We Need Housing! Now What?



Putting It All Together:
Build Your Plan

Gather. Decide. Implement.

Combine what you've learned to map out the right housing path for your loved one and family.

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Putting It All Together: Build Your Plan

Summarizing Your Loved One's Housing Needs

After visiting the relevant worksheets for your situation, write down your top concerns from each individual worksheet. Then, for each concern, consider how often it applies (High to Medium to No Concern) and review the suggested features of housing needed.

WORKSHEETS	What are your top concerns?	High Concern	Medium Concern	No Concern
Stability Assessment		Round-the-clock care facilities with qualified staff and therapeutic options	More supported housing with some community integration	Living at home with additional medical supports in nearby community
Environment Needs		More integrated housing supports to learn basic life skills and personal goals	Facilities with optional structured training to address life skills, needs, and desires	Exploring add- on community features that meet various needs and preferences
Symptoms Severity		Structured 24/7 environment with symptom- specific therapies, treatments, and interventions	Facilities with tailored medical supports as needed when symptoms are challenging	Community-based therapies, sessions, and/or medication management near living arrangement
Treatment Management		Managing both medication and treatment is all overseen in the housing facility	Housing has supports that address and/ or administer treatment and meds as needed	Housing environment providing flexibility to get medication / treatment with caregiver help
Activities of Daily Living (ADLs)		Facilities provide daily structure, programs, and routine care to fulfill everyday basic living needs	Freedom of movement in structured living environments balanced with added supports	Varying personal independence to manage daily living needs, receiving help if needed or requested

Build Your Personal Housing Plan

Now that you've explored your loved one's needs and reviewed the different housing options available, the next section helps you connect the dots. The goal is to offer a supportive framework for building a personal housing plan tailored to your unique situation.

The <u>Build Your Housing Plan</u> has a set of worksheets that will guide you step-by-step through planning the housing journey, from identifying promising options and vetting staff expertise, to sizing up costs, conducting outreach, to assess each facility – potentially in person, and mapping a smooth transition. Use this guide to keep your decisions focused, informed, and actionable:

"All you need is the plan, the road map, and the courage to press on to your destination."

- Earl Nightingale



Prepare documentation and medical records

Before visiting any potential facility or housing arrangement, gather important records and documents to ensure that providers have accurate information, and discussions can be more productive and specific to the individual's needs. Facilities often may require comprehensive documentation to verify eligibility, support specialized care, and identify funding or subsidized options. It can help speed up the application and admissions process as well.

Key information and documents include but are not necessarily limited to:

KEY DOCUMENT TYPES	Sample information to bring
Identification and Legal Documents	□ Valid ID (driver's license, state ID) □ Social Security card (if relevant) □ Insurance card □ Any legal documents such as guardianship papers, power of attorney, or health care proxy (if relevant)
Psychiatric Evaluations and Diagnoses	 ■ Most recent psychiatric evaluations and diagnosis information, including co-occurring information ■ Hospital discharge summaries (if applicable) ■ Other documentation of psychosis-related disorders, schizophrenia, or any co-occurring conditions
Medication Lists	□ A current list of all medications, dosages, and prescribing healthcare providers – pages 8 - 9 in Part 1 of the "I'm Diagnosed, Now What?" Toolkit provide some worksheets to document these details □ Notes on past medication and any known side effects or adverse reactions
Treatment/Support Plans	☐ Current or previous Individualized Treatment Plans (ITP) or service plans from mental health professionals ☐ Therapy schedules or counseling documents that detail the frequency and type of sessions (e.g., group therapy, individual therapy)
Insurance and Financial Documentation	Insurance information (Medicaid, Medicare, private insurance)Income or disability documentation for housing assistance or subsidized programs

Evaluating housing fit

Arranging tours can aid in evaluating a residence's suitability for your loved one. While websites and brochures may highlight facility features, in-person visits offer invaluable firsthand insight into the environment, staff interactions, cleanliness, and overall atmosphere. Observations during these tours often reveal important details that are difficult to assess remotely, such as how staff engage with residents, whether safety protocols are followed, and if the surroundings feel comfortable and well-maintained.

(i)

Before scheduling a tour, take time to research what types of housing options are available in your area based on your needs, such as group homes, supported apartments, or long-term care facilities; you may have already documented your findings from the **Build Your Housing Plan** worksheet.

- ➤ Use the worksheets and checklists during each tour to guide your observations and help you compare multiple facilities objectively.
- ➤ Call in advance to book your visit, allowing staff to prepare to guide you through the facility and answer your questions.

Final housing questions

Preparing for housing involves a comprehensive understanding of various aspects beyond just the physical living space and treatment support. Look at the emergency protocols for crisis situations and assess discharge planning procedures.

Emergency protocols / crisis situations

Mental health crises—such as severe psychosis episodes, suicidal ideation, or acute agitation—can happen suddenly and require rapid, well-coordinated responses to keep everyone safe and supported. A housing facility program with robust emergency protocols can make the difference between a quick resolution and a prolonged crisis.



These questions can help you better understand potential existing protocols to manage a crisis with housing residents:

1. Staff Training & Availability

- a. Do staff receive regular training in crisis de-escalation, mental health first aid, and traumainformed care?
- b. Are staff on-site or on-call 24/7, or are they only available during certain hours?

2. Crisis Intervention Steps

- **a.** What specific steps are taken in the event of a mental health crisis? When are family or designated supporters contacted, or is 911 or 988 the first call?
- **b.** Do they have a relationship with local mobile crisis teams or licensed mental health professionals who can come on-site to de-escalate?

3. Transfer to Higher Levels of Care

- a. If an individual needs hospitalization, how quickly and smoothly can that be arranged?
- **b.** Does the housing facility maintain partnerships with nearby hospitals or crisis stabilization units?

4. Follow-Up After Crisis

- **a.** After a crisis has been resolved, how does the facility handle debriefing, medication adjustments, and emotional support for the individual or their loved ones?
- **b.** Are any changes made to a resident's individualized treatment plan? If so, how?

Discharge Planning from Hospital

When your loved one is stepping down from a hospital stay, clear and coordinated discharge planning reduces the risk of relapse, destabilization, or even homelessness. Planning also ensures that important details—like medication regimens, follow-up appointments, and community resources—are well-coordinated as possible in the circumstances.

However, many facilities and hospital systems still significantly lack effective coordination when transitioning patients back into the community (Bajorek & McElroy, 2020).

- When discharged, patients often receive minimal or vague information on potential housing plans, medications themselves and side effects, and how to get answers to questions upon leaving the hospital (Burton, 2012).
- Far too frequently, individuals are discharged to unstable environments—such as emergency shelters, unsuitable group homes, unsafe housing, or no clear housing solution at all—putting them directly at risk for further trauma, relapse, victimization, or re-hospitalization.
- Furthermore, hospitals may lack a clearly designated staff member accountable for overseeing the discharge plan and ensuring continuity of care, leaving caregivers and family members to navigate complicated healthcare and community support systems without adequate guidance or preparation.

To address these challenges effectively, caregivers and family members are encouraged to do their best to actively engage with hospital social workers, staff in the discharge process, and treatment teams.

Some of these questions might help coordinate the hospital discharge process back into the housing situation:

1. Coordination with Hospital Staff

- Does the housing provider have established relationships with local hospitals?
- If at all, how do they coordinate with the hospital's inpatient treatment team to get accurate medication lists, diagnostic information, and discharge recommendations?

2. Medication Continuity

- Is there any process in place to ensure that medication routines and prescriptions continue seamlessly once someone leaves the hospital?
- Who oversees medication changes or refills, and how are psychiatrists or primary care providers involved?

3. Transportation & Logistics

- Is transportation from the hospital to the housing program provided or assisted? How can I help coordinate transport for my loved one?
- What about follow-up appointments—does the facility do anything to help schedule them or provide transportation?

Discharge planning from jail/prison

Individuals with schizophrenia or psychosis may become involved with the criminal justice system, resulting in being "housed" when incarcerated. While extensive planning is critical, many correctional facilities fail significantly at coordination for the transition from incarceration back into community-based housing, leading to potential cycles of crisis, emergency hospitalization, substance misuse, re-arrest, or reincarceration (Stainbrook et al., 2024). In many cases, incarcerated individuals with schizophrenia or psychosis disorders are released directly onto the streets with little more than a bus ticket and minimal medication, if any at all (Francis et al., 2023).

Valuable resources to help with this reentry process include **The Council of State Governments (CSG) Justice Center - Reentry's** featured resources and guides, as well as the **Vera Institute of Justice-Opening Doors'** public-housing reentry guide.



Indicators for adjusting housing types

Housing situations should evolve with your loved one's state of recovery. Continual re-evaluation of the situation is important as housing needs can shift over time, especially as the wellness journey progresses or experiences setbacks. Flexibility and open communication with housing staff and healthcare providers will help you adapt.

- Staying connected with healthcare providers, case managers, and housing staff helps ensure that any changes in symptoms or needs are addressed promptly.
- Maintaining an open dialogue and regular check-ins to share progress or concerns can be helpful to ensure that the housing situation would be the best choice for the current conditions.

Knowing when to transition to a housing type with either more or less support is essential, as your loved one's condition may change over time:





Increased Need for Support or Supervision:

- **Relapse or Worsening of Symptoms:** A notable increase in psychosis symptoms, hospital readmissions, or crisis calls can signal the need for more intensive support.
- **Safety Concerns:** If your loved one shows new or intensified self-harm behaviors, aggression, violent behaviors, or potential vulnerability (e.g., responding to paranoid delusions that lead to risky decisions), the current housing level may be insufficient.
- **Difficulty Engaging with Treatment:** Successful recovery management often relies on consistent use of medication, treatment plans, and frequent contact with mental health professionals. When an individual cannot maintain these routines whether due to cognitive challenges, lack of insight, or logistical hurdles these may indicate time to explore a more structured environment.



Increased Independence and Recovery Progress:

- **Stabilized Symptoms:** Symptoms, such as hallucinations or delusions, are well-managed in treatment acute episodes are infrequent, as well as when situations needing hospitalization or crisis interventions have decreased significantly, and the person demonstrates increased insight into their condition.
- Improved Daily Living Skills: Clear progress in self-care and contributing to daily living needs, such as can consistently prepare their own meals, perform routine cleaning, effectively manage their medication schedule, or even handle some personal finances with minimal support
- Enhanced Social and Community Integration: Greater participation in community life, such as attending day programs, volunteering, or even engaging in some form of employment they're building meaningful routines and relationships outside the residential facility, if applicable.

Recovery is not a linear journey. Sometimes setbacks or improvements in a situation can happen at any stage. Being proactive and flexible—willing to adjust the housing arrangement when needed—can significantly impact overall well-being for you and your loved ones. Not every sign requires an immediate change to the housing environment, and decisions about adjusting to the most beneficial housing situation should always involve a collaborative process with treatment team, support network, and—most importantly—the individual themselves, if possible.



Understanding care coordination

The lack of coordination between housing providers and medical support teams, especially when transitioning between housing settings, hospitals, or the criminal justice system, creates significant challenges. When a social worker cannot communicate with a psychiatrist, or when there's no clear communication pattern, the individual's needs can easily fall through the cracks due to the disruption of care and treatment, leading to relapse or worse.

This lack of coordination often means that the caregivers are frequently required to do the heavy lifting of care coordination themselves, acting as intermediaries between different service providers. However, some steps can be taken to help smooth the coordination of care as a caregiver:



Document Everything: Maintaining detailed records of all interactions with healthcare providers, housing staff, and other relevant parties can help address gaps. Include dates, times, names, and key information discussed.



Establish a Communication Hub: Create a centralized system for information documentation or sharing, such as a digital document, dedicated notebook, or specific communication notetaking app.



Learn About Relevant Laws and Regulations: Familiarize yourself with relevant laws and regulations for the rights of individuals living with psychosis-related disorder and/or disabilities, as covered in the next section.



Advocate: Be assertive about your loved ones' needs. Don't hesitate to ask questions, express concerns, and be direct so that service providers communicate with each other.



Seek Support: It's essential to seek support from family, friends, support groups, and consider getting your own therapist. Taking care of your own well-being will enable you to be a more effective advocate for your loved one's housing.

Through coordinating care themselves, the caregivers can help prevent their loved ones from being in housing situations with increased instability and take these active steps to support their loved ones' needs.



Understand legal protections

Ensuring equitable housing for individuals with schizophrenia and psychosis-related disorders involves knowing several key federal laws designed to protect their rights. Understanding these legal frameworks is crucial for evaluating housing options and being informed about various anti-discrimination mandates:



- Fair Housing Act (FHA): The FHA prohibits discrimination in housing based on disability, ensuring loved ones are afforded equal housing opportunities. FHA includes protections against refusal to rent or sell, unfairly providing different terms or conditions, or administering unequal services. Housing providers must make "reasonable accommodations" in policies and practices.
- Americans with Disabilities Act (ADA): The ADA's influence extends to the accessibility of public and common-use areas in multifamily housing complexes. For individuals with schizophrenia, accessible environments can mitigate stressors that may typically worsen symptoms.
- Health Insurance Portability and Accountability Act (HIPAA): HIPAA ensures the
 confidentiality of residents' medical information but may create barriers when
 caregivers are trying to coordinate care for a loved one who hasn't signed over
 authorization to their medical records. Medical staff in housing are trained to handle
 sensitive information appropriately, ensuring disclosures are made only with proper
 consent or as legally required
- Section 504 of the Rehabilitation Act: This statute mandates that any program or activity receiving federal financial assistance must not discriminate based on disability. For housing programs, this could translate to an obligation to offer units that are not only physically accessible but also accommodating the unique needs of individuals with mental health disorders.

Understanding your loved one's legal rights is essential when evaluating housing options, in addition to addressing practical needs like supportive services, affordability, and safety as covered earlier in this toolkit. To learn more, explore this page on knowing your fair housing rights for additional guidance, resources, and details.

By familiarizing yourself with these legal protections, you can better advocate for appropriate accommodations and make informed decisions when selecting housing that meets your needs or those of your loved one.

Shattering barriers to treatment, survival and recovery for people with schizophrenia and other psychosis spectrum disorders.

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