

ASD Task Force  
January 3, 2013  
Meeting Minutes

Information was shared by DPI on the results of a survey sent to special education units to gain input on training topics desired. The survey results are attached.

Time was spent discussing the legislative bill drafts with Senator Heckaman. The draft legislation is attached.

Dr. Dobrinski shared information on DSM 5 changes coming in the spring. Documents attached.

DHS provided an update on the ASD waiver. The waiver will begin a waiting list most likely this month. This means 30 children are being served. An update was provided on the plan to renew the waiver and make changes.

SAND grant provided updates on their training, website, etc. Task Force members were encouraged to look at the website and provide comments on needed adjustments and changes.

Public Comment – Comments received were about the need for services now not putting money to registry or personnel.

The group identified April 30<sup>th</sup> as the next task force meeting date with the understanding that this may need to be rescheduled if the Legislative session is still in session.

NDDPI PD Survey sent to the 31 Special Education Units

Q1. What areas related to ASD would you want your staff to receive training (check all that apply)?

Social skills instruction	28
Communication systems or skills	19
TEACHH, Pivotal Response, Social Stories	15
Secondary Transition	10
Preschool	9
Diagnostics/ Assessment	9
Inclusion Strategies	13
ABA	11
Conducting FBA	8
Writing Effective Behavior Plans	20
Personal Safety Skills	8
Independent Living	13

Q2. Would you be willing to pay for any portion of the cost for these trainings (i.e. professional fee for trainer, travel expenses of presenter, any school staff costs)?

yes	11
no	3
possibly	6

Introduced by

Senator Heckaman

1 A BILL for an Act to provide appropriations to the department of human services for autism  
2 spectrum disorder services.

3 **BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

4 **SECTION 1. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATE**

5 **AUTISM COORDINATOR.** There is appropriated out of any moneys in the general fund in the  
6 state treasury, not otherwise appropriated, the sum of \$494,135, or so much of the sum as may  
7 be necessary, to the department of human services for the purpose of hiring a state autism  
8 coordinator and an assistant who would be responsible for implementing a resource and service  
9 center to provide information and services for individuals with autism spectrum disorder,  
0 developing a statewide outreach plan, conducting regional meetings and an annual conference,  
1 and developing a protocol for use after screenings, for the biennium beginning July 1, 2013, and  
2 ending June 30, 2015. The department of human services is authorized two full-time equivalent  
3 positions.

4 **SECTION 2. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - AUTISM**

5 **SPECTRUM DISORDER DIAGNOSTIC TEAMS.** There is appropriated out of any moneys in  
6 the general fund in the state treasury, not otherwise appropriated, the sum of \$433,280, or so  
7 much of the sum as may be necessary, to the department of human services for the purpose of  
8 providing for autism spectrum disorder evaluation, diagnostic, and service planning teams, for  
9 the biennium beginning July 1, 2013, and ending June 30, 2015.

Introduced by

Senator Heckaman

1 A BILL for an Act to provide for the establishment of an autism spectrum disorder registry; to  
2 direct the department of human services to seek an autism spectrum disorder medicaid waiver;  
3 and to provide appropriations to the department of human services for autism spectrum disorder  
4 services.

5 **BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

6 **SECTION 1.**

7 **Autism spectrum disorder registry.**

8 **The department of human services shall establish and administer an autism spectrum**  
9 **disorder registry. The registry must include a record of all reported cases of autism spectrum**  
10 **disorder in the state and any other information deemed relevant and appropriate by the**  
11 **department in order to complete epidemiologic surveys of the autism spectrum disorder, enable**  
12 **analysis of the autism spectrum disorder, and provide services to individuals with an autism**  
13 **spectrum disorder.**

14 **SECTION 2. DEPARTMENT OF HUMAN SERVICES' AUTISM SPECTRUM DISORDER**

15 **MEDICAID WAIVER.** The department of human services, by January 1, 2014, shall seek  
16 approval from the federal centers for medicare and medicaid services to expand the  
17 department's autism spectrum disorder medicaid waiver to cover individuals from age three to  
18 end of life and to provide appropriate services that may include evidence-based practices,  
19 intervention coordination, in-home support, equipment and supplies, home monitoring,  
20 residential supports and services, extended vocational supports, or behavioral consultation.

21 **SECTION 3. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - AUTISM**

22 **SPECTRUM DISORDER REGISTRY.** There is appropriated out of any moneys in the general  
23 fund in the state treasury, not otherwise appropriated, the sum of \$200,648, or so much of the  
24 sum as may be necessary, to the department of human services for the purpose of establishing

1 and administering an autism spectrum disorder registry, for the biennium beginning July 1,  
2 2013, and ending June 30, 2015. The department of human services is authorized one full-time  
3 equivalent position for this purpose.

4 **SECTION 4. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATE**  
5 **AUTISM COORDINATOR.** There is appropriated out of any moneys in the general fund in the  
6 state treasury, not otherwise appropriated, the sum of \$494,135, or so much of the sum as may  
7 be necessary, to the department of human services for the purpose of hiring a state autism  
8 coordinator and an assistant who would be responsible for implementing a resource and service  
9 center to provide information and services for individuals with autism spectrum disorder,  
10 developing a statewide outreach plan, conducting regional meetings and an annual conference,  
11 and developing a protocol for use after screenings, for the biennium beginning July 1, 2013, and  
12 ending June 30, 2015. The department of human services is authorized two full-time equivalent  
13 positions for this purpose.

14 **SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE**  
15 **AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any  
16 moneys in the general fund in the state treasury, not otherwise appropriated, the sum of  
17 \$158,032, or so much of the sum as may be necessary, to the department of human services  
18 for the purpose of implementing a statewide autism spectrum disorder training effort, including  
19 physician training, regional training, and parent training, for the biennium beginning July 1,  
20 2013, and ending June 30, 2015.

21 **SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - BEHAVIORAL**  
22 **ANALYSTS.** There is appropriated out of any moneys in the general fund in the state treasury,  
23 not otherwise appropriated, the sum of \$198,864, or so much of the sum as may be necessary,  
24 to the department of human services for the purpose of providing funding support for individuals  
25 to complete a board-certified behavioral analyst program, for the biennium beginning July 1,  
26 2013, and ending June 30, 2015.

27 **SECTION 7. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - AUTISM**  
28 **SPECTRUM DISORDER DIAGNOSTIC TEAMS.** There is appropriated out of any moneys in  
29 the general fund in the state treasury, not otherwise appropriated, the sum of \$433,280, or so  
30 much of the sum as may be necessary, to the department of human services for the purpose of

Sixty-third  
Legislative Assembly

- 1 providing for autism spectrum disorder evaluation, diagnostic, and service planning teams, for
- 2 the biennium beginning July 1, 2013, and ending June 30, 2015.

# HUMAN SERVICES COMMITTEE

The Human Services Committee was assigned the following responsibilities:

1. Section 2 of 2011 Senate Bill No. 2268 directed a study of the current system for the diagnosis, early treatment, care, and education of individuals with autism spectrum disorder, including a review of a sliding fee scale for payment of services and the value of services provided; consideration of the recommendations of the Autism Spectrum Disorder Task Force; and input from stakeholders in private and public sectors, including families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood services providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities.
2. Section 1 of 2011 House Bill No. 1199 directed the Legislative Management to contract with a consultant to study guardianship services for vulnerable adults in the state. The study must include an analysis of the need for guardianship services in the state; the establishment of guardianships; petitioning costs and other costs with providing guardianship services; the entities responsible for guardianship costs; and the interaction between the courts, counties, state agencies, and guardianship organizations regarding guardianship services. The Legislative Management amended the directive to include a study of the efficacy of statutes governing public administrator services and methods for the timely and effective delivery of guardianship and public administrator responsibilities and services. The consultant was to provide periodic reports and provide the final report and recommendations regarding the study before June 1, 2012.
3. Senate Concurrent Resolution No. 4020 (2011) directed a study of the causes of the increases in Department of Human Services' caseloads and program utilization and the impact of federal health care reform.
4. Section 9 of 2011 Senate Bill No. 2012 directed a study and evaluation of the state's qualified service provider system.
5. The Legislative Management assigned the committee responsibility to receive the following reports:
  - a. An annual report on the autism spectrum disorder plan from the Autism Spectrum Disorder Task Force pursuant to North Dakota Century Code Section 50-06-32.
  - b. An annual report from the Department of Human Services describing enrollment statistics and costs associated with the children's health insurance program state plan pursuant to Section 50-29-02.
  - c. A report from the Health Information Technology Advisory Committee by June 30, 2012, regarding the outline on how best to standardize drug prior authorization request transactions between providers and the payers, insurance companies, and pharmacy benefit managers pursuant to Section 2 of 2011 House Bill No. 1422.
  - d. Periodic reports from the Department of Human Services regarding the status of the dementia care services program pursuant to Section 5 of 2011 Senate Bill No. 2012.
  - e. Reports from the Department of Human Services and its steering committee beginning in June 2012 regarding the development of a new developmental disabilities reimbursement system pursuant to Section 1 of 2011 Senate Bill No. 2043.
  - f. A report from the Department of Human Services before September 30, 2012, regarding the department's preliminary findings and recommendations concerning its regional autism spectrum disorder centers of early intervention and achievement pilot program and receive a written report from the department before December 31, 2012, summarizing the status of the pilot program and any findings and recommendations pursuant to Section 1 of 2011 Senate Bill No. 2268.
  - g. A report from the Department of Human Services before September 30, 2012, of preliminary findings and recommendations regarding the department's comprehensive review of the substance abuse services pilot voucher payment program pursuant to Section 2 of 2011 Senate Bill No. 2326.

Committee members were Representatives Alon Wieland (Chairman), Dick Anderson, Roger Brabandt, Donald L. Clark, Tom Conklin, Curt Hofstad, Kathy Hogan, Richard Holman, Robert Kilichowski, Vonnie Pietsch, Chet Pollert, and Jim Schmidt and Senators Dick Dever, Robert Erbele, Tim Mathern, Joe Miller, and Gerald Uglem.

The committee submitted this report to the Legislative Management at the biennial meeting of the Legislative Management in November 2012. The Legislative Management accepted the report for submission to the 63<sup>rd</sup> Legislative Assembly.

## STUDY OF THE AUTISM SPECTRUM DISORDER

The Human Services Committee was assigned the following responsibilities relating to the autism spectrum disorder:

- A study of the current system for the diagnosis, early treatment, care, and education of individuals with autism spectrum disorder, including a review of a sliding fee scale for payment of services and

the value of services provided; consideration of the recommendations of the Autism Spectrum Disorder Task Force; and input from stakeholders in private and public sectors, including families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood services providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities pursuant to Section 2 of 2011 Senate Bill No. 2268.

- Receive an annual report on the autism spectrum disorder plan from the Autism Spectrum Disorder Task Force pursuant to Section 50-06-32.
- Receive a report from the Department of Human Services before September 30, 2012, regarding the department's preliminary findings and recommendations concerning its regional autism spectrum disorder centers of early intervention and achievement pilot program and receive a written report from the department before December 31, 2012, summarizing the status of the pilot program and any findings and recommendations pursuant to Section 1 of 2011 Senate Bill No. 2268.

#### **Background Information**

An autism spectrum disorder is a developmental disorder that causes significant impairments in the areas of socialization, learning, communication, behavior, and play skills. The deficiencies can lead to serious behaviors and can interfere with daily living. Characteristics do not usually manifest until between one and three years of age. The spectrum includes autism, Asperger's syndrome, pervasive development disorder - not otherwise specified, Rett's syndrome, and childhood disintegrative disorder. Symptoms and levels of impairments vary widely.

#### **Autism Spectrum Disorder Task Force**

Section 50-06-32 establishes an Autism Spectrum Disorder Task Force consisting of the State Health Officer, the Executive Director of the Department of Human Services, the Director of special education, the Executive Director of the Protection and Advocacy Project, and the following members appointed by the Governor:

- A pediatrician with expertise in the area of autism spectrum disorder;
- A psychologist with expertise in the area of autism spectrum disorder;
- A college of education faculty member with expertise in the area of autism spectrum disorder;
- A licensed teacher with expertise in the area of autism spectrum disorder;
- An occupational therapist;
- A representative of a health insurance company doing business in the state;
- A representative of a licensed residential care facility for individuals with autism spectrum disorder;
- A parent of a child with autism spectrum disorder;

- A family member of an adult with autism spectrum disorder; and
- A member of the Legislative Assembly.

The task force is to examine early intervention services, family support services that would enable an individual with autism spectrum disorder to remain in the least restrictive home-based or community setting, programs transitioning an individual with autism spectrum disorder from a school-based setting to adult day programs and workforce development programs, the cost of providing services, and the nature and extent of federal resources that can be directed to the provision of services for individuals with autism spectrum disorder.

The task force met several times; reviewed legislation, other states' autism spectrum disorder information, plans, and funding mechanisms; developed, disseminated, and summarized a statewide autism spectrum disorder needs assessment survey; established an initial state plan; and provided prioritized recommendations regarding autism spectrum disorder services to the Human Services Committee.

#### **Department of Human Services Autism Spectrum Disorder Medicaid Waiver**

The committee received testimony from the Department of Human Services regarding the department's autism spectrum disorder Medicaid waiver and learned the waiver was approved by the Centers for Medicare and Medicaid Services in November 2010 for a period of three years (November 1, 2010, through October 31, 2013). The waiver has the capacity to annually serve 30 children ages birth through four years who have a confirmed autism spectrum disorder diagnosis. Services available through the waiver include intervention coordination, in-home supports, equipment and supplies, and environmental modifications. As of October 2012, 19 children are receiving services through the waiver. Children may receive multiple services based upon their needs. The department's budget for the children's autism spectrum disorder waiver for the 2011-13 biennium is \$1,860,324, of which \$822,144 is from the general fund. Actual total fund expenditures were \$165,613 through August 2012. Utilization of the waiver is less than budgeted due in part to the age restrictions (individuals birth through age four) and service limitations. The department is gathering stakeholder input regarding suggested changes to the waiver, including changes to the eligible age group and changes to covered services. The department will consider the suggested changes in its application for renewal of the waiver.

#### **Department of Human Services Regional Autism Spectrum Disorder Centers of Early Intervention and Achievement**

Senate Bill No. 2268 (2011) provides that the Department of Human Services may use up to \$200,000 of its legislative appropriation for the 2011-13 biennium to establish and operate a regional autism spectrum disorder center of early intervention and achievement pilot program. The pilot program must provide a

matching grant to a qualified applicant that is a nonprofit intermediate care facility for individuals with intellectual disabilities which is licensed by the department. A qualified applicant is to establish the availability of \$1 of nonstate, cash matching funds for each grant dollar awarded. The source of matching funds must be funds of the applicant. A qualified applicant is to submit a plan for the delivery and funding of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than 10,000. As a condition of a grant award under this program, a qualified applicant is to agree to collaborate with the department in developing and implementing the plan as well as postaward monitoring by the department.

As of October 2012, the Department of Human Services does not anticipate having the funding available for this purpose.

### **Testimony and Recommendations**

#### **Department of Human Services**

The committee received testimony from the Department of Human Services regarding autism spectrum disorder services. The committee learned services for individuals with autism spectrum disorder are provided by several entities, including education, mental health, primary health care, developmental disabilities, advocacy organizations, and vocational rehabilitation. The Department of Human Services provides services to individuals with autism spectrum disorder through the infant development program, the Developmental Disabilities Division, Vocational Rehabilitation Division, and Mental Health and Substance Abuse Division. In the Developmental Disabilities Division, individuals need to have a developmental or intellectual disability, must be in need of institutional level of care, and be diagnosed with mental retardation.

The Department of Human Services does not consider autism spectrum disorder services as a core service of the department. The department is unable to provide a cost estimate for providing autism spectrum disorder services as a core service of the department until decisions are made and direction is provided as to the scope, intensity, and focus of the services. A sliding fee scale is used at the department's regional human service centers and could serve as an approach to apply to autism spectrum disorder services.

#### **Department of Public Instruction**

The committee received testimony from the Department of Public Instruction regarding autism spectrum disorder services. The committee learned the Department of Public Instruction is responsible for the general supervision of the Individuals with Disabilities Education Act (IDEA), which is the federal law for special education. The Department of Human Services is responsible for the IDEA services for infants and toddlers and their families, and the Department of Public Instruction is responsible for the IDEA special education

services for children and youth with disabilities ages 3 through 21.

The committee learned each year the Department of Public Instruction identifies the number of eligible students with disabilities ages 3 through 21 who are receiving special education and related services in North Dakota public schools. The most recent statewide count was completed on December 1, 2011, and at that time, there were 13,123 such students. Of the 13,123 students, 718 students were reported as having a primary disability of autism.

The committee learned the federal Office of Special Education Programs provides IDEA Part B formula grants to states to assist them to provide a free appropriate public education in the least restrictive environment for children with disabilities ages 3 through 21. Annually the Department of Public Instruction distributes the IDEA Part B funds to local special education units. These funds may be used for locally identified special education services and activities. Special education units may also apply for discretionary grants from the department to support locally identified initiatives which may include training needs.

#### **Other Interested Persons**

The committee received the following key comments from families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood services providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities:

- Individuals with autism spectrum disorder are unique and require individualized treatment approaches and plans. Adequate care requires an individualized, systems approach that includes the individual, their family and caregivers, the educational and legal systems, medical providers, occupational and speech therapists, and vocational and community supports.
- A sufficient amount of evidence-based research has not yet been completed regarding the diagnosis and treatment of the autism spectrum disorder.
- Many schools in the state are not prepared to serve students with autism spectrum disorders.
- There is a need for coordination of services among families, communities, and schools.
- Treatment options for individuals with autism spectrum disorders in rural areas are almost nonexistent.
- Families are experiencing challenges with the Department of Human Services' autism spectrum disorder Medicaid waiver, including the length of time to be approved for the waiver and lack of quality services provided under the waiver.
- The Anne Carlsen Center has begun offering autism spectrum disorder services in the major communities throughout the state. The services include diagnostics, comprehensive evaluations, program planning and development, intervention services, referral and family support services, and education and training.

- The committee should consider encouraging the medical community and families to be educated about the autism spectrum disorder and the importance of developmental screenings for young children.
- The committee should consider education, job coaching, and independency for the growing population of adults with autism spectrum disorders.

The following is a summary of the suggestions submitted to the committee for its consideration:

Rank	Autism Spectrum Disorder Task Force	Autism Society of North Dakota	Ms. Vicki Peterson
1	State autism coordinator and assistant - Add two new full-time equivalent (FTE) positions responsible for implementing a "one-stop shop" for information and services for individuals with an autism spectrum disorder, developing a state outreach plan, holding regional meetings, holding an annual conference, and developing a protocol for use after screening. The estimated biennial cost is \$494,135, consisting of \$242,122 for the coordinator's salary, benefits, and other office costs such as information technology fees; \$132,769 for the assistant's salary, benefits, and other office costs; and \$119,244 for operating expenses for travel and annual conference expenses.	Autism spectrum disorder registry - Develop and maintain an autism spectrum disorder registry within the State Department of Health. The estimated biennial cost is \$148,132, including one FTE position, for a simple registry and \$805,298, including three FTE positions, for a more comprehensive registry.	Access and awareness - Access to services for children, youth, and adults who have an autism spectrum disorder is limited in North Dakota compared to many other states. The state's Medicaid program and private insurance carriers need to support families in accessing services, including diagnosis, therapies, respite, and general health care.
2	Comprehensive training funds - Implement a statewide training effort, including physician training, regional training, and parent training, led by the state autism coordinator in coordination with key agencies. The estimated biennial cost is \$158,032, consisting of \$4,800 for physician training, \$98,832 for regional training, \$6,400 for parent training, and \$48,000 for a statewide training fund.	Voucher system for services and support - Establish a voucher system to be used for autism spectrum disorder programs and services. The estimated biennial cost for 150 individuals is \$4.5 million.	Delivery methods of therapies and services - Examine different ways to deliver therapies and services, including emphasis on medical homes and telehealth practices.
3	Autism spectrum disorder Medicaid waiver - Expand the Department of Human Services' autism spectrum disorder Medicaid waiver to cover individuals from age 3 through end of life and to provide services, such as evidence-based practices, intervention coordination, in-home support, equipment and supplies, home monitoring, residential supports and services, extended vocational supports, and behavioral consultation. The estimated biennial cost would be dependent upon the number of individuals served. The department's current developmental disabilities traditional waiver is budgeted on each person's services and support, costing an average of \$27,239 per year for waiver services.	Educational training and support - Provide training and support to classroom teachers and other staff to implement best practices for educating and providing services to students with an autism spectrum disorder. The estimated biennial cost is \$198,000.	Training and cross-training - Develop a more standard definition of a diagnosis of autism, establish a more central location for resources in the state, and provide more training and cross-training in the educational system.
4	Behavioral analysts - Increase the number of professionals delivering behavioral analyst services by providing funding support for 16 individuals (two in each region) to complete the St. Paul online board-certified behavioral analyst program to include the required supervision up to the point of taking the certification. The estimated biennial cost is \$198,864, consisting of \$12,429 for coursework, internship, textbooks, examination, and license costs for 16 individuals.		Looking ahead - Develop programs, including assistance for children transitioning into adulthood.
5	Dedicated diagnostic, evaluation, and service planning teams - Provide funding for evaluation, diagnostic, and service planning teams comprised of a physician, occupational therapist, physical therapist, certified behavioral analyst, and family support member. The teams must interact with regional coalitions, state agencies, and the Autism Spectrum Disorder Task Force and provide timely referral and outcome reports. Evaluations and screenings currently range from \$1,725 to \$5,045 per child. The estimated cost of screening eight children in each of the eight regions would range from		

Rank	Autism Spectrum Disorder Task Force	Autism Society of North Dakota	Ms. Vicki Peterson
6	\$110,400 to \$322,880. The estimated cost of screening 16 children in each of the eight regions would range from \$220,800 to \$645,760. Health insurance mandate - Eliminate the exclusions for autism care and treatment in health insurance policies. Senate Bill No. 2268 (2011) as introduced, but not approved, provided for this recommendation. The fiscal note submitted for this version of the bill estimated a cost of approximately \$5.8 million for state government for the 2011-13 biennium.		
7	Autism spectrum disorder registry - Develop and implement an autism spectrum disorder registry. The estimated biennial cost is \$200,648, consisting of \$164,247 for personnel costs, \$20,057 for operating expenses such as travel and supplies, and \$16,344 for indirect costs.		

### Committee Recommendations

The committee recommends House Bill No. 1037 to provide for a Legislative Management study of the autism spectrum disorder. The bill provides that during the 2013-14 interim, the Legislative Management consider studying the current system for the diagnosis, early treatment, care, and education of individuals with autism spectrum disorder. The study must continue the work of the Legislative Management during the 2011-12 interim on the study of the autism spectrum disorder, consider the recommendations of the Autism Spectrum Disorder Task Force, and seek input from stakeholders in the private and public sectors.

The committee recommends House Bill No. 1038 relating to an autism spectrum disorder registry and educational training and support for teachers and other staff. The bill provides:

- The State Department of Health is to establish and administer an autism spectrum disorder registry. The registry must include a record of all reported cases of autism spectrum disorder in the state and any other information deemed relevant and appropriate by the department in order to complete epidemiologic surveys of the autism spectrum disorder, enable analysis of the autism spectrum disorder, and provide services to individuals with an autism spectrum disorder.
- A \$148,132 general fund appropriation to the State Department of Health for establishing and administering an autism spectrum disorder registry for the 2013-15 biennium. The department is authorized one FTE position for the initiative.
- A \$198,000 general fund appropriation to the Department of Public Instruction for providing training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism spectrum disorder for the 2013-15 biennium.

The committee recommends House Bill No. 1039 relating to a voucher system for autism spectrum disorder services and support. The bill provides:

- The Department of Human Services develop a voucher system for autism spectrum disorder services and support. The program is to consist of up to 100 individuals up to age 26 and up to 50 individuals aged 26 and older. To be eligible for the program, individuals must have been a resident of the state for a minimum of six months, have income levels that do not exceed 300 percent of the federal poverty level, and have a clinician's diagnosis of autism, Asperger's syndrome, or pervasive developmental disorder not otherwise specified. Eligible services for individuals up to age 26 include assessments, medical care, mental health services, occupational therapy and equipment, speech and language services, assistive technology, case management, transportation, educational supports, respite care, executive and social skills training programs, and development and implementation of behavioral intervention plans. Eligible services for individuals aged 26 and older include assessments, medical care, mental health services, occupational therapy and equipment, educational and employment services, housing, transportation, medical care, and independent living services.
- A \$4.5 million general fund appropriation to the Department of Human Services for administering a voucher system for autism spectrum disorder services and support. The department is to allocate up to \$30,000 per year to each individual enrolled in the voucher program for paying costs of eligible services.

### STUDY OF GUARDIANSHIP SERVICES

Section 1 of 2011 House Bill No. 1199 provided the Legislative Management is to contract with a consultant to study guardianship services for vulnerable adults in the state. The study must include analysis of the need for guardianship services in the state; the establishment of guardianships; petitioning costs and other costs associated with providing guardianship services; the entities responsible for guardianship costs; and the interaction between the courts, counties, state agencies, and guardianship organizations regarding guardianship

services. The Human Services Committee was assigned this responsibility.

The Legislative Assembly also provided the Human Services Committee study the efficacy of statutes governing public administrator services and methods for the timely and effective delivery of guardianship and public administrator responsibilities and services.

### **Background Information**

When a court determines an individual lacks the capacity to make or communicate the decisions necessary to manage his or her own personal affairs, a guardian may be appointed. Guardianship is the process by which a court, after determining that an individual is incompetent to make specific decisions, delegates the right to make those decisions to a guardian. Depending on the state statutes, a guardian may also be referred to as a conservator or curator. The process to initiate a guardianship and the practices following the appointment of a guardian differ from state to state. While all states require some sort of petition, notice, and judicial consideration before appointing a guardian, the extent of due process rights afforded the alleged incapacitated person varies.

Types of guardianships include:

- General guardian - Responsible for decisions in all aspects of the ward's (incompetent individual's) life.
- Limited guardian - Has authority to make decisions only in specific areas of the ward's life, such as financial or residential.
- Emergency or temporary guardian - Appointed in situations where immediate action is required to prevent harm to the ward. An emergency guardianship may not be in effect for more than 90 days and has only the authority identified by the court at the time of the appointment. The court may grant an extension beyond the 90-day limit if necessary.
- Testamentary guardian - Established when a guardian spouse or guardian parent of a person determined to be incapacitated appoints, by will, a successor guardian for that person.
- Conservator - Manages the estate and finances of a ward.

### **Consultant Services and Methodology**

The Legislative Council issued a request for proposal for consultant services for assistance in a study of guardianship services for vulnerable adults in North Dakota. The specific areas to be addressed included:

1. The need for guardianship services in the state - Review the number of guardians appointed by the courts and identify the unmet need for guardianship services in the state.
2. The establishment of guardianships - Review the services available for assistance with the establishment of guardianships and the process for the establishment of guardianships and recommend proposed changes.
3. Petitioning and other costs - Identify petitioning and other costs associated with providing

guardianship and public administrator services and financial assistance available.

4. Entities responsible for guardianship and public administrator costs - Identify the entities currently responsible for guardianship and public administrator costs.
5. Interaction between the courts, counties, state agencies, and guardianship organizations regarding guardianship services - Review the duties and responsibilities of these entities and the cooperation/collaboration and interaction between and among the entities associated with guardianship and public administrator services and recommend proposed changes.
6. The efficacy of statutes governing guardianship and public administrator services - Review the statutes governing guardianship and public administrator services, evaluate the effectiveness of the statutes, and recommend proposed changes.
7. Methods for the timely and effective delivery of guardianship and public administrator responsibilities and services - Determine the appropriate duties and responsibilities for entities involved in guardianship services, financial responsibilities, and the appropriate role for public administrators in providing guardianship services. Provide estimated costs for guardianship services for the 2013-15 biennium, identified by recommended entity responsible for these costs.

The committee received proposals from two entities interested in providing consultant services-- Mr. Winsor C. Schmidt, J.D., LL.M., University of the Louisville School of Medicine, Louisville, Kentucky, and North Dakota Center for Persons with Disabilities, Minot. The committee selected and contracted with Mr. Schmidt to conduct the study.

### **Findings and Recommendations**

The committee learned Chapters 30.1-26 and 30.1-28 govern guardianship services, and Chapter 11-21 governs public administrator services. Section 30.1-28-11(1) provides that a guardian may be any competent person or a designated person from a suitable institution, agency, or nonprofit group home. A guardian is court-appointed after a hearing for an incapacitated person. An incapacitated person is defined as any adult person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, or chemical dependency to the extent that the person lacks capacity to make or communicate responsible decisions concerning that person's matters of residence, education, medical treatment, legal affairs, vocation, finance, or other matters, or if the incapacity endangers the person's health or safety. A public administrator is an individual, corporation, or limited liability company appointed by the presiding judge as ex officio guardian and conservator of the incapacitated person for the county.

Mr. Schmidt presented the following findings and recommendations by major study area:

**I. The need for guardianship services in the state - Review the number of guardians appointed by the courts and identify the unmet need for guardianship services in the state.**

**Observations and Findings**

- There were 2,038 guardianship and conservatorship cases in North Dakota in 2010. There were 323 new filings in 2010 and an average of 311 new appointments per year from 2008 through 2010.
- Based on published national research on the extent of need for guardianship services, North Dakota's projected total population-based need for guardianship services is 751 individuals. The Department of Human Services has entered a contract with Catholic Charities North Dakota to serve 414 individuals in the 2011-13 biennium, and the department's Aging Services Division also has been provided funding to assist with the establishment of 32 guardianships for the 2011-13 biennium. Considering this, the total population-based unmet need for guardianship services in North Dakota is 305 individuals.
- The Council on Accreditation has developed adult guardianship accreditation standards. One of the standards provides that guardianship caseload sizes should support regular contact with individuals and the achievement of desired outcomes. Studies of guardianship programs recommend a 1-to-20 staff to client.
- One of North Dakota's principal corporate guardianship programs reports a guardianship staff-to-client ratio of 1-to-36-39.
- One of the several public administrators serving as guardian reports a part-time guardian caseload ranging from 22 to 29 with wards housed 210 miles apart.
- The *North Dakota Guardianship: Standards of Practice for Adults* publication provides that a guardian is to limit each caseload to a size that allows the guardian to accurately and adequately support and protect the ward, that allows a minimum of one visit per month with each ward, and that allows regular contact with all service providers.
- The National Academy of Elder Law Attorneys, the National Guardianship Association, and the National College of Probate Judges convened a Wingspan Implementation Session in 2004 to identify implementation steps relating to guardian certification. Steps include enacting a statutory framework to require education and certification of guardians and establishing a statewide registration of guardians.
- Some of the North Dakota guardianship stakeholders expressed concerns relating to oversight and monitoring of guardians and guardian annual reports and lack of requirements, such as criminal background and credit checks.

**Recommendations**

- Enact a statutory framework to require education and certification of guardians as well as continuing

education with the appointment process to ensure that all guardians meet core competencies.

- Adopt minimum standards of practice for guardians using the *National Guardianship Association Standards of Practice* as a model.

**II. The establishment of guardianships - Review the services available for assistance with the establishment of guardianships and the process for the establishment of guardianships and recommend proposed changes.**

**Observations and Findings**

- Chapter 30.1-28 provides the judicial process for the establishment of guardianships. Any interested person may petition for the appointment of a guardian for an allegedly incapacitated person. No filing fee may be required for a petition by a member of the individual treatment plan team or by any state employee. The court is to set a hearing date, appoint an attorney to act as guardian ad litem, appoint a physician or clinical psychologist to examine the proposed ward, and appoint a visitor to interview the proposed guardian and proposed ward. If the attorney appointed as guardian ad litem or other attorney is retained by the proposed ward to act as an advocate, the court may determine whether the guardian ad litem should be discharged. The proposed ward must be present at the hearing in person unless good cause is shown for the absence. If the court approves a visitor, lawyer, physician, guardian, or temporary guardian, that person may receive reasonable compensation from the ward's estate if the compensation will not unreasonably jeopardize the ward's well-being. The court may appoint a guardian only after finding in the hearing record based on clear and convincing evidence that:

The proposed ward is an incapacitated person.

There is no available alternate resource plan which could be used instead of guardianship.

The guardianship is the best means of providing care, supervision, or habilitation.

The powers and duties given the guardian are the least restrictive form of intervention consistent with the ability of the ward for self-care.

- Section 30.1-28-10 authorizes the court to exercise the power of a guardian pending notice and hearing or, with or without notice, appoint a temporary guardian for a specified period of time, not to exceed 90 days, if:

An alleged incapacitated person has no guardian and an emergency exists; or

An appointed guardian is not effectively performing the guardian's duties, and the court finds that the welfare of the ward requires immediate action.

- Some North Dakota guardianship stakeholders expressed concerns with the judicial process for the establishment of guardianships, including the

lack of mandatory reporting of vulnerable adult abuse and neglect, filing fees not waivable for indigents, limited legal assistance from state's attorneys or assistant attorneys general for petitioners in indigent cases, the lack of right to counsel or public defender for the proposed ward if the proposed ward cannot afford counsel, some proposed wards reportedly not present at hearings, and appointment of emergency guardians for up to 90 days without notice and a hearing.

**Recommendations**

- Change from voluntary reporting of vulnerable adult abuse or neglect to mandatory reporting of vulnerable adult abuse or neglect.
- Adopt model recommendations regarding the right to counsel and the duties of counsel representing the proposed ward at the hearing.
- Adopt Section 311 of the Uniform Guardianship and Protective Proceedings Act related to emergency guardians regarding required petition details, notice, the right to a hearing, the right to counsel, presence of the proposed ward at the hearing, limited duration, and the standard of proof.

**III. Petitioning and other costs - Identify petitioning and other costs associated with providing guardianship and public administrator services and financial assistance available.**

**Observations and Findings**

<b>Petitioning and Other Costs Associated With Guardianship Services</b>	
North Dakota - Department of Human Services Aging Services Division	Average petitioning cost was \$1,474 for the 2009-11 biennium. Funds available to provide a \$500 annual payment to 16 guardians in the first year of the 2011-13 biennium and 32 guardians in the second year of the biennium.
North Dakota - Department of Human Services Developmental Disabilities Division	Funding of \$2,052,415 available for 414 wards during the 2011-13 biennium, including \$51,720 for petitioning costs. The daily rate for corporate guardian services is \$6.52 per ward in the first year of the 2011-13 biennium (\$2,380 per client annually) and \$6.71 per ward in the second year of the biennium (\$2,449 per client annually).
Washington	Average annual cost per public guardian for the period 2008-11 was \$3,163.

**Recommendations**

None

**IV. The entities responsible for guardianship and public administrator costs - Identify the entities currently responsible for guardianship and public administrator costs.**

**Observations and Findings**

- The North Dakota Legislative Assembly has provided appropriations to the Department of Human Services for providing corporate guardianship services in the Developmental Disabilities Division and for petitioning costs and guardianship fee for individuals who have been diagnosed with a mental illness or traumatic brain injury or elderly individuals aged 60 and over.

- Some counties in North Dakota have provided funding for several public administrators in the state.

**Recommendations**

None

**V. The interaction between the courts, counties, state agencies, and guardianship organizations regarding guardianship services - Review the duties and responsibilities of these entities and the cooperation/collaboration and interaction between and among the entities associated with guardianship and public administrator services and recommend proposed changes.**

**Observations and Findings**

- Based on interviews with North Dakota guardianship stakeholders, the interaction between the courts, counties, state agencies, and guardianship organizations regarding guardianship and public administrator services seems generally good. There is some tension with the counties regarding funding of public administrators appointed by presiding district judges.
- The following are alternative structures for state public guardianship programs:

**Court model** - This model establishes the public guardianship office as part of the court that has jurisdiction over guardianship and conservatorship.

**Independent state agency model** - This model establishes a public guardianship office in an executive branch agency that does not provide direct services for a ward or potential wards.

**Social service agency model** - This model provides for placement of the public guardianship function in an agency providing direct services to wards. Several studies conclude this model is a clear conflict of interest.

**County agency model** - This model provides for the public guardianship function at the county level.

- North Dakota is currently a hybrid of the social service agency model and the county model.
- Guardianship stakeholders expressed concerns about lack of uniformity and statewide coverage of guardianship services.

**Recommendations**

- Change from the hybrid of the social service agency model and the county model. See Section VII regarding methods for the delivery of guardianship and public administrator responsibilities for prioritized recommended alternatives.

**VI. The efficacy of statutes governing guardianship and public administrator services - Review the statutes governing guardianship and public administrator services, evaluate the effectiveness of the statutes, and recommend proposed changes.**

**Observations and Findings**

- North Dakota has an "implicit" statutory scheme for public guardianship. Implicit schemes often name a state agency or employee as guardian of last resort when there are no willing and responsible family members or friends to serve. Explicit schemes generally provide for an office and the ability to hire staff and contract for services.
- North Dakota provides general fund appropriations to the Department of Human Services to contract with an entity to create and coordinate a unified system for the provision of guardianship services to vulnerable adults who are ineligible for developmental disabilities (DD) case management services and to individuals diagnosed with a mental illness, traumatic brain injury, or elderly individuals aged 60 and over. North Dakota statutory provisions authorize judicial appointment of a county public administrator with duties and powers to serve as ex officio guardian and conservator in specified cases. This segregation may result in vulnerable individuals with dual or multiple diagnoses and eligibilities not receiving appropriate public guardian services.
- North Dakota provides that any person interested in the welfare of an allegedly incapacitated person may petition for the appointment of a guardian. A question to the effectiveness of public guardianship is whether public and private guardianship agencies may petition for appointment of themselves as guardian. This is a potential conflict of interest.
- There are concerns regarding adult protective services and guardianship in North Dakota, including the lack of mandatory reporting of vulnerable adult abuse and neglect, and inconsistent adult protection services.
- Almost all of North Dakota's provisions for notice and hearing are comparable to the Uniform Guardianship and Adult Protective Proceedings Act. The most significant exception is the absence of provisions for informing the proposed ward or ward of rights at the hearing and of the nature, purpose, and consequences of appointment of a guardian.
- Some of the North Dakota guardianship stakeholders expressed concerns with the lack of right to counsel or public defender for the proposed ward if the proposed ward cannot afford counsel.
- Thirty-six states, including North Dakota, require "clear and convincing evidence" as the standard of proof in guardianship proceedings. The Model Public Guardianship Act recommends "clear, unequivocal, and convincing evidence" as the standard of proof.
- Several North Dakota guardianship stakeholders report insufficient physician specialists for clinical evaluations in guardianship proceedings.
- Twenty-seven states, not including North Dakota, have specific guardian background requirements like a credit check that disqualify felons from serving as guardian.
- At least 44 states specify a particular agency to serve as public guardian. North Dakota authorizes any appropriate government agency to serve a guardian as eighth priority except that an institution, agency, or nonprofit group home providing care and custody of the incapacitated person may not be appointed guardian. North Dakota also authorizes judicial appointment of a county public administrator with duties and powers to serve as ex officio guardian and conservator without application to court or special appointment in specified cases.
- Most state statutes provide that the public guardian has the same duties and general probate powers as any other guardian. Many state statutes also list additional duties and powers for the public guardian, such as requiring the public guardianship entity to maintain professional staff, contract with local or regional providers, and provide public information about guardianship and alternatives.
- Some North Dakota guardianship stakeholders expressed concerns about oversight and monitoring of guardians and guardian annual reports. Unlike a number of states, North Dakota does not have statutory provision for active court review of annual reports.
- Several North Dakota guardianship stakeholders expressed concerns with the temporary guardian statute. Compared with the emergency guardianship statutes in other states, North Dakota lacks required petition details, notice requirements, specific language about the right to a hearing pre and post order, right to counsel at the hearing, presence of the proposed ward at the hearing, limited duration, and specific language about the standard of proof.

#### Recommendations

- Adopt an explicit statutory scheme for public guardianship. See Section VII regarding methods for the delivery of guardianship and public administrator responsibilities for prioritized recommended alternatives.
- Provide public guardian services for all eligible incapacitated persons similarly, and not public guardian services for only particular diagnoses or categories. See Section VII regarding methods for the delivery of guardianship and public administrator responsibilities for prioritized recommended alternatives.
- Adopt a prohibition against the public guardian petitioning for appointment of itself.
- Change from voluntary reporting of abuse or neglect to mandatory reporting of abuse or neglect. (This recommendation is also included in Section II regarding the establishment of guardianships.)
- Adopt a version of the Uniform Guardianship and Adult Protective Proceedings Act notice provisions regarding rights at the hearing and the nature,

purpose, and consequences of appointment of a guardian.

- Adopt the recommendations of the Model Public Guardianship Act regarding the right to counsel and the duties of counsel representing the proposed ward at the hearing. (This recommendation is also included in Section II regarding establishment of guardians.)
- Adopt a right to trial by jury in guardianship proceedings.
- Consider changing the standard of proof in guardianship proceedings to "clear, unequivocal, and convincing evidence."
- Consider adopting the Model Public Guardianship Act provision regarding evaluation in guardianship. The provision provides that the alleged incapacitated person has the right to secure an independent medical or psychological examination relevant to the issues involved in the hearing at the expense of the state if the person is unable to afford such examination and to present a report of this independent evaluation or the evaluator's personal testimony as evidence at the hearing.
- Require information in the petition for appointment of a guardian and in the visitor's report about the qualifications of the proposed guardian to include the results of fingerprint, criminal history, and credit background checks before appointment of a guardian.
- Specify one public guardian agency to serve as public guardian, and make the agency independent from all service providers. See Section VII regarding methods for the delivery of guardianship and public administrator responsibilities for prioritized recommended alternatives.
- Require guardians and guardian organizations to comply with the North Dakota Guardianship Standard 13(V) that the guardian of the person visit the ward monthly and the North Dakota Guardianship Standard 23 (III) that the guardian limit each caseload to a size that allows the guardian to accurately and adequately support and protect the ward, that allows a minimum of one visit per month with each ward, and that allows regular contact with all service providers.
- List additional duties and powers for the public guardian modeled after those in the Model Public Guardianship Act. See Section VII regarding methods for the delivery of guardianship and public administrator responsibilities for prioritized recommended alternatives.
- Establish a system for active monitoring of guardianship annual reports, including filing and review of annual reports and plans.
- Adopt Section 311 of the Uniform Guardianship and Protective Proceedings Act related to emergency guardians regarding required petition details, notice, the right to hearing, the right to counsel, presence of the proposed ward at the hearing, limited duration, and the standard of

proof. (This recommendation is also included in Section II regarding the establishment of guardianships.)

**VII. Methods for the timely and effective delivery of guardianship and public administrator responsibilities and services - Determine the appropriate duties and responsibilities for entities involved in guardianship services, financial responsibilities, and the appropriate role for public administrators in providing guardianship services. Provide estimated costs for guardianship services for the 2013-15 biennium by recommended entity responsible for these costs.**

**Observations and Findings**

- North Dakota has statutory provisions for guardianship of incapacitated persons and for county public administrators. Twenty-eight of North Dakota's 53 counties do not have a public administrator. The 2010 census population of the 28 counties is 151,026, which is 22.5 percent of North Dakota's population.
- One nonprofit corporation with offices in Bismarck is reportedly the public administrator for 12 counties. These 12 counties have a 2010 census population of 147,799 (21.9 percent of the state's population) and cover an area of 16,031 square miles.
- The lack of an adequate number of public administrators in North Dakota's counties suggests that delivery of public administrator responsibilities and services is currently untimely and ineffective.

**Recommendations**

- Implement a model for public guardianship based on the strengths and weaknesses of each model and the particular needs of North Dakota. The recommended prioritization of models for North Dakota is:

Independent state office model - Establish a new state agency modeled after the North Dakota Commission on Legal Counsel for Indigents to provide public guardianship services.

County model - Timely and effective public administrator responsibilities and services appear to require replacement of uneven county funding with state funding of a public administrator in each of North Dakota's 53 counties at a funding level that would reduce guardianship caseload ratio from the reported 1:22-29 on a part-time basis to a 1:20 staff-to-client ratio on a full-time basis.

Alternative county model - Establish an independent office of public guardian within each of North Dakota's counties.

Judicial model - Establish the public guardianship office as a division of the court that has jurisdiction over guardianship and conservatorship.

### Estimated costs for the 2013-15 biennium

- Estimated costs for the 2013-15 biennium based on the 2011-13 legislative appropriation to the Department of Human Services for corporate guardianship and petitioning costs in the Developmental Disabilities Division range from \$3.4 million to \$4.5 million depending on the staff-to-client ratio.

### Guardianship Services Delivery Model Preliminary Estimated Costs

The committee received and reviewed further information regarding preliminary estimated costs of implementing the proposed guardianship services delivery models. The estimates were preliminary and subject to change as determinations are made and additional information becomes available. The cost estimates varied from \$1.2 million per biennium for the county model, \$1.36 million per biennium for the alternative county model, \$7.5 million per biennium for the independent state office model, and \$8.2 million per biennium for the judicial model.

### Responses to Findings and Recommendations

The committee received responses regarding the findings and recommendations included in the final report for guardianship services from the Department of Human Services, Supreme Court, North Dakota Association of Counties, Guardian and Protective Services, Inc., and committee members.

### Department of Human Services

The Department of Human Services indicated the final report assumes the department's current contracted guardianship services would be moved to a new guardianship services model to avoid having multiple models in the state. There are questions on how individuals currently receiving guardianship services from the department would be affected by a change in the guardianship services model. If individuals are transferred to a different guardian, it is possible that court involvement would be required resulting in additional costs.

The department indicated that the recommendation to change from voluntary reporting of vulnerable adult abuse or neglect to mandatory reporting may affect the department's Vulnerable Adult Protective Services (VAPS) program. If mandatory reporting is approved, it would be necessary to review and address the impact to the VAPS program to ensure that report of exploitation and other concerns can be reviewed and assessed in an effective and timely manner.

The department also indicated that guardianship services differ based on the individual under guardianship. There are very different needs for individuals with developmental disabilities, a traumatic brain injury, or a serious mental illness and individuals who are elderly. The differences impact guardianship costs and affect the number of individuals a guardian can appropriately serve.

### Supreme Court

The Supreme Court indicated the final report makes a number of recommendations to strengthen general procedural safeguards and emergency guardianship safeguards. The recommended changes could be incorporated into the current guardianship process with minor adjustments.

The Supreme Court supports the following recommendations included in the final report relating to the prevention of exploitation and abuse:

- Enact guardianship qualification requirements, such as requiring fingerprint, criminal history, and credit background checks before appointment as a guardian.
- Establish a system for monitoring guardianship annual reports, including filing and reviewing annual reports and plans.

The Supreme Court expressed concern with the following recommendations and also commented that they may add significant costs to the state:

- Provide the right to counsel to the proposed ward.
- Grant the alleged incapacitated person the right to secure an independent medical or psychological examination relevant to the issues involved in the hearing at the expense of the state if the person is unable to afford such examination and to present a report of this independent evaluation or the evaluator's personal testimony as evidence at the hearing.
- Adopt a right to trial by jury in guardianship proceedings.
- Change the standard of proof in guardianship proceedings to "clear, unequivocal, and convincing evidence."

### North Dakota Association of Counties

The North Dakota Association of Counties indicated the committee should consider providing an appropriation to an appropriate state agency to establish a central "clearinghouse" to oversee guardians, provide training and assistance to guardians, and pay for private guardianship services in situations where an individual has no other resources.

### Guardian and Protective Services, Inc.

Guardian and Protective Services, Inc., supported the recommendations in the final report. The organization met with representatives from the Supreme Court, North Dakota Association of Counties, Cass County Adult Protective Services Unit, AARP, guardianship agencies, and public administrators and suggested the following changes to guardianship and public administrator services:

Biennium	
2013-15	Amend emergency guardianship statutes. Transfer funding for public administrator services from the counties to the state through a general fund appropriation to the Office of Management and Budget with funds distributed through an annual grant process similar to the process provided in Section 54-06-20 or through a formula.

## DSM-V Rationale

- Autism is defined by a common set of behaviors and it should be characterized by a single name according to severity

## DSM-V changes with ASD

- Umbrella term – Autism Spectrum Disorders
- Eliminate Asperger's, PDD, etc.
- Severity Levels
  - Level 1 – requiring support
  - Level 2 – substantial support
  - Level 3 – very substantial support
- Social interaction and communication domains are grouped together as 1 domain
- No specific age of onset

## DSM-V Criteria

Must meet criteria in A, B, C, and D:

- A. Persistent deficits in social communication and social interaction across contexts; (by all 3 of the following) deficits in
  1. social/emotional reciprocity
  2. non-verbal communication behaviors
  3. developing and maintaining relationships
- B. Restricted, repetitive patterns of behavior, interests, or activities (at least 2 of the following)
  1. stereotyped/repetitive speech, motor movements, or use of objects
  2. excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior or excessive resistance to change
  3. highly restricted, fixated interests that are abnormal in intensity or focus
  4. hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limitations)
- D. Symptoms together limit and impair everyday functioning

## Potential Benefits

- Combined overlapping symptoms into one category
- Includes severity range from mild to severe
- Better accuracy in diagnosis

## Potential Concerns

- May be too restrictive; requires all 3 symptoms in criteria A be present
- No longer separate Asperger's diagnostic criteria
- May result in loss of diagnosis/loss of services (school, private therapies, and insurance)

# PSYCHIATRIC NEWS

..... *The First and Last Word in Psychiatry* .....

## **A Message From APA President Dilip Jeste, M.D., on *DSM-5***

December 1, 2012

I am pleased to announce that *DSM-5* has just been approved by APA's Board of Trustees. Getting to the finish line has taken a decade of arduous work and tens of thousands of pro-bono hours from more than 1,500 experts in psychiatry, psychology, social work, psychiatric nursing, pediatrics, neurology, and other related fields from 39 countries. We look forward to the book's publication next May.

The goal of the *DSM-5* process has been to develop a scientifically based manual of psychiatric diagnosis that is useful for clinicians and our patients. APA's interest in developing DSM dates back to the organization's inception in 1844, when one of its original missions was to gather statistics on the prevalence of mental illness. In 1917, the Association officially adopted the first system for uniform statistical reporting called the Statistical Manual for the Use of Hospitals for Mental Diseases, which was adopted successfully by mental hospitals throughout the country. It was expanded into the first *Diagnostic and Statistical Manual (DSM)* in 1952 and first revised (*DSM-II*) in 1968. Like the rest of the field in that era, these first two versions were substantially influenced by psychoanalytic theories.

With advances in clinical and scientific knowledge, changes in diagnostic systems are inevitable. The World Health Organization's *International Classification of Diseases (ICD)*—the standard diagnostic tool for epidemiology, health management, and clinical care used around the world, which covers all medical diagnoses—has been through 10 editions since the late 1800s and is now preparing its 11th edition, due in 2015. Likewise, *DSM* has undergone changes to take into account progress in our understanding of mental illnesses. *DSM-III*, published in 1980 under the leadership of Dr. Robert Spitzer, and *DSM-IV*, published in 1994 under the leadership of Dr. Allen Frances, represented the state of science of psychiatry at those times and significantly advanced the field.

In the two decades since the publication of *DSM-IV*, we have witnessed a wealth of new studies on epidemiology, neurobiology, psychopathology, and treatment of various mental illnesses. So, it was time for APA to consider making necessary modifications in the diagnostic categories and criteria based on new scientific evidence. But there were, of course, challenges inherent in revising an established diagnostic system.

The primary criterion for any diagnostic revisions should be strictly scientific evidence. However, there are sometimes differences of opinion among scientific experts. At present, most psychiatric disorders lack validated diagnostic biomarkers, and although considerable advances are being made in the arena of neurobiology, psychiatric diagnoses are still mostly based on clinician assessment.

Also, there are unintended consequences of psychiatric diagnosis. Some arise from the unfortunate social stigma and discrimination in getting jobs or even obtaining health insurance (notwithstanding the mental health parity law) associated with a psychiatric illness. There is also the double-edged sword of underdiagnosis and overdiagnosis. Narrowing diagnostic criteria may be blamed for excluding some patients from insurance coverage and needed services, while expanded efforts to diagnose (and treat) patients in the early stages of illness to prevent its chronicity are sometimes criticized for increasing its prevalence and potentially expanding the market for the pharmaceutical industry. (It should be noted, however, that *DSM* is not a treatment manual and that diagnosis does not equate to a need for pharmacotherapy.)

APA has carefully sought to balance the benefits of the latest scientific evidence with the risks of changing diagnostic categories and criteria. We realize that, given conflicting views among different stakeholders, there will be inevitable disagreements about some of the proposals—whether they involve retaining the traditional *DSM-IV* criteria or modifying them.

The process of developing *DSM-5* began in earnest in 2006, when APA appointed Dr. David Kupfer as chair and Dr. Darrel Regier as vice chair of the task force to oversee the development of *DSM-5*. The task force included the chairs of 13 diagnostic work groups, who scrutinized the research and literature base, analyzed the findings of field trials, reviewed public comments, and wrote the content for specific disorder categories within *DSM-5*. To ensure transparency and reduce industry-related conflicts of interest, APA instituted a strict policy that all task force and work group members had to make open disclosures and restrict their income from industry. In fact, the vast majority of the task force and work group members had no financial relationship with industry.

To obtain independent reviews of the work groups' diagnostic proposals, the APA Board of Trustees appointed several review committees. These included the Scientific Review Committee (co-chaired by Drs. Ken Kendler and Robert Freeman), Clinical and Public Health Committee (co-chaired by Drs. Jack McIntyre and Joel Yager), and APA Assembly Committee (chaired by Dr. Glenn Martin). Additionally, there was a forensic review by members of the Council on Psychiatry and Law. Drs. Paul Appelbaum and Michael First were consultants on forensic issues and criteria/public comments, respectively. Reviews by all these groups were coordinated in meetings of the Summit Group, which included the task force and review committee co-chairs and consultants along with members of the Executive Committee of the Board of Trustees.

There has been much more public interest and media scrutiny of *DSM-5* than any previous revisions. This reflects greater public awareness and media interest in mental illness, as well as widespread use of the Internet and social media. To facilitate this transparent process, APA created a Web site ([www.dsm5.org](http://www.dsm5.org)) where preliminary draft revisions were available for the public to examine, critique, and comment on. More than 13,000 Web site comments and 12,000 additional comments from e-mails, letters, and other forms of communication were received. Members of the *DSM-5* work groups reviewed the feedback submitted to the Web site and, where appropriate, made modifications in their proposed diagnostic criteria.

We believe that *DSM-5* reflects our best scientific understanding of psychiatric disorders and will optimally serve clinical and public health needs. Our hope is that the *DSM-5* will lead to more accurate diagnoses, better access to mental health services, and improved patient outcomes.