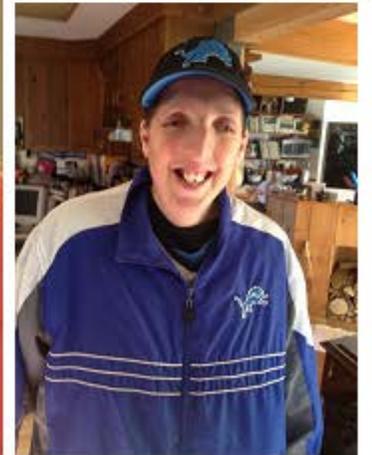


**The Maine Coalition for Housing and Quality Services:  
Working to Improve the System of Care Through  
Collective Advocacy & Information Sharing**

**Maine Down Syndrome Network Annual Conference  
11/10/18**

**Presented by: Vickey Rand  
Communications Manager  
Community Housing of Maine**



## Maine Coalition for Housing and Quality Services

**Purpose: To create a system of quality housing and personal supports that is person and family centered, with choice and dignity being at the forefront of efforts.**

## The Maine Coalition for Housing and Quality Services

- › 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.
- › There are some 4000 parents, relatives, individuals with DD/ID, providers, DHHS leadership of Adult (OADS) and Children's (OCFS) Services, Special Educators, transition specialists, and other advocates involved.

# The Maine Coalition for Housing and Quality Services

## DD Continuum of Care

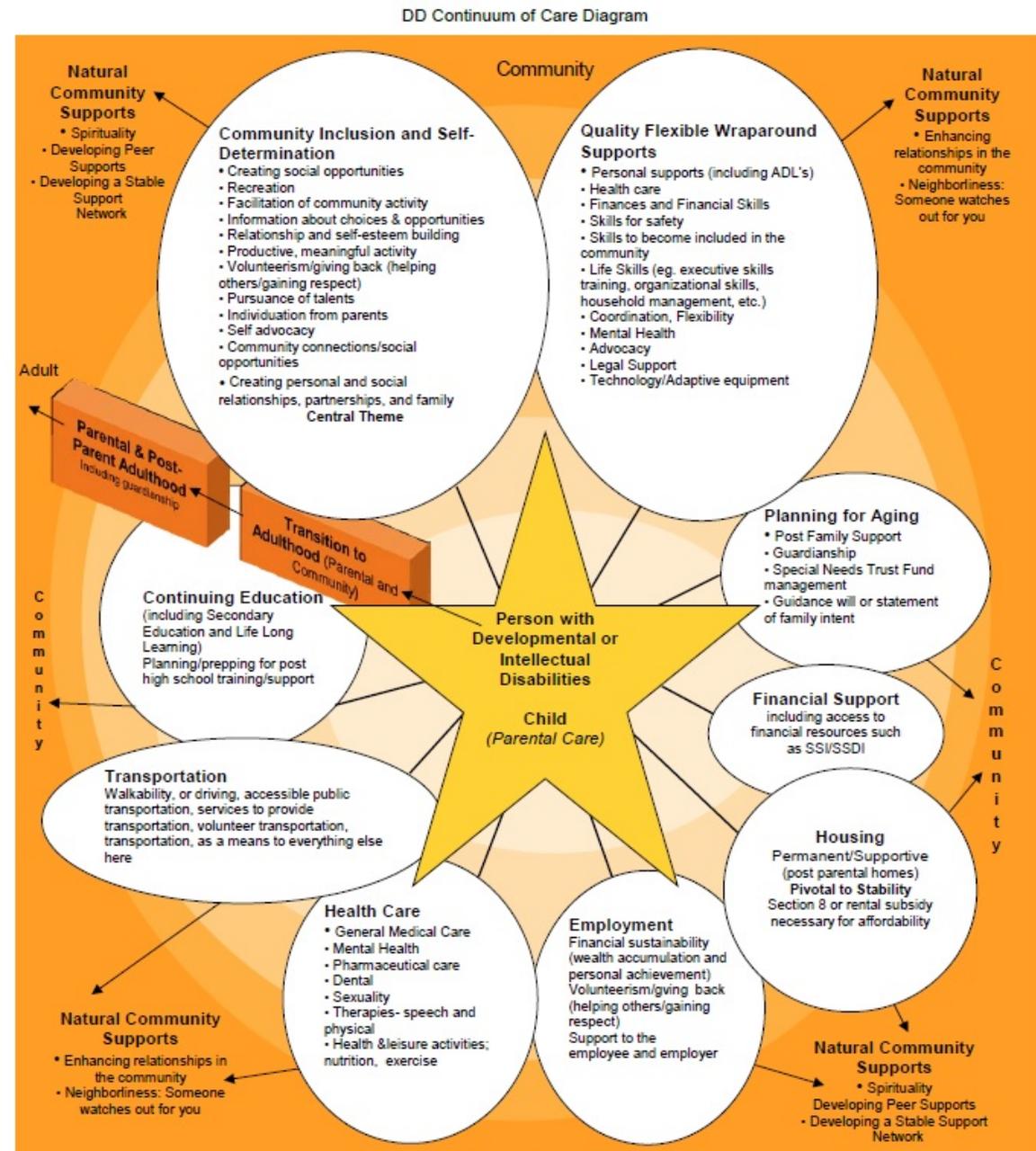
- › In late 2009 and 2010 the Maine Coalition for Housing and Quality Services initiated a parent-led project to redesign, from the ground up, a system of care for persons with developmental or intellectual disabilities. This began with a visual and conceptual diagram, evolved to a narrative, a structural design for implementation, goals and action steps to achieve them, and notes about what parents specifically don't want to repeat from the current system of care. The Coalition completed the White Paper in September 2011, which was presented to, and was received well by, the Commissioner, Deputy Commissioner, and other leadership at DHHS. The model puts the person in the center as a child under parental care, who then transitions to adulthood under a combination of parental and community care. Housing is a primary concern along with considerations for support needed for transportation, financial support, healthcare, employment, education and natural support etc., throughout the person's life. The goal is community inclusion with natural community supports, supplemented on an as needed basis with community based support.

# The Maine Coalition for Housing and Quality Services

## DD Continuum of Care

- › In 2012 the Maine Legislature created the LD 1816 Developmental Services Workgroup which was charged with studying ways to create a more efficient and effective service delivery system. This workgroup decided that the Coalition's White Paper proposed a service delivery model that addressed nearly all of the concerns the Workgroup was tasked to solve. The Workgroup made modest language changes to the document while maintaining the content. The Workgroup version was finalized after receiving input from the Coalition in January 2013.
- › On February 1, 2013 the Developmental Services Workgroup adopted an interim report to be sent to the Legislature through the DHHS Commissioner. The two groups continued to build from this existing official document to create action steps describing how to accomplish each of the goals.
- › With the new model adopted, the DD Continuum of Care is charged with seeing through the implementation of a new Continuum of Care so that housing and service needs are met for everyone, and true community inclusion occurs.

# DD Lifelong Continuum of Care Diagram



# The Maine Coalition for Housing and Quality Services

## Other accomplishments

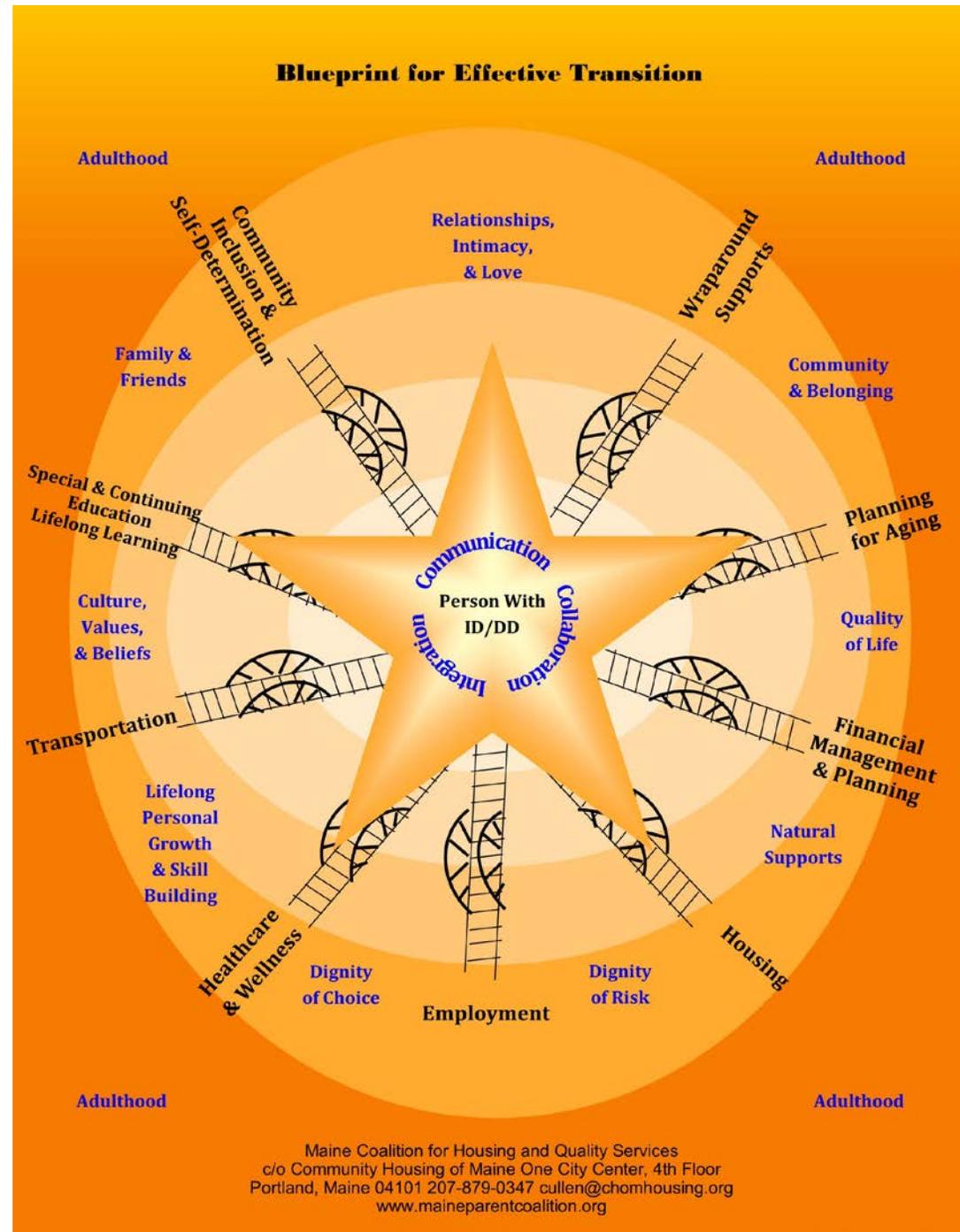
- › Action to Ensure a Supportive Housing Allocation
- › Action for Fully Restoring the HOME Fund
- › Action for Educating DHHS and MaineHousing about the importance of a variety of supportive housing models
- › Action for addressing Emergency Rule change affecting services to people with Autism
- › Action for the National Housing Trust Fund
- › Action for addressing MaineCare Section 21 Waiver Concerns
- › Action to preserve the Safety Net for Maine's most Vulnerable Citizens
- › Action to create a Housing Revenue Bond
- › Action to fight proposed budget cuts to DHHS
- › Action to increase the supply of Section 8
- › Action to create a Blueprint for Effective Transition
- › Action to for addressing Section 21 & 29 Proposed Rule Changes

# The Maine Coalition for Housing and Quality Services

## Blueprint for Effective Transition

- › The Coalition established a subcommittee to develop a blueprint for effective transition.
- › The group included people from all areas and fields interested in an effective transition.
- › They developed a visual diagram, narrative, and goals and objectives.
- › This work was completed and approved by the Coalition in February 2015.

# Blueprint for Effective Transition Diagram



# Blueprint for Effective Transition Narrative

## Maine Coalition for Housing and Quality Services Blueprint for Effective Transition

### Narrative

All human beings have value, natural abilities, dignity, and potential. By dignity, we mean: Self-respect, nobility, worthiness, and honoring choice. Through this, we set the tone for all achievement and personal growth. Transition is the movement that incorporates these inherent characteristics, creating opportunities for a meaningful and fulfilling life.

Transition is a process, not a destination or event, and leads to quality outcomes for each individual. Transition is lifelong, with milestones along the way. It is both a foundation and a springboard to a fulfilling and meaningful life that must be facilitated by the individual, family, supports, and services across all environments. Transition involves collaboration, creativity, and community, and envisions a path through which an individual figures out what he or she wants to do and how to live his or her life.

Successful transition is a journey. This journey takes the individual through many transition planning areas and promotes development of the essential elements of a fulfilling life.

### Transition Planning Areas

The transition planning areas (see diagram) describe various transitions for the individual throughout his or her lifetime. The blueprint presumes that the person begins as a child under parental care, transitions to adulthood, and thrives in a world with continued transitions. Family and community supports are present as part of a responsive natural support network. Successful transition planning involves an individual, family, community, and government partnership. Supports for any individual should be closest to “typical” for anyone.

**Community inclusion** is based on the assumption that an individual with disabilities should not be isolated but instead should be a part of and connected within the community. It means a person is engaged socially, recreationally, and culturally. It also means that the person becomes a productive community member, pursuing talents and giving back to others. As the person differentiates from his or her parents he or she begins to exercise greater **self-determination**, makes more choices, and with the necessary support takes a more active role in setting and pursuing his or her own goals. As a member of the community a person is treated with dignity and respect. A person belongs.

**Quality flexible wraparound supports** are based on need, not on what is available. These involve varying supports as needed (from minimal to maximum, and adapting to life’s circumstances) to promote appropriate development, safety, stability, and inclusion.

The rest of the transition planning areas are self-explanatory: **Planning for aging, financial management and planning, stable housing and home, employment and vocation, healthcare and wellness, transportation, and special and continuing education/lifelong learning**; all enhancing community inclusion and self-determination – central to the person’s life.

### Essential Elements of a Fulfilling Life

The interwoven essential elements of a fulfilling life (see diagram, blue font) include:

- Family and Friends
- Relationships, Intimacy, & Love
- Community & Belonging
- Quality of Life
- Natural Supports
- Dignity of Risk
- Dignity of Choice
- Culture, Values, & Beliefs
- Lifelong Personal Growth & Skill Building

These elements are achievable by way of a successful journey through the transition planning areas.

Transition is about excellence and equity. It is about investing in human potential and individual dignity.

Central to the diagram, transition involves communication, collaboration, and integration. Integration requires transcending boundaries and braiding resources to create a comprehensive whole.

# Blueprint for Effective Transition Goals & Objectives

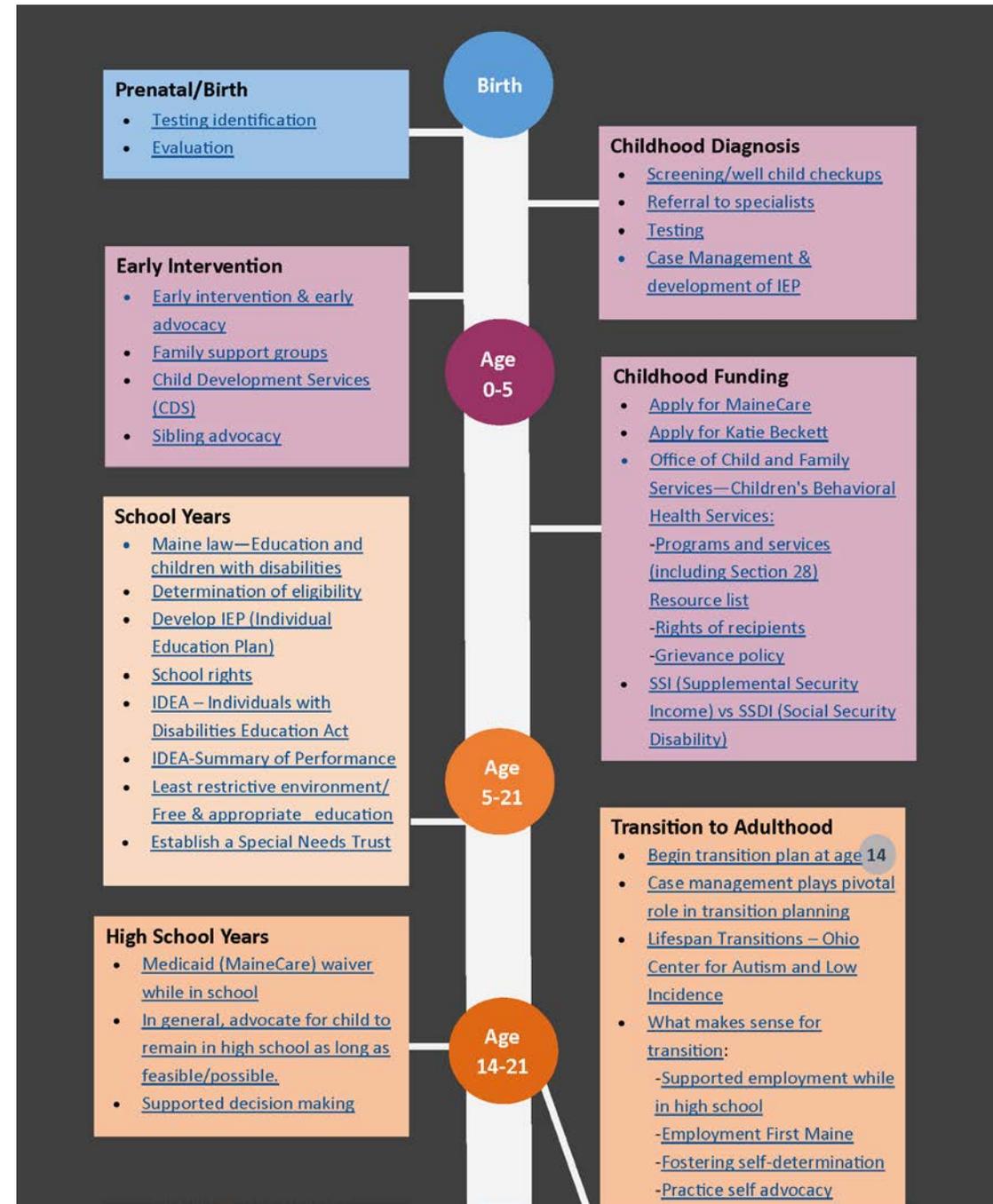
1. Collaboration, Integration, Communication
2. Individual Support, Family System Support, Natural Support
3. Self-Determination
4. Employment and Career
5. Quality of Life

# Blueprint for Effective Transition

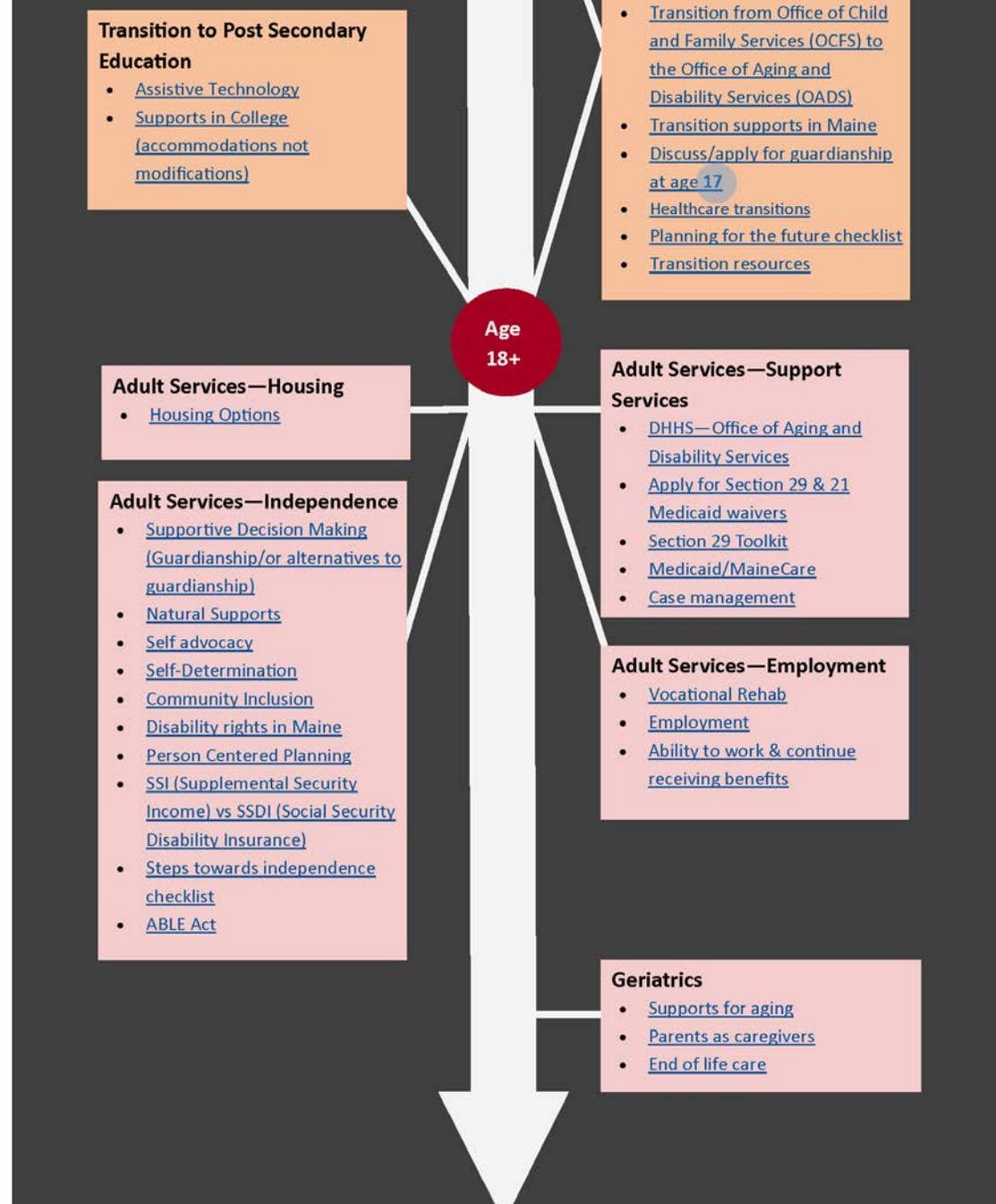


- › DHHS Office of Child and Family Services (OCFS) created A Guide to Transition Services in Maine, in part due to the efforts of the Blueprint for Effective Transition.
- › The system was responsive to us raising our collective voices.

# The Maine Coalition for Housing and Quality Services Service Timeline



# The Maine Coalition for Housing and Quality Services Service Timeline



# Why should you get involved?

## You are in Charge –Raise your voice!

- › The system of care evolved over the last 100 years. It is important to read about that history, so it's not repeated.
- › The current system is flawed in that it is very expensive, and it leaves many people out – on waiting lists for services due to a lack of funding.
- › Funding for affordable and supportive housing is very limited as well, meaning there is a lack of affordable housing, and insufficient supportive housing to meet the needs.
- › The system is responsive to us if we work collectively. DHHS and the Legislature works for us.
  - The decision makers who decide whether to allocate funding for services and housing all work for you as a citizen. They are our elected or appointed officials. They are either your representative, or they are a public servant; in either case they work for you. As such, you have a tremendous amount of power. Each of these people will listen to you if you reach out to them with your concerns.

# Why should you get involved?

## You are in Charge –Raise your voice!

- › The situation for families and individuals with developmental disabilities is very complicated, and it often takes us educating our public officials for them to see our needs and to make decisions that fully take those needs into account as they set priorities.
- › The Maine Coalition for Housing and Quality Services offers an opportunity for collective advocacy, where all of our voices can be raised in unison, raising the chances that we may improve things as a result.
- › Without us taking the time and having the courage to speak, our voice disappears, and other priorities will rise above ours.
- › By remaining informed, joining the Maine Coalition for Housing and Quality Services, and taking the minute or two to participate in Action Alert opportunities, you can make an enormous difference.

# Why should you get involved?

## Make Things Work Better For Your Loved One

- › Being a parent (or caregiver, family member, etc.) of a person with intellectual/developmental disabilities can mean an extremely busy schedule in and of itself. It can be all-consuming.
- › It is important to carve out some time to join with other parents for support, broader understanding, knowledge of the system of care and the changes it constantly faces, and to do your part as an informed citizen to stand up for your needs.
- › You can do this by signing up for emails from the Maine Coalition for Housing and Quality Services, attending meetings or reading minutes if you cant attend, and/or by coming back to our website for updates.
  - The Coalition strives to be an information clearinghouse – where parents, family members, advocates, and others can come for unbiased information on the system of care for people with intellectual/developmental disabilities.

# Why should you get involved?

## Make Things Work Better For Your Loved One

- › Raise your voice with us so that we can make the system work the way we want it to.
- › There are important opportunities to go to the State House and speak your mind on bills, policies, or rule changes that will affect your family. Please consider doing this!
- › But you can do something perhaps even more important: You can contact your representatives and invite them over to your home. Have them over for a cup of coffee, and sit and talk to them about your situation. This will allow them to see and hear about the challenges you face. You will have the opportunity to provide education to your representative by simply telling them your story, something very important and often an remarkable impression they will keep with them as they face many decisions ahead.
- › You have a very important opportunity to make things better for the people about whom you care. Please do! We'll all be better for it!

## Tell your stories!

- › Data and research has its place, but nothing is as powerful as telling your personal stories.
- › Describing how the lives of you and your loved ones are effected is compelling, and can significantly influence policy on the local, state, and federal levels.
- › Pictures, videos, and other visuals put a face to the issue.
  - Visuals and clear formats help to grab people's attention and maintain their focus.
- › Take advantage of opportunities for public comment and testifying – these are opportunities to tell your stories!



**Vickey Rand**  
**Communications**  
**Manager**

[vickey@chomhousing.org](mailto:vickey@chomhousing.org)

**One City Center, 4<sup>th</sup> Floor**  
**Portland, ME 04101**  
[www.chomhousing.org](http://www.chomhousing.org)

(office) **207-879-0347**  
(fax) **207-879-0348**