

North Carolina Supported Living Initiative Year 3 Summary Report

The Supported Living Initiative is sponsored by the North Carolina Developmental Disabilities Council and Money Follows the Person and led by Vaya Health

Special thanks to contributing consultants, Community Resource Associates, Hope House Foundation and the National Leadership Consortium and the participating partners, The Arc of North Carolina, First, Liberty Corner Enterprises, Inc., and Turning Point Services, Inc..

Report Prepared by the National Leadership Consortium on Developmental Disabilities

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North Carolina Supported Living Initiative

Year 3 Summary Report

Introduction

In January 2017, the North Carolina Developmental Disabilities Council and Money Follows the Person funded a three-year initiative, awarded to Vaya Health, to support the expansion of Supported Living services for people with intellectual and other developmental disabilities (IDD) across North Carolina. The initiative partnered with four agencies committed to enhancing the scope and quality of Supported Living services, The Arc of North Carolina, First, Liberty Corner Enterprises, Inc., and Turning Point Services, Inc.

The Supported Living Initiative included training, technical assistance and support from Vaya Health and expert leaders from three agencies, Derrick Dufresne from Community Resource Associates, Lynne Seagle from Hope House Foundation, and Nancy Weiss from the National Leadership Consortium on Developmental Disabilities at the University of Delaware. Each partnering agency received technical assistance and support from the three consultants and Vaya Health. Additionally, Vaya Health held several conferences and training opportunities for professionals, families and people using services throughout the Initiative.

Ultimately, the goal of the Initiative was to **Build capacity within North Carolina to design and implement quality Supported Living services in partnership with people with IDD.** To do that, four objectives were established:

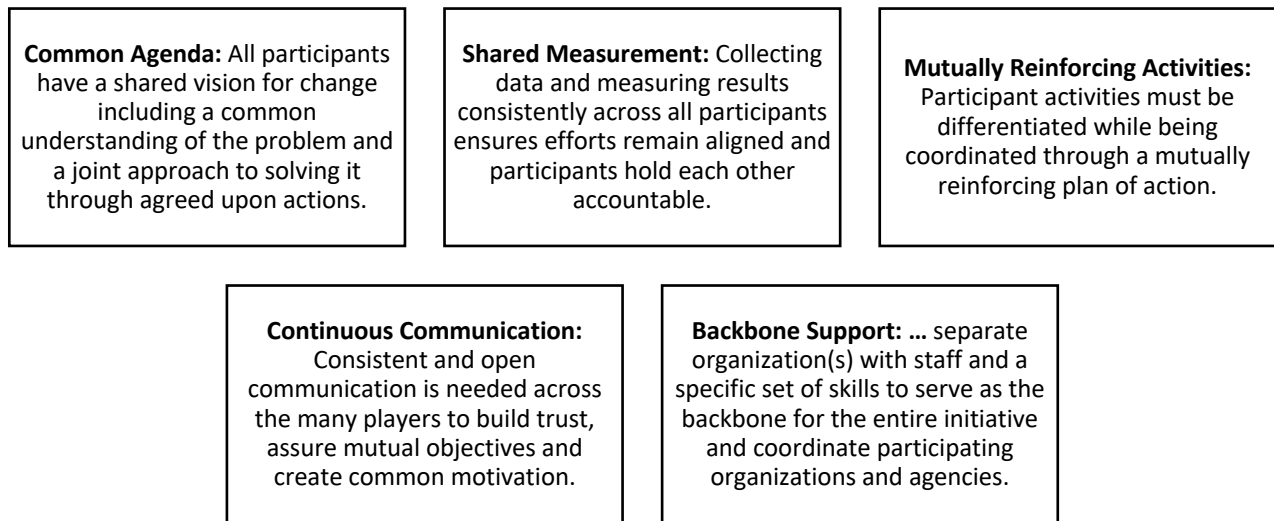
1. Support at least 3 agencies providing services to people with IDD and 18 service users (6 per agency) to transition to Supported Living services, ensuring that people with IDD control their services and lives;
2. Develop a quality measurement process to capture data, outcomes and stories demonstrating successful progress towards the statewide expansion and enhancement of Supported Living services;
3. Develop a guidebook to provide people with IDD, families, provider agencies and shareholders with resources and tools to support the transition to Supported Living services; and,
4. Share stories about Supported Living services broadly so that interested shareholders are able to see the benefit of Supported Living services for North Carolinians with IDD and their families.

The Collective Impact Framework

Under the guidance of the North Carolina Developmental Disabilities Council, a Collective Impact Framework¹ guided the design and implementation of the Supported Living Initiative. Collective Impact includes a commitment from multiple shareholders to a common agenda that aims to address a specific social issue. The framework includes five components: a *common agenda*, *shared measurement*, *mutually reinforcing activities*, *continuous communication*, and *backbone support*. Each component is described in the chart (Chart 1) on the following page.

¹ Kania, John, and Mark Kramer. "Collective impact." (2011): 36-41.
http://c.ymcdn.com/sites/www.lano.org/resource/dynamic/blogs/20131007_093137_25993.pdf

Chart 1 | The Collective Impact Framework



Information about the Evaluation

To assess progress toward Initiative goals, the National Leadership Consortium on Developmental Disabilities led a three year evaluation with shareholders invested in and impacted by Supported Living services. The evaluation was designed using the Collective Impact framework, establishing a *common agenda* and *shared measurement* in year 1, that was repeated in years 2 and 3 to assure *continuous communication*.

The evaluation sought to meet the second objective by evaluating the first objective and informing objectives three and four. The evaluation process in each year are described briefly below.

Year One

In Year One, the National Leadership Consortium researchers rolled out an intensive evaluation strategy to establish a common agenda and develop indicators for shared measurement that would be used throughout the three-year initiative. During the summer of 2017, National Leadership Consortium evaluators met with each agency participating in the Supported Living initiative as well as family members of and people who are transitioning to Supported Living services. The evaluators conducted interviews and focus groups in order to understand the process of transitioning to Supported Living services as well as the supports and barriers that affect the success of the Supported Living initiative. In total, the evaluation team met with 79 people (12 people using services, 11 family members, and 54 employees from the four partnering agencies). We asked each shareholder questions related to their expectations of Supported Living services (as they related to their role in the initiative) as well as their perspectives on the catalysts and barriers to transition and successful services.

Using a co-produced process, shareholders informed the evaluation by determining the factors that were important to focus on to ensure effective implementation of and transition to Supported Living services. Understanding the expectations gave the evaluation team indicators on which to measure the success and impact of the Supported Living Initiative. From the initial meetings in Year One, a series of metrics were developed that were used in Years Two and Three.

Year Two

In Year Two, Vaya Health and the National Leadership Consortium team rolled out the established evaluation process in the summer of 2018. Interviews were conducted with 18 people with IDD who were using or transitioning to Supported Living services, 11 family members of people using Supported Living services, and 15 agency employees from the four partnering agencies. An online survey was also sent to contacts at each of the four partnering agencies, with a request that each agency send the survey to all, or a large sample of agency employees involved in Supported Living services. In total, twenty-six agency employees responded to the online survey; agency leaders shared that they struggled to disseminate the survey and gather information from employees due to lack of reliable email addresses, lack of communication of the purpose of the survey and general business that inhibited responses. Most of the twenty-six responses came from one agency, so they are not reliable and have been eliminated from the evaluation below. In Year Three, online surveys were not disseminated, and instead in person individual and group meetings were again scheduled to gain agency feedback.





Year Three

In Year Three, in person interviews and focus groups were again repeated with people using Supported Living services, family members and agency staff. Again, each stakeholder group was asked to respond to topics and expectations for Supported Living services established in Year 1, to ensure consistency and shared measurement throughout the initiative. Additionally, agency leaders were asked to reflect on the three-year initiative to consider the ‘lessons learned’ across Years One to Three. In Year Three, ten people using Supported Living services, three Family members and thirty-seven agency staff were interviewed.

In Year Three, fewer families were available to participate in interviews, however during Year Two, a coalition of families engaged with state leaders regarding concerns with and expectations for Supported Living services. Families continue to meet with state leaders to discuss their experiences, concerns and successes with Supported Living services in North Carolina.

The chart (Chart 2) below shows the breakdown of evaluation participants in each year.

Chart 2 | Evaluation Methodology and Participation

Data Source	Methodology	Respondents		
		Year 1	Year 2	Year 3
People using Supported Living services	 One on One Interviews	12	18	10
Family Members of people using Supported Living services	 Online Surveys	11	11	3
Agency Employees providing Supported Living services	 Group Discussions and	54	15	37
	 Online Surveys		26	

Structure of the Results

Results from Years One, Two, and Three have been organized to highlight the primary takeaways from each round of data collection. In Year One, the findings outline the expectations of each shareholder group:

- People with disabilities using or transitioning to Supported Living services;
- Families of people with disabilities using or transitioning to Supported Living services; and,
- Employees of agencies involved in providing and leading the transition to and implementation of Supported Living services.

Again, the establishment of expectations in Year One guided the development of evaluation questions and metrics for Years Two and Three of the initiative. Therefore, results from Years Two and Three highlight the successes and challenges that each shareholder group experienced throughout the Initiative. Further, Year Two and Year Three findings have been combined in this report. Interviews with people using services, family members and agency employees showed that the successes and challenges related to Supported Living Services were consistent each year. As North Carolina undergoes changes to service regulations and definitions, people are facing the same challenges and supports as they utilize and provide Supported Living Services.

Finally, the report ends with an aggregated analysis of the findings, describing specific strategies that facilitate successful Supported Living services and recommendations to consider as Supported Living services continue beyond the three-year initiative.

Findings from the Supported Living Initiative Evaluation

Year One Findings | Expectations for Supported Living Services

Overall, findings from the Year One interviews showed an established appreciation for and commitment to Supported Living services from each of the shareholder groups. People interviewed valued Supported Living services as a flexible option to assure that people with IDD have the opportunity to realize their fundamental rights to control their services and lives, and live in the communities of their choosing. Therefore, expectations for Supported Living services were relatively consistent across each shareholder group. The findings below highlight themes from people with disabilities using services, family members and agency employees from the four partnering agencies.

People with Disabilities Using or Transitioning to Supported Living Services

To describe the expectations that people with IDD had for Supported Living services, it is important to note that people also accessed Supported Living in a variety of ways. The path that people took to receiving Supported Living services influenced their perceptions of the supports they received. For instance, people accessed Supported Living in the following ways:

- By asking for a change in home or services;
- Through a family member who heard of the opportunity;
- Through the agency that supported them;
- Through a step-down approach advanced by the demonstration of certain living skills: first by moving from a group home setting to living in a supervised apartment attached to the group home, then eventually moving into their own apartment and transitioning services; and,
- By meeting service definitions and needs that automatically qualified them for Supported Living without a significant transition in the type or amount of services received².

People who had accessed Supported Living services without going through a transition process that impacted their day to day lives had fewer expectations of the Supported Living service. However, they did have expectations related to the quality of services they received. Their feedback related to quality services was included in the analysis. Expectations from people using or transitioning services are outlined in the chart (Chart 3) on the following page.

² For people in the last category, many were not aware that their services had changed at all. In those instances, we talked about expectations for supports as well as what good lives (days, homes, relationships, community involvement, employment, etc.) look like and how services and supports help them (or could better help them) achieve those outcomes.

Chart 3 | Expectations of People with IDD Using or Transitioning to Supported Living Services

Themes	How Expectations were Expressed
<p>Relationships The primary topic centered on their relationships, including familial, paid and chosen. Whether people identified the support need or not, it was clear that Supported Living services should spend a significant amount of effort ensuring that people are connected to their communities and loved ones so that their lives are full of people with whom they share mutual love and connections.</p>	<p>Direct Support Professionals Quality supports were defined by the quality of Direct Support Professionals who worked for them. Important characteristics and practices shared include Respect Kindness Community connections Genuine interest in them Flexibility Putting their wants and needs first Willingness to try new things High expectations Aligned interests .</p> <p>Unpaid Support Almost every person listed someone in his or her life who was not paid to provide services and played a major role in their happiness and wellbeing. For people using services, there were a few factors that supported quality relationships Access to loved ones Being with people who value them Shared interests .</p>
<p>Strengths Based Support People using services were eager to talk about their achievements and successes, and indicated that successful Supported Living services would focus more on their strengths than weaknesses.</p>	<p>Focusing on Strengths People who use services want the agencies and staff who support them to focus more on their strengths and celebrate their accomplishments than on what they need to change about themselves. For instance, some people felt that the DSP who worked for them focused too much on health eating and working out, one woman shared that she wanted to spend more time with her family and friends who didn't care about her weight or what she ate.</p> <p>Earning Supported Living People were aware of and focused on the flaws, problems and behaviors that the system had determined and labeled them with. It was also clear from the interviews that many people have to earn their way (or the right to access) Supported Living services. For example, people shared specific skills that they needed to develop or specific behaviors that they had to stop demonstrating before they were allowed to transition to Supported Living services. People shared their frustration with the focus on their flaws and indicated that they wanted people to support them to lead, direct and live quality lives.</p>
<p>Choice and Control Finally, people using services saw Supported Living as a means to ensure their autonomy, choice and control over their supports, environment and lives.</p>	<p>Control Over Services People indicated that with Supported Living services they could choose when and how they wanted to be supported. Several people talked about a clear alignment between their personal goals, changing lives and the services they received. Further, some people appreciated the option to choose when they were supported, indicating that they could change their schedules and ask the DSPs supporting them to leave whenever they wanted or needed.</p> <p>Control Over Environment For people who previously used more traditional and congregate services, they appreciated the increased control they had over their space, including how it looked, who was allowed to be there, and what they could access.</p> <p>Community Inclusion People also noted that Supported Living services facilitated meaningful inclusion and belonging in their communities. People listed several ways that they were part of their communities, including employment, social activities, fitness, access to coffee shops and restaurants, and artistic connections.</p>

Family Members

Many of the expectations for families members aligned with those of people with disabilities using services. Families also saw Supported Living Services as a means to ensure community inclusion and belonging, and autonomy for their loved ones. Additionally, families shared expectations specific to their role as family members and support providers for their loved ones. Those expectations are listed in the chart (Chart 4) on the following page.

Chart 4 | Expectations of Families Using or Transitioning to Supported Living Services

Themes	How Expectations were Expressed
<p>Transition: A great deal of the discussions with families centered on the transition to Supported Living services.</p>	<p>Change in Scope of Services Over Time For people who have been living in group homes or similar models, services have been available 24/7; the transition for people using services (as well as their family members) is not a simple one. Consistently, families agreed that, eventually, they expected fewer services and facetime with direct support staff for their family member, however they want to ensure that their family members’ needs are met (and will be met) before decreasing the amount of support they receive.</p>
<p>Family expectations and Caregiver Role: Family members want to take on the role of the family member, rather than the role of the caregiver. Many family members shared that they have been in a caregiver role for most of their children’s lives, and that they are anxious to develop a family oriented relationship.</p>	<p>What Families Want Providers Take Over Families consistently shared that they would like the time they spend with their family member with disabilities to look more like the time they spend with their family member without disabilities. To get there, they want providers to be the primary facilitators of coordination of services, schedules and budgets, providing direct services, helping family member become more connected to their community, and finding housing and roommates.</p>
<p>Recognizing Family Trauma Past experiences of families in the services system greatly impact their perceived feasibility of Supported Living. For people whose family members have experienced rejection from agencies and services as well as abuse, neglect, injuries, bullying, etc. in and out of the service system, they bring the fear of those experiences with them as they plan for Supported Living services.</p>	<p>Ensuring Health, Safety, and Wellness Families want a concrete plan to address healthy, safety and wellness for their family members.</p> <p>Preparing for the Worst Many families asked <i>What if this doesn’t work?</i> Families want to know how the agency will respond in a crisis. Some common issues to account for include:</p> <ul style="list-style-type: none"> • People leaving the house when a DSP is not present (eloping); • Change in health or injury of the person using services; • Change in health or injury of family member; and, • General emergencies (fires, natural disasters, etc.).
<p>Transition to Supported Living Services Some families expressed frustration with the transition to Supported Living services and indicated that they expected the system to support families and transition people quickly and smoothly.</p>	<p>Time and Process Many families shared that the process to transition to Supported Living services is cumbersome due to the multiple approvals, planning and transition needed. They asked that agencies and systems leaders review and adapt processes to assure that people are able to access Supported Living services.</p> <p>Technology families do want access to technology that will support their family members to live independently. However, they noted some barriers:</p> <ul style="list-style-type: none"> • Needing to receive multiple bids for some types of technology; • Getting access to companies that provide technology; • Knowing the options for technology, smart homes and accommodations; • The time it takes to get approved for accommodations; and, • The time it takes to receive money for accommodations once approved.
<p>Levels of Support Need It was important to families to ensure that people with all levels of support needs have access to Supported Living services.</p>	<p>Adequate Budgets Families of people with high support needs (particularly Level 3 needs) noted that budgets need to be large enough to ensure adequate supports are provided.</p> <p>Ensuring Access for People with High Support Needs Some families shared concerns that Supported Living services would not be available to their family members with high (Level 3) support needs due to constraints beyond budgets. They determined that employees of provider agencies and MCOs need to be willing to offer and provide Supported Living services to all people with all types and scope of disability.</p>
<p>Communication and Information about Supported Living Services It is important to families to be informed of service, regulatory and budgetary changes, options and decisions, particularly related to the Supported Living initiative.</p>	<p>Clarity Around Definitions and Allowances Families want to understand decisions and processes related to budgets, service hours, and allowable services. Sometimes families felt like rules conflicted and the system was overly complicated, particularly during the transition.</p> <p>Sharing Information Families want increased sharing of information about Supported Living, including successful strategies and stories to support people with different scopes and types of support needs, systems changes that impact families and best practices in implementation of Supported Living services.</p>

Agencies Providing Services

Finally, people working in all levels of the four partnering agencies providing Supported Living services shared expectations related to the service from the provider perspective. Generally, agency employees recognized that Supported Living services were an ideal support for people with IDD; the successful transition to and implementation of those services highly depended on agency practices. Specifically, agency employees shared internal and external expectations and strategies that facilitate successful Supported Living services. The chart below (Chart 5) lists the internal and expectations that the four partnering agency employees described.

Chart 5 | Expectations of Agency Employees

Themes	How Expectations were Expressed
Internal Expectations	<p>Flexibility and Creativity Agencies that are having the most success with Supported Living services are those that are able to operate nimbly, flexibly and creatively. Because Supported Living services, by definition, require that agencies are responsive and able to adapt to people’s changing needs and preferences, agencies who have structures and processes in place that allow them to make quick decisions to adapt to people as they change and grow, are better able to transition to Supported Living services.</p>
	<p>Nimble Operations Agencies that are nimble find that they are better able to provide responsive and adaptive Supportive Living services, particularly to those that have higher support needs. Nimble agencies are characterized by those that have fewer layers of employees in their organizational charts, have lower overhead rates, and have leaders who know the services system well enough to know about and negotiate creative service combinations or flexible budgets.</p>
	<p>Organizational Culture Agency leaders, managers and DSPs consistently agreed that when their organization had a positive, growth oriented culture, they felt that they were better able to provide quality Supported Living services that were directed by the people they support. Key elements of culture included:</p> <ul style="list-style-type: none"> • quality of communication; • employee engagement; • relationships between all levels of employees; • the amount of support that employees felt from their supervisors, co-workers and direct reports; • positive approach to change and growth; • transparency; • alignment of values with principles of Supported Living; and, • pride in agency and work.
	<p>Traditional Service Models Agencies that were continuing to operate traditional service models shared that this was a barrier to successful Supported Living services. They indicated that it was harder to gain buy-in from Direct Support Professionals, and help employees differentiate practices when they were operating under two models.</p>
External Expectations	<p>Access to Consultant Expertise and Perspectives Agency leaders have shared that access to consultants who have experience and expertise in transforming agencies and systems from congregate models to individualized supports is helpful to support them to:</p> <ul style="list-style-type: none"> • Identify agency operations and strategies that will lead to successful transition to Supported Living; • Overcome systems and agency barriers that arise; and, • Bring people who are steeped in traditional supports along.
	<p>MCO Availability and Responsiveness Vaya Health has been very intentional to support agencies to successfully transition to Supported Living services through statewide communication and ensuring that project leaders are available and responsive to the questions and needs of each agency. Agencies shared that these actions must be adopted by all MCOs to ensure successful transition to Supported Living services for all people.</p> <p>Transition Resources and Supports: For many families, the scariest thing about Supported Living is the transition. Many people with disabilities who are considering using Supported Living are used to 24/7 services, group living and care based models that position DSPs to do for and to rather than with. Agencies have been able to support families through those fears, in part because Vaya has approved temporary increases in budgets and supports as people transition to services.</p>

Years Two and Three Findings

Primary Changes in Year 2 and 3

Results of the interviews from Years Two and Three were consistent. That is not to say that there were no changes in the scope of Supported Living services provided, or the outcomes experienced by people with IDD who were transitioning to or using Supported Living Services. However, the changes seemed to be unrelated to the time in the Initiative, and more related to the contextual factors experienced by people with IDD, their families and the four partnering agencies. The most significant changes are described in the charts (Charts 6 through 9) below.

Chart 6 | Changes for People Transitioning to Supported Living Services

For People Transitioning into Supported Living Services

Change 1 | Increased Autonomy

As people transition into Supported Living services from more traditional or congregate models, they generally gain:

- Autonomy;
- Choice and control over their services, environments and lives; and,
- Access to community resources and relationships.

Change 2 | Transition

When people gain more control over their services, lives and environments, there is generally a transition period that may be rocky as people adjust to their new environments and learn the boundaries of control.

What these Results Mean | The transition to Supported Living services offers people more control over their lives. While control is ultimately what people share that they want, learning to direct one's services and life is an adjustment. Some people were uncomfortable with the transition and others began experimenting to understand the limits of choice and control. Ultimately, when people were effectively supported to adjust to their new lives, they were more satisfied. People with IDD, themselves, did not choose to go back to more restrictive services or environments. However, this transition period is important for agencies to understand, as successful outcomes related to the transition to Supported Living services may take time.

For People Continuing to use Supported Living Services (or services akin to Supported Living)

Change 1 | Relationships

Each person who was interviewed noted a change in the nature in at least one of their personal relationships (with family members, friends, professional colleagues, or romantic partners). People spoke of gaining new relationships or deepening relationships with friends, colleagues and romantic partners, as well as losing relationships with friends, family members and romantic partners. The tenor of the conversation and the nature of the services they wanted and needed depended deeply on those relationships.

Change 2 | Housing

Six people interviewed noted that they had moved to a different home or apartment to be closer to family members or in a location more suitable to their needs during the Initiative. The amount of choice and control they had over their new environment impacted their perspectives on that change.

What these Results Mean | Once people are settled in their Supported Living services, they do not think about the service definition as long as supports are consistent and Direct Support Professionals are respectful, responsive and follow the lead of the person using services. People are significantly happier when they have meaningful connections and have access to people they care about.

However, when people do not feel that the services are respecting their choice, autonomy and right to meaningful relationships, they shared significant dissatisfaction with the Supported Living service. For instance, one person moved to a home that he did not choose (using Supported Living). He was frustrated to have lost his network of friends and saw Supported Living as a service that was being used against him.

Additionally, major changes in relationships can impact a person's satisfaction with Supported Living services. One woman expressed considerable sadness over the loss of a group of friends. She shared that she needed more support now because she is feeling so sad. She wanted the people who support her to be more aware of this need and respond by increasing their emotional support.

For Families of People Using Supported Living Services

Change 1 | Increased Demand for Adequate Level 3 Supports

Families continued to express concern about the lack of access to affordable and quality Supported Living services that people with higher support needs have in North Carolina, particularly those with Level 3 support needs. While this issue was raised as an expectation in Year 1, as the Initiative progressed, families continued to express their frustration and concern and engage with state level shareholders to address the issue.

What these Results Mean | For too long, people with the highest support needs have had less access to flexible, community based services and supports. People have been refused or terminated from services when agencies were not able to adequately accommodate to their needs. Families recognized this issue as it related to Supported Living services early in the Initiative, indicating that the service definitions, parameters and allowed budgets did not meet the needs of all people with IDD, particularly those who have the highest levels of support needs. Because the Initiative was designed to provide technical assistance and support to agencies providing services as well as resources to shareholders interested and involved in Supported Living, the issue raised by families was engaged concurrent to the three-year Supported Living Initiative. Representatives from the North Carolina state Developmental Disabilities agency, the Developmental Disabilities Council, MCOs across the state, family members and advocates have convened to address this specific issue. They will

continue to meet in 2020 to recommend systems level changes that will enhance the quality of Supported Living services statewide.

Chart 9 | Changes for Agencies Providing Supported Living Services

For Agencies Providing Supported Living Services

Change 1 | Changes in Number of People using Supported Living Services

During Years Two and Three, the number of people using Supported Living services increased statewide. However, the number of people using Supported Living services with each partnering provider agency varied. Two agencies increased the number of people while one agency remained the same and one decreased the number of people supported.

Change 2 | Increased Flexibility in Service Models and Agency Structures

During Years Two and Three, one agency transitioned its service model by closing a group home to offer more access to Supported Living services to more people supported by their agency. Another agency adopted a flexible individualized budget model to make Supported Living services successful for people who choose them. One agency did not change its structure or service model, but continued to grow and expand services, including the Supported Living service.

What these Results Mean | The agencies that have consistently had the most success in providing and growing Supported Living services for people with IDD are the agencies that have:

- Transitioned away from congregate services to more individualized services;
- Have adopted flexible, individualized budgets that ensure diversity in the types and levels of support provided to people (based on their need); and,
- Have continued to expand individualized, flexible services by supporting more people with IDD to use Supported Living or Self Directed services without compromising vision or practice to provide group-based or segregated services. (This was true for one agency that did not provide any congregate services before or during the initiative) .

The successful provision of Supported Living services continues to require flexible and adaptable agency structures and practices that are responsive to the individual needs and goals of people supported.

Successes and Challenges Impacted Supported Living Services

Ultimately, the factors that facilitated and hindered Supported Living services did not change between Years Two and Three. Essentially, presence of strategies that facilitate Supported Living services increased the likelihood that people with IDD and their families were experiencing quality Supported Living services. Similarly, absence of strategies that facilitate Supported Living services decreased the likelihood that agencies were successfully transitioning to and providing Supported Living services. As this was a technical assistance and support initiative, instead of quantifying practices and outcomes related to Supported Living services, the findings of this section center on the replicable strategies that people with IDD, families and agencies can employ to enhance the quality of Supported Living Services across North Carolina. Further, they offer recommendations to overcome current and potential challenges to Supported Living services that can be addressed as shareholders continue to expand access to and enhance the quality of Supported Living services beyond this three-year Initiative.

The chart on the following page (Chart 10) highlights the successes of the Supported Living Initiative, as they relate to the expectations described in Year 1. The chart outlines successful outcomes, as well as strategies that have enhanced access to and quality of Supported Living services for North Carolinians with IDD. The strategies listed will be useful to shareholders who are interested in utilizing or providing Supported Living services, as they offer concrete actions and resources that may be employed.

Chart 10 | Strategies that Make Supported Living Successful

Year 1 Expectations of People with IDD and Families Related to Supported Living	Years Two and Three What We've Learned about Supported Living Services	Concrete Strategies that have Led to Success
Services that assure that people who are using supports are ultimately in control	People who are using services have much more choice about where they live, how their homes are set up and decorated, who has access to their homes and when, etc.	People using services choose what they want their lives to look like and determine their own support schedules and can change their minds (ask people to leave early, stay late, etc.)
	People who are using services get much needed privacy when they want (including privacy from people providing supports).	Several people have noted that their homes feel more their own when licensing does not control their environment or have access to inspect their space.
	People are choosing how and when they engage in their chosen communities and have more access to participate and belong.	Direct Support Professionals are able to engage one on one with people who are using services, so they are better able to respond to their chosen day to day preferences, goals and needs.
	People need time to adjust to what it means to have choice and control in their lives. As they learn and adjust, they can change their minds and make different choices.	People who are providing Supported Living services know they people they are supporting well. They talk about their wants, needs and goals as an individual and appreciate who they are as a person.

Year 1 Expectations of People with IDD and Families Related to Supported Living	Years Two and Three What We've Learned about Supported Living Services	Concrete Strategies that have Led to Success
Flexible Services	People who are using services have more control over when and where they receive services and how they are provided.	<p>People using services determine their own support schedules and can change their minds (ask people to leave early, stay late, etc.).</p> <hr/> <p>Direct Support Professionals have more autonomy in their schedules; they have a say in weekly scheduling and can make in the moment decisions based on the wants and needs of people they support (leave early if asked, stay late if needed, etc.).</p> <hr/> <p>As people's lives and needs change, agencies are able to adjust the number of hours of support provided on a day/ week to week basis.</p>
	Agencies providing services report more flexible approaches to support that are led more by the wants and needs of people they support than agency traditions and norms.	<p>Agencies have used combinations of services (both formal and community based) and technology to supplement Supported Living services so that people have the amount of support they need, and can access their communities, friends and loved ones on their own schedule.</p> <hr/> <p>Agencies know the people they support very well, as individual persons; many agency employees are familiar with the preferences, support needs and short/long term goals of the people they support. This has led to widespread investment in the success of individual people as well as collaborative and creative problem solving to meet people's specific wants and needs.</p>
Responsive Services	As the needs of people with IDD and their families change, quality Supported Living services are able to respond to those changes and provide appropriate support without over supporting people.	<p>Agencies expect and anticipate that people's lives will change. They have structures and systems in place to remain in tuned with the person's needs so that they are able to adapt in the time that the person needs.</p> <hr/> <p>Agencies have flexibility in the amount of support they can provide to a person, so that if a person's needs change, they are able to quickly adapt.</p>

Year 1 Expectations of People with IDD and Families Related to Supported Living	Years Two and Three What We've Learned about Supported Living Services	Concrete Strategies that have Led to Success
Goldilocks approach to services	Agencies are working to assure that people are not under supported, and at the same time are not over supported.	The daily rate structure allows agencies to be flexible with how budgets and schedules are designed.
		Transition support/ funding has helped people receive the services they need, particularly for people who moving Supported Living services involves a significant change in where they live, who they live with and how they are supported. This has provided people with needed short-term intensity that can decrease as people become more familiar with the service and less in need/ want of heightened staffing.
		Technology supports people to have access to services without needing staff in their homes. Technology has also supported people to live in accessible homes and access non-human support so that they do not rely on Direct Support Professionals to meet every need.
		Agencies are better able to offer services that are not “all or nothing” or “one size fits all.” Each agency shared that the principles of Supported Living services were already aligned with their organizational values, Supported Living services enables them to align values and practices by offering services designed specifically for people.
Services are available to all people, including people with the highest support needs	People who receive a Level 3 diagnosis have the same access to Supported Living services as people who are categorized at lower level support needs.	Budgets reflect the service needs of people who are using Supported Living services. Budgets are not capped at rates that make Supported Living impossible for people who need more intensive and consistent support.
		Agencies employ flexible and individualized budget models that support people to control their funds and access flexible services.
		Agencies do not over support people because of their diagnosis, but provide only needed and chosen services.
		People with IDD have natural relationships and supports in their lives that allow people to have time when they are not using (or using as many) formalized services.
		Providers and Support Coordinators do not limit a person’s option to access Supported Living services because of their diagnosis. They recognize that everyone can be successful using individualized supports.

Year 1 Expectations for Agencies Related to Supported Living	Years Two and Three What We've Learned about Supported Living Services	Concrete Strategies that have Led to Success
Responsiveness, flexibility on behalf of the state and Managed Care Organizations	The state has revised service definitions and waivers to better meet the needs of people using services, feedback and input from shareholder groups across the state have been considered.	Changing state regulations to allow transition funds for people who are moving into Supported Living services will allow agencies to bill for transition services (including helping people find a home of their own, access community supports, etc.). This makes it much for feasible for agencies to support people to transfer to Supported Living services as it does not put a financial strain on the agency to provide non-billable services.
	Managed Care Organizations have provided flexible options for agencies to provide quality Supported Living services that meaningfully meet the needs of people they support.	MCOs have approved temporary budget increases to assure people have the support they need as they transition into services, or during a significant life change. This helps agencies provide increased supports as people need them, making them more responsive.
		Managed Care Organizations have invested in developmental opportunities for agencies (training, technical assistance, etc.) to assure that agencies have the knowledge, information and resources needed to provide quality Supported Living services. For instance, Managed Care Organizations sponsored a behavioral health specialist to provide a day of training and development to agencies and families across North Carolina who are involved in Supported Living services.
Transparent, Participatory Work Environments	Agencies that employ transparent and participatory management and decision making strategies are better able to transition to and maintain Supported Living services.	When Direct Support Professionals and Frontline Supervisors participate in organizational decision making, they can use their 'on the ground knowledge' to provide recommendations, and identify catalysts and barriers to Supported Living services.
		While most people agree that more individualized, responsive services are better for people with IDD, many do not agree on the processes or practices that ensure effective services. Agencies that understand (survey, collect feedback from, provide listening sessions for) employees beliefs and values regarding Supported Living services are better able to anticipate the training, education and support that employees need to successfully transition.
	Employees must feel respected in their role as a change agent to ensuring successful Supported Living services.	Employees are unresponsive to 'because I said so' leadership. Informed employees who feel like their voices are heard are more likely to adapt to change. Agencies that ensure the voices of all employees are heard during a change process are more successful.
		Primary factors that influences employee engagement are the relationships that they have with their co-workers. Agencies that foster respectful communication and management strategies through culture, training and leadership are better prepared for change.

Year 1 Expectations for Agencies Related to Supported Living	Years Two and Three What We've Learned about Supported Living Services	Concrete Strategies that have Led to Success
Staff need adequate training, support and resources to provide quality Supported Living services	Staff see that person centeredness extends beyond the people they support to others in their agency. Staff who feel that they are working for agencies that invest in their development and wellbeing are better able to provide supports that are responsive and respectful of the people they serve.	Agencies that explicitly invest time and resources in staff development, support and appreciation shared that Direct Support Professionals were prepared and on board with principles of Supported Living.
		When Direct Support Professionals had, and/or are able to access the resources (both financial and not) needed to meet the needs and desires of people they support, they felt that they were better able to provide quality Supported Living services.
		When staff had a supervisor, who was available and responsive to answer questions, address concerns, respond in a crisis or provide guidance and encouragement, they felt that they were better able to provide quality Supported Living services.
Individualized Supports Need to be Sustainable	Agencies that provide only Supported Living and person-directed, individualized services are more successful.	Some agency employees struggled to work in an agency that provides both traditional and Supported Living services as they seemed to contradict one another. When agencies adopted an individualized philosophy in services and practices, Supported Living services seemed much more natural to the agency.
		There are significant costs associated with agency transition and transformation. Because the Supported Living budget is already tight, agencies that did not have to transform were able to provide more nimble and adaptive services at a larger scale.

Recommendations to Enhance Supported Living in the Future

Throughout the three-year Initiative, results from the evaluation identified several significant challenges to Supported Living services. These challenges have impacted people with IDD and families access to and quality of experiences with Supported Living. They have impacted agencies' capacity to transition to and expand the provision of Supported Living services and they have impacted the growth of Supported Living across the North Carolina IDD system. The most common challenges identified are listed in the chart (Chart 11) below. Recommendations to address these challenges that have been identified by people using services, families and the four partnering agencies are included in the chart.

Chart 11 | Recommendations to Overcome Challenges to Supported Living Services

Challenges to Supported Living	Impact	Steps Taken	Recommended Actions/ Next Steps to Address Challenges
Lack of Affordable Housing	Supported Living services can be limited to people who have family members who can afford to pay for housing and people who have received housing vouchers.	<p>Vaya Health is working with HUD agencies to determine solutions to housing shortages in their catchment area.</p>	<p>Agencies would benefit from clarification about Supported Living Services and where/ how many people can live together or in a shared complex. Agency leaders recognized that there is a fine line between supporting multiple people to live meaningfully in an apartment complex and developing an intentional community that secludes people with disabilities to a specific area of the complex or to have more access to other people with disabilities than the entire community.</p>
		<p>Agencies have begun to develop relationships with developers and apartment complexes to discuss options for affordable housing for people using Supported Living services.</p>	
		<p>State systems leaders have convened task groups to consider their role in enhancing the availability of affordable housing for people with IDD.</p>	<p>The state can continue to address the shortage of affordable housing across the state by increasing the number of housing vouchers available, raising service rates to cover housing costs, or find unidentified solutions that will ensure more people with IDD have access to affordable, individualized housing.</p>
Disincentivizing Rates	Providers have noted that increased rates for ICF and group services, along with inadequate rates for Supported Living services do not incentivize transformation of services and practices.	<p>Families have invested in properties/ homes or are paying/ subsidizing rent for their adult children who are transferring into Supported Living services.</p>	<p>Agencies and family members have recommended statewide efforts focusing on affordable housing options for people in need across North Carolina. They recommend statewide support so that families/ agencies can learn/ strategize collaboratively.</p>
		<p>Systems leaders have noted the issue and are considering options to assure continuity of support for all people using services in the IDD System</p>	<p>The system should consider incentivizing individualized supports, including Supported Living services through increased rates to assure alignment between goals and outcomes.</p>

Challenges to Supported Living	Impact	Steps taken	Recommended actions/ next steps to address challenges
Lack of use and understanding of Supported Living services	<p>Agencies that are providing Supported Living services to a small percentage of total service users still treat Supported Living services as a niche service. Rules and training are different, so staff who are providing and overseeing Supported Living and more traditional services have to navigate different service models and expectations on a day to day basis.</p>	<p>Agencies have begun developing marketing and educational materials for staff and families to help them see Supported Living as a viable option</p> <hr/> <p>Agencies have been reallocating resources to assign staff to oversee and provide Supported Living services. One agency primarily provides Supported Living services, they shared that this has benefitted them significantly as they have a team of staff who understand the service and support the successful implementation.</p>	<p>Agencies would benefit from educational and marketing materials developed by the MCO or state that they could share to promote Supported Living services as a sustainable option to many people they support, and their families.</p>
	<p>Several agencies can't afford to have staff solely dedicated to Supported Living services because there is not enough income to support full time staff. Similar to the issue identified above, staff have to navigate dual roles and expectations that are often very different from those under traditional services.</p>	<p>A Supported Living guidebook is under development: The guidebook provides resources, exercises stories and evidence-based practices to promote access to, transition to, provision of and understanding of quality Supported Living services.</p>	<p>Agencies have asked for learning/ collaboration opportunities with other agencies providing Supported Living services. They could benefit from regular meetings with others to learn about strategies to overcome barriers and assure that more people thrive in Supported Living services.</p>
	<p>Few people using Supported Living services doesn't position the service as a viable and available option to many families and people using services. Some families don't trust that the service will be around in a few years, causing further disruption to their families.</p>	<p>Webinars have been hosted for families, agencies and stakeholders to provide information about the services, education about topics that are relevant to Supported Living services and success stories of people who are thriving in Supported Living services. These webinars are archived and will continue to be developed and available.</p>	<p>Families would benefit from materials and educational opportunities to better understand the statewide investment in the sustainability of Supported Living services so that they continue to trust that this is an ideal option for their family member now and in the future.</p>

Challenges to Supported Living	Impact	Steps taken	Recommended actions/ next steps to address challenges
Lack of use and understanding of Supported Living services on the part of Support/ Service Coordinators and Managers	Service Coordinators don't consistently understand Supported Living services because so few people are using them. Agencies are having to educate Service Coordinators about the rules and qualifications and many Support Coordinators tell people they do not qualify because they have high support needs.	A day long training was offered to Service Coordinators to help them understand the Principles of Supported Living services.	<p>Agencies and families request further training and support for Service Coordinators so they understand the service, can make recommendations and support transitioning to Supported Living services.</p> <hr/> <p>Agencies and families have requested that MCOs have appointed staff who are dedicated to Supported Living services, including education of staff and families, marketing and assuring that Service Coordinators are offering Supported Living services and have the tools, resources and information needed to help people transition smoothly.</p>
Budget Caps on services for people with highest support needs	Many people with the highest support needs do not have access to Supported Living services because MCOs or agencies cannot make the allowable budget work to meet their support needs.	<p>Families have engaged with systems leaders to enhance the rate for Level 3 supports and allow for flexible budgets for people who need more services than are covered under the current rates.</p> <hr/> <p>Agencies and MCOs have worked with families to identify areas where people may be over supported or could utilize natural, unpaid supports to ensure that people with Level 3 support needs can access Supported Living services, and also access appropriate services that do not over or under support them.</p>	State leaders and MCOs should continue to work with family advocates to assure that type and scope of disability is not a barrier to accessing Supported Living services while ensuring the fidelity of a flexible, individualized service that is directed by the person with IDD.
	Some people with higher behavioral support needs are not accessing Supported Living services, because adequate behavioral services are not identified, in place or available.	Vaya Health has engaged with experts in behavioral supports, including David Pitonyak, to educate shareholders about the meaning of behavior and develop skills to provide effective behavioral support needs.	

Conclusion

The 3-year Supported Living Initiative funded by the North Carolina Developmental Disabilities Council and Money Follows the Person exerted a tremendous effort to reignite Supported Living services across the state of North Carolina. Shareholders formally and informally involved with the initiative have committed to ensuring that Supported Living services are a viable and sustainable support available to all people with IDD.

Findings from the evaluation of the Initiative demonstrate that, while there is systemwide appreciation for Supported Living services, the capacity to provide quality supports depends on several factors at the family, organizational and systems levels. Flexibility, creativity and responsiveness enhance Supported Living services, while traditional models, rigid practices and complex approval processes hold them back.

There has been significant growth in access to and knowledge about the strategies and practices that lead to quality Supported Living services. The resources and materials developed during the Initiative will continue to inform people in the future, as the online resources will be available statewide. At the same time, North Carolina will continue to address several systems challenges, namely related to housing, education of IDD service professionals, and assuring that Supported Living services are available to all people with IDD who choose them.

Led by Vaya Health, the work of the partner agencies, technical assistance consultants, invested shareholders, families and people with IDD developed a foundation of education, resources, training and person-power that will continue to expand Supported Living services beyond the Initiative. The outcomes and outputs of the Initiative demonstrate that all involved successfully met its goal to **build capacity within North Carolina to design and implement quality Supported Living services in partnership with people with IDD.**