Department of Health and Human Services
Maine People Living Safe, Healthy and Productive Lives

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February 5, 2013

MEMORANDUM

TO: Senator Dawn Hill, Chair, Representative Margaret R. Rotundo, Chair; and Members, Joint Standing Committee on Appropriations and Financial Affairs

Senator Margaret M. Craven, Chair; Representative Richard R. Farnsworth, Chair; and Members, Joint Standing Committee on Health and Human Services

FROM: Mary C. Mayhew, Commissioner
Department of Health and Human Services

SUBJECT: **LD 1816; Section W-1; Adult Developmental Services Work Group**

I am pleased to provide you with the second update to the work being performed by the Adult Developmental Services Work Group. As you may be aware, this work group was established by LD 1816, Part W.

The members of this group include representatives from Speaking Up For Us (SUFU), Maine's Family Coalition, Maine Association of Community Service Providers (MACSP), DHHS, Maine's Oversight and Advisory Board (OAB), Developmental Disabilities Council, the Disabilities Right's Center (DRC) and community providers.

The focus of this workgroup is creating a common vision that will provide the platform necessary to reach the salient points of the legislation. Attached to this memo are three (3) documents that further clarify this focus. The first two were developed by this workgroup (a narrative overview of the broad vision of this workgroup and a set of areas and goals that the workgroup has identified as needing further development). The third document is one that was shared by the Family Coalition.

Community inclusion, self-determination and dignity of risk are at the center of our proposal. It is felt that each person served within Maine's system should be allowed the opportunity to transition effectively through to adulthood and into the community where he/she will access natural community support and receive the formal support necessary to achieve autonomy and community inclusion.

If you would like to identify further areas for the workgroup to examine or have questions, please contact Jim Martin, Associate Director of the Office of Aging and Disability Services at 287-6642.

MCM/klv

Enclosures (3)

cc: Jim Martin, Associate Director, Office of Aging and Disability Services

LD 1816 Developmental Services Lifelong Continuum of Care Narrative

The model proposed in this document puts the person in the center. It highlights transitions across the person's lifespan and maximizes the use of natural support and community inclusion.

Community inclusion and self-determination are based on the assumption that the person is a part of and connected within the community. It means the person is engaged socially, recreationally, culturally, and spiritually. The person is a productive and valued community member, pursuing talents and giving back to others. The person individuates from parents and caregivers, makes informed choices, and is respected through typical interactions with others as part of a community. The person belongs.

People with intellectual or developmental disabilities rely, like everyone else, on family, friends, neighbors, and local support like public transportation, public recreation, church, and medical professionals. Individuals with disabilities often need added support due to unique challenges at various times in the lifespan.

When considering support, we want to look first for local, informal support. Only where there are gaps should we add in supplemental formal support to maximize independence, self-reliance, choice, and dignity of risk. Any supplemental formal support, such as those required for unique or complicated medical conditions, must be flexible and designed to meet the person where he or she is. Support may ebb and flow over the lifespan as the individual's needs change. Quality flexible wraparound support means varying services as needed (from minimal to maximum) to promote personal development, safety, stability, and inclusion.

The series of circles in the diagram to follow describe various needs for the person throughout their lifespan. Of these circles, community inclusion, employment or related activity, and housing stand out. Quality flexible support stands in the background rather than being a central focus. Beyond that, various circles gain prominence based on each individual's unique needs. Natural community support becomes the backbone of each person's autonomy and independence.

The rest of the circles are self-explanatory: Stable housing, transportation, employment, healthcare, financial support, continuing education, and planning for aging, all allowing community inclusion and self determination – central to the person's life.

Transition presumes that the person begins as a child under parental care, transitions to adulthood, and thrives in a world where community support, as needed, is present as part of a responsive support network. This requires an individual, family, community, and government partnership, where support for any individual is not artificial but closest to "typical" for anyone.

LD1816 Developmental Services Lifelong Continuum of Care – Vision and Goals

Vision: Each person served within Maine's Continuum of Care will transition effectively through to adulthood and into the community where he or she will access natural community support and receive the formal support necessary to achieve autonomy and community inclusion.

Area 1: Assessment

Goal: **Each person will receive a strength-based standardized individualized assessment (currently the Supports Intensity Scale) of his or her strengths or needs, which will inform the person-centered plan.** This assessment will take into account all of the domains outlined in the Continuum of Care diagram.

Goal: **Each person will be assessed for the natural support potentially available to them**, and efforts will be made to maximize all of these as opportunities. This includes family, neighborhood, peers, and support networks. Each person should first access generic support and services that are available to everyone before disability-specific supports are considered.

Area 2: Service Delivery and System Navigation

Goal: **Maine will establish a broad menu option model designed to match the amount and kind of paid support services needed by each individual.**

- Maine will provide choices that accommodate everyone. These choices will address the need for a variety of models and ongoing adaptability to life changes or greater independence. This is the opposite of a one size fits all approach.
- Each person will also have a single point of entry that will be a gateway to all of the services needed.

Goal: **Each person will have a designated Community Resource Assistant whose job it is to help an individual at any age navigate the local available array of services.** This person would know the community and be willing to use relationships to open doors, and to connect with appropriate additional services or support. The Community Resource Assistant connects the person with services and opportunities on the ground including those in the following categories:

1. Community Inclusion and Self-Determination. The Community Resource Assistant will work to repair the divisions/breaks in community that still create exclusion.
2. Continuing Education. School will prepare an individual for transition to community and continued maximum inclusion through lifelong learning, creating true preparation for belonging and actual community participation at the fullest potential.
3. Natural Community Supports. The Community Resource Assistant will keep the support at the community level to foster natural supports. As part of the Person Centered Plan, the roles of all natural supporters will be formalized.

Area 3: Information Dissemination and Planning

Goal: **Maine will ensure a thorough and accessible Information Repository. Maine will enhance information dissemination so that it is thorough and constantly updated, and how services work and are accessed will be transparent.**

Goal: **Maine will establish early support and planning about steps awaiting the individual and their transition to and through adulthood**. Beginning at the moment the child is identified as potentially needing some type of unique support, there will be early intervention with a constant eye toward community integration

and adulthood success. Collaboration will occur in all systems so that planning for transition is lifelong and comprehensive.

Throughout elementary and secondary education and beyond, efforts to support success in the community will be fostered so that education and social activities are all part of engaging and developing skills and natural supports that continue through the lifespan. All decisions regarding the future will be founded on self-determination and individual personal choice.

Area 4: Community Inclusion

Goal: **Maine will have a formal effort within each neighborhood or community to educate, foster inclusiveness, awareness, and an "it takes a village" mentality.** Each community will form a casual safety and support web. Individual Service Plans will include the management of risk, including contingency plans (around personal crises, fires, disasters, etc.). Maine will enhance the community side of the equation. Like crime prevention strategies such as neighborhood or community "watch" locations, this effort will encourage or enhance neighborly activities that make up a safer and better-connected society for everyone. All individuals will function as a natural part of every community in which they live, work, and thrive.

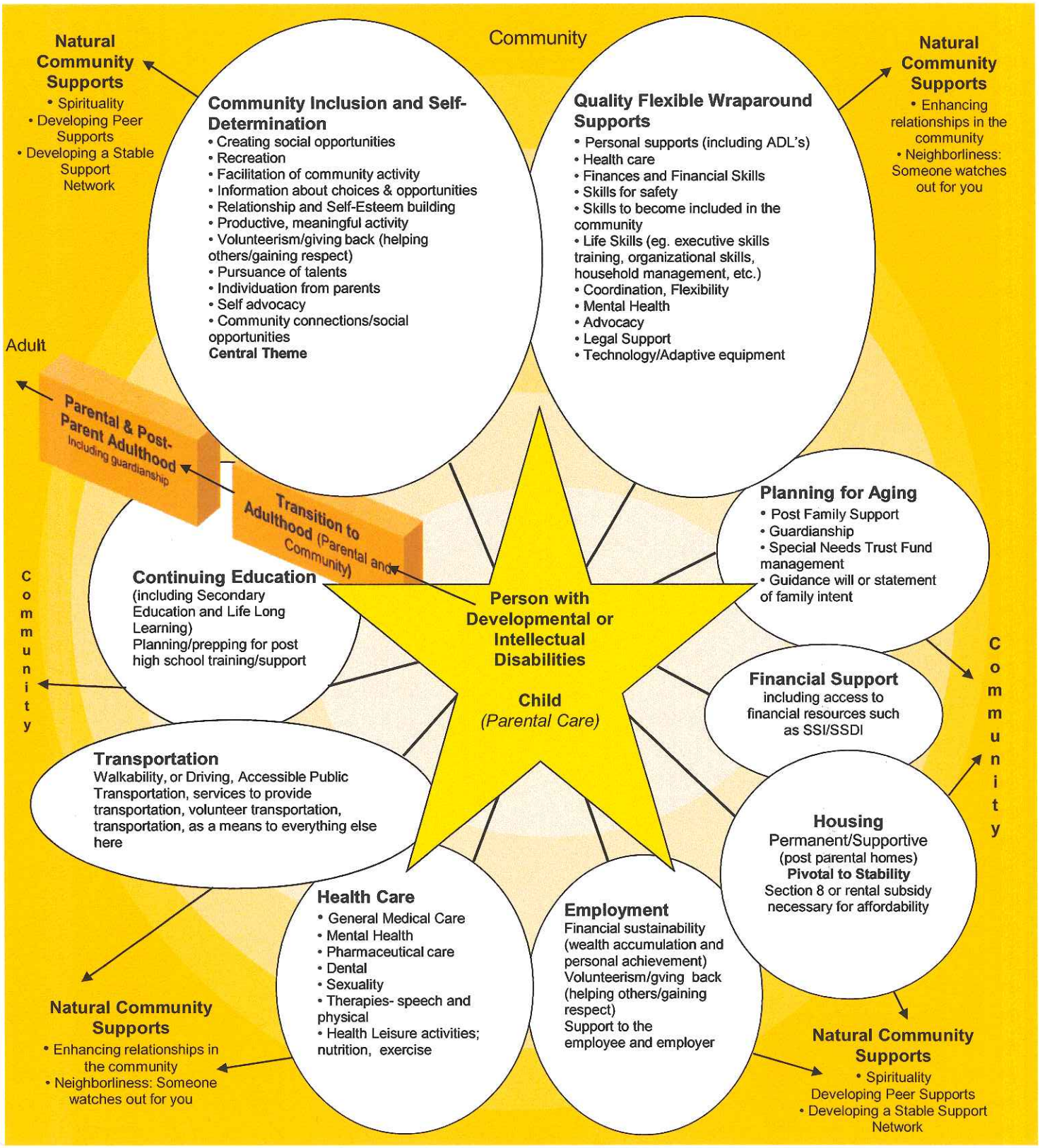
Area 5: Common Sense Service Delivery

Goal: **Maine's Developmental Services will deliver only the paid services needed; nothing more, and nothing less.** Implementation will be regularly examined so that any inefficiency can be eliminated. A Stakeholder Working Group will receive input and participate in policy decisions about real life situations/policies to continue to examine the most efficient and effective use of resources.

1. This Working Group will evaluate new methodologies or technologies that can be incorporated for success. This group would then make recommendations to improve the menu of services. They would recommend how each service can be delivered in the most efficient and effective manner. There will be regular examination of available technology to see if it can be incorporated into the achievement of goals.
2. This Working Group will regularly examine the balance of established protocols vs. acceptance of risk, i.e. one individual may accept support during the day along with very limited support during the night knowing there may be some risk associated with limited night staffing, but the trade off is acceptable to the person. This also applies to community risk – the person may engage with and make errors within society, but will have maximum opportunity to freely engage, and will have at least a safety net to avoid catastrophe. Each person would have presumed competence allowing the "dignity of risk" that comes with independence in society.
3. This Working Group will regularly examine developmental services through the lens of how the rest of the world functions. Generic goods and services available to enhance everyone's lives should be applicable to everyone in society. In this sense, individuals with developmental services needs are quite the same as everyone else. Specialized services should only be looked to when generic services alone can't support the achievement of the individual's goals.

Goal: **Formal services will be based on individual and realistic needs, not on formulaic policies.** Services will be flexible with only the necessary amount of paid support services. There will be no "one size fits all" approach. The formal delivery system will become nimble and flexible to allow for changes in a person's functioning, and it will minimize obstacles to flexible adaptation. This will eliminate the need for people to fit into "categories" so they can receive services/housing – all will receive what they need at a level appropriate to them at any point in time, whether that increases or decreases. Maine will meet each person where she or he is.

DD Continuum of Care Diagram



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