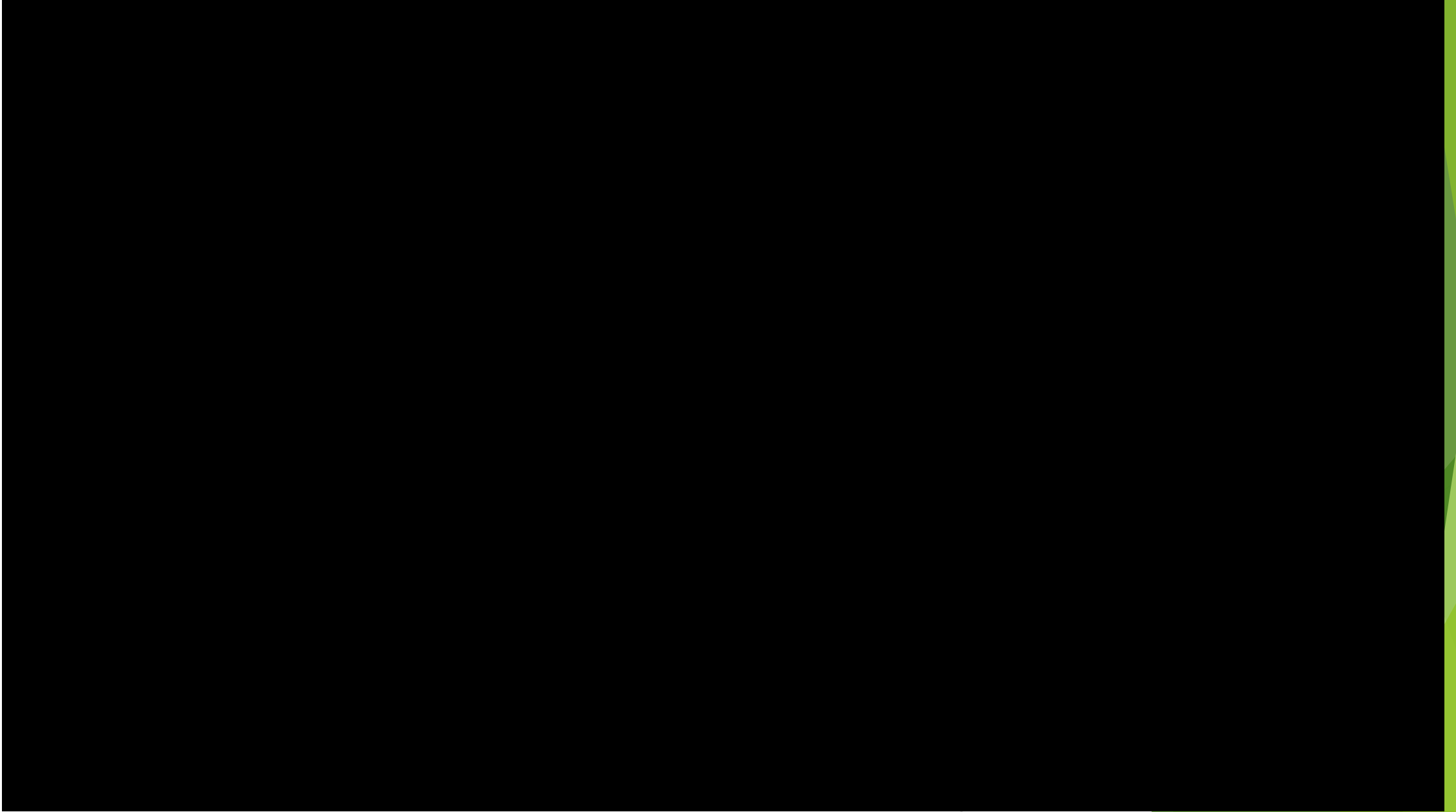
- ▶ 36 head of cattle, 100 chickens, horses and donkeys
- ▶ 12 greenhouses, 2 barns, 5 farm ponds
- ▶ Raised and sold 2,300 poinsettias in 1999. Sold them annually. Currently, growing 13,000.
- ▶ Swimming pool and fitness center
- ▶ Over 40 different jobs on the ranch
- ▶ Over half the Ranchers have their golf cart license, 7 own their own
- ▶ Ranchers attend Texas Advocates Convention, National Down Syndrome, Miss Amazing Pageant
- ▶ Swim Fest (raise money), Annual Cozumel cruise (spend money)
- ▶ Village Council for community decision making
- ▶ Too much more to list...



Down Home Ranch



Down Home Ranch



Julia and Daniel Choose a Home on the Range



Julia Chooses Her Own Life

- ▶ Went to Career Development School for “extended education.”
- ▶ Continued living at home, getting bored following parents.
- ▶ Got occasional employment placements through TIBH (Texas Institute for the Blind and Handicapped). Nothing permanent. Wasn't well received
- ▶ Her social life was minimal. No cohort. Few friends.
- ▶ 1996 worked for the Texas Department of Transportation but wasn't well received—some co-workers thought she was treated with favoritism and wasn't really earning her pay.
- ▶ One year at MAT and one year at DOT.
- ▶ She was lonely, missed the structure and friends of public school.
- ▶ Julia wanted her own place, a job to do and new friends. She wanted her own life. She wanted to advocate for herself.



Julia Chooses Her Own Life

- ▶ Julia interviews Jerry and Judy Horton, founders of Down Home Ranch, about moving to the Ranch:
 - ▶ Q: Will she have her own room? A: Yes
 - ▶ Q: Will there be bugs like at camp? A: No, no bugs
 - ▶ Q: Will I have a job? A: Yes, many
- ▶ Julia moves to the Ranch Jan. 2006. She finally has new and good friends close by—in her own home and in her neighborhood.
- ▶ In 2007 Julia is interviewed by Steve Hartman of CBS news and she tells him:
 - “I’m different from my mother and father.*
 - They are city folks but I’m a country girl.”*
- ▶ Julia reads a poem by the tree she planted in memory of her dear dad.



Daniel Chooses His Own Life

- ▶ After high school there is was little structure and few friends for Daniel.
- ▶ He continued living at home and cleaning homes with his mother.
- ▶ His brothers and sisters were growing up, getting married and starting families. Daniel was not.
- ▶ Though he love his family, was bored and restless, having no real job, few friends and little in the way of opportunity.
- ▶ He continued his interest in music—especially Elvis—and history.
- ▶ He stayed in touch with his high school friend Mike and in 1995 they went to Ranch Camp at Down Home Ranch.



Daniel Chooses His Own Life

- ▶ Judy had taught Daniel to play the guitar.
- ▶ Daniel wants to move to Austin, have his own place, his own job and be near the music scene.
- ▶ His dream was 100% supported by Down Home Ranch.
- ▶ However, Daniel needs to get his permanent resident card—which would take three years. (Jerry and Judy became his legal sponsors.)
- ▶ While waiting for his “green card” (and Social Security card) Daniel went to college, spending a year at Eastern New Mexico State University.



Daniel Chooses His Own Life

- ▶ Friends help Daniel get a garage apartment and a job in Austin.
- ▶ Later he moves back to Houston, back with his family.
- ▶ But he missed his community and friends and jobs and his good life at Down Home Ranch.
- ▶ In 2015, Daniel moves back to the Ranch as a staff member.
- ▶ He lives in an RV while waiting for a micro-house to be built for him.