

**VERMONT
DEVELOPMENTAL
DISABILITIES SERVICES**

“IMAGINE THE FUTURE”

TASK FORCE REPORT

November 2014

PREPARED FOR:

**SUSAN WEHRY, M.D., COMMISSIONER
VERMONT DEPARTMENT OF DISABILITIES, AGING AND
INDEPENDENT LIVING**

**CAMILLE GEORGE, DIRECTOR
DEVELOPMENTAL DISABILITIES SERVICES DIVISION**

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August 2014

**Report prepared by David Peebles for the
Developmental Disabilities Services Task Force
and presented to:**

**Susan Wehry, M.D., Commissioner
Vermont Department of Disabilities, Aging and
Independent Living**

**Camille George, Director
Developmental Disabilities Services Division**

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1. Introduction

The Developmental Services’ “Imagine the Future” Task Force (Task Force) was established by Susan Wehry, M.D., Commissioner of the Vermont Department of Disabilities, Aging, and Independent Living (DAIL), in August 2013.

The Task Force was charged to:

....create a long-range strategic vision for Developmental Disabilities Services in the State of Vermont. The Task Force is a working partnership among people who receive services, their family members, providers, advocacy organizations, Department staff and other stakeholders who want to insure Vermont’s Developmental Disabilities Services System is strongly rooted in our shared values and is the absolute best it can be.

It is important to note that Commissioner Wehry, in her invitation to Task Force members, noted the following:

We undertake this journey during this 20th anniversary year of the closing of the Brandon Training School. This is a year in which we have committed ourselves at DAIL to Remember the Past, Celebrate the Present and Imagine the Future. Vermonters are justifiably proud of our system of Developmental Disabilities Services, for which we are recognized as a national leader. We want to continue to lead the way and to be at the cutting edge as we continue our journey towards full and meaningful inclusion.

We also undertake this journey in parallel with the development of the State’s next System of Care Plan for Developmental Disabilities Services for State Fiscal Years 2015 – 2017, which guides the distribution of resources to support the needs of people with developmental disabilities, their families and communities. We envision the two processes will inform each other.

The work of the Task Force follows on the heels of the legislatively mandated summer work group which focused on current fiscal challenges and on creating a sustainable system. The summer work group came up with a number of interesting ideas for the Task Force to consider as it shapes the future of developmental disabilities services.

A very significant influence in the consideration of developing a future vision for Developmental Disabilities Services was the charge to “determine the next best steps for bridging the present challenges (emphasis added) with that future vision.” Much of the focus of Task Force activities was driven by current fiscal, policy and legislative events. The day-to-day operational realities and concerns of consumers, families, advocates and providers were very real and influenced the process of thinking about the future in a manner that kept present needs very much in hand. Additionally, significant changes at Developmental Disabilities Services over the past several years contributed to the concern of many Task Force members about the present and made conversations about the future more complicated. The “present challenges” were addressed in detail by the Task Force and built a more solid foundation for working on issues such as Eligibility and Health Reform which were identified as “keys” to strategic considerations for the future.

2. Task Force Composition

The following individuals were appointed and serve as Task Force members:

Bill Ashe, Executive Director, Upper Valley Services

Anne Bakeman, Advocate member of the DDS State Program Standing Committee

Max Barrows, Green Mountain Self-Advocates; Advocate member of the DDS State Program Standing Committee

Linda Berger, Lamoille South Supervisory Union; Advocate member of the DDS State Program Standing Committee; member DAIL Advisory Board

Nancy Breiden, Director, Disability Law Project, Vermont Legal Aid

Gail Falk, Advocate; Former Director of the Office of the Public Guardian, DAIL

Susan Hardin, Family Representative on the DDS Equity Committee

Nicole LeBlanc, Green Mountain Self-Advocates; Recipient member DDS State Program Standing Committee

Deborah Lisi-Baker, Assistant Director, Center for Disability and Community Inclusion, University of Vermont

Lisa Maynes, Parent, Director Family Support Health, Vermont Family Network

Ed Paquin, Executive Director, Disability Rights Vermont

Cheryl Phaneuf, member of the Vermont Developmental Disabilities Council

Jackie Rogers, Director, Office of Public Guardian, DAIL

Camille George, Director, Developmental Disabilities Division, DAIL

Sr. Janice Ryan, Advocate; Former Deputy Commissioner of Corrections

Susan Ryan, Executive Director, Center for Disability and Community Inclusion

Karen Schwartz, Executive Director, Vermont Developmental Disabilities Council

James Smith, Budget and Policy Manager, Division of Vocational Rehabilitation, DAIL
Jennifer Stratton, DDS Director, Lamoille County Mental Health
Tracy Thresher, Advocate
Karen Topper, Executive Director, Green Mountain Self-Advocates
Marlys Waller, Vermont Council of Developmental and Mental Health Services
Theresa Wood, Co-Chair and Professional member of the DDS State Program Standing Committee
Marie Zura, DDS Director, HowardCenter
Sue Buckley, Research Professional and Private Guardian *

David Peebles, Chair, DDS “Imagine the Future” Task Force

**Member withdrew partway through term of the Task Force*

The diversity of consumers, family members, advocates, professionals and Developmental Disabilities Services staff contributed to a Task Force with a richness of experience and a keen understanding of the history of Developmental Disabilities Services in Vermont. In addition to members, the Task Force had a regular and contributing group of public members who added positively to the discussions. Additional DAIL staff were also regular attendees and invaluable resources to the Task Force.

3. Contextual Resources Available to the Task Force

In addition to the many subsequent sources of data and experiences brought forward by staff and Task Force members, at the onset of the Task Force the following materials were made available and suggested as vital to the work.

- *Developmental Disabilities Act of 1996* and associated regulations
- Vermont State System of Care Plans
- *Developmental Disabilities Services SFY 2013 Annual Report*
- 2013 Legislative Work Group Report and associated cost saving ideas
- FY14 and proposed FY15 budgets
- National Core Indicators data
- Equity and Public Safety data
- Student disability data
- *Shared Living in Vermont: Individualized Home Supports for People with Developmental Disabilities* (2010)
- *Considering the Options: Paying Parents with Medicaid* (2010 memo)

4. DAIL Mission Statement, Core Values, and Principles

DAIL Mission Statement

The mission of the Department of Disabilities, Aging and Independent Living is to make Vermont the best state in which to grow old or to live with a disability ~ with dignity, respect and independence.

DAIL Core Values

- **Person-centered:** We help people to make choices and to direct their own lives – pursuing their own choices, goals, aspirations and preferences.
- **Natural Supports:** We recognize the importance of family and friends in people’s lives. We respect the unique needs, strengths and cultural values of each person and each family.
- **Community Participation:** We support consumers’ involvement in their communities, and recognize the importance of their contributions to their communities.
- **Effectiveness:** We pursue positive outcomes through effective practices, including evidence-based practices. We seek to develop and maintain a trained and competent workforce, and to use staff knowledge, skills and abilities effectively.
- **Efficiency:** We use public resources efficiently – avoiding unnecessary activities, costs, and negative impact on our environment.
- **Creativity:** We encourage progress through innovation, new ideas, and new solutions. We accept that creativity involves risk, and we learn from mistakes.
- **Communication:** We communicate effectively. We listen actively to the people we serve and to our partners. We are responsive.
- **Respect:** We promote respect, honesty, collaboration and integrity in all our relations. We empower consumers, staff and partners to achieve outcomes and goals. We provide opportunities for people to grow, both personally and professionally.
- **Leadership:** We strive to reach our vision and to demonstrate our values in all our work. We collaborate with consumers and other partners to achieve outcomes, goals and priorities. We are accountable.

Principles of Developmental Disabilities Services

Services provided to people with developmental disabilities and their families must foster and adhere to the following principles¹:

Children's Services. Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. The quality of life of children with developmental disabilities, their families and communities is enhanced by caring for children within their own homes. Children with disabilities benefit by growing up in their own families; families benefit by staying together; and communities benefit from the diversity that is provided when people with varying abilities are included.

Adult Services. Adults, regardless of the severity of their disability, can make decisions for themselves, can live in typical homes and can contribute as citizens to the communities where they live.

Full Information. In order to make good decisions, people with developmental disabilities and their families need complete information about the availability, choices and costs of services, how the decision making process works, and how to participate in that process.

Individualized Support. People have differing abilities, needs, and goals. To be effective and efficient, services must be individualized to the capacities, needs and values of each individual.

Family Support. Effective family support services are designed and provided with respect and responsiveness to the unique needs, strengths and cultural values of each family, and the family's expertise regarding its own needs.

Meaningful Choices. People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values and needs, and assure that each recipient is directly involved in decisions that affect that person's life.

¹ Developmental Disabilities Act of 1996, 18 V.S.A. § 8724.

Community Participation. When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.

Employment. The goal of job support is to obtain and maintain paid employment in regular employment settings.

Accessibility. Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services, thereby forfeiting natural community support systems.

Health and Safety. The health and safety of people with developmental disabilities is of paramount concern.

Trained Staff. In order to assure that the goals of this chapter are attained, all individuals who provide services to people with developmental disabilities and their families must receive training as required by Section 8731 of the Developmental Disability Act.

Fiscal Integrity. The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.

5. Brief Summary of Task Force Meetings

The Task Force met a total of ten times between September 2013 and June 2014. Two mid-winter meetings were cancelled due to poor weather conditions. In addition to the meetings of the full Task Force, there were numerous individual and work group meetings that supported the Task Force. Minutes of all Task Force meetings are available at DAIL’s administrative offices. Below is a summary of key activities during each of the full Task Force meetings.

First Meeting – September 23, 2013

- Commissioner Wehry welcomed Task Force members and delivered the charge for the DDS *Imagine the Future* Task Force (Task Force).
- Review of the 2013 Summer Legislative Policy Work Group report and recommendations.
- Review of key data influencing fiscal and programmatic issues in Developmental Disabilities Services.
- Discussion of the need for macro level thinking to create a better foundation for considering the future.
- Discussion of outside factors which need to be considered (e.g., emergence of Accountable Care organizations and new federal Department of Labor ruling regarding companionship services).
- Consideration of some basic Results-Based Accountability questions, for example: Who are we here for? How well do we do what we do and is anybody better off? How will we know the answers to these questions?

Second Meeting – October 21, 2013

- Review of State budget issues and discussion about the work of the Task Force and the relationship to the SFY15 – 17 DDS State System of Care Plan.
- Review of the framework for using a Results Based Accountability process as a planning approach towards a future vision.
- Task Force concentrated on the question, “Who are our customers?” Discussion clearly portrayed the complex history of customers and the key role of “eligibility” as we look to the future. (Eligibility became the subject of a concentrated review and key findings of the Task Force at a later meeting.)

- Discussed a variety of DDS issues including the longer life expectancy of people with a DD, an increased population of people diagnosed with Autism Spectrum Disorders, differences in the state and federal definitions of developmental disability, age of consumers served, public safety concerns, new Americans and their unique circumstances, issues with the lack of “seamlessness” in the current system, and huge shifts in the community since the closing of the Brandon Training School.

Third Meeting – November 5, 2013

- Discussion of issues related to extending current DDS State System of Care Plan.
- Decided to not focus on the upcoming System of Care Plan, but rather to examine the future needs of Developmental Disabilities Services.
- Discussed budgeting issues.
- Additional discussion of how to develop certain recommendations of the Legislative Work Group.
- Process based discussions on the need for comparative analysis and concern about the ability to complete the task at hand in light of reduced state resources – “the amount of funding dictates what the system looks like, not who the people are and what they need.”

Fourth Meeting – November 25, 2013

- Discussion of State budget and operational updates.
- Presentation on the National Core Indicators and Vermont’s history with this data source as well as the varied metrics used by different jurisdictions which make accurate comparisons difficult.
- Discussion of the question, “How will we know and be able to measure if consumers of Developmental Disabilities Service are better off?”
- Detailed conversations regarding the elements of “better-offness” and the indicators available which are, or could be, used to measure impact.
- Discussion of population shifts, technology, medical advances, and consequences for developmentally disabled populations and how these factors all influence the future vision for DDS in Vermont.

Fifth Meeting – December 16, 2013

- Focus of the meeting was answering the question, “What do we want Vermont to be like for someone with an intellectual or developmental disability in 2034?”
- Several key themes emerged from this discussion, including:
 - Needing flexibility regarding funding.
 - Increasing education and supports so more families can self-manage.
 - Making use of emerging technologies.
 - Increasing housing options.
 - Building more livable communities.
 - Focusing on relationships and natural supports.
 - Rethinking models of service and having the person-centered planning in place.
 - Improving training for support staff; rethinking employment options and decreasing disincentives to employment; increasing quality assurance.
 - Taking a detailed look at future demographic projections to better understand the population base and having a clearer understanding of health and payment reforms to better anticipate the consequences of coming changes.
 - Recognizing the “disconnect” between Developmental Disabilities Services and the Agency of Education and creating a future where there is a seamless system for persons with significant disabilities.
- After the official Task Force meeting ended, there was an open meeting to follow up on some of the recommendations for cost-saving and innovative ways of providing services that came out of 2013 Summer Legislative Policy Work Group. Three work groups were established to examine three of the ideas in close detail and to develop recommendations on: Employment, Housing, and Technology. It was agreed that after the work groups completed their work, they would present their findings and recommendations to the Task Force.

Sixth Meeting – January 27, 2014

- Review of previous meetings and the need to focus on key issues.
- After significant discussion of the potential consequences of these key areas, the decision was made to dedicate the next three meetings to Health Reform and Eligibility for DDS.

- Sub-committees were established to take responsibility for researching the issues and recommending strategies for the future.

Seventh Meeting – March 31, 2014

- Significant work was completed by the sub-committee on the subject of Health and Payment Reform and its potential impact on consumers and developmental disabilities services providers and operations.
- The focus of discussion at the Task Force meeting was on Accountable Care Organizations (ACOs) and their current focus on acute care as well as the many unknowns for disabilities and long term services and supports (DLTSS).
- The Task Force also discussed what Principles and Guidelines should be considered for implementing Health Care and Payment Reform on DDS.
- A draft letter on the topic of Health Reform was reviewed and amended. The Task Force acknowledged that the goals of health care reform today – to improve care, access and affordability – are consistent with the principles set forth in Vermont’s Developmental Disabilities Act, but expressed concern that disabilities and long term services and supports were not being adequately addressed and stressed the importance of not only involving, but listening to, consumers and professionals involved with disabilities and long-term services and supports. It was agreed that the letter would be sent to Commissioner Wehry with copies to key Health Reform leaders emphasizing the concerns and recommendations of the Task Force. Task Force members who are also members of the DDS State Program Standing Committee agreed to share the letter with this committee. A copy of the Task Force’s letter can be found in the appendices of this report.

Eighth Meeting – April 28, 2014

- The focus of the meeting was on Eligibility – “Who do we serve?”
- There were two primary areas of consideration:
 - First: detailed discussion of “Should Developmental Disabilities Services be for adults only?”
 - Positives and negatives of the question led to a very detailed look at several issues as the Integrated Family Service (IFS) initiative of the Agency of Human Services (AHS), the relationship with the Agency of Education, the historic pattern

- of Developmental Disabilities Services becoming more of an adult-focused operation, and the unique expertise of Developmental Disabilities Services which is not always present in partner organizations.
- The Task Force did not reach a clear consensus, but the majority of members recommend that Developmental Disabilities Services continue to serve both children and adults.
 - Second: detailed discussion of “How will we define Developmental Disabilities Services for the next twenty years?”
 - The sub-committee presented three well-researched options:
 - 1) Use Intellectual Disability only;
 - 2) Stay the same as current policy (Intellectual Disability and Autism Spectrum Disorder); and
 - 3) Adopt the federal definition of Developmental Disability.
 - Positives and negatives of these options led to a detailed and complex discussion. A majority of Task Force members recommended that Vermont not adopt the federal definition of developmental disability. A second consideration was to review the impact of shifting to an Intellectual Disability definition for eligibility. The consequences of any change to eligibility were discussed. It was clearly noted that any consideration of changing eligibility criteria would require more in-depth analysis and a comprehensive public process.

Ninth Meeting – May 22, 2014

- Reports from the Work Groups looking at Employment, Housing and Technology were presented.
- Employee Contracted Work Supports Group presented their recommendation to develop employer responsibility for providing work supports to consumers by employers/co-workers or site teams.
 - The goal is to have the whole organization support the employee.
 - Three pilots have been recommended and were generally endorsed by the Task Force with qualifications.
 - It was also noted that this model can and should be viewed as an employer support and training model and that this should be reflected in the proposal prior to submission to the Commissioner for her consideration.
- Supported Living and Technology Work Groups provided a joint

presentation since many of the same issues are inherent in both areas. The overall recommendation of these Work Groups was to create an Independent Living Task Force which would have four primary areas of concentration:

- Create more options and opportunities for rental assistance.
- Increase affordable, accessible, and appropriate rental units and alternate housing.
- Build a culture of high expectations and greater independence.
- Enhance the use of technology to support independence and social "connectiveness."

During the Task Force discussion, it was noted that many of the ideas and options that were discussed could be done today and did not necessarily require further work from a task force.

- The majority of the Task Force members were in favor of creating an Independent Living Task Force and recommended that Commissioner Wehry consider this recommendation.

Tenth Meeting – June 23, 2014

- The Report of the Developmental Disabilities Act Subcommittee was discussed in detail. This committee was charged with considering what changes, if any, should be made to the 1996 Vermont Developmental Disabilities Act (DD Act).
- There was consensus that the DD Act is very sound legislation and provides an excellent framework for the future. Concern by the Work Group and the Task Force was evident in conversations relative to the as-of-yet unknown impacts to Developmental Disabilities Services from the Accountable Care Organizations (ACO) and the Integrated Family Services (IFS) Initiative of the Agency of Human Services. There was no recommendation made to “open” the DD Act for amendment.
- Individual recommendations by Task Force members were reviewed by the full Task Force and a number were selected for inclusion in the final report.

6. Key Findings and Recommendations

Review of any and all available data indicates that Vermont has worked hard in developing and delivering Developmental Disabilities Services. Vermont's reputation as a national leader is well-deserved. The following observations and recommendations are in the spirit of the continuing efforts to make Vermont be the best place to live for an individual with a developmental disability.

1. Self-management and family-management are appropriate options for more individuals and families. The Department is encouraged to allocate sufficient resources and quality assurance to allow for an increase in the number of successfully self-managing and family-managing services.
2. The number of people diagnosed with Autism Spectrum Disorders (ASD) has markedly increased in recent years. Current diagnostic data indicate a continued upward pressure for Developmental Disabilities Services which will create increased demand for resources. It is important for the Department to stay informed about both the population trends and best practices for working with people with ASD, and to factor any anticipated upward pressures into DDS caseload projections.
3. Certain individuals with developmental disabilities who have committed a criminal act or demonstrated serious sexual or violent behaviors are managed by Developmental Disabilities Services rather than, or in collaboration with, the judicial or correctional systems. Two hundred and thirty (230) current consumers of Developmental Disabilities Services have been identified as posing a risk to public and often present unique and very expensive challenges to the Developmental Disabilities Services agencies. Over the years there have been reports and analyses of this issue; and the Department is encouraged to review and update them, if necessary, when considering the policy implications for services to this group.
4. Quality review, assurance, and improvement are key elements of Developmental Disabilities Services. At many points the Task Force considered the role of quality assurance and recommends that all future operational and organizational developments be accompanied by a complete and fully resourced quality assurance and improvement component. Attachment H of the Developmental Disabilities Services State Fiscal Year 2013 Annual Report fully describes the *Sources of Quality Assurance and*

Protection for Citizens with Developmental Disabilities and the Task Force noted these commitments but also the need to insure the full operational deployment of quality assurance in all future activities and relationships, especially in regard to those changes in health care, payment reform, and the Integrated Family Services Initiative of the Agency of Human Services.

5. Vermont’s refuge population especially in Chittenden County has increased in recent years. In FY13 alone, 24 refugees received new DDS funding. Attention should be given to the anticipated number of future refugees as well as their cultural differences which can make service delivery more complicated.
6. The population served by Developmental Disabilities Services is growing each year. In FY13, services were provided to over 4,000 individuals. Increases in longevity and need for life-long support, in many cases, indicate a future with significant new demands. Vermont has historically experienced an average population increase of 100 individuals receiving developmental disabilities home and community-based services per year, which is significant financially when the cost per individual is considered (over \$50,000/person on average for Home and Community-Based Services in FY13). Consideration of a variety of services that prevent people with developmental disabilities from needing state-funded services may yield less costly and less intensive services over the long run.
7. The Legislative intent is clear that Developmental Disabilities Services will be delivered to a defined population of individuals rather than all individuals who meet clinical eligibility. It is estimated that 25% – 30% of Vermont’s population of people with developmentally disabilities that are eligible for services actually receive services because of Vermont’s practice of focusing funding on those with the most urgent needs. The Task Force considered the “All or Nothing” status of funding on numerous occasions. This refers to the fact that for many people, if an individual does not meet one of the existing funding priorities for DDS, there are very few resources available to the individual. In addition, some funding priorities contain their own set of limitations or restrictions. The Task Force concluded that future planning to see if selected needs of the currently non-served population could be addressed in an effort to stem future demands. For example, if there was better capacity to provide support to family members sooner, it may be possible to avoid a crisis in the long-term.

8. The financial pressures inherent in serving a growing population that generally needs a full range of long-term services and supports are considerable. The Task Force reviewed population trends and financial histories of delivered services and did not find avenues of apparent savings or demand reduction beyond further limiting the funding priorities or changing eligibility criteria; and any changes to either the funding priorities or eligibility will have a potential impact on individuals with developmental disabilities and their families and would require thorough analysis.
9. While there was historical concern about some loss of flexibility in the shift to the Global Commitment to Health 1115 Medicaid Waiver, the fact that 100% of all community-based services are now matched with federal funds has been a significant milestone. In fact, even prior to the implementation of the Global Commitment Waiver, the State was able to match 97% of community-based services with federal funds to support Developmental Disabilities Services through its 1915(c) waiver. Looking forward, the Task Force has great concerns about many unknowns related to the evolution of Accountable Care Organizations and exactly how these organizations, which are generally focused on acute care systems, will impact the long-term care environments such as Developmental Disabilities Services. Accountable Care Organizations information and data reviewed by the Task Force was insufficient for meaningful analysis or to allay concerns.
10. On April 16, 2014, the Task Force issued an open letter to Commissioner Susan Wehry, M.D. that raised questions about the role of the Department and how developmental disabilities services system will be expected to function within the framework of health care reform. Without clarity relative to how the developmental disabilities services system will operate in the emerging world of health care and payment reform, there exists concern about the potential return to a “medical model” of service delivery which Vermont proudly took a generation to re-invent with national recognition for the many improvements to long-term services and supports in the community (see Appendix A).

The Task Force included an attachment to the April 16, 2014 open letter to Commissioner Wehry; “Excerpt from the National Council on Disability’s Policy Brief on Designing and Operating Medicaid-Managed Care Systems Servicing Children and Adults with Chronic Disabilities.” The twenty two principles included in this policy brief are specific to “managed care” but are

also appropriate to Vermont’s health care reform efforts. The Task Force requested an opportunity to discuss these issues with Vermont’s Health Reform “Core Team” but did not receive an invitation to do so. Commissioner Wehry, however, did respond to the Task Force (see Appendix A). It is recommended that DAIL management continue to hold the unique needs of the developmental disabilities population they serve as examples of components that must be included in all reform initiatives.

11. As the Task Force considered the question, “How will we know and be able to measure if our consumers are better off?”, it reviewed the information available in the National Core Indicators as well as the results of the most recent Consumer Survey Project report (available on the Developmental Disabilities Services Division website). Clearly, Vermont is a national leader in the provision of quality Developmental Disabilities Services both from the perspective of the consumer/family and from available national comparable data. Areas for emphasis in the future are the expansion of community inclusion/activities; a focus on the development of meaningful relationships for consumers; and more effort to develop employment opportunities and supports.
12. Several key areas for future development emerged in reviewing the landscape of what the Task Force envisioned Vermont to be like in twenty years for consumers and families. Technology and all it promises – in areas such as housing, communication, transportation, enhancing available information and self-determination, employment and independence – is an area that the Task Force recommends that DAIL management pursue with full diligence. It is recommended that an Independent Living Task Force be created and charged with pursuing the conceptual work done by the technology and housing sub-committees of the Task Force.
13. The Task Force reviewed the principles of person-centered planning including informed decision-making; availability of a stable, well-trained workforce and contractor network including peer-run services; flexibility in services and funding; and the need to have the interests and needs of individuals guide service coordination and delivery. Developmental Disabilities Services has a thirty year history of evolving a person-centered focus and the Task Force recommends that this commitment be reaffirmed and enhanced. The role and importance of self-advocacy was also identified as key to the future of Developmental Disabilities Services.

14. A major focus of the Task Force was on the subject of “eligibility.” Two areas of discussion were ages of people eligible for services and how to define “developmental disability” for the purposes of determining clinical eligibility for DDS in Vermont for the next twenty years. The many elements of these two areas were detailed in a matrix that sorted the choices by positive and negative consequences. In summary, the majority of Task Force members felt Developmental Disabilities Services should continue to serve both children and adults. The Task Force was in agreement that prior to making any proposed changes to eligibility criteria they must be the subject of thorough analysis and full public input.
15. The Task Force considered the work of the Employer Contracted Work Supports Group which was tasked with improving quality of work supports and service options for service recipients through new and innovative strategies. A pilot proposal (3/26/2014) was reviewed (see Appendix B) and the Task Force recommended, with conditions, that the pilot be considered by Developmental Disabilities Services Division management. Some members of the Task Force further noted that certain aspects of the proposed pilot may be able to do with existing resources and may not require special “pilot” funding.
16. The Task Force also considered the work of the Housing and Technologies Work Groups, which eventually merged into one group (see Appendix C). Given the importance of housing and housing supports and the strong links to technology, the majority of the Task Force members recommended the creation of an Independent Living Task Force to address issues raised by the work group as well as to explore opportunities potentially available to consumers and their families. Task Force members emphasized that if such a group is formed, it should focus on taking action as opposed to doing any further research.
17. A final question before the Task Force was, “Should the 1996 Developmental Disabilities Act (DD Act) be changed?” A sub-committee issued a report (see Appendix D) to the Task Force which essentially found the DD Act to be very sound legislation which could well serve the future as it has well served the past and present. However, concern was clearly noted that current unknowns in health and payment reform, the development of the Integrated Family Services (IFS) for children and families effort by the Agency of Human Services, and the need for more clarity relative to self-advocacy and

self-determination may present a need at some point for additional legislation. There was no recommendation to amend legislation at this time.

7. Additional Recommendations Made by Individual Task Force Members

Individual Task Force members were given the opportunity to have the entire Task Force consider any other recommendations/observations they suggested. The Task Force reviewed the input and selected the following for inclusion in this report. While they are not formal recommendations from the Task Force, the following recommendations received general support from the membership. Those that did not receive a majority of positive support are not included in the list below.

- Individuals will have a full voice in quality services, living in homes they prefer, while being employed and fully included in their community. Individuals will live confident that adequate funding for necessary supports will continue into the future to meet their needs.
- Increase the participation of individuals with ID/DD in employment such that Vermont has a greater number of individuals with ID/DD in competitive integrated employment working at or above minimum wage for at least 20 hours a week.
- Independence: The individual’s personal and economic independence will be promoted.
- Living Well: The individual’s services and supports will promote health and well-being.
- Real support for peer mentoring and hiring peers to provide Developmental Disabilities Services at all levels. Establish an ongoing committee including a majority of leaders in the self-advocacy movement to develop a strategic plan. Bring allies with access to resources to the team.
- Effective use of technology is and will continue to be an equalizing factor in the lives of people with developmental disabilities. Establish a long-term committee to identify technology that eliminates and minimizes barriers to full access. Committee members should embrace technology and not be afraid of it. There is a global precedent for this approach. In many parts of

the world there is a commitment to one child, one lap top. If six year olds in Rwanda and other countries with limited resources can get a lap top, we are confident that Vermont can figure this out.

- The System gets in the way of true inclusion. The "institutionalized" words make people seem different. Typical Vermonters do not say, "I am going into the community" when headed out to see a friend. Assistance needs to be more natural and invisible. We need to capture 50 examples of ideal services. These stories are to be told by people receiving services.
- People receiving Developmental Disabilities Services are very poor. They need jobs. They need opportunities beyond washing dishes and cleaning bathrooms.
- Learn from other states. Work with the Vermont State Housing Authority to access subsidies (i.e., Section 8) for two people with disabilities to live together.
- Regardless of diagnosis, individuals with developmental and intellectual disabilities who need disability-related accommodations and support to be able to succeed in community living, employment and education are able to access needed funding and individualized services, though funding levels for each person served will vary depending on level of functional and financial need.
- Inclusion and success is planned for and supported within the system and in our work with the broader community. Program data and qualitative surveys (across disability experience, ages and region of service) indicate a high percentage of individuals eligible for services from the DDS system have the options and supports they need for health and well-being; are active in community life; and successfully engaged in education, competitive employment activities and social activities that further their personal goals.
- All agency staff and contractors will attend pre-service and ongoing periodic "values" training to learn and reinforce such concepts as presumption of competence and self-determination. Classes will be led by self-advocates and allies steeped in the principles underlying the concepts. Self-advocates and allies will be encouraged to attend. Classes will be interactive and infused with humor and practice in collaboration and creative problem solving. Food will be provided if desired. Outcomes may

include: (1) Individuals' right to make their own decisions about their lives (who they would like to live with, where they would like to work, etc.) will be recognized, respected and encouraged by support personnel; (2) Trainees will have a clearer idea of their role and be more likely to enjoy and stay with their work.

- IQ testing will be abolished as an eligibility screening tool for DD Services, on the grounds that (1) "the association between intelligence...and the condition recognized as (intellectual disability) is an artifact of a nineteenth century world view buttressed by early twentieth century scientific and cultural bias"*, (2) the testing results are not instructive in any meaningful way (i.e. they tell us little about the individual's performance in activities of real life), and (3) the testing process does not take into account the individual's sensory, movement, or other physical or psychological issues they may be experiencing. Eligibility should be determined solely through assessment of performance of "daily living" skills, including observation and anecdotal descriptions.

(*from Donnellan and Leary, *Movement Differences and Diversity in Autism/Mental Retardation* (1995), DRI Press, p. viii.)

8. Acknowledgements

Appointed members of DAIL's Developmental Disabilities Services *Imagine the Future* Task Force represent a diverse and passionate group of experiences and talents. Their collective experiences are an outstanding asset to the developmental disabilities world. Task Force members generously gave both their time and knowledge to the varied discussions. We thank them for their contribution. In addition, a number of public members regularly attended and engaged in the discussions as well as the outside research and associated work. These public participants most notably include Nicole LeBlanc, Susan Yuan, Betty Milizia, and Kirstin Murphy.

Finally, the staff of the Department of Disabilities, Aging and Independent Living provided the necessary research, data, and context to enable factual discussion. June Bascom, Clare McFadden, Bard Hill, Jennie Masterson, James Smith and others are sincerely recognized and appreciated for their contributions. A very special acknowledgement goes to Tina Royer who provided not only administrative support for this effort but kept the parade moving despite the weather.

Appendix A

April 16, 2014

Open Letter to:

Susan Wehry, MD, Commissioner
Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

Dear Commissioner Wehry,

Vermont is an exciting place to live; it's a place where all people are valued and where government endeavors to provide the best and most affordable health care and supportive services for all Vermonters, including those with intellectual and developmental disabilities. It is with this backdrop and sense of common understanding that we write to you about the worries Vermonters with disabilities and their families are facing.

You have asked this group to “imagine the future” for people with developmental disabilities in the State of Vermont – to envision what life could be like in the next 10 – 20 years. Our conversations over the last several months have invariably led us to the topic of health care reform and the changing landscape of Medicaid services. While the need to reform Vermont's health care system is evident, the implications of those reforms do not impact all Vermonters equally. In fact, it is our belief that Vermont's citizens with developmental disabilities have the potential to be impacted to a greater degree than the general population – primarily because these citizens rely on a tightly coordinated array of medical and social services to live each day as members of our communities.

The Department of Disabilities, Aging and Independent Living plays an important role in the development, financing and oversight of Medicaid services for people with developmental disabilities. The changes enacted and proposed in the management of health care/social support services leave us with significant questions about the role of DAAIL beyond the next two-three years. As we look at the ACO expectations for the future, it also leaves us wondering how the developmental services system is expected to function within this framework. Who will have responsibility for insuring that services meet the intent of the DD Act? How will existing statutes be modified to reflect changing roles and responsibilities and the inclusion of ACO's? If

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ACO's are intended to have responsibility for monitoring outcomes, how does that affect the role of DAIL? For providers who are expected to sign agreements with ACO's as well as grant agreements with DAIL, how does this additional layer of administration improve outcomes and lower costs?

Services for Vermonters with developmental disabilities moved away from a fee-for-service model more than two decades ago. Leadership at the time recognized that the fee-for-service payment methodology did not promote the goals of individualized, integrated community living at a predictable cost. Instead, payment reform that included individualized per member per month payments for all necessary social/supportive/specialized services was enacted. These services include, but are not limited to services coordination, residential services, supported employment, psychotherapy, psychiatric services, medication management, transportation, physical therapy, communication services, etc.

At the same time, expectations for DD service providers to manage the full array of medical, specialized and supportive community services for those individuals they serve were implemented. And although their payment does not include medical services, through effective case management/care coordination, the expectation to manage health care services is an expectation and contractual requirement. During this overall systemic change, consensus was reached that decisions are best made closest to the individuals affected most directly by those decisions. Likewise, for long term care services, agreement was reached with the Centers for Medicare and Medicaid Services, that a Qualified Developmental Disabilities Professional is the most qualified individual to lead the team involved with planning and implementing services for people with developmental disabilities, not a physician. Therefore, the requirement for a physician signature on the plan of care was eliminated. Also, as is well known, demand for services exceeds the resources available. Currently, DAIL has federal and legislative authorization to manage those demands through the State System of Care Plan process. Again we ask, if ACO's are involved in the payment and accountability for services, what process will be used to effectively prioritize limited resources? How will the ACO's add value for people who receive services?

The anxiety felt by many in the changing health care landscape is that long term care services – services that many will need for an entire lifetime – are not being adequately considered in terms of what impact structures like the ACO's will have on service recipients, their families and the providers that assist them every day to live meaningful lives in Vermont's communities. There is a long history of public education about understanding that individuals with disabilities are people first – who happen to live each day with a disability. Breaking the chains of medically-managed services took a generation to achieve and everything we read or hear about whether it's a medical record, an advisory board, staff at an ACO, expectations of "who's in charge", etc. all have a medical background. While this is appropriate for acute medical services – it is not at all

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appropriate for long term care community services. You may have noticed, we have not once used the word “patient” to refer to an individual, and we never will.

We fully recognize that health care reform initiatives include various work groups and committees, some that are charged with addressing implementation issues that surround the disability community. However, the individuals from the long term care world who have been involved in various work groups and meetings report often feeling deflated and not listened to as they try to engage those responsible for planning and implementing health care reform in the considerations and impact of changes for people with lifelong disabilities.

The National Council on Disability, an independent federal agency committed to disability policy leadership, issued a policy brief on the impact of health care reform efforts on people with disabilities. It can be viewed in its entirety at the following site: <http://www.ncd.gov/publications/2013/20130315/>. We have included the recommendations from this policy brief in Attachment A. Though we know that Vermont’s health care reform efforts are not considered a “managed care system” per se, we believe that the principles stated in the NCD’s policy brief are still valid to Vermont’s efforts.

In the disability world there is a phrase that has real meaning – “Nothing About Us, Without Us”. Vermonters with developmental disabilities have been involved in the promotion of outcomes that are important to the success of the developmental services system. We ask that more concerted effort be made to include people with developmental disabilities and their families in the health care reform discussions taking place. The developmental disability service system is sometimes tagged as being reluctant to change. This correspondence is not at all aimed at “digging in our heels”; instead it is about opening up real dialogue about how we can be meaningful participants in envisioning the future of health care reform for people with developmental disabilities, and how to maintain and improve the flexibility, effectiveness and availability of supports and services, including long term care services *and* health care services.

The goals of health care reform today – to improve care, access, and affordability – are consistent with the reforms enacted by the DD service system. Research has proven that people who are well supported in their communities are generally healthier. Healthier people = lower health care spending. We believe we have important expertise to bring to the health care reform table. The DD service system has a proven track record of providing effective supportive services and coordinating health care.

We would like the opportunity to fully discuss these issues with the Core Team and also suggest that it would be beneficial for the Core Team to hear from Nancy Thaler, Executive Director of the National Association of State Directors of Developmental Disability Services, a nationally-recognized leader in disability policy – including impacts of health care reform on individuals with developmental disabilities and their families.

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We look forward to furthering this dialogue and insuring that the health care and social services needs of Vermont's citizens with intellectual and developmental disabilities and their families are met.

Respectfully,

Imagine the Future Committee Members

Bill Ashe, Upper Valley Services
Anne Bakeman, State Program Standing Committee
Max Barrows, Green Mountain Self-Advocates
Linda Berger, Lamoille South Supervisory Union
Nancy Breiden, Disability Law Project, Vermont Legal Aid
Gail Falk, Advocate, Former Director of Public Guardianship
Susan Hardin, Developmental Services Equity Committee
Nicole LeBlanc, Green Mountain Self-Advocates
Deborah Lisi-Baker, Center for Disability and Community Inclusion
Lisa Maynes, Parent, Vermont Family Network
Ed Paquin, Disability Rights Vermont
Cheryl Phaneuf, Vermont Developmental Disabilities Council
Jackie Rogers, Office of Public Guardian
Sr. Janice Ryan, Advocate, Former Deputy Commissioner of Corrections
Susan Ryan, Center for Disability and Community Inclusion
Karen Schwartz, Vermont Developmental Disabilities Council
James Smith, Division of Vocational Rehabilitation
Jennifer Stratton, Lamoille County Community Connections
Tracy Thresher, Advocate
Karen Topper, Green Mountain Self-Advocates
Marlys Waller, Vermont Council of Developmental and Mental Health Services
Theresa Wood, State Program Standing Committee
Marie Zura, Howard Community Services

Copies to:

Anya Rader Wallack, Chair, Vermont Health Care Innovation Project
Al Gobeille, Chair, Green Mountain Care Board
Paul Bengston, CEO, Northeastern Vermont Regional Hospital
Steve Voight, King Arthur Flour
Doug Racine, Secretary, Agency of Human Services
Mark Larson, Commissioner, Department of Vermont Health Access
Robin Lunge, Director, Health Care Reform
Virginia Lyons, Chair, Health Care Oversight Committee
House Human Services Committee
House Health Care Committee
Senate Health and Welfare Committee

ATTACHMENT A

Excerpt from National Council on Disability’s Policy Brief. Although specific to “managed care”, the principles are also relevant to Vermont’s health care reform initiatives.

Recognizing the many unique challenges involved, NCD recommends that the following guiding principles be rigorously applied in designing and operating Medicaid managed care systems serving children and adults with chronic disabilities:

- 1. The central organizing goal of system reform must be to help people with disabilities to live full, healthy, participatory lives in the community.*
- 2. Managed care systems must be designed to support and implement person-centered practices, consumer choice, and self-direction.*
- 3. Working-age enrollees with disabilities must receive the supports necessary to secure and retain competitive employment.*
- 4. Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.*
- 5. States must ensure that key disability stakeholders are fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of Medicaid managed care services.*
- 6. Managed care delivery systems must be capable of addressing the diverse needs of all plan enrollees on an individualized basis.*
- 7. States should complete a readiness assessment before determining the subgroups of people with disabilities to be enrolled in a managed care plan.*
- 8. The provider network of each managed care organization should be sufficiently robust and diverse to meet the health care, behavioral health, and where applicable, long-term support needs of all enrollees with disabilities.*
- 9. States planning to enroll Medicaid recipients in managed long-term services and supports plans should be required by the Centers for Medicare and Medicaid Services (CMS) to cover both institutional and home and community-based services and supports under their respective plans.*
- 10. The existing reservoir of disability-specific expertise, both within and outside of state government, should be fully engaged in designing service delivery and financing strategies and in performing key roles within the restructured system.*
- 11. Responsibility for day-to-day oversight of the managed care delivery system should be assigned to highly qualified state and Federal Government personnel, with the authority to proactively administer the plan in the public interest.*
- 12. States should design, develop, and maintain state-of-the-art management information systems with the capabilities essential to operating an effective managed care delivery system.*
- 13. States electing to compensate managed care contractors through a capitated payment system should adopt a fair, equitable, and transparent methodology for calculating and adjusting payment rates. Rates should be sufficient to allow a managed care contractor to (a) afford beneficiaries a choice among qualified providers and (b) address all of the service and support needs among plan enrollees with disabilities.*

14. *The Federal Government and the states should actively promote innovation in long-term services and supports for people with disabilities.*
15. *CMS should rigorously enforce the Affordable Care Act “maintenance of effort” provisions in granting health and long-term service reform waivers and mandate that any savings achieved through reduced reliance on institutional care be reinvested in home and community-based service expansions and improvements.*
16. *Primary and specialty health services must be effectively coordinated with any long-term services and supports that an individual might require.*
17. *Participants in managed care plans must have access to the durable medical equipment and assistive technology they need to function independently and live in the least restrictive setting.*
18. *The state must have in place a comprehensive quality management system that not only ensures the health and safety of vulnerable beneficiaries, but also measures the effectiveness of services in assisting individuals to achieve personal goals.*
19. *All health care services and supports must be furnished in Americans with Disability Act (ADA)-compliant physical facilities and programs.*
20. *Enrollees should be permitted to retain existing physicians, other health practitioners, personal care workers, and support agencies that are willing to adhere to plan rules and payment schedules.*
21. *Enrollees with disabilities should be fully informed of their rights and obligations under the plan, as well as the steps necessary to access needed services in accordance with the requirements of the Social Security Act.*
22. *Grievance and appeal procedures should be established that take into account physical, intellectual, behavioral, and sensory barriers to safeguarding individual rights.*

Appendix B

**Vermont Developmental Disabilities Services Proposed Pilot:
Employer-Contracted Work Supports**

A supported employment (SE) support tool

Drafted by Jennie Masterson 3/26/14

Background: During the summer 2013 a Legislative Work Group, formed to explore ways that DDS could improve quality and service options for service recipients through new and innovative strategies. The idea of reimbursing businesses that employ people with ID/DD to be the primary job support came from these sessions. Under the chair of David Peebles, the *DDS, Imagine the Future* work group continues to work on innovative processes, one of which is to explore if this model will increase natural work supports and decrease agency-staffed hours. James Smith and Jennie Masterson of DAIL created a work group tasked with designing a pilot to test the model. The work group included Green Mountain Self Advocates, Supported Employment Program Managers, and agency Directors. Four employers experienced with supported employment services were consulted. In addition, we interviewed the State of Oklahoma to learn about their *Contracts with Industry*, which supports 23 people statewide in jobs supported by co-workers.

Service History: The DDS SE programs currently provide job site support to more than 1088 supported employees. The SE systems change initiative begun 34 years ago continues to endure today with employment services provided by all DDSD providers.

This is credited to

- Employer education
- Systematic training
- Retention strategies
- Positive relationships
- Customized job shaping

These essential methodologies will continue to be the primary job placement framework for individuals with ID/DD, but if successful, the Pilot is expected to broaden support options.

Intent

The Pilot is not to be construed or offered as a wage subsidy. Supported employees must be employed at competitive wage and be on payroll as an employee of the business. The option is a specialized tool to enhance natural supports, not an expectation to be used with all supported employees.

The goal is to explore how SE staff might mentor businesses to assume the support their ‘supported’ employees beyond the natural supports already in place, and to assess the impact on employer, employee, and the DDS SE system. The pilot tests the notion that work supports provided by the work site team or by a co-worker will lead to authentic inclusion and increased investment in the employee by their work team. The goal is to support the whole organization to support the employee. The Pilot will explore:

- The social and/or cultural benefits for employer and employee
- The procedures needed for SE program mentoring and oversight
- Methods for fiscal reimbursement
- The level of SE personnel time spent training and monitoring
- Changes in employee sense of inclusion and/or competence
- Changes in co-workers and work environment
- Effect agency staffing
- Effect funded services and/or the cost of SE personnel

Design:

- This is a proposed pilot to explore an *employer-provided support* model based on a contract with an employer to provide their employee with support that extends beyond the customary supervision and training typically provided in the business. Payment to defray support costs provided by their team or co-workers is made to the business.
- A contract may be offered at the time of hire, or offered for individuals in existing jobs.
- The pilot permits DA/SSA contracts with business for job coaching and other work site supports that enable the employee to succeed at work.
- This strategy is an option for supported employees and should not be used to replace individualized supports if doing so is not in the best interest of the employee.
- Via a contract, the employer designates the co-worker(s) best suited to assist the supported employee. It may be one person, or several co-workers supporting different need areas, or an entire unit sharing in the supports.
- Employers are reimbursed for providing direct assistance *beyond what is typical* guidance or assistance in a particular work culture.
- Throughout the length of the contract, per DDS funding requirement, and with the employer's knowledge, the SE program performs oversight, just as they do with all other placements.
- The process for DAIL to fund the pilot will be determined and will utilize non-waiver funding. A system for suspending but retaining the individual's waiver for possible post Pilot use is an outcome of this Pilot.

Employee selection:

- The employee is assisted by the SE staff to discuss with the employer the most suitable co-worker(s) match
- The employee, their support team, and legal guardian must approve the worksite as appropriate for the pilot, prior to the development of a contract with an employer.
- The Pilot will assure a hold-harmless guarantee. If employer supports are not successful, DDS will honor the job placement and provide the typical SE funded supports via SE services. Contracts will include an opt-out for the employee.

Business selection:

- Employer contract offers are based on their genuine interest to collaborate on behalf of their employee's long-term success.
- Businesses are culled from trusting business relationships already in place between programs and employers.
- Employers will need to provide *process* feedback.
- Employer reimbursement is short term—not to exceed one year—and will focus on the highest level of employee self-reliance while creating sustainable environmental supports that will endure beyond the contract.

Role of SE Program:

- The SE program designee mentors the employer. This model does not imply that SE programs are completely delegating the entire support to the employer.
- The SE Program provides training in a) DDS SE curriculum, b) DDS guiding principles, c) person specific training, and d) training methodology.
- The SE program provides quality assurance with on-going oversight and close follow-along of the employer and employee.
- SE Program public relations will promote the idea that employees often need some level of additional work supports so the pilot reallocates existing resources to employers who want to collaborate for a more natural and inclusive process. By paying the employer's support costs, employers interested in cultivating a supportive environment for their employee will be able to expand their natural supports while continuing to receive mentoring help from the SE program.
- Contract development includes discussion about the short-term nature of the model and absorbing the level of support needed at the contract's end.
- The SE program designee develops the terms of the direct support contract through dialogue with the employer and employee. It is difficult to project what long term supports are needed, therefore contract lengths may need to be flexible.
- Higher reimbursement may occur at the contract start with expectation that the employer and work team will develop creative and sustainable job supports over time. Contracts may be paid at an hourly rate or on a fixed monthly amount to cover the cost of co-workers assisting the employee.
- Contracts should not to exceed one year and cover less time when achieving the learning curve or developing work site support strategies is projected to take less time. At the contracts halfway mark, a ramp down plan for the business to absorb support for the long term is developed in order for the employer to feel confident in continuing to provide the support strategies for the long term.
- The specific types of support needed are documented in the contract.
- The SE Program will receive training from the Pilot Advisory Group in the difference between employer-provided ADA Accommodations and the intent of the employer contract.

When appropriate?

- To allow employees to work atypical schedules at times when agency coaching is not available
- To 'place' high school graduates without long term funded supports.
- To honor an employee's desire to be less reliant on agency-staffed supports.
- When co-workers seem amenable to learning how to support the employee.
- When an employee has minimal support needs.

Pilot Implementation:

- Sample across employees with diverse support needs
- Sample 1 urban, 1 rural, 1 small town
- Sample 4 people at 3 DA/SSAs = 12 employee sample at 12 different work sites
- Sample from large employer and small employer
- Chose employers where managers and teams are consistent and have good communication systems
- Chose employees who can participate in the pilot feedback
- Understand that Some DA/SSA's do not have the SE program resources to implement and oversee the pilot

Evaluation:

- Pilot Advisory group will manage the Pilot and produce final recommendations/report.
- GMSA will perform a qualitative survey with sample employees and families
- The Advisory group will develop a process evaluation by CDCI or another entity doing external interviews or other evaluation processes. This can be as simple as process interviews with all the stakeholders.
- A data collection tool will be provided to pilot sites and include a tool to capture the cost of contracts, SE program oversight costs, and other fiscal analysis.
- The use of individual Medicaid Waiver budgets as the long term funding mechanism is a priority goal of the Pilot.

Funding Pilot:

DDSD non-waiver funds will be utilized to test the pilot

Housing and Technology Work Group Report

Imagine the Future

Opportunities to Enhance Independence, Relationships and Community Inclusion for Vermonters with Intellectual and Developmental Disabilities through Supported Living and Technology

Background

Two work groups charged with addressing ideas from the summer task force:

- ❖ **3.1, Housing:** Expand supervised apartment living, including arrangements where same age-peers share space.
- ❖ **3.2, Technology:** Support the use of technologies that enhance independence.

Met separately to review opportunities and challenges. Then met together to develop a **draft set of recommendations** for the *Imagine the Future* Group.

Opportunities: *The Future is Here*

- Increasing pressure to develop new models for adult living coming from individuals and families who have experienced full inclusion throughout their education.
- A world of new technologies and design standards
 - Smart homes, portable “tiny houses,” tele monitoring
- Federal policy initiatives
 - The Frank Melville Supportive Housing Investment Act of 2010
 - New CMS Guidelines

Vermont: *Old Fashioned Challenges*

- Second oldest housing stock in the country.
- Sec.8 vouchers are limited, especially since sequestration.
- High rents and limited stock of affordable units.
- Limited access to public transportation.
- High speed telecommunications capacity is not statewide.
- Self-advocates report that some experience isolation & loneliness with independent apartment living situations where one person lives by themselves.

Desired Outcomes

- ❖ Vermonters with I/DD have more choices in terms of where they live, who they live with, and how they are supported, including technology-based supports.
- ❖ Vermonters with I/DD enjoy a higher quality of life, reporting greater social connectedness and reduced loneliness.

Overview of Recommendations

1. Create more Options & Opportunities for Rental Assistance

Already in the Works

Vermont application for HUD 811 Grant, a collaboration between the Vermont Housing Finance & AHS.

If received, grant will initially subsidize existing units.

- ❖ Explore creative use of housing vouchers for sharing subsidized apartments by two housemates
 - ❖ Explore options around HUD's "one apartment one voucher" rule so that two housemates with

- I/DD could share an apartment.
- ❖ Seek advice from other states using the Housing Choice Voucher program to allow two bedroom unit vouchers for two unrelated people with disabilities
- ❖ Explore other avenues to increase funding for and availability of housing.

2. Increase Affordable, Accessible, & Appropriate Rental Units/Alternate Housing

Already in the Works

Vermont application for HUD 811 Grant, a collaboration between the Vermont Housing Finance Authority and AHS.

Grant funds can be used to create new units.

- ❖ Consider assistance to bring available housing up to DAIL's safety and accessibility standards.
- ❖ Explore how self advocates, housing professionals, service providers, etc. can collaborate to increase access to affordable and accessible housing.

3. Build a Culture of High Expectations and Greater Independence

- ❖ Create a dialog with stakeholders (self-advocates, family members, providers) about self-determination, independence, and the dignity of risk in regard to expanding interdependent/independent living.
- ❖ Educate and encourage school transition teams to plan for independent living.
- ❖ Support peer mentoring to foster social connectedness and build confidence as individuals seek greater independence.
- ❖ Work with technology consultants from other states/countries with a proven track record of increasing the use of technology.

4. Enhance the Use of Technology to Support Independence & Social Connectedness

- ❖ Make it a priority to explore how to increase access to the use of phones, internet, and social media for individuals with I/DD.
- ❖ Create an online *Technology Resource Guide*.
- ❖ Develop the capacity to train and support users, including addressing privacy, safety concerns and social isolation as well as troubleshooting when problems arise.
- ❖ Explore use of You Tube or other online media to demonstrate and teach practical skills of interest to Vermonters with I/DD
- ❖ Develop opportunities for individuals & families to have a hand-on experience with an array of technologies – for example, a technology fair.

Thanks to All who Contributed

Anne Bakeman, June Bascom, Sima Breiterman, Cathie Buscaglia, Amber Fulcher, Lorraine Gaboriault, Bard Hill, Kathy Hamilton, Nicole LeBlanc, Kirsten Murphy, David Peebles, Dustin Redlein, Karen Topper, & Marlys Waller

Apologies if list is not complete.

**Report of the Developmental Disabilities Act Subcommittee
Imagine the Future Task Force
June 19, 2014**

Developmental Disabilities Act Subcommittee Members: June Bascom, Nancy Breiden, Gail Falk, Nicole LeBlanc, Kirsten Murphy, Ed Paquin, David Peebles, Jackie Rogers, Karen Schwartz, Karen Topper, Marlys Waller, Susan Yuan.

The Subcommittee (“Committee”) met two times to consider what changes, if any, might be made to Vermont’s Developmental Disabilities Act, 18 V.S.A. §8721, et seq. (DD Act or “the Act”) as we “imagine the future.” At the first meeting on May 14th we identified areas of concern as we look to the future of developmental services in Vermont, and discussed how those concerns might be addressed through amendments to the Act. Following the meeting a first and second draft of proposed statutory changes were circulated for comment. At a second meeting on June 12th, we came to consensus on areas of concern and draft statutory language to address those areas of concern. The discussion was lively.

At the outset it should be noted that on the whole we felt that Vermont’s DD Act is sound legislation. Much of our discussion focused on how the Act might be amended to ensure that the strong principles embedded in it are preserved in the changing landscape brought about by the advent of Accountable Care Organizations (ACOs) and Integrated Family Services (IFS). As more is unknown than known at this point about how services and supports for Vermonters with intellectual and developmental disabilities and their families may be impacted by ACOs and IFS, many of our recommendations are general in terms. Where we do propose specific statutory amendment language, it is for the purpose of suggesting how identified areas of concern *might* be addressed: we are making no recommendation regarding whether the DD Act should be opened for amendment at this time. All suggested statutory changes merit further discussion and consideration before being acted upon, as does the question of whether to chance the risks inherent anytime a statute is “opened up” for amendment.

The areas of concern identified by the committee are: 1) ensuring the principles of the DD Act are maintained in the world of Accountable Care Organizations and Integrated Family Services; 2) recognition of the right to self-determination; 3) gaps related to identifying unserved persons and training of crisis placement providers; 4) other specific concerns.

Ensure principles of the DD Act are maintained in the world of Accountable Care Organizations and Integrated Family Services

The primary concern identified by the committee is the recognition that as Vermont moves forward with Accountable Care Organizations and Integrated Family Services, other agencies and entities, such as the Department of Health, the Department for Children and Families, and ACOs, are becoming more involved in the lives of Vermonters with intellectual and developmental disabilities and their families. We felt it was imperative to ensure that the strong principles embedded in the DD Act be maintained no matter what entity is funding or overseeing the services. We were particularly concerned with the following language from the contracts entered between the Medicaid and Medicare ACOs, the state, and provider agencies:

“Any AHS employee and/or contractor who provides care coordination services to Medicaid eligible persons shall, to the best of his/her ability, and so long as it is consistent with AHS programs or procedures and with Medicaid’s legal obligations, *cooperate with the Clinical Model or Care Model developed by the ACO.*” (Emphasis added)

To address this concern, the committee recommends consideration of amending the DD Act as follows:

- At §8723 Department of disabilities, aging and independent living; duties

Add new subsection (b):

(b) The Department shall have primary authority and responsibility for establishing standards of quality and for monitoring such standards for any services funded by Medicaid through the Department or any other organization selected by the Agency of Human Services to provide long term supports and services to individuals with developmental disabilities and their families. This authority takes precedence over any provision in a contract between the state and a non-state entity such as an Accountable Care Organization, or among non-state entities such as a provider and an organization such as an Accountable Care Organization.

- At §8724 Principles of service

Amend introductory clause as follows:

Services provided to people with developmental disabilities and their families **by any entity funded through the State of Vermont** shall foster and adhere to the following principles:

Add new subsection (13) as follows:

(13) Residential services. Unless reflecting the choice of the individual receiving services or as required by issues of safety, residential services shall not be provided in settings that have the effect of isolating individuals receiving services from the broader community.

Recognition of the right to self-determination

The committee discussed how at the time the DD Act was written following the closing of the Brandon Training School, much of the focus of the Act was on supporting families. Twenty years later, while supporting families remains important, we have reaped the rewards of the self-determination movement and Vermont may want to consider amending its DD Act to reflect and incorporate the principles of self-determination. To that end, we recommend consideration of amending the DD Act as follows:

- At §8723 Department of disabilities, aging and independent living; duties

Amend subsection (6) as follows:

(6) facilitate or provide pre-service or in-service training and technical assistance to service providers consistent with the system of care plan and **in collaboration with the self advocacy community.**

- At §8724 Principles of service

Add new subsection (1):

(1) Self-Determination. Adults with developmental disabilities will have authority over how, where, and with whom their lives will be lived; the resources needed for their support; and responsibility for their own decisions and actions.

Amend subsection (5) as follows:

(5) **Support for Families** Family-support. Effective family **support services for families** shall be designed and provided with respect and responsiveness to the unique needs, strengths, and cultural values of each family; ~~and~~ the family's expertise regarding its own needs; **and the chronological age and need for independence of the person with a developmental disability.**

Gaps related to identifying unserved persons and training of crisis placement providers

The committee considered the issue of Vermonters with intellectual and developmental disabilities who may be eligible to receive developmental services, but who are unaware of services or who have never applied for services. This issue arose with some frequency in full Task Force discussions of what developmental services might look like as we “imagine the future.” To address this issue, we recommend consideration of the following amendment to the DD Act:

- At §8723 Department of disabilities, aging and independent living; duties

Add new subsection (13) as follows:

(13) Work with other areas of State Government to identify individuals with developmental disabilities who would benefit from receiving developmental services including informing individuals with developmental disabilities and their families what services may be available .

The committee recognizes that individual provider agencies are responsible for regional crisis response service and that when a person receiving residential services requires a crisis placement due to the incapacitation, illness or loss of a home provider, the agencies are almost always able to place the person in the home of someone familiar with the person (such as a respite provider, family member, or friend). However, we were concerned with the harm that could result if crisis placement is made with an individual who does not have the level of training necessary to ensure the safety of the person receiving services. To address this concern, we recommend consideration of the following amendment to the DD Act:

- At §8723 Department of disabilities, aging and independent living; duties

Add new subsection (14) as follows:

(14) Establish a protocol for emergency placements to include minimum level of training for persons serving as crisis placement providers.

NOTE: At least one committee member was also concerned that there is no duty specifically addressing crisis intervention overall.

Other specific concerns

Finally, the committee identified several specific areas of concern or issues which merit further consideration and a broader discussion as we “imagine the future.” These areas are:

- More clearly defining what quality assurance looks like;
- Development of a conflict resolution process;
- How to square DAIL’s responsibilities with IFS;
- Rights and responsibilities of people receiving services.

Respectfully Submitted,

Members of the Imagine the Future Task Force, DD Act Subcommittee

IMAGINE THE FUTURE TASK FORCE, DD ACT SUBCOMMITTEE
DD ACT AMENDMENTS FOR CONSIDERATION

§ 8723. DEPARTMENT OF DISABILITIES, AGING, AND INDEPENDENT LIVING;
DUTIES

The Department shall plan, coordinate, administer, monitor, and evaluate State and federally funded services for people with developmental disabilities and their families within Vermont. The Department shall be responsible for coordinating the efforts of all agencies and services, government and private, on a statewide basis in order to promote and improve the lives of individuals with developmental disabilities. Within the limits of available resources, the Department shall:

(a)(1) promote the principles stated in section 8724 of this title and shall carry out all functions, powers, and duties required by this chapter by collaborating and consulting with people with developmental disabilities, their families, guardians, community resources, organizations, and people who provide services throughout the State;

(2) develop, maintain, and monitor an equitably and efficiently allocated statewide system of community-based services that reflect the choices and needs of people with developmental disabilities and their families.;

(3) acquire, administer, and exercise fiscal oversight over funding for community-based services, including the management of State contracts;

(4) identify resources and legislation needed to maintain a statewide system of community-based services;

(5) establish a statewide procedure for applying for services;

(6) facilitate or provide pre-service or in-service training and technical assistance to service providers consistent with the system of care plan and **in collaboration with the self advocacy community;**

(7) maintain a statewide system of quality assessment and assurance for services provided to people with developmental disabilities and provide quality improvement support to ensure that the principles of service in section 8724 of this title are achieved;

(8) encourage the establishment and development of locally administered and locally controlled nonprofit services for people with developmental disabilities based on the specific needs of individuals and their families;

(9) promote and facilitate participation by people with developmental disabilities and their families in activities and choices that affect their lives and in designing services that reflect their unique needs, strengths, and cultural values;

(10) promote positive images and public awareness of people with developmental disabilities and their families;

(11) certify services that are paid for by the Department; and

(12) establish a procedure for investigation and resolution of complaints regarding the availability, quality, and responsiveness of services provided throughout the State;

(13) work with other areas of State Government to identify individuals with developmental disabilities who would benefit from receiving developmental services including informing individuals with developmental disabilities and their families what services may be available; and

(14) Establish a protocol for emergency placements to include minimum level of training for persons serving as crisis placement providers.

(b) The Department shall have primary authority and responsibility for establishing standards of quality and for monitoring such standards for any services funded by Medicaid through the Department or any other organization selected by the Agency of Human Services to provide long term supports and services to individuals with developmental disabilities and their families. This authority takes precedence over any provision in a contract between the state and a non-state entity such as an Accountable Care Organization, or among non-state entities such as a provider and an organization such as an Accountable Care Organization.

§ 8724. Principles of service

Services provided to people with developmental disabilities and their families by any entity funded through the State of Vermont shall foster and adhere to the following principles:

(1) Self-Determination. Adults with developmental disabilities will have authority over how, where, and with whom their lives will be lived; the resources needed for their support; and responsibility for their own decisions and actions.

(1) Children's services. Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. The quality of life of children with developmental disabilities, their families and communities is enhanced by caring for children within their own homes. Children with disabilities benefit by growing up in their own families; families benefit by staying together; and communities benefit from the diversity that is provided when people with varying abilities are included.

(2) Adult services. Adults, regardless of the severity of their disability, can make decisions for themselves, can live in typical homes and can contribute as citizens to the communities where they live.

(3) Full information. In order to make good decisions, people with developmental disabilities and their families need complete information about the availability, choices, and costs of services, how the decision making process works, and how to participate in that process.

(4) Individualized support. People with developmental disabilities have differing abilities, needs, and goals. To be effective and efficient, services must be individualized to the capacities, needs, and values of each individual.

(5) **Support for Families** Family support. Effective family support services for families shall be designed and provided with respect and responsiveness to the unique needs, strengths, and cultural values of each family; ~~and~~ the family's expertise regarding its own needs; **and the chronological age and need for independence of the person with a developmental disability.**

(6) Meaningful choices. People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values, and needs and assure that each recipient is directly involved in decisions that affect that person's life.

(7) Community participation. When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.

(8) Employment. The goal of job support is to obtain and maintain paid employment in regular employment settings.

(9) Accessibility. Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services, thereby forfeiting natural community support systems.

(10) Health and safety. The safety and health of people with developmental disabilities is of paramount concern.

(11) Trained staff. In order to assure that the goals of this chapter are attained, all individuals who provide services to people with developmental disabilities and their families must receive training as required by section 8731 of this title.

(12) Fiscal integrity. The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.

(13) Residential services. Unless reflecting the choice of the individual receiving services, or as required by issues of safety, residential services shall not be provided in settings that have the effect of isolating individuals receiving services from the broader community.

