

# *Transformation and Disability Supports*

## **The Role of Individualized Funding**

A summary  
presented to the  
**Ministry of Community and Social Services**  
by the  
**Individualized Funding Coalition for Ontario**

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Supports for citizens with disabilities can be characterized in two ways;

- *Disability supports* refer to those supports and services that help a person deal with their impairments or disabilities. Disability supports are generally very practical and assist the person with personal care, access to the community, and assistance with daily life participation. For many people with disabilities, these supports need to be individualized and available on a regular basis. Disability supports could include, but not be limited to, attendant services, personal assistance, homemakers, technical aids, therapeutic services, coordination and facilitation, etc.
- *Income supports* refer to those supports that provide funds for living, and include employment supports, pension income schemes, etc.

This review will focus primarily on disability supports.

## **Toward a New Paradigm of Disability and Community**

During the last twenty years, support systems for citizens with disabilities have been undergoing significant changes. The traditional community service delivery system that was established in the 1960's and 1970's is firmly established throughout Canada. At the same time, there have been many alternatives proposed and a large number of innovative projects that demonstrate the principles outlined in *In Unison*. There is a growing body of literature and research that points to principles, processes, and strategies for shifting the paradigm in community support systems.

Let us begin with a summary of some of the features of the traditional service delivery system and the emerging paradigm.

### **The Traditional Service Delivery System**

The *traditional service delivery system* for people with disabilities in Canada has many features that are typically seen across various types of disabilities;

- delivery of services is usually done through transfer payment agencies
- funds are available only to agencies and not directly to individuals
- many services are provided in congregate settings, rather than being individualized
- supports tend to be professionally driven, and citizens with disabilities play a minor role in planning and directing their supports
- the focus of many community services are rehabilitation oriented and institutional services play a major role in people's lives

- services are designed to “help” rather than being designed to build capacity of the person, their family and the community
- services are usually poorly co-ordinated, and duplication of services is common
- the focus of supports is generally on practical supports rather than on facilitation of social inclusion in community.

### **An Emerging Paradigm of Disability and Community**

An *emerging paradigm of disability and community* reflects significant changes in the traditional service delivery system. Paradigms of disability and community have emerged in theory and practice in the last twenty years. They can be seen in a patchwork approach to innovation across the country. Research is beginning to reflect the new paradigm, and show very positive outcomes for people with disabilities. The features of the emerging paradigm are consistent with the principles articulated in *In Unison* (Nelson, Lord, and Ochocka, 2001; Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999; Individualized Funding Coalition, 2000; Roeher, 1991). Some of the features of the emerging paradigm of disability and community are:

- people with disabilities have control and choice in the way their disability supports are provided
- there is a focus on individualized planning, support, and funding, that are designed to facilitate natural, informal support (family and friends) and to build citizenship opportunities
- there is a focus on positive social roles that involve personal relationships, participation in the community, and opportunities to contribute. These domains are seen as critical to reducing the vulnerability of people with disabilities and safeguarding quality of life.

- planning and support are emphasized to include both formal and informal support. Formal support is paid support, with the person and their network determining whom they will hire. Informal support includes family, friends and others in the network of the person.
- funding is often dedicated to the individual. The person and/or their designate have control over the funds and choose how the money is to be administered. Funding moves with the person; and people with disabilities live and work where they choose.
- planning for the individual tends to be unencumbered, and kept separate from service provision. Infrastructures, such as facilitators, are in place to assist individuals and their networks to plan and access their disability supports.

With the exception of *In Unison*, there are only a few national or provincial policies that currently support the emerging paradigm. On the other hand, researchers and policy analysts have proposed various policy frameworks that fit with the emerging paradigm. A recent study of community mental health outlines a paradigm that emphasizes empowerment and participation, community integration and support, and access to valued resources and social justice (Nelson, Lord, and Ochocka, 2001). The Roeher Institute has proposed a framework that focuses on self-determination, democracy, and equality (Roeher Institute, 1996). A recent national study identified factors, including relationships and individualized support that facilitate a “textured life” for people with developmental disabilities (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999; Pedlar, Hutchison, Arai, & Dunn, 2000).

**The Individualized Funding Coalition of Ontario recently sponsored a Round Table on Individualized Funding that produced a policy framework for an individualized system of disability supports.**

Across Canada, the patchwork approach to innovation has also produced several interesting and important evaluation reports that shed light on how to implement the emerging paradigm (Kendrick, 2001; Lord, 1998, 2000; Nelson, Lord, & Ochocka, 2001; Pedlar, et al., 1999; Roeher, 1997, 2000; Women's Research Centre, 1994). Many of these policy frameworks and innovative practices will be discussed further in the sections that follow.

## **Understanding the Context**

This section will set the context by identifying some societal factors that are having an impact on service delivery. These factors include;

- an aging society
- determinants of health research
- first generation of parents committed to inclusion
- growing dissatisfaction with agency driven support systems and consumer demand for change
- re-discovery of the power of community

## **Aging Society**

Canadian society has been aging during the last three decades and is expected to continue to do so over the next fifteen years. Statistics Canada (1998) data further confirms that disability increases with age. The disability rate is 5.2 percent in the 0-14 age group, 5.7 for those 15-34, 15.5 percent among those aged 35-64, and 45.5 percent of people over 65. Of people over 65, more than 75 percent have multiple disabilities.

These two factors, an aging society and the relationship of aging to disability, have enormous implications for community service systems. First, it is creating extensive demands for more appropriate services that address issues of aging. Service systems are responding slowly to the demand for more appropriate services. Research on aging and disability is growing, showing that more individualized and flexible approaches are needed.

Second, issues of our aging society are spawning creative approaches that help ensure the long-term security of individuals and families. One of the dilemmas that many families face is the “uncertainty” of what will happen to their adult children with disabilities when the parents die. PLAN (Plan Lifetime Advocacy Network) in British Columbia has developed a family based support system to assist families with these issues. Individuals are supported to develop their networks as the basis for long-term security, while families are supported to plan appropriately for their wills and estates. Al Etmanski has written the book *A Good Life* (2000) that outlines in detail the PLAN approach.

While the aging society will undoubtedly continue to stimulate innovations such as PLAN outside the service system, *the service system itself is being driven to be more flexible and individualized as more and more Canadians experience disability personally or within their families.*

### **Determinants of Health Research**

Definitions of health are changing and this has created a new context for understanding disability supports. For decades health was considered “absence from illness.” The Lalonde report in the 1960’s re-framed health to encompass lifestyle factors. By the mid-1980’s, it was clear that even a lifestyle approach to health was limited. The World Health organization has defined health as “the extent to which people have control over their lives” (World Health Organization, 1987). Determinates of health research has shown that health is a function of several factors, including income, social support, personal control, and participation (National Forum on Health, 1998).

The reality is that a large number of Canadian citizens with disabilities experience many of the indicators associated with poor health – powerlessness, unemployment, social isolation, and poverty. Determinates of health research creates a context to view disability in broader terms and to work toward changing conditions that can empower people to enhance their quality of life. *Ensuring that people have access to quality disability supports is increasingly seen as critical to addressing determinates of health* (Lord & Hutchison, 1998; Individualized Funding Coalition of Ontario, 2000). When people can access individualized and high quality disability supports, they have a base for participation and employment. Obviously, income and employment policies as well as housing



policies need to complement disability support policy, but one will not work without the others.

### **First Generation of Parents Committed to Inclusion**

The focus of parents that have children with disabilities has changed dramatically during the last three decades. Parents who had children growing up in the 1950's and 1960's advocated for segregated schools and group homes. This work helped establish what we now call the "traditional" service system. Parents who now have young children with a disability have a different focus. They have grown up in times of rights, broader acceptance of disability, and a widespread focus on inclusion and integration. This first generation of parents committed to inclusion is having an impact on the evolution of service systems.

*More and more parents are demanding home supports, control over disability supports, and genuine options for their sons and daughters when they reach adulthood.* In the 1993 evaluation of the Special Services at Home Program in Ontario, the most important feature of the program for families was "control" (Lord, McGeown, & Ochocka, 1993). The focus of families on having control over supports as well as inclusion in community life is pushing service systems to create more responsive disability supports.

**It is clear from the work completed by the Individualized Funding Coalition that many, many families in Ontario are ready for individualized funding. This is the result of many workshops that families have attended across the province as well as growing dissatisfaction with agency driven services, which is discussed below.**

## **Dissatisfaction with Agency Driven Support Systems and Consumer Demands For Change**

Most community service systems have been designed in order that community agencies receive block funding and then provide support to individuals or groups. Access rules are generally determined by the agency, and family and consumer participation is limited. People with disabilities and family members have become increasingly dissatisfied with these agency driven support systems (Felce, Lowe, Perry, Jones, Baxter, & Bowley, 1999; Fulcher, 1999; King, 2000; Marquis, & Jackson, 2000).

In the last two decades, there have been several outlets for people with disabilities to express their views and critique current practice. Several Canadian organizations have been instrumental in framing alternative approaches to providing disability supports. At the heart of these alternatives is the critique of professionalization and dissatisfaction with limited options. If the group home agency is the only option, is this really a choice? If the apartment complex with attendant care is the only option, is it really a choice? *Consumer demands are framed in many ways, but what they have in common is a strong desire for choice and control.*

Among the national groups that have articulated alternative approaches to providing disability supports, the work of the Canadian Association of Independent Living Centres illustrates the emerging paradigm (Hutchison, Pedlar, Dunn, Lord, & Arai, 2000). The Canadian Association has challenged the rehabilitation paradigm, which is seen as being professionally controlled, focused on deficits, and treating people as dependent clients (Canadian Association for Independent Living Centres, 1991; Schwartz, 1992). Independent living was introduced as an alternative to traditional services (De Jong, 1979). The

independent living paradigm emphasizes that the problem lies in the environment, in segregation, discrimination and in a dependency upon professionals (Carpenter, 1991; Crewe & Zola, 1984). In terms of disability supports, the main principles of the Canadian Association of Independent Living Centres include; consumers define their own needs, consumers direct the supports they require, and consumers have choices and knowledge that empower them to participate fully in community life (Hutchison & Pedlar, 1999; Hutchison, Pedlar, Lord, Dunn, McGeown, Taylor, & Vanditelli, 1997).

Other consumer and family advocacy groups, such as the Canadian Association for Community Living, the Canadian Mental Health Association, and the Council of Canadians with Disabilities, have emphasized similar elements. *Frameworks and alternatives emerging from consumer and family organizations are consistent with In Unison and create a positive context and demand for change.*

### **Re-Discovery of the Power of Community**

In the last two decades, the power of community has been re-discovered. From the 1950's through the 1970's, most efforts related to disability supports focused on improving formal service systems. The dissatisfaction with agency driven approaches described earlier was accompanied in the 1980's and 1990's by a growing interest in community. People with disabilities were more and more viewed as citizens with the same rights as others. Disability movements were beginning to stress the importance of inclusion and full participation.

The re-discovery of the power of community has had a significant impact on our view of disability supports. Person-centred planning and network building are just two of the ways community is emphasized in many new disability support

approaches. Person-centred planning involves gathering people around a person with a disability to assist the person in developing a plan for their life (O'Brien and Lyle O'Brien, 1998). Network building addresses the isolation that many people experience and intentionally invites people into the life of the person. Support circles, support clusters and other similar approaches are becoming widely utilized as concrete approaches for facilitating person-centred planning and network building (Lord and Hutchison, 1998).

*Community and citizenship become key elements in a service system designed to reflect In Unison.* In practice, this means disability supports must become more individualized and tailored to the needs and gifts of individual citizens. It means that informal supports are incorporated alongside formal, paid supports. Finally, it means that citizens with disabilities will have genuine self-determined personal support options that enable full participation in community life.

**The Individualized Funding Coalition believes that citizenship approaches by their very nature demand that supports be individualized. This means, as reflected in the *Round Table Report of the Coalition*, that infrastructure supports, such as independent planning and facilitation, must be available along with individualized funding, in every community of Ontario.**

## **Toward Individualized Supports and Funding**

Consumer demands and the limits of agency driven systems have led to increased focus on individualized support and funding. At the moment, there is a patchwork of individualized approaches throughout Canada. Research and evaluation reports point to very positive outcomes for services and systems that are individualized. One focus of particular interest is the notion that individualized approaches builds capacity of individuals, families, and communities. Emerging policy frameworks also raise questions about the best policy alternatives. In this section, we shall explore each of these ideas.

### **Some History of the Move to Individualize Support and Funding**

In early 1980's, there were parallel initiatives within various disability sectors that pointed to the need to make disability supports more personalized. The independent living movement, developed in the 1960's in Berkeley, California, spearheaded the idea of personal support services and attendant care. Throughout the western world, people with physical disabilities began to advocate for attendant services that were directed by the person requiring support.

During the same time period, the community living movement in Canada was a primary advocate for deinstitutionalization. During the deinstitutionalization of the Woodlands Institution in British Columbia, the Woodlands Parent Group got the government to agree that a brokerage system would make sense. Essentially, brokerage services are separate from other direct services, and enable the individual consumer to pick and choose from an array of

available services and community opportunities. This was possibly the first individualized funding approach in North America.

All the early movements for individualized support and funding based their belief for change on common new directions. One was that *housing and support should be de-linked, no longer dependent one upon the other*. This was a radical idea at the time, because it meant that disability supports could be accessed wherever you lived. By the mid-1980's, alternatives to congregate living were in full bloom. Supported independent living projects, individual apartments with support, and more flexible support worker schedules were emerging. In most cases, however, these early ideas related to individualized support were within the structure of community agencies, and did not relate to individualized funding. *People were beginning to experience options and they wanted more choice and control!*

As more and more individuals and families experienced individualized support, the desire for more control and choice became a rallying call for improved disability supports. In the mid-1980's, the province of Alberta developed the most comprehensive approach to individualized funding, and by 1990, it had become the official way for service delivery in that province. Financed and administered under the Social Services Act and the Persons with Developmental Disabilities Act, there are two separate programs, one for people with developmental disabilities, and the other for adults with physical disabilities. *Although there were significant delivery issues with Alberta's approach to individualized support and funding, the widespread use of these approaches created an important context for learning.*

During the same time period, the province of Ontario was developing the Special Services at Home Program (SSAH). Under SSAH, families with children

who have physical or developmental disabilities can receive individualized funds for respite, family support, community integration, or individualized supports. SSAH created an important history of learning around direct funding in Ontario. The 1993 SSAH evaluation showed that families appreciated having more control over the disability supports in their lives (Lord, McGeown, & Ochocka, 1993). Since 1995, Family Alliance Ontario has stressed that SSAH is a very effective program and has asked the Ontario government to fund “consumer-directed individualized funding” more widely. In recent years, other provinces have begun to implement individualized family support programs.

Also during the mid-1980’s, groups of citizens with physical disabilities were advocating for direct funding for attendant services. Up to that point, most attendant service projects in Canada were linked with housing, which meant that people had to live in a certain setting in order to access attendant services. The most successful group in Canada was the Ontario Attendant Care Action Coalition, which advocated for a direct funding pilot project. In addition to advocacy, a major review of support services (Lord, Hutchison, & Farlow, 1988) provided impetus for the province of Ontario to initiate the Direct Funding Project as part of their reform to long term care in 1993 (Roehrer, 1997). Since that time, several other provinces have started developing direct funding for attendant service projects.

### **Elements of a Personal Support System that is Individualized**

*All of the initiatives outlined above have created a context for learning about how to implement more individualized disability supports for people with disabilities.* By the mid-1990’s, there were numerous projects and pilot initiatives across North America and Europe and a growing movement committed to individualized approaches. As examples, the Ontario Association for Community

Living adopted a policy in favour of individualized funding by the early 1990's. The Canadian Council of Canadians with Disabilities has been a strong advocate of direct funding for attendant services. In the United States, the National Program on Self-Determination, funded by the Robert Wood Johnson Foundation, has sponsored self-determination and individualized funding projects in nineteen states (National Self-Determination Program Office, 2000), and in the year 2000, collaborated with other groups to sponsor an international conference attended by more than 1600 people in Seattle. And in 1996, Great Britain adopted a Direct Payments program that is linked to local authorities who provide infrastructure supports to individuals and families.

*The Individualized Funding Coalition for Ontario has developed a number of important ideas and resources related to individualized support and funding.* The Coalition's belief in the value of individualized funding sets the tone for these ideas.

The Individualized Funding Coalition supports the self-determination of persons with disabilities. We believe that all people should have control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives. In order to achieve this, we recognize that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated to his/her supports.

In the fall of 1998, the Coalition sponsored a two-day Symposium that provided a framework for change. In the Symposium Report, entitled *Individualized Funding: A New Vision*, the Coalition identifies five "building blocks" that are necessary for successful individualized outcomes:

- person-centered planning
- personal support relationships
- individualization of funds



- management supports
- community development (Individualized Funding Coalition, 1999).

These elements for creating an individualized system of disability supports are consistent with the findings of the national self-determination projects in the USA. The *Self-Determination Projects* are based on four guiding values and principles.

- freedom: the ability to plan a life with supports rather than purchase a program
- authority: the ability to control a certain sum of dollars to purchase supports
- support: through the use of resources, arranging formal and informal supports to live within the community
- responsibility: accepting a role within the community through competitive employment, organizational affiliations, and general caring for others within the community; and accountability for spending public dollars in life-enhancing ways.

Self-determination projects have found that increasing consumer choice must be accompanied by building community capacity to provide personal supports in non-traditional ways (New Hampshire Self-Determination Project (n.d.; Michigan Department of Community Health, 1999). At the same time, efforts must be made to shift the organizations that provide services.

*This three pronged approach (expand consumer control and choice, build community capacity, and shift traditional services) has proved to be a challenge, but essential as part of the process of the transformation in many jurisdictions.*

In the Canadian context, Torjman (2000) argues that individualized funding and consumer choice is a critical part of implementing *In Unison*, but that resources must also be directed at building the supply of personal disability supports.

**The Ontario Round Table on Individualized Funding (2000) places person-directed planning and network building at the heart of a reformed system. They envision individuals and families coming together with the assistance of a facilitator, expanding their network, and then developing a plan for personal supports. This plan would go to government or independent body that would provide individualized funding. People could then use their money to create supports or buy existing ones. Infrastructure supports for families and individuals would be available at all stages of the process, including a supply of workers and personal support services.**

*Direct individualized funding of disability supports is viewed by many as a mechanism for ensuring that the paradigm shift toward disability and community is grounded in genuine options and increased control for individuals and families.* In many ways, individualized support and direct funding is consistent with the world-wide trend toward increased democracy, self-determination, and community involvement. In the last decade, we have learned a great deal about the elements of a system that must be in place to provide individualized support and funding. In the next two sections, we look at research that points to the specific ways that these elements can best be organized and delivered.

## **Examples of Initiatives that Focus on Individualized Support and Funding**

In the last decade, numerous jurisdictions have initiated projects that have focused on individualizing personal supports and funding. The types of initiatives with selected examples are outlined in the following chart.

<b><u>Initiatives</u></b>	<b><u>Examples</u></b>
Provincial or state government initiative	<ul style="list-style-type: none"><li>• Alberta – two programs through two separate departments.</li><li>• Manitoba – In the Company of Friends, project designed to build networks and provide individualized funding for people returning from institutions.</li><li>• Ontario – family support program for children with developmental and physical disabilities (SSAH)</li><li>• Ontario – Direct Funding Project for adults with physical disabilities who can self-direct.</li><li>• Western Australia – Local Area Co-ordination and Direct Funding for all citizens with disabilities.</li><li>• British Columbia is implementing 17 planning centres throughout BC along with direct funding</li></ul>

Community-wide or province-wide non-government initiatives for families and networks.

- British Columbia - Micro-Boards for adults with developmental disabilities,
- Ontario - Windsor-Essex Brokerage for Personal Supports, part of system reform for the region.
- 19 states in the USA – Self-Determination Projects

Independent projects

- Ontario - Toronto Options Project (originally the Quality of Life Project) provides facilitation and individualized funding.
- Manitoba – Self-Managed Brokerage Project for attendant supports, through the Independent Living Centre.
- Some Foundations Projects (Sarnia, K-W, Hamilton, others)

Service organization re-design

- Ontario – Community Living St. Marys and Area creating two departments, one that focuses on person-centred planning, network building, and community development, the other on direct service.

- Several other organizations are currently working toward the same goal.

### **Summary of Research Evaluations on Programs and Projects that Provide Individualized Support and Funding**

A recently completed review examined ten programs that utilize individualized support and funding. Each of the programs had research evaluations completed on their process and outcomes. Lord (2000) and his colleagues identified several lessons from this research.

1. Language and practice related to individualized disability supports is inclusive and citizenship oriented.
2. Clear values and principles are a critical guide for programs and projects that are focused on individualized disability supports.
3. A policy framework for individualized disability supports provides coherence and equity.
4. There are pros and cons to attaching direct funding projects to service reform efforts.
5. Infrastructure supports for individuals and families are separate from the service delivery system, thereby providing opportunities for people to plan and have genuine choice.
6. The role of a facilitator/broker is a main feature of successful projects.
7. A direct funding mechanism is separate from infrastructures and there is a well understood approach to accountability.
8. “Learning as you go”: it is important to pay attention to process.
9. Many positive outcomes can be attributed to programs and projects that focus on facilitation, individualized support, and direct funding.

For a further analysis of these 9 attributes, see *More Choice and Control for People with Disabilities*, published by the Ontario Federation of Cerebral Palsy (2000)

**The Ontario Round Table on Individualized Funding (2000) reviewed existing projects and programs that deliver individualized disability supports. The Round Table indicates that there should be five major components to a policy framework.**

- principles to guide programs and individual processes, such as equity and portability
- infrastructure supports for individuals and families, including person-directed planning supports, network building supports, and administrative supports
- a mechanism for direct funding
- a well understood, simple approach to accountability
- a mechanism for individuals to transition to this approach from traditional supports and services

(Ontario Round Table Report on Individualized Funding, 2000)

In conclusion, *a policy framework is important for building sustaining approaches to individualized disability supports*. Few initiatives that were studied have coherence among policy, principles, and practice. Exceptions would include the Ontario Direct Funding Project and Western Australia Local Co-ordination, where principles are understood and experienced in policy, implementation directions, and practice. Many programs in Canada are not based on policy, but have emerged from pilot projects and local initiatives. Successful programs in Great Britain and Australia are based in policy and legislation, as is the Direct Funding Project in Ontario. ***The most successful policies and programs have a***

*blend of infrastructure supports for individuals/families, an individualized funding mechanism, and a well understood approach to accountability.*

## **Our Recommendations**

**Based on its previous work, the Individualized Funding Coalition for Ontario is making the following recommendations to the MCSS transformation process:**

- 1. Transformation should include the development of a new initiative that enhances choice and control for people with disabilities and their families, including more options for individualizing disability supports.**
- 2. The Round Table Report produced by the Coalition in the year 2000 should serve as the foundational guide for the development of this new initiative, with its principles and guidelines for direct funding and infrastructure development.**
- 3. Local infrastructures and direct funding must be part of this new initiative, including independent planning and facilitation.**
- 4. This new initiative should be embedded in legislation that ensures local, independent planners separate from service provision. An adjudication process for direct funding, including transparent appeal mechanisms.**





5. **To insure developmental success, this new initiative must be developed by MCSS in collaboration with experts in individualized approaches *and* with the Coalition, which has close relationships with several on-the-ground successful projects that are individualized.**
  
6. **To ensure developmental success, MCSS and its collaborators should consider phasing in such a new initiative over three years. There are several possible starting points for phase I implementation, including 1.) creating options for SSAH and Foundations graduates who have already experienced individualized supports, and 2.) creating individualized funding for families who are supporting individuals with complex needs (this latter area is especially critical since many families draw their support from at least two ministries – MCSS and Health – and individualized funding would allow for a seamless, co-ordinated approach to funding and support).**

- 7. Where to place the local infrastructure supports in communities will be a huge issue for the Ministry, but they will need to insure that any such supports are independent of service provision. Given the bureaucratic nature of the access centres, it is unlikely that infrastructure supports could be placed there either. Finding truly community based existing organizations, and twinning that with local steering committees and strong provincial leadership will help insure that independence is maintained.**
- 8. It is recommended that an expert panel of innovative service providers, researchers, self-advocates, and family members study systems that have created spending frameworks for individualized funding and make recommendations to MCSS.**
- 9. To fund a new Individualized Funding Initiative MCSS must be strategic in its analysis of funding mechanisms. Strategies include carrying out a savings audit on existing access centers and transfer payment agencies, re-framing the current residential services spending approach, and ways to provide cost effective incentives for innovation.**