STANDING COMMISSION ON HEALTH

Membership

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The Rev. Marshall Scott, *Vice Chair*, 2018
The Rev. Stannard Baker, *Secretary*, 2018
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Ms. Stephanie Cheney,
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The Rev. Dr. Patricia Hanen,
  Representative of the President of the House of Deputies
Ms. Jayce Hafner, *Staff*

Summary of Work

Mandate: To identify and study national and international health care issues, practices, and policies and the Church's health care ministries; and to make recommendations to General Convention.

The direction for our subcommittee is in response to Resolution 2012-D068, "Move Toward Full Inclusion of Persons with Developmental Disabilities," in which the 77th General Convention made the following commitment:

> *Resolved*, the House of Deputies concurring, That the Church recognizes that all people are children of God, regardless of mental abilities; and be it further
> *Resolved*, That those with developmental disabilities, including but not limited to persons with Asperger's syndrome, persons on the autism spectrum, persons with Down syndrome, and persons with ADHD, require different approaches to education and pastoral care; and be it further
> *Resolved*, That the 77th General Convention create a Task Force to study what resources are currently available, and to create resources that can be used to help educators and clergy to tend to this population, and to foster the unique talents found in this population that should be embraced and encouraged.

Meetings:
- Nov. 12-15, 2012
- Jan. 7, 2013, 12:00 pm-1:00 pm (teleconference)
- Feb. 4, 2013, 7:00 pm-8:30 pm (teleconference)
- Apr. 9, 2013, 7:00 pm-9:00 pm (teleconference)
- June 20, 2013, 3:00 pm-5:00 pm (teleconference)
- July 22, 2013, 3:00 pm-5:00 pm (teleconference)

The Standing Commission on Health initially organized into several subcommittees, and at the same time began planning for a face-to-face meeting with two other standing commissions of The Episcopal Church. The shared hope was that these three commissions could collaborate on a narrow set of shared policy priorities that were agreed upon early in the triennium. Unfortunately, the planned meeting was prevented from happening by directives that required the funding for each of the commissions to be allocated before the meeting could take place.

The three-commission meeting had been planned in an economical fashion, and the subsequent meetings of the Standing Commission on Health (all of which were held virtually via Adobe Connect) demonstrate that abundant funds would have been available for this initial meeting.

The Standing Commission on Health moved forward with its subcommittees, and excellent work was accomplished by those subcommittees. What follows is the report of one subcommittee that was most appropriate for full reporting in the record of work for the 2013-2015 triennium. I wish to thank the members of the Standing Commission on Health for the commitment, expertise, passion, and good humor they brought to bear on this important work.

While health care reform is arguably the most prominent accomplishment of President Obama's administration to date, and while each member of the Standing Commission on Health is passionately committed to a range of issues under the general heading of "health," it would yet be fair to say that it is unclear in the impending reorganization of The Episcopal Church if this Standing Commission should move forward into another triennium in its current form. The issues clustered under "health" remain of paramount importance, but the question of how our Church should best engage these issues seems an open one.

Specifically, building on the original impulse to coordinate the work of three standing commissions — including that on Health — and drawing from the Health commission's discussions about health in the broader context of the new United Nations goals for sustainability, it might be well to reimagine this subject within a more embracing frame.

Work on Resolution D068 from TEC's 77th General Convention

> "How, as a Church, are we changed by inclusion? Let us proclaim that we are all enriched by inclusion — similar to the full inclusion of women as clergy in the life of the Church, and the full inclusion of people of color and of LGBT people."
> *[From a Diocese of Vermont focus group participant]*

At the meeting of the Standing Commission on Health held in St. Louis in November of 2012, a small subcommittee was formed to respond to Resolution D068. While grant funds were sought for the work of this Subcommittee, none were forthcoming. Work went forward nonetheless. Following the advice of the full SCoH to survey The Episcopal Church and talk with people in dioceses and parishes, forums were held in the Diocese of Vermont and the Diocese of Los Angeles in the fall of 2013 and were attended by families of people with Developmental Disabilities (DD), people with DD, and by those with interest in or passion for this topic.

The questions asked at the forums were:
   1) What has worked for you or your family in your parish, diocese, or in church-related activities?
   2) What has not worked, what are the gaps, or what needs to be improved?
   3) What is your vision of a more inclusive future for your parish, the diocese, or the larger Church?

These forums were informative and moving, as participants told stories of grace-filled moments of inclusion and shared painful memories of exclusion from church activities. Participants were unified in proclaiming the

need for a culture of inclusion in TEC; for training for clergy, lay leaders, and church school teachers; for access to resources; and for flexible liturgy options.

These forums were followed by a church-wide survey in late summer 2014 that was sent, in English and Spanish, to all bishops and General Convention deputies. Questions included in the church-wide survey were informed by, or arose from, the forum discussions.

While there was some criticism of some of the survey questions that asked respondents to quantify numbers of people with DD, 762 people responded to the survey with valuable suggestions about formation curriculum, adaptations to liturgy, and ways to develop a culture of inclusion in our Church. It became clear that survey questions asking for people to identify numbers of people in their parishes or dioceses with Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), or Intellectual Disabilities (ID) were difficult or impossible for bishops or clergy and lay leaders from large churches to answer, since a more direct knowledge of particular members of each congregation is necessary for this. Nonetheless, our Church has significantly large numbers of members with these disabilities, including children, teens, adults, and some of our clergy and lay leaders.

Without doubt, access to resources for formation at all levels, to ideas for creating a culture of inclusion, and to designs for liturgical flexibility options or adaptations are very much needed. In their narrative responses, many testified to the richness that comes from the inclusion of people with Developmental Disabilities. (For more details on response to the survey, please see the Appendix: Summary of Responses to Survey on Inclusion of People with Developmental Disabilities.)

Future Work in This Area; Resolution

A representative from the Standing Commission on Lifelong Christian Formation and Education (SCLCFE) has recently been in touch with our Subcommittee to inform us that they are drafting a resolution for General Convention 2015 recommending that resources be made available for the full inclusion of people with DD.

Our findings on curricula and resources have been relayed to the SCLCFE. Its resolution is a much-needed and logical extension of our work. It is hoped that the Commission can receive some modest funds not necessarily to create new materials, but to disseminate them, and to educate clergy and lay leaders about current available information and resources for formation and worship.

In our view, it would be extremely helpful if, in the course of their work, a brief handbook were to be prepared outlining worship and formation options and ideas for clergy, lay leaders, and congregations. As our view is informed by professional practice in this area, we recommend that the SCLCFE receive approximately $15,000 for this work.

The Standing Commission on Health, on the other hand, will not extend into the next triennium, and as such, will not be asking for a budget.

Budget

Following is a breakdown of the expenses for the Standing Commission on Health during the 2013-2015 triennium:

Original budget: $17,000
2013 Expenses: $425 Adobe Connect Licensing Fee (for teleconferencing)
2014 Expenses: $425 Adobe Connect License for 2014 (for teleconferencing)

No budget is requested for 2016-2018 triennium.

APPENDIX: Summary of Responses to Survey on Inclusion of People with Developmental Disabilities

[Extracted from the Survey on Inclusion of People with Developmental Disabilities, compiled by The Rev. Stannard Baker, creator of the survey and Co-chair with Mimi Grant of the Subcommittee on Full Inclusion, with approval and oversight by The Rt. Rev. Marc Andrus, Chair of the Standing Commission on Health.]

"We have a sense of radical welcome about this and the neighborhood we inhabit."
[From the narrative portion of the survey – Question 11]

Introduction

1. Surveys were sent to all General Convention deputies: lay and clergy from the House of deputies and all bishops from the House of Bishops. Some of those to whom the survey was sent delegated response to others in their dioceses or sent it to others in addition.

2. Responses were received in English and Spanish from 762 people.

3. The three developmental disabilities surveyed were as directed in Resolution D068.

4. It was difficult for bishops and clergy or deputies from large churches or dioceses to answer questions 5,6, and 7. However, many parish clergy and lay leaders felt that they could answer these questions reliably, and the responses to these questions demonstrate that substantial numbers of those in our congregations are people with developmental disabilities. **However, please note that these are not reliable numbers as they are "best guesses," and some felt they could not respond because they are understandably not aware of parish- or church-school-level detail.**

5. Some respondents were leery of identifying people with developmental disabilities because they felt that they were being asked to provide diagnoses even though they were not skilled diagnosticians. The intent of the survey was for people to give information they already had from individuals and parents, and not to provide diagnostic information from unknown parishioners.

6. In the end, we were gratified by the large number of people who did fill out the survey, and we found the data provided and the narrative comments very helpful.

Question 1: Diocese
Responses came from all almost all dioceses.

Question 2: Order of Ministry
Lay = 53.5 percent
Priest = 40.4 percent
Deacon = 3.2 percent
Bishop = 2.9 percent

Question 3: Is someone in your family a person with one of the below?
Autism Spectrum Disorder (ASD): 106
Intellectual Disabilities (ID): 99
Attention Deficit Hyperactivity Disorder (ADHD): 176
None of the above: 429

Question 4: Are these persons (select all that apply):
Adult: 203
Teen: 73
Child: 82
Yourself: 25
Not applicable: 416

Question 5: How many adults in your parish have one of the above?
ASD: (492 responses); 10,604 individuals estimated, 21.55 percent
ID: (518 responses); 10,906 individuals, 21.05 percent
ADHD: (466 responses); 11,080 individuals, 23.78 percent

Question 6: How many teens in your parish have one of the above?
ASD: (491 responses); 10,444 individuals estimated, 21.27 percent
ID: (473 responses); 10,329 individuals, 21.84 percent
ADHD: (483 responses); 10,745 individuals, 22.25 percent

Question 7: How many children in your parish have one of the above?
ASD: (494 responses); 10,526 individuals estimated, 21.31 percent
ID: (470 responses); 10,315 individuals, 21.95 percent
ADHD: (486 responses); 10,941 individuals, 22.51 percent

Question 8: What has worked best for you or your family in your parish-, diocesan-, or church-related activities?
Top three responses:
1. 506 (69.8 percent): Church community is open and welcoming to people with developmental disabilities for worship, formation, and activities
2. 395 (54.5 percent): Inclusion of youth as acolytes
3. 353 (48.7 percent): Understanding that full inclusion of people with developmental disabilities is part of our radical welcome as a faith community

Question 9: What has not worked? What are the gaps, or what needs to be improved?
Top three responses:
1. 397 (54.8 percent): Lack of information/education
2. 111 (15.3 percent): Worship and church activities are not friendly to people with Developmental Disabilities and their families
3. 104 (14.3 percent): No attempt made to include people with developmental disabilities

Question 10: What is your vision of a more inclusive future for your parish, the diocese, or the larger Church?
Top five responses (percentages are much closer together on this question):
1. 446 (61.5 percent): Lead by example — have people who will act as mentors or leaders in inclusion
2. 398 (54.9 percent): Create experiences as well as resources
3. 377 (52.0 percent): Proclaim that we are all enriched by inclusion
4. 274 (37.8 percent): Study and converse about how our Church culture needs to change
5. 270 (37.2%): Make more specialized resources available

A brief summary of narrative responses to questions 11 & 12:

Question 11: Do you have specific recommendations for Sunday school or adult education curriculum?
1. By far, the most numerous themes related to:

a. The need for inclusion or integration in formation and worship through:

 i. Adaptation and flexibility in worship

 ii. Use of "buddies" or adult partners

 iii. Occasional special worship services, but also inclusion in ongoing worship

2. The need for training and resources for formation and faith leaders

3. Curriculum resources most often mentioned are specifically intended for those with special learning needs, or are adaptable and flexible and take into account the need for sensory experiences, movement, a variety of media and modalities, and active and interactive moments. (It was noted that adaptations made to formation and liturgy materials usually benefit everyone.)

a. Scanlan & Snyder, *Rhythms of Grace: Worship and Faith Formation for Children and Families with Special Needs*

 i. Complete lessons for church school created with special needs in mind

b. *Catechesis of the Good Shepherd*, from The National Association of the Catechesis of the Good Shepherd

 i. http://www.cgsusa.org

 ii. An interactive approach to worship and formation that involves children, families, and others in Eucharist adapted, and that was created for those with special needs

c. *Godly Play*

 i. http://www.godlyplayfoundation.org

 ii. The hands-on quality of this church-school curriculum makes it easily adaptable for those with special needs

d. *Confirm not Conform: A Confirmation Program that Celebrates Questions and Choices*

 i. http://www.confirmnotconform.com

 ii. This confirmation curriculum has specific suggestions for those on the Autism spectrum that are also helpful for those with ADHD. It is also quite easily adaptable.

e. J2A (*Journey to Adulthood* from Leader Resources)

 i. http://leaderresources.org/j2a_youth

 ii. Can also be adapted

f. *Lectio Divina*

 i. Can work well with adults with special needs

4. Also mentioned:

a. **Forma**: an association and dynamic community of Christian educators, formation professionals, and their institutional partners that celebrates and upholds the diverse ministries of Christian formation across The Episcopal Church. With members from more than 40 states and 60 dioceses, Forma is an independent, nonprofit 501(c)(3) organization that is linked to, but not legally affiliated with, TEC.

 i. http://episcoforma.org

b. *Rotation Sunday School*

 i. http://www.rotation.org

c. Videos from Christ Church, Budd Lakes, NJ

 i. Excellent footage of an interactive worship service and church school beautifully created for those with special needs. These are "unified" experiences that include everyone — those with special needs and others participating together.

 ii. http://www.christchurchbuddlake.org/category/videos

d. *Buelah Land*: Flannel board story telling

e. *Curriculum for Disability and Faith*

 i. Faith Alive Resources/Disability Ministry

f. Friendship Ministries

 i. http://www.friendship.org

 Focused on including those with intellectual disability in Christian communities

g. *Praying with the Body from Paraclete Press*

      i. A way to use physical movement and to involve the whole body in prayer

5. Books:
    a. *Child-by-Child: Supporting Children with Learning Differences and Their Families* by Susan Richardson (Moorehouse)
      i. How-to, with theological grounding with integrated programs and activities, including worship
    b. *The Special Needs Acceptance Book* by Ellen Sabin
    c. *The Autism Acceptance Book* by Ellen Sabin
    d. *Young Children and Worship & Journey to Adulthood* by Sonia Stewart

Question 12: Do you have ideas or tips for inclusion in liturgy of people with Autism Spectrum Disorder, Intellectual Disability, or Attention-Deficit Hyperactivity Disorder?

"Include, include, include! Invite people to vest and serve on the altar as acolyte, crucifer, etc. Listen and pray. Practice, patience: It's a holy time and place — it will be OK."
[Quotation from the narrative portion of the survey – Question 12]

1. The most numerous themes in response to this question were:
    a. Use of lay participants encouraged
      i. Individual coaching before a role is performed
      ii. Use of buddies, shadowing
    b. Benefit of inclusion in liturgy
      i. Hold an instructional liturgy
      ii. Clear structure, with flexibility, increase hands-on
    c. Practicing radical welcome to all
    d. Rector's attitude
    e. Environmental adaptations
      i. Flexibility and movement in services
      ii. Awareness of sensory environment
      iii. Shorter and more flexible
      iv. Include opportunities for movement (use of American Sign Language for the Sanctus or Lord's Prayer)
      v. List of duties required of them helpful to children with ASD (and to others) — have something visual
      vi. Include something for <u>everyone</u> to read in the Bulletin
    f. Holding special services: Joy Mass (see below), Rhythms of Grace, Catechism of the Good Shepherd
      i. Most responders felt that these should be offered regularly but that all should be welcome in every service
      ii. There was some worry about special services becoming exclusionary
2. Resources:
    a. Video of Joy Mass at Trinity Episcopal Church, Seymour, CT
      i. http://www.trinityseymour.ctdiocese.org — find "videos" on the drop down menu
        1. A Joy Mass takes about 25 minutes
    b. Tony Briggle at St. Michael's in Dallas is an expert on formation of youth acolytes with disabilities
3. Books and websites:
    a. *Including People with Disabilities in Faith Communities* by Eric Carter
    b. Books by Cathy Hooperman for use in formation:
      i. *All Cats Have Asperger's Syndrome*
      ii. *All Dogs Have ADHD*
      iii. *Inside Asperger's Looking Out*
    c. *Building Faith* articles at: http://www.buildfaith.org

i. Christian formation inspiration from the Center for the Ministry of Teaching at Virginia Theological Seminary

ii. Available at this website: Sharon Ely Pierson: Youth Curriculum Charts, VTS

1. http://www.buildfaith.org/2014/11/05/curriculum-charts-for-youth-and-adults/

d. Disabilities and Faith website:

i. http://www.disabilitiesandfaith.org/resource

1. Training faith-based organizations in how to be more welcoming and accessible