Supported Living: Making the Difference: Year 1 Findings and Recommendations

During the summer of 2017, researchers from the National Leadership Consortium on Developmental Disabilities met with shareholders involved in the Supported Living Initiative, led by Vaya Health and funded by the North Carolina Developmental Disabilities Council and Money Follows the Person Project.

Using an approach grounded in Collective Impact,[1] National Leadership Consortium researchers 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 *(see chart below for description of the Collective Impact Framework).* The researchers conducted interviews and focus groups in order to establish a common agenda and develop indicators for shared measurement 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. Specifically, we used the information gathered to develop evaluation recommendations for the end of year 1, and through years 2 and 3 of the initiative, researchers. In total, we met with 79 people.

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. The findings, themes and recommended evaluation strategies are outlined below.

Liberty Corners LLC	
Agency Leaders	12
Agency Managers	4
DSPs	4
Family Members	-
People Using Services	4
First	
Agency Leaders	3
Agency Managers	1
DSPs	5
Family Members	2
People Using Services	2
Arc of North Carolina	
Agency Leaders	13
Agency Managers	3
DSPs	1
Family Members	4
People Using Services	2
Turning Point	
Agency Leaders	2
Agency Managers	3
DSPs	5
Family Members	5
People Using Services	4

Collective Impact Framework and Components

Common Agenda: All participants have a shared vision for change including a common understanding of the problem and a joint approach to solving it through agreed upon actions.

Shared Measurement: Collecting data and measuring results consistently across all participants ensures efforts remain aligned and participants hold each other accountable.

Mutually Reinforcing Activities: Participant activities must be differentiated while being coordinated through a mutually reinforcing plan of action.

Continuous Communication: Consistent and open communication is needed across the many players to build trust, assure mutual objectives and create common motivation

Backbone Support: … separate organization(s) with staff and a specific set of skills to serve as the backbone for the entire initiative and coordinate participating organizations and agencies.

---

[1] Framework for Collective Impact pulled from Collective Impact. Kania, John & Kramer, Mark; 2011; Stanford University https://ssir.org/articles/entry/collective_impact

In a recent article published in the Journal of Intellectual and Developmental Disability, researchers found that for some people who had transitioned to Supported Living services in the UK, although they appreciated the greater amount of choice and control in their lives, they still had little control over their services and infrequent access to the community and loved ones. Researchers concluded that Supported Living services, in themselves, are not sufficient for a quality life, but that staff must be trained and supported to align their practices with Supported Living principles in order to ensure that people can truly lead quality, connected self-directed lives. The findings from the interviews conducted with people using services, family members and agency staff confirmed these findings. Ultimately, what we learned that Supported Living will be successful when there is alignment across shareholder values and visions for inclusion, services and supports AND when all shareholders have the support and resources they need to realize those visions for all people with disabilities in North Carolina.

Previous Services

For People Using (or Transitioning to) Supported Living Services

We spoke to 12 people using services who were either planning to, in the process or had transitioned to Supported Living services. People using services had a variety of diagnoses and support needs, demonstrating a range of people who have access to Supported Living. The table on the right shows the total number of people who have been identified to use or transition to Supported Living services in the first year of the initiative, as well as the level of support that people have been approved to receive. They had also accessed Supported Living in a variety of ways, which influenced their perceptions of the services. For instance, people accessed Supported Living in the following ways:

#	Level of Support
5	Level 1
4	Level 2
3	Level 3

- 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 received[2]

Strengths of Supported Living: For too long, many people with disabilities have been subjected to services that were created to care for people in ways that were convenient to systems and agencies. Supported Living services offer an opportunity for people design and direct their supports to meet their needs, goals and desires. **So far, the greatest strengths of Supported Living services, for people who use them, have been the responsiveness and adaptability of supports to shift power from the service provider to the people who choose them.** For the first time in their adult lives, many people are determining what their days look like, who is allowed in their homes and when and how they utilize available services; this is a profound shift. Even for people who generally directed their services previously, Supported Living has offered opportunities for people to change their schedules and receive support to help them achieve goals that they choose. The table below outlines the differences people are experiencing when they shift to Supported Living services.

---

[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.

	Supported Living Services
Agency, family and staff controlled daily schedule	People using services control how and when they receive support, and thus how their days are spent
Focus on chores, hygiene and health	Because budgets are more flexible, people are able to use services and resources to pay for non-traditional services that don't require them to gain skills in cleaning, hygiene, etc., but support them to have access to technology and people who can supplement or replace traditional services focused on improving activities of daily living.
Services designed to meet specific definitions and goals	Services have more flexible definitions, so DSPs can spend their time focusing on the support that they want rather than focusing on specific goals, habilitative work, etc.
Focus on habilitation and improving skills	Many people using services have access to more support hours under the Supported Living definition
Services limited to hours determined agency and service definitions	Because people have more control over their own time and day, they can also determine when they want services based on their own schedules, and not the schedule of the agency or group based scheduling
People lived with family members or in group settings	By definition, people who are using Supported Living services must choose where and with whom they live, and they cannot receive services in the family home or group setting. This means that many people, for the first time, get to live on their own or with a chosen friend or roommate based on shared interests, rather than similar diagnoses or support needs.

John F. Kennedy Jr., wrote in a 1996 report from the President's Committee on (what is now) Intellectual and Developmental Disabilities: "Quality is defined at the point of interaction between the staff member and the individual with a disability." He recognized what we consistently heard from many people using services, that **what makes their services great are the people that support them.**

Many of the qualities and characteristics of great support staff identified by people using services were well aligned with the core competencies of DSPs as outlined by the NADSP Code of Ethics. During summer 2017, NADSP began training DSPs of all agencies participating in the Supported Living Initiative (as well as many agencies under the Vaya Health catchment area). Part of the training focuses on the Code of Ethics, supporting DSPs to adopt values, practices and strategies that demonstrate key beliefs and competencies and lead to quality services. The table below outlines the common strengths of DSPs (shared by people using services who were interviewed) as they align with the Code of Ethics key competencies.

NADSP Code of Ethics	Indicators of Quality Service Providers
As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.	People show up when they are supposed to
	People care about me
	People who support me stay with me for a long time (low turnover)
As a DSP, I will commit to promote the emotional, physical, and personal well-being of the people I support. I will encourage growth and recognize the autonomy of those receiving support while being attentive and energetic in reducing the risk of harm.	People support me to be healthy and productive
	People don't try to change me, but support me to be my best me
	People are there when I need someone to talk to
	The people who support me know me really well, they know when I'm having a good day and when I'm having a bad day
As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.	I can change my mind if/when I want to
As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.	People respect my things and my space
As a DSP, I will affirm the human rights as well as the civil rights and responsibilities of the people I support. I will promote and practice justice, fairness, and equity for the people I support and the community as a whole.	People are kind to me
As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person who I support as valuable and promote their value to our communities.	The people who support me like me
	The people who support me focus on my strengths
As a DSP, I will assist the people I support to develop and maintain relationships.	People support me to make, have and spend time with friends, family and significant others
As a DSP, I will assist the people I support to direct the course of their own lives.	People ask me how I want to spend my time
	People support me to try new things
	People help me with the things that I want them to help me with
As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.	People support me to be part of my community
	The people who support me are connected to our community and help me to become connected too
	The people who support me know me well enough to recommend activities, events and things that I might like to try in my community

Full Description of Common Themes: In our conversations with people using services, several themes emerged. Those themes are outlined below:

Relationships are critical: During our discussions with people using services, the primary topic with all people 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.

- DSPs: For all people using services, quality supports were defined by the quality of Direct Support Professionals who worked for them. Specifically, people using supports listed the following characteristics and practices as important aspects of quality services:
    - Respect
    - Kindness
    - Community connections
    - Genuine interest in the person using supports
    - Flexibility
    - Putting the wants and needs of people using supports first
    - Willingness to try new things (and support people using services to try new things)
    - High expectations for people using services; and,
    - People shared that when their interests aligned with the interests of the person supporting them, they were more satisfied with the quality of services; however, when there was misalignment people expressed frustration with their supports.
- People using supports also talked about the importance of relationships with people other than staff in their lives as well. Almost every person listed someone in his or her life who played a major role in their happiness and wellbeing. For people using services, there were a few factors that supported quality relationships:
- Access: people need to have access to their loved ones. Many people shared that seeing their friends or family was an important part of their life. At the same time, some people talked about friendships or romantic relationships that ended because people changed services and no longer had access to people in their lives. An important role of services and staff in Supported Living services will be to ensure that people have access to their loved ones, even as their lives change
- Having people who value them: people described their relationships with friends and loved ones by the ways that they valued one another. People talked about the qualities that they admired, or the people who were proud of them.
- Shared interests: people who used services wanted more relationships with people who have similar interests and hobbies. Many people shared that they want a friend who will do _____ with them.

Strengths Based Supports: People who are using supports were eager to talk about their accomplishments and successes. Each person shared something in his or her life that he/she loved and was proud of and shared examples of how the agency and staff supported them to achieve their goals. At the same time, many people spent a good amount of time listing their flaws or areas on which they need to improve. From those conversations, we learned the following:

- People using supports are very aware of and focused on their flaws, problems and behavior; they often listed them in "services speak". For instance, people said things like "when I have a behavior..." instead of "when I get mad…" or "when I have a problem…" Interestingly, although none of the interview questions focused on people's issues, most people who use supports brought them up on their own.
- Moreover, it was 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. Specifically, people listed the following skills that needed to be gained or issues that needed to be mitigated:
    - Skills: cooking, chores, maintaining and clean house, emergency preparation and response, laundry
    - Issues/ Behaviors: "acting out", emotional and mental stability, sleeping through the night
- 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.

Transition, Change and Adaptability: While people using supports did not speak as much about the transition to Supported Living services, the DSPs who support them thought a lot about what makes that transition successful. They

recognized that for many, Supported Living services are very different from the supports that they were previously receiving, and that the transition requires not only a shift in services and the expectations of the people who support them, but that people who are using services have to adapt as well. Specifically, they shared that:

- The transition from group to individual mindset takes time. Many people who were used to being supported in groups needed to adjust to services and a day that focus only on their needs and priorities and not those of an entire group. DSPs shared that many times when asked, *what would you like to do today,* people using services would follow every request with *Is that okay?*
- Similarly, DSPs shared that the transition from service focused to person focused supports takes time. In addition to looking for reassurance and affirmation that their thoughts and requests were okay, people also had a hard time identifying how they would like to spend their time and use their services when they were solely focused on them.
- Finally, people's expectations for their lives are based in what they know. The operationalization of the principles of choice and control happened differently for people using services based on their previous experiences and expectations for their lives. Some DSPs shared that the question *What do you want to do*, did not work well for people who are experience poor, as they often deferred back to the DSP (*I don't care, whatever you want to do),* or only listed things that they were familiar with. DSPs shared that as people were transitioning into Supported Living services, it was often helpful to give people options and introduce them to new activities and events to support people's development and growth.

It was clear from these conversations that as people's lives change, their services need to change with them. For many, it did or will take time to adjust to the paradigm shift in how services are delivered. As people's lives change and they get used to making choices and expanding their expectations, services need to expand with them.

For Families of people Using (or Transitioning to) Supported Living Services[3]

While we recognize that not all people who are transitioning to Supported Living have family members who take an active role in their services, those who do, by and large, drive the services that their family member receives. For instance, many of the interviews conducted involved family members only (and did not include the people who were using services); we get the impression that families and agencies are planning services, then inviting their family members in to discuss once service decisions have been made.

> One mother summed up a sentiment we heard from many family members: (paraphrasing) *if families aren't happy, they will change the services that their family member receives*. She described families as gatekeepers.

Strengths of Supported Living: By far, the greatest strength of Supported Living, for families, is the **alignment of values across the principles of Supported Living and what families want for their members who are using services**. Families want their family members to be supported to live their best lives, recognizing their individual strengths and needs. Supported Living services, by definition, are flexible and responsive to the unique wants and needs of people with disabilities. Supported Living services value individuality and are designed to support people to live the lives they desire in the homes, communities and relationships of their choosing. The table below shows the common values of both Supported Living services and family members; many families shared that it was comforting for them that they didn't have to argue with Vaya about the underlying values that drive services.

Principles of Supported Living	Family Members Want Services that
"Supported Living supports facilitate four basic outcomes. A person who experiences a disability partners with an organization, family, friends and community resources to experience life in a way that results in:	- Ensure their family member's safety and health while promoting autonomy and independence - Hold high expectations for their family member

[3] *It is important to note that the only family members we spoke with were parents of people using services. A few did share that they expected their family members' siblings to become more involved in the planning process as time went on*

- A safe and decent home of one's own
- Personalized Assistance
- Choice
- Support from others who care about and respect the person.[4]"

Specifically, Supported Living adopts the following principles:
- Supports are structured based on the person's interests, preferences and needs.
- Supports are flexible to meet the person's changing needs or circumstances
- People choose who they live with based on preference and mutual need (not disability and support need)
- Management of services and budgets are led by people using supports, not by the agency or family

- Value their family member's strengths and good qualities
- Focus on meaningful growth and development for their family member
- Focus on community connections and meaningful relationships
- Focus on community and societal contribution (and expect that from their family members)
- Value the importance of family member's time
- Appreciate their family members for who they are
- Enjoy spending time with their family member
- Value their family member's choice and place him/her in control of his/her services, days and lives*
- Are flexible and adaptive to the changing needs and preferences of their family members

---

his was true for family members to an extent. Many shared that their family member needed someone to support him/her to make good choices that ensured that they were healthy and having meaningful days and lives.

Flexibility and Adaptability: Families who are most satisfied with the transition to and quality of Supported Living supports consistently cite instances when the agency providing services and LME-MCO demonstrated flexibility and adaptability to design and adjust services to their family member. The table below shows examples of how agencies and Vaya have demonstrated flexibility and adaptability.

Indicator of Flexibility and Adaptability	Example of how Agencies and Vaya have been Flexible/ Adaptive
Adjustable services: Services are not rigid, but can flex as peoples' lives change	Vaya has provided flexible and additional service hours (and funding) for people as they transition to Supported Living, recognizing that many people need higher supports during transitional periods in their lives
	When agencies are able to plan for the "what ifs" with families and ensure that services will adjust to meet peoples' needs as they change, families are more confident that Supported Living services will be successful (especially when their family members are going from 24/7 supports to fewer service hours)
	Agencies that are able to get away from "that's how we've always done it" and think of creative solutions to combine services options, assure families that their family members are more important than the agency's traditions
Families as Experts: When families have a say in the planning and implementation of services	Vaya and agencies providing supports have met with families to discuss what a successful transition would look like, plan for services and supports to ensure a successful transition and identify barriers that families have experienced in the past (so as not to repeat them)
Timeliness: Planning, transition and services are timely and happen at the pace that families want	When families have been involved in and have set the pace for transition to Supported Living services, they are much more comfortable with and satisfied with the timeline
	When services and resources (technology allowances, etc.) are approved quickly, families are confident in an agency's capacity to respond to their family member's needs
	When agencies are able to find housing and roommate options quickly, families are more confident
Streamlined Processes: Families are able to access Supported	Vaya did not require an RFP process for agencies to provide Supported Living services, meaning that families were able to approach and access services they knew and trusted

---

[4] Definition pulled from: Supported Living, What's the Difference? O'Brien, John; 1993; Syracuse University
https://mn.gov/mnddc/parallels2/pdf/90s/93/93- SLD- RSA.pdf

Living services (and related supports) without having to "jump through a lot of hoops"	When families are able to go to one place (agency) or person for approval of services, resources and funding, they are more satisfied with the process

Full Description of Common Themes: In our conversations, several themes emerged across families. Those are listed below:

Transition: A great deal of the discussions with families centered on the transition to Supported Living services. 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. Specifically, families asked for a weaning process; many families want more services provided to their family members as they transition and at the beginning of Supported Living supports. They expect that services will decrease as their family member becomes more independent and comfortable with the new setting and service methodology, but they want to ensure that their family members have what they need. Some family members cited the difficulty of obtaining services as the reason for this approach, they shared that they want all available services until they figure out what their family member needs, rather than losing services that they will have to fight to gain back if and when their family member requires them.

Family expectations and Caregiver Role: By and large, we heard from family members that they 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 with them in the future. For instance, they shared that:
- They would like the agency to coordinate services, schedules and budgets;
- They would like the agency to be the only service provider (not family members, however, for many family members this was not an option given the available budget and service hours determined by the rates of funding);
- 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;
- They would like the agency to be connected in their communities to support their family member to become more connected (activities, employment, relationships, events, etc.). They feel that the agency should be the coordinator of community connections, rather than the family members; and,
- They would like the agency to support their family member to find housing and roommates (a few families have been told that the agency will support their family member once they find a house and services. Some families have purchased housing for their family member and feel that this is an unnecessary burden that positions this service for families who have the means to pay for additional housing)

Further, how families think about the capacities of their family members using services is critical. Most families felt that their sons or daughters had been underestimated by service providers at some point in their lives, and they challenged services to expect more from their family member related to how they could live, the support they needed, the jobs they could attain, the relationships they could have, etc. At the same time, families' experiences, particularly negative experiences, also framed their expectations for what their family members could achieve and/or what their lives could look like *(more on this below)*.

Family Trauma and Preparing for the Worst: 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.
- Families want to prepare for the worst when they are planning Supported Living services, many times families asked *What if this doesn't work*? Families want to know how the agency will respond in a crisis. Some common issues to account for include:
  o People leaving the house when a DSP is not present (eloping);
  o Change in health or injury of the person using services;
  o Change in health or injury of family member (especially if it impedes the family's capacity to provide supports); and,

- General emergencies (fires, natural disasters, etc.)
- Families also want to prepare for services to ensure that their family member is living a healthy life, including:
  - Healthy eating, nutrition and exercise;
  - Healthy sleeping habits (many people mentioned are night owls);
  - Healthy relationships and having good people in the house who will not take advantage of or steal from their family members; and,
  - Monitoring daily medication and general health

Technology: To mitigate some of the above issues, technology solutions have been recommended. Families are wary of technology. They recognize the need for it, and at the same time don't feel that technology will help them respond quickly enough in the case of an emergency. (For instance, one parent said that if his daughter leaves the house and technology alerts them, there are still several minutes before someone can get there to try to catch up with her and/or make sure that she's safe).

> One family interviewed, has since decided not to use the SL services because of the time and process to transition to new services. They feel that their family can provide the same (or better) quality of supports under their current service definition without having to "jump through a lot of hoops."

Cumbersome Processes: Many families shared that the process and time it takes to transition to Supported Living services has become a deterrent. While they understand that Supported Living is, in many ways, uncharted territory in North Carolina, they would like to know what to expect, and would like the MCO and agency providing supports to walk them through the transition smoothly and expeditiously. Specifically, families listed some of the following issues:

- Process: Families shared that the process to transition to SL services takes longer than they would like. The approval processes, and number of people who have to sign off on changes and services involves too many people and too much paperwork and does not move at the pace that families and people who are using services need. Quite a few families and agencies did note, though, that Vaya's process has been, by far, the smoothest of the MCO's. For instance, families noted that because some MCO's put out an RFP that required interested agencies to apply for permission to provide SL services, which not only slowed the process, it also meant that provider options are much more limited. One family, whose son was denied services at both eligible agencies in her area, feels enhanced mistrust of the system.
- Access to Technology: families do want access to technology that will support their family members to live independently. However, they noted that the time it takes to get technology (if they do not pay out of pocket) is unreasonable. Specifically, they noted some barriers:
  - Needing to receive multiple bids for some types of technology (especially related to smart homes);
  - Getting access to companies that provide technology;
  - Knowing the options for technology, smart homes and accommodations for their family members (by and large, this was the biggest barrier- families don't know what's available to even ask for);
  - The time it takes to get approved for accommodations (and the extraordinary measures families have to go through to prove that their family member would benefit from the technology); and,
  - The time it takes to receive money for accommodations once approved
- Values: Families also noted that, because they do not have to try to convince Vaya staff that Supported Living is a viable and ideal service for their family member, the process takes less time and feels much more manageable.
- Monitoring: The more streamlined monitoring processes (and required documentation), the better. Agencies have shared that families are opting not to change services, apply for technology accommodations, etc. if there is additional monitoring involved.

Communication and Information about Supported Living: It is important to families to be informed of service, regulatory and budgetary changes, options and decisions, particularly related to the Supported Living initiative. Families hold agencies and the LME-MCOs (particularly Vaya) responsible for communication and information related to policies and the initiative, and are concerned that they are being left out of important decisions that will affect their family members. Specifically:

- Families recognized that there was a lot of confusion about the definition and allowances related to Supported Living. They were unclear about who ultimately decided how and how much their family members could be supported. Many families, particularly parents of children with higher support needs, were frustrated by decisions about budgets and service hours and felt uninformed about what was available to their family member and other people with disabilities. Families request more and more frequent information.

- Families consistently asked about the progress of the initiative (what's been done, what have we learned, etc.). There has been great concern that the Supported Living Initiative will not lead to statewide access to quality Supported Living services for their family members
- Families are asking for successful Supported Living models and strategies that other states and experts have implemented. They are not generally satisfied with the "learning as we go" process.

For Agencies Providing Supported Living Services

The four partnering agencies represent a diverse range of services, serving many people statewide. Each agency has identified at least 6 people who have been or will receive Supported Living services in year 1.

Our focus groups and interviews included people working at all levels of each of the four partnering agencies to gather a well-rounded perspective of what agencies need to be able to provide quality Supported Living services. Specifically, the table below shows the types of interviews and focus groups that were conducted by agency.

Agency	Number of People Interviewed/ Included in Focus Groups				
	Executive Staff	*Directors/ Leadership*	*Middle Management*	*Frontline Supervisors*	*DSPs*
Arc of North Carolina	2	11	3	-	1
First[5]	1	2	1		5
Liberty Corner Enterprises	4	8	2	2	4
Turning Point	1	1		3	5

---

[5] *It is important to note that First is a significantly smaller agency than the other three partnering agencies, therefore, they do not have the same levels or numbers of staffing*

Strengths of Supported Living: Each agency that we spoke with had experienced successes in transitioning to and providing Supported Living Services. Generally, the categorized those successes by internal strengths that led to quality services and external strengths/ supports that allowed them to provide services in the context of a new service and changing state climate.

Internal Strengths: Agency employees listed specific strategies and structures that led to quality Supported Living services. First and foremost, employees across agencies consistently expressed **their excitement for the opportunity and support to provide more services that aligned with their core values of inclusion and independence**. Each organization saw this initiative as an opportunity to shift their services to be more aligned with their mission statements and core values about how people with disabilities should be supported. Further, **agency employees shared that providing services that people wanted was (for the most part) much more satisfying than providing services in groups.** Staff were more sure that they were not only meeting the needs of the people they supported, but that they were making a difference to improve their lives. Gallup, an organization that measures best practices in leadership, management and employee engagement has found that a key factor to employee engagement (a factor that costs US businesses between $450 and $550 billion annually) is whether or not employees get to do their best work every day. When staff are able to provide services that are meaningful, they are more engaged in their work and their agency, leading to higher quality services and lower turnover[6]. The table below shows the commonalities between the principles of Supported Living and the mission and vision of each partnering agency.[7]

Principles of Supported Living	**Mission and Vision of Partnering Agencies**
"Supported Living supports facilitate four basic outcomes. A person who experiences a disability partners with an organization, family, friends and community resources to experience life in a way that results in: • A safe and decent home of one's own • Personalized Assistance • Choice • Support from others who care about and respect the person.[8]" Specifically, Supported Living adopts the following principles: • Supports are structured based on the person's interests, preferences and needs. • Supports are flexible to meet the person's changing needs or circumstances • People choose who they live with based on preference and mutual need (not disability and support need) Management of services and budgets are led by people using supports, not by the agency or family	People have the right to: • Direct their services • Choose who supports them • Experience lives as close to adults who don't use services as possible • Choose where and with whom they live (and who and when people are allowed in their homes) • Choose how they spend their time • Have meaningful relationships with people they love and care about (not limited to familial and staff relationships) To do this services and support staff should: • Be Person Centered • Ensure that people are healthy and safe • Follow the lead of people using services • Put the needs and choices of people using services above their own (while they are working) • Provide the services and resources that people need and want to live as independently as they wish • Focus on supporting people to build quality relationships in people's chosen communities • Connect people to their communities • Focus on the goals and supports that are important to people who use services • Respect and celebrate people's unique characteristics, wants and needs (instead of trying to change them) • Ultimately, respect people's rights and autonomy

---

[6] Gallup (2017). State of the American Workplace Annual Report

[7] Values were expressed in multiple ways and in different scopes. There was not perfect agreement across each agency that each of these values were important. For instance, many people talked about limits to choice and control in the presence of risk to safety or health.

[8] Definition pulled from: Supported Living, What's the Difference? O'Brien, John; 1993; Syracuse University
https://mn.gov/mnddc/parallels2/pdf/90s/93/93- SLD- RSA.pdf

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. For instance, many agencies across North Carolina are struggling to design and implement Supported Living services to people with the highest support needs under the current service definitions and rates structure. However, organizations that have had the most success have been able to identify a new and different combination of services and resources for which people are eligible to ensure that they receive services that not only meet their needs, but also ensure that they are in control of every aspect of their lives.

What's more, 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;
- are not tied to traditional services or buildings; and,
- have leaders who know the services system well enough to know about and negotiate creative service combinations or flexible budgets

Finally, the **culture of an organization is a key strength for organizations who are able to provide quality Supported Living services**. There is a significant amount of research outlining the importance of culture on organizational growth, development and sustainability. For instance, Gallup[9] found that positive, growth oriented organizational culture can improve performance by 240%. Agencies with positive cultures have employees that are more engaged in their work; they are more motivated to do their jobs, they are more sure of their purpose and they have higher potentials than employees who work in agencies with unhealthy culture[10]. Further, agencies with positive cultures are better able to handle change, turmoil and turnover[11].

> *"because culture is instrumental to an organization's performance; it either facilitates and supports success or undermines and inhibits it... culture forms a core component of an organization's identity"*
>
> *Gallup News, April 6, 2015*

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:

- 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;
- trust;
- positive approach to change and growth;
- flexibility and openness;
- transparency;
- alignment of values with principles of Supported Living;
- alignment of values and practices; and,
- pride in agency and work.

---

[9] Sorenson, S., & Garman, K. (2013). Getting the most out of the employee-customer encounter. *Gallup News*
[10] McGregor, L., & Doshi, N. (2015). How company culture shapes employee motivation. *Harvard Business Review.*
[11] Dvorak, N., & Ott, B. (2015). Five ways to preserve company culture amid turnover. *Gallup News*

External Strengths: Agency leaders have also recognized that there are external factors that support the successful adoption and implementation of Supported Living services. Specifically, Vaya has provided flexibility and supports that have been particularly helpful. The boxes below outline specific instances and indicators that have demonstrated Vaya's flexibility and support.

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:

- *Identify agency operations and strategies that will lead to successful transition to Supported Living*
- *Overcome systems and agency barriers that arise*
- *Bring people who are steeped in traditional supports along*

Streamlined Approval Processes: Agency leaders have consistently shared that Vaya's approval process for both agencies to provide Supported Living, and people using services to access Supported Living has helped. Specifically, most agencies cited examples of approval processes with other LME-MCO's that were so selective about which agencies can provide Supported Living that families had a hard time accessing the service. Further, agencies have recognized that care coordinators with Vaya believe that Supported Living is a good option for people using supports. Agencies and families don't have to spend time convincing Vaya staff that people should be approved for and/or will be successful using Supported Living services. This has made perceptions of Supported Living much more positive for agency employees and families.

Vaya Availability and Responsiveness: Vaya 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. Specifically, they have:

- *Attended meetings with families to answer questions and provide guidance around service definitions and allowances*
- *Made themselves available to quickly respond to specific agency questions*
- *Provided forums and webinars to share information about the Supported Living initiative, progress and specific examples of successful strategies and best practices*

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.

Full Description of Common Themes: In our conversations, several themes emerged across agencies providing services. Those are listed below:

Support: We heard consistently from employees across the agency that the way they were supported to transition to and provide Supported Living services was crucial to their success. While the support needed was different, depending on peoples' roles, it was clear that when employees felt valued and supported (rather than "mandated to") they were more likely to provide quality Supported Living Services.

- *DSPs:* DSPs want to feel like the agency supports them to provide direct services that are aligned with the Supported Living principles and definitions; they recognized that the quality of supports they are able to provide is directly impacted by the support they receive. When DSPs felt supported, they were confident that they were able to provide high quality services. Specifically, DSPs need the following kind of support:
  - o *Alignment with expectations and Supported Living principles.* Job descriptions and written and unwritten expectations need to align. For many DSPs, because this is a shift in the way services are provided, they recognized that their supervisors' and agency's expectations for them need to shift as well.
  - o *Flexibility:* DSPs shared that in order to provide flexible services, they needed flexibility from the agency to shift schedules, goals and services expectations. DSPs shared that for the people they are supporting who are coming from more congregate services models, they are learning how to live their lives on their own terms. As they learn, their goals, expectations and day to day schedules change; to keep up with them, DSPs need to be able to adapt their schedules and expectations as well. Further, we heard from a few DSPs that they are not able to take the people that they support to do what they want (e.g. go to the movies, etc.) because they do not

have the money to spend on the activity or gas. For example, one DSP shared that the person she supports likes to go to the movies, but she (the DSP) cannot take her because she doesn't have the extra money to be able to go with her and does not get reimbursed for travel beyond a certain number of miles, which limits the person she supports.

- o *Access to budgets/ financial information:* On a related note, DSPs shared that when they don't know about the budgets of the agency and/or people they support, they are not able to support people to choose how to spend their time and resources (when they require money).
- o *Quality manager/ supervisor relationship:* DSPs shared that the relationships that they have with their manager and/or supervisor directly impact their understanding of Supported Living, and the quality of the services they are able to provide. Specifically, DSPs shared that when managers are available, model open and positive communication, give regular (constructive) feedback, and are eager to answer questions and provide the support that people need, they felt better able to provide quality Supported Living services.
- o *Risk:* Balancing risk and safety are key issues for agencies; ultimately, the responsibility to ensure that people are safe falls to DSPs. We heard from many DSPs that they struggle to balance their responsibilities to try new things and take risks with people, and to also ensure that they are meeting health and safety expectations. Risks included things like going out of the house into town to try new things, taking classes, etc. (nothing drastic). DSPs want assurance that if they take risks with people they support, they will not lose their jobs if something goes wrong.
- o *Training and Understanding of Supported Living services:* Many DSPs shared that they need more training in order to provide quality Supported Living services. What came through was that many DSPs were very sure of the work that they did on a daily basis (in their current role), but they weren't sure that they had the skills and understanding to provide Supported Living services. Some of this related to confusion about what Supported Living services really are, and are not. While DSPs absolutely need sufficient training to understand how to successfully implement Supported Living services, we also heard that they need regular support and supervision to ensure that their understanding and translation into direct support aligns with the heart of Supported Living.
- o *Balancing choice and control with DSP job stability:* DSPs recognized that because Supported Living services are fundamentally different than traditional services, they needed to focus more on ensuring that the people that they support have choice and control over their lives. However, they shared instances when choice and control threatened the stability of their jobs. For example, some DSPs shared that because people control their schedule and when they receive supports, they can also refuse services; meaning that some DSPs have arrived at people's apartments for their shift to be turned away (and not reimbursed for their time or travel). Because DSPs are generally paid so little, they count on the hours that they are scheduled. DSPs ask that the agency supports them to realize the essential pieces of Supported Living services (including choice and control over services) while also ensuring stability in their role.

- *Managers:* Managers (including Frontline Supervisors, "Q's" Middle Management and Administrative Managers) felt the responsibility of translating leadership decisions to the DSPs who would be directly providing Supported Living services as well as families and people using services. Foremost, managers want to feel that the agency supports them to have the knowledge, information and skills to be able to translate the heart of Supported Living to shareholders who are in charge of or affected by the operationalization of the service. To effectively translate and manage Supported Living services, managers need the following kind of support:
  - o *Communication and Support:* The communication of the Supported Living initiative and the support managers received to understand and translate Supported Living into action is critical to ensure the success and sustainability of quality Supported Living services. For instance, when Supported Living is presented as a positive opportunity (rather than something managers have to do) and is accompanied by training and consistent feedback and support to ensure that managers not only understand it, but are able to establish foundation to ensure quality, Supported Living services were something that managers saw as
    - Possible;
    - Positive;
    - Exciting; and,
    - A growth opportunity for the organization and people they support.
  - o *Understanding their role in making Supported Living a reality:* Managers need to be able to directly connect the work that they do in their own role to the overall mission of Supported Living. For many managers, this meant breaking down silos between departments (agencies that had fewer people and departments were more able to see how their piece fit into the overall success of the initiative.)

- o *Alignment between Supported Living principles and agency services:* Quite a few people shared that although Supported Living was a great idea in theory, it did not align with the "way things were done" in their agency. They were hopeful that the service would benefit the people they support, but recognized that the agency had to value choice, control, increased independence, complexity and change to truly align Supported Living services as they are written and implemented.
  - o *Vision:* Managers who were able to understand the organization's vision related to principles and values Supported Living and how that translates to services for all people that they support felt better equipped to manage. For instance, some managers were told that this initiative is a project for some people, they were much more limited in their understanding of Supported Living and how it impacted the future of their organization than managers who saw this as the direction of the agency.
  - o *Encouraging Out of the Box Thinking:* Managers who felt that their agency was most able to provide Supported Living services were managers who worked in organizations that encouraged new ideas and approaches. They recognized that Supported Living, by definition, cannot be a one size or one service fits all model, and they felt that their agency was most successful when they were willing to:
    - ▪ try new combinations of services;
    - ▪ change policies and practices;
    - ▪ listen to and try ideas from DSPs and people using supports;
    - ▪ incentivize creativity;
    - ▪ provide the service differently to different customers; and,
    - ▪ restructure organizational departments or teams
- • *Leaders:* Agency leaders identified many of the same support needs to successfully provide Supported Living services. Additionally, leaders had a broader perspective and focused on many of the organizational and systems factors that impacted their agency's capacity to successfully transition to Supported Living Services. Leaders identified the following support needed:
  - o *Organizational Infrastructure:* Agency leader recognized that the implementation of Supported Living services required agency infrastructure and operations that supported the service to succeed. Agency leaders requested support from initiative consultants and Vaya in order to ensure that their organizational infrastructure was set up to transition to Supported Living. Specifically, each of the agencies identified current factors and practices that helped or hindered them from providing Supported Living services well, including:
    - ▪ Management structures and strategies;
    - ▪ Overhead rates (as they were tied to organizational charts, management practices and agency structure);
    - ▪ Leadership;
    - ▪ Training and development;
    - ▪ Culture;
    - ▪ History and traditions (organizational and mindsets); and,
    - ▪ Perspectives about the capacity and limitations of the people they support
  - o *Leveraging expertise of agency leaders:* On a related note, some agency leaders shared that they have expertise and experience that the initiative should leverage in order to support other agencies to successfully transition to Supported Living services.
  - o *Divesting of Bricks and Mortar:* Agencies that owned property (particularly, group homes) are struggling to scale up Supported Living services for many people they support. Many leaders identified financial issues, sharing that they need to continue to fill group home beds as people move out in order to remain financially viable. Furthermore, agencies struggle with long term HUD contracts that bind them to the homes that they own, making this a long-term problem that seems to have no solution. Many leaders are asking for support, advice and examples of successful agency transformations who were able to divest of their property and remain solvent.
  - o *Alternate Funding Sources:* Similarly, agencies shared that in order to make Supported Living a sustainable service (particularly without group homes), they needed to explore and identify alternate sources of funding beyond the approved Supported Living rates. For instance, one agency is considering buying apartment complexes, and requested support to explore that option. Other agencies wanted advice and support around fund raising to supplement current income.
  - o *Systems Support:* Agency leaders were much more aware of systems issues as they pertained to Supported Living services. Specifically, they focused on the definition and funding of services:

- *Definition:* Because Supported Living is a relatively new service in North Carolina, there is still a lack of understanding about what the service definition entails and what it does not entail. For instance, there are discrepancies in the written definition that contradict rules and regulations in other parts of the definition. Agency leaders shared that having a support system (that was accessible and responsive) to answer questions about the service definition and allowances was necessary to successfully implement Supported Living services. Agency leaders shared that Vaya's responsiveness was better than most MCOs; specifically, when Vaya was able to be flexible in their interpretation of the definition, agencies were able to better meet the individual needs of people using or transitioning into Supported Living services. However, when care coordinators and Vaya staff are unclear of service definitions, or frame them as rigid models similar to traditional services, agencies struggle to successfully implement.
        - *Funding:* Agency leaders were concerned with Supported Living funds and rates. Specifically, they noted that the rates for people who had higher support needs were much less manageable than rates for people who had lower support needs. They felt that the rates did not adequately escalate with increased support needs. Several agency leaders shared that they could "make it work" for people who were classified and funded as "level 1 and 2," but not for people who were classified at "level 3". However, agency leaders did note that Vaya's capacity to approve extra funds and supports as people transition services gave them time and space to figure out, with families, the support that people needed and didn't need and how to pay for it.
        - *Timelines:* Agency leaders struggle to balance the timelines and expectations of families and people using services with the pace of MCO response, approval processes, services transitions, etc. Leaders from each agency shared that they were not able to move as quickly as families wanted. However, again, leaders noted that because Vaya was making efforts to streamline, timelines and processes were less cumbersome than with other LME-MCOs.
    o *Consultant Support:* Agency leaders were consistently unclear about the role of initiative consultants, specifically related to the access that they have to consultants, the pathways to contacting and scheduling consultant time, the coordination of training and development opportunities, etc. Agency leaders have taken different approaches, some have started directly contacting consultants to ask for support, while some have waited for direction from Vaya. Leaders shared that clarity about the relationships with consultants and how/ when they were able to use them would help significantly.

Service Definitions and Funding: Agency leaders talked about how the established service definitions and rates made Supported Living more feasible for people who were categorized as needing lower levels of services and supports (levels 1 and 2) than those who were categorized as needing higher levels (level 3).

- *Relatively easy to make happen for people categorized as "level 1 and 2"*
    o Generally, agency staff shared that transitional support was easier for people with lower support needs. For instance:
        - People who are already living on their own did not need a great deal of transitional support;
        - People who were already directing their services did not need to change their thoughts about how services should be provided. They were used to making choices and having more control over how, with whom and where their time is spent. Some DSPs shared that one of the most difficult transitions for people to make when they started Supported Living services was the actual direction of their own supports. People consistently asked for assurance that what they said was "okay" or "allowed." This was not the case for people who had already been self-directing.
    o There is less disruption in services for people with lower support needs. Agency employees noted that many people didn't notice a distinct change in services or how they were provided. Agency leaders and staff were happy that they were able to provide more flexible services that better meet the needs of the people they support.
- *Harder to make it happen for people categorized as "level 3"*
    o Many agency leaders have shared that the rate for people with high support needs is not adequate to provide the needed Supported Living services. As outlined above, many people with high support needs are coming from 24/7 services and supports, their family members are not confident that they will be safe with less. Agency leaders are struggling to figure out how to provide the level of supports that people (families) want while remaining financially solvent. This is particularly difficult for agencies with higher overhead rates.
        - Agency leaders have noted that due to the rates, there is no incentive for organizations or the system to offer Supported Living services to people with higher support needs. Because of this, parents must

advocate for their adult children and have had to "figure it out" for their children. For instance, 4 families bought additional homes and are paying for them so that their family members have a place to live (that they don't have to use their service funds to pay for). Although, more and more, family members are saying that they want to switch their roles from caregivers to family members only, one agency leader noted that Supported Living would only happen for some people if it was led by the family.

- Agency staff recognize that, for many people with higher support needs, they do not know how to provide individualized services that are directed by the people who use them. Many struggle because:
    - They have focused on caregiving models rather than supports that are directed by the people who use them, they don't know how to make the shift
    - They don't have the training needed to develop skills to help people control their own lives and services;
    - They are used to thinking about the needs and schedule of a group rather than one person. Managing a group of people is much different than being led by one. Agencies and staff need to adjust;
    - Similarly, agencies struggle when people change their minds or make spontaneous decisions. It is hard to schedule staff for spontaneity and to allow for flexible supports schedules.
    - They don't believe that people with higher support needs can be part of their chosen communities, have real jobs, etc.
    - They believe that people must develop certain skills before they can live independently
    - They do not trust technology to take the place of a person to provide certain supports
    - They believe that people need them to make good and healthy decisions that they could not make on their own
- Agency employees have shared that the transition to Supported Living services is more difficult for people with higher support needs; however, the difficulty is not necessarily only for the person using services, but for their family members and agencies. People benefit greatly when staff and agencies are aware of the following tendencies, and when they are able to respond accordingly.
    - People using services: sometimes people who are using services also have to get used to the shift in their lives that comes from Supported Living. As described above, people who are used to making very few choices in their lives have to adjust to a life that they control.
        - For many people it takes quite awhile before they are comfortable determining how they will spend their days and directing their services to meet their needs and goals. DSPs have shared that they need to give people time and space to make decisions and try new things, rather than setting a schedule for them.
        - Further, people are not used to being able to change their minds and be spontaneous. DSPs have noted that many people need consistent assurance that it is okay if they change their minds, it is the staff and agency's job to work with them to adjust.
        - People using services, particularly people coming from congregate or even family settings are often experience poor. It is hard for them to direct their days and make choices, when they don't know about the options available to them. People benefit from staff who know them well enough to know their preferences, and who also know their communities enough to know about opportunities to try new things. Once people are more aware of their options and opportunities, they are able to make more choices about how they spend their time.
    - Families struggle with the what if's. Agency employees must be able to figure out how to assure to families that:
        - Someone can be available to respond quickly if something goes wrong (without having to have someone physically present)
        - That technology can be used to support their family members
        - That even though they cannot map out the step by step transition from a previous setting to Supported Living services (and new home, apartment, etc.), they will be there to respond to their family member's changing needs
        - Their family member will be safe without the same level of 1:1 support they received previously.

Competition: Several agency leaders have noted that through the Supported Living initiative, part of their role as partners on the grant, involves collaboration with the other partners to share ideas, strategies and best practices. However, leaders also noted that, ultimately, the agencies are in competition with one another for services. Because of this, they struggle to

balance information sharing and transparency with being cutting edge and leading innovation that sets them apart to customers.

Supported Living Metrics: All of the information and responses collected above were used to develop a series of draft metrics that can be used to evaluate the progress of Supported Living for people using services, family members, agency employees and agencies themselves. These tools used language directly from each shareholder group to ensure that the questions asked align with the priorities of the people who are most involved in the Supported Living initiative.

In order to triangulate responses, some questions repeat across multiple surveys. This will allow initiative staff to assess the differences and similarities between each shareholder group. One of the most consistent factors identified as a catalyst to successful implementation of Supported Living was alignment across the values and perspectives of people receiving services, families and people providing services. Understanding this alignment will help Vaya, consultants, the DD Council and statewide shareholders to identify the key strengths and weaknesses of the Supported Living initiative today, as well as the support needs going forward.

For People Using Services

General				
Name	Open Ended			
Agency who supports you	Open Ended			
Is someone helping you fill this survey out?	Yes		No	
(if so) who?	Open Ended			
How Well People Know You				
The people who support me know				
What makes me happy	Agree	Neutral	Disagree	Not Sure
How to help me when I'm having a bad day	Agree	Neutral	Disagree	Not Sure
Who my friends and loved ones are	Agree	Neutral	Disagree	Not Sure
About new and interesting things to do in my community	Agree	Neutral	Disagree	Not Sure
Kindness and Respect				
People who support me listen to me	Agree	Neutral	Disagree	Not Sure
People talk about me in front of me (instead of to me)	Agree	Neutral	Disagree	Not Sure
People who support me are kind to me	Agree	Neutral	Disagree	Not Sure
People who support me try to change me	Agree	Neutral	Disagree	Not Sure
People who support me show up when they say they will	Agree	Neutral	Disagree	Not Sure
Change				
When I change my mind about my services, people listen to me	Agree	Neutral	Disagree	Not Sure
When I change your mind about my schedule, people listen to me	Agree	Neutral	Disagree	Not Sure
The people who support me help me to try new things	Agree	Neutral	Disagree	Not Sure
The people who support me help me meet new people	Agree	Neutral	Disagree	Not Sure
Relationships				
Who are your friends?	Open Ended			
What do you like to do with your friends?	Open Ended			
Who do you love?	Open Ended			
What do you like to do with the people you love (if different than friends)	Open Ended			

	I can see my friends, family and loved ones when I want to	Agree	Neutral	Disagree	Not Sure
	(If no) What gets in the way of you seeing your loved ones?	Open Ended			
	Who misses you when you're not there?	Open Ended			

Where and How You Live

	I chose to live in my current home (apartment, home, etc.)	Agree	Neutral	Disagree	Not Sure
	What do you like about living here?	Open Ended			
	Would you like to live somewhere else?	Yes	Neutral	No	Not Sure
	(If yes) how would you like to live?	Open Ended			
	Do you have a roommate?	Yes		No	
	Did you choose your roommate?	Yes		No	
	What do you like about your roommate?	Open Ended			
	Would you like a different roommate?	Yes	Sometimes	No	Not Sure
	(if yes) Who else would you like to live with?	Open Ended			

Choice and Control in Your Life

	Who has the most control over				
	Your services	I do	My family member	DSPs who support me	The agency that supports me	Other _____
	Your days	I do	My family member	DSPs who support me	The agency that supports me	Other _____
	Your evenings	I do	My family member	DSPs who support me	The agency that supports me	Other _____
	When you see your friends, family and loved ones	I do	My family member	DSPs who support me	The agency that supports me	Other _____
	Your home	I do	My family member	DSPs who support me	The agency that supports me	Other _____
	What is something that you love to do?	Open Ended			
	The people who support me know that I love this	Agree	Neutral	Disagree	Not Sure
	I get to do this as much as I'd like	Agree	Neutral	Disagree	Not Sure
	(if no) why?	Open Ended			
	Is there anything that you're not allowed to do?	Yes	Sometimes	No	Not Sure
	(if yes) Please tell me about that	Open Ended			

Your Goals and Dreams

	What is an important goal in your life?	Open Ended			
	The people who support me know about this goal	Agree	Neutral	Disagree	Not Sure
	The people who support me help me achieve this goal	Agree	Neutral	Disagree	Not Sure
	Is there anything we forgot to ask about? (If so, please share)	Open Ended			

For Families

General				
Name	Open Ended:			
Relationship to person you are responding about	Open Ended:			

How Well People Know Your Loved One

The people who support my loved one know him or her well enough to know:

What makes him/her happy	Agree	Neutral	Disagree	Not Sure
How to help him/her when he/she's having a bad day	Agree	Neutral	Disagree	Not Sure
Who his/her friends and loved ones are	Agree	Neutral	Disagree	Not Sure
About new and interesting things to do in his/her community	Agree	Neutral	Disagree	Not Sure
How to support him or her to be safe	Agree	Neutral	Disagree	Not Sure
How to support him or her to be healthy (and signs of declining health)	Agree	Neutral	Disagree	Not Sure

Choice and Control

The people who support my loved one have high expectations of him or her (i.e. they support him/her to live up to his/ her potential)	Agree	Neutral	Disagree	Not Sure
People that support my loved one put unnecessary restrictions on his/her life	Agree	Neutral	Disagree	Not Sure
(If so) Please describe	Open Ended:			

Who has the most control over your loved ones:

Services	My loved one (using supports)	I do	DSPs who support my loved one	The agency	Someone else (please indicate who)
Schedule	My loved one (using supports)	I do	DSPs who support my loved one	The agency	Someone else (please indicate who)
Opportunities to see friends, family and loved ones	My loved one (using supports)	I do	DSPs who support my loved one	The agency	Someone else (please indicate who)
Home	My loved one (using supports)	I do	DSPs who support my loved one	The agency	Someone else (please indicate who)

Relationships and Connections

The people who support my loved one help him or her to try new things	Agree	Neutral	Disagree	Not Sure
The people who support my loved one help him or her meet new people	Agree	Neutral	Disagree	Not Sure

The people who support my loved one have the skills and connections to help him or her:

Become a meaningful member of groups, teams, classes, activities and opportunities in his/ her community	Agree	Neutral	Disagree	Not Sure
Build meaningful relationships outside of his family and paid support staff	Agree	Neutral	Disagree	Not Sure
Achieve and maintain meaningful employment	Agree	Neutral	Disagree	Not Sure

Respect

The people that support my loved one respect him/ her?	Agree	Neutral	Disagree	Not Sure
The people that support my loved one refer to him/her by his level of service need ("he's a level 2")	Agree	Neutral	Disagree	Not Sure
People talk about my loved one in front of him or her (instead of to him or her?)	Agree	Neutral	Disagree	Not Sure

Family Experiences and Expectations

What are some experiences that you and your loved one have had with previous services that you want to see continue in your loved one's life?	Open Ended			
What are some experiences that you and your loved one have had with previous services that you never want to see happen again?	Open Ended			
How can an agency best support you to ensure that it doesn't?	Open Ended			
When I visit my loved one, I feel at ease when I leave? (i.e. do you feel certain that your loved one is	Agree	Neutral	Disagree	Not Sure

receiving supports to help him or her live a quality life when you're not there?)				
As my loved one's service needs change, the agency is able to quickly adapt to ensure that he or she continues to have a quality life	Agree	Neutral	Disagree	Not Sure
(If no) Please tell us why	Open Ended			
How would you describe the agency that provides services to your loved one (please list 3 to 5 words)	Open Ended			
How would you describe the LME-MCO that oversees services for your loved one (please list 3 to 5 words)	Open Ended			
How would you describe your main role in your loved one's life?	Care/ support provider	Involved family member/ loved one	Uninvolved family member/ loved one	Not Sure
In general, how do changes to your loved one's services make you feel?	Anxious	Excited	Happy (more change the better)	Fearful
I trust the agency that supports my loved one to				
Provide quality Supported Living services	Agree	Neutral	Disagree	Not Sure
Ensure my loved one's safety	Agree	Neutral	Disagree	Not Sure
Develop effective plans to mitigate risk	Agree	Neutral	Disagree	Not Sure
Respond efficiently and effectively if something goes wrong	Agree	Neutral	Disagree	Not Sure
I feel confident that the agency supporting my loved one will continue to provide quality supports as I (and my family members) age and our roles/ relationships change	Agree	Neutral	Disagree	Not Sure
(if no) what would make you confident?	Open Ended			
Specific to Supported Living Services				
How would you describe your feelings about the transition to Supported Living services?	Open Ended			
I feel that I understand the definition and rules related to Supported Living Services	Agree	Neutral	Disagree	Not Sure
I am satisfied with the following aspects of the transition to Supported Living services:				
Timeliness	Agree	Neutral	Disagree	Not Sure
Paperwork required	Agree	Neutral	Disagree	Not Sure
Availability of the following to answer my questions				
Agency staff	Agree	Neutral	Disagree	Not Sure
Care Coordinator	Agree	Neutral	Disagree	Not Sure
LME-MCO staff	Agree	Neutral	Disagree	Not Sure
Understanding of Supported Living definitions, regulations and decisions from				
Agency staff	Agree	Neutral	Disagree	Not Sure
Care coordinator	Agree	Neutral	Disagree	Not Sure
LME-MCO staff	Agree	Neutral	Disagree	Not Sure
My loved one's budget	Agree	Neutral	Disagree	Not Sure
The decision-making process that led to how my loved one's budget is spent	Agree	Neutral	Disagree	Not Sure
My loved one's services	Agree	Neutral	Disagree	Not Sure
The decision-making process that led to determining your loved one's services	Agree	Neutral	Disagree	Not Sure
Approval process for services and resources	Agree	Neutral	Disagree	Not Sure
Choice and control my loved one had in directing the transition process	Agree	Neutral	Disagree	Not Sure
Choice and control I had in directing the transition process	Agree	Neutral	Disagree	Not Sure
What (if any) hoops do you feel that you've had to jump through to make Supported Living a reality for your loved one?	Open Ended			
Do you think that there has been a change in the dependency that your loved one has on you?	Yes, it has increased	Yes, it has decreased	No, it has stayed the same	Not sure
I would recommend Supported Living services to other families	Agree	Neutral	Disagree	Not Sure
What didn't we ask that we should know?	Open Ended			

Agency Staff

For DSPs				

Your Role				
I am clear about the roles and responsibilities associated with my job	Agree	Neutral	Disagree	Not Sure
The factors on which I am evaluated as a DSP align with the principles of Supported Living	Agree	Neutral	Disagree	Not Sure
I have the support I need to meet all expectations of me in my role	Agree	Neutral	Disagree	Not Sure
This agency supports DSPs to do their best work	Agree	Neutral	Disagree	Not Sure

Knowledge about People You Support				
I know the people I directly support well enough to know:				
What makes them happy	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
How to help them when they are having a bad day	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
Who their friends and loved ones are	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
About new and interesting things to do in their communities	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
How to support them to be safe	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
How to support them to be healthy (and signs of declining health)	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
Support them to make informed decisions	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
I am able to share my knowledge and insight of the people I support in regular and meaningful ways	Agree	Neutral	Disagree	Not Sure

Relationships					
How much priority does your agency place on supporting people to meet new people and build relationships outside of agency staff and family members?	This is the top priority of my agency	This is a high priority for my agency	This is kind of a priority for my agency	This is not a priority for my agency	Not Sure
I have the skills and resources to help the people I support					
Meet new people	Agree: For all people I support	Agree: for some people I support		Disagree	Not Sure
Building meaningful and lasting relationships	Agree: For all people I support	Agree: for some people I support		Disagree	Not Sure
Navigate social cues and norms	Agree: For all people I support	Agree: for some people I support		Disagree	Not Sure
Understand healthy romantic and sexual relationships	Agree: For all people I support	Agree: for some people I support		Disagree	Not Sure
Do you support people to meet new people and make new friends?	Yes, I spend a good deal of services are dedicated to this	Yes, some time and services are dedicated to this		No	Not Sure
Do you support people to try new things?	Yes, I spend a good deal of services are dedicated to this	Yes, some time and services are dedicated to this		No	Not Sure
I am able to provide services that help people achieve the goals and outcomes that are important to them	Agree: For all people I support	Agree: for some people I support		Disagree	Not Sure
I have enough information about the budgets of the people I support	Agree: For all people I support	Agree: for some people I support		Disagree	Not Sure
I have enough information about the agency budget	Agree	Neutral		Disagree	Not Sure

Choice, Control and Flexibility	
How have you successfully supported people to make more decision and have more control over their lives? Please share a story and include:	Open Ended

• What was happening before? • How you supported someone to have more control? • What happened for the person you were supporting?				
When the needs of the person that I support change (in the ways listed below), I have the skills and support that I need to adapt how I provide services:				
When there is a significant change in the person's health	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
When there is a significant change in a family member's health or wellbeing	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
When the person gains or loses a job	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
When a key relationship in the person's life changes (breakup, death of a loved one, someone moves, etc.)	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
When the person wants a change to his or her regular schedule	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
When a person wants a change to his or her regular services	Agree: For all people I support	Agree: for some people I support	Disagree	Not Sure
Agency Support				
How many jobs do you currently hold?	Open Ended			
Have you considered any of the following changes in your employment:				
Applying for another position in the agency to earn more money	I am actively Doing this	I am considering this	I have not considered this	Not sure
Finding another job that pays more (at another agency in this field)	I am actively Doing this	I am considering this	I have not considered this	Not sure
Finding another job that pays more (at an agency or business outside of this field)	I am actively Doing this	I am considering this	I have not considered this	Not sure
adding a second (3rd or 4th) job to make ends meet	I am actively Doing this	I am considering this	I have not considered this	Not sure
When I am scheduled to work, I know that I will work my shift and be paid for it	Agree	Sometimes	Disagree	Not Sure
How would you describe your job? (circle all that apply)	Uplifting | Stable | Rewarding | Demoralizing | Difficult | Flexible | Frustrating | Easy | Other _____			
How could the organization better support you to provide services that are led by the people you support?	Open Ended			

Survey for Agency Leaders in Charge of Supported Living Initiative				
How would you describe your feelings about the transition to Supported Living services?	Open Ended			
Do you feel that you understand the definition and rules related to Supported Living Services?	Yes	Somewhat	No	Not Sure
(if no) what do you feel you need to understand better?	Open Ended			
I am satisfied with the following aspects of the transition to Supported Living for the people we support:				
Timeliness	Agree	Neutral	Disagree	Not Sure
Paperwork required	Agree	Neutral	Disagree	Not Sure
Availability of the following to answer my questions				
Care Coordinator	Agree	Neutral	Disagree	Not Sure
LME-MCO staff	Agree	Neutral	Disagree	Not Sure
Understanding of Supported Living definitions, regulations and decisions from				
Care coordinator	Agree	Neutral	Disagree	Not Sure
LME-MCO staff	Agree	Neutral	Disagree	Not Sure
Rates and individual budgets	Agree	Neutral	Disagree	Not Sure
Decision making process that lead to how budgets are spent	Agree	Neutral	Disagree	Not Sure
Decision making process that lead to determining services that a person will receive	Agree	Neutral	Disagree	Not Sure
Approval process for services and resources	Agree	Neutral	Disagree	Not Sure
Choice and control that people who use services have in directing the transition process	Agree	Neutral	Disagree	Not Sure
Quality of communication with families throughout the transition process	Agree	Neutral	Disagree	Not Sure
Quality of communication with LME-MCO staff throughout the transition process	Agree	Neutral	Disagree	Not Sure
What (if any) hoops do you feel that you've had to jump through to make Supported Living a reality for the people you support?	Open Ended			
Do you feel that there is alignment across Supported Living services (definitions and what's allowable) and what people and their families want their services to look like	Yes	Neutral	No	Not Sure
How can the LME-MCO leverage your expertise to make Supported Living services successful in organizations across North Carolina?	Open Ended			
How can the LME-MCO support your agency to partner with other agencies who are transitioning to Supported Living services?	Open Ended			
How have the consultants supported your agency to successfully provide Supported Living services?	Open Ended			
How can the consultants better support your agency to successfully provide Supported Living services?	Open Ended			

Survey for All Agency Employees:						

Person-Centered Planning

I have good insight into what is important to the people our agency supports	Agree	Neutral	Disagree	Not Sure
I feel that I understand how the principles of Supported Living align with the work that I do in my role	Agree	Neutral	Disagree	Not Sure
Agency employees regularly refer to people by the level of support they receive? (i.e. "he's a level 2")	Agree	Neutral	Disagree	Not Sure
I feel that services that we provide to people reflect their actual wants, goals and desires and what is important to them	Agree	Neutral	Disagree	Not Sure
I feel that we support people to have lives that would be meaningful to most other people of their age with and without disabilities	Agree	Neutral	Disagree	Not Sure

Who has most input into the service plans of the people you support **(circle one):**	Person using services	His/her friends	His/her family	Another staff at my agency	Case manager	Other

I feel that the agency is able to provide individualized supports that are directed by each person who chooses our services	Agree	Neutral	Disagree	Not Sure

8a. If disagree, what do you think would help ensure that people at this agency are able to individually direct their own services?

In your position, how are you able to contribute to person centered services for people who use agency supports?

Culture and Work Environment

The team meetings I participate in are meaningful and helpful	Agree	Neutral	Disagree	Not Sure
I can rely on my supervisor to follow through when there is an issue	Agree	Neutral	Disagree	Not Sure
I can rely on my co-workers to follow through on work responsibilities	Agree	Neutral	Disagree	Not Sure
I feel that my knowledge and input are valued at this agency	Agree	Neutral	Disagree	Not Sure
This agency recognizes and celebrates my achievements and good work	Agree	Neutral	Disagree	Not Sure
I can rely on this agency leadership to follow through on expectations and promises	Agree	Neutral	Disagree	Not Sure
I have opportunities for advancement at this agency	Agree	Neutral	Disagree	Not Sure
I plan to work with this agency for at least another year	Agree	Neutral	Disagree	Not Sure
Please write three words that you would use describe the culture at this agency?	Open Ended:			

Communication

I feel that there is good communication between the following:

Between me and my team	Agree	Neutral	Disagree	Not Sure
Between me and my manager/supervisor	Agree	Neutral	Disagree	Not Sure
Between day and residential programs	Agree	Neutral	Disagree	Not Sure
Between me and the family members of people I support	Agree	Neutral	Disagree	Not Sure
Within the agency as a whole	Agree	Neutral	Disagree	Not Sure

22a. If you chose "disagree" for any of the above questions, please explain:

Please describe the following relationships (if applicable to your position): **CIRCLE ALL THAT APPLY**

I feel that my supervisor is	Accessible	Responsive	Flexible	Interested in listening to my ideas	Respectful	Visible	Not Sure
I feel that the Program Director of my Division is	Accessible	Responsive	Flexible	Interested in listening to my ideas	Respectful	Visible	Not Sure
I feel that the Human Resources department is	Accessible	Responsive	Flexible	Interested in listening to my ideas	Respectful	Visible	Not Sure
I feel that the Finance department is	Accessible	Responsive	Flexible	Interested in listening to my ideas	Respectful	Visible	Not Sure
I feel that the External Relations	Accessible	Responsive	Flexible	Interested in	Respectful	Visible	Not Sure

(Communications and Marketing) department is				listening to my ideas			
I feel that the Executive Director is	Accessible	Responsive	Flexible	Interested in listening to my ideas	Respectful	Visible	Not Sure

I feel well-informed of agency policies and decisions	Agree	Neutral	Disagree	Not Sure
I am proud to work for _____ (agency name)	Agree	Neutral	Disagree	Not Sure

Values about People Who Use Supports

The people with disabilities we support can direct every aspect of their services and lives	Agree: all people we support	Agree: most people we support (depending on the level and type of disability)	Agree: for very few people we support	Disagree	Not Sure
To keep people health and safe, the people with disabilities we support need someone to make decisions for them	Agree: all people we support	Agree: most people we support (depending on the level and type of disability)	Agree: for very few people we support	Disagree	Not Sure
The people with disabilities we support want to live and work with others who are like them	Agree: all people we support	Agree: most people we support (depending on the level and type of disability)	Agree: for very few people we support	Disagree	Not Sure
The people with disabilities we support can and should have romantic and sexual relationships	Agree: all people we support	Agree: most people we support (depending on the level and type of disability)	Agree: for very few people we support	Disagree	Not Sure
Supported Living is an appropriate service for the people with disabilities that we support	Agree: all people we support	Agree: most people we support (depending on the level and type of disability)	Agree: for very few people we support	Disagree	Not Sure
The community is ready for the people with disabilities that we support	Agree: all people we support	Agree: most people we support (depending on the level and type of disability)	Agree: for very few people we support	Disagree	Not Sure

Transition to Supported Living

How does your agency generally respond to change?	We thrive in change	Change is welcome	Generally apprehensive	Opinions are usually split	We like things to stay how they are	Not Sure

Our agency is ready to provide Supported Living services	Agree	Neutral	Disagree	Not Sure
Our agency's written values align with the principles of Supported Living services	Yes, for all people we support	Yes, for some people we support	No, for very few or none of the people we support	I am not familiar enough with the principles of Supported Living to respond
Our agency's practices align with the principles of Supported Living Services	Yes, for all people we support	Yes, for some people we support	No, for very few or none of the people we support	I am not familiar enough with the principles of Supported Living to respond

Ongoing evaluations for participants of Supported Living Initiative:

Partnering Agencies	
Date	
Please respond to the questions below about your progress in transitioning to and providing Supported Living services	
Number of people using Supported Living services	
Number of people interested in Supported Living services	
Please list and describe some lessons learned up to this point	
What is something that you didn't expect in this process?	
What is an issue that you overcame that other agencies might encounter as well?	
What have been your biggest successes?	
Please list and describe a few issues that you're having that you need support with	
Anything else you want to update initiative staff about?	

Families	
Date	
Please respond to the questions below about your family member's progress in transitioning to and using Supported Living services	
Please list and describe some lessons learned up to this point	
What is something that you didn't expect in this process?	
What is an issue that your family overcame that other families might face?	
What have been the biggest successes for your family member with Supported Living services?	
How have your family member's services changed since transitioning to Supported Living?	
How has your family member's life changed since transitioning to Supported Living?	
Please list and describe a few issues that you're having that you need support with	
Anything else you want to update initiative staff about?	

People Using Services	
Date	
Please respond to the questions below about your progress in transitioning to and using Supported Living services	
Please list and describe some lessons learned up to this point	
What is something that you didn't expect in this process?	
What is an issue that your family overcame that other people transitioning to Supported Living services might face?	
What have been the biggest successes for you with Supported Living services?	
How have your services changed since transitioning to Supported Living?	
How has your life changed since transitioning to Supported Living?	
Please list and describe a few issues that you're having that you need support with	
Anything else you want to update initiative staff about?	

For families and people using services who chose not to move forward with Supported Living services	
What made you decide not to use Supported Living services?	
What were the barriers you faced to transitioning to Supported Living services?	
Why did you initially choose Supported Living?	
What would make you choose Supported Living services again?	
Anything else you want to share?	

Additional Indicators to Consider:

Agency Indicators:

- Turnover in people's lives (look at differences for people who use Supported Living services and those who don't)
- Additional services that people receive (that supplement Supported Living services)
- Amount of time spent supporting people to have relationships (documentation)
- # of people transitioning to supported living services in each support category

Project Indicators

- Networks analysis and connection to other families of people with disabilities
- Participation in webinars and trainings offered
- Satisfaction with webinars and trainings offered
- Participation and use of community of practice
- Satisfaction with community of practice
- Vaya's incentivization practices: how they incentivize best practices in:
  - Organizational practices
  - Supported Living services
  - Individualized services and supports