

LIST OF STATE-LEVEL WISCONSIN COUNCILS, BOARDS, COMMITTEES OR ORGANIZATIONS that have some responsibility or interest in issues relating to children and families, disability, and/or long term support

I. Those Most Directly Related to Genetic Services

Name of Entity	Mission or Purpose	Target Group	Origin or Authority	Membership Composition	Members with children under age 21/person under 21:	Standing Committees	Other Information
Newborn Screening Advisory Group	Advise the state on all elements of the newborn screening program, including laboratory tests, follow-up after diagnosis, and education of parents and physicians.	Children identified as having a condition detected by newborn screening	State Statute: 253.13	Physicians, nurses, dietitians, genetic counselors, public health representatives, and parent members	6 members. Currently 3 parent representatives have children under age of 21	1. Metabolic 2. Cystic fibrosis 3. Endocrine 4. Hemoglobinopathy 5. Education	Committees tend to meet twice a year. Travel and meal expenses are paid for. Membership on any committee has no set term length.
Council on Birth Defect Prevention and Surveillance for Wisconsin	Advise the state on all elements of the registry, including physician reporting, follow-up with families, legislation, and recommendations for prevention	Children identified as having a birth defect (defined by state statute)	State Statute: 253.12	Nurses, physicians, public health representatives, parents of children with birth defects. Also, groups and organizations with an interest in the treatment and prevention of birth defects.	No set number. Currently 1 parent representative.	None	Committee meets at least once a year in person and a few times a year by phone. Travel and meal expenses are paid for. Term length is 4 years, but is flexible.

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Region IV Genetics Collaborative	Address genetic services issues in Region IV (Kentucky, Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin)	All members of the community with an interest in genetic services and provision.	Federal Maternal & Child Health Bureau, Health Resources & Services Administration	Physicians, nurses, public health representatives, community members, and parents of children with genetic conditions	No set number. Currently at least 8 members are considered "parent representatives."	<ol style="list-style-type: none"> 1. Access to Services for Underserved Populations 2. Community Collaboration and Family Support 3. Implementation of Medical Homes 4. Public and Professional Education 5. Data Systems Integration 6. Long-term Follow-up and Evaluation of Outcomes 7. Newborn Screening and Short-term Follow-up 8. Clinical Diagnosis and Management 	Committees tend to meet by phone. In-person meetings take place once every 18 months or so. Travel, meal, and lodging expenses are covered. Membership on any committee has no set term length.

For more information about joining one of the groups listed above, contact the Statewide Genetics Coordinator at 608-267-7148.

II. Those with Significant Relevance to Genetic Services

Name of Entity	Mission or Purpose	Target Group	Origin or Authority	Membership Composition	Members with children under age 21/ person under 21:	Standing Committees	Other Information
Wisconsin Council on Developmental Disabilities	Plan for & oversee the State's responses to the needs of people with DD, and to act as an advocate to insure the provision of adequate, appropriate & humane services.	People w/DD (includes children), uses Federal definition	Federal Law: DD Assistance & Bill of Rights Act = Sections 101(b), 121, 124(c). State Statute: Chapter 51 = 51.437 (14r)	Appointed by Governor to 4-yr. terms. Half are people w/DD or their parents, guardians or immediate relations. Also, groups & agencies concerned w/ services to persons w/DD plus reps. from DWD, DHFS, DPI, UW system, WCA.	26 members. Currently 5-6 with children under age of 21	1. Executive 2. Nominations & Membership 3. Governmental Affairs 4. County Plans & Budgets	Has Executive Director and several other staff.
Family Support Program (FSP) "Policy Advisory" Committee	Advise DHFS/BDDS on guidelines /rules that govern FSP	Children/families eligible for the FSP	State Statute: 46.985 (2)(a)	"County departments, providers of education pgms. & other services, reps of families."	No set number. Numerous members with children under 21 – 40% in 1994	None	Meets as needed.
Birth to Three Interagency Coordinating Council (ICC)	Advise & assist lead agency in development & implementation of policy, achieving full participation of all appropriate state public agencies, resolution of disputes, assignment of financial responsibility, & transition to Part B services.	Children that meet Birth – 3 definition of eligibility and their families	Federal Law: Idea Part C 303.600	Appointed by Governor & meets qtrly. Represents state pop. with several specific appointees. Suggests parent reps not be employed by any agency providing B-3 services. At least 20% are to be parents. See 303.601	16 members and currently two are parent representatives	None Use Work groups to address issues – ex. Medical Outreach and Quality Assurance.	Seen by some as only council that relates exclusively to children w/disabilities. Language on membership states reps. must have sufficient authority to engage in policy dev. & implementation on behalf of their agency.

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Wisconsin Council on Mental Health	Advises Governor, legislature, and DHFS on allocation of MH Block grants & evaluates/reviews MH system's progress towards achieving improved client outcomes & the adequacy of MH services in the State.	Persons of all ages with mental illness	Federal Law: 102-321 State Statute: 15.197 (1)	Appointed by Governor and meets bi-monthly. At least 50% consumers &/or family members. More detailed language in 1914 (c)(1)	15 members and two currently are parents of children.	1. Public Awareness 2. Planning & Monitoring 3. Legislative & Policy 4. Strategic Planning Sub-Committees: 1. Children's Issues 2. Criminal Justice	Governor's Blue Ribbon Commission on MH 6/96-2/97 was created by executive order to parallel LTS Redesign initiative and focus on recommending model MH delivery system including children.
Wisconsin COP/LTS Statewide Advisory Committee	Advises/reacts to DHFS recommendations re: COP policies & waivers (mainly CIP-II & COP-W)	All people eligible for COP = Community Options Program	State Statute: 46.27(2) (d) Established in 1982	County agencies, nursing homes, program participants plus providers, advocates, & other associations.	None	None	DHFS is exploring possibility of combining with LTC Council. Little to no attention to children's issues to date – but could be.
Wisconsin Council on Physical Disabilities	Develop & implement a state plan for services to people w/ PD, make recommendations on relevant legislation, promote public awareness & prevention.	People w/ PD as defined in state statute	State Statute: Act 202, 15.197 (4) and 46.29 Established in 1990	Appointed by Governor to 3 yr. terms & meets qtrly. Must have Governor's rep., at least 6 people w/PD, and 1 member must be service provider	14 members Currently 2 parent reps but do not know their child's age	1.Executive 2.Housing 3.Long-term Care 4.Transportation	\$8,000 budget to cover cost of meetings.

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Wisconsin State Independent Living Council	Collaborates with state vocational rehabilitation (VR) agency to develop, monitor, & review state independent living plan.	All disabilities, all ages	Federal Law: Section 705 of Rehab Act of 1973 and 1998 amendments	Appointed by Governor. Must include an ILC exec. & rep. from state VR agency (ex-official role). Within "other potential" members is listed: parents & guardians of people with disabilities. Majority of voting members must be individuals w/disabilities.	Youth representative	Executive	Has Executive Director and receives Federal operations money. Also has \$ to distribute in grants.
Wisconsin State Council on Alcohol and Other Drug Abuse	Review pending legislation, develop comprehensive state plan for AODA programs, coordinate efforts & expenditures to prevent/control AODA, evaluate & analyze "select" AODA pgms. each biennium.	People (children & adults) with substance abuse	State Statute: WI Act 210 (enacted 4/6/94). 13.098 and 14.24	Governed by 14.017 (2) of WI statutes. 22 members with 16 specifically denoted. Plus 6 "public" members. No consumer or parent requirements.	22 members NA	1. Planning & Funding 2. Prevention 3. Intervention & Treatment 4. Diversity 5. Interdepartmental Coordinating	Coordinator, Planner & Assistant within DHFS
State of Wisconsin Council for the Deaf and Hard of Hearing	Provide advice and support to governmental bodies, private groups, & individuals.	Deaf, deaf-blind, hard of hearing people	State Statute: 15.197 (8)	Governor appointed. Represents diverse professional & volunteer organizations working w/population. Parent(s) of deaf/hard of hearing children. Must include 3 deaf, 3 hard of hearing, 1 deaf/blind & 2 at large.	9 members Parent of 2 deaf children at Wisconsin School for the Deaf	1. Communication 2. Education/voc. 3. Executive Sub-Committees: 1. Legislative Initiatives 2. Interpreter Statute Drafting 3. Library 4. Mental Health – children and adults.	\$15,000 – covers costs of mtgs. and member expenses. This year council is also focusing on long term- universal newborn hearing screening and B-3 services.

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Milwaukee Child Welfare Partnership Council	Formulate policies, plans, evaluation, and funding priorities for operating and improving the child welfare system in Milwaukee County.	Children and families in Milw. County.	State Statute: WI Act 303 1995 46.023	Requirements 15.197(24)(a). No specific recipient member “slots.” Several County Board & State Leg. Reps.	19 members	1.Executive 2.Adoption 3.Cross Systems 4.Intake, Initial Assessment & In-Home Services 5. Out of Home Care (Case Management and Placements)	None
Disability Rights Wisconsin	Mission is that all people with disabilities and their families shall be empowered to exercise and enjoy the full extent of their rights and pursue the greatest quality of life.	People w/DD, serious mental illness, PD, & sensory disabilities; all ages.	Federal Law: DD Act P.L. 94-103 ('75) P&A for MI Individuals Amend Act 1991, P.L. 102-173 P&A of Indiv. Rights 1992, P.L. 102-569 State Statute: 51.62(2)	Designated by Governor as State P&A. Majority must be persons w/ DD, PD or MI; or their family members. Reflect balance of age, sex, race, and geography of State’s population.	Not less than 11 or more than 17 members. Several members with children under 21 yrs. of age	1. DD Advisory 2. Mental Health Advisory 3. PAIR Advisory 4. Nominating	Addresses school related issues, prevention of institutionalization and return to community, assistive technology, etc. Staff has leadership role in Quality Education Coalition.
Medical Assistance Advisory Committee	Advises and assists in the development of general policy involved in the provision of medical services under T19 of Social Security Act.	MA recipients and/or families – elderly, disabled, children and low-income	Federal Law: 42 CFR 431.12 State Statute: 15.04 (1) (c)	Meets qtrly. Membership groups: physicians, health care providers or professional agencies, consumer advocates, MA recipients, & Dir. of PH Dept. or designee.	19 current members, includes parent of children with disabilities	Steering	Very large scope of issues and services to address.

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Children Come First Statewide Advisory Committee	Support the development of a comprehensive system of coordinated care for children with severe disabilities and their families.	Children with severe disabilities and their families. Includes mental, physical, sensory, behavioral, emotional, & developmental disabilities.	State Statute: WI Act 31 46.56(14)	Long list of possible reps. Co. Depts., DPI, professional experts, family members, advocates, DVR, technical college, court officials, & health care providers.	Unknown	None. Create work groups around issues as needed.	Working on establishing a “Coordinated Services Executive Committee” composed of policy decision makers from key systems, i.e. DPI, DHFS, Juvenile Justice, etc.
Wisconsin Lifespan Advisory Council	Advises the Respite Care Association of WI Board of Directors on issues specific to Lifespan Respite Care	All individuals needing respite care regardless of age or special need.	State Statute: WI Act 9 First mtg. in 2003	Meets qtrly. Individuals across the lifespan representing at least 51% consumers.	10-15 members Two members with children under 21	None	Staffed by staff from Special Needs Adoption. No expenses paid.
Wisconsin Rehabilitation Council	Review, analyze, & advise DVR regarding performance of its responsibilities in providing quality services to people w/disabilities.	People w/disabilities eligible for DVR services	Established in 1993 by Executive Order #196 of the Governor	51% has to be individuals w/physical, cognitive, sensory, or mental disabilities. Family members, guardians, advocates, or authorized reps. of people w/disabilities. Current & former applicants or recipients of DVR services.	22 members Have had parents as members in the past.	1.Executive 2. Evaluation & Consumer Satisfaction 3. Annual Report & State Plan	Current issue is transition age youth (16 yrs. plus). In general also address issues for students who meet 504 guidelines & supported employment funding for long term follow-up services.

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Governor's Committee for People with Disabilities	Advise Governor & state agencies re: disability issues, review legislation, promote effective publicly administered services, increase public awareness, & encourage involvement of people w/disabilities in government.	All disabilities – AODA, sensory impairment, DD, MH, & PD	Established by Governor Executive Order. Gov. Doyle has not yet issued order to keep the committee in existence.	Meets qtrly. Appointed by Gov. with majority people with disabilities or parent – guardian. Reps. from Council on Blindness, Council for Deaf & H-of-H, DD, MH, & AODA	No more than 20 members, currently 16 Unable to provide	1.Executive 2.Business Leadership Network (BLN) 3.Youth Leadership Forum	BLN in cooperation with DVR offers employers a pool of applicants with disabilities plus support info. and services. \$40,000
Council on Children with Long-Term Support Needs (established 2005) formerly Children's Long-Term Support Committee	Develop a proposal with the best options & recommendations about how services to children with long term care needs should be designed & managed.	Families with children with long term support needs	Established in 9/97 by DHFS Secretary	No specific membership requirements or process for appointments. Currently, 31 community representatives and 17 govt. representatives Meets 4 times a year	Currently, 20 members are parents of children with disabilities	None	Staff and resources from Waisman Center and DHFS/BDDS
Wisconsin Council on Long Term Care Reform	Report annually to the legislature & Governor on status of Family Care pilots and assist DHFS develop broad policy issues related to long term care services.	Primarily frail elders & adults w/DD or PD 18 years of age or older.	'99 WI Act 9 sunset 7/01 & became advisory group to DHFS on emerging issues in LTC on 9/01	Appointed by DHFS Secretary. Meets monthly for 5 hours.	Increased from 15 to 17 members in 9/01 to included reps. from CLTS Redesign Comm. & MH/AODA managed care pilots.	None	

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Maternal and Child Health Program Advisory Committee	Advises and makes recommendations to the Division of Public Health for a comprehensive Maternal and Child Health Program in Wisconsin.	Children through age 21 and women of child bearing age	Serve at the discretion of administrator of the DHFS Div. of Public Health	Parents, local Health Depts., Children with Special Health Care Needs Centers, not-for-profit agencies, and Great Lakes Inter-Tribal Council reps.	48 members 8 parents	None	Three meetings and one symposium or event held each year.
Wisconsin Early Childhood Collaborating Partners	Transform early childhood care & education. Develop a plan that permits every child & family in WI access to a blended, comprehensive delivery system for high quality early childhood care & education.	All children Birth to age 8	Ad Hoc Voluntary membership	At least 2 statewide meetings/ year 40 + Endorsing Partners 96 + Participating Partners 400 + Interested Others	Organizations belong more than individuals	Group functions as action team that oversees action plan	Suggested that Governor establish Children's Council or Cabinet. Have paper written re: this recommendation.
Wisconsin Coalition of Independent Living Centers	Lobbying, grant writing, statewide cohesiveness of ILCS	All disabilities, all ages	Optional structure supported by ILC dues	Dir. & Asst. Dir. of 8 ILCS – meet 2 days ever other month	NA	None	NA
Wisconsin Council on Children and Families	Promote well-being of children & families in WI by advocating for effective & efficient health, education, & human service delivery systems.	All children & families within WI	Non-profit, multi-issue child & family advocacy agency.	29 members from across the state	Unknown	None	

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Wisconsin Council of the Blind	Promote dignity & independence of people in WI who are blind & visually impaired by providing services, advocating for legislation & educating the general public.	People who are blind and visually impaired	Private, not-for-profit agency established in 1952	Board of Directors. 19 volunteer delegates: 11 appointed by 5 organizations representing people who are blind, 8 elected at-large	19 members	Nine	Receives no govt. funding - \$ via grants, bequests, & annual drive