UPDATE ON MEDICAID PLANNING ISSUES
FOR PEOPLE WITH DISABILITIES AND ELDERS

Presented by Patricia E. Kefalas Dudek

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DSM-5 Proposed Criteria for Autism Spectrum Disorder Designed to Provide More Accurate Diagnosis and Treatment

ARLINGTON, Va. (Jan. 20, 2012)—The American Psychiatric Association (APA) has proposed new diagnostic criteria for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) for autism. While final decisions are still months away, the recommendations reflect the work of dozens of the nation’s top scientific and research minds and are supported by more than a decade of intensive study and analysis. The proposal by the DSM-5 Neurodevelopmental Work Group recommends a new category called autism spectrum disorder which would incorporate several previously separate diagnoses, including autistic disorder, Asperger’s disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified.

The proposal asserts that symptoms of these four disorders represent a continuum from mild to severe, rather than a simple yes or no diagnosis to a specific disorder. The proposed diagnostic criteria for autism spectrum disorder specify a range of severity as well as describe the individual’s overall developmental status—in social communication and other relevant cognitive and motor behaviors.

Dr. James Scully, Medical Director of the American Psychiatric Association said, “The proposed criteria will lead to more accurate diagnosis and will help physicians and therapists design better treatment interventions for children who suffer from autism spectrum disorder.”

The draft DSM-5 criteria will provide a more useful dimensional assessment to improve the sensitivity and specificity of the criteria. This change will help clinicians more accurately diagnose people with relevant symptoms and behaviors by recognizing the differences from person to person, rather than providing general labels that tend not to be consistently applied across different clinics and centers.

Proposed DSM-5 criteria are being tested in real-life clinical settings known as field trials. Field testing of the proposed criteria for autism spectrum disorder does not indicate that there will be any change in the number of patients receiving care for autism spectrum disorders in treatment centers—just more accurate diagnoses that can lead to more focused treatment.

Criteria proposed for DSM-5 are posted on the DSM-5 website and will be open for additional public comment this spring. More information on the process for developing DSM-5 is also available on the website. Final publication of DSM-5 is planned for May 2013.

DSM is the manual used by clinicians and researchers to diagnose and classify mental disorders. The American Psychiatric Association (APA) will publish DSM-5 in 2013, culminating a 14-year revision process. For more information, go to www.dsm5.org.


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Dear all:

Thank you for the calls and the emails. We are having a positive effect, and with 10 months before the final version of the new DSM is due, we have a chance of reversing the Committee's intentions of significantly reducing the numbers of those who would qualify for a diagnosis. Please keep it up starting Monday morning.

Once again, the New York Times is speculating that the new criteria would qualify only 76% of those currently diagnosed with classic autism, 24% of those currently diagnosed with Asperger's, and 16% of those currently diagnosed with PDD-NOS. This means that:

• Children who do not qualify for a diagnosis under the new revisions will almost certainly be denied special education funding by their cities and states (after all, what school board will spend money on a child with no officially recognized learning challenge?)

• Many adults on SSI, SSDI, or Disability who barely meet the criteria for these services may not have those services (and health coverage) anymore.

• We risk a possible return to the days of 1993 and prior where negative interpretations of behavioral differences were rather status quo.

The motivations behind these mind-boggling changes, are very much unclear to us. While the autism world in our current void of information is speculating a multitude of possibilities—the most dramatic being improper influence of insurance companies—we would urge people to continue pressing the DSM-V committee with the idea that the current committee members have experience only with the more-challenged end of the spectrum. None have any real experience with the end of the spectrum whose challenges are less physically-visible.

In addition to your talking points, and if you believe that the motivations are in any way fiscal, we urge you to remind the committee of how, in the big picture, the DSM-IV (which expanded spectrum diagnoses) saved us money. When you think of (though cannot estimate) the reduction in anxiety, anger, and depression, that was caused by legions of people finally understanding who they were—that they were wired differently, not rude . . . argue the mind-boggling cost of returning to those levels of anxiety, anger, and depression. (I am inserting my comment here- this part is not from the letter forwarded from Mr. Carley but I feel it is crucial that we continue to stress this as well-- we cannot underestimate the long term savings due to appropriate supports
and services that were provided prior to adulthood that will reduce the need for extensive supports and services throughout the lifespan. If appropriate supports and services are provided prior to adulthood, more individuals are able to achieve independent living skills with fewer supports in place. Without these appropriate supports and services, more individuals will end up reliant upon extensive social services throughout their lifespan, but they likely will not qualify under these new guidelines.-- What do they plan to do about all the adults they will be cutting off now because they no longer will qualify for services- who is going to provide assistance and what do we do with a soon to be burgeoning population that has no supports in place- the societal cost will be catastrophic-- Insurance companies in their infinite wisdom will ultimately be sticking social services and families with costs that will literally and utterly bankrupt the system which will end up hurting us all).

Responses

While in our last update, we conveyed the APA's statement that they were not taking comments at the present time, committee members and other organizations are now starting to respond through either internal or external media. In general you should feel you have every right to respond to these responses. The two most frequently seen tones (followed by our suggestions) are follows:

1. "Well, yes, your child may not qualify for specialized education under the new criteria, but please bear with us. Our hope is that this will improve services for all." They do not go on to explain how this is possible.

1R. Our no-brainer suggestion is to point out how senseless this response is. If they're admitting that fewer will qualify, how does this improve chances of "improving services for all." If your anger is getting the better of you, politely state that their response makes things worse because you feel your intelligence is being insulted.

2. These events are reviving the dormant "competition of suffering." Many people (who likely have some connection to a significantly-challenged fellow spectrumite) across the country in facebook posts, tweets...etc. are proclaiming "Good! Autism needs to be less confusing. These (AS or PDD-NOS) people never should have been brought in to the spectrum equation."

2R. Do not meet their hate with hate. The self-incriminating and emotionally-unhealthy nature of these attacks is the product of their being unable to grasp the complexity of the spectrum, or they are simply overwhelmed and underserved when compared with their needs. Yes, they may simply be bad people, but we won't know that (and we have bad people too). As they invalidate the experiences of others, do not match their ugliness. If you must respond, something appropriate would be akin to "I find it so sad that you would deny help to someone else simply because you still need help (embellish with detail that perhaps pertains to your experiences)." Show them, do not tell them, how ill they were in the moment of writing.

Once again our facebook page is the best place to dig up prior developments. And once again, keep the calls coming. Call the American Psychiatric Association at 703.907.7300. They will ask you not to call, but please keep calling. In addition, please email them at dsm5@psych.org and apa@psych.org (apologies: we misspelled the latter in our last correspondence).

Look for a survey from us soon too.

With massive thanks, we are
Yours, y'all,

Michael John Carley
Executive Director

GRASP
The Global and Regional Asperger Syndrome Partnership, Inc.
666 Broadway, Suite 825
New York, NY 10012
p + f = 1.888.474.7277
www.grasp.org

Subscription management information: http://www.copaa.org/membership/copaa-member-faqs/
Contact listowners: listowner@copaa.org, read archives:
http://listserv.icors.org/archives/copaa.html
Redefining Autism

In a preliminary analysis, three researchers estimate that far fewer people with autism or a related disorder would meet the criteria for autism spectrum disorder after a change proposed for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, or D.S.M.

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<th>Current definitions (D.S.M.–IV)</th>
<th>Percentage who would qualify under new definition</th>
</tr>
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<tr>
<td>Classic autism</td>
<td>76%</td>
</tr>
<tr>
<td>Asperger syndrome</td>
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</tr>
<tr>
<td>P.D.D.–N.O.S.*</td>
<td>16%</td>
</tr>
</tbody>
</table>

*Pervasive developmental disorder, not otherwise specified

Source: Fred R. Volkmar, Yale University School of Medicine

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**Autism spectrum disorder**

**Dealing with Depression?**
Currently taking antidepressants? Join our depression research study.

**Bi Polar Symptoms**
LearnAbout What To Look For. Consult Mental Health Experts Now!

**3 Symptoms Of Depression**
The (3) Scariest Depression Signs That May Be Hiding In Plain Sight.

**Symptoms Of Bi Polar**
Learn About Symptoms Of Bi Polar! HealthyNow Can Be Your Guide!

**Business Secure USB Disk**
Unleash Any Other USB Disk You’ve Seen - Better, Stronger, Faster!

**5 Symptoms Of Depression**
Find 5 Symptoms Of Depression. Get Expert Health Tips Right Now!

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**Most Popular - U.S.**

1. A Sharper Mind, Middle Age and Beyond
2. What You (Really) Need to Know
3. Note Book | Equity: One Percent Education
4. A Bridge to Recovery on Campus
5. On Education: In Race to the Top, the Dirty Work Is Left to Those on the Bottom
6. The Caucus: Gabrielle Giffords Says She’s Leaving the House
7. How Big-Time Sports Ate College Life
8. FiveThirtyEight: Did Gingrich’s Win Break the Rules?
9. This Land: In a City Fighting Blight, ‘Ghost Signs’ as Portals to a Bygone Era
10. A Nurse Need Never Forget

Go to Complete List »
New Definition of Autism Will Exclude Many, Study Suggests

By BENEDICT CAREY

Proposed changes in the definition of autism would sharply reduce the skyrocketing rate at which the disorder is diagnosed and might make it harder for many people who would no longer meet the criteria to get health, educational and social services, a new analysis suggests.

The definition is now being reassessed by an expert panel appointed by the American Psychiatric Association, which is completing work on the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders, the first major revision in 17 years. The D.S.M., as the manual is known, is the standard reference for mental disorders, driving research, treatment and insurance decisions. Most experts expect that the new manual will narrow the criteria for autism; the question is how sharply.

The results of the new analysis are preliminary, but they offer the most drastic estimate of how tightening the criteria for autism could affect the rate of diagnosis. For years, many experts have privately contended that the vagueness of the current criteria for autism and related disorders like Asperger syndrome was contributing to the increase in the rate of diagnoses — which has ballooned to one child in 100, according to some estimates.

The psychiatrists’ association is wrestling with one of the most agonizing questions in mental health — where to draw the line between unusual and abnormal — and its decisions are sure to be wrenching for some families. At a time when school budgets for special education are stretched, the new diagnosis could herald more pitched battles. Tens of thousands of people receive state-backed services to help offset the disorders’ disabling effects, which include sometimes severe learning and social problems, and the diagnosis is in many ways central to their lives. Close networks of parents have bonded over common experiences with children; and the children, too, may grow to find a sense of their own identity in their struggle with the disorder.

The proposed changes would probably exclude people with a diagnosis who were higher functioning. “I’m very concerned about the change in diagnosis, because I wonder if my daughter would even qualify,” said Mary Meyer of Ramsey, N.J. A diagnosis of Asperger
syndrome was crucial to helping her daughter, who is 37, gain access to services that have helped tremendously. “She’s on disability, which is partly based on the Asperger’s; and I’m hoping to get her into supportive housing, which also depends on her diagnosis.”

The new analysis, presented Thursday at a meeting of the Icelandic Medical Association, opens a debate about just how many people the proposed diagnosis would affect.

The changes would narrow the diagnosis so much that it could effectively end the autism surge, said Dr. Fred R. Volkmar, director of the Child Study Center at the Yale School of Medicine and an author of the new analysis of the proposal. “We would nip it in the bud.”

Experts working for the Psychiatric Association on the manual’s new definition — a group from which Dr. Volkmar resigned early on — strongly disagree about the proposed changes’ impact. “I don’t know how they’re getting those numbers,” Catherine Lord, a member of the task force working on the diagnosis, said about Dr. Volkmar’s report.

Previous projections have concluded that far fewer people would be excluded under the change, said Dr. Lord, director of the Institute for Brain Development, a joint project of NewYork-Presbyterian Hospital, Weill Medical College of Cornell University, Columbia University Medical Center and the New York Center for Autism.

Disagreement about the effect of the new definition will almost certainly increase scrutiny of the finer points of the psychiatric association’s changes to the manual. The revisions are about 90 percent complete and will be final by December, according to Dr. David J. Kupfer, a professor of psychiatry at the University of Pittsburgh and chairman of the task force making the revisions.

At least a million children and adults have a diagnosis of autism or a related disorder, like Asperger syndrome or “pervasive developmental disorder, not otherwise specified,” also known as P.D.D.-N.O.S. People with Asperger’s or P.D.D.-N.O.S. endure some of the same social struggles as those with autism but do not meet the definition for the full-blown version. The proposed change would consolidate all three diagnoses under one category, autism spectrum disorder, eliminating Asperger syndrome and P.D.D.-N.O.S. from the manual. Under the current criteria, a person can qualify for the diagnosis by exhibiting 6 or more of 12 behaviors; under the proposed definition, the person would have to exhibit 3 deficits in social interaction and communication and at least 2 repetitive behaviors, a much narrower menu.

Dr. Kupfer said the changes were an attempt to clarify these variations and put them under one name. Some advocates have been concerned about the proposed changes.

“Our fear is that we are going to take a big step backward,” said Lori Shery, president of the
Asperger Syndrome Education Network. "If clinicians say, ‘These kids don't fit the criteria for an autism spectrum diagnosis,’ they are not going to get the supports and services they need, and they're going to experience failure."

Mark Roithmayr, president of the advocacy organization Autism Speaks, said that the proposed diagnosis should bring needed clarity but that the effect it would have on services was not yet clear. "We need to carefully monitor the impact of these diagnostic changes on access to services and ensure that no one is being denied the services they need," Mr. Roithmayr said by e-mail. "Some treatments and services are driven solely by a person's diagnosis, while other services may depend on other criteria such as age, I.Q. level or medical history."

In the new analysis, Dr. Volkmar, along with Brian Reichow and James McPartland, both at Yale, used data from a large 1993 study that served as the basis for the current criteria. They focused on 372 children and adults who were among the highest functioning and found that overall, only 45 percent of them would qualify for the proposed autism spectrum diagnosis now under review.

The focus on a high-functioning group may have slightly exaggerated that percentage, the authors acknowledge. The likelihood of being left out under the new definition depended on the original diagnosis: about a quarter of those identified with classic autism in 1993 would not be so identified under the proposed criteria; about three-quarters of those with Asperger syndrome would not qualify; and 85 percent of those with P.D.D.-N.O.S. would not.

Dr. Volkmar presented the preliminary findings on Thursday. The researchers will publish a broader analysis, based on a larger and more representative sample of 1,000 cases, later this year. Dr. Volkmar said that although the proposed diagnosis would be for disorders on a spectrum and implies a broader net, it focuses tightly on "classically autistic" children on the more severe end of the scale. "The major impact here is on the more cognitively able," he said.

Dr. Lord said that the study numbers are probably exaggerated because the research team relied on old data, collected by doctors who were not aware of what kinds of behaviors the proposed definition requires. "It's not that the behaviors didn't exist, but that they weren't even asking about them — they wouldn't show up at all in the data," Dr. Lord said.

Dr. Volkmar acknowledged as much but said that problems transferring the data could not account for the large differences in rates.

*Amy Harmon contributed reporting.*
SPECIAL NEEDS TRUST
LIST OF PERMISSIBLE DISTRIBUTIONS

The Trustee(s) of a Pooled Account Trust may utilize any of the foregoing listing for expenditures from the Trust. The following list of non-support items is provided for purposes of description and shall not limit the Trustee(s) in making other distributions for other items of amenities that the trustee may believe are in the best interest of the beneficiary. Those items may include, but are not limited to:

1. Automobile/Van
2. Accounting services
3. Acupuncture / Acupressure
4. Alterations or mending to clothing – shoe repairs
5. Appliances (TV, VCR, stereo. Microwave, stove, refrigerator, washer/dryer and maintenance/repairs)
6. Bottled Water or water service
7. Bus pass/public transportation costs
8. Camera, film, recorder and tapes, development of film, photo albums, scrapbooks and supplies
9. Clothing
10. Clubs and club dues (record clubs, book clubs, health clubs, service clubs, zoo, Advocacy Groups, museums)
11. Computer hardware, software, program, maintenance/service
   a. Internet service
12. Conferences and travel related to same
13. Courses or classes (academic or recreational) including supplies
14. Curtains, blinds, drapes and the like
15. Dental work not covered by Medicaid, including anesthesia.
16. Down payment on home or security deposit on apartment.
17. Dry cleaning and/or laundry services and/or supplies
18. Elective surgery
19. Fitness equipment
20. Funeral expenses
21. Furniture, home furnishings and insurance
22. Gasoline and/or Maintenance for automobile
23. Haircuts / Salon services
24. Holiday Decorations, parties, dinner dances, holiday cards
25. Home alarm and/or monitoring/response system
26. Home improvements, repairs and maintenance (not covered by Medicaid), including tools to perform home improvements, repairs and maintenance by homeowner
27. Home Purchase (to the extent not covered by benefits)
28. House cleaning / maid services/lawn services/snow removal
29. Independent Care Managers/Case Managers
30. Insurance (automobile, home and/or possessions)
31. Insurance Co-Payments not covered by any other source
32. Legal Fees/Advocacy
33. Linens, towels, bedding and other household furnishings
34. Massage, facials and other similar services/treatments
35. Musical instruments (including lessons and music)
36. Non-food grocery items (laundry soap, bleach, fabric softener, deodorant, dish soap, hand and body soap, personal hygiene products, paper towels, napkins, kleenex, toilet paper, any household cleaning products)
37. Over the counter medications (including vitamins and herbs, etc.)
38. Personal Assistance Services not covered by Medicaid
39. Pet and pet’s supplies, veterinary services
40. Physician specialists if not covered by Medicaid
41. Private counseling if not covered by Medicaid
42. Repair services (appliance, automobile, bicycle, household, fitness equipment)
43. Snow removal/Landscaping/Lawn Service
44. Sporting goods/equipment/uniforms/team pictures/travel to games/tournaments
45. Stationary, stamps, cards, etc.
46. Storage Units
47. Taxi cab
48. Telephone service and equipment, including cell phone, pager, etc.
49. Therapy (Physical, Occupational, Speech) not covered by Medicaid.
50. Tickets to concerts or sporting events (for beneficiary and an accompanying companion)
51. Transportation (automobile, motorcycle, bicycle, moped, gas, bus passes)
52. Utility bills (direct TV, cable TV, electric, heating)
53. Vacation (including paying for personal assistance to accompany the beneficiary)
Examples of Trust Distributions which will Reduce SSI Benefit

1. Basic shelter related expenses
2. Food
3. Cash for any purpose

Examples of Impermissible Trust Distributions

1. Paying for a service already paid for by another source
2. Distribution not in the best interest of the beneficiary (made primarily for the benefit of another person)
Getting My Own Address For People With Autism Spectrum Disorders And Other Developmental Disabilities

Getting My Own Address: Upcoming Presentations

Getting My Own Address for People with Autism Spectrum Disorders and Developmental Disabilities (GMOA) is a program for people with autism spectrum disorders and developmental disabilities and their families.

The program makes clear the steps, options and choices that are available to plan for housing in the community of one’s choice.

The GMOA program consists of:

- **Workshops** to walk you through the long-term housing planning process -- it's never too early to start
- The Getting My Own Address Guide - available for free online (see links below) or for a nominal cost in print
- **Roommate database**
- **Housing Support Group** - meet other individuals and families to learn from one another, share resources and make connections with potential roommates (meets the 3rd Tuesday each month at 6:00 p.m. at Community Housing Network’s Troy office (570 Kirts Blvd., Suite 231, Troy, MI 48084)
- **One-on-one assistance** to help with more in-depth, individualized housing planning
- **Additional resources** and considerations: most are FREE

The GMOA program and guide was compiled with input from individuals with autism spectrum disorders and developmental disabilities, and their families and supports (including teachers, transition coordinators, supports coordinators, caregivers and others).

We welcome your comments and feedback. Please feel free to send your comments to Linda Brown at LBrown@chninc.net.

Getting My Own Address for People with Autism Spectrum Disorders and Developmental Disabilities is made available through a grant from the Autism Society of Oakland County.
Getting My Own Address for People with Autism Spectrum Disorders and Developmental Disabilities: THE GUIDE
© 2011 Community Housing Network, Inc.

PLEASE NOTE: We encourage you to print out and share Getting My Own Address for People with Autism Spectrum Disorders and Developmental Disabilities and its contents (including chapters, worksheets, etc.). However, you may not print, copy, distribute electronically or by other means Getting My Own Address for People with Autism Spectrum Disorders and Developmental Disabilities for financial or other gain. For questions regarding usage of content, please contact Community Housing Network at (248) 928-0111.

GMOA Title Page & Acknowledgments

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Getting My Own Address: Upcoming Presentations

Community Housing Network continues with the Getting My Own Address (GMOA) Overview across Oakland County, in cooperation with Oakland County School Districts.

Please see below for GMOA-related presentations and events.

GMOA Overview:
This FREE overview presentation for Individuals/Parents/Professionals introduces many of the options, choices and decisions that are involved in long-term housing planning. The GMOA guide will be available, along with worksheets and Internet links that will be provided to enhance your experience and promote successful implementation.

Please note: the same presentation will take place on the below dates:

Thursday February 9, 2012
6:30 PM - 8:30 PM
Lamphere Center
29685 Tawas
Madison Heights MI 48071

Wednesday February 15, 2012
5:30 PM - 7:30 PM
West Bloomfield School District
7071 Orchard Lake Road, Suite 120 (Back of building)
West Bloomfield MI 48322

Color hard copies of the 294-page GMOA guide, including binder, will be available for purchase at a subsidized rate. Guides will be for sale 30 minutes before each Overview Presentation. $25 - Oakland County parent/individual, $35 Oakland County professional, $40 Outside of Oakland County.

Navigating the System series:
Friday, March 2, 2012
10:00 AM - 12:00 PM
MORC
1270 Doris Road
Auburn Hills, MI 48326

Transition Planning? What's That? I Just Want to Help Young Adults Reach
Their Hopes and Dreams: Part II -- Sponsored by Michigan Family-to-Family Health, Information and Education Center. Focus on employment, local community living and housing resources, and Social Security for young adults.

March 26, 2012
9:00 AM – 3:00 PM
Washtenaw ISD
1819 South Wagner Road
Ann Arbor, MI 48106
(734) 994-8100

April 23, 2012
9:00 AM – 3:00 PM
Wexford Missaukee ISD
General Education Building
Room 516
9905 13th Street
Cadillac, MI 49601
(231) 876-2265

April 25, 2012
9:30 AM – 3:30 PM
Power Hope and Grace
Bible Church
6495 West Warren
Detroit, MI 48210
(313) 895-7464

Please contact Linda Brown at CHN for more information at: (248) 269-1346 or lbrown@chninc.net
A disability policy for the 21st century

By David Stapleton and David Mann, researchers at Mathematica - 01/16/12 01:33 PM ET

Of the roughly 17.5 million working-age people in the United States living with a disability, nearly 70 percent receive disability benefits. A recent study revealed that 12 percent of all federal spending goes to supporting this population—$357 billion in 2008. Just 33 percent of working-age people with disabilities are employed, compared to 73 percent of those with no disability. This costly system is failing both people with disabilities and taxpayers.

The federal government began offering Social Security Disability Insurance (SSDI) benefits to older workers no longer able to work because of long-term impairments in 1956. The nation has since expanded SSDI coverage and launched additional programs to support Americans living with significant disabilities. This support system, however, has failed to keep up with the changing needs of Americans or the realities of current economic times. Despite the promise of the Americans with Disabilities Act, people with disabilities, as a group, are falling further behind their peers without disabilities and are becoming more—not less—dependent on government programs.

The disability support system has two fundamental structural flaws. First, our major programs define disability as an “inability to work” due to “medically determinable” impairments, even though advances in medicine and technology now make it possible for some people with very significant impairments to work. Structured around this definition, the current system discourages work and encourages long-term dependence on public supports. Of the nearly 13 million working-age Americans receiving SSDI or Supplemental Security Income (SSI) benefits today, over half live in poverty. Most will continue to receive benefits until they become eligible for Social Security retirement benefits or die.

Second, the patchwork of state and federal disability support programs, each with different entry points, creates pervasive inefficiencies and perverse incentives that hinder substantive reform. For example, states are responsible for delivering employment services to help people with disabilities become self-sufficient, but...
they have little incentive to do so because the federal government pays for almost all income support and most health care for people who are not self-sufficient.

An overhaul of the disability support system is needed to encourage and empower people with disabilities to seek employment, to reduce service duplication, to improve program efficiency and to increase the return on taxpayer investment. Implemented incrementally, comprehensive reforms could facilitate greater economic independence for people with disabilities and curb the growth in public spending for their support.

Transforming the disability support system should start with a vigorous debate on alternative approaches and a commitment to ensuring that large-scale changes are based on solid evidence. Congress could jump-start this process by creating a national disability demonstration commission. Such a commission could develop and test bold new ideas that comprehensively address the problems of our flawed and fragmented system. Instead of making minor tweaks, the commission could facilitate real change across government jurisdictions, integrating innovative financing with effective service delivery. The commission would need to allow waivers of current regulations, and interventions would need to be carefully designed and thoroughly tested to minimize risk for current beneficiaries.

To start the conversation on rethinking disability policy and restructuring the disability support network, we offer, in a recently released report, one possible method of reorganizing support for this population. We suggest creating a state- or locally based system of disability support administrators (DSAs) to act as central points of intake and coordination for people needing services. This service-coordinator approach could simplify the process for applicants and improve individual outcomes. We also describe how financing could be realigned to promote the objectives of the restructured system. Further, we point to the need to make funding allocations more reflective of the business cycle, increasing during economic contraction and decreasing during rapid economic expansions. Will this approach work? We won’t know until it is tested, but we are convinced that no substantial progress will be made if we fail to test such comprehensive approaches to reform.

Reforming the national disability support system is critical to improving outcomes and reducing costs in the long term. Without structural reforms that enable people with disabilities to participate more fully in the economic mainstream, the efforts of fiscal reformers to tighten eligibility and trim benefits for existing programs will only lead to an increasingly bleak economic future for this population.

David Stapleton is the director of Mathematica Policy Research’s Center for Studying Disability Policy. David Mann is a researcher at Mathematica.

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1/23/2012 12:13 PM
Disabled Idahoans Sue State over Medicaid Cuts the State Refuses to Explain

Monday, January 23, 2012

Thirteen disabled Idahoans, living with disabling and chronic conditions such as epilepsy, muscular dystrophy, Down's Syndrome, schizophrenia, and developmental disabilities ranging from mild to severe, are suing the Idaho Department of Health and Welfare (IDHW) over cuts to their Medicaid benefits that IDHW refuses to explain.

The issue is how IDHW calculates their annual health care budgets. For example, plaintiff "C.M." (the lawsuit names the plaintiffs only by their initials) is a 53-year-old woman with muscular dystrophy who has lost an eye, has a history of heart problems, and is unable to evacuate on her own in an emergency or administer her medications without help. She requires 24-hour attendance, yet in 2010 IDHW assigned her a health care budget of only $53,119.69, which was nearly doubled, to $105,500, when she appealed the amount. Nevertheless, in 2011 IDHW again cut her budget, this time by 21% to $82,576.32. Under her reduced budget, C.M. cannot afford the 24-hour assistance she needs, but IDHW has refused to provide any reason for the cut or how it was calculated, making it next to impossible for C.M. to challenge the decision. The situations of the other twelve plaintiffs are similar, with IDHW claiming that its budget calculation method is a "trade secret" it need not disclose.

As AllGov has reported, the Great Recession has caused state tax revenues to decline even as poverty rates and the number of persons eligible for Medicaid, which is jointly funded by state and federal government, have grown. Unable or unwilling to raise taxes to cover the shortfalls, state governments have been cutting benefits and tightening eligibility. The Idaho lawsuit argues that under both state and federal law, Medicaid patients have a right to know how their health care budgets have been calculated, so that they can challenge a number that is too low to pay for the care they need. The Medicaid Act requires the states to make their budget-setting methods "open to public inspection." As the lawsuit was filed on January 18, 2012, the state of Idaho has not yet filed its answer, nor has it issued a public statement on the subject.

-Matt Bewig

What's the Big Secret? Disabled Are State (By Phillip A. Janquart, Courthouse News Service)
Complaint Filed January 18, 2012 (pdf)

Comments

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The ABLE ACT of 2011 (112th Congress)
Posted By admin On November 10, 2011 @ 9:40 am In 2012 | 1 Comment

Those who have participated in previous NFXF Advocacy Days and responded to prior Action Alerts know that we advocated for passage of the ABLE Act in the 111th Congress. That term ended without passage of the bill however we are pleased to report that a new ABLE Act will soon be introduced in the current Congress.

Purpose:

To encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independent, and quality of life.

To provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not replace, benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary’s employment, and other sources.

Created under Existing 529 Codes for Qualified Tuition Programs:

- Creates a new subsection (f) ABLE Account within Section 529 of the Internal Revenue Code.
- ABLE in the 112th Congress has been re-drafted to follow all the requirements and regulations of a traditional 529 qualified tuition program.
- Easy to open and available in any state.
- Same annual contributions apply (After $13,000 gift tax rules apply)
- Same tax-free treatment of account applies (Income earned grows tax-free, withdrawals for qualified disability expenses are tax-free)
- Same reporting requirements apply as to a traditional 529
- A beneficiary may have either an ABLE account or a traditional 529 qualified tuition program. (Multiple ABLE accounts or multiple 529 plans still allowed)
- Rollovers allowed from an ABLE account to traditional 529 if beneficiary is no longer deemed disabled. (All other 529 rollovers apply to ABLE accounts)
- Rollovers allowed to other family member’s ABLE account or their traditional 529

Qualified Disability Expenses:

- Education- including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- Housing- Expenses for a primary residence, including rent, purchase of a primary residence or an interest in a primary residence, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- Transportation- Expenses for transportation, including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- Employment Support- Expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- Health Prevention and Wellness: Expenses for health and wellness, including premiums for health insurance, mental health, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance.
- Other Approved Expenses- Any other expenses which are approved by the Secretary under regulations and consistent with the purposes of this section.
- Assistive Technology and Personal Support- Expenses for assistive technology and personal support with respect to any item described in clauses (I) through (vi).
- Miscellaneous Expenses- Financial management and administrative services, legal fees,
expenses for oversight, monitoring, or funeral and burial expenses.

**How to Qualify for an ABLE Account:**

Any individual who is receiving, deemed to be, or treated as receiving supplemental security income benefits or disability benefits under Title II of the Social Security Act.

OR

Any individual who has a medically determined physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 month or is blind, and provides a copy of their diagnosis signed by a physician.

No one who qualifies for an ABLE account is able to use that eligibility to secure supplemental security income benefits or Medicaid.

**Federal Treatment of ABLE Account under Supplemental Security Income Program:**

When the assets in an ABLE account reach $100,000, if the beneficiary is receiving Supplemental Security Income (SSI) benefits, any monthly SSI benefits will be placed in suspension

If the assets in the ABLE account drop back below $100,000, the SSI benefit suspension ceases and any SSI benefit resumes.

The beneficiary will not have to reapply for SSI benefits once the account drops back below the $100,000 threshold

**No Impact on Medicaid Eligibility:**

Under no circumstance will anyone with an ABLE account who is currently receiving Medicaid benefits lose their benefits – even if their SSI benefits are suspended.

The beneficiary will never lose their eligibility for Medicaid based on the assets held in their ABLE account.

**Medicaid Payback Provision:**

In the event the qualified beneficiary dies (or ceases to be an individual with a disability) with remaining assets in an ABLE account:

The assets in the ABLE Account are first distributed to any State Medicaid plan that provided medical assistance to the designated beneficiary.

The amount of any such Medicaid payback is calculated based on amounts paid by Medicaid after the creation of the ABLE Account.

Article printed from National Fragile X Foundation: [http://www_fragilex.org](http://www_fragilex.org)

Grab Your Water Wings: how and when to use a Pooled Special Needs Trust when
planning for the elderly client
By Michele P. Fuller

Consideration of a Pooled Special Needs Trust as a planning tool for obtaining or
preserving means-tested governmental benefits, such as Supplemental Security Income
(SSI), Section 8 housing, Medicaid, Veteran benefits, Waiver services, and long-term
care Medicaid Assistance, is under-utilized among elder law practitioners when planning
for a single individual over the age of 65. There is a debate even among top practitioners
as to their use for the elderly disabled client with excess assets. However, in my opinion,
there is no other planning method for a single individual by its nature and design that
preserves the assets of the individual for their sole benefit in order to supplement their
care and increase their quality of life. Whether a client is currently receiving long term
care Medicaid Assistance and unexpectedly receives funds as a result of a cause of action
or an inheritance, or is in need of obtaining benefits for an initial Medicaid application,
becoming a member of a Pooled Special Needs Trust should be considered as part of the
planning process for the practitioner assisting the single elderly disabled client who is in
need of Medicaid Assistance. Other planning options exist for married couples that are
of greater benefit and pooled trusts are typically not advisable in those situations.

A Pooled Special Needs Trust is an exception to the general rule that trusts are
generally countable assets, and were created as an exception pursuant to 42 USC
§1396(p)(d)(4)(C). Pooled trusts are also referred to as “(d)(4)(C)” trusts as a shortened
reference to the statute, or PAT’s (pooled account trust). The term “pooled” refers to the
investment structure whereby the individual’s funds are pooled together for greater return
on investments. Based on economies of scale, a pooled trust is also intended to allow the
cost of administration, including asset management fees, to be spread among all the participants at a cost savings to all.

A pooled trust has several elements which must be met in order to become a member of the trust, and has several important differences from what practitioners think of as a classic special needs trust drafted for a specific individual:

1. To join, an individual must be disabled (which is also required for a (d)(4)(A) special needs trust),

2. There is no age limit to join a Pooled Trust (unlike a (d)(4)(A) which limits age to 65 or less for both the creation and funding of the trust),

3. The trust must be established and managed by a non-profit corporation,

4. Each individual’s funds are allocated to separate accounts, but are pooled together for investment purposes, and established for the sole benefit of the individual,

5. The Grantor can be the disabled individual, parent, grandparent, guardian, or the court. At times an individual who is appointed power of attorney for the Grantor will sign on their behalf. A power of attorney is not named in the statute as an acceptable Grantor, and would only be allowable if the power of attorney were to specify that the agent had the authority to create a trust.

6. With a (d)(4)(C) trust, any assets remaining at the death of the beneficiary are retained by the non-profit, and those funds must be used for the benefit of other disabled individuals. However, most pooled trust administrators will allow an individual to choose to reimburse the State and allow the remaining funds to be distributed to the family. The family may also choose to allow remaining assets to be
retained for the benefit of a disabled family member who would then be able to become a member of the pooled trust themselves. These options are particularly useful when planning for a single individual with fairly significant assets who is entering a nursing home, and must be given careful consideration based upon the likelihood that there would be enough assets remaining after death to both reimburse the State and leave assets to be distributed to the family depending on each individual’s situation.

When planning for the single individual over age 65, often the use of a pooled trust is more flexible than using what is commonly referred to as “half-a-loaf” planning. Half-a-loaf planning involves gifting approximately one-half of the excess assets and placing the remaining one-half into an annuity (so as to render the person “otherwise eligible” for Medicaid, i.e. they have sufficiently divested sufficient assets to be able to meet the $2,000 limit in countable assets). The gift results in a penalty period during which the individual must pay for their nursing care privately. The annuity pays the nursing home during this time on a monthly basis. If the practitioner under or over estimates the annuity payment to the nursing home it can negatively impact the client. Using a pooled trust in place of the annuity allows for minor adjustments in the monthly fee which can vary month to month, or major adjustments, especially if there is an unexpected hospitalization. In addition, if there is any overage, the remainder can be used for additional care or needs of the Beneficiary during their lifetime.

If an individual is receiving 24 hour care in a nursing facility, typical disbursements include guardianship fees, legal fees, Guardian Ad Litem fees, hair care, podiatry, handicap or medically necessary transportation, additional attendant care, and translators. Many individuals with memory loss can, over time, lose their ability to speak
English if it is not their primary language, and interpreters have been necessary in cases where there is no one to assist with communication needs. Some of the most frequent disbursements are for bed holds. If an extended hospitalization occurs, the Beneficiary is very likely to suffer a loss in capacity due to the trauma of the event. This is compounded if they are discharged to an unfamiliar environment and unfamiliar caregivers. It can also be very stressful on the family to search for another facility in a short period of time or face placement in an undesirable facility. Other common disbursements are for the preservation and maintenance of the home, including taxes and necessary repairs like roofing and window replacement, lawn care, snow removal, etc.

Despite the benefits to the aged individual in need of Medicaid Assistance for their long term care, many respected practitioners do not consider using pooled trusts for their clients. There are several reasons for this. First, its use and the advantages are not well known among elder law practitioners. For many years, those that did know of the pooled trust as a planning tool had no issue with the transfer of excess assets to obtain benefits for their clients. However, beginning with the implementation of the Deficit Reduction Act of 2005, the planning options for single individuals was severely limited. Many elder law attorneys recall the days of serial gifting fondly. After that planning method was eliminated, pooled trusts became more attractive and after a period of time the State began imposing a penalty for the transfer. Pooled trust administrators and their counsel have successfully challenged the imposition of penalties, which the administrative law judges have consistently characterized as an allowable conversion of assets. Since successfully challenging the State's policy, no further penalties have been imposed to date. Many practitioners and their clients choose to employ planning tools or
methods which may not be as beneficial to the client rather than run the risk of having to appeal an unfavorable decision. An appeal can compound the stress and expense of an already exhaustive process, and the family may face additional pressure from a nursing facility for payment or eviction of their loved one.

There is also a national debate among experts as to whether the transfers for those over age 65 are allowable by the federal Medicaid policies, promulgated in the Social Security Administration Program Operations Manual (POM’s). However, as Medicaid is a federal benefit implemented by each state according to its own plan, policies regarding transfers for the over 65 population may vary state to state. For example after similar policies were litigated in Oregon and Wisconsin, the State of Oregon does not allow transfers for the over 65 without penalty, while Wisconsin does allow them. In Michigan, there is a current bill pending in the Senate regarding pooled trusts and their administration, which would codify the State’s position that transfers for individuals over the age of 65 are allowable. However, from a public policy standpoint, due to the direct benefit to the individual, and because remaining assets after death are used to either reimburse the State or retained by a non-profit organization for the benefit of other individuals with disabilities, pooled trusts are a planning tool for elderly disabled individuals that is worth preserving.

Michele P. Fuller is a partner with Fuller & Stubbs, PLLC based in Shelby Twp., Michigan, and serves as Director for Advocacy, Inc., a non-profit corporation, which administers special needs trusts including the Michigan Preservation Trust, a pooled accounts trust. A busy mother of four, she is a council member for the Elder Law and Disability Rights section of the State Bar of Michigan, serves as Treasurer of the Macomb County Probate Bar Association, and is an active member of Academy of Special Needs Planners and National Academy of Elder Law Attorneys.