

Maine Coalition for Housing and Quality Services

Housing Options
An Overview



April, 2019

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Introduction

In 2006, parents of individuals with developmental and related disabilities met with Community Housing of Maine and University of Maine's Center for Community Inclusion and Disability Studies to discuss ways to improve quality in services. It became apparent to this initial parent and advocate group that there was much concern and a critical need for safe, affordable housing with quality supports to meet the individual needs of their family members.

Thus, the Maine Coalition for Housing and Quality Supports was born as a parent-driven, quality oriented, and action focused advocacy group. As of 2019, it is over 4,000 members strong and continues to work with all interested others to improve policies and make quality housing and supports a reality for individuals with developmental disabilities in Maine. This is a person and family-centered coalition, with choice and dignity at the forefront of efforts. It is inclusive and everyone is invited to participate in monthly meetings, or via list serve updates.



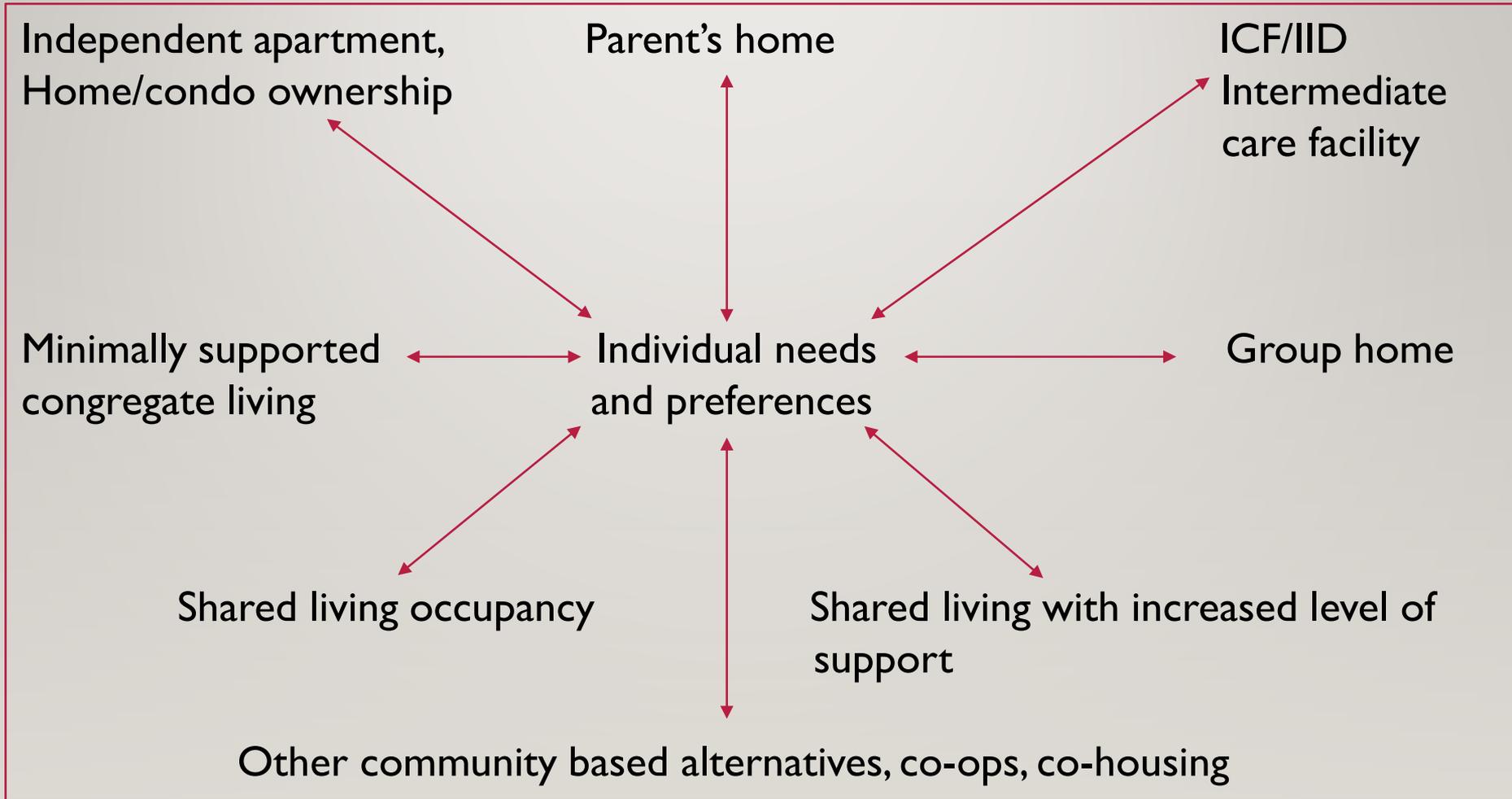
Housing Overview

This housing presentation contains the most common models of housing supports within the state of Maine as of this year. As it would be unrealistic to list individual programs, which do change, this is intended to provide the reader with a general guide to options, and some points to consider. Everyone is encouraged to think about their needs and preferences as an individual, set goals, and to talk with others about possibilities.

This system presents itself as a changing one; with new innovations, new models, or new obstacles appearing within the system at any given time. You are invited to contact the Maine Coalition for Housing and Quality Services with any new options. It is forecast that housing needs with quality supports within the community for this population will continue to grow. The Maine Coalition believes that by advocating for the sufficient allocation of funds, optimizing resources, and pulling together as one voice, we can improve outcomes, offerings, and enhance individual lives.



Basic Options



Options with Levels of Support

Least supportive

Independent apartment,
home/condo ownership

Minimally supported
congregate living

Other community based alternatives, co-ops, co-housing with varying level of support depending on program, set-up, and agency.

Moderately supportive

Parent's home

Shared living occupancy

Most supportive

ICF/IID

Group home

Shared living with
increased level of
support



Definitions and Considerations

Independent apartment or home/condo ownership

Independent apartment or home/condo ownership

Definition: Independent apartment or home, an apartment or condo in an apartment complex, or a group of apartments within a larger shared housing unit.

Considerations:

- This could allow for the option of living alone.
- Depending on location, this could allow for more natural supports from family, friends, and community.
- Rental or housing arrangements could possibly be made through known support networks.
- Services could be provided on site, or accessed in the community, based on individual preferences.
- Ownership can be more complex than renting, and can expose one's vulnerability.
- Ownership can increase permanency, allow for optimal choices in all aspects of the environment, and help sustain a sense of community place / belonging.



Minimally supported congregate living

Minimally supported congregate living

Definition: This could be roommates sharing an apartment, or a group of people requiring minimal support living within a large home; each with a separate bedroom and shared common areas.

Considerations:

- This can be similar to a group home, but may or may not have 24-hour staff.
- Levels of staff assist can vary widely across situations.
- These residences may be owned or leased by a group of individuals or their families, and not necessarily by an agency.
- This could allow for more creativity in meeting needs, and in contracting with an agency for support services.

continued...



Minimally supported congregate living, 2

Considerations: (continued)

- Support may be arranged individually, or by the group or condo association contracting with a provider agency.
- There is a variation in cost depending on the home or apartment.
- Some parent groups have raised interest and assistance from other community members and stakeholders to create these more unique situations in their communities.
- Some parents like this idea due to the opportunities for socialization, community inclusion and the possibility of a more permanent arrangement if ownership is involved.



Parent's home

Parent's home

Definition: Receiving support from and living in the family home with one or both parents.

Considerations:

- Services can be arranged in-home to supplement support from parents.
- Some individuals may prefer this arrangement in their own community with possibly other family nearby.
- For some individuals, this can be individually supporting, maximizing family collaboration and resources, and possibly enhancing future independence.
- Depending on circumstances, this can be isolating.
- This is usually time-limited.



Shared living occupancy

Shared living occupancy

Definition: An arrangement of place and supports that provides a family atmosphere; with a shared home, family, and community.

Considerations:

- Services can be provided in an individual's own home which is owned, leased or rented, or by joining a family in a residence owned, leased or rented by the family. Replaces old "foster parent" model.
- The hired service provider can be parents, siblings, a friend, or an individual or family not related to the person.
- This model was popular in New Hampshire and imported to Maine.
- All shared living providers must meet training requirements set by the state of Maine.
- Caregiver must balance the individual's needs with their own family needs to maintain quality and timely service provision.
- Oversight should be provided to ensure it is a good fit for the individual and that it continues to be a desirable arrangement for the individual over time.



Shared living with increased level of support

Shared living with increased level of support

Definition: Similar arrangement to shared living, except the individual is entitled to receive additional support coming into the home, based on their needs.

Considerations:

- This enables an individual with additional needs to be supported in a family atmosphere, rather than seeking an alternate or more restrictive setting.
- Additional care needs would have to be requested as part of the person centered plan, documented and reviewed in order to keep this higher amount of support.



Group home

Group home

Definition: Living with one or more others in a home, facility or other setting usually managed by an agency with 24-hour staffing.

Considerations:

- There remain group homes within the state of Maine, usually small and serving varying numbers of people dependent on the facility/program.
- Section 21 agency group homes serve between 1 and 6 people. This has been the practice prior to the HCBS/ Home and community-based Services settings rule release.
- Several of these are called PNMI's (private non-medical institutions under direct state funding/ MaineCare state plan) and can range in size from 4 to 16 consumers. These may be owned by individuals or agency operated and have 24/7 staffing to meet higher levels of support.
- According to the Office of Aging and Disability Services, as of April, 2019, there are thirty-three PNMI's in Maine serving 224 people.

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Group home, 2

Considerations: (continued)

- Maine has many 2 person group homes; typically thought of as “section 21 waiver homes”.
- These are currently unlicensed homes with less specific requirements to be fulfilled by the provider and less state oversight, in general.
- Some homes have elected to be licensed voluntarily. There is currently a state proposal to license 1 and 2 person homes by 7/20, with a 1 year transition period. As of this writing, it is a proposed rule only.
- According to OADS, there are an equal number of 3 to 6 person homes, as there are 1 to 2 person group homes.
- Smaller home settings allow for more individuality in activities and surroundings, and are placed within a community. However, nearness and access to the community can vary depending on location and availability of options.
- As of 2019, staffing shortages continue, with lack of adequate funding for direct care staff, and high turn-over rates for support providers. These factors, as well as lack of consistent standards for staff training, impact quality of services in these settings.

ICF/IID Intermediate care facility

ICF/IID Intermediate care facility for IDD; intellectual or developmental disability.

Definition: Residential treatment facilities considered by the state of Maine to be an institutional setting. Exists to meet the intensive medical or treatment needs for those with IDD requiring very high levels of support.

Considerations:

- Typically small staff-intensive institutions able to serve between 5 to 16 people.
- Currently there are 16 facilities able to accommodate 187 people.
- Licensed facilities with specific protocols, emphasizing a medical approach.
There are 2 types of ICF/IID; those which provide 8 hours of nursing supervision per day, and those who do not.
- Not considered a community-oriented or home model of support.
- These facilities are limited in number, and may serve people with other disabilities with high care requirements.



Other community based alternatives, co-ops, co-housing

Other community based alternatives, co-ops, co-housing

Definitions: Innovative ways of owning and managing housing and providing supports in collaboration with individuals, families, and their communities.

- Co-housing can be described as a collaborative community of housing designed in particular for and by residents, which may be attached, or alongside other homes in a certain area.
- A co-op is a shared ownership of housing, and is a corporation made up of the people who live in the house or the apartment. Individuals own shares of stock in the corporation rather than owning the unit.
- A condominium is an apartment or housing unit owned by an individual or family and having ownership responsibilities with others in that group.

continued...



Other community based alternatives, co-ops, co-housing, 2

Considerations: (continued)

- Certain provider agencies for adults with developmental disabilities may be able to work with the individual and their family on housing options and goals, based on the individual's goals, and their personal situation.
- Partnerships with other parents, provider agencies, community and charitable and faith-based organizations have resulted in innovative and quality housing.
- These options can facilitate home ownership. Home ownership in turn, whether it is achieved individually, or collaboratively, can result in an increased sense of permanency in one's community.
- There are several on-line resources available on the Maine Coalition for Housing and Quality Services website which provide a wealth of information related to considering and obtaining best outcomes in housing and service options. These are "Autism Speaks: Housing and Residential Supports Tool Kit", and the "Opening Doors" report by Southwest Autism Research and Resource Center, and partners, in which residential options are discussed in detail.



Housing Development, Funding, and Services

About Supportive Housing Models

Definition: Housing owned or leased by an individual with supportive services added independently of the ownership or rental agreement. These services are based on the individual's needs, and usually through a formal arrangement if paid through waiver services.

Considerations:

- Quality, safe, and affordable housing with individual choice and consistent supports grows stability and a place to belong. All aspects of health and opportunity depend on this.
- There is no “one-size-fits-all”
- It will take a variety of designs and options to meet individual needs.



The Process of Housing Development: Some Basics

Considerations and housing development perspectives:

- There is a lot of risk associated with supportive housing development. Funding for support services through DHHS is really only guaranteed one year at a time, and it can be very cyclical. Supportive housing typically has covenant restrictions attached at closing calling for thirty or more years of steady service to the target population. While that obligation stands, funding for services may go away at any time; meaning that the building could be empty with repayment obligations confounded by covenant restrictions.
- Supportive housing projects really need to be developed without any debt because operating costs, even for energy-efficient and well-constructed buildings generally outpace rents over time.
- Supportive housing does not cover its costs as an operation. It has to be a mission-driven effort with solid commitment.
- Generally, it is easier for non-profit organizations to access funding for supportive housing.



The Current State of Funding Options for Housing

Considerations and housing development perspectives:

- MaineHousing's website lists several programs to encourage private development of affordable rental housing for families, seniors, and persons with special needs. Low income housing tax credits, development loans, direct development subsidies, affordable housing tax increment financing, and options to restructure debt are available. Developers are required to ensure that housing developed with MaineHousing financing remains affordable.
- MaineHousing lists the Supportive Housing Program with definition of "Providing reduced interest rate debt financing and subsidy funds to eligible nonprofit developers to create housing for low and very low income persons with special needs" as: "Currently Unavailable" (April, 2019) This has been the case for the past several years as all previous funding has been used with no replenishment through legislative actions, bond referendums, or other streams.
- MaineHousing lists the National Housing Trust Program as available for the creation of affordable rental housing for extremely low-income households, that perhaps could be utilized for supported housing with some developers, although it is not the funding source such as previously available through the Supportive Housing Program.



The Current State of Services Integral to Supportive Housing

Considerations:

- Section 21 and Section 29 are the 2 waiver programs which afford Maine adults with IDD (intellectual or developmental disabilities) the opportunity to opt for services in the community, instead of a more formal or facility type setting.
 - Services must be agreed upon in a person centered plan. Three other waiver programs support adults with other diagnoses.
 - A waiver program is a funding source that an individual must qualify for medically, with a qualifying diagnosis and financially through the state of Maine.
 - Section 21 is the "comprehensive" home and community based benefit, with the widest coverage of support services to meet higher levels of need.
 - A waiver service is a wait list program and applicants must meet the eligibility criteria for a funded opening based on priority; 1 (highest), 2 and 3 for Section 21. Currently, there are approximately 1,600 adults waiting for these services.
 - Some of those waiting are able to access Section 29 services, which are also based on financial and medical eligibility, and provide a less comprehensive array of services.
- continued.....



The Current State of Services Integral to Supportive Housing, 2

Considerations: (continued)

- Section 29 was expanded in 2017 to include more services with a higher cap, and can include community, home and work supports.
- Rental agreements/ “room and board” are negotiated separately for these small group homes, apartments, etc. Many individuals use the majority of their social security disability benefits to pay rent and some other services covered under the agreement. It leaves very little for personal spending. In some instances, support provider agencies can assist a client in obtaining rental assistance through public housing programs. This could allow the individual to use disability or other funds toward personal spending needs, thereby enhancing quality of life.
- Individuals can access those programs available to all Maine residents based on income, such as the food supplement program.
- Several new bills have been brought to the Legislature this session to address the need for housing and related support services, and need to locate housing and obtain modifications. Another bill would look at service delivery improvements for those in home and community based services. continued...

The Current State of Services Integral to Supportive Housing, 3

Considerations: (continued)

- There has been an on-going funding-for-services crisis for this populations' needs for some time. Currently, there remains a critical lack of quality, safe, affordable housing that is community integrated with quality supports for adults with intellectual, developmental, or related disabilities.
- Advocacy by parents, and in conjunction with advocacy groups, have improved some issues incrementally, however opportunities remain for improvement in quality and expansion of services.
- Staffing shortages, staff turn-over, (which impact training and consistency) and low wages continue to impact quality of services in existing group homes.
- National estimates are very concerning in terms of the number of adults needing supportive housing in the next five to ten years with current housing needs still unaddressed; in terms of availability and funding.
- Maine is making progress in it's quest for community inclusion. Families, self advocates, advocacy agencies, the DD network, communities, service providers, OADS, and others are involved in looking at quality housing solutions in the community, thereby enhancing choice and quality of life.

Projects in Other States

Projects in Other States

- The New Hampshire Bureau of Developmental Services is currently supporting approximately 1,900 “enhanced family care homes”. These shared living homes accommodate between one and three adults, and services are determined by the SIS/support intensity scale. Both New Hampshire and Massachusetts have three waiver programs to support various levels of support in the community.
- Massachusetts’ shared living program is termed “residential habilitation”. Although there are 24/7 group homes, the state is no longer licensing any new facilities, and in the spirit of “the community rule” there are fewer center-based day programs. Massachusetts has a strong base of advocacy, and it’s Autism Housing Pathways group provides education, family and community training, and workshops to inform consumers on housing options, and to advocate for change. A recent think tank was organized with a coalition of advocacy groups, and projections were reported to the Autism Commission, and to the Legislature. Strongly supported was the need for “sustainable and self-directed housing” as approximately 17,500 adults with developmental disabilities will need housing with supports in Massachusetts by 2025. continued...



Projects in Other States, 2

- Parents across the country are starting their own initiatives by coming together, collaborating with developers, community, and seeking innovative ways to finance, design, and involve all levels of decision makers and their adult children in this process. Several of these efforts have resulted in apartment complexes which include adults with developmental and related disabilities as part of an integrated community.
- Wisconsin's parent efforts are now materializing in a Place of Our Own; a forty unit apartment complex with a quarter of the units specially designed to enhance functioning and opportunity for the adult children of this parent group. This is expected to open in the fall of 2020, and has been guided by a set of principles and a model they intend to make replicable.
- The Washington Post recently reported "Rockville [Maryland] parents build a rental complex for their son to share with adults with disabilities – and also be part of the community". Opening this year, Main Street will feature one, two, and three bedroom apartments, with a café, movie room, teaching kitchen, an art gallery and yoga and wellness center. continued...

Projects in Other States, 3

- One quarter of the apartments will be available for the disability population and will have strong connections to the local culture in an urban center.
- Connecticut's governor has a recent budget proposal which would pay for seventy new apartments for adults with IDD over the next two years. This state's developmental services agency serves 16,000 Connecticut residents, with 2,000 on a waiting list for in-home services or residential support. A Hartford Courant file photo in this article featured an advocate, possibly a parent, holding a sign with a picture of a stated forty year old woman with the caption: "23 Years On Waiting List". The ARC of Connecticut and other advocacy groups support moves toward apartments such as these, as they provide opportunities for individuals with IDD to gain more freedom, citing: "You serve more people, you create more options, you don't lower quality, but you do lower cost."
- The above examples represent a "sampling" only of some state's efforts, and is not a full representation of those states, or of states not included.



Visions for the Future



Visions for the Future

- “In 20 years, I envision the state of Maine as having sufficient affordable, accessible, decent housing options (including home ownership) in order that people with disabilities living in poverty can live free from the conflicting relationship of landlord and support provider.”
- “This is best accomplished by expanding affordable living (Section 8) housing in communities across Maine, significantly increasing access to Section 8 vouchers, disseminating information to people with disabilities and their allies about state and federal home buyer programs that currently exist (USDA Rural Home Loans, FHA Insured Loans, HUD/First Time Homebuyer Program, HUD Dollar Home Program, Maine State Housing/First Time Homebuyer Program, Community Down Payment Assistance Programs (Bangor), Community Rental Assistance Programs...).”

Gail Fanjoy, CEO of KFI

- “In 20 years, I envision the state of Maine as continuing to struggle conceptually and financially with the housing needs of our citizens with disabilities unless they begin now to work proactively with organizations that have a vision of change.”
- “This is best accomplished by moving on from what is not working and by supporting models of change, even those that are quite different from what we have always done.”

Dennis Dean, Dad, A House for ME, Executive Director.

continued...

Visions for the Future, 2

- “In 20 years, I envision the state of Maine as having developed a network of exemplary local housing and program models that allow for all vulnerable adults to live in and engage with their home community – with professional and natural supports that enable them to flourish through work, volunteerism and recreation.”
- “This is best accomplished by state offices working closely with parent groups and agencies that can provide housing and services.”

Roberta Raymond, Board Member, Local Solutions for Maine

- “ In 20 years, I envision the state of Maine as supporting adults with IDD/DD in a wider range of supportive housing settings and creative waivers or funding streams to support these various models.”
- “This is best accomplished by Self-Directed Funding (Money follows the person), allowing individuals to make decisions for themselves on who can provide the support they need and where.”

Mary Chris Semrow, Parent and Consultant to Families, Specialized Housing, Inc.



An Invitation

An Invitation

To join the Maine Coalition for Housing and Quality Services visit on-line, click “join” and provide your name and e-mail.

Uniting with others provides parents and advocates with a stronger voice and opportunities to improve the system of care. Improving the system of services is crucial for improving outcomes for all of our children, and adult children.

Much work has been done, and much work remains.

All participants on any level will gain a better understanding of the broader system, and have opportunities for advocacy, and connection with other parents.

The Coalition has connections with other advocacy groups within the state and regularly invites guests to share information on topics of interest.

The Maine Coalition for Housing and Quality Services welcomes and invites your participation. Together, we are strong and effective.

