

“A Home That’s Right For Me”
**Valuing Choice, Evolving Individualized
Residential Options**



Summary Report of Policy Forums
Sponsored by the
Ministry of Community and Social Services

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Part I: Background & Foundational Elements

1. The Individualized Residential Model (IRM) Initiative and the Policy Forums

In 2007-08, the Ministry of Community and Social Services (MCSS) provided funding under the Individualized Residential Model (IRM) initiative to create individualized residential arrangements for people with a developmental disability. The purpose of the IRM initiative was to allow people with a developmental disability and their families to work with an agency and propose an individually-tailored residential model concerning where and how they live.

IRM is unique because each living arrangement:

- is designed together by people with a developmental disability, their families and an agency;
- is tailored to each person's needs and preferences; and
- recognizes the ability of families to provide supports.

Eighty-nine people with a developmental disability are now living in an IRM that is right for them, in addition to many others who developed individualized residential arrangements before the ministry introduced funded IRM in 2007.

In April 2009, four policy forums were held in Ontario, sponsored by the then Developmental Services Branch (now known as the Community and Developmental Services Branch) of MCSS. The Forums were designed to seek input and feedback from agencies and family members who had experience in working together to develop individualized residential approaches.

The Forums were held in Toronto, London, and Ottawa, and a videoconferenced session reached 10 sites across North and North Eastern Ontario. More than 250 people with a developmental disability, family members, and agency staff participated in the Forums.

The objectives for the Forums were:

- to identify the concepts, values and practices which are part of an 'individualized' way of thinking and doing business when providing residential support;
- to identify ways of building on current individualized residential approaches and the Individualized Residential Model Initiative (IRM) funded by the ministry in 2007-2008; and
- to identify strategies and actions for moving forward together towards a more "individualized" way of thinking and doing business when designing and delivering residential support.

The sections below summarize what was heard in response to these questions. In Appendices A, B, and C are additional resources that were identified as useful for designing and creating individualized residential arrangements.

2. The Foundations of Individualized Residential Support

The foundations of an individualized residential situation identified by those who have built and are living in, or supporting people in, individualized situations are:

The Possibility of Options:

- Individualized residential approaches are developed through personal choice and exploration or consideration of options regarding home.

A Vision or Dream of ‘Home’:

- Individualized residential approaches are developed from an individual’s vision or dream of what ‘home’ means to and looks like for them.

A Plan for ‘Getting to Home’:

- Individualized residential approaches are developed through an intentional planning process which puts into concrete terms an individual’s dream. The plan identifies what ‘home’ will look like, who it might be shared with, what will make it feel secure, what supports will be needed, and who will provide them.

Understanding ‘Home’:

- Individualized residential approaches come from an understanding that a person’s home is a refuge, a place of privacy, and is not a ‘program’, even if the person may need staff support at times.

Directing your Life:

- In an individualized residential situation the person is in charge, although their family, or other trusted people, may also be involved in decision making. Things don’t happen without the person being ‘in the driver’s seat’. Decisions around changes are within the individual’s scope of control, again, sometimes shared with trusted members of a circle of support. Funding that is allocated is to be used to support the person to fulfill the outcomes of their individualized plan for home.

“I used to be in the middle of the person-centred planning group, with everyone around sitting around me in a circle, running the show and making decisions, sometimes checking in with me. Now I’m directing where I live, who supports me, when I pay them, all my choices related to home. This person-directed approach is quite different.” (Self-advocate)

Selecting, Building, and Directing the Supports:

- Individualized residential approaches include a realistic understanding of the supports that a person needs, offered by people who are part of the individual's community, and selected by the person. Many supports can be natural, informal, not just offered by paid staff. Where supporters are paid, the person has a lot of say about who they are.

“Our son now is very clear about who he enjoys spending time with – about which people he wants in his life. And he communicates with his own workers about how he wants to do things and how he would like the support delivered. He is also very clear on what works and what does not.” (Parent)

Security, Safety and Sustainability:

- In individualized residential situations, the person is able to define the level of independence they want, and all efforts are made to respect the person's will to be autonomous, building from their capabilities. The person and their trusted supporters will be involved in discussions about safeguards to ensure that to the extent possible, risks are thought through and safeguards are in place.

“For the people supporting us – for health and safety reasons they “BUBBLE WRAP” us, but we have to take the layers off. What if I wrap you and you can't do what you want to do – you don't get bruised but you can't handle your shopping, handle money. You have to let us be independent and have the experience.” (Self Advocate)

“Safety and security comes from informal human ties and relationships not from formal structures. People engaged in relationship act because they care about the other person. People's lives must be shaped and supported by their personal relationships (friends and family) not by services and programs” (Beth French, Brockville and District Association for Community Involvement - Forum Presenter, 2009)

Inclusion:

- Individualized residential situations are not 'islands' within their community, but are part of a neighbourhood, where people with a developmental disability can take on the roles associated with community citizenship and participation. There are many natural connections which can grow, as a range of roles are taken on by the person, who is not a program recipient or client, but a community resident. The person is a 'householder' just as anyone else in the neighbourhood.

“We wanted a home in the local community where our daughter grew up and has family and connections – you are safer, more connected where you are well known. She now lives in her own apartment where she is able to walk to places instead of always having to drive, therefore more visible – close to family, and walking distance from our family home so more inclined to mutual visits, drop-ins, etc.” (Parent)

3. Conditions to Support Individualized Residential Approaches

Within Developmental Services Sector Agencies

In order to support the development and sustaining of 'home' the following conditions have been identified as enabling effective individualized residential support in addition to the above foundations:

- Individualized budgets within the agency
- Portability of funding and transparency around funding to person and family
- Resources and options for independent individualized planning
- Education and resources available to **all** families not just those in service relationships, and a willingness to support the development of networks including autonomous family groups and self advocacy groups
- Clear board values and mission consistent with responsive individualized approaches; firm value base and how it will be implemented
- Willingness to be flexible – unbundled, undo, redo – to meet a person's needs
- A culture of change, innovation, learning and responsiveness
- Strong and trusted partnerships with people with a developmental disability and their families based on honest, mutual respect and a willingness to challenge each other's thinking

Ideally, the vision is that the person not only gets a "home" of their own making, but that the home becomes an anchor in the pursuit of a rich and rewarding life. Since one's home life intersects with so much else in a person's life, getting it right helps put in place the other key pieces necessary for a deeply satisfying and uniquely suitable life. (Michael Kendrick, 2009)

Within Community

The following conditions have been identified as critical to supporting and allowing the kinds of choices and experiences of home in an equitable way to all citizens:

- Awareness and education of community members around citizenship and inclusion rights and capabilities of all people with a developmental disability
- An adequate range of affordable housing options
- Adequate levels of income for people who are unable to achieve gainful employment due to their disabilities, enabling them to be tenants, and homeowners
- Sustainable funding to support people in homes of their choice

4. Outcomes To-date

Many people with a developmental disability, families, communities, and agencies across Ontario have made substantial progress over the past few decades in helping people achieve their dream of “home”. There are many individualized support arrangements across Ontario which predated the Individualized Residential Model (IRM) Initiative which was funded in 2007-08. With the IRM initiative, however, more people seeking a home that's right for them and their families were able to move from dream to reality.

In 2007-08 MCSS received and approved a diverse range of individually-tailored proposals from across the province in response to the IRM initiative. Eighty-two proposals were submitted to regionally-based offices and 62 were approved for implementation. As a result, a total of 89 people will be supported in their homes of choice when all 62 approved proposals have been fully implemented. This included 14 people who have moved from an existing ministry-funded space into an innovative model that better meets their needs and preferences. These numbers reflect the number of applications only, and it should be noted that several innovative model proposals include service for more than one person.

In total, \$3.6 million was allocated to individualized residential proposals in 2007-08, with an average allocation of \$42,000 per person. The cost per person, however, varied widely, with some receiving \$14,000 to back-up family and housemate support to an individualized residential situation, and one person with high support needs receiving \$110,000 where paid support was needed on a 24/7 basis.

Living arrangements were created for people of all ages – from young adults graduating from high school, to older adults whose aging parents were becoming less able to provide care. Families have been active and involved – from designing the living arrangements to coordinating supports. Agencies have continued to play a key role in these situations, with varying degrees of involvement. For example, in some situations, the agency provides brokering and selection services around hiring supports, in other situations, it is the agency staff who coordinate and provide 24/7 support. Agencies have also been particularly helpful to families in assisting with accountability requirements, developing service agreements and contracting with support workers and housemates, as well as in helping people with a developmental disability and families keep the plan on track and the dream alive.

At the Forums, people with a developmental disability, families and agencies identified the outcomes related to moving toward their vision of “home”:

Comments from people with a developmental disability about finding home:

- “My funding is my funding; I hire my own staff – if I don’t like them, I say “see you later”. I make sure things get done. I have volunteer friends. One is like a brother to me.”
- “I live in a 2 bedroom condo with no roommates. I didn’t want to share my home. I know my neighbours and they know me. I am unique – I control everything around me – if I’m not in the mood to do it, I didn’t have choices when I grew up. Now I have choices.”

- “The benefits for the community are big– less stress on our health care system, and more effective use of government funds. I was deemed to need support 24/7. Now I have a worker who I’ve had for 9 years. At the beginning I needed her constantly...now she is a fly on the wall.”

Comments from family members about their son/daughter finding home:

- “I think the biggest benefit with our son is that he’s almost had a personality change – in the 90’s when he first moved, he had 24 hours a day of support. Now he’s gone down to 20 hours of support a week – and he’s saying that he doesn’t want that. He’s more talkative and assertive. It reflects something about him and what he’s experiencing.”
- “It’s not something we like to talk about – but it’s CHEAPER. Services cost money. My son went from 24 hours a day of support down to 15-20 hours per week in his apartment. I have to give credit to the person approach – every year his budget seems to be getting less.”
- “The family involvement became much more as family visitors were part of their ‘home’ life instead of going into a ‘facility’. And there was a ripple effect as the supports came naturally. And you have the neighbours and family friends that start getting involved – a great benefit for everyone.”

Comments from family members about working with agencies and funders:

- “Both organizations made an effort to get to know what our daughter wanted and needed; and what our family wanted and needed, and took the time to listen. I can’t say when the transition took place – but now it is well beyond partnerships and relationships. I don’t want to say friendships, but it is a very comfortable place to be in.”
- “Ministry people who have been real advocates for our cause have supported us in what we’re trying to do and they understand.”
- “We are fully involved in the hiring, the screening, the orientation, the training, and we co-supervise. There is a huge trust between the agency, the brokerage and us. We use the agency for overnights and when we take vacations. We keep a contract and we are fully aware of the responsibilities that we have, and we know about finances at any point in time – it’s important. It puts us in the driver’s seat with our daughter – we believe families need to take responsibility for their individualized funding.”

People with a developmental disability and families spoke about the range of housing environments that have developed to respond to a person’s needs and preferences, and also some of the unique support arrangements which have been established (See Appendix A for housing and support arrangements and more detailed stories about some of the individualized residential arrangements which are being supported in Ontario).

Why we need to move in this direction

Why would a person, a family, or an agency want to move ahead with a more individualized approach to residential arrangements? What we heard from people with a developmental disability, families and agency staff about the reasons for going in this direction were:

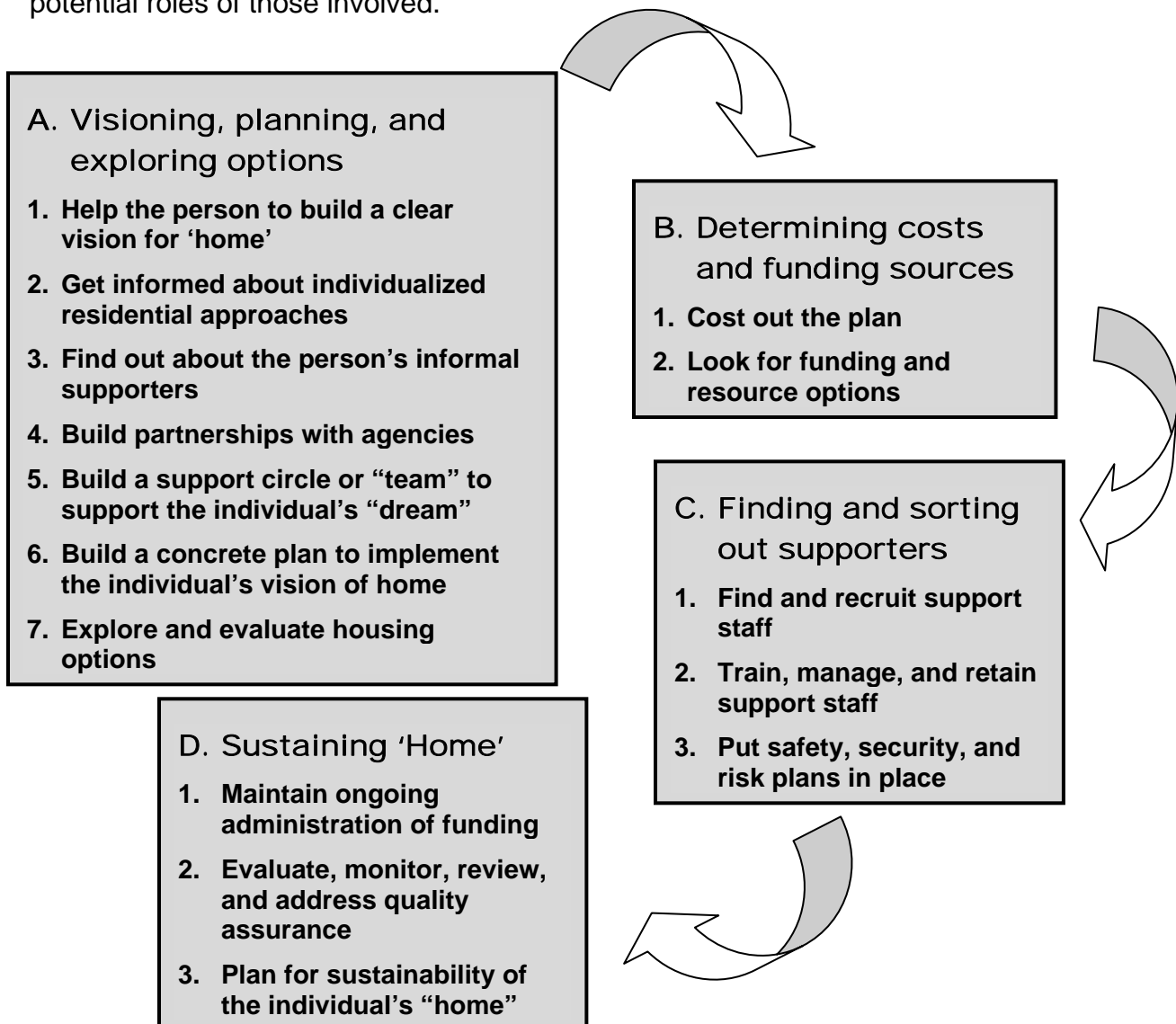
- People with a developmental disability are citizens, and have the right to independent living to the degree they want, so people can live in dignity and feel safe, and valued in their own communities.
- It is the best way to support people to live a full, good, quality life, live their choices, take ownership of their life, and grow their capabilities.
- It is what this new generation of young people who are used to integration and inclusion want.
- It builds on person uniqueness – all citizens have a contribution to make to their community and this will allow people to add value in our communities, to be seen differently as full citizens, and to build stronger inclusive communities themselves.
- An individualized approach is not necessarily more expensive and the satisfaction rate is considerably higher for the person and the family.
- It is the best use of resources, and as a result, agencies can provide services to more people.
- When people grow and develop their own abilities over time, they end up requiring less support, which again results in lower support costs.
- When an individual's needs are met, it also results in fewer crises.
- Staff who support these people report a higher level of job satisfaction and motivation.
- Support arrangements have developed into innovative initiatives with new partners contributing. Together these partners have increased the capacity of the community to support people with developmental needs.

Part II: Guide to Developing Individualized Residential Approaches

The following guide outlines a step-by-step process for developing an individualized residential arrangement. It includes key questions to ask during each step, whether you are a person with a developmental disability, an agency, or a family member of a person seeking a home that's right for them.

The process of 'finding home' includes some common experiences and steps, although these steps may not always be in the same sequence for all people with a developmental disability and their families. It is critical to remember that this is not a 'lock step' process, but an evolving one, and that we are focusing in this document on the elements of 'finding home'. The vision, plan, and relationships that develop around supporting a person to have a good life will need to include many aspects of a person's dream and plan, but the 'home base' is a critical anchor for creating that good life.

The graphic below includes the four key components of an IRM and the steps involved. On the following pages these steps have been 'fleshed out' with a discussion of the potential roles of those involved.



A. VISIONING, PLANNING, AND EXPLORING OPTIONS

1. Build a clear vision for 'home'

People need to be encouraged and supported to explore their hopes, dreams, and vision for the future in terms of 'a home' that's right for them. Others need to listen, to contribute, and to stimulate thinking. Focus on how the person wants to live and be supported. Also focus on how the 'feel' of the home, rather than just on the actual physical aspects of the home. Be willing to try out new ideas, think about possibilities, and explore them. Some people with a developmental disability and their families are quite comfortable having visioning discussions on their own; other people with a developmental disability, families and support circles have found it quite helpful to involve a facilitator, broker, or third-party planner.

I wouldn't have been able to think in broad terms about (our daughter's) future and possibilities of it without the facilitator prompting and asking questions. And having them listen to what my reaction was. And then they would supply a thought that turned it in a different direction – it provided me with an opportunity to think differently. I thought I had a clear idea – but realized I needed some prompting to think in different directions – I found it enormously helpful.” (Parent)

Below are some questions that may help a person think about what home would look like and mean for them. In addition, to ensure there are quality indicators that can be used in the evaluation process down the road, it is important to think about how the person would know they were successful in achieving their dream of 'home'.

- What is important about 'home' for them? (e.g., feeling safe and secure; having their own key and coming and going as they wish; being in charge of who comes and goes; choosing who they live with and who supports them) **What would this look like if it was achieved?**
- What are the good things the person wants in their 'home'? (people, things, environment 'feel') **What would they see if these things were present?**
- What kind and amount of support does the person need? What are the important characteristics of supporters and relationships in their 'home'? (E.g., they listen and take my word seriously; they do what they say they will; they call before they come). How would the person observe that this is the case? **What would they see?**

People seeking a home that is right for them need to:

- Start planning and visioning early, before leaving the school system.
- Think about what is important about 'home', where they live, who they live with, and who they have to support them.
- Talk to other people who were successful in finding a 'home' that was right for them and ask them about their dreams.
- Think about the things they need help with and the things they can do on their own where they live; think about what they would like to learn to do more of on their own when they are in their 'home'.

- Ask questions and learn about housing options.
- Have an open and honest discussion with family and other trusted people about their future vision of “home”. (If the person is unable to speak, they should use other communication methods to let their circle of supporters know what they want.)
- Go to all of the planning sessions with their trusted circle and their family. (If they cannot go, or find this too difficult at some points, they need to communicate about their preferences for ‘home’ to someone they trust.)

Family, friends, and support circle members need to:

- Recognize that the person needs to be stimulated and supported to dream so that they can create a clear vision of what they are seeking in terms of ‘home’. Give the visioning process the time it deserves.
- Draw in those who can support and be the foundation for building an individualized ‘home that’s right’. Include creative people who are forward-thinkers. Include people who know the person well.
- Practice putting the person first. Listen, take in, and work from the individual’s desires and preferences, rather than trying to contain them. Hold back from a desire to protect and think about ‘what’s best’ for the person, or from having your own solution in mind.
- Support each other, debate, challenge, vision – really listen to the person (experience shows that family members also need to broaden their thinking).

“The vision for our daughter was based on ‘what do typical individuals, typically do, at any typical age in a typical situation. A person has the right to a life independent from parents; siblings should be siblings; parents have the right to be empty nesters at a reasonable age. It took many years to get to the stage where we had a clear vision of what a home and life for our daughter should look like. It took a lot of going down different paths working with agencies to get it right.” (Parent)

2. Get informed about individualized residential approaches

Persons with a developmental disability and their families need to be proactive and become informed about individualized residential approaches. Agencies need to help families by providing the information they need.

People seeking a home that’s right for them need to:

- Talk with friends about what being independent means; learn from each other.
- Visit and interview peers who already live independently in a variety of situations.
- Learn about what is involved in running a home, including budgeting, safety and security, healthy eating, the risk of loneliness and change, and hospitality.
- Get informed about options for living with others or on their own.

Family members need to:

- Actively seek knowledge and information. Ask questions and engage in research – find out what else is happening in the province. Seek the advice and support of professionals, and best practice information.
- Engage in informal or formal networking; have parent-to-parent conversations to hear success stories to inspire and stimulate thoughts; join or develop a parent group for information and support purposes; think creatively with other families about how to share resources and collaborate on solutions.
- Be willing to move out of their ‘comfort zone’ to honour their son’s or daughter’s desires...learn from other families about how they coped with that.
- Establish a connection with an agency and develop an understanding of what they can provide and assist with.
- Communicate to the Ministry of Community and Social Services and providers about needs.
- Investigate planning options in their local area (through agencies, third-party, brokerage, family organizations) in order to have knowledge of choices when funding is available.
- Think outside of the current agency services menu to investigate options even if they do not exist already.
- Learn about the reporting and accountability requirements.

Agencies need to:

- Disseminate and share information at town halls, forums, training sessions, and through family groups/networks (both formal and informal ones) around housing and planning options.
- Encourage parents to start thinking and planning early.
- Hold orientation and information sessions for families and meet with families when new initiatives come up.
- Assist in building a parent group.
- Help families know what some of the best practices, approaches and options are, and who they can connect with in the province to find out more.

“There is a pressing need for education all around...from all levels of the ministry and to all providers of residence of any sort now serving in our communities. Proper education will bring enlightenment to all, remove fear of the unknown, allow this new development to be a cooperative success and bring Canada in line with many other parts of the world. (Parent)

“We initially became interested in Life Sharing residential models when we learned about the L’Arche movement and how non-disabled companions made a commitment to share their lives with someone who has a disability. We then learned about the Supportive Roommate model where ordinary citizens live with persons with disabilities in exchange for reduced rent. We decided that in our situation, both models needed to be combined because they are both critical for securing a stable, loving, and nurturing living environment for our daughter.” (Parent)

3. Find out about the person's informal supporters

People seeking a home that is right for them and families will need to think about what support has meant, and currently means, to them – to look at the past, current and potential natural supports in the person's world, and challenge community members to support participation. There is a tendency to think about paid agency supports, and although there will be a place for this, likely, it will be around those areas where natural supports cannot be accessed, or where the role is perhaps too personal to be filled by friend or family.

“There is great power in informal structures. Safety and security does not come from formal structures but from the people who freely give their time to be in relationships with vulnerable people and from the commitment they have to the well-being of those people.” (Beth French, Brockville and District Association for Community Involvement – Forum Presenter)

“I notice that people start to look for community first, rather than agency – and that leads to more creativity in supports that are not agency based.” (Agency staff)

People seeking a home that is right for them need to:

- Think about what natural connections have been positive and comfortable.
- Think about places in the community that have been welcoming – where connections have been built.

Family members need to:

- Look at the community with open eyes – friends, faith community, neighbourhood, son's/daughter's connections. Think about who may be able to have a role as a natural support – even push a little.

4. Build partnerships with agencies:

Getting to know what the different agencies offer, the values they are committed to working from, and the various options for their involvement (in addition to being the “paymaster”) is something people with a developmental disability and families should be doing in the early stages of planning. There are many agencies in Ontario doing leading-edge work when it comes to helping families to create individualized residential arrangements for their sons/daughters. These agencies have been instrumental in building a culture of alliance and partnership with people with a developmental disability and their families. People with a developmental disability and their families need to work towards building a strong relationship with an agency so that they will have caring, concerned professionals available when they may need them. It is only over time that an agency can come to know the person and their dreams and preferences. There will need to be discussion about how involved the person and family want, and need, an agency to be. Within the relationship between the individual, the family, and the agency, it will be important to identify who has the skills, the resources, and the will to manage the administration, hiring, and contracts.

Agencies can help with:

- Assessing appropriate options and seeing possibilities
- Identifying support needs and costs, and identifying all administrative support requirements
- Recruiting for support needs and training
- Supervising workers
- Assisting with application processes
- Finding a skilled planner to facilitate the planning process
- Ensuring that the person's plan is carried on when family members are no longer able to help

"We all have to let down barriers and appreciate this is an opportunity to work together – and we have to set aside our defences and put the person at the centre – and work on their behalf. Agencies who partner with families can help to steer the process, but can also help you figure out how to make a REAL home for the individual" (Beth French, Brockville and District Association for Community Involvement – Forum Presenter)

"For me personally and for my son it's the common values that you work from. If you don't have that, you don't have the respect and the trust. Around citizenship and participation, contributions that my son makes to the community. Those things are fundamental. The fact that you have a partnership with an organization that shares common values is big. You can't work with an organization that has a different set of values than you do." (Parent)

The division of roles and responsibilities can be sorted out in a number of ways to suit the particular needs and resources of the person and their family:

1. Agency takes the lead, seeking direction and input from the person and family (e.g. hiring and monitoring staff and contractual arrangements, fund management, quality monitoring, risk assessment/review).
2. Negotiated partnership arrangement (many options for shared roles by the agency, family, and person with a developmental disability) based on a clear and documented understanding of roles and responsibilities of the person, the family, and the agency. In these situations, a service agreement is recommended and it then becomes the basis for the relationship and the accountability mechanism for making sure all the pieces get done.
3. Agency has brokerage role for funding flow through, and the person and/or the family manage all aspects of the individualized residential arrangement, ensuring that all reporting requirements are met.

Some families are very willing to take on a leadership role, and comment that 'it's like running a small business'. It doesn't have to be complicated and can be quite straightforward once the systems are in place and it's clear what is expected of everyone. Families may take on:

- Full responsibility for recruitment, hiring, training, scheduling, retention, and remuneration of all support staff under an independent contractor agreement.

- Providing all mandated hiring documents (i.e. medical and police clearance, current First Aid and CPR qualifications) to the lead organization; ensuring maintenance of annual requirements and forward documents to lead agency.
- Co-ordinating bi-annual and annual review meetings.
- Overseeing and ensuring development, implementation, and operationalization of plans/ services as set out in the service agreement.
- Providing monthly statistics, receipts, and invoices to the lead organization.

“Only 20% of families will choose to direct and manage their funding. At end of the day, when families are older, they will turn to the agency they had a relationship with all along to partner with them. We don’t need to worry. Families will turn to us, and there will always be lots of work for agencies if we are responsive and worthy of their trust.”
(Xavier Noordermeer, *Community Living Windsor* (Forum Presenter))

Family members need to:

- Identify what specific skills and resources are needed from agencies.
- Research the agencies in the area – spend some time interviewing agencies to find the one which is most responsive to their needs. Find out about their core values, their experiences in partnering with families, and the agency's plans for the future regarding developing and supporting individualized residential arrangements in partnership with families.
- Remain open to possibilities of how an agency can partner with them – keep a positive mindset and allow an agency to demonstrate their value. Recognize that trust cannot be built overnight – give it time.
- Share their hopes and dreams with agencies and ask agencies to help.

Agencies need to:

- Make it a point to find out what is happening in their own community – what families, people with a developmental disability and other agencies are doing when it comes to individualized residential support arrangements.
- Take direction from the person and family to implement their plan.
- Hear input from people with a developmental disability and families on what type of supports are needed.
- Be receptive to proposals; be open minded to new ways of offering support.
- Communicate and build relationships based on expectations for honesty and transparency.

“We don’t fund programs – we fund individual’s needs. It’s important to invest in PEOPLE not PROGRAMS (Archie Dowker, Sout East Grey Support Services – Forum Presenter)

5. Build a support circle or team to support the individual's dream

Here are some key considerations in building a support circle:

- Create the support circle early on in the process – this can include friends, family, community members, trusted supporters, and agency staff – so that they can participate in visioning and planning.
- Include people with different qualities – a) confidante, b) intellectual, c) loving, warm, caring person, d) family who carry the person's needs in their hearts (Alison Ouellette, *A Place Called Home*, page 77) – as well as visionaries who keep the big picture in mind.
- Although there is much variation, it would not be unusual to have between 8 and 20 people in a support circle.
- At the outset, include the circle members in the discussion of the individual's vision for the future. Share the values, beliefs, culture and lifestyle that are important to the person and the family.
- Ensure that all team members understand the concepts of inclusion and dignity of risk.
- Support circle members may take on significant direct support roles, or may be more involved as trusted advisors during planning and decision making processes.

See Appendix B for additional resources on this topic.

People seeking a home that is right for them need to:

- Help build their trusted circle – identify people who have listened to them before and taken their inputs seriously, and who they trust.
- Find ways to communicate to the team the details about their dream.
- Identify anything that makes them nervous about their dream of 'home'.
- Give direction to their trusted circle.
- Think about how to include important people who are participating from a distance (e.g., use of computer equipped with a Webcam or teleconference).

Family members need to:

- Make sure the person's voice is heard. Ask the person who they want in their support network.
- Engage in actions that will help to build relationships in the community – to widen the possibilities of who might be included on the support team.
- Consider what qualities they want the team members to have and what expertise and commitment is required.
- Spend lots of time connecting, helping each person to get to know the individual, perhaps at a deeper level than they might have experienced in a relationship before: this is new territory!

- Determine how decisions will be made and how they will capture opinions of people who cannot be present.
- Plan for review and issue resolution: address concerns as they come up in the support partnership (mediate across differences, troubleshoot, problem solve, resolve conflicts).
- Consider using a facilitator to help with team building and exploration of fundamental values and beliefs.

6. Build a concrete plan to implement the individual’s vision of “home”

The crucial thing was getting the assistance with making the plan – having that as a blue print or guideline early on. (Parent)

Planning is a way of making concrete a person’s vision for a future ‘home’ by determining strategies to achieve the “dream”. It is worthwhile developing a good plan, whether or not there is a funding available to support it. A good plan will outline clearly how the individual’s goal will be achieved by laying out step-by-step actions. Doing so will also help to ensure stability and sustainability. Some plans are very narrative and are very much about the person – who they are and what they want. At some point, however, that has to be translated into responsibilities, commitments, and timelines for each element.

Some things to consider around developing a plan for an individual:

- Start early by reading information about ‘intentional planning’ and person-directed planning.
- Consider engaging a planner or facilitator to assist, either through an agency, or a ‘third party’ facilitator (who will be a neutral person, not directly connected with one of the delivery agencies).
- Outline roles for various people in the individual’s support circle.
- Ensure that the plan is meaningful, realistic, and respectful.
- Build in measures or markers of success that are clear and understandable, and show that progress is being made toward the intended results of the plan.
- Set achievable time frames for measuring achievements.
- Identify who will be accountable to ensuring the plan is carried out.
- Understand that planning is a continuous process that must evolve, be flexible, be revisited regularly, and incorporate changes over time. Families have found that they need to make a commitment to life-long planning and learning.

In addition to the ‘dream’, a plan for ‘home’ would need to include (but not be limited to) information about the individual’s:

- Strengths, skills, gifts, and assets (from all relevant perspectives relating to home and community participation).
- Meaningful relationships and valued roles.
- Particular vulnerabilities in a number of areas related to independence, safety, and personal/health care concerns.
- Specific support needs and preferences.

People seeking a home that is right for them need to:

- Participate in every part of developing the plan and ask questions; challenge people and tell people what is important to them.

Family members need to:

- Be willing to move forward with planning even when there is no commitment of funding.
- Make it clear from the outset that it will be their family member who will own the plan.
- Involve the circle of support and other key people who have been a part of the individual's life and know them well.
- Separate planning from decision making so it is not about picking from an agency menu – but about what the person needs, regardless of who will provide it.
- Investigate and seek out a facilitator – talk to other families and agencies to find out what exists in terms of this kind of service.
- Learn some practical planning skills if they are not going to work with a facilitator.
- Begin to think about the key elements of a solid plan. Build a 'skeleton' plan which begins to identify support needs in a concrete way and which can eventually be turned into an individual budget in order to prepare to apply for funding. This can be fleshed out later once various options have been considered. For example, some aspects of the plan might include:
 - Paid support worker needs (how many, from where, what role will they play, how many hours will they be needed, and at what times) and relationship boundaries – roles and responsibilities of different partners. There are many ways to look at this – consider a roommate or shared housing, arrangements of rent-free accommodation in lieu of paid support hours, etc.
 - Unpaid support from within the individual's community or circle of support (again, who, what, where, when, etc.).
 - Safety and risk factors.
- Determine how the plan will allow the person to continue to grow and develop – build in flexibility and openness to change.

Agencies need to:

- Have a contact person who can specifically help with applications and plans.
- Help people with a developmental disability and their families with planning for the future or divest this service to independent planners.

“Independent facilitation can create “ohh” moments – it challenges us to do things differently.” (Xavier Noordermeyer, Community Living Windsor – Forum Presenter)

7. Explore and evaluate housing options

While exploring the possibilities:

- Ensure that the person (perhaps over time) develops some flexibility about the range of options. Involve the person in looking at various options.
- Be open to seeing the world of possibilities; be prepared to try different settings to find the ideal “home” for the person.
- Where the person does not have an active family, or family resources, it will be important to identify affordable housing options, as well as opportunities and interest with respect to house sharing.
- Become informed about what is available and relevant for the person and put some pressure on agencies and government to develop affordable options for vulnerable people, where family resources are not available.

People seeking a home that is right for them need to:

- Make their voice heard about where and how they would like to take part in community life – e.g., being close to the community centre, swimming pool, church or other religious centre, and other essential services.
- Be clear about whether they prefer to live with one or two house mates, or on their own (with or without supports).
- Ask and learn about the kinds of housing in their area – learn about choices.
- Ask to have any agreements that are made about them discussed with them and signed by them, so they are fully informed.
- Ask about how much individualized funding has been allocated to them.
- Be prepared to challenge those who do not agree with their choice or perspective, or who question what they want (even if it is because they love or care about the person or want to support them).

Family members and support circle members need to:

- Select the particular area of city/town where the person would like to live – based on where they work/volunteer, proximity to friends, essential services, etc.
- Learn about the housing market or shared living options in the person’s area of choice, whether there are affordable housing options, and what the municipality is planning with respect to supported units.
- Look at realities of renting versus ownership, shared ownership, and different options within ownership; take the short-list of possible “homes”, and do a pro/con analysis – be transparent in discussing this with the individual.
- Look around for potential development partners (private investors, developers, service clubs, businesses/corporations) – involve the broader community in developing options – communicate and step outside the developmental services world.

Agencies need to:

- Support persons with a developmental disability and families to think and learn about options, and to make an application for affordable housing, if they qualify.

B. DETERMINING COSTS AND FUNDING SOURCES

1. Cost out the “plan”

Before investigating and evaluating various funding options, it can be extremely helpful to take the individual’s plan and cost out the various elements – from physical housing (rent, mortgage, etc.) through support needs, to security features. In addition, look at existing funding that the person already has, and what the family may be able to contribute (any savings, etc.) in order to obtain a full picture.

Family members and support circle members need to:

- Partner with an agency – they do not necessarily need to do this on their own or reinvent the wheel – agencies have a great deal of experience with this.
- Be willing to do some homework to find out the accurate costs attached to various elements of the Plan.
- Consider cost of living increases when projecting into the future.

“When you’re waiting for service – have a plan costed out. It’s imperative so that when snippets of funding come out, you are ready.” (Archie Dowker, South-East Grey Support Services – Forum Presenter)

2. Look for funding and resource options

Getting funding in place to realize the individual’s vision of “home” can be both a frustrating exercise, as well as a creative problem-solving process. Before receiving the required resources and funding to implement the plan, there are actions that can be taken.

Existing Agency Funding:

Agencies are being creative about how current resources can be allocated to support individualized alternatives. People interested in moving from a group home to a more independent situation can explore with agencies how they may continue to access residential funding which can be transferred to the Individualized Residential funding stream.

New Ministry Funding:

There is not always new funding for residential services in a given year. What this means for people with a developmental disability and families is that they need to be prepared for new funding announcements. They need to be ready, have their groundwork done, have the costing sorted out, and know that they have the elements in place that will contribute to a strong proposal.

If No Funding is Available Right Now:

Many families who have been involved in developing an individualized residential arrangement with their family member have not waited for specific individualized residential funding, but have moved ahead in creative ways. Some useful strategies are:

- Layer resources and use respite and other funds in creative and transparent, ways. “Cobble together” support dollars from a number of different sources – e.g., Passport, individualized dollars through agencies, respite funds, or Special Services at Home (SSAH).
- Think about the resources that the family or support circle members can offer as far as support capacity.
- Think of whether there are creative ways to ‘try out’ a more independent situation within an area of the family home, where more separation or privacy can be attained, and where monitoring may be manageable, as a transitional step.
- Identify whether there are any affordable housing options that can be accessed to reduce actual housing costs. Municipalities are responsible for developing affordable housing for those on a fixed income.
- Generate interest with a market landlord or private developer to apply for a rent subsidy.
- Look for start-up funds from service clubs, other community organizations, or other relevant sectors (e.g. Ministry of Health and Long-Term Care funded Supportive Housing and/or rent subsidies where significant investments have been made over the past several years).

Other Government Funding:

As mentioned, there are other sources of funding and grants related to housing, renovation, and retrofitting. Some of these funding options have been included in Appendix C.

Family members need to:

- Make a list of possible funders and funding options, including community resources, and develop a plan for making contacts and getting the information they need.
- Determine what range of funding will suffice; find out about sources of funding for planning; look at different ways to maintain housing that would impact the amount of funding required.
- Seek information on what is available from various government sources for funding – e.g., in-home suites, retrofitting, also tax credits (see Appendix C).
- Develop partnerships with other funders or organizations that provide access to services (Community Care Access Centres, Local Health Integration Networks, Ministry of Municipal Affairs and Housing).
- Connect with other families to identify where there may be ways to share resources, build on collective capacity, and share support functions.

- Think about applying for affordable housing resources in the community which may offset the need for capital investment.

Agencies need to:

- Be informed about other service sectors and community organizations which can support affordable housing development and delivery, and support families to develop relationships.

C. FINDING AND SORTING OUT SUPPORTERS

1. Find and Recruit Support Staff

The person's individual plan should identify the type of supports they will have. It should also outline the characteristics they are looking for, the actual work that will be carried out, and the times and number of hours when supports will be needed. In order to find and recruit staff, some families have partnered with agencies to assist them with sourcing staff and screening. Other families and people with a developmental disability have found that they are more comfortable finding and recruiting support staff on their own.

Some ways to achieve success in finding appropriate support people include:

- Listen to what the person wants and involve them in the process. As one parent commented about the hiring process, "individuals have good instincts", so we should involve them.
- Keep in mind that an effective support person (for some person situations) is not necessarily someone who has special training, but someone with life experience, and interests that align with those of the person (e.g., animal care, arts, music, etc.).
- Expect that needs will change over time when a person is living in their "home" and are able to become a valued citizen, and develop more confidence in their own abilities. Many parents talked about their sons/daughters needing 24/7 support in the beginning, but over time their support needs (and costs) were significantly reduced, with much more support offered by unpaid natural support people.

Many families have found creative ways to get the funding they need for staff support and often combine funding and support alternatives (e.g., utilizing an agency program for 12-15 hours per week, individualized residential funding for 10-15 hours per week, plus lots of scheduled and unscheduled support from family, friends and neighbours). The individual, family, and agency will need to work together to confirm and implement the hiring process and to develop orientation and training approaches. They will also need to agree on roles for natural support persons.

People seeking a home that's right for them need to:

- Think about what is important about people who help them. Think about how they want those who support them to communicate with them. What exactly do they want them to do?
- Be as involved as possible in the hiring process itself (interviews, reviewing applicant resumes, etc.).

- When interviewing, use their good intuition to get a “feel” for the person and whether they are comfortable with them or not.

“I get a cheque from (the agency), I hire my workers, I ask them to do what I need, I get them to do their timesheets, I check them, I pay them by cheque, I send the sheets to (the agency). If there are problems I find a new worker. I’m the boss!” (Self Advocate)

“The most important thing was that our son was always included. Nothing was decided upon without him there. He didn’t like meetings – he would go underground. So we had to refer to them as coffee breaks instead of meetings. Now he speaks up at meetings. He was quite verbal in what he wanted – it used to be that he wouldn’t say anything. You have to ask the questions in all kinds of different ways. He was involved in the hirings, and a couple of firings too. And he was very proud of it.” (Parent)

Family members need to:

- Understand the status of support workers as independent contractors if they are hiring them. Where an agency is providing support staff, become familiar with any employment practices, standards and regulations which may apply (e.g. Workplace Safety and Insurance Board – WSIB)
- Take intentional steps to ensure natural (unpaid) supports are in place. Maximize what families, friends, and neighbours offer in terms of natural support to augment paid support hours.
- Get past the emotional barrier of hiring only family/friends. Be clear about paid workers and friends – and their roles; be very clear about when a person is an employee or not.
- Be direct and clear about what they want – but be open to possibilities – i.e., sharing one or more workers with another family.
- Build alliances with other families. Consider developing “family cooperative networks” to share recruitment as it is time consuming and costly. Interview workers in a group with other families and find the best suited worker for the person out of a broader outreach, shared advertising, and hiring process.
- Not reinvent the wheel; network with agencies who get resumes all the time. Network with churches, community groups, etc. to identify support people.
- Document the process and outcomes for next time.

“Yes, the agency takes a big role in our case. So they give us options, but the final word is my daughter’s and ours – (our daughter) sometimes has problems expressing herself and so on.We discussed options with (her) and did some trials. Finally she said – she wanted to live in the house and with which person” (Parent)

Agencies need to:

- Develop good partnerships with families – offer to help the family with interviewing and attracting candidates.
- Provide a “how to” guide for families and a repository of resources and templates (qualifications needed, asking for references, benefits, liability, contracts, etc.); Clarify employment standards as they relate to individualized supports where workers are provided by the agency.
- Create a list of supporters (a pool) who have been pre-screened so families have options.
- Screen resumes that are received and have supply of possible workers; make referrals of workers to families.

“(The Agency) is good at respecting (our son’s) personhood. They will screen people who have applied to work as a support worker to see whether or not we ought to interview them. And we and (our son) make the decision whether to hire them or not.”
(Parent)

2. Train, manage, and retain support staff

There are a number of ongoing roles and responsibilities related to managing support staff:

- Up-front training
- Ongoing staff development
- Dealing with contracts, timesheets, and other required support worker administration
- Dealing with illness
- Addressing “no shows” and reliability
- Addressing any work quality or behavioural concerns
- Firing

Some families are comfortable and confident in being support coordinators by taking on these roles themselves, as are some people with a developmental disability. Other families have found that developing a partnership with an agency is what they need in order to be successful. An agency can take on all of these roles, or some of the ones the family is less comfortable with. The key is developing a true partnership where there is trust that the process will run smoothly.

There are a few organizations in Ontario which have the capacity to respond to the administrative and financial needs of families at various stages. It is important to identify up front the potential roles of the particular agency and what they are able to take on from the administrative and financial perspective, and what others (family, support circle) are able and willing to take on. There are a number of tools and documents which agencies have developed to support these functions (see Appendix C).

“We are the support coordinators – we have a complex little business almost – we have contracts with support personnel; contract with agency; timesheets; ways to submit for reimbursement; quarterly and annual statements; guidelines for fire drills; we’re still working on it (the package). We also have had a lot of help from a family support and planning organization – and they helped us in two key areas: 1. with the difficult transitional period in the early days – how to interview properly – how to define the scope of work – how to make good choices and how to evaluate; and 2. they help us with the management of our circle of support.” (Parent)

Some ideas that families and agencies have used in training support people include:

- Documenting “Principles for Support” to guide the support relationship and use this in training.
- Ensuring staff have training/support in understanding “life without programming” and the values of the person/family.
- Creating a legacy binder to transfer the knowledge of the family and other close support persons, and how best to support the individual to other supporters.
- Developing teaching tools, through the use of a video camera, to document personal care and medical procedures, and other important personal preferences and skills.

“Now he is the master of his own place. He can invite people over to his place, and he is connecting to his neighbours fairly regularly and he’s only been there a year and a half or two years. They look out for him. The other part, a challenge, is to have continuous staffing. The house piece is a piece of cake – you take some money and buy a house – you just have to find money, and the formula to sustain it. And it’s done. But the support piece – keeping good staff who are supportive of (his) will and desires, rather than to try to lead (him) – that has always been a challenge.” (Parent)

See Appendix C for:

- Sample Principles to Guide Support
- Sample Quality Assurance, Accountability and Monitoring Agreement
- Sample Personal Support Agreements
- Information Package about Independent Contractors
- Sample Self-Employed/Independent Contractor Agreement

Family members need to:

- Consider how to ensure a safe, healthy and quality workplace for supporters to increase their satisfaction and address any liability issues up front.
- Not always think that staff turnover is a negative thing – it can bring about new synergies.
- Be prepared to ‘run a little business’ (and all that entails) or have someone else do that.

- Try not to let workers leave until they help to find a replacement – recognize that they have good networks of other potential supporters.

Agencies need to:

- Develop good partnerships with families – offer to help the family with training, supervising, and staff development.
- Create alternatives for training support people – teleconference, video conference, webcast.
- Educate and assist families with human resource functions, so that they can take on what they are able and willing to, but have agency back up where the demand exceeds their resources.
- Bring in mentors (other people with a developmental disability, families, and agency staff) from agencies that successfully incorporated staff within individualized residential approaches.

3. Put safety, security, and risk plans in place

Once the actual physical home is selected and taking shape, it will be essential to determine any areas that present safety concerns or risks – both to the person being supported or others.

Some considerations around safety management:

- Think through the concerns of the person and the family members, and talk about how to address each concern.
- Understand that, in a person's home, it is not appropriate to have to conform to safety standards which have been developed for group home facilities. These environments are under the control and management of the 'householder', and agreements which clearly embed this understanding need to be made between the individual, family, and agency so that the home-like environment can be sustained.
- Acknowledge that people are vulnerable – think about, and set up, living arrangements which are safe by identifying specific areas of vulnerability.
- Acknowledge and learn that as people are able to be more autonomous, they actually build their capabilities and skills and this has a huge ripple effect on what their support arrangements need to look like.
- Think about 'dignity of risk' and respect person choice. This will mean balancing citizenship, choice, and autonomy for the person against concern for safety.
- Consider 'technologies' and communication strategies which can be put in place to satisfy concerns of the person and their family. Some practices include:
 - External video monitoring (via a surveillance camera in the ceiling of the kitchen for example) so the family can monitor it from their own location in case of intruders, fire, or a crisis situation.
 - An audio monitor (hard-wired to a neighbour's house) so the person can call for assistance if needed.
 - An alarm system to wake the caregiver or supportive housemate at night.

- An electronic ‘blog’ for regular communication so family and other supporters can check in when they are not at the site.
- Use of visual aids for safety checklists in the house.

The overarching guide here is to remember that this is a person’s private home and not an agency-run program (such as a group home) and that risks need to be assessed differently. When we respect person choice, we have to recognize that risk-taking is part of that choice.

“When we got together, my son, myself and people from the agency, we could think differently about what was really needed. I have a tendency to be overprotective. That’s what mothers do, so I did have to be challenged on that.....to let go....to let him find his own way, and what he could do. I can’t believe what he is doing now....I never would have imagined it!” (Parent)

“The challenge sometimes is this issue of control – I think we do provide and protect, and give security, but if you exercise too much control, a person has no chance to learn. I’ve used (agency staff) as a sounding board. I want them to tell me and I need them as a gauge to help me give up control, and have him gain from me giving up that control.” (Natural community supporter)

People seeking a home that is right for them need to:

- Identify anything that makes them nervous about their safety in their new “home”.
- Try doing things on their own, with safeguards built in, and be prepared to learn some new things to make it work for everyone around them who cares.
- Identify the non-negotiables in terms of their particular safety concerns and get involved in decision making and planning around implementing solutions.

Family members need to:

- Know what the person is capable of in terms of using their own judgement and problem solving during crisis situations – using the phone, pushing a help button, etc.
- Use role plays to address possible problem areas: Can the person use the stove safely? Engage in fire drills? Handle unsolicited phone calls?
- Build a clear plan or systematic process to mitigate risk; identify areas of concern and brainstorm potential risks and solutions (e.g., call blocking, fire safety arrangement, visual cues for problem solving).
- Consider engaging neighbours, informal support network, and natural supports (e.g., siblings who live down the street) as part of the plan (i.e., to provide support by checking in as good neighbours do).
- Ensure they have liability insurance to cover any accidental occurrences relating to the person or the support worker, and be willing to advocate with insurance companies as needed to build their understanding about the supports and services offered in the home.

Agencies need to:

- Prepare and share guidelines/processes and any tools on how to assess risk factors; give families resources they can learn from.
- Listen to the person and what they want – take a team approach which will reduce the risk.
- Understand all the real liability issues and explain them to the family.

See Appendix C for:

- Sample Protection from Harm Agreement
- Sample Principles to Guide Support
- Sample Self Employed/Independent Contractor Agreement

D. SUSTAINING 'HOME'

1. Maintain ongoing administration of funding

Once funds have been integrated from existing sources, or new funds have been allocated, there are a number of ongoing activities that must be taken care of in order to maintain the funding and comply with reporting and accountability requirements. This is simply a 'non-negotiable' requirement for managing public funds. Most agencies have very specific processes that include having the invoices signed by the person being supported or guardian, sending in receipts for funds used, and completing timesheets and expenses. Agencies can also send each person a regular statement indicating how much has been paid out for the month and year, along with the budgeted amount and the remaining funding available.

Family members need to:

- Learn about the reporting and accountability requirements and be clear on their responsibilities (by documenting them in a service agreement with partners).

Agencies need to:

- Review and document the roles and responsibilities involved in administering the funding – identify what the person and family member is interested in doing and how much they want to be involved. Be prepared to share roles and responsibilities, and be clear and specific about agency requirements, rather than creating unnecessary 'red tape'. Try to make it simple for everyone.

See Appendix C for:

- Sample Cost Summary and Sample Invoice
- Sample Inclusions in a Service Agreement

2. Evaluate, monitor, review, and address quality assurance

The quality points and indicators which were determined by the person and their trusted others early on in the visioning and planning process become, at this step, the benchmarks for outcome evaluation.

In addition to monitoring 'quality points' at pre-determined check-points (e.g., every six months), the family, agencies, and support circle would be advised, to ask themselves on a regular basis:

- What is working well? What is not?
- Do we have good processes in place to address problems early?
- How will we resolve conflicts or deal with complaints?
- How well are we doing in ensuring a satisfying, sustainable, supported arrangement for the person in their home of choice?

"The Circle of support makes it harder for parents to exercise veto power – we have to remember that it is the person we have to focus on." (Parent)

Some important outcomes that the person, their family and the agency are aiming for are:

- That person goals and preferences regarding quality have been met/are present to the satisfaction of the person (and that this is measured based on identified indicators).
- That the relationship between the person, their supporters, the family, and the agency involved is flexible, based on open, honest and respectful communication, and supports the achievement of person preferences and goals. Areas of disagreement or concern are addressed and resolved through shared commitment to success.
- That the person is healthy, safe, and secure in their home of choice with a critical mass of caring people around them.
- That the roles and responsibilities of each person involved are clear.
- That support staff/workers are monitored and evaluated to ensure they do what they say they will do, are supporting the person according to the principles determined by the support circle, and that their relationship with the person is truly respectful and evolving.
- That the plan for support at 'home' is sustainable and that individualized funding is portable.
- That the financial systems and controls are in place for management of funds to support the individualized residential approach, and that the systems satisfy the reporting requirements of MCSS and agency policy. Ongoing accountability requirements for the funder need to be addressed – recognize that completing annual paperwork also helps to ensure ongoing goal setting and planning.

3. Plan for sustainability of the individual's home

One of the key pillars for an individualized residential approach is to ensure that their home can be sustained as long as possible. Clearly family members and the person's support circle place a high degree of importance on this.

People with a developmental disability and families are very concerned about what will happen after key family members are gone. Parents worry about how their family member's home will be sustained. They need peace of mind. This is a major issue that needs to be addressed within the developmental services sector, especially as more individualized arrangements are chosen and supported.

Some areas that need to be considered around sustainability are:

- Who is going to hold the vision into the future? Determine how to ensure that things will be in place in support of the person once the parents or key supporters are no longer alive.
- Where people with a developmental disability/families have a support circle, they may then want to consider formalizing this team to become an incorporated, legal, non-profit entity established to assist the person in maintaining his/her home even when other family members are no longer there. This more formal entity would meet less often than the support circle – likely when circumstances in the person's life change. Typically the individual, his parents, and friends, become the “directors” of such an entity (See Appendix A for Velo Microboards and Aroha web links).
- Make sure that everyone involved is comfortable and aligned with the sustainability plan and their particular roles and responsibilities, and that the person is fully aware of the plan.
- Families need to identify and consult with organizations (e.g. Planned Lifetime Advocacy Networks, Families for a Secure Future, Velo MicroBoard) with whom they can develop partnerships in order to be given the support and resources they need for building sustainability plans that support the individual's future – health, finances, routines of daily living, recruitment and hiring of staff, developing and managing a sustainable legal entity.
- Develop a crisis plan to address unplanned changes in the family (change of circumstances, accidental death, etc.).

The Person being supported needs to:

- Make sure they understand the sustainability plan, and if not, ask questions.
- Make sure to communicate changes in needs or preferences, or any new safety concerns.

Family members and support circle members need to:

- Become familiar with options for a sustainable entity to support their family member, including supported decision making options, power of attorney for property, power of attorney for personal care, and trust arrangements.
- Develop written agreements which define roles and responsibilities during times of change.

- Set up their own will, power of attorney for personal care, power of attorney for property, and trusts – that are aligned with the agreed upon sustainability plan for the person.
- Develop a relationship with a service provider so they have someone in place in the system – recognizing that trust builds over time.
- Share the individual's plans and philosophy with the agency and document same, so staff changes can support a consistent approach that works.
- Involve the agency in this process – and work with the agency to ensure this is continued when they are no longer able to be active, or following death.

Agencies need to:

- Ensure new staff, during their orientation, have time to learn about the person, their plan, and their values and preferences to ensure continuity of approach.
- Develop a strategy and create an environment to retain staff to ensure continuity.
- Prepare written agreements defining roles and responsibilities.
- Ensure funds are attached to the person and family (individualized, portable, evolving as needs change).
- Learn from other agencies and organizations (e.g. Legacy Supports, Brockville and District Association for Community Involvement, Lifetime Networks, Planned Lifetime Advocacy Networks) that have set up ways of committing to sustainability and succession.
- Ensure families are provided with written confirmation of individualized dollars and commitment over time.

Part III: Moving Forward Together

Many of the resources needed, and specific actions that people with a developmental disability, families, and agencies need to take, to develop and support specific individualized residential approaches have been included in the previous section. At the Forums, participants were also asked what family members, agencies, and funders need to *have* and need to *do* in order to move forward together towards a more individualized way of thinking and doing business when designing and delivering residential support. There were many thoughtful contributions from participants about making this shift, some of which are included below.

A. RESOURCES AND ACTIONS FOR PEOPLE SEEKING A HOME THAT IS RIGHT FOR THEM

What do they need to have?

- Their rights considered, choices respected, and voices heard.
- A community which does not exclude them.
- An opportunity to become informed and educated, and to have input into their own plans as well as into educating peers, families, and community.
- A 'home' of their choice and the opportunity to choose which agency supports them.

What do they need to do?

- Come together with one strong voice; approach agencies/funders together with their collective ideas to individualize residential supports; participate in policy forums and training.
- Challenge agencies when they are not putting the interest of the person first.
- Develop skills and comfort level in voicing their needs and preferences, as well as highlighting their capabilities.

B. RESOURCES AND ACTIONS FOR FAMILIES

“Families need easy, accessible information. They need models that they can see and feel comfortable about.” (Family member on web survey)

“The more success stories and innovative ideas I hear of, the more I can refine my own innovative ideas or these might trigger completely new ideas I had not thought of.”
(Family member on web survey)

What do families need to have?

Voice and Choice

- A voice to ensure their family member’s rights are considered and choices are respected.
- A channel and/or forum to ensure that they can communicate needs and preferences to responsive organizations and funders who will take them seriously and listen, even if what they want and need does not exist now.
- The choice to identify which agency they work with; options for accessing skilled planning and facilitation resources.
- Real choice around hiring, including equity in the funding they receive to hire dependable people (agency and non-agency staff) at same pay levels.
- Assurance that human resource supports (i.e., help with recruiting, hiring, paying, and managing staff) will continue after they are gone (“peace of mind”); someone to advocate for their family member into the future.

Connections

- Networks of other families and family/community groups, both along geographic and culturally specific lines/connections.
- Opportunities to meet with other families – workshops, training, brainstorming.

Resources

- Assistance with writing proposals, funding applications, administration of funding, hiring and managing support staff, case coordination, financial planning on sustaining ‘home’, estate planning. Information on intricacies of independent supporter contracts versus agency-hired supporters.
- Real examples of how models are evolving and what has been done – the costs of support, funding eligibility, owner and tenant rights, legalities regarding shared living arrangements, legal issues, strategies for sustainability (information about wills, savings, legal entities and trusts, power of attorney), tax exemptions and credits – to spark imagination and thinking, and to support realistic planning and sustainable solutions.
- A how-to manual accessed through a provincial website, including best practices for individualized residential approaches – guidelines/process for identifying risk, regulations (e.g., siblings cannot be paid caregivers), hiring own workers, estate planning, contract templates, job descriptions, etc.

- Assistance in preparing funding proposals and building creative funding strategies – including flexibility around what funds can be used (e.g., respite funding, sharing respite funding, and converting Special Services At Home (SSAH) funding)
- Resources for communication, community building, information and education, ‘seed’ money for development and facilitation of family networks (and assistance to access resources from other funders/sources).
- Access to affordable housing units and subsidies, separate from support funding.
- Information about by-law issues and condominium regulations which may impede the rights of people who need support and their need to share living spaces.
- Information about the role of the Ministry of Municipal Affairs and Housing, Ministry of Health and Long Term Care/Local Health Integration Network, municipalities, and private developers/investors in development of affordable and market housing.

What do families need to do?

Voice and Choice

- Be prepared to advocate for their own and others’ needs: do not expect that the system will provide a solution. Take an active role advocating for municipal bylaws which support citizenship, choice, and shared living (e.g. in-home suites, as-of-right condominium ownership, shared accommodations). Take an active role in pressing housing providers (municipality, other ministries, developers, and private landlords) to develop affordable housing options.
- Support and respect the choices and preferences of other people and families who may not choose individualized approaches.

Connections

- Join or develop a parent group or family network (could be an “online” group) in their community for information, support, and inspiration; share experiences with other families (document your journey for your family and others); mentor younger families.
- Build alliances and effective, open partnerships with responsive agencies. Help them to broaden their role to support people with a developmental disability and families in developing and sustaining individualized residential arrangements. Communicate, to local agencies, plans and proposals regarding the need for funding for individualized residential approaches, so that the demand can be accurately represented to funders.
- Learn to work together with agencies even when there is tension – use problem solving, conflict management, and mediation approaches to work through issues. Challenge agencies if they are not putting the interests of the person and family first.
- Work with agencies, unions, and communities to develop skilled support people. Plan to interact directly with union representatives and help the union understand your needs, the shift to individualized approaches to ‘home’, and the continued and expanding need for skilled support. Share information about job satisfaction

and conditions of staff who are supporting individualized residential arrangements.

Resources

- Look for alternative sources of funding (e.g. Ontario Trillium Foundation, United Way, Foundations) for person planning, communications, community development, and family networks.
- Look at the viability of combining funds to support people with a developmental disability or sharing support workers in order to create shared connections, capacity, positive conditions for supporters, and efficiencies.

C. RESOURCES AND ACTIONS FOR AGENCIES

What do agencies need to have?

Organizational Cultures and Structures

- Organizational cultures (including mission and clearly aligned practices), which are values driven and are committed to be responsive to the needs and preferences of people who have developmental disabilities.
- Structures and clear policy guidelines that will enable them to respond to the stated needs and preferences of those who are seeking individualized approaches to ‘finding home’, including:
 - Accountability structures and guidelines to ensure transparency;
 - Service agreements which identify roles, responsibilities and liabilities with regard to ‘home’ and ‘supports’ offered in home situations;
 - Clear risk management/liability guidelines to support maximum independence and control by people with a developmental disability and families;
 - Financial management policies and procedures in order to develop transparent budgeting processes and support transition to individualized budgets;
 - Problem and conflict resolution mechanisms and guidelines;
 - Portability guidelines and structures (so that person budgets can be separated out, and follow the individual); and,
 - Governance guidelines which support people with a developmental disability and families to have input into how the agency role evolves, how needs are met, how outcomes are evaluated, and how support quality is monitored.

Knowledge, Skills, and Competencies

- Knowledge about effective community development practices; good connections to community; better, or more effective, outreach to identify needs and assets.
- Accurate information about demographics, service clubs/associations, housing capacity and providers/developers; knowledge of who the marginalized groups are in each community; information about cultural diversity and makeup of developmentally disabled population (numbers, how many with family, how many do not have contact with family).
- A resource document for agency staff which includes good information on best practices around Ontario, but also beyond; information to keep abreast of current changes in the field regarding individualized residential approaches, promotion of community inclusion, community development.
- Knowledge of best practices in developing individualized approaches with transitional-aged youth, with ethno-racially diverse populations, and with people with a developmental disability who do not have active family involvement (in particular children coming out of the child welfare system) to ensure equity of access and choice for people who may be marginalized.

- Skilled, trained, and flexible staff who work from a person-directed approach and can address the support requirements in individualized residential situations.
- Knowledge of evaluation methods to demonstrate impact of individualized residential approaches and resources for evaluation.

Partnerships

- Strong partnerships (trusted relationships) with families at the person level, but also in building agency and community capacity to support individualized residential arrangements and community inclusion.

What do agencies need to do?

<p><i>“Take courageous steps to do things differently.” (Parent)</i></p>
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Organizational Cultures and Structures

- Clarify their core business and mission by asking: *What are we here to do? What will it take to respond to the needs of people with a developmental disability and families in this community, not just those currently receiving services, and to build community in order to support inclusion for people (and embrace the individualized residential support option)?*
- Clarify their core values by asking: *What values drive what we do? Are person choice and person-directed living, supporting people towards full inclusion, equipping people with a developmental disability and families to take the lead, and building community capacity top of mind?*
- Align board leadership and staff around mission and values which are consistent with the foundations of individualized residential approaches, and demonstrate that they are ‘living’ these values.
- Deconstruct and reconstruct at least part of their organization – for example, some organizations recommend the separation of support and housing development functions, and the separation of planning and support functions (with housing development and availability becoming a responsibility of the community, rather than just the developmental services sector).
- Recognize that not everyone has a family – may need to ‘redefine’ family, think about equity and access.

Knowledge, Skills, and Competencies

- Be willing to innovate with new areas of practice to build knowledge and evidence of creative approaches; share best practices and success with funders, publish in newsletters, journals.
- Take a retrospective look at what worked, didn’t work – lessons learned, evaluations, feedback from the person being supported and the family, including outcomes from each of the funded individualized residential approaches (as they have not all been implemented as intended).

Partnerships

- Be transparent, and communicate more with families, about challenges and pressures– creating a dialogue and a trusting relationship to work through barriers.
- Work with people with a developmental disability and families – engage, educate, ask what they want, even if they are not connected, and even if you do not have what they want.
- Be prepared to let people with a developmental disability and families take charge – not only about finding ‘home’ for the individual, but also around what the organization needs to do, what their values are, and their commitment to quality and accountability.
- Understand the most important elements of partnership are building trust through open communication, honesty, availability, not being in control of everything, commitment, and sharing leadership and resources. Be receptive to proposals; be open minded to new ideas of supports and prepare to be flexible (rather than saying ‘we do not offer that’ or ‘there is no funding for that’, or ‘we cannot’).
- Address labour relations issues by strengthening the relationships, and increasing communication with unions; share information including feedback from staff who are working in individually focused support roles (especially where the support staff have reported increased satisfaction, flexibility, autonomy, sense of purpose). Continue to review, address, and negotiate the collective agreement to increase flexibility around staff roles.
- Find new partners to help stimulate thinking, build connections at person and agency level, and develop housing options (e.g., bring in non-traditional collaborators – business people, developers, service club leaders, mental health providers, and/or the municipality).
- Share the real picture of the needs and demand for services with funders, e.g., sharing the specific requests and identified needs of people with a developmental disability and families in order to build the conditions at the system level to support individualized residential approaches. Send in proposals to Regional Offices and planning tables (where appropriate) which move the possibilities forward, are creative approaches to ‘home’, and include collaboration around housing development with other funders.

Delivery Offerings and Responses

- ‘JUST DO IT’ – start with one person and build the resources, tools, and supports needed as the process evolves.
- Focus on quality standards by using evidence-based and needs-based approaches.
- Engage people with a developmental disability and their families, including those in culturally-specific communities, those with younger children who are just coming through the school system, and first generation immigrants with developmentally disabled children by offering outreach, orientation sessions, training days, education, and forums. Provide information in multiple languages and broadcast information broadly and in different formats (via phone, websites,

flyers, etc). Use existing family groups and informal networks, schools, medical offices, and central access points to disseminate information.

- Offer essential services which support individualized residential approaches, including planning (lifelong planning options, support circle development, sustainability planning, and financial planning services), coordination of in-home supports (hiring, screening, managing, paying, contracting out, or actually delivering supports), accounting and administrative services (including assistance in completing applications for funding as needed), housing development, community development, and innovation support components.
- Provide tools and resources to support individualized residential approaches, including easy software for reporting and accounting, practices for transitioning to individualized residential approaches, and assistance with grant applications and proposals.

D. MESSAGES TO MINISTRY OF COMMUNITY AND SOCIAL SERVICES

In relation to capacity building

- Make funding available for training, mentoring, secondment approaches to build capacity in the sector and in the 'inclusion' community (e.g., second staff from organizations who are best practice leaders to inform/mentor other people and organizations).
- Fund community development, influence and partner with other ministries to build community capacity for inclusion, increase affordable housing options, and address poverty issues which are barriers to 'finding home'.

In relation to communication, information and resources

- Develop and circulate a consistent, clear definition of IRM which incorporates more than the family partnership and physical descriptions – include values-based planning processes as underpinnings.
- Fund the development of, and distribute, a comprehensive best practices document and framework for the individualized residential approach.
- Implement a broad communication strategy (multi-language and media) regarding the developmental services transformation, community inclusion, and individualized residential supports.
- Hold a conference for agency staff and boards – “how to” move to this approach and address the areas that hold them back (particularly the tension between transformation principles and accountability and risk management requirements); develop quality and accountability guidelines for agencies.

In relation to change leadership

- Provide values-based training to Ministry staff.
- Request and use accurate data for long range, needs-based planning – actual prevalence rates and projections, number of persons/families requesting individualized residential supports.
- Make individualized residential funding a clear and stated priority, fund it, and promote it.
- Allow the space for risk taking – Ministry needs to define an acceptable level of risk and promote innovation; fund creative projects and celebrate the innovation that results. Promote, incent and support agencies to evolve and provide choice and diversity in residential options.
- Take some bold moves: identify expectations and standards for a meaningful percentage of all new funding to be allocated to individualized residential approaches; require unbundling and move towards individualized budgets.
- Ensure financial strategy during transitions to support organizational change and shift to more individualized approaches.
- Ensure accountability for funds is based on outcomes for people, not just number of beds and dollars spent.
- Develop more flexible reporting requirements to facilitate moving funding resources to person budgets and integrating funding streams.

- Identify outcomes for people with a developmental disability and communities (benchmarks and performance standards, measurable indicators).
- Develop online application processes that are streamlined and easy to use.
- Encourage and fund research and evaluation related to individualized residential approaches.

In relation to policy and legislation issues

- Ensure policies, guidelines, legislation, and enabling regulations which support individualized residential approaches are entrenched.
- Build more options with regard to home ownership and other potential sustainable solutions (e.g., Mortgage subsidy, savings plans, ODSP regulations).
- Address the ODSP income support funding levels which are a barrier to renting apartments at market rates.
- To enable agency Boards to move ahead and develop specific policy guidelines re: risk and accountability, funding flexibility, individualized funding envelopes/budgets, portability of funding, funded third party planning, supported decision making.
- Provide education and information sharing for Executive Directors and Boards to back up policy guidelines with clear messaging related to risk, accountability, quality expectations.
- Change eligibility criteria for IRM away from focus on priority to allow families to access funding earlier on in their planning process.
- Lead the way with the other Ministries to integrate policy and leverage scarce resources through joint initiatives, in particular Ministry of Municipal Affairs and Housing on housing unit development and development of enabling municipal by-laws.
- Develop a recession strategy: press for infrastructure funding for affordable housing for marginalized, vulnerable people and development of 'social capacity infrastructure'.