

Maine Coalition for Housing and Quality Services

To: Mary Mayhew, Commissioner of DHHS
Subject: DD Lifelong Continuum of Care White Paper
Date: September, 2011

The Maine Coalition for Housing and Quality Services began in May, 2006, formed by a group of parents of children with special needs. Ultimately, the goal of the Coalition is to create a system of quality housing and personal supports that is person and family centered, with choice, dignity, and efficiency being at the forefront of efforts. The Coalition is meant to be a consortium of interested parties including those from other advocacy groups interested in these two issues. It is inclusive, and effective, and all interested parties are invited to attend or to participate through the email list serve. Some 4000 individuals, primarily parents, participate in the Coalition, which includes some 14 other distinct councils and advocacy groups, now united with a large voice in their efforts directed at housing and quality in services.

Since the middle of 2009, the Coalition has been developing a Continuum of Care for persons with developmental disabilities. The model is described below, followed by a diagram, and a description of a vision and goals:

DD Continuum of Care:

This model puts the person in the center. It examines the transition to adulthood, with a goal of community inclusion maximizing natural supports within the community.

The series of circles (see diagram) describe various needs for the person throughout their lifetime. Of these circles, community inclusion and housing stand out. Conversely, rather than being a central focus, quality flexible wraparound supports stands in the background creating minimal but necessary supports to allow pursuit of community inclusion and stability. Beyond that, which circles stand out will vary with each individual's unique needs.

The transition presumes that the person begins as a child under parental care, transitions to adulthood under a combination of parental and community care, and ultimately achieves adulthood where care, as needed, is present within the community such that the parent can pass away knowing the son or daughter is stably housed with an adequate support network. This speaks to a parent, community, and government partnership, where supports are not artificial but closest to "typical" for anyone.

Quality flexible wraparound supports mean varying supports as needed (from minimal to maximum) to promote appropriate development, safety, stability, and inclusion.

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

Community inclusion and self determination is based on the assumption that the individual with disabilities should not be isolated but instead should be a part of and connected within the community. It means a person would be engaged socially, recreationally, and culturally; the person is informed about choices and a productive community member, pursuing talents and giving back to others. The person would individuate from their parents, make his or her own choices, and earn respect from typical interactions with others as part of a community. The person would belong.

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DD 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 take advantage of natural community supports and receive other supports necessary to achieve community inclusion.

Area 1: Assessment

Goal: Each person will receive an individualized assessment of his or her strengths or needs which will inform the person centered plan, and money will follow to deliver said plan. This assessment will take into account all of the domains (bubble areas) outlined in the Continuum of Care. 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 be assessed for the natural support potentially available to them, and efforts will be made to maximize all of these as opportunities. This includes neighborhood, peers and support networks.

Area 2: Service Delivery and System Navigation

Goal: (“Menu of Services Model” – with “meal” items being a clever combining of ingredients – options). **Maine will establish a tracking system to determine level of functioning and generally establish an appropriate level of care for each person,** (e.g. high, medium, or low needs).

- Maine will establish an array of choices (i.e. five different models) associated with each level of care. The category options are to be general but incomplete; services will need to be individualized from that point on.
- There need to be choices that accommodate everyone (a low needs person might live with a high needs person, but would benefit from staffing within the home and the community as a result). This takes into account that there needs to be a variety of models, not a one size fits all approach.

Goal: (“Welcome Wagon – School, library, pediatric office”). **Each person will have a designated Community Resource Assistant whose job it is to help a parent and child navigate the local available array of services.** This person would know the community and be willing to use relationships to open doors, and to develop appropriate additional services. Someone facilitates this, and connects the person with services and opportunities on the ground including those in the following categories:

1. The Community Inclusion and Self-Determination bubble. The Community Resource Assistant will work to repair the divisions/breaks in community that still create exclusion.
2. The Continuing Education bubble. School will prepare for a system that is there, creating true preparation for belonging (it will be in synch).
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, roles of family and neighbors will be formalized.

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Area 3: Information Dissemination and Planning

Goal: Maine will create an **Information Repository** (Bubble bath) by establishing county-based or local Central Resource Repository Boards to adequately serve each person/family with updated, applicable information readily available about each bubble or resource area. These will include:

- Formal information – 211 – Local
- Informal information – The how it works and what you need to do information.

Parents will be expected to volunteer to serve on a local board once their child is housed, to form meaningful forums for parents needing information.

These Boards would receive clerical support for minutes/email distribution.

Goal: (“Early Intervention, with an eye toward community integration and adulthood success”). **Maine will establish early on support and planning about steps awaiting the person and their transition to adulthood.** Much of this will happen while the person is young and in the original family home. Beyond school and support, efforts to support eventual success in the community are fostered while at home – education, social activities – all should be part of engaging and developing skills and natural supports to carry on. All decisions regarding services will lie with the clients and family, rather than an agency or the state.

Area 4: Community Inclusion

Goal: (“Neighborhood Disability Watch” – similar to Neighborhood Crime Watch). **Maine will have a formal effort within each neighborhood to educate, foster inclusiveness, awareness, and an “it takes a village” mentality** so that each community forms a casual safety and support web, watching out for and nudging the person in the right direction when needed. Part of the plan will be managing the risk, including contingency plans (around personal crises, fires, disasters, etc, or impending ones).

Area 5: Common Sense Service Delivery

Goal: (“Deliver only what is needed, nothing more, nothing less”). **Efficiency of implementation will be regularly examined so that all waste can be eliminated.** A 50%/50% Parent/DHHS Working Group will receive input and make policy decisions about real life situations/policies such as redundant comprehensive assessments to determine if a person remains disabled when realistically only a miracle would cause that to change. This Working Group will discuss reasonable elimination of protocols/acceptance of risk, i.e. parents may accept day services along with very limited night services knowing there may be some risk associated with limited night staffing, but the trade off is acceptable to them. This also applies to community risk – the person may engage with and make errors with society, but will have maximum opportunity to freely engage, and at least a safety net to avoid catastrophe.

Goal: **Services will be based on functionality of the individual and realistic needs, not on formulaic policies.** 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.

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Our proposal:

Using the above as a guideline, we are ready to see the system of care changed to both better serve those receiving services, and to ensure that everyone in need is able to access adequate services. Specifically, we request that Section 29 be rewritten to add more flexibility and to create a menu of services. This would allow families and each individual served to select the best option of services to support his or her own community inclusion. Those options could include in-home support, day support in the community, employment support, respite care, or some combination of any of these as applicable to the individual.

We would like to see the Section 29 Waiver re-named the “Community Support Waiver”. It would include supports related to home, work, and community. Some of this would occur by allowing people on the comprehensive Section 21 Home and Community Support Waiver to be blended in the community with people on the less comprehensive Section 29. In this way, some additional natural community supports could be maximized, but there would be a nearby “safety net” or go-to person to solve small problems or redirect to other necessary supports as needed. We think this can be accomplished without an increase in funds.

We also propose that technology be used within the Section 21 Waiver (and the Section 29 Waiver) to allow a greater level of independence particularly in the overnights, and consequently an acceptance of some increased risk associated with this greater independence. The use of technology, where possible, would reduce the costs associated with overnight staffing. This would diminish the overall costs of support in numerous cases. These efficiencies could be translated into moving people as needed onto outcome-based programs such as a revitalized Section 29 Waiver rather than leaving them languishing on growing waiting lists for both programs.

We believe that further individualization and targeting of supports to individuals will allow additional efficiencies to be created. Our goal would be for all people to be met “where they are at” rather than being fit into a “one size fits all” type of model, such as we tend to have today. We would also like to develop strategies to create incentives for efficiency of service provision, and natural community supports. Examples include allowing siblings to participate in community outings to foster continued family involvement, or allowing direct service employees to interface as natural supports outside of work hours (rather than being ordered to avoid the person when seen off duty).

We would like to see new money be directed into this type of program. The Supports Intensity Scale would determine levels of service, and the person centered plan would allow the individual at the center to decide, with support from the family, the best array of services on an evolving basis. Section 29 would mean (up to) 1125 hours/year, or 21.63 hours/week of community support. We would work collectively to allow providers to digest and adjust to this strategy.

Our model prizes the concept of “No one size fits all”. We would like to keep all options open – group homes, apartments, and other forms of housing. We would like to simply adapt services to people in housing most appropriate to their needs and goals.

We would hope to meet with you in the very near future to think together about what would stand in the way of moving to this approach, and ultimately devise a plan of implementation.

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