Supported Living in NC: *Where We Are*

A Data Snapshot

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with support from Lu Xu, Business Systems Analyst, DMA

April 20, 2018
Big Thanks!!

To Our Community Colleagues

• To beneficiaries and their families
• To MCO partners, particularly care coordinators
• Our Making A Difference colleagues
• To provider partners, particularly direct support staff

To Our State Colleagues

• Our I/DD, Behavioral Health, MFP colleagues.
• A special shout out to our Business Information Division (our data wonks 😊)
Supported Living is a Simple Concept....

“A person with a disability, who requires long-term, publicly funded, organized assistance, allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own.“

John O’Brien
Supported Living is NOT...

∅ A “program” to fix or change people
∅ Isolation & loneliness
∅ Segregation by disability or income
∅ Forcing people to live the way we think is good for them
∅ A way to avoid responsibility for careful decisions about threats to people’s vulnerabilities
∅ An excuse for letting bad things happen to people
∅ Targeted at a particular (dis)ability group

∅ Another stop on the service continuum
∅ A test to see if you can live with no problems & if not, you get sent back to group living
∅ Segregation by disability or income
∅ Forcing people to live the way we think is good for them
∅ A way to avoid responsibility for careful decisions about threats to people’s vulnerabilities
∅ An excuse for letting bad things happen to people
∅ Targeted at a particular (dis)ability group

∅ An incentive or reward for good behavior
∅ A kind of “slot” or “bed” with prerequisite entry & exit criteria
∅ Expecting that the amount of assistance necessary will always decrease
∅ Just getting an apartment to live in
∅ Being grouped on the basis of disability
∅ Being assigned roommate(s).
∅ Having permission to live in an agency controlled apartment
∅ Signing a lease on a place that staff control
∅ A set of uniform requirements & procedures
∅ Justified because it is always or necessarily cheaper than group living

Supported Living IS...

- A safe & decent home of your own
- Choice
- Personalized assistance
- Support from others who care about & respect you

John O’Brien, Supported Living, What’s the Difference?
Where We Are
(Always, but Especially Now):
The Learning Phases
The “Pond of Supported Living”: Statewide Data
Our “Deep Dive:”

Individual Surveys and Interviews on “Supported Living Essential Elements”
**Supported Living: Macro Data Qualifiers and Limitations**

- Surveyed all MCOs
- Conducted data clarification seminar.
- Learning exercise: we learned of some ambiguities in data request and data collection that we’ll correct for next round.
- All data should be considered preliminary and reflects a “point in time” (12/31/2017).
Supported Living Macro Data: What We Wanted to Know

• How Many People are Using Supported Living?
• What Levels are Being Utilized?
• How Many Folks Receive Exceptional Rates?
• How are People Finding Housing?
• How are People Funding Housing?
• Other Statewide Trends
Supported Living Macro Data: The Basics

As of 12/31/2017, 120 beneficiaries statewide were utilizing the Supported Living service.

Supported Living Level Profile

- Level 1: 58 (48.33%)
- Level 2: 38 (31.67%)
- Level 3: 24 (20.00%)

Supported Living Level By Enhanced Rate

- Level 1: 58 (100.00%)
- Level 2: 37 (97.37%)
- Level 3: 18 (75.00%)

Very few exceptional rates. Under 6% of total.
Supported Living Macro Data: What We Wanted to Know
How Old Are the Folks Using this Service?

Appx. 2/3 of all Supported Living recipients are over 30 years old.
Where Did They Live Before?

• Preliminary data suggest that most folks currently utilizing Supported Living services have lived in their own homes before or transitioned from their family homes.

• Notable trend of folks transitioning from both community-based and facility-based group living scenarios as well.

• Will explore further in next data pull.
Supported Living Macro Data: What’s the Support Level Distribution?

Supported Living Levels by MCOs

<table>
<thead>
<tr>
<th>MCO</th>
<th>Level of Supported Living Service</th>
<th>0%</th>
<th>5%</th>
<th>10%</th>
<th>15%</th>
<th>20%</th>
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<th>45%</th>
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<tbody>
<tr>
<td>Eastpointe</td>
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Note: The lighter color in a bar represents the enhanced rate, the darker color in a bar represents no enhanced rate.
Supported Living Macro Data: Reviewing Level by Age Distribution

Age by Supported Living Level

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
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<tbody>
<tr>
<td>18</td>
<td>0.00%</td>
<td>50.00%</td>
<td>50.00%</td>
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<tr>
<td>19-20</td>
<td>2.00%</td>
<td>31.00%</td>
<td>68.00%</td>
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<tr>
<td>21-25</td>
<td>13.00%</td>
<td>38.00%</td>
<td>50.00%</td>
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<td>26-30</td>
<td>21.00%</td>
<td>61.00%</td>
<td>20.00%</td>
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<td>31-35</td>
<td>18.00%</td>
<td>28.00%</td>
<td>54.00%</td>
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<tr>
<td>36-40</td>
<td>12.00%</td>
<td>25.00%</td>
<td>63.00%</td>
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<tr>
<td>41-45</td>
<td>13.00%</td>
<td>23.00%</td>
<td>64.00%</td>
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<tr>
<td>46-50</td>
<td>11.00%</td>
<td>36.00%</td>
<td>53.00%</td>
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<tr>
<td>51-55</td>
<td>9.00%</td>
<td>44.00%</td>
<td>47.00%</td>
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<tr>
<td>56-60</td>
<td>7.00%</td>
<td>43.00%</td>
<td>50.00%</td>
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<tr>
<td>61-65</td>
<td>7.00%</td>
<td>43.00%</td>
<td>50.00%</td>
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<tr>
<td>65+</td>
<td>6.00%</td>
<td>50.00%</td>
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</table>
**Supported Living Macro Data: What We Wanted to Know**

**What Types of Diagnoses do People Using Supported Living Services Experience? (primary only)**

<table>
<thead>
<tr>
<th>CCS Dx Category</th>
<th>CCS Dx Category Description</th>
<th>Prim Diag</th>
<th>Prim Diag Desc</th>
<th>Count</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>82</td>
<td>Paralysis</td>
<td>G80.1</td>
<td>Spastic diplegic cerebral palsy</td>
<td>1</td>
<td>0.83%</td>
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<tr>
<td>95</td>
<td>Other nervous system disorders</td>
<td>G71.0</td>
<td>Muscular dystrophy</td>
<td>1</td>
<td>0.83%</td>
</tr>
<tr>
<td>653</td>
<td>Delirium, dementia, and amnestic and other cognitive disorders</td>
<td>F02.80</td>
<td>Dementia in other diseases classified elsewhere without behavioral disturbance</td>
<td>1</td>
<td>0.83%</td>
</tr>
<tr>
<td>654</td>
<td>Developmental disorders</td>
<td>F70</td>
<td>Mild intellectual disabilities</td>
<td>50</td>
<td>49.17%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F71</td>
<td>Moderate intellectual disabilities</td>
<td>33</td>
<td>32.50%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F72</td>
<td>Severe intellectual disabilities</td>
<td>10</td>
<td>8.33%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F79</td>
<td>Unspecified intellectual disabilities</td>
<td>2</td>
<td>1.67%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F88</td>
<td>Other disorders of psychological development</td>
<td>1</td>
<td>0.83%</td>
</tr>
<tr>
<td>655</td>
<td>Disorders usually diagnosed in infancy, childhood, or adolescence</td>
<td>F84.5</td>
<td>Asperger’s syndrome</td>
<td>1</td>
<td>0.83%</td>
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<tr>
<td></td>
<td></td>
<td>F84.0</td>
<td>Autism spectrum disorder</td>
<td>10</td>
<td>8.33%</td>
</tr>
<tr>
<td>657</td>
<td>Mood disorders</td>
<td>F33.2</td>
<td>Major depressive disorder, recurrent severe without psychotic features</td>
<td>1</td>
<td>0.83%</td>
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</tbody>
</table>
Supported Living Macro Data: What We Wanted to Know
What Types of Services do People Using Supported Living Services Utilize
(Innovations Waiver Only)

Macro - Other Innovation Services Beneficiaries are Receiving - Definition Categories

<table>
<thead>
<tr>
<th>Service Description (Definition Categories)</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Navigator</td>
<td>83</td>
<td>68.03%</td>
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<tr>
<td>Community Networking</td>
<td>79</td>
<td>64.75%</td>
</tr>
<tr>
<td>Day Supports</td>
<td>40</td>
<td>32.79%</td>
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<tr>
<td>Supported Employment</td>
<td>37</td>
<td>30.33%</td>
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<tr>
<td>Specialized Consultation Services</td>
<td>27</td>
<td>22.13%</td>
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<tr>
<td>Assistive Technology Equipment and Supplies</td>
<td>10</td>
<td>8.20%</td>
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<tr>
<td>Community Transition</td>
<td>6</td>
<td>4.92%</td>
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<tr>
<td>Financial Support</td>
<td>4</td>
<td>3.28%</td>
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<tr>
<td>Crisis Services: Primary Response</td>
<td>1</td>
<td>0.82%</td>
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<tr>
<td>Home Modifications</td>
<td>1</td>
<td>0.82%</td>
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<tr>
<td>Out of Home Crisis</td>
<td>1</td>
<td>0.82%</td>
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<tr>
<td>Others</td>
<td>9</td>
<td>7.38%</td>
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</tbody>
</table>

Note on “Other:” Data request instruction called for allowable Innovations services only. Some additional information provided on some MCOs’ spreadsheet, reflecting state-funded or MH services. Additional exploration of these services next data pull.
Supported Living Macro Data: How did People Secure Their Housing?

### Beneficiary's Housing Source - Category

- **House, mobile home or apartment**—identified and secured by beneficiary or family/natural supports: 65 (54.17%)
- **House, mobile home or apartment**—identified and secured collaboratively between beneficiary/family and Supported Living Provider: 28 (23.33%)
- **House, mobile home or apartment**—identified and secured by Supported Living Provider: 17 (14.17%)
- **House, mobile home or apartment**—identified and secured in manner not otherwise listed: 5 (4.17%)
- **Null**: 6 (5.00%)
Supported Living Macro Data: What We Wanted to Know
Who Funds the Housing?

Housing Funding Summary

<table>
<thead>
<tr>
<th>Beneficiary's Housing Funding - Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ONLY private funding from ONLY beneficiaries/roommates</td>
<td>41</td>
<td>34.17%</td>
</tr>
<tr>
<td>ONLY private funding from beneficiaries/roommates AND family</td>
<td>27</td>
<td>22.50%</td>
</tr>
<tr>
<td>Housing Choice Voucher (aka Section 8 voucher from local housing authority)</td>
<td>24</td>
<td>20.00%</td>
</tr>
<tr>
<td>Targeting/Key Housing Subsidy funding</td>
<td>9</td>
<td>7.50%</td>
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<tr>
<td>Subsidized by Supported Living provider</td>
<td>5</td>
<td>4.17%</td>
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<tr>
<td>Other funding source or combination not listed above</td>
<td>2</td>
<td>1.67%</td>
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<tr>
<td>Null</td>
<td>13</td>
<td>10.83%</td>
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Our “Deep Dive:”
Individual Surveys and Interviews on “Supported Living Essential Elements”

• How can we work to honor the supported living philosophy through the “real life” implementation of the Supported Living definition?

• Working to ensure any review process of supported living service definition does not contradict the underlying philosophy the definition works to advance.

• Working slowly and carefully—gathering feedback through the people with disabilities, their families, agencies, LME-MCOs and others in the Learning Community.
### Our “Deep Dive:” Individual Surveys and Interviews on “Supported Living Essential Elements:” What We Wanted to Know

<table>
<thead>
<tr>
<th>Emerging Essential Element (Topic)</th>
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<tbody>
<tr>
<td>People live in their own homes</td>
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<td>People are involved in hiring and training their own staff.</td>
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<td>People choose who live with them.</td>
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<td>The agency is constantly learning about what is working and what isn’t working for each person.</td>
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<td>People’s schedules are tailored to meet their individual interests and needs.</td>
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<td>People control their own money to the extent possible.</td>
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<td>Providers are partners in supporting a person’s community life.</td>
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<td>People have dignity of risk/experience.</td>
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<td>People feel safe.</td>
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Care Coordinators asked and collected responses to specific questions, during in-person visits.

Care Coordinators then also ranked their conclusions about whether the identified Element was present in the person’s life.
Our “Deep Dive:” Individual Surveys and Interviews on “Supported Living Essential Elements”

Qualifiers and Limitations

- This is just a snapshot—sample not big enough to be determinative or statistically significant.
- Not random—Care Coordinators were allowed to select individuals to be surveyed.
- Pilot activity: revealed ambiguity in questions as designed and other opportunities for improvement.
- Due to time, not all results presented here today. Prioritizing those that are most meaningful.
The Basic Stats of Participation

• MCOs= 7
• Organizations Represented: 15
• Participants: 19
• Care Coordinators: 17

No material changes between baseline and follow up data. Baseline data represented here. Person-specific changes noted.
Some slides may not calculate to total if no response provided to specific question.
Where did those Surveyed Live Before Utilizing the Supported Living Definition?

NOTE: This slide has been added since 4/20/2018 presentation.
Supported Living Deep Dive:
People Live In Their Own Homes

Deep-dive Element 1: People live in their own homes

Overall Ratings

1. Responses clearly reflect that this is the person’s home and person has control over it separate from provider agency. 83.33%

3. Responses demonstrate confusion about whose home it is or authority within it. 16.67%

Do you have a landlord?

15/83.33% Yes
3/16.67% No

If you decided to change from your current agency, would you have to move?

4/22.22% Yes
14/77.78% No
Supported Living Deep Dive:
People are Involved in Hiring & Training Their Own Staff

Deep-dive Element 2: People are involved in hiring and training their own staff

1. Responses clearly demonstrate an opportunity to be involved in staffing and indicate satisfaction with level of involvement: 77.78%

2. Responses are mixed—reflecting some involvement but not extensive: 11.11%

4. Responses demonstrate a clear lack of opportunity to be involved in staffing selection and hiring process: 11.11%

Deep-dive Element 2:
Did the beneficiary have a say in hiring your Directed Support Professional (DSP)?

- Yes: 76.47% (13 responses)
- No: 23.53% (4 responses)
Supported Living Deep Dive:
People are Involved in Hiring & Training Their Own Staff

Deep-dive Element2: How did (DSP) get to know you?

- 14 (77.78%) Response indicates by spending time together
- 1 (5.56%) Response suggests formal person-specific training
- 3 (16.67%) Response not clear
Supported Living Deep Dive: Learning about What is Working and What Isn’t….

Deep-dive Element 5: The agency is constantly learning about what is working and what isn’t working.

1. Responses indicate organization actively seeks/develops opportunities, outside the ISP process/organization-wide satisfaction survey to learn what is working and what isn’t working in a person’s life.

2. Responses indicate organization is open to receiving feedback from person/family about what is working/ isn’t working, but does not actively seek it outside ISP and consumer satisfaction survey.

3. Responses indicate person/family confused or doesn’t know how organization learns about what is working/not working.
Supported Living Deep Dive:
Learning about What is Working and What Isn’t....

Deep-dive Element 5
What kind of things does the Agency ask for your opinion on?

- 6 | 33.33% Living quality
- 4 | 22.22% Staff performance
- 5 | 27.78% Staff performance & Living quality
- 1 | 5.56% Everything
- 1 | 5.56% NA
- 1 | 5.56% Nothing

Deep-dive Element 5
How often does provider ask for your opinion?

- Monthly: 27.78%
- Daily: 16.67%
- When necessary: 16.67%
- Never: 11.11%
- Bi-yearly: 5.56%
- Frequently: 5.56%
- Occasionally: 5.56%
- Very frequently: 5.56%
- Weekly: 5.56%
Supported Living Deep Dive:
People’s Schedules are Tailored to Meet their Individual Interests and Needs

Deep-dive Element 6: Are you supported to spend time without your staff when this is your preference?

18 | 100.0%
Yes

Deep-dive Element 6
Can you tell me about how you like to spend your time?

Deep-dive Element 6
What kind of things do you like doing with your staff?
Supported Living Deep Dive:
People Control Their Own Money to the Extent Possible

Deep-dive Element 7: People control their own money to the extent possible

1. Responses indicate person either controls own money or provider supports person to access money in a way that is acceptable to the person.

100.0%

Deep-dive Element 7: When you want to spend your money, what do you do to get it?

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response suggests person manages directly and may receive support</td>
<td>9</td>
<td>50.00%</td>
</tr>
<tr>
<td>Response suggests some external authorization required</td>
<td>1</td>
<td>5.56%</td>
</tr>
<tr>
<td>Response unclear</td>
<td>8</td>
<td>44.44%</td>
</tr>
</tbody>
</table>

Deep-dive Element 7: Does anyone else have say in how you spend your money?

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
<td>50.00%</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>44.44%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
<td>5.56%</td>
</tr>
</tbody>
</table>
Supported Living Deep Dive: People Have Dignity of Risk & Experience

**Deep-dive Element 9:** Do you have to get permission from anyone before doing something you want to do?

- **No:** 55.56%
- **Yes:** 27.78%
- **Sometimes:** 16.67%

**Deep-dive Element 9:** Do you feel like you have support from [agency] to try new things?

- **Yes:** 88.89%
- **No:** 11.11%
**Supported Living Deep Dive:**  
**People Feel Safe**

**Deep-dive Element 10:** Is there anything about where you live that makes you uncomfortable?

- Beneficiary noted in the follow-up survey: "Not now since I got a new door."
- 1 | 5.56% Door
- 1 | 5.56% Neighborhood
- 16 | 88.89% No

**Deep-dive Element 10:** When something goes wrong with your apartment or house, who do you call?

<table>
<thead>
<tr>
<th>Contact</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff</td>
<td>6</td>
<td>33.33%</td>
</tr>
<tr>
<td>Family</td>
<td>4</td>
<td>22.22%</td>
</tr>
<tr>
<td>Landlord</td>
<td>4</td>
<td>22.22%</td>
</tr>
<tr>
<td>Family &amp; Landlord</td>
<td>1</td>
<td>5.56%</td>
</tr>
<tr>
<td>Landlord &amp; DSP</td>
<td>1</td>
<td>5.56%</td>
</tr>
<tr>
<td>Staff &amp; Family</td>
<td>1</td>
<td>5.56%</td>
</tr>
<tr>
<td>Staff &amp; Landlord</td>
<td>1</td>
<td>5.56%</td>
</tr>
</tbody>
</table>
Takeaways from Data Collection Process Effort

Feedback on the Tool

• Most care coordinators found tool/conversation to be productive, asking and securing new information not otherwise collected.
• Several indicated survey took too long.
• Noted areas where questions could be more clearly phrased.
• Noted if direct support staff were present, it seemed to be helpful to beneficiary.

Next Steps

• Determine if tool will be used moving forward.
• Refine tool.
• Refine statewide data collection process—
  • Refine identified questions
  • and additional questions.
  • Examples include: SIS, prior living arrangement, other services utilized, other.
• Develop regularly scheduled data collection process.
NC Innovations/Supported Living Resources Available

• NC Innovations Waiver webpage
  – https://www2.ncdhhs.gov/ncinnovations/
    • FAQs
    • Supported Living: A Guide to Supported Living Concepts and the NC Innovations Waiver Supported Living Service Definition
      • Including comparison chart of design differences between Supported Living and traditional residential services.
    • Developing Roommate Agreements under the NC Innovations Waiver Supported Living Service Definition

• Making A Difference Webpage
  – https://nccdd.org/supported-living-making-the-difference.html
    • Cross links to NC DHHS site
    • Provides additional context of supported living work in NC and additional supported living resources.
    • Links to Making a Difference, a technical assistance initiative to support NC’s supported living activities
[NAME] has been living in her own apartment with supported living services in place for almost a year (4/1/2017). She has been a perfect candidate for this program. She has desired to live on her own, with no roommates for years. She can now have staff when she wants/needs for her access to community needs. Liberty Corners supports her and are amazing advocates for her. She and her team have made this possible along with Assistive Technology supports from Simply Home that enable her to live safe and promote her independence daily. She has truly shined with this service and will continue to do so for years to come.

Carla H., Care Coordinator