



Literature Review: Promising Models of Housing and Support for Transition-Aged Youth with Dual Diagnosis

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Contents

INTRODUCTION.....	2
Objectives of the Literature Review	2
Methodology	2
FINDINGS.....	2
Overall Findings	2
Principles.....	4
Models of Housing.....	5
Description of Some Common Housing Types for Individuals with Dual Diagnosis	5
Other Examples in the Literature.....	15
Considerations for Housing Design.....	15
Housing Model Case Studies.....	16
Case Study #1: Snow Goose (Elmira, Ontario)	17
Case Study #2: Community Living Options (Evanston, Illinois).....	18
Case Study #3: Prairie Housing Co-operative (Winnipeg, Manitoba)	20
Case Study #4: Ottawa Share Equity Housing (Ottawa, Ontario)	21
Case Study #5: Home in the Annex (Toronto, Ontario)	22
Case Study #6: START Model (United States)	23
Case Study #7: Simcoe Community Services (Barrie, Ontario)	24
Case Study #8: Kerry's Place (York Region, Ontario)	24
Case Study #9: City Club (Burnaby, BC)	24
Case Study #10: Southern Okanagan Association for Integrated Community Living (BC)	26
Transition Models and Approaches for Youth with a Dual Diagnosis	27
Case Study #11: Mary's PATH	30
Promising Support Services Components.....	31
Case Study #12: Neighbours Allied for Better Opportunities in Residential Support (NABORS)	33
CONCLUSIONS.....	34
REFERENCES.....	35

INTRODUCTION

Objectives of the Literature Review

This literature review focused on the question “What is the evidence related to the most promising housing and support models (e.g., physical/structural considerations, staffing, clinical supports and selection of participants) for transition-aged youth (aged 16-24) with a dual diagnosis of developmental disabilities and mental health concerns or complex needs. This report summarizes the available literature and information related to this question. It is by no means intended to provide an overview of all housing and support options available to individuals with a dual diagnosis, or a detailed description of different housing models. Rather, this report describes some of the unique, innovative or forward-thinking ideas and models that are described in journals, online and by service providers, which can be used as a foundation for further exploration and planning.

Methodology

Peer-reviewed and “grey” literature were reviewed. Search terms included developmental disabilities, intellectual disabilities, dual diagnosis, mental health, complex needs, housing models, supportive housing, transition aged youth, youth, and transition. Exclusions included addictions, substance use, elderly, and homeless, as these terms typically generated articles that were not specific to the population being researched. Articles from 2000 to 2015 were accessed through multiple databases including OvidSP (which includes searches across Medline, PsychInfo, and Embase), CINAHL, Web of Science, HealthSTAR, Cochrane Database of Systematic Reviews, ERIC, PubMed, Scholars Portal, JSTOR, PsychARTICLES, Social Services Abstracts and Google Scholar.

An internet search, and a search of relevant leading organizations’ and associations’ websites, was also conducted. The search focused on reports and publications as well as descriptions of programs being offered by these organizations. Executive summaries were scanned and promising reports were reviewed.

Eight key informant interviews were conducted with staff of organizations working with people with developmental disabilities, with dual diagnosis and complex needs or challenging behaviours. Relevant input from all of these discussions was included in this report.

As this report is intended for internal planning purposes only, the descriptions of programs and services provided in this report have not necessarily been vetted or approved by the agencies who provided them.

FINDINGS

Overall Findings

The overall conclusion of the literature review is that no specific types or models of housing are best suited to transition-aged youth with a dual diagnosis. Rather, the type of housing, and the related support services, should be based on each individual’s housing and support needs, the individual’s preferences, and the financial and support services available to the individual; and chosen in partnership with the young people and their families. “It is the interplay of these considerations that determines what housing model is ‘ideal’ in a given situation” (BCNPHA Research Department, 2009).

The housing and support services should also uphold key principles including inclusion, accessibility, person-centred support, flexibility, portability and choice. They should improve quality of life for young people and their families, and should be sustainable over the long term.

Based on the literature review and discussions with service providers, the key considerations for the planning process for the HKPR Transition-Aged Youth Pilot Project include the following:

- Involving young people who may participate in the demonstration project, and their families, in the Steering Committee's planning process. The perspectives, assets and needs of youth and their families should be the foundation of the model that is designed and implemented. This implies structuring the planning process in an inclusive and accessible way so that youth and their families can have meaningful involvement.
- Involving youth in a transition planning process before their transition begins. The literature recommends beginning around age 14 to plan for the young person's desired future with a transition team, building the skills these youth will need to move forward, and preparing the resources, relationships and tools that will be needed to support the transition.
- Tailoring any housing model that is developed to the needs and strengths of the particular young people who will live there. This could, of course, be an iterative process of designing housing options while at the same time working with a group of young people on an individual planning and transition process, and then matching people and housing.
- A comprehensive planning approach. A comprehensive plan would take into account the many aspects of housing and support that need to align with each other. Research documents the need to incorporate many aspects such as housing, self-care skills training, support services, clinical and behavioural assessments and services, health services, community inclusion, participation in recreation and leisure activities, developing social networks and belonging, and empowering young people to achieve their goals, together in a comprehensive plan that recognizes the whole person who is being supported.
- While housing is a key foundation needed to participate in the community and achieve one's dreams, the literature describes the provision of individualized, high-quality and consistent support services as likely the most important aspect of any initiative to support transition-aged youth with dual diagnosis.

A number of housing barriers for people with dual diagnosis were identified in the literature, and there was recognition that some individuals face multiple, intersecting barriers. One overarching gap that was identified was a lack of *housing options that address important life transitions*" (BCNPHA Research Department, 2009). Very little literature, either published or "grey", related specifically to housing and support service models for transition-aged youth with a dual diagnosis. However, the literature and discussions with practitioners pointed to many different promising components or aspects of support for young people with a dual diagnosis, including several principles that should underpin any planning for youth with dual diagnosis, and the clear need to provide more extensive, accessible, person-centred and comprehensive services for this vulnerable population.

This report describes a range of housing models that could be adapted to meet the needs of transition-aged youth with dual diagnosis; some considerations and best practices for transition planning with youth; and some key considerations for the support services that would accompany any housing model for TAY. This information, taken together, can be used as a foundation for designing an innovative approach that meets the needs of clients, families and service organizations in Haliburton, Kawartha Lakes, Pine Ridge and Peterborough.

Principles

The literature identifies several principles that should form the basis of a supportive housing model for TAY with a dual diagnosis. It is recommended that supportive services will:

- Be person-centered (In Unison, 1998; UK Department of Health, 2007; HSC Vision, 2012)
- Be flexible (In Unison, 1998)
- Be tailored to the needs of the individual (In Unison, 1998)
- Be portable, in the sense that the funding for the services is *not* linked to the funding for the housing (FTP Accord on Disability, 1998; Koenig 2014)
- Provide the opportunity for people to choose their place of residence, where and with whom they live, on an equal basis with others (UN Convention on the Rights of Persons with Disabilities)
- Provide a range of in-home, residential and other community supports, including assistance to support independent living and inclusion in the community and prevent isolation (UN Convention on the Rights of Persons with Disabilities)
- Be “de-linked” or considered separately but interdependently from housing, as neither is sufficient without the other (UN Convention on the Rights of Persons with Disabilities).

The literature supports providing services within the community and avoiding out-of-area placements whenever possible. Community-based service models and cross-sectoral coordination are considered key in caring for people with a dual diagnosis. This requires “appropriately trained, specialized, interdisciplinary clinicians and direct care professionals who can support and link to mainstream mental health services, in order to care for clients in their own communities. Where mainstream services are not able to care for the very complex client situations, the goal is to avoid out-of-area placements wherever possible, and to ensure continuity of and transitional care” (HSC Vision, 2012).

Housing for people with intellectual disabilities must meet CMHC’s basic housing requirements, as defined in 2008. These standards include adequacy, suitability, affordability, accessibility, sustainability, possessing appropriate disability supports, and facilitating social inclusion (Crawford, 2008). Sufficient choice in housing is also a central principle described in the literature. “It is considered increasingly important to provide a variety of housing options for persons with developmental disabilities because the population with developmental disabilities has diverse housing needs and preferences” (BCNPHA Research Department, 2009).

There is a great deal of research affirming the power of self-determination within the process of planning for the transition to adult life for youth with disabilities (Held, M. F., Thoma, C. A., & Thomas, K., 2004). Numerous articles describe the critical role of self-determination of young people with developmental disabilities in leading to positive individual outcomes (most notably by Dr. M. Wehmeyer at University of Kansas, Department of Special Education). As the RENEW project¹ at University of New Hampshire describes, young people with emotional or behavioural challenges need to develop positive relationships and influences as a foundation for planning relevant next steps for themselves. Youth need to see the relevance of their participation in any program in order to buy in and engage in those activities.

¹ RENEW project: http://www.iod.unh.edu/Projects/renew/renew_main/renew_about.aspx

Models of Housing

Housing is generally referred to as a fundamental aspect of the support for people with disabilities. A review of the literature demonstrated that there is no model of housing best suited to transition-aged youth. Rather, the best arrangements are those built around the needs of individuals, and incorporating effective clinical, health and social supports.

Description of Some Common Housing Types for Individuals with Dual Diagnosis

Supportive housing can be structured in many ways, but “ultimately provides a combination of affordable housing with wrap-around supportive services in a variety of settings based on the needs of the person with disabilities” (Koenig, 2014). Research has demonstrated that supportive housing produces positive outcomes and high levels of satisfaction among residents (Koenig, 2014).

According to the current literature around housing for people with developmental disabilities or dual diagnosis, most forms of housing fall into the categories described in Table 1 below, though they are neither exhaustive nor distinct categories, and there is no standard language used in the literature to describe different types of housing models. Where available in the literature, opportunities/benefits and challenges/critiques/considerations for each type of housing are described. Cost comparisons are not provided, as very little of the existing research compares affordability across the spectrum of housing options for people with developmental disabilities (BCNPHA Research Department, 2009).

The information in Table 1 describes general categories of housing from a theoretical viewpoint, and includes both ‘mainstream’ and ‘innovative’ models. Table 1 provides an overall summary of many of the housing models currently in use, as a starting point for discussion. These models are not necessarily being recommended for transition-aged youth with a dual diagnosis. Table 1 is followed by a diagram that describes options for some of the components of different housing models (see Figure 1). Next is a series of case studies that describe specific scenarios of how these types of housing have been implemented in various communities, with a focus on promising or innovative approaches in development or in use in Canada and the United States.

Table 1. Overview of Some Common Types of Supportive Housing for Individuals with Dual Diagnosis²

Housing Model	Description	Opportunities/Benefits	Challenges/Critiques/Considerations
1. Residential living, including group homes, supervised living, farmstead programs, etc.	<ul style="list-style-type: none"> Homes in the community where one or more persons with disabilities live and staff members are available to provide supports. Group homes are relatively small, staffed, residential facilities with a higher level of support than supported living (see #2 below). The second most prevalent housing model in Canada, after family home, for people with developmental disabilities and autism spectrum disorders. Supervised living models are residential in nature and are designed to provide a higher level of supervision than in a supported living model but less support than in a group home model. Farmstead programs are supervised residential service models with a 'working farm' approach. 	<ul style="list-style-type: none"> Provides a living arrangement within a community setting and with access to supportive services. Provides 24/7 support where needed. Can provide opportunities for community-building within the home. Typically small, but can be larger. Enables the provision of both individual and group services. 	<ul style="list-style-type: none"> Some are too large, which can result in lack of integration with the general community. Criticized for adopting a "one size fits all" approach which does not fit diverse needs and unique personalities. Some have inflexible schedules and high levels of staffing and control, and less opportunities for personal choice. While set within communities, residents may remain fairly separate from those communities. Housing and support services are often linked, thereby offering little flexibility and choice to the resident. Residents typically do not have much choice or control over where they live, who they live with, who provides their services, or how they spend their time and money. With farmstead programs, integration in the community may be minimal as the focus is on life skill development related to the farmstead environment.³
2. Supported living / semi-	<ul style="list-style-type: none"> Individuals live in the community, either on their own 	<ul style="list-style-type: none"> Supports are generally personalized and tailored to the individual. 	<ul style="list-style-type: none"> Limited planned activities can lead to social isolation.

² The information in Table 1 was adapted from BCNPHA Research Department, 2009; Greenspan & Raine, 2006; HSC Vision, 2014a; HSC Vision, 2014b; and Koenig, 2014.

Housing Model	Description	Opportunities/Benefits	Challenges/Critiques/Considerations
independent living & independent living. Includes cluster housing, Supported Independent Living (SIL) and intensive supported living.	<p>or with others (e.g., a roommate). Non-intensive support services are provided separately from the housing arrangement. Can involve any type of housing and a range of hours of support.</p> <ul style="list-style-type: none"> • Service providers are often in close proximity (e.g., as neighbours) or share living quarters. • Cluster apartments are one type of supported living, where individuals with developmental disabilities live closely together (e.g., several units within a large apartment complex). • One promising example is housing with University students providing peer support and overnight availability alongside more formal support services and staffing available during the day (see case study for Snow Goose, Elmira, below). 	<ul style="list-style-type: none"> • Independent living is considered a model that promotes flexibility and choice.³ • These approaches support increased competence in daily living and quality of life. • May result in more interaction with people without disabilities than group home settings. • Under the cluster apartment approach, tenants can share support staff and resources, form intentional communities of attachment, and share group social events. • The intensive supportive housing model is recommended for those most difficult to serve who have not traditionally been able to live within the community, as it offers more intensive supports, comprehensive case management and rehabilitation.³ 	<ul style="list-style-type: none"> • Relative to group homes, there may be fewer formal safeguards. • Requires individuals to be able to live fairly independently. Would not typically provide the level of support needed by young people with complex needs.
3. Co-ops and co-op-like arrangements	<ul style="list-style-type: none"> • A housing co-operative can be any type of building (apartments, townhouses, detached houses, etc.). The responsibilities and relationship 	<ul style="list-style-type: none"> • Considered a model that promotes flexibility and choice.³ 	<ul style="list-style-type: none"> • Housing co-operatives are governed by the legislation regulating co-ops in the province or territory where they are located.

³ HSC Vision, 2014. Final Report to Toronto Network of Specialized Care.

Housing Model	Description	Opportunities/Benefits	Challenges/Critiques/Considerations
	<p>of the residents make the co-op model unique. A housing co-op is a legal association created to provide housing to its members and is run for their common benefit.</p> <ul style="list-style-type: none"> • As one example, a group of individuals build their own multi-unit building and give up private space for the creation of community spaces, striving for both housing and community support. This is one example of a “co-housing” approach. • An “equity co-op” is an incorporated group of shareholders who jointly hold title. Through the purchase of shares, members are entitled to live in a unit.⁴ 		

⁴ Greenspan & Raine, 2006, page 14.

4. Home sharing / family home / within-family housing / foster home	<ul style="list-style-type: none"> • An individual with a developmental disability lives with others who provide support but are not an immediate relative. The shared home is the primary residence of both the support provider and the individual with a disability. 	<ul style="list-style-type: none"> • Provides a home-like environment. • The individual often has choice and input regarding the home and the home-sharing provider. • Encourages increased community participation, and learning towards independence. • Individualized services and supports. 	<ul style="list-style-type: none"> • Finding a suitable roommate or family can be a challenge. • Risk of caregiver burnout. • The individual may have to move if they change caregivers. • Some individuals report that they feel like they would be betraying their family by living with another family. • There are some concerns about limited monitoring of the quality of home share arrangements.
5. Volunteer-based communities, intentional communities and village communities	<ul style="list-style-type: none"> • L'Arche homes, l'Abri en Ville and Camphill are examples of intentional communities. • The Camphill movement aims to "create and sustain a community where people with and without disabilities live, work and care for each other in an atmosphere of mutual respect and equality". Camphill communities support the education, employment and daily lives of adults and children with developmental disabilities, mental health concerns or other special needs. There are over 100 Camphill communities worldwide⁵. Support staff live with or near people who need support. Meaningful work is 	<ul style="list-style-type: none"> • Support staff can be shared among the group, creating efficiencies in staffing and reduced costs. • Promotes social inclusion, and provides opportunity for organized social events and community-building within the group. • Communities like Camphill boast a long list of activities and opportunities for learning, growth and development. Residents live, work, contribute, build self-confidence and empowerment; belong and build social connections; are involved in decision-making for the community; and develop independent living skills. • Studies have found that positive outcomes derive from the absence of the overt subordination of residents to staff, the facilitation of friendship with other people with an ID, high levels of meaningful employment and a sense of community 	<ul style="list-style-type: none"> • With some small homes funded on a contractual basis by public authorities, cost pressures reduce wage levels for staff resulting in difficulties in retaining suitable staff and a consequent high staff turnover (Randell and Cumella, 2009).

⁵ Source: Wikipedia. January 10, 2016.

Housing Model	Description	Opportunities/Benefits	Challenges/Critiques/Considerations
	<p>embedded in daily life, through farms, gardens, workshops such as weaving and craft-making, and shops that sell the products grown or created in the communities. Strong focus is placed on choice and inclusion in decision-making.</p>	<p>(Randell and Cumella, 2009).</p>	
<p>6. Home ownership, adaptation of family homes, or rental with support(s)</p>	<ul style="list-style-type: none"> • There are multiple models of home ownership and rental, including individual, with roommates, joint ownership, agency/resident ownership, ownership or rental with live-in support, and ownership through incorporation. • In one example of ownership with live-in support, an aging parent moves out of the family home into a seniors' home, he or she "sells" the home to the adult child with a developmental disability and arranges to have a student move in and provide support services in exchange for free accommodation. A service agency oversees the arrangement and provides a small salary to the student. 	<ul style="list-style-type: none"> • Considered a model that promotes flexibility and choice.³ • Individuals with disabilities can successfully purchase and own their own home (provided they or their families have sufficient resources), live in a community with others in a non-restrictive environment for the long-term, get access to the help they need and achieve their goals. • This model can improve quality of life by giving people with disabilities a choice and respect. • Having security of tenure (UN Habitat, 1996, as cited in Sheuya et al., 2007) and not having to worry about being forced to move out (Clark & Kearns, 2012) is associated with better mental health outcomes (HSC Vision, 2014b). 	<ul style="list-style-type: none"> • Rarely available to people with intellectual disabilities. • Requires significant financial investment, which may be inaccessible for many people with developmental disabilities. • Need to be no threat to self or others, without intensive monitoring or support.
<p>7. Dormitory</p>	<ul style="list-style-type: none"> • There is some literature available on having young 	<ul style="list-style-type: none"> • Results of one study indicated that the experience of living away from home for 	<ul style="list-style-type: none"> • Individuals would need to be able to live fairly independently, in a non-secure

Housing Model	Description	Opportunities/Benefits	Challenges/Critiques/Considerations
	people with developmental disabilities housed in campus dormitories.	the first time was in some ways comparable to that of a typical college student. Improvement in life skills, including increased awareness of personal goals, enhanced vocational goals, increased maturity or assertiveness, was reported. ⁶	setting with minimal support services. <ul style="list-style-type: none"> There may be some risk of “not in my backyard” thinking from families of other students living on campus.
8. Boarding houses with supervision	<ul style="list-style-type: none"> Large, licensed facilities housing 20-30 consumers who pay for accommodations, with the addition of on-site staff who are there primarily to supervise, maintain order, and administer medications. 	<ul style="list-style-type: none"> Cited as low-cost housing options. Potential advantages are personal independence and empowerment, freedom of movement the availability of privacy and social involvement. Meals are provided and the environment may be friendly and caring. 	<ul style="list-style-type: none"> There are no life skills programs delivered, despite the fact that these facilities tend to be for people with severe disabilities. The model would seem quite antithetical to the desire of people with intellectual disabilities and their families for places to live other than large congregate care arrangements. There is potential for incompatibility of residents, and for supports to be lacking. There is a risk of social isolation and loneliness and individuals may be vulnerable to exploitation and abuses by supervisors and other residents. This approach appears particularly ill-suited for housing young people.
9. Alternative models of housing for people with disabilities	<ul style="list-style-type: none"> Alongside the models of housing mentioned above, and due to the serious resource constraints of the developmental services sectors in many Western countries, families are increasingly 	<ul style="list-style-type: none"> Various models of home ownership with supports, co-ownership with a non-profit organization, group ownership shared by a number of families, and other approaches have been implemented across Canada in recent decades. Many provide a level of flexibility, person- 	<ul style="list-style-type: none"> The arrangements can be difficult to explain to government or fit in to policies and funding envelopes. It can take many years to develop each housing arrangement. Families assume a higher level of risk associated with the financial and other

⁶ Kirkendall, A. & Saladino, A., 2009.

Housing Model	Description	Opportunities/Benefits	Challenges/Critiques/Considerations
	designing their own models of housing, support and funding to meet their son's and daughter's needs.	centred support and independence that may be unavailable through service providers.	aspects of the housing arrangement. <ul style="list-style-type: none"> Housing often needs to be shared to be affordable, which may result in interpersonal conflicts for residents or families.
10. Transitional or short-term approaches	<ul style="list-style-type: none"> Some residential settings are able to provide transitional housing, which implies a short-term residential placement with the goal of transitioning the person back to their previous environment or to a new environment (e.g., settings providing intensive inpatient care, intensive life skills courses, etc.). Some housing includes space for respite care or "short stay beds", where an individual can stay for a short time to provide respite to other caregivers. 	<ul style="list-style-type: none"> Useful for people who need a break from their current setting for diagnostic work, medication change, and/or intensive behavioural work. Respite spaces have also been used to help individuals (and staff) gradually transition to a new living arrangement. 	(No discussion or review of these approaches was found in the literature.)

Table 1 (above) described a range of supportive housing models or approaches that are in use. These examples may or may not be well suited to the needs of unique individuals. Set alongside the housing model, the description, benefits and challenges columns include a range of housing types, service arrangements and funding models, among other considerations. Figure 1 (below) is meant to demonstrate some of the possible types of housing, funding approaches and components of services that could be combined in different ways to provide a supportive housing model for young people with a dual diagnosis, depending on individual needs. The diagram is meant as a starting point for discussion and brainstorming around what combination of resources might work well together.

Figure 1: Examples of Components of Housing Models⁷

HOUSING APPROACH	HOUSING TYPE	LIVING STYLE	SERVICES PROVIDED	FINANCING / FUNDING
Residential living – e.g., group homes, supervised living, farmstead programs.	House	Single/private accommodation (e.g., bachelor, one-bedroom, suite)	None	Owned by the individual or a single family
Supported, semi-independent or independent living	Modified home (e.g., living space built on to a family home)	Shared accommodation (e.g., 2 or more bedroom unit, roommate, live-in caregiver, co-housing)	Call-in support	Joint ownership (e.g., owned by a group of individuals or families)
Co-operative arrangements	Apartment (e.g., home apartment, duplex, 4-plex, 6-plex, multi-plex)		Friendly neighbours, volunteers, family members or others who drop in to provide support	Rent, lease, condominium
Home sharing, family home, foster home	Condominium	Flexible space that can transition between shared and private as needed (e.g., areas within the building that can be opened and separated as needed)	Staff come in to the home (weekly, daily, part-time, full-time, 24/7, intensive staffing (e.g., two staff per client))	Costs off-set by commercial space in the building, or other forms of mixed-purpose space
Volunteer-based, intentional and village communities	Co-housing (i.e., some private and some shared spaces)		Day programming outside the home	Non-profit or other organization
Home ownership, adaptation of family homes or rental with supports	Group home	Housing location is also a site where people who do not reside there come in for programming	Live-in staff, peers or caregivers; or living with a family	Agency/resident co-ownership
Dormitory	Village community		Live within the support setting (e.g., group home)	Social housing/government-owned
Boarding houses with supervision	Boarding room		Specialized services brought in, e.g. assertive community treatment	In trust
Alternative models	Dormitory			Donor-sponsored
				Public-private partnership

⁷ This diagram was developed by the researcher, based on all of the information collected as part of the literature review.

Figure 2: Housing Model Example

A hypothetical housing model example was created in the figure below (see shapes with bold text and outline), loosely based on the “Snow Goose” model described below. This example is meant to demonstrate that different housing types and services could be combined in innovative ways to address the specific needs of individuals.

HOUSING APPROACH	HOUSING TYPE	LIVING STYLE	SERVICES PROVIDED	FINANCING / FUNDING
Residential living – e.g., group homes, supervised living, farmstead programs	House	Single/private accommodation (e.g., bachelor, one-bedroom, suite)	None	Owned by the individual or a single family
Supported, semi-independent or independent living	Modified home (e.g., living space built on to a family home)	Shared accommodation (e.g., 2 or more bedroom unit with roommates, live-in caregivers or students)	Call-in support	Joint ownership (e.g., owned by a group of individuals or families)
Co-operative arrangements	Apartment (e.g., home apartment, duplex, 4-plex, 6-plex, multi-plex)		Friendly neighbours, volunteers, family members or others who drop in to provide support	Rent, lease, condominium
Home sharing, family home, foster home	Condominium		Staff come in to the home (weekly, daily, part-time, full-time, 24/7, intensive staffing (e.g., two staff per client))	Costs off-set by commercial space in the building, or other forms of mixed-purpose space
Volunteer-based, intentional and village communities	Co-housing (i.e., some private and some shared spaces)	Flexible space that can transition between shared and private as needed (e.g., areas within the building that can be opened and separated as needed)	Day programming outside the home	Non-profit or other organization
Home ownership, adaptation of family homes or rental with supports	Group home		Live-in staff, peers, University students or caregivers; or living with a family	Agency/resident co-ownership
Dormitory	Village community		Live within the support setting (e.g., group home)	Social housing/government-owned
Boarding houses with supervision	Boarding room	Day programming is offered in the building, for both residents and non-residents	Specialized services brought in, e.g. assertive community treatment	In trust
Alternative models	Dormitory			Donor-sponsored
				Public-private partnership

Other Examples in the Literature

“Exploring Housing Options for People with Developmental Disabilities in British Columbia” (page 22-23) describes several actions that can increase access to affordable rental housing options, affordable home ownership options, encouraging community inclusion, increasing the supply of accessible housing, facilitating connections with needed services and supports, integrating natural supports into housing, and facilitating housing transitions. Various support arrangements can also be used to help an individual stay in their family’s home (Children’s Mental Health Ontario, 2015). These can include (but are not limited to):

- In-home intensive treatment which provides services to help both the families and children improve functioning directly in the home. Because services are home-based and involve the participation of the family, this model can effectively help children and their families learn to manage mental illness in everyday and real life situations – which makes the transition to less-intensive programming easier.
- Expanded day treatment where children are provided supports in community-based settings well beyond traditional day treatment, which is typically matched to regular school hours.
- A combination of expanded day treatment and intensive in-home treatment. This might involve a mix of out-of-home day treatment in the community and family-centered intensive supports during key transitions at home. Respondents noted that clinical supports could be provided at home during key daily events that can be stressful for families, such as meal time, bed and wake time and transitions to and from school or day treatment.

Considerations for Housing Design⁸

The physical design of housing plays a large role in the quality of life of the people living there as well as the success of the services provided. HSC Vision’s 2014 report (2014b) outlines ten principles for housing design. These include: 1) ensuring safety and security; 2) maximizing familiarity, clarity, and stability; 3) minimizing sensory overload; 4) allowing for opportunities for controlling social interactions and privacy; 5) provision of adequate choice and independence; 6) fostering health and wellness; 7) enhancing dignity; 8) ensuring durability; 9) ensuring affordability; and 10) ensuring access and support in the surrounding neighbourhood. These design principles provide the beginnings of a framework for physical/structural elements that need to be considered for any housing model development or redesign. In the context of a demonstration project, design would ideally “build in maximum flexibility and scalability so that properties can be reconfigured and programs adjusted or expanded in response to changing needs within the community” (HSC Vision, 2014b), and to support adjustments as the project partners observe what is working well and what changes would be valuable. The report goes on to provide more detail on how these principles could be applied to a housing demonstration project for people with a dual diagnosis⁹:

1. Ensure maximum adaptability of the physical components of the property so that they can be adjusted to meet the needs of individuals with diverse abilities (e.g., developing pods that can be reconfigured, a variety of room lay-outs, and spaces with varying degrees of privacy etc.). Ensure that spaces are adaptable regardless of the physical needs of the resident (e.g., provide doorways that are wide enough to accommodate wheelchairs, showers with ease of access and grab bars etc.).
2. Ensure safety and security by minimizing hazards and utilizing modern communications technology to provide security (including locks) and safety monitoring. Generally, locked facilities are not recommended

⁸ Source: discussion with George Braddock, Creative Housing Solutions, Oregon.

⁹ HSC Vision, 2014, pages 44-45.

for individuals with developmental disabilities, but due to the nature of the behavioural and/or serious mental health concerns of those with complex needs, some locked situations are required.

3. Aim for simplicity, intuitiveness and clarity by developing structures that are simple to understand and easy to use, including signage. Maximize familiarity, clarity and stability of the physical elements of the property. Ensure that physical amenities are usable with a minimum amount of effort.
4. Provide flexibility so that it is possible to accommodate preferences and allow choice.
5. Ensure that there are spaces for people to be together (for social interaction) and spaces for independence and privacy (to enhance dignity).
6. Minimize sensory overload by providing calm, uncluttered environments.
7. Use durable materials and furnishings.

By incorporating person-centred planning principles in the design of physical spaces, the range of housing options available to people with challenging behaviours and complex needs can be significantly increased. Creative Housing Solutions in Oregon provides customized housing design and modification in order to tailor housing to the needs of individuals with disabilities, including people with dual diagnosis, complex needs, and challenging behaviours¹⁰ (and similar services are available in Ontario). Elements of the physical environment can be a trigger for negative behaviours for people with some forms of disability or mental health concerns, such as autism spectrum disorder, anxiety disorders, or difficulties with impulse control. Investing in the right supportive physical environment increases the likelihood that the services, staffing and supports involved with the given housing model will succeed (Braddock & Rowell, 2011).

For example, for people with poor impulse control, Creative Housing Solutions has used industrial-strength building materials, tempered glass, pocket doors which are difficult to slam, secure furniture, greater control over lighting and temperature, soft rooms, and high-quality housing components. They have incorporated sensors to increase safety, and prompts to support activities of daily living such as garbage removal. By meeting with the individual, doing an assessment, determining what aspects of previous challenging behaviour may have been exacerbated by elements of the physical environment, and then designing new housing or modifying current environments based on the needs of the individual, Creative Housing Solutions has had great success in supporting independent living over the past thirty years.

Environmental design and modification can be very effective in combination with applied behavioural analysis assessments, in order to dig deeply in to the causes of challenging behaviours, and then address those that are rooted in the individual's surroundings. Of course, the model of housing selected plays an important role as well, such as whether an individual will have the best success living with others, living alone, or living in housing that provides a combination of shared and private space.

Housing Model Case Studies

This section provides several examples of real-life housing scenarios to “flesh out” and bring to life the information provided in Tables 2 and 3 above. The case studies that are included in this report are intended to provide a snapshot of various housing models and examples to foster consideration of new approaches. There are undoubtedly other unique, innovative and informative models being implemented in many communities, which are not included in this review.

¹⁰ Creative Housing Solutions website. <http://gbcchs.com/>

Case Study #1: Snow Goose (Elmira, Ontario)

Model: Supported living with daytime staffing and live-in peer support

Background:

Elmira District Community Living implemented an innovative housing model in 2010 in Elmira, Ontario (Waterloo Region). Two university students are provided with free tuition and accommodation in exchange for sharing a home with four adults with developmental challenges. Paid employees provide daily support. The live-in students provide companionship and are available in case of an emergency. This project enables developmentally challenged adults to live more independently.

Financial arrangements:

This model is considered very cost effective. The house cost \$1.2 million to build. The federal government contributed \$360,000, the Region covered developmental fees of \$22,620, and the Elmira District Community Living group raised the rest of the money. Annual operating costs are about \$100,000 compared to the \$450,000 it costs to operate a group home which provides round-the-clock supports which may not be necessary. The cost of scholarships (about \$6,000 per student) to cover tuition and free accommodation is less expensive than having a paid employee stay overnight, and graduating with work experience is appealing to the students.



Resident (left) and university student decorate a Christmas tree while another resident (right background) and support staff remove a casserole from the oven at a housing project in Elmira that supports developmentally challenged adults.

How it Works:

In exchange for free tuition and accommodation, the two students provide up to 15 hours a week of “social activity time” with the four tenants. The level of social interaction provided through this model is seldom available at group homes. The two students commit at least one year to the project and can also work at other facilities run by Elmira District Community Living to earn money and gain more work experience.

J.H. has a one-bedroom unit with a full kitchen and living room. Her dream was someday to have her own apartment. Down the hallway, M.A. (36) and J.M. (30) share a two-bedroom apartment. They have been best friends since childhood. This is the first time the two men have moved away from home.

Benefits:

- People with developmental disabilities are able to build peer relationships with people with and without disabilities, and interact with the friends of the students who live in the house. A level of social interaction is provided that is seldom available at group homes.
- Ongoing support is in place for when the family is no longer able to provide it.
- The model is very cost effective for the service provider.
- Development of skills, work experience and references for students, as well as coverage of tuition and accommodation costs, and opportunities for paid work.
- Mutually beneficial partnerships between community organizations and universities.

Source: Waterloo Region Record, December 31, 2010.

Case Study #2: Community Living Options (Evanston, Illinois)

Model: Partnership with a non-profit housing developer - ownership or rental in a community-based setting

Background:

The Centre for Independent Futures' (CIF) "Community Living Options" supportive housing model facilitates affordable rental situations or home ownership for individuals with disabilities. The model focuses on the housing piece of supportive housing, but in partnering with groups such as CIF and others, supportive rental housing provides another option for those who are interested in a community-based setting.



Community Living Options housing in Evanston, Illinois

How it Works:

This innovative supportive housing solution addresses the issue of sustainability by placing home ownership in the hands of the person with a disability, often with the help of their family and community members. Each person is able to live alone in their own home. The house is owned by the individual so the housing portion of supportive housing is secured. The four Community Living Option (CLO) Residences, based in Illinois, provide supports for individuals to live independently. Established by families seeking a new vision for their loved ones, the CLO Residences are structured on a philosophy of community engagement and support. The four communities are located in diverse neighborhoods, near public transportation and local businesses.

A Community Builder provides overnight emergency support and facilitates community, including social events and weekly decision-making meetings. Each resident also works one-on-one with a Skills Tutor to strengthen independent living skills. Together, residents and CIF staff foster individual choice and exploration while supporting community connections. Before moving in, all residents participate in CIF's Skills Inventory to determine their current skill levels, support needs, and interests. CIF also provides support to other communities to develop similar programming and housing in their areas."

Funding arrangements:

CIF has partnered with a local housing development non-profit, Housing Opportunity Development Corporation (HODC). HODC's mission is to develop, manage, and preserve the stock of housing that is affordable to low- and moderate-income people. This is done by developing small-scale rental and for-sale housing. Completed units serve families, seniors, people with disabilities, homeless households, and local workers. These partners are focused on both rental and ownership models.

When CIF used their CLO model to help three individuals with developmental disabilities purchase homes in a new condominium project, HODC worked with the developer to help acquire condos within a new project in suburban Chicago. The condominium development included four separate eight-storey buildings completed in phases with over 200 units. CIF arranged for clients to buy units up-front which helped the developer meet requirement for affordable housing and pre-sales for financing. Although only three units ultimately closed, CIF's involvement helped the city and the developer meet a municipal affordable housing goal. CIF was responsible for finding buyers to make sure that they were income-qualified, able to afford the mortgage, and able to live independently with appropriate wrap-around services available through CIF.

Homebuyer counseling was provided to each purchaser by HODC. Because the units were considered "affordable" under the city's housing goals, the developer discounted the selling price for the units from the \$357,500 market rate by \$67,500. Buyers provided their own downpayment, but because the "affordable" price of \$290,000 was still too high for buyers to support the mortgage, down payment funding was needed to reduce the effective purchase price. In order to make the home purchase affordable, HODC also worked with local and state governments to provide forgivable loans that are only repaid when the buyer sells the home.

Monthly mortgage payments, real estate taxes, and insurance, in addition to other housing expenses, are covered by social security income, employment income, and family support. CIF works with members to get employment so most participants have full- or part-time jobs, which are often low paying but provide a steady source of income. Those who took advantage of this program were all employed. Many families also used a financial management tool called a Special Needs Trust (SNT) created for the protection of public benefits for individuals with disabilities. Because the condominium complex was being built from the ground up and they bought-in early, buyers were able to purchase a new unit that was designed for them with physical accommodations built-in. Moreover, because the building was handicapped accessible, they could reside on any floor. This permitted another special feature of the project: clustered living. The three buyers all purchased units in the same hallway so that they could live near each other, yet completely independently. A fourth unit nearby was purchased by CIF for the Community Builder.

HODC also offers a Permanent Supportive Housing Program model which combines apartment rental by an individual with developmental disability, apartment ownership by a non-profit organization who rents scattered site apartments, and supportive funding through multiple sources (Koenig, 2014, p15). The housing developer locates, purchases and renovates suitable apartment buildings; arranges for rent subsidies through local or state governments; and provides all property management services. Single unit and shared accommodations have been developed using a one-year lease agreement. The services provider is responsible for all supportive services, and identifies suitable tenants. (Koenig, 2014, p15.) These partners also work with clients to have enough money for rent, monthly living expenses, and supportive services.

Benefits:

This model would be appropriate for individuals who have financial resources and are able to live safely in the community with supports. This model creates supportive housing through homeownership, encourages choice, creates independence with supportive services, and builds community by facilitating interaction. It supports people with disabilities to successfully purchase and own their own home, or rent an affordable and accessible space that is fully integrated with others, in a non-restrictive environment for the long-term, get access to the help they need, and achieve their goals. This person-centered model can improve quality of life by giving people with disabilities greater choice and respect. It meets a real need for individuals, families and service providers and does not require supportive services to manage housing roles.

Challenges:

This model is not common because there are financial hurdles of down payment and higher monthly housing costs. There is also the expense of purchasing the Community Builder's unit. New construction opportunities are infrequent in many areas so the clustering might be difficult to arrange. There is also a financial risk that housing funds will run out resulting in foreclosure. Still, the elements of homeownership using layers of funding along with the Community Builder could be an important supportive housing alternative. This model requires long-term sustainable funding for ongoing housing management. HODC cautions that the process of housing development is complex, politically risky, and likely to "derail" the other services that an organization needs to provide. They recommend partnering with a non-profit housing developer.

Sources:

Koenig, R. (2014). Supportive Housing for Persons with Disabilities: A Framework for Evaluating Alternative Models. *Housing Studies*, 30(3), 1-17.

Centre for Independent Futures website. <http://www.independentfutures.com/clos.html>. Retrieved Dec 23, 2015.

Case Study #3: Prairie Housing Co-operative (Winnipeg, Manitoba)

Model: Co-operatively owned cluster housing with de-linked support services

Background:

Prairie Housing Co-operative is located in Winnipeg, Manitoba. Established in 1982, it includes 37 units. The co-operative was developed through one individual's desire to leave an institutional setting. A group of his friends and family got together to come up with an independent housing arrangement and this led to the formation of the co-op, which now owns 19 suburban family homes and 28 units in a converted warehouse in the historic Western Saddlers building in Winnipeg.

The co-op is comprised of several 'clusters' of houses wherein non-disabled neighbours and housemates provide volunteer support to residents with disabilities. Paid support workers provide additional support where needed. Cluster locations were chosen in neighbourhoods close to other family members and friends, and close to amenities, employment opportunities and community services. In each neighbourhood, the co-operative purchased clusters of several houses or apartment units. No more than two people with disabilities live in each home. The housing arrangement remains separate from the paid service support to ensure that the security of housing is not affected by the service relationship.

Funding arrangements:

Funding came from Canada Mortgage and Housing Corporation (CMHC) for the first 18 units, and the Manitoba Department of Co-operative Development helped establish the structure of the co-operative.

Considerations:

The individuals housed through this model require minimal supports and have a strong existing network of support and advocacy between family and friends.

Source:

Bruce Kappel and David Wetherow. "People Caring About People: The Prairie Housing Cooperative." *Entourage* 1(4), pp. 37-42. 1986. As summarized in Greenspan & Raine, 2006.

Case Study #4: Ottawa Share Equity Housing (Ottawa, Ontario)

Model: An innovative financial model for Supported Independent Living (designed but not implemented)

Background:

In response to a long waiting list for group homes, the Ottawa-Carleton Association for Persons with Developmental Disabilities (OCAPDD), in collaboration with the development consultant Stewart & Associates, developed an innovative financing model to allow parents to share in the cost of housing for their adult children who will receive quality service in a supported independent living environment.

How it works:

The partners developed a plan to purchase an 18-unit building with financial support from CMHC and the families of future residents. Through their financial contribution of an equity share in the co-op, the families would guarantee the right to lease a unit for their family member on a permanent basis. As the capital cost of the building is prepaid through the equity contributions, there is no ongoing mortgage expense, only ongoing operating costs. These operating costs were expected to be covered through the shelter allowance of the disability benefits received by residents, based on approximately 20 residents sharing a support worker. In this specific case, the developer was able to secure other capital funding and the equity co-op model was not used, but it is believed that it would have been a financially viable model that could be duplicated elsewhere.

Benefits:

Can be developed without government funding, where parents have available resources (including equity in their own home). Family members are able to relieve some of the stress and concern for support of their relatives.

Considerations:

This model was based on a 1:20 ratio of supports staff time, therefore is suited to people with low support needs. The model also requires the individual or a member of their network to provide a large sum of money up-front, or to have a fair bit of equity available in their home.

Source:

Described in Greenspan & Raine, 2006, page 15.

Case Study #5: Home in the Annex (Toronto, Ontario)

Model: A caregiver-led housing approach to rental housing

Background:

In 1991, six families came together to work on future plans for their young adult children with developmental disabilities. Meeting monthly for years, they came to an arrangement for independent living for all six. They organized a planning session for the young adults to identify their plans for the future. They ended up renting a 2-bedroom apartment for two of their children to move in and develop their independent living skills as an interim step before moving to their own apartment. The intention was that after the first two individuals had moved out, another two would use the apartment to develop their skills. However, after the two initial residents reached a sufficient level of independence, they did not want to leave the apartment. The group of families decided to rent another unit in the same building to use for training the next two individuals. Again, these residents did not want to leave the apartment when their training phase was over, and another unit was rented in the same building. After 3 years, the group wanted their own independent units.

Housing Characteristics:

Each of the individuals lives in a two-bedroom apartment in the Annex neighborhood of Toronto, where they grew up. The building has a mix of private market rental units and subsidized units.

Financial Arrangements:

The group pays market rent for apartments from government income benefits. As rents have risen and benefits have not, all families are subsidizing their monthly payments. The rents are guaranteed by a corporation as none of the young people have incomes adequate enough to sign a rental agreement.

Non-housing Supports and Services:

A family support worker assisted with transition. Once the first two moved in into the first apartment, they held Tuesday night training sessions for the six involving preparing food, eating and cleaning up a meal together, having a safety lesson, and planning a meal for the next Tuesday. The support worker also assists with cleaning and shopping. Support needs were provided by Community Living Toronto and student interns from the community colleges.

Opportunities:

This living arrangement has resulted in freedom for the residents and independence; the collaborative planning approach illustrates how to plan with people with developmental disabilities and not for them; and the arrangement provides a mix of segregated and integrated settings which is effective because it recognizes the need of persons with developmental disabilities to be in contact with others who experience similar challenges as well as opportunities to participate in mainstream life. Research identified this arrangement to be a positive example of providing life skills training to young adults with developmental disabilities leaving the family home for the first time. The model is also more financially accessible than some others described in this report.

Challenges:

The housing arrangement requires families to subsidize market rents for their children, and its success is contingent on roommates living successfully with one another.

Sources:

Itay Greenspan and Laurel Raine. Creating Housing Choices for People with Developmental Disabilities in Ontario: A Resource Guide, April 2006 http://www.kehilla.ca/images/resource_guide.pdf

Carolyn and James Lemon. "Community-based Cooperative Ventures for Adults with Intellectual Disabilities" *The Canadian Geographer* 47.4 (2003)

Case Study #6: START Model (United States)

Model: Community-based system-linkage model providing access to mainstream as well as specialized services

Background:

In the United States, the most prevalent model in use for service linkage is the START Model. START stands for Systemic, Therapeutic, Assessment, Respite and Treatment model¹¹. The START model is described as an evidence-based systems-linkage approach for promoting the use of mainstream services, while allowing for specialized support for the most complex dual diagnosis client situations. Prevention and intervention activities occur at the local level (Beasley, 2002). The START model uses a systems-linkage approach to provide services that "are most effective when everyone involved in support and treatment is allowed to participate actively in treatment planning and service decisions" (Centre for START Services, 2011, paragraph 2).

Major components of START include:

- The development of collaborative linkages which may include crisis coordination plans, training and assistance to community partners, and development of affiliation agreements with hospitals and community providers
- Emergency coordination whereby one member of the clinical team serves as a liaison for inpatient and outpatient services, first responders and community crisis providers
- After-hours contact (including crisis response and emergency consultation)
- Respite services which include both emergency and planned respite
- Ensuring that discharge planning occurs at the point of admission.

This model is in use across at least 14 States. While there are slight differences in the governance of the START clinical team, it is typically composed of a medical director, a clinical director, a respite director, several coordinators, and other multidisciplinary direct support staff. Regional programs also have a regional director. The START model is based on a caseload of approximately 30 clients per coordinator.

Opportunities:

This model is geared towards individuals with dual diagnosis and complex needs. The model promotes the use of mainstream services whenever possible, but allows for specialized care and services for the few who need them. It provides linkages between multidisciplinary providers and improves professional capacity across systems of care. The model is a person-centred 'least restrictive model of care and support' that serves people with a dual diagnosis through prevention and intervention including crisis response, training, consultation and respite services, all at the community level. This model reports good outcomes in reducing emergency service use (Beasley, 2002), and in high rates of satisfaction by families and individuals receiving support (Rubin, Fahs & Beasley, 2007).

¹¹ Beasley, 2002; Rubin, Fahs & Beasley, 2007.

Sources:

Beasley, 2002; Centre for START Services, 2011; HSC Vision, 2012; NC START Annual Report, 2011; Rubin, Fahs & Beasley, 2007.

Case Study #7: Simcoe Community Services (Barrie, Ontario)

Model: Enhanced supported independent living, leased by a non-profit organization, clustered apartment model

Background:

Simcoe Community Services had been approached by a developer in the Barrie area interested in building a 6-unit apartment building and leasing it to the organization. This would allow Simcoe Community Services to support people in an enhanced Supported Independent Living (SIL) situation. The organization currently has one housing development similar to this model, and is interested in further development.

How it Works:

The current building includes four units and houses individuals who are not well suited to group living, but need more support than traditional Supported Independent Living can provide. Individual and shared units are available (to keep costs affordable) with one night staff for the building, and part-time staff who come in to provide support. This model is not a full 24-hour supported living situation, but provides much more than the 4-6 hours normally provided with SIL. Support levels are determined by the needs of the people living in the units.

Opportunities:

This model is appropriate for individuals with dual diagnosis and mental health challenges who are able to live independently with part-time supports and without live-in support. It extends the housing options available to people with a dual diagnosis.

Challenges:

Simcoe Community Services has identified a need for more housing of this nature.

Source: Key informant interview with Maxine Johnson, Simcoe Community Services, January 2016.

Case Study #8: Kerry's Place Autism Services (York Region, Ontario)

Model: Staffed residential living for adults with complex needs

Background:

Kerry's Place Autism Services' "Homestead" site in York Region, Ontario is a residential housing model for adults diagnosed with Autism Spectrum Disorder with complex support needs including mental health and medical issues. This housing model, designed for very challenging individuals, affords them with both shared and private living spaces. The bungalow-style housing includes common areas, as well as personal suites each with a living room, table and chairs and ensuite bathroom – essentially a private apartment with no kitchen. Each suite has direct access to outdoors. There is additional common space on the lower level as well as activity rooms and a sensory room.

How it Works:

Each person has one-to-one staffing support along with individual programming within a customized home-like setting. The home has 24-hour staffing through rotating shifts; dedicated clinical supports that include

behavioural consultation overseen by the Kerry's Place psychologist; and ongoing psychiatric consultation at the Kerry's Place psychiatric clinic, one of three such clinics at Kerry's Place.

Some of the lessons learned from the development of housing models such as Kerry's Place include:

- A thorough environmental assessment is carried out by the Kerry's Place behaviour therapist in order to gain as much information as possible about what the supported person requires in their residential environment as well as how the supported person's behavioural profile will affect housemates. This is also essential information in determining the personal preferences and dislikes for particular stimuli.
- Support staff will need about 4-6 weeks of training before the first supported person is admitted. Best practice has shown that the best outcomes are seen when the service provider takes time to transition the supported person gradually. Transition for young people with a dual diagnosis and complex needs is critically important, as they will have significant difficulty with transitions, and the process will require time and patience.
- Relationship-building and strong assessment processes are very important. Support staff and members of the clinical team visit the supported persons in their current residential environments in order to begin building rapport with the supported person, interview and exchange information and shadow current support staff before any transitions begin.
- Environmental modifications unique to each individual are critical before the youth move in. Examples include reinforced drywall, durable flooring, reinforced glass, etc. Specialized architects and 'handymen' have been brought in to design, build or modify existing facilities to maximize the safety of the supported person, housemates and support staff.

Opportunities:

The model has proven successful for people with very challenging behaviours who have not had success in other models.

Source: Interview with Vickie Merilees (York Support Services Network) and John Clarke (Mackenzie Health), January 12, 2016. Additional resource information received from Myra Sugar, Chief of Clinical Supports and Services – Kerry's Place Autism Services, February 23, 2016.

Case Study #9: City Club (Burnaby, BC)

Model: Supported living in a clustered rental housing arrangement

Background:

This model was motivated by individuals and their desire to live more independently despite obstacles (primarily physical disabilities) in 1994. The initial tenants were group home residents who wanted their own apartments and wanted to live alone. Community Living Society (CLS) served as a convener and brought together CLBC and the Ministry for Children and Family Development.

How it Works:

CLS owns 10 condominium units in a strata complex that is 22 stories high and rents them out to clients. The other units are privately owned. The suites are all located on 10 different floors but are clustered close to stairwells to be more accessible for the overnight staff. Half are located on top of each other on one side of the building proximate to a stairwell. The other half are on the other side of the building and are also located on top of each other by a stairwell. Some units have one bedroom, while others have one bedroom plus a den.

Overnight staffing is provided by CLS as part of the housing arrangement. All other supports and services are separate from the housing model. Assistance ranges from a few times per week to 24-hour support. Daytime supports are provided by a range of agencies.

Financial Arrangement:

It is unclear how the initial units were purchased. The cost varies by unit. Some are subsidized, some are full market rents, some are subsidized by BC Housing, and some tenants pay a user fee to CLS.

Opportunities:

The arrangement provides affordable housing in an integrated setting; residents are independent and have their own personal living space; the units are fully accessible which allows individuals to age in place; some overnight staff support is provided; and the cost of providing overnight support is shared among the ten units.

Challenges:

The arrangement has the potential to be socially isolating for people who do not seek out social activities; it can be risky for individuals to live alone in an apartment, especially if they have difficulty communicating; this is a very costly option for individuals with intensive 24-hour support needs; one-on-one support is relatively more expensive and can be vulnerable to cuts in government funding.

Source: Key informant interview with Theresa Huntly, Director of Quality and Innovation, Community Living Society, January 6, 2009. In BCNPHA Research Department (2009), "Exploring Housing Options for People with Developmental Disabilities in British Columbia".

Case Study #10: Southern Okanagan Association for Integrated Community Living (BC)

Model: Supported living, owned by a non-profit, providing affordable rental housing with a commercial space to off-set rental costs

Background:

Since 1994, the Southern Okanagan Association for Integrated Community Living has been involved in developing residential spaces for their clients. This was born out of a recognition of the lack of affordable housing in the Okanagan and a desire to phase out Beaver Lodge (a small scale institution). The first building (1994) was a building in downtown Oliver with apartments and commercial space. This venture was successful and two years later SOAICL used assets to purchase a second building located on the main street of Osoyoos, British Columbia, which includes both apartments and a commercial space.

How it Work:

The first Oliver building includes a commercial space and three apartments. There is ground level access to the apartment units. Two of the apartments are 2-bedroom units, for those who can live relatively independently. One apartment is a 3-bedroom unit which includes one bedroom for staff. Five residents have developmental disabilities.

The second building is located in Osoyoos and has a downstairs commercial space and two 2-bedroom apartments located upstairs. There is currently one resident with a developmental disability. The other unit is rented at market rate as a flight of stairs means it is not accessible to people with physical disabilities.

There is one live-in staff member in the first Oliver building. Night time staff and personal safeguards are included. In the Osoyoos building, there is no link between housing and supports.

Financial Arrangement:

The organization was able to purchase the first building by using a piece of owned property to leverage their assets. A supportive credit union looked at the organization's assets and cash flow and provided financing. The commercial space for both buildings is rented out and used to offset rental costs. In the first Oliver project, rents for clients range from \$350 to \$400. Non-community living tenants pay \$500-700. In the Osoyoos building, current rent for the two-bedroom unit is \$400 while non-community living tenants pay \$500-700.

Opportunities:

Provides affordable housing; provides housing in an integrated setting; and the close proximity to services is helpful due to the lack of public transit in Oliver and Osoyoos. The purchase of a commercial building provides a unique opportunity to offset rental costs through renting out the commercial space.

Challenges:

The Osoyoos project is only suitable for individuals who can live fairly independently and can access suitable supports since there is no staff on site; and the Osoyoos building is not accessible since the apartments are located upstairs.

Source: Key informant interview with Richard Little, Executive Director, Southern Okanagan Association for Integrated Community Living, February 25, 2009. From BCNPHA Research Department (2009), "Exploring Housing Options for People with Developmental Disabilities in British Columbia".

Transition Models and Approaches for Youth with a Dual Diagnosis

Youth with developmental disabilities may face several life transitions, including school to work or postsecondary education, family home to community living, child oriented health care to adult care (Antosh et al, 2013), and more. They may experience multiple intersecting transitions at the same time, or the "transition-aged" changes may follow an earlier series of transitions related to housing, service providers, caregivers, health status, etc. These transitions can involve foundational aspects of people's well-being such as one's space and sense of "home" (as with changes in housing), relationships (as with transitions between agencies and staff who had been trusted supports, or loss of connections and friendships when leaving school, programs or housing), and the security of knowing how one's core needs will be met. This degree of change, and possibly loss, would be challenging for any individual, but can be particularly complex for individuals with multiple challenges. Individuals and families have identified that it is very important to ensure they can plan and prepare for a gradual and safe move into an independent or supported living arrangement (Legislative Assembly of Ontario, 2014) or between services.

The following section briefly discusses some of the key concepts related to transitions for young people with a dual diagnosis, to round out the discussion of developing a supportive housing model for TAY with dual diagnosis.

Transition Principles

Research has provided causal evidence of the importance of self-determination for young people with developmental disabilities to achieve more positive transition outcomes (Antosh et al, 2013). Youth, even those with dual diagnosis and complex needs, should be able to expect self-determined transitions with coordinated support from family, community, professionals, and agencies. However, they and their families often experience very little choice, control, or collaboration from the myriad of systems to which they look for support and services

for transition (Antosh et al, 2013). The literature indicates that transitions should embody the principles of inclusion, person-directed planning, and individual choice (Legislative Assembly of Ontario, 2014). Antosh et al. propose the following core concepts essential to effective transition plans and processes, which are echoed throughout the literature on transition planning for youth with a dual diagnosis:

- A comprehensive transition plan should be developed and include a place to live and work; skills to manage one's living environment and navigate the community; self-care skills to ensure safety and personal health; to be included in community activities of one's interest; a social network of friends, family members, and allies that support the individual; and opportunities to participate in leisure/recreation activities (Antosh et al, 2013). Transportation is also considered an essential support for the transition to community living (including both transportation resources as well as travel orientation/training) (Antosh et al, 2013).
- Self-determination should be the foundation for transition planning. Promotion of the self-determination of adolescents with disabilities has become a best practice in transition services. Promoting self-determination refers to equipping students with the skills, knowledge, and attitudes they need to assume primary control and responsibility for an array of life activities (Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007). They also need to participate in the transition services, for example, attending meetings (Antosh et al, 2013) and becoming empowered to direct their own planning as time goes on (Inclusion BC, 2012).
- The voice of the young person should be central to the transition process. Effective practices include implementing student involvement tools and processes (Antosh et al, 2013).
- Transition planning should begin early (Antosh et al, 2013); for example, health care transitions are recommended to start between 12 and 14 years of age.
- Transition planning should be person-centred (Antosh et al, 2013; Inclusion BC, 2012).
- Families should be involved in transitions (Smart, 2004; Antosh et al, 2013). Using navigators helps students and families understand support systems and service options to develop specific strategies for implementing transition plans (Antosh et al, 2013).

“Promotion of the self-determination of adolescents with disabilities has become a best practice in transition services.”

Tools and Approaches to Support Self-Determination

Several tools or approaches can help promote self-determined behaviour among young people with developmental disabilities. Education systems appear to have the strongest focus on transition issues for youth with developmental disabilities, based on the focus and sources of literature. The government of British Columbia set out a protocol for educators to support transition planning for youth with special needs (Province of British Columbia, 2009). This direction has implications for any transition of youth between housing models, or supporting transition-aged youth within their existing housing. The protocol recommends that planning for youth should begin at age 14 and may continue beyond age 19 to ensure that there is a coordinated and supported process both during adolescence and into adulthood. Youth and their families are central to the process and are supported to actively participate. The process includes:

- Initiating the planning process by providing the youth and family with information on the process.

- Establishing a transition planning team, which may include family, caregivers, friends, school staff, service providers, community supports, etc. One member is designated the Transition Coordinator and plays a key role in coordinating the process, gathering information and developing the transition plan.
- The transition plan focuses on the youth's abilities and strengths and connects these to their dreams, goals and desires.
- The youth is assisted in connecting to the many supports in their community and implementing their transition plan.
- The transition planning team reviews and evaluates the plan at least once per year.¹²

Microboards

A Microboard is formed when a small group of committed family and friends join a person with challenges to create a non-profit society (board). Together, this small group of people addresses the person's planning and support needs in an empowering and customized fashion. A Microboard comes out of the person-centered planning philosophy, and is therefore created for the sole support of one individual. Members can then become a trustee of government funding to help the supported individual in areas such as financial management and recruiting and training staff (Greenspan & Rains, 2006). A microboard could be a useful component of an innovative housing model that includes ownership, joint ownership or equity ownership of housing by the individual with dual diagnosis.

Transition Tools

Individuals and families need person-centred planning and assistance to navigate the many different sources of funding, service providers, health care providers and other supports in their communities. Support is needed in the form of support team development, information management (finding and keeping track of all the potential supports one might access), as well as help to navigate these systems (such as manoeuvring through eligibility processes, wait lists, consent processes or representation agreements, etc.).

PATH, Maps and Essential Lifestyle Plans

The PATH process developed by Helen Sanderson Associates (UK) is a process for engaging individuals and their support networks in person-centred visioning and action planning for their future. Maps, PATH and Essential Lifestyle plans are examples of tools to bring family and friends together to plan for the future. These planning tools are very collaborative and are supported by graphics.¹³

PATH is suited to complex situations requiring concerted action and engaging people and resources over the long term. The "focus person" (or young person with a dual diagnosis) and the people they want to invite meet with two facilitators. They describe their personal vision for the future, develop longer-term and interim goals, analyse the steps needed to achieve their goals, determine who can help the young person to move forward and plan how support will be provided, identify how the focus person will build strength and sustain the changes they make, and plan how the team will monitor progress. PATH involves the focus person in meaningful ways in planning for a future they want to live. PATH works well when an individual has a group of people around them who are committed to making things happen. Helen Sanderson Associates describe other tools such as MAPS, Care and

¹² Note: Appendix C in the Cross Ministry Transition Planning Protocol for Youth with Special Needs provides a detailed list of transition team member roles and tasks.

¹³ Information on these tools is available at <http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning/essential-lifestyle-planning-.aspx>.

Support Planning, and person-centred thinking tools to help people explore what is important to them in housing. These planning tools also support staff and agencies in prioritizing services for their clients when financial resources are limited.

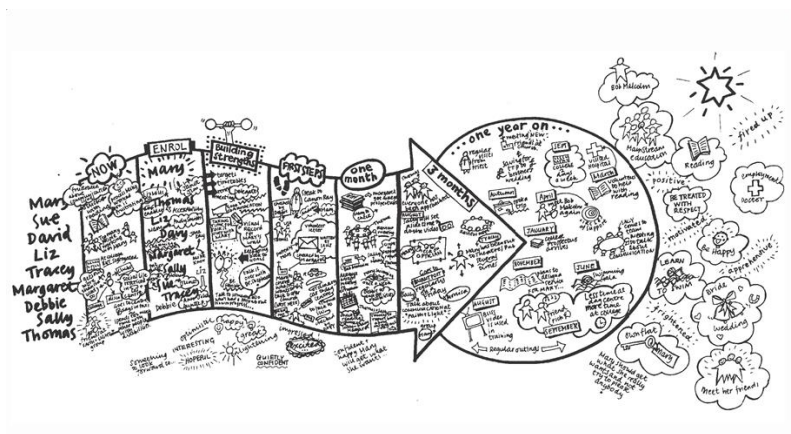
Case Study #11: Mary's PATH

Mary has never enjoyed living with other people with whom she cannot communicate. Mary's experience of planning is typical. She has had hundreds of assessments done to her throughout her life, none of which made any attempt to involve her in a meaningful way. She has some very clear ideas for the future and she has a strong group of people around her who get on well.

Mary is her own best advocate, continually campaigning to change arrangements which do not suit her. Mary and her support staff decided to invite in outside facilitators to help them plan for change, using PATH. An all-day meeting was scheduled to which Mary invited her parents, her keyworker from the day centre, members of the house team and her speech therapist.

A year later, Mary has achieved many of her goals. She goes out weekly to the same pub, she is learning to read and she has been on holiday to York. However, in many ways it has been a frustrating year for Mary. She still lives in the same house, although plans are being made for her to move on. It has taken a year for the social work department to agree to fund a dayworker so she can cut down her days at the Adult Training Centre to three a week. Mary has been to biology classes in an ordinary school but it is proving difficult to persuade a college to offer her a place in an integrated class.

The review meeting had a very different tone from the original PATH. The same outside facilitators were asked in and the same people attended the meeting. This time Mary took far more control of the process than she had the year before. She did not allow anyone else to speak on her behalf. When people suggested that she needed to get out and meet more people she indicated that this is not a priority for her. She feels that she has enough people to talk to although sometimes they do not have enough time to talk to her. Her main priorities at the moment are her reading, her classes and moving into her own home. Things had changed. The other people at the meeting were there to listen to what Mary wanted and to say what contribution they could make to supporting her to get it. Mary now has a dedicated team including her parents and paid workers, many of whom also see themselves as her friends. Person-centred planning has helped Mary become an assertive young woman who is both sure of what she wants and determined to get it. However, she is still frustrated by the amount of time it takes for her to get anything and by how much still has to be achieved. She chose to have a plan because she was not satisfied with her quality of life. The planning was the start of a process of change which has not moved fast enough for her.



Community Transition Committees

Teen Transition Planning in British Columbia has implemented community transition committees, which are described in the following way on their website¹⁴: “Teen Transition Committees are essential to building “transition-ready” communities. These committees are formed when small groups of individuals from different organizations and different sectors within social services unite forces. The aim of most committees is to try to create a solution to the large number of unmet needs surrounding the highly complex Transition Planning process...through their realization that no one person or agency can meet the need, committee members reach out, collaborate with each other, share resources, organize information fairs and information nights. They plan and host parent orientation events to create hope and unity amongst families in their community. They arrange for their fellow professionals to become better trained in the tools of Transition Planning.”

Promising Support Services Components

Although the service components of a supportive housing model for transition-aged youth with dual diagnosis are generally outside the scope of this review, it is worth mentioning some of the key aspects of support that are strongly related to or impact any housing models that may developed, and should therefore be part of the comprehensive planning process. The following section discusses some aspects of support, though it does not attempt to provide a comprehensive review of this topic.

As stated in HSC Vision’s 2014(b) report, “While there is agreement that design features of housing are important to the health and well-being of individuals, the greatest challenge in providing high quality housing settings that will support a range of needs is related to staffing and clinical supports and to the availability of local effective support services. Service provider challenges include the recruitment and retention of well-trained staff and ongoing support of care staff by ‘external’ professionals, challenges, which unmet, will result in relatively high care staff vacancy rates and increases in ‘out-of-area’ placements for people with developmental disabilities and complex needs. The literature suggests that partnerships with local authorities and local investments can improve services for those in need.”

Barriers to accessing needed non-housing supports can prevent individuals with developmental disabilities from accessing appropriate housing. The goal of supportive housing is to provide services needed for the person to be

¹⁴ Source: <http://www.teentransitionplanning.ca/committees/>

as independent as they can, but also allow adaptation as peoples' needs and situations change (Koenig, 2014). Service providers have indicated that they have found success when the following are in place: (HSC Vision, 2014b)

- The ability to create continuums of service within their own organizations
- Having the clinical resources required to support high-needs individuals
- Having the staffing expertise within their residential settings, along with providing staff support and training
- Having the overall capacity to meet the needs of the clients
- Having the ability to address risk/liability issues within their own agencies
- Having strong partnerships with other agencies, including Behaviour Management and the local CCAC
- Making efficient use of a nurse within their own agency

An individual's success in a particular living arrangement is largely contingent on having access to the required supports. Depending on the individual, support needs vary greatly from someone who needs almost no assistance in daily living to someone who requires 24/7 support. In some cases, people with developmental disabilities rely on service providers for their support needs, and in other cases on natural supports (i.e., friends and family) or a mix of both. Even when an appropriate and affordable housing unit is available, a person with a developmental disability cannot make it their home unless the support services they require are already in place and funding for the supports is readily available (BCNPHA Research Department, 2009). In light of this complex interplay between housing and supports, the following section describes some considerations for support components to include in a model of housing for TAY with a dual diagnosis.

Effective clinical assessments, support, monitoring and follow-up

Key informants strongly recommended including expert functional behaviour assessment (FBA) and positive behaviour support in any model for transition-aged youth with a dual diagnosis. This process helps support people to describe the behaviours that are occurring, identify the sources (such as frustration, barriers to communicating needs, etc.), and structure the individual's environment and day in a way that decreases these triggers. Many young people are referred to a psychiatrist for medication or get counselling, when intense behaviour support programs are actually the priority. Once behavioural support is in place, it becomes much easier to identify the appropriate model of housing for the individual. Ideally the behavioural consultants will stay involved with the young people in an "intensive, long-term support" arrangement, and do some intensive training with program staff, so that the interventions will continue to work. Once an in-depth behavioural analysis is complete, the housing design principles described above can come in to play in order to create an environment that will support well-being and positive behaviours.

Accessible supports that meet clients "where they are at"

Assertive Community Treatment teams are one example of a service that is tailored to the needs of individuals with mental health concerns. The ACT model was developed to meet the needs of clients with severe mental illness who often experienced relapse and re-hospitalization, in some cases due to their inability or unwillingness to go to local mental health centres. An ACT team provides around-the-clock support and services, such as case management, assessment, psychiatric care, employment and housing assistance, family support and education, and other services that help a person to live in the community (Lunsky & Weiss, 2012). The Central East CNSC has been developing a multi-disciplinary outreach team that can travel across the region to where the individual resides. This can help reduce the need for access to more intensive out-of-home placement (HSC Vision, 2012, p12). This type of person-centred resource could be useful as part of a comprehensive model focused on young people with a dual diagnosis.

The use of health care or service system “navigators” is also recommended to help families navigate the complex system of supports in their community. A navigator can come alongside an individual or family, help them manage the vast amounts of information they will need to find, support access to organizations and services, help families ‘make sense of it all’, and generally reduce the anxiety or confusion many families experience in trying to navigate complex systems of support. This resource is well suited to transitions in care.

Highly skilled staff with effective supports in place

Unsurprisingly, skilled staff were referred to many times in the literature as a necessary foundation for providing effective supportive housing services. According to a report by Children’s Mental Health Ontario (2015), “the need for a large investment in consistent and high quality staff training was noted by nearly all service providers and front line workers”. A report specific to dual diagnosis (HSC Vision, 2012) recommended a service system that includes “appropriately trained, specialized, interdisciplinary clinicians and direct care professionals who can support and link to mainstream mental health services, in order to care for clients in their own communities”.

Case Study #12: Neighbours Allied for Better Opportunities in Residential Support (NABORS)

Model: individualized personal support services with board management

Background:

NABORS was established to provide support and services to 12 individuals with developmental disabilities living in two co-operative housing buildings. The focus is on individualized personal support and community building.

How it Works:

NABORS is run by a board, separate from the board of the co-operative housing development, which includes the 12 individuals or their representative, plus three ‘friends’ of NABORS. NABORS acts as a vehicle to receive funding from the Ontario government on behalf of the 12 individual members. The organization works on a ‘support circle’ model, where each individual is supported at the centre of a circle of friends and family who provide and coordinate supports for the individual. Each member hires and supervises their own support staff and manages their own budget. However, the network of relationships, rather than services or staff, is the core principle of NABORS. NABORS also works to ensure the full participation of its members in the housing co-op and to develop their social networks and community connections. In conjunction with the housing co-operative, NABORS received grant funding for two community facilitators, whose job is to support the development of community within the co-op and support NABORS members in being part of the community.

Source: Greenspan & Raine, 2006, page 17.

As stated above, this section was intended only to provide some considerations for the planning of support services to accompany an innovative housing model. Further study should be undertaken to uncover other recommended aspects of supports.

CONCLUSIONS

Overall, the literature offers little evidence related to “favoured” or evidence-based models of housing for young people with a dual diagnosis. The grey literature, and “on the ground” experience of organizations across North America, have, however, interesting models to share.

Regardless of the favoured model, researchers and authors agree that a range of housing options is needed to serve people with developmental disabilities, mental illness and/or complex needs. The needs and preferences of these populations vary considerably and no single housing model can successfully accommodate everyone (CAMH, 2002; Hallam et al., 2002; Stevens, 2004; CMHC, 2009; Sundberg, 2010; Bertelli et al., 2013; Community Living Ontario, 2013). Housing decisions should take in to account the strengths, goals, needs and resources of the individuals who will access these services, as a starting-point for decision-making.

This review has put forward some promising ideas and tools to support the design of an innovative housing approach for transition-aged youth with a dual diagnosis, which can serve as a foundation for further discussion, planning, consultation, prioritization, modelling, design, development and evaluation.

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Held, M. F., Thoma, C. A., & Thomas, K. (2004). "The John Jones Show": How One Teacher Facilitated Self-Determined Transition Planning for a Young Man with Autism. Focus On Autism & Other Developmental Disabilities, 19(3), 177-189.	Peer-reviewed.	There has been a great deal of research reaffirming the power of self-determination within the process of planning for the transition from school to adult life for a student with disabilities. Much of the focus of that research has been on teaching core component skills or changing parts of the process such as the transition Individualized Education Program meeting itself. Although these strategies are effective, they only begin to scratch the surface of what is necessary to facilitate self-determined transition planning throughout the year. This article describes the efforts of one teacher to infuse self-determination throughout both the curriculum and the school year.
HSC Vision (2012). Final Report on the Effectiveness Evaluation of the Implementation of the MOHLTC/MCSS Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis.	Grey literature.	Evaluation report, prepared for Joint Steering Committee - Ministry of Health and Long-Term Care and Ministry of Community and Social Services, by HSC Vision Group in 2012.
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Kirkendall, A. & Saladino, A (2009). Transitional Services for Youth with Developmental Disabilities: Living in College Dorms.	Peer-reviewed	This study evaluates the impact of a college-based dormitory program on transitioning youth with intellectual disabilities. A qualitative study, with interviews at pre and post, was conducted to evaluate the program's impact. Data were collected with semi-structured interviews from young adults with intellectual disabilities who participated in a college-based residential program and their parents or guardians. Three general themes emerged from the data: Participants reported experiences that were (a)

Referenced Materials	Type	Abstract/Notes
		typical of normative life transitions, (b) typical of growing pains associated with significant life transitions and learning new skills, and (c) one step forward. Results indicate that the experience of living away from home for the first time was in some ways comparable to that of a typical college student. Improvement in life skills, including increased awareness of personal goals, enhanced vocational goals, increased maturity or assertiveness, was reported. Respondents were generally satisfied with the program.
Koenig, R. (2014). Supportive Housing for Persons with Disabilities: A Framework for Evaluating Alternative Models. <i>Housing Studies</i> , 30(3), 1-17. DOI: 10.1080/02673037.2014.953449	Peer-reviewed.	The need for supportive housing is growing as people with disabilities seek less restrictive housing options and those who care for them search for long-term solutions. Supportive housing includes housing in a variety of styles that is affordable to people with disabilities but is also connected to services that allow personal independence. Persons with disabilities are seeking community-based residential living arrangements within their abilities and means due to changing attitudes, funding, and legal requirements. As aging parents realize that their disabled adult children will outlive them, they are searching for new models but there is a lack of understanding of supportive housing options. A comprehensive framework is needed to evaluate models by looking at housing and services as separate but interrelated issues. This article explores the need for supportive housing for people with disabilities, offers a framework for evaluating supportive housing options, and provides two case studies of innovative person-centered models for people with developmental disabilities.
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Randell M, Cumella S (2009). People with an intellectual disability living in an intentional community. Journal of Intellectual Disability Res. 2009 Aug;53(8):716-26. DOI: 10.1111/j.1365-2788.2009.01181.x. Epub 2009 Jun	Peer-reviewed.	<p>BACKGROUND: Hospital closure programmes in England have generally sought to attain a fulfilling life for people with an intellectual disability by locating them in domestic-style housing in urban settings. Few have been placed in intentional or 'village' communities. Yet comparative studies of different housing types have found that intentional communities have better or similar outcomes for their residents than dispersed housing or residential clusters on former hospital sites. A possible explanation is the distinctive pattern of social relationships that exist in many intentional communities and the impact this has on the lives of their residents. This paper reports the results of research that explores the perceptions of people with an ID living in an intentional community and the meaning of their community to them.</p> <p>METHODS: The research used an ethnographic approach to interview a sample of 15 residents in a large intentional community (Botton Village), which is part of the Camphill Movement. Interviews used Makaton, pictures and symbols where required.</p> <p>RESULTS: Respondents included 10 men and 5 women aged between 38 and 78 years. Length of residence in Botton Village ranged from 5 to 50 years. All lived with the families of co-workers and valued these relationships. All but one (who had retired) worked in a diverse range of employment in the village. Almost all were positive about their work. Respondents reported that they took part in both individual and communal leisure activities and all but two had a network of friends. Opportunities for friendship were enhanced by proximity to other people with an ID and a sense of personal security in the village. As in many villages and communities in society in general, these advantages were balanced by some loss of privacy.</p> <p>CONCLUSIONS: Results confirm those from earlier studies of intentional</p>

Referenced Materials	Type	Abstract/Notes
		<p>communities and suggest that positive outcomes derive from the absence of the overt subordination of residents to staff, the facilitation of friendship with other people with an ID, high levels of meaningful employment and a sense of community. These factors contrast with the experience of living in small homes funded on a contractual basis by public authorities, in which cost pressures reduce wage levels for staff resulting in difficulties in retaining suitable staff and a consequent high staff turnover.</p>
<p>Smart, Melanie. "Transition planning and the needs of young people and their carers: the alumni project." <i>British Journal of Special Education</i>, 31 (3), 2004.</p>	<p>Peer-reviewed.</p>	<p>Melanie Smart is a research associate at Sunfield School, Worcestershire, and a trainee clinical psychologist. In this article, she reports the results of a small-scale survey which looked at the views of 17 parents whose children with severe and/or complex learning difficulties had made the transition from a residential special school to an adult placement. Parents were asked their retrospective views on the transition planning process; their own involvement; and how the adult placement met the needs of their children. Melanie Smart's findings indicate that the majority of parents were very much involved in the planning process, although they reported struggling to get consistency of approach and basic information. The young people themselves were found to be marginalised in the planning process, with very few being involved in any decision making. Most parents were happy with the eventual placement, but those who had concerns were still pushing for basic services and care. Of those who had suffered placement breakdowns, the major factor was lack of consistency of approach and failure to use prior information about the child. This survey shows that parents and their learning disabled children experience difficulties in the transition process. There seems to be a distinct lack of person-centred planning, particularly with this user group, by both child and adult services. Parents are vital to this type of planning approach, particularly when the young people themselves cannot voice their needs or advocate their own rights to quality service provision. Melanie Smart argues that parents need access to better quality information and reassurance that their children will receive the services</p>

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