

DEVELOPMENTAL DISABILITIES
DEFINITION TASK FORCE

REPORT

November 21, 2008

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November 21, 2008

Ms. Karen Beye, Executive Director
Colorado Department of Human Services
Ms. Susan R. Hunt, Interim Director
Office of Adult, Disability and Rehabilitation Services
1575 Sherman Street
Denver, CO 80203

Dear Ms. Beye and Ms. Hunt:

Enclosed you will find the Report of the Definition for Developmental Disabilities Task Force. It represents the collective work of a broad and varied group of stakeholders. As you read the report, please consider the strength of the recommendations based on the fact that the Task Force reached full consensus on each of the recommendations.

The purpose of the Task Force, as identified in Ms. Hunt's directive to the Task Force dated September 8, 2008, was two-fold:

1. The Task Force is to determine what changes may be necessary through rule making or other processes to more clearly operationalize the existing statutory definition for developmental disabilities in C.R.S 27-10.5-102, and to specify what criteria will be used to determine whether someone meets the definition of a developmental disability.
2. The Task Force is to develop a potential new statutory definition and criteria to determine eligibility for developmental disabilities services that are funded under C.R.S. 27-10.5-104 in Colorado. The new definition must use clear and unambiguous language that is readily understood by the reader. This recommendation must also include specific criteria to be used to determine whether someone meets the new definition of a developmental disability.

Recommendations:

The Task Force does not recommend changing Colorado's current statutory definition. The Task Force believes that Colorado's current statutory definition (C.R.S 27-10.5-102) adequately describes the characteristics of people with developmental disabilities. After considerable deliberation about possible changes to the current statute, the task force concluded the existing statute is sufficient if CDHS modifies Rules to include individuals who have substantial functional adaptive behavior limitations.

The Task Force does recommend the revision of CDHS Rules to make them more consistent with the Colorado Statute 27-10.5 These recommendations are as follows:

A person can be determined to have a developmental disability by having mental retardation or a related condition that results in either:

- o Impairment of general intellectual functioning (currently adequately defined in rule as having an intelligence quotient that is 70 or less);

Or

- Adaptive behavior similar to that of a person with mental retardation (that would be defined as having adaptive behaviors which are two standard deviations below the mean in three or more of seven areas of major life activity). These adaptive behavior deficits will no longer be required to be related to intellectual functioning deficits.

The Task Force also recommends revising the rules to indicate that determination of a developmental disability must be made using a comprehensively administered, standardized and norm referenced instrument completed by a professional who is qualified and trained to administer the instrument.

- The Task Force recommends that the Department convene a work group to assist with the rule making process and components of implementation, determining impact on eligibility, program services and budget, and the development of an implementation plan for the revised rules.

Thank you for the opportunity to assist the State in addressing the needs of people who have developmental disabilities. We appreciate your inclusion of such a broad group of stakeholders with extensive experience and knowledge regarding this population. We have been honored to serve in this capacity. We are willing and available to assist the Department as it works toward implementation should you decide to make the changes we have recommended.

Respectfully Submitted,

Definition for Developmental Disabilities Task Force

| | |
|--------------------|--|
| Christy Blakely | Family Member and Family Voices Colorado |
| Nina Cruchon | Denver Options |
| David Eaton | Consumer |
| Wayne Eckerling | Family Member and Autism Society of Colorado |
| Liz Fuselier | The Legal Center for People with Disabilities and Older People |
| Dan Griffin | Dungarvin, Inc. |
| Sharon Jacksi | Division for Developmental Disabilities |
| Pat Jefferson | Family Member and Developmental Disabilities Resource Center |
| Jeff Konrade-Helm | Family Member |
| Keith Larsen | Arc of Mesa County |
| Rep. Don Marostica | Colorado House of Representatives |
| Senator John Morse | Colorado Senate |
| Barbara Prehmus | Department of Health Care Policy and Financing |
| Corry Rosenberg | JFK Partners, University of Colorado School of Medicine |
| Marijo Rymer | The Arc of Colorado |

c: Leslie Herod, Governor's Office
Sarah Sills, OSPB

RECOMMENDATIONS

The following recommendations represent the collective work of the Task Force over the last 3 months: These recommendations have been made after thoughtful and thorough consideration of many and varied options, extensive review of research and other materials regarding developmental disabilities, repeated consultation with national experts in the field and, most importantly, with full consensus on every point.

No changes to the current Colorado Statute, C.R.S. § 27-10.5-102 (11) (a).

Task force members agree that current problems with the definition of developmental disability in Colorado can be addressed with changes in the Department of Human Services rules and their implementation.

The following language is intended to identify the content that should be included in the proposed rule change. Out of respect for the rule making process and with understanding that rule language must be drafted in a specific and structured manner, the Task Force refrained from recommending exact wording and instead developed the following content. Therefore, any change in wording should be for the purpose of rule making requirements only and not to alter content.

Revise Colorado Department of Human Services rules, 2 C.C.R. 2503-1 § 16.120, to reflect , as Colorado Statute does, that a developmental disability can be identified in more than one way, all of which require:

- **Onset before the age of 22; and**
- **That the condition constitute a substantial disability to the affected individual; and**
- **That the condition is attributable to mental retardation or related conditions when such conditions are not attributable only to mental illness or a physical or sensory impairment;**
- **And when such conditions result in either:**
 - **Impairment of general intellectual functioning which means that the person has been determined to have an intelligence quotient which is two or more standard deviations below the mean (70 or less assuming a scale with a mean of 100 and a standard deviation of 15) as measured by a norm referenced, standardized test of general intellectual functioning comparable to a comprehensively administered Wechsler or Stanford-Binet (as revised or current to the date of administration) and administered by a licensed psychologist or a school psychologist;**

Or

- **Adaptive behavior similar to that of a person with mental retardation** which means that the person has overall adaptive behavior which is two or more standard deviations below the mean in 3 or more areas of major life activity (self care, receptive and expressive language, learning, mobility, self direction, capacity for independent living or economic self sufficiency) as measured by a norm referenced instrument which is standardized, comprehensive, and appropriate to the person's living environment, comparable to the Vineland Scales of Adaptive Behavior and administered and clinically determined by a qualified professional (a professional with specific training or experience in adaptive behavior assessment).

The Task Force emphasizes that the intent of their recommendation is to ensure that the rule is consistent with the Statute: that a person can be determined to have a developmental disability, given that the underlying requirements are present, either by deficits in general intellectual functioning as described above or by the presence of deficits or limitations in adaptive behavior as described above.

This means that a person who demonstrates adaptive behavior similar to a person with mental retardation as described above does not also need to demonstrate deficits in general intellectual functioning to be determined to have a developmental disability. In other words, low IQ is only one way to determine that a person has a developmental disability and it is not required when the primary determination is made using the requirements associated with adaptive behavior.

This proposed change will include people currently eligible or previously determined to be eligible for services, because the ability to determine that someone has a developmental disability still includes the single factor of impairment of general intellectual functioning.

The recommendation includes the change from two to three adaptive behavior limitations and from 10 skill areas to 7 areas of major life activity, to ensure that only those individuals who have a developmental disability will be identified using this definition. The recommendation to change the former skill areas to areas of major life activity for assessing deficits in adaptive behavior were made on recommendation of our national experts. This change will make Colorado's assessment of behavioral deficits more consistent with current practice in other states. This, in turn, will allow Colorado to better utilize data from other states to assist in the prediction of possible impact to the eligibility process and to better assess possible fiscal impact as well.

Any professional administering assessments under this rule should demonstrate proficiency with the evaluation tool being utilized. Clarification in rule of the qualifications of assessors and of what constitutes a comprehensively administered or complete assessment, are being recommended to ensure that only complete and appropriate assessments are submitted. This should identify people who qualify accurately and with greater consistency in the assessment and eligibility determination process.

Research indicates that impact of changes in definition on numbers of people eligible for service and on costs is profoundly difficult to predict. The impact depends on implementation practices and specific eligibility requirements for differing services provided through different funding sources. Consequently, the following recommendations are being made.

The Task Force recommends that a work group be convened by the Department to assist with the rule making process and to address additional components of implementation, service population impact and costs. The work group should consist of any Task Force members who are willing to continue, additional subject matter experts and Department staff. The work group should create a time sensitive work plan to include periodic reporting to CDHS. The charge of this group is to address the following policy and service expansion issues and the resulting fiscal impact, if any:

- **Examine the criteria proposed in the recommended rule to address impact on eligibility and service needs.**
- **Analyze and further identify the new population that will be eligible for DD services under the revised rule.**
- **Design an implementation plan, which will revise the eligibility determination process to ensure consistency and transparency.**
- **Analyze the fiscal impact of the recommended revisions and make appropriate recommendations for any related costs.**

DEVELOPMENTAL DISABILITY DEFINITION TASK FORCE MEMBERS

| <u>Task Force Member</u> | <u>Affiliation</u> | <u>Representing</u> |
|---------------------------------|--|------------------------------------|
| Christy Blakely | Family Member and Family Voices | Advocacy Group |
| Nina Cruchon | Denver Options | Community Centered Boards |
| David Eaton | Self Advocate | Consumers |
| Wayne Eckerling | Family Member and Autism Society of Colorado | Advocacy Group |
| Liz Fuselier | The Legal Center for People with Disabilities and Older People | Legal Advocacy Group |
| Dan Griffin | Dungarvin, Inc. | At Large Member |
| Sharon Jacksi | Division of Developmental Disabilities, CDHS | CDHS |
| Pat Jefferson | Family Member and Developmental Disabilities Resource Center | Community Centered Boards |
| Jeff Konrade-Helm | Family Member | Families |
| Keith Larsen | ARC of Mesa County | Advocacy Group |
| Rep. Don Marostica | Colorado House of Representatives | General Assembly |
| Mike McCarty*** | Developmental Disabilities Council | Developmental Disabilities Council |
| Senator John Morse | Colorado Senate | General Assembly |
| Barbara Prehmus | Department of Health Care, Policy and Financing | HCPF |
| Corry Rosenberg | JFK Partners, University of Colorado School of Medicine | UCHSC |
| Marijo Rymer | The ARC of Colorado | Advocacy Group |

*** Mr. McCarty did not attend any of the Task Force Meetings

STAFF ASSISTING THE TASK FORCE

In recognition of the scope of the task assigned to the Task Force, the Department contracted with national experts, **Ric Zaharia, Ph.D, Daniel Overbeck, Ph.D. and Rebecca Wright, Ph.D.**, from the Consortium on Innovative Practices, to provide technical expertise, background material on what definitions are used by other states,

analysis of the potential implications to the state for the various definitions that may be developed, and general advice and consultation to the Task Force.

In order to ensure that all participants perceived the process as fair and unbiased and that the Task Force complete its work in the time allotted, the Department hired an independent facilitator, **Jean G. McAllister**. She served as facilitator for all meetings of the Task Force, assisted the Task Force with the development of their work plan, kept minutes of the meetings and has had the primary responsibility for writing this report.

Additionally, staff from the Division for Developmental Disabilities, the Department of Health Care Policy and Financing, the Attorney General's Office, and the Governor's Office were available to Task Force members and at all meetings to answer questions, provide expertise, technical assistance and support during the deliberations of the Task Force. Those staff members were:

| | |
|-----------------|---|
| Amy Haight | Department of Health Care, Policy and Financing |
| Leslie Herod | Governor's Office |
| Susan Hunt | Office of Adult, Disability and Rehabilitation Services |
| Wade Livingston | Office of the Attorney General |
| John Miles | Division for Developmental Disabilities |
| Sarah Sills | Governor's Office of State Planning and Budgeting |
| Kerry Stern | Division for Developmental Disabilities |

Additional Attendees at Task Force Meetings

Bill Hanna
Marhya Kelsch
Karen Large
Cami Learned
Angela Van Manen
Jeremy Schupbach
Marica Tewell

TASK FORCE PROCESS

- The Task Force initially met on September 8, 2008 to review their charge and to begin development of a work plan.
- Eight additional working meetings were held, including a meeting to hear public comment (a list of attendees and those who provided public comment to the Task Force is at the end of this section of the report).
- A decision was made to attempt to work toward full consensus in all decisions and to use a modified version of Robert's Rules of Order to conduct meetings and for voting on formal motions.
- The Task Force began its work by educating itself extensively through presentations from content experts, document review (a list of documents reviewed by Task Force Members follows this section), submission of questions to and a full meeting to discuss answers with the national experts and by sharing their individual knowledge and expertise. They addressed current practice here and in other states, implementation processes, assessment and eligibility practices, service population impact and costs. They continued to generate questions for the national experts, for one another and for staff throughout the process. They substantially utilized the answers in the formulation of their recommendations.
- The Task Force began forming recommendations by first developing an accurate definition of developmental disabilities without attempting to draft specific language related to statutory or rule changes.
- They then developed draft language for a possible statutory change.
- They proceeded to work on draft language for a possible change in rules under the current Statute. The Task Force, at this point, recognized that the current statutory definition adequately addresses the needs of people with developmental disabilities.
- After substantial work on the language for a possible rules change, the Task Force made the decision that this would be the best way to address the need for a clear definition and decided unanimously to recommend no change to the current Statute. They decided to focus instead, on a change in rules and a more structured and consistent way to operationalize and implement that change.
- Throughout the process, the Task Force identified issues that were not strictly included in their initial charge, but that they felt needed to be addressed to successfully make the recommended changes or to improve the existing service system.
- They consistently struggled with the repeated information from all sources that predicting impact on service populations and costs is nearly impossible without addressing implementation, assessment and eligibility determination practices. Even with this information, there is still a huge range of possible outcomes.
- All recommendations were made by full consensus of the Task Force and a final draft of this report was reviewed, discussed, revised and approved by the Task Force at their final meeting on November 17, 2008.

DOCUMENTS REVIEWED BY THE TASK FORCE

- Centers for Disease Control (Surveillance Summaries February 9, 2007 / Vol. 56 / No. SS-1)
- Summary of DD denials since 2004
- Standard Measurement Tools for Identifying the Developmentally Disabled Population by R. Lee Henney, Ph.D., April, 1982, revised July, 1982
- Autism Newsletter, September 2008
- The Normal Curve and It's Relationship to Various Derived Scores (i.e., Bell Curve Graph)
- Defining Developmental Disability: Determining Eligibility for Services in Colorado, January 5, 2007, by David A. Ervin and Chris J. Olsen
- Office of Special Education Programs, Table 1-3. Students ages 6 through 21 served under IDEA, Part B, by disability category and state: Fall 2003
- Office of Special Education Programs, Table 1-14. Children ages 3 through 5 served under IDEA, Part B, as a percentage of population^a, by disability category and state: Fall 2006
- Community Contract and Management System data on active eligibility counts
- Community Contract and Management System data on active waiting list counts
- Colorado State and Federal Definitions of Developmental Disabilities
- DD Eligibility Denials by Community Centered Boards since 2004
- Division for Developmental Disabilities Programs and Services Descriptions and Funding FY 2007-08
- Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR Fourth Edition (Text Revision) by American Psychiatric Association, Diagnostic criteria for Mental Retardation, Autistic Disorder, Pervasive Developmental Disorders, Asperger's Disorder
- National Institute on Alcohol Abuse & Alcoholism R37: AA01455-1-33, Prenatal Alcohol Exposure and the Developing Fetus: Links to Developmental Disabilities
- Residential Supports for People with Developmental Disabilities in Colorado: System Capacity and the Waiting List, by Gary Smith, May 24, 1999
- A list of Generic Agencies Not Funded through Denver Options
- Colorado Department of Health Care Policy and Financing Medicaid Program Eligibility Chart
- Colorado Department of Health Care Policy and Financing Medicaid Waiver Chart, April 2008
- Assessment Instruments and Community Services Rate Determination: Review and Analysis, Human Services Research Institute, June 30, 2006
- IQ Test: Where Does It Come From and What Does It Measure? by Jan Strydom, M.A., H.E.D., D.Ed. & Susan Du Plessis, B.D., B.A. Hons (psychology)
- Status Report: Home and Community Based Services for People with Disabilities, by Human Services Research Institute, May 23, 2007
- National Association of State Directors of Developmental Disabilities Services (NASDDDS) Litigation Updates, May 2007 to January 2008 and January - July 2008

- Colorado Counties Population by Age Group - 2000 Census, Colorado Office of Demography
- Colorado Counties Population by Age Groups as a Percent of Total Population, - 2000 Census, Colorado Office of Demography
- The State of the States in Developmental Disabilities 2008 by David Braddock, Richard Hemp, Mary C. Rizzolo
- Summary of Figure Setting information for the Division Developmental Disabilities for March 5, 2008
- Overview of Community Centered Board Intake and Eligibility Process for Individuals age 5 and Older (September 2008), Nina Cruchon and Pat Jefferson
- The Vineland Adaptive Behavior Scales
- Decision Tree for “Federal Definition of Developmental Disability (dd)” target group on Wisconsin Long Term Care Functional Screen, State of Wisconsin
- Testing the Reliability and Validity of the Wisconsin Long Term Care Functional Screen, State of Wisconsin
- Tests and Measurements for the Parent, Teacher, Advocate & Attorney by Peter W. D. Wright, Esq. and Pamela Darr Wright, M.A., M.S.W.
- Variety of Information provided by the Consortium on Innovative Practices, including
 - Percent of Population and Population at each IQ Point on (SB5 – Wechsler Tests – DAS – KABC – LIPS R)
 - List of States Eligibility Criteria
 - Power Point Presentation on October 2, 2008
 - Responses to Queries from the Task Force
 - People served Per Capita in Home and Community Based Services Across the States
- Current State Statute and Rules
- State Rules prior to October 1, 2008
- Declaratory Order
- Federal Statute
- All public comments submitted to the Task Force

PUBLIC COMMENT

In the interest of ensuring that they had fully identified problems with the current definition in Statute and Rule, the Task Force held a meeting to gather public comment regarding potential changes in the definition of developmental disability on October 2, 2008 at the State Capitol. A list of people who testified, submitted written comment and attended the meeting follows.

Public Attendees Who Testified

Mona Askwig
Harriet Austin
Verlene Betzen and son Veren
Eileen Bisgard
Randy Chapman
Cynthia Eikenberg
Vanessa Hayes-Quiniana
Tami Johnson
Debbie Krisher
Sharon Langendoerfer
Karen Matthews
Jamie Matthews
Debbie Nelson
Kelly Stahlman

Written Comments Submitted Outside of the Public Hearing

William Cambell
Mark Emery
Nathan Johansen
Philip Foster
Cindy Lee
Todd Lowther
Inna-Paul Porter
Candace Webb
Sylvia Wilson
Theresa Wrangham
Two Comments received from Unknown Individuals

Public Attendees

Georgia Edson
Bill & Barbara Elus
Sarah Fisher
Cami Learned
Vickie Livesay

Julia Martinez
Carol Meredith
Marcia Tewell