

2011

The Maine DD Network – Striving For “The Way Life Should Be” For All Mainers

Maine Developmental Disabilities Council

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The Maine DD Network



Maine's State Animal is the Moose!

– Striving For “*The Way Life Should Be*” For All Mainers

The “State” of Maine

- Largest state in New England – over 33,000 square miles
(in fact, all of the other New England states would fit within Maine’s borders)
- Over 3,500 miles of coastline
- 80% of land is forest



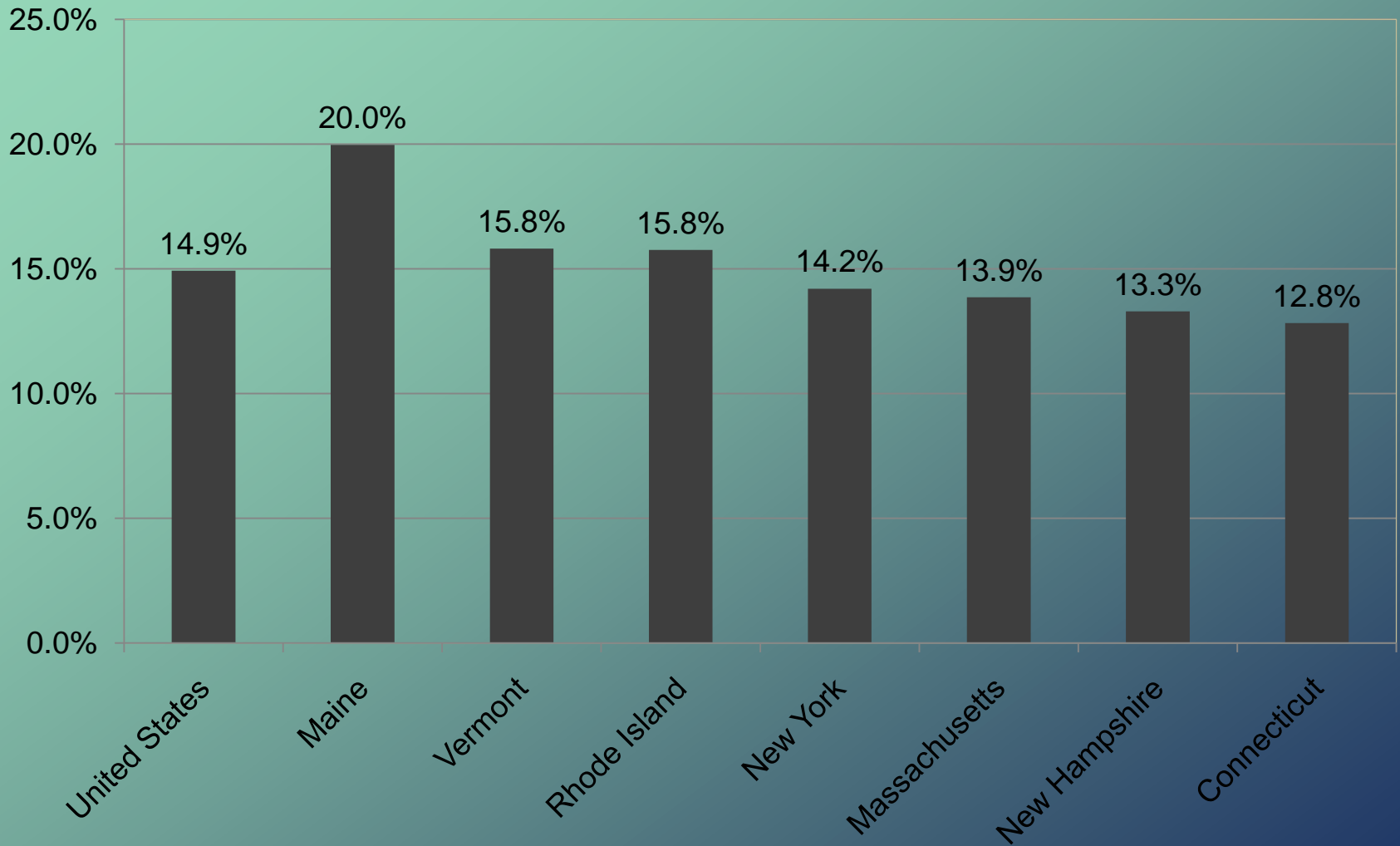


- Population – approximately 1.3 million people
- Oldest median age in the country (42 years, compared to national median age of 36.8 years)
- Prevalence rate of disability in population over age 5 is 20% (ranks 7th in country & highest in New England)

Maine State Bird: Black-Capped Chickadee
Maine State Flower: White Pine Cone and Tassel

Statistics from the 2007 Disability Status Report, Rehabilitation Research & Training Center on Disability Demographics and Statistics, Cornell University (www.DisabilityStatistics.org) These are the most recent statistics available, as the American Community Survey results for 2008 regarding disability status use different criteria and the sample size is too small for evaluation purposes.

Prevalence Rate in Northeastern States



Services for Adults with DD in Maine

- No State-run institutions in Maine
- Narrow definition for eligibility (ID/Autism)
- Numbers by type of service - adults

Community Services Programs	# of persons
Private ICF-MR	~ 185 persons
Comprehensive Waiver	2,856 persons
Supports Waiver	1,449 persons
Other private group home	~ 225 persons

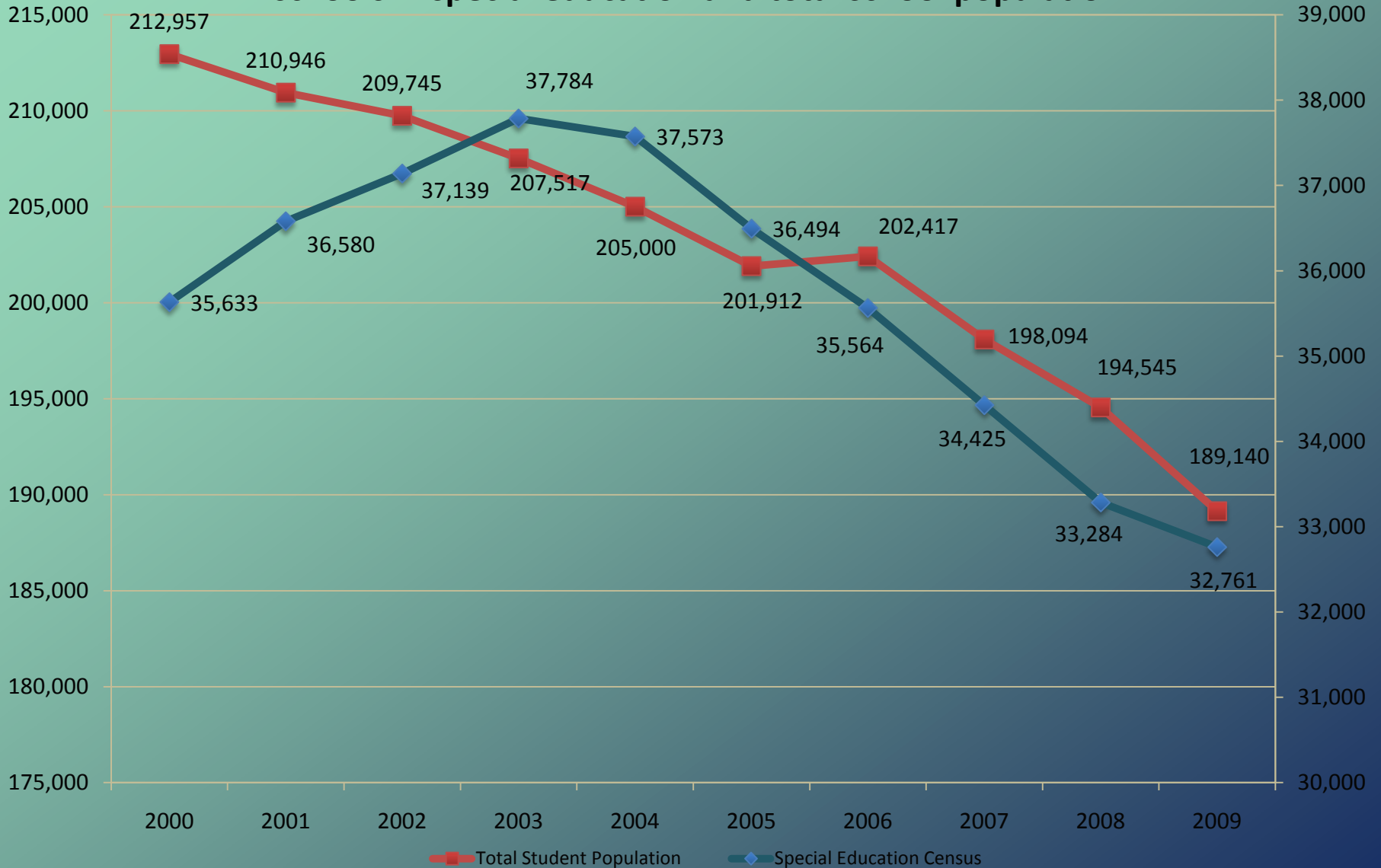
- As of May, 2010 – 412 people on waiting lists for services (~500% increase over December, 2008)

Children & Youth with DD

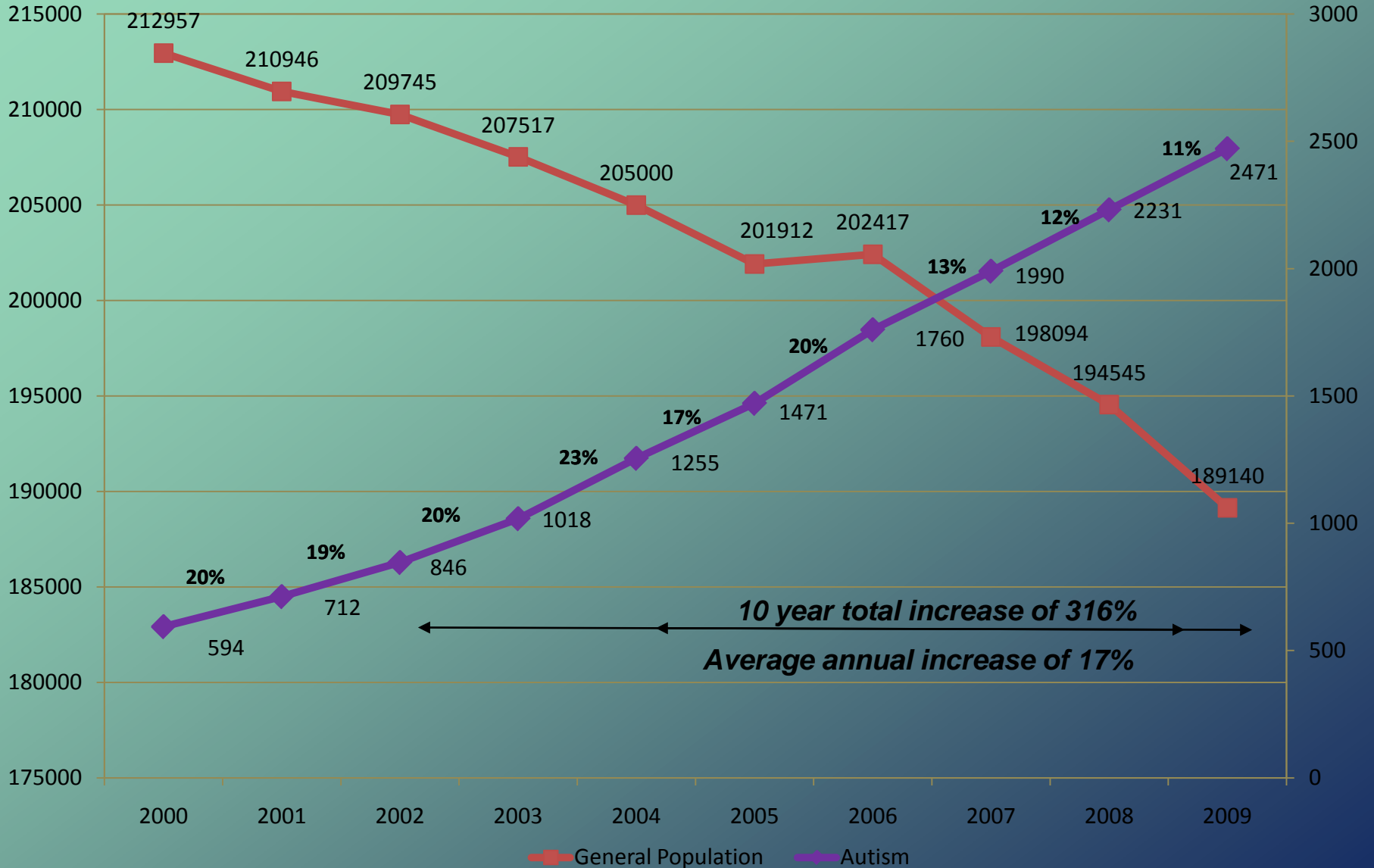
State budget shortfalls and associated cuts in funding have impacted services across the board, including:

- Growing waitlists for in-home support services and targeted case management
- Changes in eligibility for Katie Beckett Waiver reduced # of children covered by nearly 50%
- Budget shortfalls result in cuts to Child Development Services and Education, while numbers of children and youth with DD (especially Autism Spectrum Disorders) are increasing dramatically.

Comparison of 10-year trends in # of children served in Maine public schools in special education and total school population



Comparison of 10-year trends in # of children served in Maine public schools under the category of autism and total school population



DD Network Collaboration

The Center for Community Inclusion and Disability Studies, the Disability Rights Center and the Maine DD Council have a long history of close collaboration in a variety of activities and addressing a broad range of issues important to persons with developmental disabilities and their families.



Maine State Berry: Wild Blueberry

Collaboration Among Network Partners



Ongoing communication, coordination and planning among Executive Directors



Staff collaboration on wide range of issues



Staff retreat in June, 2009 for key staff working on DD issues from each of network organizations



Development of DD Network listserv and Newsletter (including our fourth partner, Speaking Up for Us – a.k.a. SUFU, Maine's statewide self-advocacy organization).
First issue of newsletter to be published September 2010.



The Maine State Insect: is the Honey Bee

Promoting Collaboration for Systems Change with Other Groups



Maine Disability Advocacy Coalition - more than 20 statewide organizations addressing issues important to persons with disabilities



Maine Education Advocacy Alliance – five statewide organizations working together to educate policymakers and promote increased family involvement in policymaking activities.



PDD Systems Change Initiative and Maine's Act Early Summit Team – public and private organizations and agencies, family members and self-advocates, addressing systemic challenges in meeting the needs of persons with PDDs.

Examples of Collaboration & Complementary Activities of the Maine DD Network Partners

Center for Community Inclusion & Disability Studies,
University of Maine – CCIDS

Disability Rights Center of Maine – DRC

Maine Developmental Disabilities Council – MDDC

Education & Early Intervention

- **Special Education Rules and Programs –**



MDDC & DRC provide ongoing consultation to Maine Legislature's Education & Cultural Affairs Committee regarding Special Education rule-making.



MDDC & DRC leading informational meetings across the state for parents regarding pending rule changes.



MDDC & DRC providing ongoing information to other organizations and formal/informal parent networks to encourage their participation in administrative and legislative action on special education services.



CCIDS collaborating with Maine DHHS and MDOE to provide statewide technical assistance & professional development on inclusive practices for early care and education providers.

Education and Early Intervention

- **Low-incidence Disabilities –**



DRC filed systemic complaint against Maine DOE for statewide failure to provide appropriate educational services for children who are blind or have visual impairments. Corrective action plan resulted, among other requirements, in creation of state workgroup needed to assure FAPE/EIS for these students. MDDC and DRC both involved.



CCIDS, in collaboration with MDOE and MDDC, developing evidence-based resources to enhance Maine capacity to educate students with low-incidence and complex disabilities.



CCIDS, in collaboration with MDOE & Maine Deaf-Blind project, developing & disseminating information re evidence-based practices related to education of these students to parents & professionals.

Education and Early Intervention

- Children with Pervasive Developmental Disorders –



PDD Systems Change Initiative – MDDC, as grantee, coordinates broad-based interagency effort to improve systemic capacity to provide early identification and early intervention services for young children with PDDs. DRC and CCIDS both involved in initiative work groups and activities.



Standards & training for education of children with PDDs:

- CCIDS collaborating with MDOE to provide intensive technical assistance & professional development to public schools supporting students with PDDs.
- MDDC facilitating & staffing work group (with active roles for CCIDS and DRC) per Legislative directive to examine standards & training needs for professionals involved in education services for children & youth with PDDs.

Quality Assurance – Promoting Self Advocacy

- **Support for Speaking Up for Us (SUFU), Maine's Statewide Self-Advocacy Organization**



MDDC provides funding for SUFU through a long-standing contract, which supports SUFU's collaboration with others in DD Network to strengthen advocacy voice of self-advocates across the state.



DRC serves as fiscal agent for SUFU, & provides technical assistance in organizational management for this young non-profit organization.



CCIDS provides ongoing technical assistance & support to SUFU in areas of professional development, website development & updates, and technical assistance.

Promoting Self-Advocacy



Disability Leadership Institute – MDDC, in collaboration with DRC, CCIDS & SUFU, offers a 2-year leadership training program for self-advocates and parents of children with DD.



Disability Advocacy Day – MDDC, with collaboration of SUFU & DRC, conduct bi-weekly half-day weekly.



Involving Self-Advocates in Community Leadership – DRC, CCIDS & MDDC collaborate with SUFU to promote self-advocate participation in boards, councils & coalitions, other community initiatives, voting, & advocacy at the state & national level.

Health Care & Community Supports

- **Services for Persons with Dual Diagnosis (ID/MH)**
 - MDDC-funded and facilitated two-year project – Statewide Task Force, nationally-known expert consultant – to accomplish systems redesign and provide broad-based training opportunities (DRC and CCIDS both partners in this effort)
- **Services for Children and Youth**
 - MDDC request resulted in legislation requiring interagency work group to examine State compliance with Medicaid EPSDT requirements – MDDC and DRC are collaborators in this effort, along with separate work group related to Katie Beckett program redesign.
 - CCIDS, in collaboration with Maine DHHS, is developing RELATE, a statewide model for early childhood mental health consultation, now being implemented in several regions of the state.

Other Areas of Collaboration are too numerous to mention in this short presentation, but we look forward to sharing more with you in the future about Maine DD Network collaborative efforts and accomplishments!

Final notes

To assure that this presentation is complete –

The Maine State Cat:



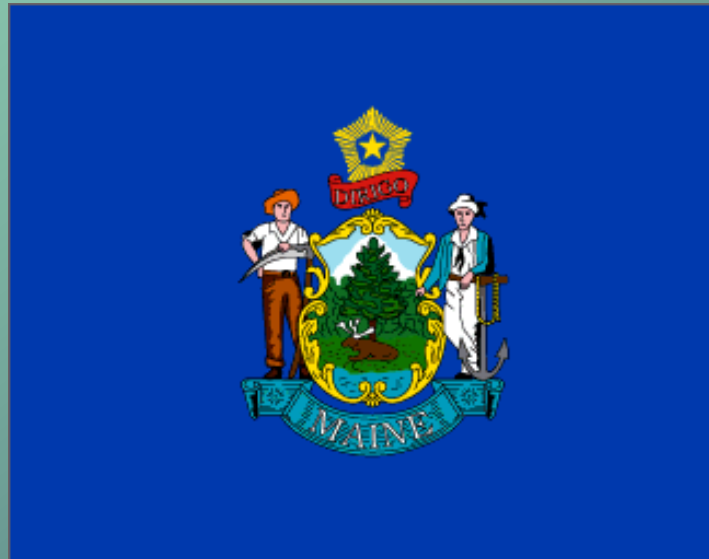
Maine Coon Cat

Maine State Fish:



Landlocked Salmon (or Sebago)

And our DD Network reflects
Maine's State Motto:



DIRIGO – I (We) Lead!