

The International Journal for Direct Support Professionals

Developing Partnerships for Family-Managed Supportive Living Arrangements

By Zoe Kariunas

Alternative living situations are the talk of the developmental service world right now. Families are asking for more flexible and creative ways of facilitating the development of unique supportive living situations. This article is focused on one particular aspect of this puzzle, the search, and development of a family partnership between two or more individuals living together in a supportive living situation.

Most of us have tried living with a roommate before, likely with mixed success. Thinking about all the learning from that experience, we often expect the process to be similar for those individuals and their families we support. It's actually very different. Mostly because, for many of us, our parents were not involved in our decision to have a roommate or subsequent decisions we made in our homes. Families who are trying to create a uniquely supportive living situation for their loved ones with Intellectual and Developmental Disabilities (IDD) are much more involved than ours likely were. It makes sense, as there is often an element of sharing support, as well as facilitating communication about needs in the home. This is an emotional leap for many families that requires skilled facilitation.

Finding roommates and facilitating an exploration process to determine if the roommates and support circles are well matched is an unexplored area in the tools and literature. Based on my match-making experience with partnering families for over five years, I've created a framework to help guide conversations during this process. These are all factors I've seen come up during the process or while the living situation is operational. Some have been so impactful that partnerships have been dissolved because of fundamental misalignments. Many families who have been through the process liken it to a marriage. There may only be two people in the home but, if the families don't see eye to eye, there will be problems. Of course, there are living situations with more than two roommates, which often makes it more complex, as there needs to be group consensus building to progress. This might be more analogous to complex family dynamics, for example, intergenerational family homes.

It's important to recognize that each person living in the home is unique, so it is to be expected that some of these factors in this framework might not weigh as heavily as they might for others. This framework aims to offer a guide for individual exploration for individuals and families before beginning the search for a

Editors: Angie Nethercott, M.A., RP
Chanelle Salonia, M.A., BCBA



Hands | Mains

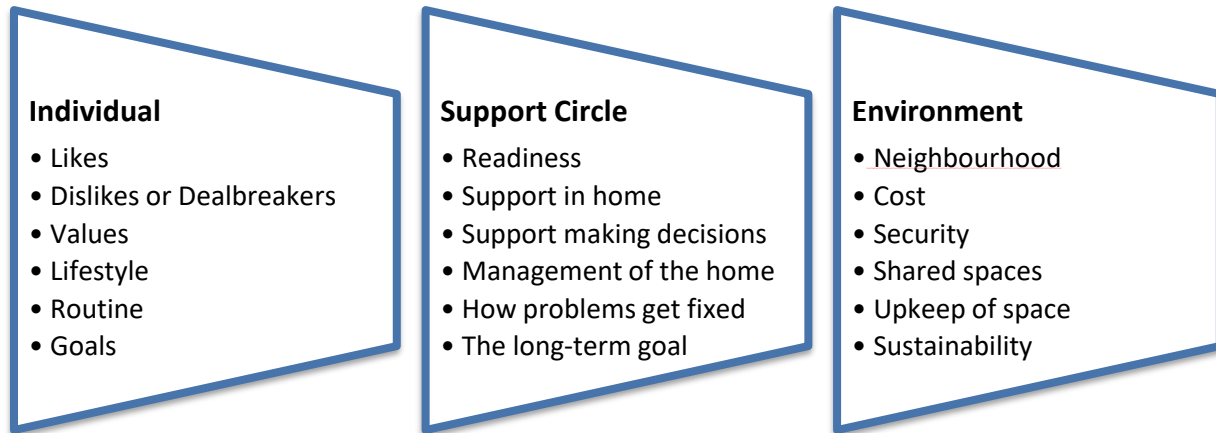
TheFamilyHelpNetwork.ca

LeReseaudaideauxfamilles.ca



roommate, as well as offer topics for discussion during the initial stages of meeting a potential roommate and forming a partnership.

The Roommate Matching Framework



The framework divides the factors into three broad categories: Individual – the person living in the home, support circle – the people around them who support them in their living situation, and the environment – the physical home and community space around the home.

Individual

The person living in the home is often where roommate matching questions start. People living with and seeing each other most days must get along. My experience has been that many people with disabilities living with a roommate, even for the first time, are much more adaptable than given credit for. Most roommates are excited and proud to have a place of their own, and they are often willing to be much more flexible with roommates than they might have been while living with family.

Likes

It's helpful to have a good relationship with a roommate. The most effective way to create relationships is to do activities together that both enjoy. I've seen someone respond to a roommate ad because the ad mentioned a TV show of which the person was a huge fan. Sometimes, the more unique interest, the better because there is often someone else out there who also likes that thing. Examples could be cooking a treat, ordering dinner from a favourite restaurant, doing some arts and crafts, or playing video games. It's an opportunity for roommates to connect. If there is no common ground for an enjoyable connection, the relationship just won't develop in the same way.

Dislikes or Dealbreakers

Generally, this refers to behaviours or traits that one might find triggering. It should be clear that these traits or behaviours aren't necessarily bad or something to be changed. Often, it's just differences that a person might have a hard time getting past. Nobody wants to be routinely triggered in their safe space at home. It's also important for us all to be upfront and honest about these things, as well as to recognize that change is really hard for most of us. To give an example, some people are very triggered by swearing, whereas, for others, it's just a part of their vocabulary. It's very likely, if you have a person triggered and a person in the habit of swearing in daily conversation, there will be tension from that. Sensory preferences can also be dislikes, for example, a person who speaks at a high volume due to hearing loss might not be the best roommate fit for a person who is triggered by hearing yelling.

Values

These are beliefs of what is important or worthy of consideration. Many values come from larger systems and can be cultural, political, religious, generational, gendered, or familial. I've seen roommate tension stem from a consensual romantic relationship that one roommate had with her boyfriend. The other roommate felt it was wrong that two unmarried people might be intimate and sleep in the same bed. Another example might be what food is acceptable in the home. Many religions have specific dietary requirements whether it be vegetarian, kosher, or halal. Yet another example is beliefs held about the LGBTQIA+ community which could have a direct impact on roommates, as well as people they care about in their lives.

Lifestyle

The intention of this is not to change activities or preferences but rather to consider if roommates have similarities in lifestyle to create a home where everyone is comfortable. To give an example, think about comfort levels with having visitors coming over. Some people have an open-door policy where anyone is free to drop by whenever they would like, whereas others might prefer their home to be a private place where they can recharge. Consider the effect the pandemic had on folks' risk tolerances for having visitors at home.

Routine

The daily flow of activities for a person. This is important for a few reasons. Firstly, sharing common spaces – especially the bathroom and kitchen – can require some planning. It's helpful if roommates can use common spaces without disturbing others or monopolizing the space. The most obvious example is early birds living with night owls. It can be challenging to find a common time and share space with obvious differences in how the day flows for each roommate. Secondly, if support is going to be shared, there needs to be a time when roommates are available. Support shouldn't mean a person has to give up an activity they enjoy like social events, clubs, hobbies, etc., but there needs to be space in the day to get that support. Many things in the home need to happen on a daily or weekly basis, and it's important to review schedules to ensure there are openings to get that support for all roommates.

Goals

Many folks are keen to move into a place of their own but may have different ideas on how that might look. For some, it's a huge step towards living more independently, and that might mean that they plan on making most of the decisions in their home rather than asking for support. It might also mean that they wish to do things their way which likely will include a learning curve. In this case, a goal might be to learn how to wash and dry clothes without help. Others might be more cautious about learning skills to live independently and might have a goal of having family members over often to maintain a close tight-knit family group. Others still might require tremendous support, and their goal might be to get used to new surroundings and new relationships. Goals will likely be easier to achieve if there is a sense of solidarity, mutual support, and understanding from roommates.

Support Circle

This category is typically families but could involve any number of people supporting the individual in an ongoing way, paid or unpaid. It's the people in someone's life who help to manage, advocate, and plan. For family-managed living situations, it's the people who will manage the home.

Readiness

One of the first questions I would ask when matching is the timeline of when the support circle imagines the move happening. If there are significantly different timelines, say 10 years versus 10 months, the match won't be successful. This is largely because the process of letting go for

support circles, especially for primary caregivers, is emotionally intense. Most families will take a few steps backwards at some point due to emotions running high. This is completely normal and should be expected. Even those who say over and over that they are ready, will get scared when it becomes “real” for them. Our role in supporting this is to offer empathy and recognition to the support circle that what they are doing is a huge leap, and it’s natural to feel mixed feelings that come along with that. It’s critical that those conversations don’t involve the person moving out, as it can negatively impact their confidence in moving into more independent living. We need to support families in the background and allow them to be cheerleaders for their family member.

Support in home

I promote the “just enough” support model. That means working through days/weeks/months to get a sense of what support a person requires, how often, and what type. I will usually ask support circles to keep track of the support they provide along with what that support looks like, and who would be providing that support once their loved one moved out. Many support circles like to retain the medical and financial support piece but step back from the day-to-day support needed like transportation, meal preparation, cleaning, and hygiene. For many support circles, it’s now an opportunity to be a family member or friend who advocates rather than in-home caregiver. This is an opportunity to discuss with support circles how they envision their lives moving forward after this move, as it’s a change for them as well. Many couples and families experience feelings of empty nests that require adjustment.

Support making decisions

This is specific to how decisions in the home are made day to day, as well as how conflicts are managed. We know that, oftentimes, facilitation is required for folks with disabilities to make decisions, especially if they are now making them with a roommate. There might be a learning curve involved. It’s often natural for support circles to jump into assisting with decision-making, as they might have while living with their loved one. This can create problems; however, when communication breaks down between support circles, emotions can run high when families perceive that they need to advocate for their loved one. It’s very helpful to have discussions, along with examples of how decisions are made and problems are solved before they happen. A family might feel that day-to-day household decisions should be made between the roommates with support of paid staff, whereas larger decisions might be made as a group at a regular house meeting. It’s more important that support circles are on the same page than the actual agreed-upon process itself for decision making.

Management of the home

The nitty gritty logistical legal details of the home. These situations can be very different, so it’s important to consider how the living situation is set up so everyone can be aware of their legal rights and responsibilities based on their role. Consider things like whose name is on the lease, who has primary contact with the landlord to make requests, who is named on the utility bills, how do bills and rent get paid i.e., out of what account, etc. Many people with low income need to consider having a co-signor or guarantor to apply for market-rate rentals. Support circles should consider who might do this if required. We are also seeing many families taking on the role of the landlord, as well as a partner. This adds another layer of legal complexity to the situation, and I always encourage families to get legal advice on the financial impacts of this arrangement for them, as well as for their loved one. The setup matters and everyone should become familiarized with the Residential Tenancies Act (RTA) (or the equivalent in your area) to learn more about the rights and responsibilities of being a tenant or landlord.

How problems get fixed

When conflicts become threats to the living situation, it’s important to have a process of intervention to attempt conflict resolution. In our "Roommate Partnership Agreement" resource

which can be found at [Developmental Service Ontario's Housing Toolkit](#), we include conflict resolution steps for discussion. Many support circles put enormous amounts of time and energy into making living situations work, so it's important to exhaust all options before dissolving a partnership. Sometimes tensions run high, and it's helpful to have a neutral third party to help mediate.

The long-term goal

Life happens and things change. This is expected; however, I encourage support circles to have an open, honest dialogue about future intentions. Some see living situations as a way to try things out and get some experience, others hope for a funded supportive living spot in the future, and others yet consider this the long-term plan for their loved one. It's important to make the partnering support circles aware, as well as keep them updated regularly as things change, as it might impact the support circles' ability to maintain the living situation.

Environment

This refers to the physical space of the home, as well as the space around the community, including both the services available, and the general ambiance of the community.

Neighbourhood

Many people express wanting to live in a community or neighbourhood in which they grew up, or with which they are very familiar. This is logical from the perspective that it's known, family might live nearby, and there might be natural supports present already. There can be barriers, however, including availability and cost of housing, as well as potentially limiting partnership opportunities in other communities. I encourage people to consider first what is important to have in the community rather than becoming fixed on the specific community. Amenities to consider may be access to transportation, grocery stores, pharmacies, location of programs or employment, desired community space such as pools or parks, and overall atmosphere of the community, i.e., safe, welcoming, etc. By reframing this as an amenity-driven discussion rather than a location-driven discussion, it can open more opportunities, as well as help minimize barriers such as cost and availability of rentals.

Cost

Individuals and their support circles should do an independent budget first to determine how much they can afford for rent and utilities. Conversations should be realistic and consider any potential funding sources. I encourage people to do a scan of average market rent to get a realistic idea of what they might expect to pay. Roommates and partnering families should be upfront about their budget before viewing any potential rentals to avoid getting swept up into signing a lease without knowing how they will be able to afford it.

Security

As technology becomes more accessible and less costly, many families are turning to security cameras, code-operated keypads, smart home devices, etc. to increase safety in the home. While these technologies can offer significant benefits to creating more independent homes, there are also factors to consider. It's important to have honest conversations about how to balance privacy and security by discussing the purpose and access of camera feeds or other data. It's also important to consider other safety requirements such as who has a key to the home, when might a person access the home, what rooms might have locks on the doors, whether there is a fire escape plan, etc. For many, security also factors into the immediate area outside the home. For example, inside the apartment building – is there security personnel present, how strict are other building occupants on letting strangers come in with them through the main building doors, and are the hallways/stairwells well lit? Bad things can happen in safe neighbourhoods, so teaching community safety skills is always the most critical thing to ensure safety, but these are additional factors to consider.

Shared spaces

Along with discussing who might be decorating and cleaning the common spaces (generally the living room, kitchen, and bathroom), it's helpful for roommates to consider how and when the spaces might be used. For some, it might require some new sharing of the TV or bathroom, so a schedule can be helpful. For others who want to do activities with their roommates, it might be helpful to schedule a time when everyone is using the living room, so connections can happen. Discussion of expectations is important in understanding how common space might be shared.

Upkeep of space

Space in this concept refers to the home and property, and this point reflects on the process of doing maintenance and major repairs. It's perhaps more visible in a home with a yard that needs landscaping, a driveway and sidewalk that need snow shovelling, and garbage to be put out at the curb. It is often the landlord who does or is responsible for these tasks, but it can become a bit trickier to navigate if a family member is the landlord. I would often suggest to families in the position of being a landlord to consider their capacity to do these tasks regularly and structure their involvement based on that. For some, that might mean hiring an external company to do lawn care/snow removal. This cost should be built into the rent. Any other major repair to the home caused by general wear and tear, as well as ongoing services such as pest management or functioning smoke detectors is the landlord's responsibility. I encourage family landlords to create a repair fund in their own budgets that is funded at least partially, through rent payments. Other repairs that might have been caused by tenants are usually the tenant's responsibility to fix or pay for. It's encouraged for both landlord and tenant to know the RTA to understand their rights and responsibilities for the general upkeep of space.

Sustainability

The development and operationalization of a living situation requires a tremendous amount of time and energy from the support circle, and it's important to set things up in a way that promotes success in the future. Managing costs in the future is an especially key aspect of this. Each roommate needs to have an individual budget that considers cost inflation of fixed costs over time. Costs can increase dramatically if the home isn't rent-controlled, which is determined by the RTA. In Ontario, rent-controlled homes can only have rent increased by the landlord annually by a fixed percentage (determined by the province). Any increase above that percentage is called an above-guideline rent increase and needs to be approved by the Landlord Tenant Board. This protects tenants from massive arbitrary rent hikes. For those owning homes, major costs associated with maintaining the property must be accounted for, for example, furnace replacements, driveway repaving, new windows, or new appliances. If the landlord is a partnering family, I would always encourage them to build a cushion into the rent to set aside for repairs and maintenance as needed. Often, families feel pressure to keep rent at a rate that is affordable for tenants, occasionally to their detriment, as this can mean they might incur massive expenses that may force them to re-think if they can continue to afford the home. If the landlord cannot afford to keep the shared home and is forced to sell for financial reasons, this does not benefit the tenants or the landlord in the long run. I've seen families be forced to sell after running at a deficit for years only to lose a huge chunk of money because of the venture. It's important to consider the long-term financial sustainability regardless of the role families are in.

Conclusion

Direct support workers must increase their knowledge of family-managed supportive living situations, as we are likely to see more and more as time goes on. We tend to rely on pioneering families that have been doing this for years to lead the way, but our sector needs to become knowledgeable in matching individuals and family's needs, and be prepared to facilitate. My hope is this framework can be a jumping-off point for many in helping families create unique living situations for their loved ones.

About the author

Zoe Kariunas is an experienced facilitator working with individuals and their support circles to create individualized living situations. During her time with LIGHTS at Community Living Toronto, she has walked alongside hundreds of support circles to create a vision, build a viable plan and budget, explore partnerships, and move their loved ones into more independent living. She currently works with Developmental Services Ontario in Toronto housed at Surrey Place as a Housing Navigator. Her role includes consulting with families and professionals on community housing options and creating resources for those looking to learn about more independent living in community. Zoe also works with Siblings Canada, an initiative of the Canadian Centre for Caregiving Excellence, to co-facilitate ACT workshops for siblings. She is currently pursuing a Masters of Social Work at the University of Windsor and plans to continue working with caregivers after graduation.

Resource

Our DSO Housing Toolkit has further information and resources for developmental service professionals, support circles, and individuals about roommates, and much more on exploring living situations in community. It can be found at [Welcome to the DSO Housing Toolkit | DSO \(dsonario.ca\)](https://www.dson.org/Welcome-to-the-DSO-Housing-Toolkit)

Answers to FAQ's about the journal

- 1) The journal is intended to be widely distributed; you do not need permission to forward. You do need permission to publish in a newsletter or magazine.
- 2) You may subscribe by sending an email to anethercott@handstfhn.ca
- 3) We are accepting submissions. Email article ideas to anethercott@handstfhn.ca
- 4) We welcome feedback on any of the articles that appear here.