From Mental Retardation to Intellectual Disabilities: Changing Terms and Changing Minds*

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* This article is based on portions of a presentation at the DDD conference in Kona, Hawaii in February 2007.

For decades, the label mental retardation assaulted the dignity and self-esteem of people who were described with this term. Change has already come to the terminology applied to these people. The more important question, however, is how the mind of the public can be changed regarding who people with intellectual and developmental disabilities really are, and what they need in order to claim their rightful place as citizens in our democracy.

Mental Retardation: It’s Like a Box of Chocolates; You Never Know What You’ve Gonna Get

In 1992, the American Association on Mental Retardation (now the American Association on Intellectual and Developmental Disabilities) listed more than 350 causes of mental retardation. This list of causes does not, of course, take into account the varying degrees of retardation or other disabilities associated with each of the etiologies. When those variables are considered, the universe of human conditions subsumed under the term mental retardation is overwhelming. The staggering list of causes of mental retardation illustrates the allure and power of typological thinking. This is the belief that complex individual variations can be reduced to underlying human types or essences. Stephen Gelb (1997) has found that definitions of mental retardation, regardless of their particulars, are grounded in typological thought.

The term mental retardation has thus been used to describe people who are more different than they are alike (Gelb, 1997). It has been used as an amalgam for very diverse human conditions. The core of mental retardation as a field has been the assumption that somehow there is an “essence” that eclipses all of the differences that characterize people described by the term. It has truly been a box of chocolates, however, because in Forrest Gump’s words “you don’t know what you’re gonna get” when you reach into the category. Maybe it will be someone who needs constant care, or maybe it will be someone much like yourself, but who needs help with academic skills. Maybe it will be someone with severe physical disabilities, or maybe it will be someone who you would pass on the street without notice.

Changing Names or Changing Minds?

There has been much discussion and some action in recent years regarding the use of the term mental retardation. Mental retardation has been questioned as both a concept and as a description. It has been called a myth (Smith, 2005). On the other hand, caution has been advised in changing the terminology of mental retardation given the potential funding and service implications of a major change (Luckassen and Reeve, 2001). Changes in language are already evident in the titles, policies, (continued on p. 8)
President’s Message

Polly Parrish

As a classroom teacher, I confess I do love “being off” for the summer. For me, one of the indulgences summer vacation affords is the time and opportunity to read and even reread some of my favorite books and writings. Before you misunderstand, it is not that I do not read during the school year; I do. However, during the summer break I read without a specific purpose in mind—save enjoyment. And yet, I am reminded of the words of Kahlil Gibran in his book, The Prophet “if it is a care you would cast off, that care has been chosen by you rather than imposed upon you.” So, it is no surprise that midway through my random summer rereading of my favorite children’s books (such as Because of Winn Dixie) and classics (East of Eden, to name one) I slowly return to more “purposeful” reading on topics that will enhance my teaching. Once again, I eagerly anticipate Fall, the start of a new school year, the possibilities it brings and the care I do so enthusiastically choose.

One book I randomly picked up this summer was In Search of the Promised Land—The Collected Papers of Burton Blatt. In his poem “Aphorisms of a Burned-out Pessimist,” Blatt (1970) writes:

Optimism is not in believing that things will turn out well, objectively,
But in believing that one can face things, subjectively, however they turn out.
Optimism is not feeling good,
But in feeling that good has a chance to survive.

I am thrilled and honored to work on the Division of Developmental Disabilities (DDD) Board of Directors and with DDD members who are, in Burton Blatt’s words, “burned-out pessimists.”

Today, with the many issues and legislation before us, controversies arise. Blatt wrote in “The Controversies of Mental Retardation” (1987, published posthumously) that we, in our field, should spend time “grappling with our controversies” because we would discover “facts often become truth only when they are tested by articulated values.”

As a division we are fortunate to have members who choose to “grapple with controversies” and test the facts “by articulated values” in search of the truth. Darlene Perner, DDD Express newsletter editor and Communications chair, has done both of these in the DDD position paper, “No Child Left Behind (NCLB): Issues of Assessing Students With the Most Significant Cognitive Disabilities,” which is currently posted on the DDD Web site. She brings to light the issues, or as Blatt would call them, “the controversies,” NCLB creates in assessment of students and youths with significant cognitive disabilities and presents recommendations for addressing these “controversies.”

Bob Stodden and Nikki Murdick, Critical Issues co-chairs, continue to present the Board of Directors and membership with critical issues to “grapple with” and groundbreaking projects such as the DDD position paper, “Technologies for Self-Determination for Youth With Developmental Disabilities.” This critical issues brief, also on the DDD Web site, gives an overview of an innovative project developed by James R. Skouge, Mary L. Kelly, Kelly D. Roberts, David W. Leake and Robert A. Stodden to assist youths with self-determination.

Rosa Lockwood, DDD’s Diversity co-chair, “grappled with” diversity issues on behalf of the division. She developed diversity strategies incorporated throughout DDD’s strategic plan. At the CEC Convention and Expo in Louisville, DDD co-hosted with CEC’s Diversity Standing Committee the first ever Shared Agenda Meeting with CEC divisions. Rosa conceived, coordinated and moderated this event and is currently summarizing the information and recommendations from the Shared Agenda Meeting to present to the board and membership in the near future.

Scott Sparks, another “burned-out pessimist,” continually demonstrates that “facts often become truth only when they are tested by articulated values” through his work with standards. Scott, past president of DDD, DDD’s Professional Development and Professional Standards chair, and chair of CEC’s Knowledge and Skills Sub-Committee, recently collaborated with a group in Ohio to develop a set of autism standards. He is leading DDD’s Professional Standards committee as they currently review and edit the autism standards to incorporate into the DDD strand of CEC’s Advance Standards. Scott is also working with the Autism Society of America to develop standards.

To quote Burton Blatt one more time (and I make no apologies for it):

The lucky man neither works to live, nor does he live to work . . . .
He has difficulty deciding what is work and what is pleasure,
Not because he cannot recognize joy in leisure but because
he does not encounter drudgery in work.

It is with great excitement I begin my term as president, knowing the caliber of “burned out pessimists” with which I will have the privilege of working. But my excitement is also tempered with cautious anticipation. I do not presume to step into the shoes of DDD’s most recent president, Phil Parette. They are much too large. As appointed Kara A. Peters Endowed

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Meet the Newly Elected DDD Board Members

Emily Bouck, Vice President. Emily Bouck is an assistant professor of Educational Studies in the Special Education Program at Purdue University. She received her baccalaureate at Northwestern University, her master’s degree at the University of Michigan, and her doctorate degree in special education from Michigan State University. Emily’s research has two main lines of focus; curriculum and instructional environments for secondary students with mild mental impairment (especially issues related to functional curricula), and assistive technology for secondary students with high incidence disabilities in the content areas. She has made several national presentations and published many articles on these issues in the field of special education.

Toni Fuller Merfeld, Secretary. Toni is the owner/director of Metro West Learning Center in Clive, Iowa working with children on the autism spectrum in social language groups and children with ADHD and other learning needs. She teaches teacher prep/special education course work for Upper Iowa University and is a member of the North Central Association High School Accreditation Board. Toni has a master’s degree in emotional/behavioral disturbance from Drake University and her post-graduate work has been in elementary and secondary administration. She has been in the special education profession for 28 years. Toni has also been president of the Iowa Federation and of the Iowa DDD subdivision.

Linda Laz, Far West Member. Linda Laz currently teaches at Jefferson Elementary School in Boise, Idaho. She has worked with children in an extended resource/self-contained classroom for 20 years. Five years ago, Linda created and implemented a structured learning classroom dedicated to working with children with autism. She has participated in numerous statewide leadership meetings, and within the Boise School District provides consultation for teachers and staff on autism and positive behavior supports. In 2006, Linda received the Red Apple Award from the Boise School District for outstanding service to education. She has been a member of CEC-DDD since 1998.

Angi Stone-MacDonald, Student Governor. Angi Stone-MacDonald is a third-year doctoral student in special education at Indiana University. She is from Bloomington, Indiana, and has lived in Germany and Saudi Arabia. Angi’s main area of research looks at the role of culture and language in curriculum and schools for students with developmental disabilities in Africa and the African diaspora. She is also interested in early intervention and technology in education. Angi’s dissertation will be about a school in Tanzania that is working with students with developmental disabilities to become active members of their community and educating the local communities to be accepting of these students in their society.

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Mark your calendar!
The 11th International DDD Conference
Sheraton San Diego Hotel & Marina
San Diego, California
October 8–10, 2008

For further information, please contact Cindy Perrus, Conference Coordinator cindy.perras@cogeco.ca
Call for Nominations

DDD is currently seeking nominations to fill vacancies on the Board of Directors for the following positions, which will commence July 1, 2008:

- **Vice President** – Candidate must be willing to provide a four-year commitment to DDD in the following sequence: Vice President; President Elect; President; and Past President.
- **Treasurer** – Candidate must be willing to serve a three-year term of office.
- **Canadian Member** – Candidate must reside in Canada and be willing to serve a three-year term of office.

All candidates must be willing to serve as a committee chair and participate in board activities. For more information on each position, please see the "What's New" page on the DDD Web site (http://www.dddcec.org/new.htm).

Nominations for these positions must be received by **November 15, 2007**. The person submitting the nomination and the person being nominated must be members of CEC-DDD. Contact information and a brief bio of the nominee should accompany the nomination. Send this information directly to Phil Parette, Nominations and Elections Committee Chair (hpparet@ilstu.edu).

New Conference Coordinator!

At the Annual Business Meeting in Louisville, Kentucky, DDD's membership approved the motion for a Board-appointed position—conference coordinator—effective July 1, 2007. In addition to serving as a member of the Conference Committee, the conference coordinator will have responsibility for organizing DDD’s International Conference and regional training institutes, and will assist subdivisions with developing professional learning opportunities.

DDD’s Board of Directors is pleased to announce the appointment of **Cindy Perras** as the new conference coordinator. Over the past 12 years Cindy has been actively involved with DDD’s conferences as program chair and/or conference chair. Welcome Cindy!

Technologies for Self-Determination for Youth With Developmental Disabilities: A Critical Issues Brief

Robert A. Stodden,
**Critical Issues Committee Co-Chairperson**

A team of researchers from the University of Hawaii at Manoa have developed and submitted a new Critical Issues Brief for the membership which focuses on the issue of using “technologies for voice” as related to the self-determination of youth with developmental disabilities. The authors describe a self-determination model that values family-focused, community-referenced pedagogies employing “new media” to give voice to youth and their families. In line with the adage that a picture is worth a thousand words, many youth and families find they are better able to convey their life situations and express their hopes and fears using multimedia (e.g., camcorders, voice recorders, digital cameras, PowerPoint) to find their voices in transition and IEP planning meetings. Systematic strategies are described to support teachers and other youth advocates to employ multimedia technologies as tools of self-determination. The new **Critical Issues Brief** can be found on the "Positions Papers" page of the DDD Web site (http://www.dddcec.org/positionpapers.htm).

Attention Student CEC Chapters . . .

**Receive a $75 Student Recruitment Grant!**

Here is an opportunity for your student chapter to receive $75 from the Division on Developmental Disabilities. Simply complete the **Student Recruitment Grant Application** on the Web site (http://www.dddcec.org) by the September 30, 2007, deadline and submit it to: Kara Hume, DDD Membership Co-Chair, 812 S. Gatewood Dr., Bloomington, IN 47403.

To receive an additional $100 award, you must be the student chapter that has recruited the most new student members to the DDD of CEC between October 1, 2007, and March 15, 2008. Students, please take the opportunity to receive the $75 grant to assist with your student CEC activities while at the same time increasing the membership in the Division.
CEC-DDD Awards

The Division on Developmental Disabilities of the Council for Exceptional Children is pleased to provide for the annual recognition of individuals and subdivisions through a number of awards, as listed below:

The BURTON BLATT HUMANITARIAN AWARD is available to honor an individual who is a member of DDD, and who has demonstrated exceptional effort in furthering the cause of persons with mental retardation/cognitive disabilities, autism and other developmental disabilities.

The LEGISLATIVE AWARD is available to honor an individual who has been involved in the development, support, and/or enactment of legislation designed to meet the needs of persons with mental retardation/cognitive disabilities, autism and other developmental disabilities. The person need not be a member of DDD.

The TEACHER OF THE YEAR AWARD is available to recognize a special education teacher or regular classroom teacher from each subdivision for exceptional performance in supporting students who have mental retardation/cognitive disabilities, autism and other developmental disabilities. The teacher need not be a member of DDD, and each state/provincial subdivision is encouraged to nominate an individual for this award.

The PARAEDUCATOR OF THE YEAR AWARD is available to recognize a paraeducator from each subdivision who participates as a member of the teaching team, and who exhibits exemplary personal and professional skills in supporting students who have mental retardation/cognitive disabilities, autism and other developmental disabilities. The paraeducator need not be a member of DDD, and each state/provincial subdivision is encouraged to nominate an individual for this award.

Nominations/applications and requests for additional information regarding DDD awards should be forwarded to: Toni Merfeld, DDD Awards Committee Chair, 15136 Sheridan Ave., Clive, Iowa 50325; or by fax (515/987-1487); or by e-mail (fullertjm@qwest.net).

Please note: Any CEC-DDD member may nominate individuals for the BURTON BLATT HUMANITARIAN AWARD or the LEGISLATIVE AWARD. Only subdivision presidents may nominate individuals for the TEACHER OF THE YEAR AWARD and the PARAEDUCATOR OF THE YEAR AWARD; additionally, subdivision presidents may apply for consideration for the JOHN W. KIDD SUBDIVISION AWARD by writing to the chairperson of the DDD Awards Committee. Nominations/applications, accompanied by appropriate supporting data/information to allow the selection committee to judge the suitability of the individual or subdivision as a candidate for the award, must be submitted for consideration NO LATER THAN JANUARY 15, 2007.

Please note that awards nominations must be submitted by DDD members, and that awards are presented during the DDD Annual Business Meeting at the Annual CEC Convention, only during a year when nominations meet the stated criteria. Nominations/applications and requests for additional information regarding DDD awards should be forwarded to: Toni Merfeld, DDD Awards Committee Chair, 15136 Sheridan Ave., Clive, Iowa 50325; or by fax (515/987-1487); or by e-mail (fullertjm@qwest.net).

Students’ Corner

Angi Stone-MacDonald, Student Governor

Hi, my name is Angi Stone-MacDonald. I would like to introduce myself to the readers of this newsletter and the students especially. If you have interests, concerns, or questions related to DDD as a student, please contact me (akstone@indiana.edu).

I am a third-year doctoral student in special education at Indiana University and I am from Bloomington, Indiana, but I have lived in Germany and Saudi Arabia. My main area of research looks at the role of culture and language in curriculum and schools for students with developmental disabilities in Africa and the African diaspora. I am spending my summer in Tanzania learning about special education at a school for students with developmental disabilities in the Western Usambara Mountains and improving my Swahili. During my time here, I noticed many of the similarities, but also cultural differences, between students with developmental disabilities in the United States and in Tanzania. Many of these differences center on differences in the way of life of people here. For example, many people in the villages here fetch water from a stream or public well and eat ugali, a corn mash with meat and vegetables, served with their hands. I was watching some of the students eat and help with the daily chores around school and thinking about the differences, and that students with autism tend to have fewer sensory difficulties than students with autism in the U.S., but meet all the other diagnostic criteria for autism. I encourage our students who are training to be teachers to notice the similarities and differences among students with disabilities from different cultures. Our classrooms are becoming much more diverse and we need to be aware of how disabilities can look or be perceived in other cultures. If you have questions, ask the parents, as they are very knowledgeable about their culture and their children. In special education, we know one size doesn’t fit all, and some children with disabilities from other cultures may need other approaches or just some-

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News from the Diversity Committee
Rosa Lockwood, Chairperson

Shared Agenda Update
During the Council for Exceptional Children’s (CEC) convention on April 19, the Diversity Committee, with support from the Developmental Disabilities leadership, joined with CEC’s Standing Committee to co-host a shared agenda breakfast meeting. The stated purpose was to interface with other divisions/diversity committees and discuss diversity issues within individual divisions, identify commonalities across divisions, and consider collaborative ways to address common issues. Nine divisions accepted our invitation and 10 representatives attended the meeting along with DDD board members and CEC headquarters staff.

The meeting was set up with five topics highlighted on posters to allow each division to showcase their diversity initiatives/activities. Five additional topics were identified to allow participants to focus on common issues shared across divisions. Four of these were:

1. Division support for a diversity committee within individual divisions;
2. Division support for including division/diversity issues in policies/practices;
3. The ability to identify and work through challenges encountered by division/diversity committees; and
4. Problem-solving frustrations experienced by divisions/diversity committees.

The fifth topic was the most important activity for the group; the identification of shared opportunities for cross-division collaboration. During the group discussion of this topic, representatives considered opportunities for divisions to work together and individually, and identified one suggestion that would allow cross-division collaboration. (These ideas will be shared at a later time.)

We were able to leave the meeting acknowledging that we already share an individual division focus in our quest to address division/diversity issues, have and continue to duplicate efforts, and could be more effective if we collaborated across divisions. There will be follow-up contact with participating divisions. Action steps for developing shared opportunity/next steps will be developed in an appropriate format to move this initiative to the next level, which will be cross-division collaborative work. This step will involve cross-division conversations to determine the group’s initial focus. This initiative will continue to provide DDD with the opportunity to facilitate a diversity agenda within the Division and give leadership for collaboration across divisions.

Kara Hume, Co-Chair
Many thanks to Jim Forristal and Kent Gerlach for their years of service to the Membership Committee! Through their efforts, DDD’s membership has grown in the past several years and we are grateful for all of their contributions, including the establishment of the student recruitment grant, the organization of the membership table at the annual conventions, and the collaboration with other divisions to increase membership. We hope to keep their great initiatives going and continue to add new members to DDD.

Kara Hume, the former student governor (karahume@aol.com), and Debora Wichmanowski (Southeast Member–dwichman@pasco.k12.fl.us) will be the new co-chairs of the Membership Committee. We’d like to welcome the new and returning Board members that are serving on the Membership Committee: Linda Laz (Far West Member–lpaddy@earthlink.net), Dianne Zager (Northeast Member–dzager@pace.edu), Nikki Murdick (Midwest Member–murdickn@slu.edu), and Leslie Broun (Canadian Member–fljj@rogers.com).

Last year’s student recruitment grant was very well-received by chapter advisors and student members, with 10 universities participating. We’d love to see that number continue to rise in our seventh year. The membership committee will be contacting student CEC chapters and advisors to inform them about the grant, and an application is available on the DDD Web site (http://www.dddcec.org). All chapters that apply will receive $75 to assist in a DDD membership drive, and the chapter recruiting the most new members will receive an additional $100 for the chapter. The grant deadline is September 30, so get those applications in!

For information about the student recruitment grant or any membership initiatives or questions, feel free to contact the co-chairs or committee members. We look forward to keeping the positive membership trend going and welcome your thoughts and ideas.

Attention DDD Members! Please participate in DDD by joining a DDD Committee.
For more information, go to: http://www.dddcec.org/committees.htm

Membership and Unit Development Committee News

Kara Hume, Co-Chair

DDD Express
Debbie Wichmanowski, Southeast Member. Debbie Wichmanowski has taught classes in the areas of PMH, TMH, EMH, SLD and EH at the elementary, middle and high school levels for six years in Illinois and 23 years in Florida. For the past six years she has served as an assistant elementary school principal. In 1995 Debbie was named the Pasco County, Florida Teacher of the Year. In 2001 she was named the Florida CEC/MRDD (now DDD) Teacher of the Year and subsequently the Florida CEC Teacher of the Year. She received her master’s degree in Educational Leadership from the University of South Florida. Debbie is married to her husband Chip, and has three children; Nick, Jamie, and Alicia.

Executive Director’s Corner
Tom E. C. Smith, Executive Director

The CEC conference in Louisville was very successful and DDD accomplished a great deal during the several days of board meetings. At the business meeting, the membership approved several changes to our constitution and by-laws. The primary change was to add a position on the Board as conference coordinator. This individual will be responsible for coordinating all DDD conferences, which currently occur every two years. With the conference coordinator being a permanent member of the Board, it is likely that it will move to expand conference offerings to every year, with a focus on regional and topical conferences.

North Carolina’s subdivision is being rejuvenated. If you live in a state where a subdivision has been dormant for several years, or where there has never been a subdivision, please contact me for some assistance in getting a subdivision up and running. DDD can help with this process in many ways. For example, we can grant subdivisions seed money and sponsor a member of the national DDD Board to attend one of your state meetings. It is also the time of year for subdivisions to submit annual reports. Please send me a list of your officers for the 2007–2008 year so we can send you your subdivision rebate. Contact me (tecsmith@uark.edu) if I can help in any way.

Publications Committee
Jack Hourcade, Publications Committee Chair

The Publications Committee of CEC’s Division on Developmental Disabilities is pleased to announce plans for the latest two volumes of DDD’s Prism series of monographs. These new issues, tentatively titled Embedded Instruction in General Education Classes: An Implementation Guide and Functional Math for Students with Developmental Disabilities, are scheduled for late 2007 and 2008.

In addition, the long awaited revision of DDD’s classic publication Best and Promising Practices in Developmental Disabilities is in the final stages of production. Now entitled Research-Based and Best Practices in Developmental Disabilities, it should be available in late 2007.

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one to understand that they are learning about the U.S. culture and maybe the English language. I encourage each of you to learn more about the background of a student from another culture when you work with this year. As a teacher, it will be important to be aware of the cultural backgrounds of your students and their parents. I know I have learned so much this summer about a different way of life.
and mission statements of a number of the organizations, including DDD (ARC, 2004; Stodden, 2002). The American Association on Mental Retardation became the American Association on Intellectual Disabilities in January, 2007. A change in terminology is a move in a very positive direction. Mental retardation became the most stigmatizing of the disability labels and laundering the term of its stigma is impossible; it has had too many negative connotations for too long. People who have been labeled with the term “mental retardation,” and their families, should be asked how they wish to be known. I can find no evidence that they have ever been asked. Dudley (1997) has pointed out that other minority groups have determined for themselves how they should be made (e.g., the historical changes in terminology from Negro, to Black, to Afro-American to African American). Mental retardation will soon become only an historical footnote. And yet changing the label alone will not serve the people currently categorized as mentally retarded very well. Changing our thinking about people is even more important than what we call them.

It is widely recognized that changes in the field of special education have had a direct and causative influence on the numbers of students in the intellectual disability category, and on the interest and resources invested in the field. Many of the students who would have been designated as mildly retarded and were served as such a generation or two ago are now served in learning disabilities contexts. Unfortunately there has also been a “forced migration” of others of these students from special education into a Neverland of no service at all. It is not uncommon to find significant numbers of students who are unofficially considered to be simply and unquestionably “slow learners,” ineligible for special education. Many special educators, including myself, have stood by in relative silence while many of these students have been “disenfranchised” from special services. Inordinate numbers of these students are, of course, children and adolescents from poverty, minority, and language disadvantaged backgrounds.

Polloway (2004) has asked whether the time has come for a eulogy for mild retardation. I think he then answers his own question not only about mild retardation, but about retardation as a whole. Yes, the term is dead and deserves a decent burial. But no, we cannot allow recognition of the needs of large numbers of children and adults to “pass away.” It is incumbent upon the many of us who began our careers in the field of mental retardation that we strive to rekindle interest in and commitment to the students who have escaped a negative identity, but who may now be adrift with little help for their significant learning needs.

The time is overdue for professionals, professional organizations, parents, self-advocates and others to reinvigorate the dialogue, to engage in the research, and push for the funding that will bring new life to the field that gave birth to special education. This is the legacy of Jean Itard, Maria Montessori, Elizabeth Farrell, Lloyd Dunn, Sam Kirk, and others who saw potential and possibilities where most educators saw obstacles. To repeat myself, even more important than changing a name is changing our minds, and the minds of others, about a largely misunderstood population of children and adults.

References


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Chair in Assistive Technology at Illinois State University, Phil wore many hats this past year as director of Special Education Assistive Technology (SEAT), editor of Assistive Technology Outcomes and Benefits, and DDD president. And yet Phil exemplified Blatt’s words in each of these endeavors as he “does not encounter drudgery in work.” Phil has led the division this past year efficiently and effortlessly and has given the division a high standard in which we, as members and “burned out pessimists,” will strive to maintain. Being a member of DDD continues to be one of the “cares” I choose, as many of our members thankfully do.