

PA12-136

HB5437

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**CONNECTICUT
GENERAL ASSEMBLY
HOUSE**

**PROCEEDINGS
2012**

**VOL.55
PART 3
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colleague, the mayor of New Haven -- the Mayor of New Haven John DeStefano, who has brought with him, from the great city of New Haven, pizza for all of us to enjoy from -- from Pepe's. Sally's wasn't available, so we've got Pepe's Pizza today thanks to the Mayor of New Haven who's joined us today.

SPEAKER DONOVAN:

Thank you, Mayor. Thank you for joining us here today. It's good to see you. Thanks for all you do, all the good work you do in New Haven, and you can join us anytime, with or without pizza, but thank you very much. We appreciate it.

Will the Clerk please call Calendar 231.

THE CLERK:

On page 19, Calendar 231, Substitute for House Bill Number 5437, AN ACT CONCERNING THE DEFINITIONS OF MENTAL RETARDATION AND INTELLECTUAL DISABILITY, a favorable report by the Committee on Public Health.

SPEAKER DONOVAN:

Representative Christopher Lyddy, you have the floor, sir.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, I move for acceptance of the Joint

Committee's favorable report and passage of the bill.

SPEAKER DONOVAN:

The question is on acceptance of the Joint
Committee's favorable report and passage of the bill.

Will you remark?

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, this bill updates the definition of
the term "mental retardation and intellectual
disability" to be in line with the American
Association of -- or on Intellectual and Developmental
Disabilities. I want to make it clear that the new
definition in section (a) of this bill will clarify
that an individual with mental retardation or
intellectual disability must have a significant
limitation in intellectual functioning, concurrently
with deficits in adaptive behavior. Both must have
originated before the age of 18 and also be present at
the time when the disability determination is made.

Mr. Speaker, I'd also like to point out that this
legislation does not in any way bring in more people
into the system for services but simply directs more
targeted services to those individuals already

eligible.

Mr. Speaker, I urge passage.

SPEAKER DONOVAN:

Thank you, Representative.

Would you care to remark further?

Representative Jason Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

If I could, just one brief question, for the proponent of the bill, through you.

SPEAKER DONOVAN:

Please proceed, sir.

REP. PERILLO (113th):

Thank you, sir.

Currently, the psychiatric -- psychological community is seeing a change in their DSM manual. They're going from the DSM 4 to the DSM 5. Just curious as to whether or not this new definition is consistent with the DSM 4 or what we are moving toward, which is the DSM 5.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

This legislation does, in fact, line up with both the DSM 5 revision, as well as the AAIDD recommendations.

SPEAKER DONOVAN:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker, and I thank the gentleman for his answer to the question.

The second question I was going to ask, Representative Lyddy already answered, which is whether or not this would have a fiscal impact and expand the pool of individuals eligible, and that is indeed not the case. There is no fiscal impact in this bill. There's broad support for it, and I would urge it's -- a positive vote today.

SPEAKER DONOVAN:

Thank you, Representative.

Would you care to remark further? Would you care to remark further on the bill?

If not, staff and guests please come to the well of the House. Members take their seats. The machine will be open.

THE CLERK:

The House of Representatives is voting by roll

call. Members to the chamber. The House is taking a roll call vote. Members to the chamber, please.

SPEAKER DONOVAN:

Have all the members voted? Have all the members voted?

Please check the roll call board to make sure your vote has been properly cast.

If all the members have voted, the machine will be locked.

The Clerk will please take a tally.

Clerk, please announce the tally.

THE CLERK:

House Bill 5437.

Total Number Voting	137
Necessary for Passage	69
Those voting Yea	137
Those voting Nay	0
Those absent and not voting	14

SPEAKER DONOVAN:

The bill passes.

Representative Sharkey.

REP. SHARKEY (88th):

Thank you, Mr. Speaker.

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been very clear, you know, what the procedure is and also the need for this. So I'd like to return to our regular sign up here.

REP. BECKER: Very good, Madam Chair. So if they still would like to testify they can wait and --

SENATOR GERRATANA: Absolutely.

REP. BECKER: -- be taken in order at that time.

SENATOR GERRATANA: Absolutely.

REP. BECKER: Thank you very much.

SENATOR GERRATANA: Yes. Thank you so much.

REP. BECKER: Thank you and thank the committee.

SENATOR GERRATANA: Absolutely.

Thank you all for coming.

ALYSSA TEMKIN: Thank you.

SENATOR GERRATANA: You're welcome. You're welcome, Alyssa. Take care.

Next to testify is James McGaughey, from the Office of Protection Advocacy, testifying on House Bill 5437.

JAMES MCGAUGHEY: Good morning, Senator Gerratana --

SENATOR GERRATANA: Good morning.

JAMES MCGAUGHEY: -- Representative Ritter.

My name is Jim McGaughey. I'm director of the Office of Protection and Advocacy for Persons with Disabilities. It's always tough to follow

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children, but I'm here to speak on behalf of Raised Bill 5437, AN ACT CONCERNING THE DEFINITIONS OF MENTAL RETARDATION AND INTELLECTUAL DISABILITY. This bill updates the definition of the term "mental retardation" in Section 1-1g of the General Statutes and clarifies that it has the same meaning as the term "intellectual disability," which is used in a number of other statutory sections.

I have submitted written testimony. I won't read the entire -- the entire submission to you.

Basically, our office participated over the summer in some discussions with the Department of Developmental Disabilities and with other advocacy groups, in part, because there is a general dissatisfaction with the language in the current definition because it tends to focus on negative and measurements of deficiency. And I guess that, you know, it's part -- part of the problem we have with that language is that it's just sort of pejorative in its descriptions but also because there are better definitions available, in particular, from the professional association that has historically defined the concept and -- and given content to the definition in terms of establishing psychometric measurements and also other types of criteria for defining this concept.

The concept has evolved over time. We don't even like to use the term "mental retardation" anymore. We like the term "intellectual disability" at this point. And as the concept has evolved so, too, has the legal definition over time. In fact, our statutory definition has historically been tied to this professional definition. It's time to update it.

However, they are so progressive that they have -- they have come up with a definition or a set of criteria now that are not sufficiently precise for statutory purposes. So what you have before you now is a bill that attempts to incorporate the progressive ideas in that -- that professional definition with some of the objective criteria that are really necessary to express in statute. There's a lot that is tied to the statutory definition. There is potential for eligibility for state services; there is an issue about protection from discrimination; there is civil rights implications, as well. There are lots of places where the General Statutes refer to the definition in Section 1-1g. So we think this is a reasonable and -- a reasonable attempt to put together what needs to be expressed in statute with the more progressive understanding of what this concept really is.

It strikes a fair balance between that thinking and a need to have that level of specificity in statute, while at the same time, replacing some of the archaic terms that are present in our current definition.

DDS has been clear that it does not believe the language in the bill creates -- changes its criteria for eligibility so nobody is going to get services because of this change in definition who would not currently be eligible. Our office supports the measure and we would hope that you would, as well.

So that's all I have to say on it, and if you have any questions, I'll try and -- try and answer them.

SENATOR GERRATANA: Thank you, Mr. McGaughey.

I do have a question. You said that this is a professional standard. What is the source? Where does this definition come from?

JAMES MCGAUGHEY: Oh, yeah. It's from the American -- well, parts of it come from the American Association on Intellectual and Developmental Disabilities. It's the -- which itself has changed its name several times over the last 60 years to reflect a more progressive view of the -- the contributions and positive attributes of the people that they're concerned with. So it's -- but it is that -- that body is the first professional organization that defined the concept of mental retardation, and they did establish psychometric test results and things like that as part of the criteria. Those were always the basis upon which our statutes have -- have been written. So, in a sense, we're sticking with the same organization that -- that has been the basis of our statutory definition historically.

SENATOR GERRATANA: Good -- that's good work.

Would you do -- do us a kindness and just send us an email, perhaps, I mean by "us," the committee members or at least the chairs, of the source of the definition --

JAMES MCGAUGHEY: Certainly.

SENATOR GERRATANA: -- that you just --

JAMES MCGAUGHEY: Certainly.

SENATOR GERRATANA: -- just quoted. Just so I have a point of reference, and I can also do a little more research.

JAMES MCGAUGHEY: They have a whole book on the subject so it's a --

SENATOR GERRATANA: I'm sure. I love books.

JAMES MCGAUGHEY: -- right. Okay.

SENATOR GERRATANA: But at least so I have a point of reference, if you will.

JAMES MCGAUGHEY: Sure.

SENATOR GERRATANA: And I thank you so much for that.

Are there other questions?

Senator Welch.

SENATOR WELCH: Thank you, Madam Chair.

I have a question with respect to how this practically works. I understand that Subsection C, we're essentially getting rid of the definitions of "general intellectual functioning and significantly subaverage" and I guess replacing them with one defined term, "significant limitation on intellectual functioning." But as far I could tell, the nuances in that definition look materially the same, and I just want to confirm that -- that we're talking about two standard deviations. We're talking about the same kind of tests and --

JAMES MCGAUGHEY: Yes. I -- I think that's correct, and that's the basis upon which, I mean, I assume that DDS will be submitting testimony, as well. But I think that's the basis upon which they have concluded. It's not going to make people eligible who are not currently eligible.

SENATOR WELCH: Okay. Thank you, sir.

JAMES MCGAUGHEY: So, yes.

SENATOR WELCH: Thank you, Madam Chair.

SENATOR GERRATANA: Thank you, Senator.

Representative Perillo.

REP. PERILLO: Madam Chair, thank you very much.

A question I'm not sure if -- if you can answer it, but as I read through your testimony and I look at the language that's currently in statute as to a definition, the proposal is that we update language to match the upcoming DSM-5 language. From your perspective, would it make more sense if rather that insert language as definition, why wouldn't we just reference the definition within DSM-5?

JAMES MCGAUGHEY: Well, in part, because the -- we have no, I think, no control over whatever direction the authors of the Diagnostic and Statistical Manual are going to take in their next evolution. And in fact, there's a -- I'm not sure if the committee is aware of it, but there's right now a controversy raging over the definition of autism that is going to be implanted in that -- in that upcoming manual. There's a lot of controversy about that.

So I think people -- people would be more comfortable -- there's a lot that -- a lot that can be -- I'm not sure that the State wants to throw it open to the professional organization to have control over eligibility for services, for instance. And, you know, to the extent that eligibility can depend on a definition, they -- I think that they'd rather have it expressed in concrete terms in statute, and then bring it back to the General Assembly if

that's going to change materially rather than just leave it open to the professional bodies to define things like that.

But I also think there's the issue of, you know, sometimes the professional groups have competing understandings of what -- what's -- I mean the AAIDD arrived at its definition after considerable discussion amongst its membership, and there was a lot of, like, give and take in that discussion so, you know, it's not being fully incorporated here into this proposal. Some of -- some of what's in this proposal is still pretty objective and tied -- tied to very express -- very explicit criteria.

So I think there's -- there's a lot at stake for individuals, and you need to be clear in the statute as to what you're talking about.

REP. PERILLO: I understand your point. And as you mentioned there was considerable discussion within the professional body in order to come up with the proper definition. You know, to be honest, I have a lot of respect for my colleagues here around the table but only one of us is a physician and he just walked out to go to another meeting.

I'm much more comfortable with a professional body making these --

JAMES MCGAUGHEY: Right.

REP. PERILLO: -- definitions then us because what it does is simply politicize these issues. I would rather they be professionalized. So your point is well taken, but I'm wondering if, you know, from 50,000 feet, we're going down the wrong path by frequently redefining the statute what is already defined by a professional body. And we're in a situation where we are going

from a 4 to 5, we could simply update it as time goes by and as new versions come out.

And you're right, you know, we are acutely aware of the issue in terms of the definition of autism. And, in fact, we have argument on the opposite side of the issue --

JAMES MCGAUGHEY: Yes.

REP. PERILLO: -- in that regard where, you know, you don't like the definition of the DSM-5, so we want --

JAMES MCGAUGHEY: Right.

REP. PERILLO: -- keep it in 4. You're arguing essentially the opposite with a different definition --

JAMES MCGAUGHEY: With this particular definition.

REP. PERILLO: -- correct. So I mean can we have it both ways?

JAMES MCGAUGHEY: Well, you are the legislature. I don't know.

REP. PERILLO: I guess we are pretty good at having it any way we want.

JAMES MCGAUGHEY: Yeah.

REP. PERILLO: But thank you. That shed some light. I appreciate it

JAMES MCGAUGHEY: Okay.

SENATOR GERRATANA: Wordsmithing.

Thank you, Representative.

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10:00 A.M.

REP. PERILLO: Thank you.

CARIN VAN GELDER: Thank you.

SENATOR GERRATANA: Thank you so much.

CARIN VAN GELDER: Thanks.

SENATOR GERRATANA: Next we will hear testimony on
House Bill 5437. First up is Sandy Trionfini.

Welcome.

SANDY TRIONFINI: Good afternoon --

SENATOR GERRATANA: Good afternoon.

SANDY TRIONFINI: -- Senator Gerratana and members
of the committee.

My name is Sandra Trionfini, and I am an attorney in the Waterbury office of Connecticut Legal Services. My specialization is providing advocacy services and legal representation for folks with developmental and intellectual disabilities. I'm here today to speak in favor of House Bill 5437, AN ACT CONCERNING THE DEFINITIONS OF MENTAL RETARDATION AND INTELLECTUAL DISABILITY. This bill represents the result of negotiations between Legal Services, the Office of Protection and Advocacy, the Department of Developmental Services, and The ARC Connecticut. We are pleased to present this language as the product of the coordinated efforts of these groups.

Senator Gerratana, this is the book that you requested from Jim McGaughey this morning.

SENATOR GERRATANA: Or at least the reference of it.

SANDY TRIONFINI: -- in reference. It's the 11th --

SENATOR GERRATANA: I wanted to write it down.

SANDY TRIONFINI: -- the 11th Edition of the AAIDD Definition Manual and it was published in 2010. Our present statute uses the second publication of this manual. It was called the "Manual on Terminology and Classification in Mental Retardation," and it was published in 1977, so we are using a quite antiquated definition. The term "intellectual disability" as defined in the new AAIDD definition and as proposed in House Bill 5437, covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type and duration of the disability. However, the new definition modernizes the diagnostic criteria, enabling a better use of the tools used to identify those who are deemed eligible for the services of DDS.

The changes proposed are quite subtle but will help bring our criteria into modern usage. Few -- first, this proposed language recognizes that deficits in adaptive behavior are of equal significance to limitations and intellectual functioning. This reflects the current best professional thinking regarding the identification of those who require service intervention.

In conclusion, we do not propose to bring more people into the system for services but to direct more targeted services to those who are eligible. In this regard, House Bill 5437 provides for a better tool to serve those who are intellectually disabled and their families in Connecticut.

Thank you.

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SENATOR GERRATANA: Thank you so much for your testimony and that was very helpful.

Are there any questions or --

Representative Perillo.

REP. PERILLO: Madam Chair. Thank you.

Just to clarify any question, this new language which is being proposed, would that create a definition that is consistent with the forth coming DFM-5

SANDY TRIONFINI: Yes, we've used a combination, some of the language in the AAIDD definition along with the DFM-5. So it's a compilation of both of the most modern thought, regarding the definition.

REP. PERILLO: Question, why don't we just reference either one of those documents in statute rather than recreate the language every X number of years?

SANDY TRIONFINI: I heard that question this morning. And perhaps --

REP. PERILLO: Oh, I asked it, yeah.

SANDY TRIONFINI: -- yeah, perhaps that's something that we could do in the future. However, I am here today with a sound bill, and that's what I'm in favor of, but in the future, certainly, that could be something we could look.

REP. PERILLO: Oh, no, I'm not -- I'm not challenging well, what you put forth before us -- what has been put forth before us. I'm just wondering, going forward, why -- what would be the obstacle -- what would be the concern about just --

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SANDY TRIONFINI: Well, as Jim McGaughey said this morning, the current AAIDD definition is -- is quite lengthy and -- and obviously, what we have before you now is a result of a negotiation regarding the wording in that current definition, along with bringing some of the DFM-5 in. I don't see an obstacle that stands out to your question, but I think that we have a good product here. That's my best answer.

REP. PERILLO: Okay. Thank you.

SANDY TRIONFINI: Okay? Thank you.

SENATOR GERRATANA: Thank you.

Next is Leslie Simoes.

Hi, Leslie.

LESLIE SIMOES: Hi, Senator Gerratana, Representative Ritter and members of the Public Health Committee.

My name is Leslie Simoes. I'm the director of advocacy for The ARC of Connecticut. I'm actually pleased to say that The ARC is turning 60 years old this year, and for 60 years, we've been advocating for the basic civil rights of individuals with intellectual and developmental disabilities.

We're here today in support of Raised House Bill 5437, AN ACT CONCERNING THE DEFINITIONS OF MENTAL RETARDATION AND INTELLECTUAL DISABILITY.

My testimony is quite similar to my friend and fellow advocate, Sandy, before me. The ARC Connecticut supports redefining the term "mental retardation" to, quote, a significant

limitation in intellectual functioning and deficit in adaptive behavior that originated during the developmental period before eighteen years of age, end quote. And because that is consistent with both the proposed -- the proposed DFM-5 revision and that AAIDD definition practices.

As Sandy mentioned, the last time that we updated the definition was in 1977. And so using this more up-to-date definition will allow professionals to have the tools to better identify the supports and services for this population. It will also allow professionals - - so they will also be able to utilize a variety of appropriate tools in concert with the statutorily defined general intelligence test so they can measure intellectual functioning.

As Sandy also mention, over the past four years The ARC Connecticut, in partnership with other advocacy organizations, have worked toward the goal of passing this language in this bill and we commend the Public Health Committee for raising it, and we urge its passage.

So thank you for your time and consideration today.

REP. RITTER: Thank you for -- whoops -- for your testimony. That's not how we feel. And I appreciate you've worked with us through a couple of sessions on this issue and very much appreciate your patience and willing to educate us to all of these issues, as well.

Are there any questions from the committee?

I might submit that you've done a good job doing that education process and, perhaps,

that's why we don't have too many questions for you.

Thank you very much.

LESLIE SIMOES: Thank you very much. Thank you.

REP. RITTER: That testimony brings us to our next bill, which is House Bill Number 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE.

And our first speaker is Carol Garfield, to be followed by Mag Morelli.

CAROL GARFIELD: Good afternoon.

REP. RITTER: Good afternoon.

CAROL GARFIELD: Thank you for the opportunity, members of the Public Health Committee. My name is Carol Garfield. I live in Wolcott.

I'm testifying today in support of the HB 5499, AN ACT CONCERNING REGULATIONS RELATED TO HOSPICE CARE.

I wanted to testify today to express my gratitude for the great care that my dad received during his short stay at the Vitas Hospice Center in Waterbury. I'm sorry.

REP. RITTER: Take your time. We're here for a little while.

CAROL GARFIELD: He passed away in late January. Please note that although very difficult to speak of, I am so very thankful and overwhelmed by the amount of support both physically and spiritually, everything that each of the Vitas staff so lovingly, genuinely, has generously gave during such a difficult time.

**JOINT
STANDING
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HEARINGS**

**PUBLIC
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PART 5
1367 - 1694**

2012


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Testimony of Sandra Trionfini

Before the Public Health Committee

Regarding HB 5437, AAC the Definition of
 Mental Retardation and Intellectual Disability

March 16, 2012

My name is Sandra Trionfini and I am an attorney in the Waterbury office of Connecticut Legal Services, Inc. My specialization is providing advocacy services and legal representation on behalf of individuals with developmental and intellectual disabilities (ID). I am here today to speak in favor of H.B. No. 5437, An Act Concerning the Definitions of Mental Retardation and Intellectual Disability. This bill represents the result of negotiations between Legal Services, the Department of Developmental Services, the Office of Protection and Advocacy for Persons with Disabilities and Arc Connecticut. We are pleased to present this language as the product of the coordinated efforts of these groups.

Connecticut's current definition of intellectual disability (ID was referred to as mental retardation when CT's definition was enacted) was developed during the mid-1970s and was based on the 2nd publication of the "Manual on Terminology and Classification in Mental Retardation" published by the American Association on Intellectual and Developmental Disabilities (AAIDD). Although CT still relies on the definition from the 2nd edition, the AAIDD published its 11th Edition in 2010.

The term "intellectual disability" as defined in the new AAIDD definition and as proposed in HB 5437, covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type and duration of the disability. However, it modernizes the diagnostic criteria, enabling a better use of the tools used to identify those who are deemed eligible for the services of DDS.

The changes proposed are quite subtle but will help bring our criteria into modern usage. First, the proposed language recognizes that deficits in adaptive behavior are of equal significance to limitations in intellectual functioning. This reflects the current best professional thinking regarding the identification of those who require service intervention. Secondly, the

language in HB 5437 will enable clinicians to use current tools of diagnosis, testing and clinical evaluation ~~that are~~ designed to interact with the more modern definition.

We do not propose to bring more people into the system for services but to direct more targeted services to those who are eligible. In this regard, H.B. 5437 provides for a better tool to serve intellectually disabled individuals and their families in Connecticut.

FACTS about **Modernizing DDS Eligibility Standards**

CT needs to modernize its approach to intellectual disability (ID) issues by adopting the 2010 definitions contained in the 11th edition of the American Association on Intellectual and Developmental Disabilities (AAIDD) manual. Although the AAIDD definition has been updated 11 times, CT is still using the version that was proposed in the 1977 manual.

Why does CT need to update its ID eligibility standards for services?

- The definition of ID relied upon by DDS is 35 years old. Over the past three decades there have been significant advances in understanding and assessing ID. CT's eligibility statute, CGS 1-1g, is impeding CT's ability to evolve along with the social and psychological construct of ID.
- Adopting the 2010 definition continues a trend towards moving away from an emphasis on testing and IQ scores and looks more to consideration of an individual's overall adaptive functioning. A greater emphasis on adaptive functioning means that everyday conceptual, social and practical skills are given greater import. Examples of adaptive functioning skills include grasp of money, time and number concepts, social problem solving, personal care and transportation needs and ability to use a telephone and follow rules.
- Modernizing means determining eligibility based upon a holistic understanding of the individual and not IQ alone. The antiquated definition of ID in CGS 1-1g is inconsistent with best practices as it places an emphasis on IQ without equal consideration of adaptive behavior.

This proposal does not create an entitlement to services. Access to services will remain subject to availability and funding.

The intent of the new definition is not to bring more people into the system for services but to direct more targeted services to those who are eligible.

This proposal will define the population in a more equitable manner so that individuals are served more appropriately. Services will be more tailored to achieving optimum functioning by meeting adaptive functioning needs.

FACTS about **Modernizing
DDS Eligibility
Standards**

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Testimony to the Public Health Committee
March 16, 2012
By Leslie Simoes, Director of Advocacy

Testimony in support of:

Raised House Bill 5437: AN ACT CONCERNING THE DEFINITIONS OF MENTAL RETARDATION
AND INTELLECTUAL DISABILITY

The Arc Connecticut is a 60-year old advocacy organization committed to protecting the rights of people with intellectual and developmental disabilities and to promoting opportunities for their full inclusion in the life of their communities.

The Arc Connecticut supports redefining the term "Mental Retardation" to "a significant limitation in intellectual functioning and deficit in adaptive behavior that originated during the developmental period before eighteen years of age" because it is consistent with both the proposed DSM-V revision and the AAIDD definition practices. The last time Connecticut chose to update this definition was in 1977. Using this more up to date definition will allow professionals to have the tools to better identify the supports and services for this population.

Further clarification of "a significant limitation in intellectual functioning" as "an intelligence quotient more than two standard deviations below the mean as measured by tests of general intellectual functioning that are individualized, standardized and clinically and culturally appropriate to the individual" will also allow professionals to better identify the supports that individuals need. They will be able to utilize a variety of appropriate tools, in concert with the statutorily defined general intelligence tests, to measure intellectual functioning.

Over the past 4 years The Arc Connecticut, in partnership with other advocacy organizations, have worked toward the goal of passing the language in this bill and we commend the Public Health Committee for raising it and urge its passage.

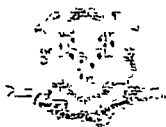
Please do not hesitate to contact me with questions, for clarification or to arrange a visit with a private provider of community based services for individuals with intellectual and developmental disabilities in your area. Thank you for your time and consideration.

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Department of Developmental Services

DDS

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Commissioner

Joseph W. Drexler, Esq.
Deputy Commissioner

DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY
BEFORE THE PUBLIC HEALTH COMMITTEE

Raised Bill No. 5437, An Act Concerning the Definition of Mental Retardation and Intellectual Disability

March 16, 2012

Senator Gerratana Representative Ritter, and members of the Public Health Committee. I am Terrence W. Macy, Ph.D., Commissioner of the Department of Developmental Services (DDS). Thank you for the opportunity to submit testimony in support of **Raised Bill No. 5437, An Act Concerning the Definition of Mental Retardation and Intellectual Disability**.

DDS was approached by, and has worked with, several advocates from the Legal Assistance Resource Center of Connecticut, Connecticut Legal Services, ARC-CT and the Office of Protection and Advocacy requesting that the department consider updating the definition of intellectual disability. I'd like to thank these groups for their continued advocacy which really made this bill a reality. You may recall that the term mental retardation was changed to intellectual disability during the 2011 legislative session in most instances in the Connecticut General Statutes; however mental retardation still exists in a few sections of the statutes where federal terminology has not yet been changed. Therefore, section 1-1g of the Connecticut General Statutes continues to define both terms with the same definition.

While DDS was amenable to updating the language in the section 1-1g definition, we needed to work through potential concerns that if the language was not carefully thought out, there could be implications on expanding eligibility for DDS supports and services and thus creating an unfunded liability for the state. This was clearly not the intent of DDS or the advocates. The proposal that you have before you is the result of many discussions and compromises between all parties. DDS agrees that this updated definition provides better guidance on what constitutes an intellectual disability, and is consistent with updated terminology used by other states and national groups such as the American Association on Intellectual and Developmental Disabilities (AAIDD) as well as with proposed updates to the Diagnostic and Statistical Manual of Mental Disorders (DSM)-V.

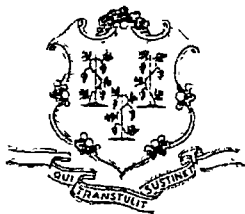
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The intent is not to change who is or is not eligible for DDS services, but to provide a clearer understanding of what constitutes an intellectual disability.

The new definition in section (a) will clarify that an individual with mental retardation or intellectual disability must have a significant limitation in intellectual functioning concurrently with deficits in adaptive behavior. Both must have originated before the age of 18, and also be present at the time when the disability determination is made. In section (c), the new language uses both AAIDD and DSM-V values that the standardized testing used in determining an individual's intellectual and adaptive levels of functioning, needs to be both clinically and culturally appropriate to the individual. In other words, the clinician or test evaluator needs to understand, and be sensitive to, both the individual's disability and their cultural background. This does not change, in any way, who would be eligible for DDS services, but it does update the older language to reflect current best practice and goals and values of both the Department of Developmental Services and the advocacy organizations.

One technical concern with Raised Bill 5437 as written is that the word deficit in subsection (a) in line eight should be pluralized to "deficits" in adaptive behavior.

Thank you for the opportunity to comment in support of House Bill 5437. Please contact Christine Pollio Cooney, DDS Director of Legislative Affairs, at (860) 418-6066 with any questions that you might have.



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Testimony of the Office of Protection and Advocacy for Persons with Disabilities Before the Public Health Committee

Presented by James D. McGaughey
Executive Director
March 16, 2012

Thank you for this opportunity to comment on Raised Bill No. 5437, AN ACT CONCERNING THE DEFINITIONS OF MENTAL RETARDATION AND INTELLECTUAL DISABILITY. This Bill updates the definition of the term "mental retardation" in Section 1-1g of the General Statutes, and clarifies that it has the same meaning as the term "intellectual disability", which is used in a number of other statutory sections.

Our Office has participated in several discussions about these proposed changes with other advocacy groups and the Department of Developmental Services. Those discussions occurred, in part, because there was dissatisfaction with some of the negative, judgmental language of the current definition (e.g. "significantly subaverage general intellectual functioning and deficits in adaptive functioning..."), and in part because there was a desire to bring our statutory definition closer to the dynamic, progressive definition adopted by the leading professional organization – the American Association on Intellectual and Developmental Disabilities (AAIDD).

At one time called the American Association on Mental Retardation and, even earlier, the American Association on Mental Deficiency, AAIDD's definitions have historically served as the basis for statutory definitions throughout the U.S. and Canada. The evolution of the organization's definitions, both in terms of the psychometric criteria they reference, and the increasing awareness they have generated regarding social context and individual capacities, has generally paralleled progress in the conceptualization of support services for people with intellectual disability. And, to the extent those definitions have found their way into law, they have become significant factors in establishing eligibility for publicly supported programs and services, for protecting against discrimination, and sometimes even for justifying restrictions on the exercise of rights (e.g. guardianship and civil commitment). As with most aspects of law that impact civil rights, the classifications that are written into statute both reflect our cultural values, and, at the same time, help shape them. So, the definition contained in our statutes is more than a matter of scholarly interest and professional pronouncement – it can have a very real impact on civil rights and on the extent to which individuals and their families can rely on the support and protection of the State.

Unlike previous definitions, the most current AAIDD definition does not stress categorical difference or assume that intellectual disability can be accurately understood in terms of a listing of personal deficiencies. Rather, it encourages us to see people in terms of their social environments, and the

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types of supports they may need to live fulfilling, contributing lives. The language of this Bill attempts to incorporate some of those concepts into our statutory definition while retaining sufficiently clear criteria to inform the expectations of individuals, families, service systems, courts and the general public. It strikes a fair balance between the progressive thinking that underlies the current AAIDD definition, and the practical realities inherent in our need to determine eligibility for State assistance and legal protection. At the same time, it replaces archaic and offensive language which implies that people with intellectual disability are somehow "deficient". DDS has been clear that it does not believe the language of this Bill changes its criteria for eligibility. Our Office supports the measure, and urges the Committee to act favorably on it.

Thank you for your attention. If there are any questions, I will try to answer them.

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So ordered.

SENATOR LOONEY:

Thank you, Madam President.

Calendar page 25, Calendar 532, House Bill 5304.

THE CHAIR:

I'm sorry. That's on page 25, sir?

SENATOR LOONEY:

Oh, we'll have to doublecheck. That maybe on an agenda. It's not showing on the sheet. If we would just withdraw that one, Madam President, and we'll move to some additional items.

Madam President, calendar page -- page 3, Calendar 299, House Bill 5437, move to place the item on the consent calendar.

THE CHAIR:

So ordered, sir.

SENATOR LOONEY:

Thank you, Madam President.

Calendar page 29, Calendar 355, Senate Bill 418, move to place on the consent calendar.

THE CHAIR:

So ordered, sir.

SENATOR LOONEY:

Thank you, Madam President.

Calendar page 6, Calendar 362, House Bill 5011, move to place the item on the consent calendar.

THE CHAIR:

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SENATOR LOONEY:

Yes.

THE CHAIR:

The Calendar Number 444 --

SENATOR LOONEY:

Yes.

THE CHAIR:

-- House Bill 5037 has just been added.

Senator Looney.

SENATOR LOONEY:

That's right, Madam President.

And -- and also, Madam President, calendar page -- excuse me, it's -- rather I don't have the calendar page but it's Substitute -- it is Calendar 507, Substitute for House Bill 5467, Madam President, move to place that item on the consent calendar.

THE CHAIR:

Got it. Thank you, sir.

SENATOR LOONEY:

Now, Madam President, if the Clerk would now proceed to call the consent calendar.

THE CHAIR:

Mr. Clerk, you may call the consent calendar now.

THE CLERK:

House Bill 5358; House Bill 5148; House Bill 5394; House Bill 5326; House Bill 5025; House Bill 5534; House Bill 5539; House Bill 5320; House Bill 5462; House Bill 5394; House Bill 5511.

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(HB 5283)

On page 3, Calendar 240, House Bill 3283; page 3, Calendar 299, House Bill 5437; page 5, Calendar 349, Senate Bill 374; page 6, Calendar 375, House Bill 5440; page 6, 362, House Bill 5011.

On page 7, Calendar 376, House Bill 5279; on page 7, 387, House Bill 5290; on page 8, 394, House Bill 5032; on page 8, 396, House Bill 5230.

Also on page 8, Calendar 398, House Bill 5241; on page 8, Calendar 393, House Bill 5307; on page 9, Calendar 403, House Bill 5087; on page 9, Calendar 406, House Bill 5276; on page 9, 407, House Bill 5484; on page 11, Calendar 424, House Bill 5495; on page 12, Calendar 435, House Bill 5232; on page 13, Calendar 5 -- excuse me Calendar 450, House Bill 5447; on page 14, Calendar 455, House Bill 3 -- I'm sorry -- House Bill 5353.

On page 14, Calendar 453, House Bill 5543; on page 14, Calendar 459, House Bill 5271; on page 15, Calendar 464, House Bill 5344; on page 15, Calendar 465, House Bill 5034; on page 16, Calendar 469, House Bill 5038; on page 17, Calendar 475, House Bill 5550; on page 17, Calendar 474, House Bill 5233; on page 17, Calendar 477, House Bill 5421.

Page 18, 480, House Bill 5258; on page 18, Calendar 479, House Bill 5500; page 18, Calendar 482, House Bill 5106; on page 18, Calendar 483, House Bill 5355; on page 19, Calendar 489, House Bill 5248; on page 19, Calendar 488, House Bill 5321; on page 20, Calendar 496, House Bill 5412.

On page 21, Calendar 504, House Bill 5319; page 21, Calendar 505, House Bill 5328; on page 22, Calendar 508, House Bill 5365; on page 22, Calendar 510, House Bill 5170; on page 23, Calendar 514, House Bill 5540; on page 23, Calendar 517, House Bill 5521.

Page 24, Calendar 521, House Bill 5343; page 24, Calendar 518, House Bill 5298; page 24, Calendar 523, House Bill 5504; page 29, Calendar 355, Senate Bill 418; on page 13, Calendar 444, 5037; and Calendar 507, House Bill 5467.

THE CHAIR:

Senator -- Senator Suzio.

SENATOR SUZIO:



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Bills placed on the Consent Calendar on May 9, 2012

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Bills from Senate Agenda Number 3 from the May 9th Senate Session that were placed on the Consent Calendar

HB5304
HB 5342

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Good evening, Madam President.

I just want to clarify. I thought I heard the Clerk call House Bill 5034? Is that on the consent calendar?

THE CHAIR:

Do you know what page that is, sir?

SENATOR SUZIO:

No I -- he was reading so fast, Madam, I couldn't get it.

THE CHAIR:

It's -- yes it's 53 -- I don't know.

SENATOR SUZIO:

5034.

THE CHAIR:

5034, yes sir.

SENATOR SUZIO:

I object to that being put on the consent calendar, Madam President.

THE CHAIR:

Okay, that will be removed.

Senator Looney.

SENATOR LOONEY:

Thank you, Madam President.

Yes, just seeing that -- ask to remove that item from the consent calendar.

THE CHAIR:

So ordered.

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At this time we'll call a roll call vote on the consent calendar.

Mr. Clerk.

THE CLERK:

Immediate roll call has been ordered in the Senate.
Senators please return to the Chamber. Immediate roll call has been ordered in the Senate.

THE CHAIR:

Senator Coleman, we need your vote, sir.

Senator Kissel, Senator Kissel. Senator Kissel, will you vote on the consent calendar please?

All members have voted?

If all members have voted, the machine will be closed.

Mr. Clerk, will you call the amendment -- I meant the tally.

THE CLERK:

On today's consent calendar.

Total Number Voting	36
Necessary for Adoption	19
Those Voting Yea	36
Those Voting Nay	0
Those Absent and Not Voting	0

THE CHAIR:

The consent calendar has passed.

Senator Looney.

SENATOR LOONEY:

Thank you, Madam President.

Madam President, I believe the Clerk is in possession of Senate Agenda Number 6 for today's session.