# CREATING A WELLNESS ENVIRONMENT

## FOR PEOPLE WITH AUTISM

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shine light

# INTRODUCTION

## If you are a parent, professional, caregiver, friend, community partner, or even someone with a deep concern for people with ASD, this book is for you!

Ironically, this career path wasn't my first choice. I originally planned to be a pediatrician. Those plans changed when I walked into an Intro to Psychology course as a sophomore at UNC-CH. Even then, I had never even heard the term autism, but the course changed my life. It put me on a path I did not envision, but I am so glad I discovered it.

Upon graduation, finding a job didn't prove as easy as I thought. I started my career as a Direct Support Professional. This meant that I worked directly with individuals in their every-day lives. I had no idea that I was being set up for what would become a life long career. It's 20 plus years later, and I'm so grateful for all I have learned. In this course, I plan to lay out some truths that I discovered the hard way. Looking back, I know that I could have saved a lot of heart ache and time, that the people I have been assigned to help would have been better, quicker, if I knew then what I know now. While I know that there will always be things we learn through life experience, not ALL things have to be learned that way. For the sake of the autistic community, I am developing this course. I hope that no matter where a person finds themselves on the spectrum, they have the support that they need to live the life they desire and deserve. Let's dig in!

SECTION 1

# WHY DO WE NEED THIS BOOK?

Did you know that according to a recent study, the cost of care for autism is between 1.4 and 2.4 million dollars over the lifespan? Did you know that the care of a child with autism can cost a family an average of $60, 000/ year? Did you know that the prevalence of autism continues to be on the rise? The most recent CDC statistic from 2021 was 1 in every 44 children. This is an increase from 1 in 68. Have you considered the impact that longer lifespans have on the quality of life, especially for people with autism? How long do you think people can continue to get the supports they need at a price tag of $1.4 million? Have you considered that even in a society as rich as ours, there are still people that are not connected to the funds that they need to receive the supports they need? Knowing the huge impact that research based intervention can have on the outcome for people with autism, especially early intervention, imagine the number of people that never live the life they want because they never had the support they needed.

Just imagine your life without the community and inherent supports that come along with that you have developed over the years. If you really consider this, I'm sure the first thing you would notice is that the quality of your life would be significantly reduced.

These are the challenges people with autism face. They are the reasons there must be a focus on the development of programs that positively impact and provide a lasting network of support. Programs that bring awareness to the needs of people with autism and how to meet those needs.

It is all the more reason why we work to support people with ASD so that they too can experience the quality of life that comes through community and the support that comes from being connected to community. It is why our focus shifted to wellness environments. Now together, let's turn this challenge into an opportunity!

I have witnessed over and over again the power of the environment. Whether someone with autism or not, the environment is a powerful determinate of future success or failure. Let's take a look at some steps to creating an environment conducive for success. Let's take advantage of the opportunity to provide solutions to the challenges we face.

SECTION 2

# WHAT IS A WELLNESS ENVIRONMENT?

Firstly let's deal with the environment. Webster defines it as "the circumstances, objects, or conditions by which one is surrounded". We must consider that environment is not just location. It is not just the physical component. What happens in that location is just as important as the location itself.

Even though an environment goes beyond the physical location, it is important that we discuss that aspect, especially for people with autism. Our organization has found that our service niche is providing housing options. Over the past sixteen years, we have witnessed how surroundings impact anxiety, etc. From our observations in serving people in the housing arena, we witnessed something as trifling as a telephone ringing, being the catalyst for outbursts. I am going to list some things you may want to consider in the physical environment for people with autism. This list is not meant to be exhaustive, but to provoke thought.

## NOISE

Are there noises in the house that many people can filter out, but that is overwhelming for people with auditory sensitivities? Are people using calming tones and voices? Do people need white noise, and if so, how can it be accomplished?

## SENSORY STIMULATION

Are there things in the environment that can cause over-stimulation? For example, are the colors of the walls calming, or might they have the opposite effect?

## TEXTURE

This is related to sensory stimulation, but what kind of fabric are the chairs made of? What about the clothes that people wear, are the textures comfortable for them? Do you notice any irritation or aversion in this area? Have you considered this in the area of food? Do people respond negatively to different textures of food? Are there opportunities for stimulation throughout the environment for people whose systems may be under stimulated? Can they enjoy time in a sandbox, on a trampoline, or a swing?

Recently we observe a push in our society for a holistic approach to wellness. It's reflected in the normalization of therapy and taking care of our mental health as much as we take care of our physical health. Obviously, a person isn't well just because they go to the gym. That is only one component of their wellness, but what about the others? The same is true with the environment. Even if we address all of the physical components of the environment, our results would not be as promising as if we took it to the next step.

believe the next integral part of the environment that has to be addressed is the culture. If we are going to offer an environment conducive to people becoming the best version of themselves (this is my definition of a wellness environment), Ithe culture of that environment must be aware of the components that determine wellness for those they are a part of it. Furthermore, it must be a culture that values connections outside of itself, and lastly, it must be a culture that understands that it's connections are for the purpose of connecting those they serve to the resources they need to become the best version of themselves.

I remember when this concept was birthed at our agency. We brought in a marketing team to increase our sales. The research of our company demonstrated that we had a few niches, and one was serving people with autism specifically. Another was developing and/or finding housing opportunities for people with autism in their communities. Wherever these opportunities were found, our goal was to make sure people's houses were homes. Environment is a major part of reaching this goal. In order to accomplish these environments for people, we understood
to address the environment and culture of the agency.

Out of this, the concept of a Wellness Environment was born. As defined above this is an environment that promotes the development of the best in each person that is a part of it. Once I understood the task at hand, I set out to make sure ShineLight embodied and exemplified this concept of a wellness environment. Here I am going to share the turns we took on the road to Creating A Wellness Environment for People With ASD.

# BECOMING A WELLNESS ENVIRONMENT

## OH THE POSSIBILITIES: CREATING MENTAL PICTURES

When we think of culture, we usually think of big groups. We think of entire ethnicities or religious groups, just to name a couple. The truth is that culture exists in the smallest organism, take a family for example. Organizations, church, and companies all have their own culture and it is infused by the beliefs of those involved. It is made up of their thoughts and their perceptions. Many times these things aren't even spoken, but they are lived out by those that are a part of the culture. They impact the lives of those that are a part of the culture, often in unconscious ways.

At ShineLight, the first thing that I noticed was that there were thoughts and beliefs about the people we were serving that contradicted a wellness environment. I saw this in the way we interacted with people and I knew that if we did not deal with this, no matter what else we did, people would not experience their lives as they chose them to be.

People were not experiencing the meaningful days that lead to a quality life. They were not connected to their communities and engaging in relationships that lead to quality life. What I realized is that even in a system that promoted community over institutionalization, people were still living as though they were institutionalized.

I found it to be a result of a misconception of wellness. In our quest for wellness for people, we continued to think of them in very limited ways. We sustained the false belief, that we knew best. As we read, interact with people, and grow, we came face to face with our misconceptions. We were challenged with concepts such as the dignity of risk, which suggests that the same choices I could make and risks I could take with my life, we were taking from people with autism. Instead of them being empowered to be the best version of themselves, they were required to live out our version of their best self.

Of course none of this was intentional. We thought that we were keeping people safe. We were, but we were also taking their autonomy, which has an adverse effect on the environment. Consider this scenario:

In the morning when you wake up, there is a person that meets you in your bedroom. You hit snooze on the alarm clock because you want just a few more minutes of sleep. You are told to get out of bed because it is time for work, but you also know that you have set your clock such that you have those few extra snooze minutes if you need them. This person, however, is relentless and refuses to leave until you get up.

I know this is dramatic, and for some of us we are thinking, no one is going to make me get out of my bed. I propose that in our quest to help people that truly need support to be their best selves, we rob them of their autonomy. I do not know about you, but the reality is there are times when I choose to hit snooze, knowing that the chances are I will be late, but I choose poorly anyway.

Granted , I suffer the consequences, but the choice still belongs to me. Sadly, in our support-driven culture, many times people's right to choice are, even choose poorly, are invaded.

How would you respond if this happened to you day after day?

When we realized this, we debunked the myth that we as professionals knew best. Just as you and I determine what quality and wellness are for ourselves, we realized that so should people with autism, or any disability, for that matter. Even in our new quest to provide a culture that offers wellness, we have to remain cautious against egocentrism. We must continue to look at the lives of people and ask, “Do their lives look more like they want, or do their lives look more like what you think they want?”

Our thoughts and belief systems changed, We began to see the potential everyone we served possessed. We began to believe that they could tell us what they wanted, all we had to do was learn to listen. This change in our thoughts and beliefs meant an automatic change in our culture.

We experienced a paradigm shift, or a change in our thought patterns that led to a change in our language. Language speaks volumes about our belief. In this case, how you talk about people, even how you refer to them, is a thermometer reading on what you think about them. It indicates your beliefs about them as people, and their potential. As we began to be more aware of our language, we realized that it did not reflect a belief system that

was congruent with our journey towards wellness environments for all of those we served.

We used evidence-based approaches such as a person's first language to begin to alter our language. I believe that our beliefs are built and based upon what we hear. As a result, we began to speak into the culture about what we wanted to see in the culture. The change in our language was the catalyst for the change in our culture.

Now if you walk into our programs, you will see an emphasis on visual communications, as this is the predominant preference of people with autism. We used natural teaching moments to demonstrate where we were located versus where we were going. In other words, we created a mental picture of the beautiful possibilities that waited for people, if we only changed the way we thought, consequently changing our actions, and ultimately impacting our environment.

The more we talked to and about people as though they were the experts, the more we realized this was true. Here is a caveat to creating this mental picture. You must be in this for the sake of service. You must realize that you don't know it all, no matter how much education you have, and no matter what prefix follows your name. The beauty of the mental picture though, is that the possibilities create excitement that drives change. As this mental picture is created, you will begin to identify all of the circumstances, objects, conditions, thoughts, beliefs, and surroundings that get in the way of our goal, which in this case was a wellness environment. The possibilities that we now envisioned versus the realities in the lives of the people we served were enough to push us to change.

## THE ART OF ASKING QUESTIONS

As we begin to change our language, the next important step was to ask questions. Even in this we were challenged. I can hear my leaders now, of course we ask questions, but I discovered two errors in our current method of questioning.

1. **WE WERE NOT ASKING THE RIGHT QUESTIONS**

This error was deeply rooted in our misconception of the potential of the people we served. Instead of finding ways to ask questions whose answers truly informed us, we were asking simple questions. Questions that people could give a yes or no answers. Questions that did not require us to truly do the work of making sure people understood what they were being asked.

Again, this was not because we did not care. We cared, and care deeply, but our communication at the time was was influenced by the misconception that as professionals we do not have to listen long. Of course, we were all wrong! We began to focus on making sure communication was going on in the daily lives of the people we served. This communication included asking questions about their day, how they wanted their lives to look, what did they want in their homes and bedrooms, what type of job they preferred, and the list goes on and on. We discovered first that people are multi-dimensional and always evolving. We could not take for granted that what we knew today would hold tomorrow. We discovered that we could not support people to be their best selves without a culture, an environment that valued people through committing to know them. This meant a commitment to learning, a commitment to asking questions.

**2. WE WERE NOT ASKING THEM THE RIGHT WAY.**

Furthermore, we learned that we were poor at communicating. How did we learn this? It happened because we came to realize that people were not processing what we were saying. They were not processing the questions we were asking.

People with autism communicate and process communication much differently than people that do not have autism. Does that mean that we do not communicate? Does this give us the right to assume that we should make decisions based on what we think? I remember traveling to Europe for the first time. I landed in Germany, where my cousin played professional basketball. Many people in Luxembourg spoke English, so ordering my first lamb

Gyro was not difficult. However, our second day was spent in Paris. We had breakfast that morning, and the crepe was amazing! Ordering it, however, was a challenge. The menu was in French. Go figure! How dare they not have an English version of their menu?

Well when I left my country of birth, I knew I would be traveling to places where their language was different. I knew that I couldn't travel to those places and make them speak my language. I knew I would have to communicate with these people to get my needs met. I knew if I was going to communicate, I would have to find a way to speak their language.

At ShineLight we had to learn to speak the language of those we served. We had to become experts in understanding the language of each person. We had to become experts in speaking the language of each person we served.

Honestly, we are still learning this. We are still figuring out how we will ensure that each person experiences respectful communication with all who come into contact with them. At our core though, our culture is committed to, and exemplifies a deep understanding of the need to be respectful in communicating with people with autism.

Before I end the conversation on culture, I want to return to a statement from earlier. As we set out to develop this Wellness Environment, we encountered a major barrier. Our strength of digging in and solving problems by using the resources from within, how now become the thing that kept us from our goal. We were so used to solving our problems from within, that we have fenced ourselves, and those we served, in. We did not have the connections and relationships needed to connect others to resources that could only be found outside of ourselves. It is true that we are better together. No matter how good and efficient a person is, efficiency is not just added but multiplied when people put their resources together. We will return to this topic later, but for now, just know that inherent in a wellness environment is a culture that understands the importance of community and relationships.

## STRUCTURING THE ENVIRONMENT: THE SKY IS THE LIMIT

In addition to the culture of the environment, there are two vital components that must be present if the environment can wellness. Those two things are consistency and structure.

These two things, especially for people with autism, provide organic safety by offering a sense of predictability.

How would you feel if every day on your job, you are scheduled to go to work? They schedule your time to go in, but they never give you a time that you get off? Really stop and think about this. Every day, you have no idea what time you are going to get off work. How would that affect you? How would it make you feel? How would it affect the areas of your life outside of work?
I propose that this is exactly how people with autism feel when their environments are not structured and do not have consistency. The ways that it makes you feel, are the exact ways that people feel when their environments are not structured so that they understand what's next.
This safety, as I described above, gives them predictability which leads to autonomy. Let me show you how.

The component of consistency that I want to touch on here deals with offering a degree of. sameness. We mean that people can move from place to place, but still know that certain things will remain the same.

Such as dignity and respect in how people communicate with them. In an organization such as ours, another important part of this sameness is ensuring that no matter who is clocked in, there are fundamental components of their environment that do not change.

To be plain, how do we make sure that from school, to home, to wherever else a child spends the bulk of their day, there is

sameness? If we have identified that a child prefers picture communication, how do we make sure that this is implemented in the environments where they spend the bulk of their time? Furthermore, how do we ensure that how this system is used is fundamentally the same in these environments?

Hear this caveat. This does not mean that we take away the individuality of the people interacting with the individual with autism in these environments. How this looks is an ongoing process that evolves with the person as they evolve.

What we have found though, is that when we are at our best at providing this to people, is when we see them thrive. It is when we see a great reduction in people communicating using behaviors that negatively impact them in the long run.

Consistency also means that we show up for people. That we have integrity and keep our word. It means that people can trust that we will follow through with what we say. Again, these things go a long way in supporting the development of people in the best way.

Another important thing that must be provided in their environment, is structure. I love the following definition of structure provided by Webster: “something arranged in a definite pattern of organization”. It creates a mental picture for me of an environment that is consistent and Structured. It indicates organization, which provides predictability, which provides autonomy. Let’s deal a little bit with what a Structured environment looks like.

At ShineLight, we found that the single most important thing we could do to positively impact the lives of people, was to understand their preferred way to communicate. We just remember that communication has not occurred until the persons receiving the message understands the message as the sender intends.

What is it that we need to communicate you may ask? If the environment does not communicate the expectations, then there will be chaos. Make sure that their environment communicates in a way that they can understand, what is expected of them and when. Make sure it communicates what comes next.

This usually means some form of visual communication. It could be as simple as objects that tell people their expectations. For example, a child sees a school bus and understands that today is a school day. We may take something that small for granted, but for an individual that has not processed space and time, this will go a long way in structuring their day, providing autonomy, and safety that they are familiar with.

Another method that could be used is a picture. In this case, the child would have a picture of a school bus to let them know that this is a school day. This picture communication system (also known as PECS which stands for Picture Exchange Communication Systems), can also be in the form of calendars, for people that can read and that have an understanding of time. Why would a person that this understanding need a system of communicating expectations? I'm glad you asked! It is because even with their level of cognitive functioning, because of how their brains process information, they are more successful if they have visual reminders.

Once the components of culture lead to an environment that supports people to thrive, it is important to make sure people have something realistic to aim for. This can not happen without a team that knows the person well and knows how to fully engage their level of satisfaction. If the expectation is outside of the realistic capacity of the person, this can be a set back. It will cause people to become frustrated and even cause self-doubt. People may see this as proof of their inabilities, rather than their abilities.

When the environment comes with clear and obtainable expectations, it result in feelings of accomplishment that lead to further success. When the obstacle is a little more difficult, people pull from their previous accomplishments and at least believe that they can. What I have found, is that when expectations are clear and obtainable, setting an individual up for success, the sky is the limit.

We understood that an essential component of this environment was the agency's connections.

# INDIVIDUAL VERSUS COMMUNITY

“It was the best of times, it was the worst of times.” In many ways our society reminds me of this famous quote from Charles Dickens, A Tale of Two Cities. While we live in a society where the answer to any questions is at the tip of the finger, a society where we have access to more information than ever, it is also a time of loneliness and isolation. Our focus on “Doing You” as we like to say, has had the unfortunate effect of a loss of true community. We can have up to 5000 Facebook friends, but no community. Suicide rates are rising, and I believe a major reason is that without community, things look hopeless.

What does this have to do with a Wellness Environment? We learned the hard way that “no man is an island”. No matter how much we changed from within if we didn't have relationships that reached outside of us, we were not going to be able to complete our mission. How could we connect the people we served to the resources that they needed to achieve their definition of wellness if we were not connected in some way to those resources? If we were not aware of where to look, or connected to people and organizations that were connected to these resources, how could we serve as a connector?

It was impossible to do this, unless we began to develop relationships. My mother used to tell me this: ”Sometimes it is not what you know, but who you know.” I'm advocating in every way for our society to return to an awareness of the importance of community. If you are trying to develop a program to support the

needs of others, if you are trying to surround people with Wellness Environments, then community is a must. We cannot afford to allow life's amenities to isolate us.

We must seek out connections. I am in no way proposing an artificial sense of networking that leads to databases used for emails blasts. Although this is necessary, we must have connections whose foundations are relationships, and this is mutual. Eventually we can even hope to see Environments that are conducive to developing the best in people.

# CONCLUSION

I want to end with a reiteration of something I have already stated. At ShineLight, our niche is housing. The programs that we have developed and most of what we have learned came from that setting. We use these programs though, no matter the physical setting of the environment. We have seen these things work. I'm thinking of the smiles that we have witnessed as a result of the happiness of people when we have been intentional about their surroundings. I cannot wait to hear about all of the smiles that you will witness as you infuse these steps into your environment. We hope you will share!