



SWEETWATER SPECTRUM

Life With Purpose

A GUIDE TO STARTING YOUR OWN COMMUNITY

2021





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INTRODUCTION

THE FIVE W's

If you are reading this, you have reached a crossroads in your life — likely having a need for housing and a long-term plan for a person with autism or a related development disorder. When determining the requirements for your new and enhanced solution, it always pays to remember the five W's.

WHY

We all know that the numbers of individuals with developmental disabilities aging into adulthood is expanding exponentially and there is a serious dearth of housing outside the parental home. **These individuals want and deserve a home of their own.**

WHO

You need serious project partners. This is a lot of work — identifying funding, finding a site, building or renovating, and creating the community. Two or three “founding” families, plus at least as many community partners, is an appropriate start.

WHAT

Non-profit or privately-owned? This decision will affect funding opportunities, as well as the ability to serve those who can't afford the capital expense (and, therefore, the diversity of the community). Size? Autism-specific vs mixed-disability? Mixed-disability only or a larger project with non-disabled community members?

WHERE

Urban, suburban or rural? Assess the availability of staff, and of community-integration opportunities.

WHEN

Now, of course! You may be thinking, “but, my child is only a teenager and I have plenty of time.” That is a common refrain, but is faulty thinking. It takes a great deal of time to develop a suitable life solution. **Sweetwater Spectrum was a vision in December 2006 — it did not open its doors until SIX YEARS later.**



This starter guide was developed to **help you think through the steps** and offer some guidance on **what is needed to be successful.**

ASSESSING THE NEED

Just off the old town square in Sonoma, California, is Sweetwater Spectrum, a 2.8-acre plot of land that is home to 16 adults with autism spectrum disorders (ASDs). As a supportive living model, Sweetwater and the community of support providers, Sweetwater staff, their families, and the greater town of Sonoma, enable residents to live a full life of their own making.

There are more individuals living with ASDs than ever before — now over 3.5 million in the United States. Based on data from the Centers for Disease Control and Prevention (CDC), that number will only grow. In the coming decade, 500,000 children with autism will reach adulthood, and many of these young adults will need ongoing support that ensures their safety while also giving them opportunities to build independence and communities of their own. The founders of Sweetwater Spectrum believe that adult children with ASDs are entitled to these three elements — safety, independence and community — because they are essential to fostering lives lived with purpose.

Yet, many of the existing housing options for individuals with ASDs lack one or more of these essential elements. A private household could offer independence, but the relative isolation — living alone or with a few roommates and a caregiver — limits the chance to build a community. Residential care facilities or group homes sometimes engender a small and insular community of others with ASDs, and these facilities can ensure individuals' safety, but often at the expense of their independence and choice. Housing that does manage to provide safety, independence and community is often prohibitively expensive, far away from families, has waiting lists of eight to ten years, or all three.





Sweetwater's founders garnered community support and came together over this dearth of satisfactory housing options — and the consequent anxiety they shared for their children's future. In pooling their resources, time and energy, they recognized an opportunity to not only build a space that would be a lifetime home for their children, but to create a model that others could replicate. While remarkable in its impact on the 16 individuals who live there, the Sonoma campus is a mere drop in a very dry bucket of resources and living options for adults with ASDs. Alone, one supportive living campus cannot give the oncoming tidal wave of young adults with ASDs the housing options they need. In telling the Sweetwater story, we — the Sweetwater community — intend to give others the tools to expand their options and, in turn, to multiply opportunities for adults with ASDs to live lives of purpose.

Thank you for showing interest in Sweetwater Spectrum. This starter kit is intended to assist future projects in getting off the ground. It should help you focus on the preliminary big questions which drive both the decision to proceed AND where to head from there. **Obviously, this is not a thorough step-by-step guide to getting a project completed — there are thousands of steps on that path.** But, hopefully it will drive your thinking and efforts in the near term.



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GETTING REAL WITH YOURSELF

To start, you must honestly assess your time and resources to undertake a project. It cannot be approached as a part-time endeavor that you do at home each night after your day job.

And, it cannot be done alone — you will need partners and team to back you along the way, keep you moving when you are tired or just stuck, and to share in victories along the way. And even further, someone must take a leap of faith to get started. Please look at the following graphic and assess your situation — if are missing a piece of this puzzle, ask yourself if there is a way to bridge the gap. There is no getting around the need for **all FOUR pieces**.

TIME

Can we **commit** to doing the project?
It is **NOT** a hobby — it is a **JOB**.

TEAM

Can we rally a small, “**committed**” team?
We will need **multiple skillsets**.

YOUR DREAM



THE 4 PIECES

MONEY

Do we have the ability to **find funds**?
It might be a **combination of sources**.

KNOWLEDGE

Are we **willing** to research and learn?
There are **multiple facets** to any project.



A Define Your Goals with Core Families

First things first: decide what you want to achieve. This is done by ensuring you put a lot of thinking into what your goals are for your project. We suggest having one main goal and a number of smaller goals that will ultimately lead you to project success. Document your goals and objectives in a project charter or project statement.

THE SWEETWATER STORY

Sweetwater Spectrum began when two families of teenage children with autism met at a Christmas party in 2006. Both families had long been thinking about their child's transition from schools that provided the structure and support needed to learn and thrive. After basic research, and with high school graduation looming, it became increasingly clear that existing housing models did NOT provide the best possible environment or long-term living solutions for their aging children. After a few meetings, they realized they shared a common goal. Both wanted more than just a house for their children — they wanted a community, one that would sustain and nurture their lives and interests long after their parents were gone. Though not put to paper until a few years thereafter, the founders of Sweetwater shared a common vision early in their project.

Sweetwater Mission:

To provide adults with autism, or similar intellectual / developmental disabilities, innovative, community-based, long-term housing that offers individual choice and challenges each resident to reach his or her highest potential.

Sweetwater Founding Principles:

- Celebrate and support the full range of autism spectrum disorders
- Encourage active resident involvement in their home, household, neighborhood and surrounding communities
- Provide access to productive enriching choices that support a life with purpose
- Utilize autism-specific design, which addresses both safety and sensory issues
- Nurture high-value relationships between residents, families and support staff
- Create and foster a model that can be replicated nationwide
- Offer the potential for lifetime residency
- Accommodate a broad financial spectrum

Today, Sweetwater Spectrum is a living, breathing and thriving community of adults with autism (and related disabilities). Residents have lives supported in the community by residential care staff, day programs, jobs and some community colleges. It is a life that supports choice — choice of housing and furnishings, choice of housemates, choice of support staff, choice of food and clothing, choice of daily activities and friends and, above all, a choice to live as independently as appropriate. Parents still are involved to the extent they desire and are an active community on their own — there is strength in numbers. Walking onto the Sweetwater campus feels much like walking on to any apartment community — it's often empty on weekdays as residents are off doing their own thing. No two lives are the same. Residents (and

their families) pay for rent, food, utilities, furnishings and clothing. The State of California and the regional center system provide funding for support staff throughout a resident's day. Many residents receive 1:1 staffing 24/7 — those with less intensive needs require less. Nothing is cookie-cutter, and each resident's Individual Program Plan dictates his or her needs and services. As due diligence proceeded, the team realized a small urban setting would be most appropriate for us due to ease of access to services and day opportunities — it would facilitate integration of residents into the community.

We've illustrated how Sweetwater's founding families defined their compelling vision and followed it through to realization — what will your vision look like?

Items to Consider & Questions to Ask Yourself

- Whom will our project serve (age, level of need, number of residents)?
- Where will it be located — geographic, city/urban/rural? Will the proposed neighborhood or town be a supportive community? Does our proposed location have available supports — potential for staff, jobs, transportation, government assistance, shopping, medical, leisure activities, ...?
- Can we provide appropriate levels of choice, self-direction, and community integration?
- What is our proposed ownership structure? Privately-owned housing, nonprofit, LLC, ...? Will it be market-rate or affordable housing?
- What is our service model? Independent living, supported living, group home, ...?
- Do we have special design issues for the housing?
- What are our preliminary options for resident recruitment, application and admission?
- Which of the above decisions are flexible for us? Which are non-negotiable?



Nothing is **cookie-cutter**, and each resident's **Individual Program Plan** dictates his or her needs and services.

B

Identify Your Team

The second step on the ladder to beginning your project is the identification of the various team members to be involved. This step must be considered from a number of viewpoints. First, who do we already have? Hopefully you have already identified some core family partners by this point, but more evaluation is needed. Identify the partners' strengths and weaknesses. Second, whom do we need? Spot gaps in your team based on your goals and fill them with others with the necessary skill sets.

THE SWEETWATER STORY

In conducting their research and articulating a vision for Sweetwater, the founding group connected with other individuals who were committed to building the right supportive housing model for adults with ASDs. Upon realizing they needed help in nearly every regard, from choosing a site and working with the Regional Center, to incorporating as a nonprofit, choosing a name and managing finances, they turned to the wider community in search of a board. The two original families sought out deeply invested individuals; creating a nonprofit was hard work, and this would be an unglamorous, working board. Yet, they also recognized the need to balance out members like themselves, who had a massive personal and emotional stake: *their children*. They recruited non-family members who had enough commitment to weather the storms of launching a nonprofit, but who could also offer more objective perspectives. Crucial to these other perspectives was a broader representation and understanding of the autism spectrum so as to not limit Sweetwater's services to the needs of the founding families' children.

The founding board, at the time of incorporation in May 2009, consisted of two family members and three non-family members with the following skillsets: *real estate, finance, medical, nonprofit finance/governance, civic leadership/philanthropy and consultation in supported living services*. As all boards must, this board grew and evolved over



time. By 2011 (the year that Sweetwater hired its founding executive director), three additional board members, two of whom were parents of adults with ASDs, had joined the initial group: two attorneys and the managing partner of an executive search firm.

Time, financial support and talent were three critical characteristics for Sweetwater's board members, and each individual brought a different proportion of these characteristics. From this diversity, leadership roles emerged to oversee committees that included development, finance, audit, building and community (resident life). To make the most of the board's collective time, resources and talent, they instituted best practices early on, such as keeping committee and board meeting minutes, instituting board bylaws and conducting routine self-evaluations.

Items to Consider & Questions to Ask Yourself

- How many people do we want to engage (as board members or “worker bees”) at the early stages?
- How will we conduct outreach to parties interested in helping?
- What skillsets do we have, and what are we missing?
- Who serves on our board (if a nonprofit)? How large should it be initially? Who is in charge and second in command? Developing good governance and board structure from the start is critical.
- How is our organization structured? Committees, task forces, work groups, ...?
- Who has rights to make which decisions?
- What committees are needed to implement our plan?
- What outside parties should be added to committees (advice – engage more “disinterested parties”!! It cannot be just family members and parents)?
- What resources (financial, legal, real estate experts, architects, ...) are needed to supplement the committees?
- Are there conflicts of interest between the organization and individuals on the committees (i.e., between the organization's plans and a parent's personal interest for his or her)?
- How will we communicate?
- Does our team know what is expected of them (this is not a passive activity)?



Time, financial support and talent were three critical characteristics for Sweetwater's board members, and **each individual** brought a different proportion of these characteristics.

What is the actual work that you will need to do in order to achieve your goals?

This is done by focusing on each individual goal you have decided upon, and agreeing with your team on what needs to be done in order to achieve it. Define the tasks as clearly as possible and ensure there is no misunderstanding between the various members of the group. Delegate the tasks. So simple, yet so vital! Delegating work will not only allow you to work faster, but it will develop the skills of the rest of the team...so everyone wins! But make sure you're delegating smartly — no point in having the legal team member being in charge of architectural design.

THE SWEETWATER STORY

Sweetwater operated quite informally between 2006 and 2008. There was a small team of families and interested parties working on concepts and refining their vision. Sweetwater Spectrum headed down a number of paths at the same time and juggled many tasks at once. We had very aggressive expectations for getting the project from its start to completion — and this required a major commitment of hours from the two founding families, in particular. One parent spent 100% of his waking hours on the project — two others were engaged close to 50% of the time.

During the first year after incorporation, the board branched out and defined the following areas as critical:

- Raising public awareness about the project
- Recruiting other founding families
- Organizing the board, committees, procedures and financial reporting
- Generating development budgets
- Fundraising
- Finding a suitable property — first creating a grid with acceptable parameters
- Outreach to service providers and government funding sources

Items to Consider & Questions to Ask Yourself

- Where does our project stand at present? What is our timeline for the first phase and getting started?
- What are our immediate priorities and needs (big picture goals, only)?
- Do we need outside help (facilitator or a consultant) to help us get focused?



We had **very aggressive** expectations for getting the project from its **start to completion**.



Create an actionable, systematic and logical plan that you know you can achieve.

Ensure you create an overall project deadline date and also assign deadlines to the sub-tasks that you created in step three.

THE SWEETWATER STORY

Sweetwater is not just a piece of real estate — it is a complex community with many moving parts. Though a nurturing place to live, it has all the elements of any business — finance, legal, administration, management, marketing and product development. These components must be carefully planned along the way. Sweetwater did not develop its first written strategic plan until March 2011. Prior to that, an extensive “to-do list” functioned to keep us focused in the short-term. We conducted a series of focus groups with families who showed interest in having their children reside at Sweetwater — this helped us fine tune our model, and the parameters for an acceptable site. The critical part of the plan was identifying and contracting for the purchase of a suitable property for development.

Although informal at first, Sweetwater always had a small team of families and interested parties working on concepts and refining their vision. Sweetwater headed down a number of paths at the same time and juggled many tasks at once. The team had very aggressive expectations for getting the project from its start to completion — and this required a major commitment of hours from the two founding families, in particular. One parent spent 100% of his waking hours on the project — two others were engaged close to 50% of the time.

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The initial strategic plan was prepared at a full-day board retreat, and contained the following main goals (with sub-goals and timelines to attain them). Sweetwater was fortunate to identify and acquire its Sonoma site prior to this plan being developed (December 2010) and had already prepared an accurate development budget.

- Program Service Development – Supported Living **AND** Sweetwater Programs
- Financial Planning & Capital Raising
- Model Replication
- Future Staffing (Executive Director recruitment)

(In hindsight, the Model Replication goal was premature, as the innumerable variables encountered were not even known in 2011.)

Items to Consider & Questions to Ask Yourself

- How will we break down goals into “action items”? Develop a why statement for each goal, describe the goal's importance to stakeholders, create a grid for timelines/responsible parties and document its strategic importance.
- How will we document our plan? Strategic plan, “to-do” lists, ...?
- Who will conduct a property search for your project? What is the process for vetting a property and making an offer? Are we buying an existing housing project or developing from scratch?
- Where is our funding coming from? Create a funding plan.
- How will we recruit interested residents? Media outlets, speaking engagements, schools, regional centers, ...?



We conducted a **series of focus groups** with families who showed interest in having their children reside at Sweetwater—this **helped us fine tune our model**, and the parameters for an acceptable site.



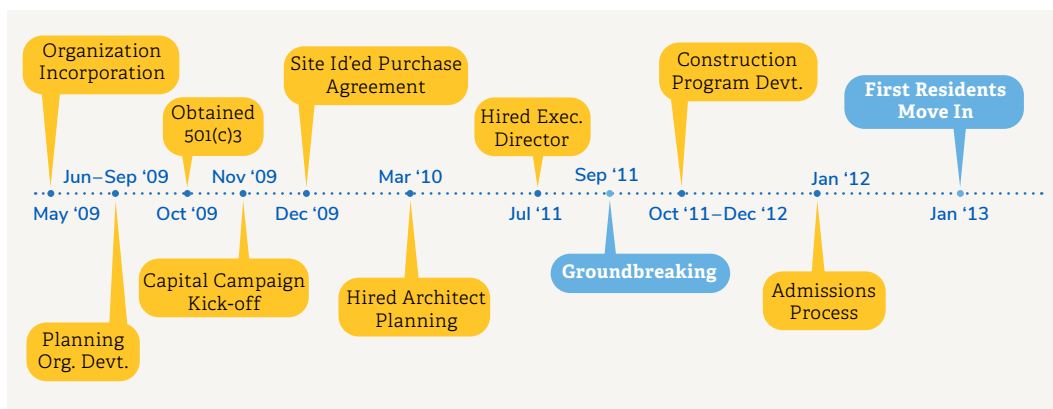
E Execute and Monitor

The final step is to start working on your project and monitor it continuously throughout the process using a project management tool. Keep open lines of communication throughout that will ensure you and your teammates are up to speed with what is going on around you. Try and meet regularly to go over your progress and make any necessary changes due to unexpected bumps in the road!

THE SWEETWATER STORY

Sweetwater was relatively informal in its early years (2008–09) about planning, as the primary focus was on locating a site for the community. Once that happened in December 2009, it became (by necessity) meticulous about executing and monitoring the necessary steps to make it a reality. The Board vetted the acquisition of the property in early 2010 and was vigilant about creating timelines and “to-do” lists as it moved forward. The number of items juggled during 2010 and into early 2011 was mind-boggling. Not only was a property being purchased and buildings designed, there was a full-scale capital campaign underway. In addition, the Board was looking forward to program development, resident admissions, developing legal parameters, hiring staff and ongoing budgets and operations. This was 100% Board-driven until July 2011 when an executive director was added to the management team. Monitoring the planning approvals, permit process and construction (and change orders) was essentially a full-time job.

Below is an abbreviated timeline of Sweetwater’s history from incorporation until the new residents took occupancy. After incorporation, Sweetwater came to fruition in approximately 3.5 years due to its ability to focus and execute tasks in a timely manner.



Items to Consider & Questions to Ask Yourself

- Do we have a process to keep us on task?
- What is our process for adapting to changes in our plan and approving new directions?
- How is our team held accountable for completing and reporting their tasks (require committee reports)?
- How often is progress monitored?
- Are we taking time to adjust our goals and assimilate new information?
- Are we celebrating our successes?

F How Can Sweetwater Help You?

Nationwide, there are few housing choices available for adults with autism or similar intellectual/developmental disabilities. Our model, with its first campus in Sonoma, uniquely encompasses a “life with purpose” for its residents and provides a lifelong home. The interest in our model is clear, as Sweetwater Spectrum regularly responds to inquiries about its approach from all over the world.

To assist aspiring founders in developing their own communities, Sweetwater has put together a collection of educational resources and has launched a consulting service. In addition to this Starter Kit, make sure you review Sweetwater’s “FAQ” and videos, which provide additional information to help you understand the choices and tradeoffs that were made to make Sweetwater what it is today.

While Sweetwater has developed a wealth of knowledge, we are not the only ones passionate about housing. There are many others, and they also have provided a plethora of resources. Sweetwater has done the work of filtering through the abundance of information available and has identified a short list of high quality resources that can help kick-start your project. Specifically, these resources can help you to:

- Differentiate between potential housing types
- Understand funding options
- Find existing and emerging housing projects throughout the United States
- Understand the steps involved with developing a housing solution
- Discover symposiums/conferences on disability housing
- Identify expert consultants who can help make your project a reality

This short list of resources can be found on the replication tab of Sweetwater’s website.



Our model, with its first campus in Sonoma, uniquely encompasses a “**life with purpose**” for its residents and **provides a lifelong home.**

SWEETWATER CONSULTING SERVICES

Sweetwater knows that building a housing solution is hard. You can gather as much information online as possible, but there's nothing quite like speaking with a person. And Sweetwater has you covered!

If you've exhausted Sweetwater's online resources, understand the basic requirements of building a housing solution and are still passionate about taking things to the next level, experts from the Sweetwater team can be engaged as fee consultants to help you. These experts are knowledgeable on a variety of topics from refining your vision, to building a budget, to establishing an effective board. A full list of topics that Sweetwater is available to consult on is available on the replication tab of Sweetwater's website.

If you are interested in consulting, please fill out the consulting request form on the Sweetwater website. We're looking forward to hearing about your vision and working with you on your project!



Thank you for reading our Starter Kit! We hope you find this helpful in your path to realizing your vision for special needs housing in your community.



For more information about replicating the Sweetwater Spectrum model in your community, visit our website at www.sweetwaterspectrum.org. You may also email Sweetwater's Executive Director, Kory Stradinger, at kory@sweetwaterspectrum.org.

