Written Public Comments

IACC Full Committee Meeting

January 17, 2018

List of Written Public Comments

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Dr. Debasis Kanijilal **January 17, 2018**

Dear Highly Respected All Committee Members,

THIS IS 132 TH EMAIL DIRECTLY TO NRP (National Resuscitation Program) AND CC TO ALL OTHER COMMITTEE MEMBERS.

I WROTE OVER 6,000 EMAILS TO ALL PRESIDENTS, PMs, MONARCHS, DICTATOR (NORTH KOREA), ALL IVY LEAGUE INSTITUTIONS, ALL JOURNALS, ALL MAJOR NEWS PAPERS, ALL RESPONSIBLE ORGANIZATIONS (WHO, UNICEF, UNITED NATION, DOCTORS WITHOUT BORDERS, RED CROSS, ALL HUMAN RIGHTS , ANIMAL RIGHTS, AUTISM, DISABILITIES, CARING FOR CHILDREN, NIH, CDC AND OTHERS), ALL NOBEL PRIZE WINNERS AND THOUSANDS OTHERS
EXCEPT CHINA (NO EMAILS) SINCE 2014 TO SAVE THE NEWBORN BABIES IN THIS WORLD:

This is a follow up email from Jan 6 , Jan 9, Jan 10, Jan 11, Jan 13, Jan 15, Jan 18, Jan 19, Jan 21, Jan 22, Jan 23, Jan 24, Jan 25, Jan 27, Jan 29, Jan 30, Feb 3, Feb 4, Feb 7, Feb 9, Feb 10, Feb 12, Feb 13, Feb 14, Feb 15, Feb 16, Feb 19, Feb 21, Feb 23, Feb 24, Feb 27, March 2, March 3, March 4, March 7, March 8, March 10, March 13, March 17, March 20, March 21, March 23, March 26, March 27, March 30, April 2 April 4,April 10, April 16, April 19, April 20 , April 21, April 23, April 26, May 1, May 4, May 7, May 11, May 12, May 17, May 19 and May 23, May 26,May 30, June 1, June 6, June 8, June 16, June 19, June 20, June 23, June 25, June 26 and June 27, July 1, July 3 and July 8, July 11, July 13, July 17 and July 21, July 31, Aug 2, Aug 3, Aug 4, Aug 12, Aug 14, Aug 21, Aug 24, Aug 25, Aug 27, Aug 28, Aug 29, Sept 1, Sept 3, Sept 5, Sept 7, Sept 8, Sept 9, Sept 11, Sept 12, Sept 13, Sept 14, Sept 15, Sept 16, Sept 17, Sept 18, Sept 19, Sept 21, Sept 23, Sept 24, Sept 25, Sept 26, Sept 27, Sept 28, Sept 29 , Sept 30, October 1, Oct 3, Oct 4, Oct 8, Oct 9, Oct 12, Oct 13 , Oct 15, Oct 17, Oct 18, Oct 19, Oct 21 and Oct 22, 2017.

Greetings to you all.

My humble request to you all:

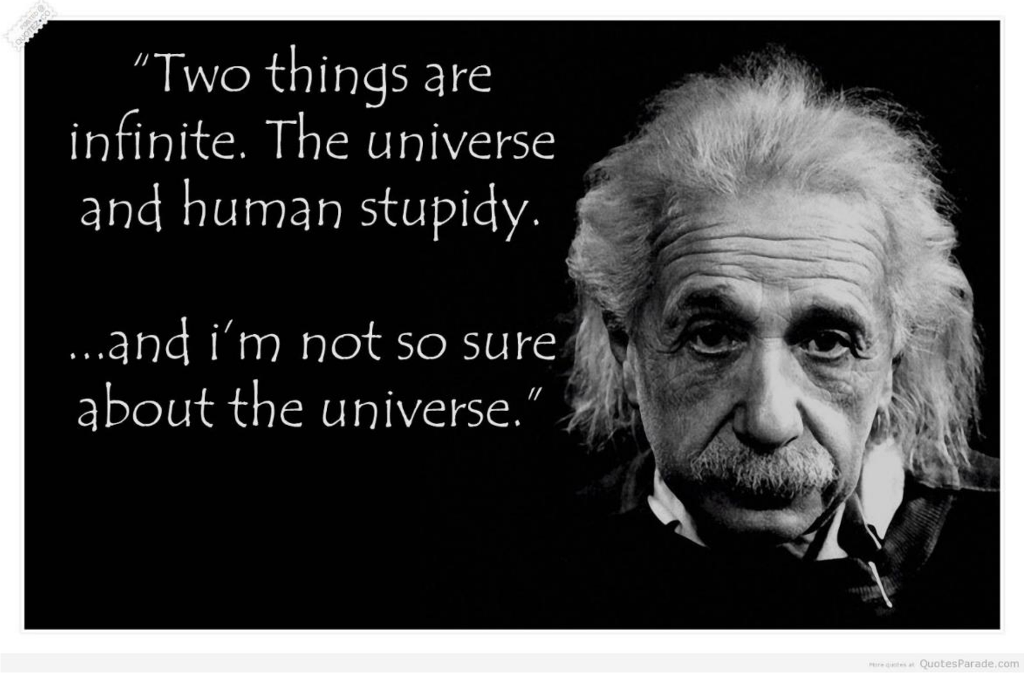
PLEASE SAVE THE CHILDREN IN THIS WORLD NOW AND MAKE A BETTER WORLD FOR TOMORROW .

ALL OVER THE WORLD NEWBORN BLUE BABIES HAVE BEEN SUFFERING FROM HYPOXIA (LOW OXYGEN) INJURIES TO THEIR BRAIN, BEGAN IN 2006 AND MUST END IN 2017 NOW.
NRP / ILCOR / ANZCOR / European Newborn Resuscitation Committees (ERC) are " guiding physicians not to help newborn blue babies to breathe quickly, adequately, effectively and advising them not to give adequate oxygen in blue babies for the first 10 minutes of their lives and more than 10 minutes in Europe. European resuscitation committee (ERC) members don't even bother to specify how long they want to keep their newborn babies blue".

PREVALENCE OF AUTISM IN AUSTRALIA In 2015:
a) 2.5% (high) in 4-5 years old children were born in 2010-2011
b) 1.5% in all 10 -11 years old children were born in 2000-2001.

(since low oxygen pre-ductal saturation recommended by Dr. Jennifer A. Dawson (Nurse with PhD, Australia; Dr. Vento, Spain; Dr. Morley, UK in 2010 and that nonsense was implemented all over the World).
Defining the Reference Range for Oxygen Saturation for Infants After Birth (AAP, Australia, Spain, UK, 2010)
Jennifer A. Dawson, C. Omar F. Kamlin, Maximo Vento, Connie Wong, Tim J. Cole, Susan M. Donath, Peter G. Davis,Colin J. Morley

Dr. Dawson got her PhD in 2009 from this study and tens of millions of newborn babies lost their brain functions in this World.



THANKS AND REGARDS FOR YOUR VALUABLE TIME
DR. KANJILAL
MOUNT SINAI/ELMHURST HOSPITAL
[PII redacted]

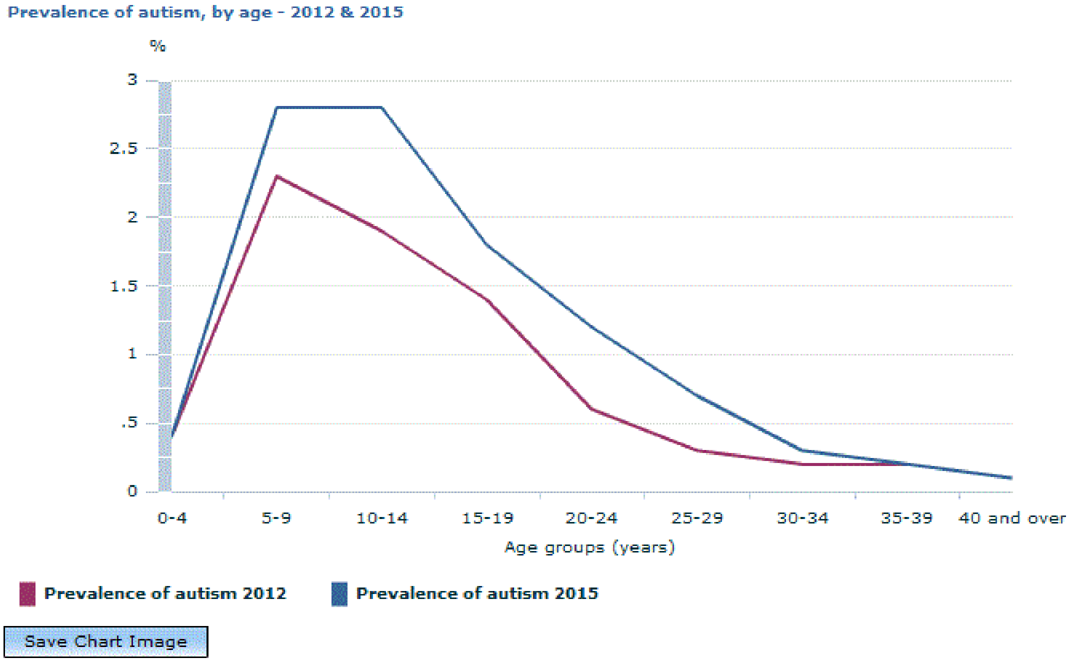
1)
AUTISM IN AUSTRALIA (Australian Bureau Of Statistics)
Disability, Ageing and Carers, Australia: Summary of Findings, 2015

PREVALENCE OF AUTISM IN AUSTRALIA In 2015: Rising 2.5% in 4-5 years old children were born in 2010-2011; 1.5% in all 10 -11 years old children were born in 2000-2001
(since low oxygen pre-ductal saturation recommended by Dr. Jennifer A. Dawson (Nurse with PhD, Australian), et all in 2010 and that nonsense was implemented all over the World)
http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015

Researchers have found that 1.5 per cent of all 10 and 11 year olds have an autism spectrum condition, compared to 2.5 per cent of four and five year olds.
We found that the prevalence of autism was 2.5 per cent in the younger cohort compared to 1.5 per cent in the preschool cohort.

This provides some evidence that children born more recently had a higher prevalence of autism compared to those children born earlier.

http://www.abc.net.au/pm/content/2015/s4299872.htm



Australian Bureau of Statistics

1)
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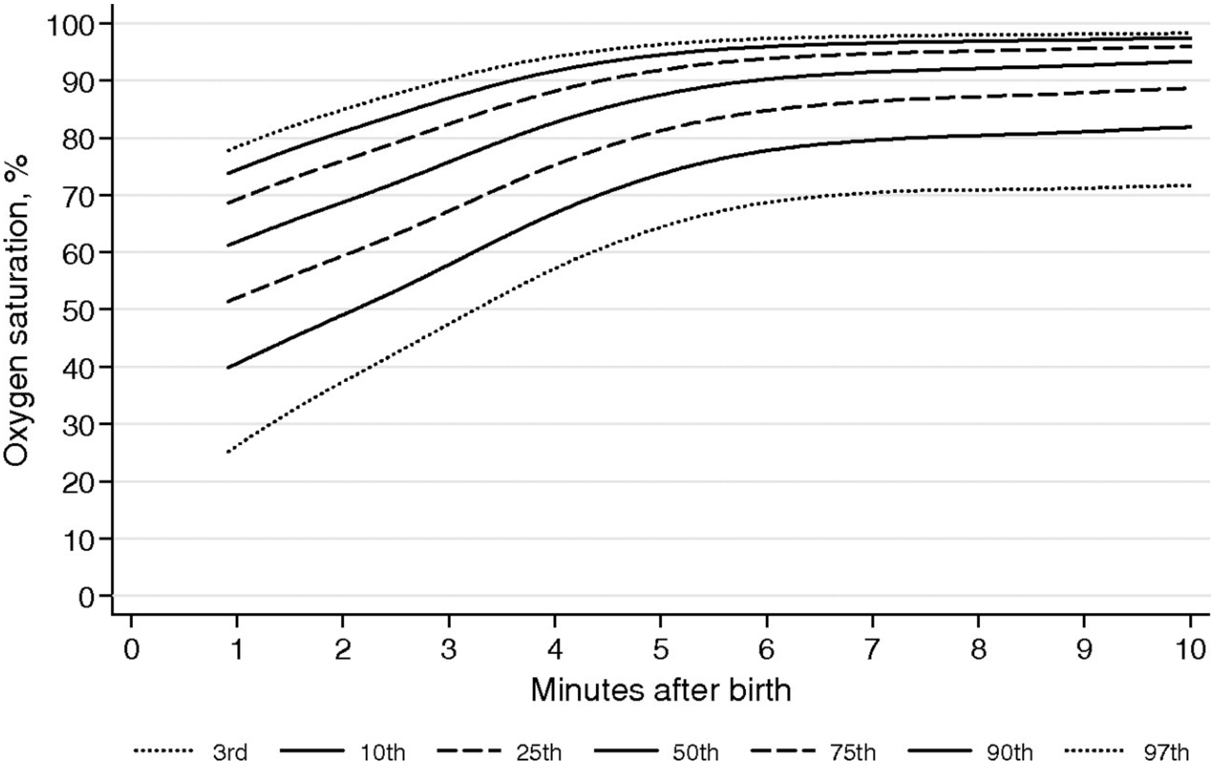
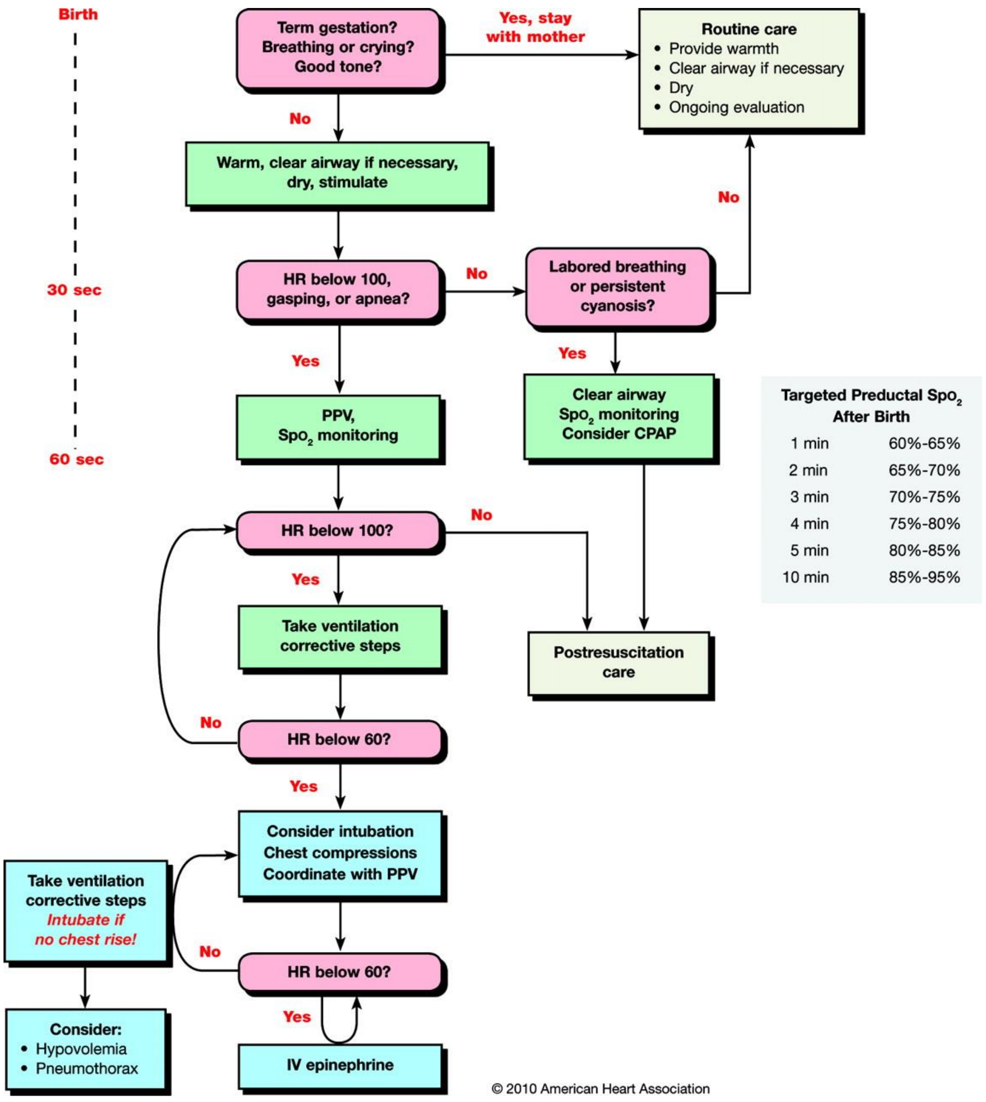
http://pediatrics.aappublications.org/content/early/2010/05/03/peds.2009-1510



2)

NRP / ILCOR targeted saturations below:

a) 1 minute : 60-65 % (50-75th percentile); babies are blue
b) 2 minutes: 65-70% (25-50th percentile) babies are blue
c) 3 minutes: 70-75% (25-50th percentile) babies are blue
d) 4 minutes : 75-80% (close to 25th percentile) babies are blue
e) 5 minutes : 80-85% (close to 25th percentile) babies are blue
f) 10 minutes : 85-95% (85% is below 10th percentile, blue; 95% is above 95th percentile, pink)



Targeted Preductal SpO_2 After Birth	
1 min	60%-65%
2 min	65%-70%
3 min	70%-75%
4 min	75%-80%
5 min	80%-85%
10 min	85%-95%

© 2010 American Heart Association

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NRP HISTORY OF PROGRESSION FROM 1987-2005, FOLLOWED BY DETERIORATION UNTIL NOW:
WHY AUTISM WAS RISING SINCE 1980s BUT LESS ?

1983- 2008 : In the delivery room, Ambu bag with 100% oxygen was used in newborn babies who were not breathing, followed by blowing oxygen to face (blow- by) after they started breathing but still experienced respiratory difficulties. Babies were transferred from the delivery room to NICU (Neonatal Intensive Care Unit) by blowing oxygen to face.

Blowing oxygen to face: not reliable means of oxygen delivery and only less than 30% oxygen is delivered but still recommended. It is better to use Neo Puff to recruit lungs alveoli.

In NICU: babies with respiratory distress, either placed on head box with 40- 100% oxygen or NCPAP or intubated depending on the severity.

The goal: To make them better ASAP (as soon as possible). We never kept any babies blue over 10 minutes that was absolutely unacceptable.

The results : only few babies suffered from low oxygen injuries to their brain. Autism was there but much less because oxygen was given to blue babies.

1987 : NRP was formed.

1992: ILCOR (International Liaison Committee on Resuscitation) was formed to provide a liaison between principal resuscitation organizations.

ILCOR is composed of the American Heart Association (AHA), the European Resuscitation Council (ERC), the Heart and Stroke Foundation of Canada (HSFC), the Australian and New Zealand Committee on Resuscitation, the Resuscitation Councils of Southern Africa (RCSA), the Resuscitation Councils of Asia (RCA) and the Inter American Heart Foundation (IAHF).

2005: THE PROBLEM STARTED BY American Heart Association (AHA) recommendations: " Try room air resuscitation that is 21% oxygen in newborn babies".

2005 American Heart Association (AHA) guidelines for cardiopulmonary resuscitation (CPR) and emergency cardiovascular care (ECC) of pediatric and neonatal patients: pediatric basic life support.

American Heart Association, Pediatrics. 2006.

Show full citation

https://www.ncbi.nlm.nih.gov/m/pubmed/16651298/

The following are the major neonatal resuscitation changes in the 2005 guidelines: Supplementary oxygen is recommended whenever positive-pressure ventilation is indicated for resuscitation; free-flow oxygen should be administered to infants who are breathing but have central cyanosis. Although the standard approach to resuscitation is to use 100% oxygen, it is reasonable to begin resuscitation with an oxygen concentration of less than 100% or to start with no supplementary oxygen (ie, start with room air).

If the clinician begins resuscitation with room air, it is recommended that supplementary oxygen be available to use if there is no appreciable improvement within 90 seconds after birth. In situations where supplementary oxygen is not readily available, positive-pressure ventilation should be administered with room air

2006: The recommendation is to give room air (21%) until heart beat drops less than 60/ minute (baby is almost dead with damaged brain), then give 100% oxygen. That was the recommendation by Dr. Ola Didrik Saugstad (Norway) and his cheer leaders.

THAT IS THE MOST RIDICULOUS RECOMMENDATION IN HUMAN HISTORY.
WHY DO WE NEED TO WAIT UNTIL THE BABIES ARE DYING ?
WHAT KIND OF NONSENSE IS THAT ?

Since 2008: Neo puff is used for newborn with respiratory distress in many institutions; still not used in every institutions for financial and other reasons. Neo puff is good for preterm babies but it is not good for big babies with no respiratory effort, then Ambu bag must be used with 100% oxygen (not 21%). The use of Neo puff caused less Pneumothorax (air inside pleura) than Ambu bag.

We can resolve Pneumothorax easily but not the brain.

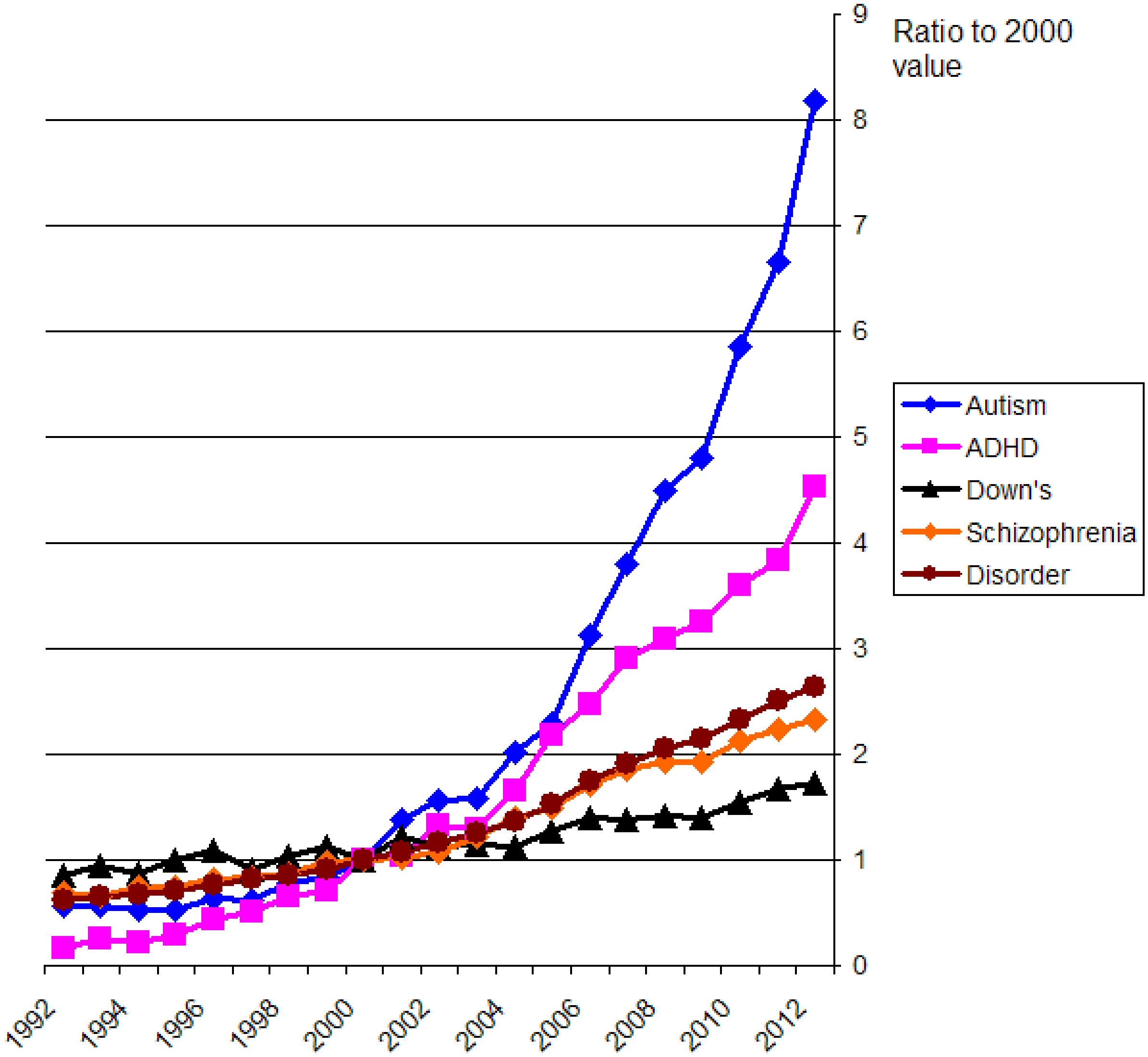
NRP / ILCOR / ERC committees are more worried about lungs than brain.

2010: Dr. Dawson's (Australia) recommendation " To monitor oxygen saturation; to keep blue babies blue for 10 minutes and beyond 10 minutes in Europe ".

2017: All nonsense continues. Tens of millions of children in this World are suffering from

brain damages resulting in Autism, ADHD, learning disabilities, cancers and deaths.

Autism experts and general public are not aware of this atrocity in the delivery room !
The time has come to take this matter very seriously in order to protect the children in this World.



THANKS AND REGARDS FOR YOUR VALUABLE TIME
DR. KANJILAL
MOUNT SINAI/ELMHURST HOSPITAL
[PII redacted]

1)

Oxygen delivery systems for infants, children, and adults (Up To Date 2011)

Author
Pamela Bailey, MD
Section Editors
Susan B Torrey, MD
Polly E Parsons, MD
Deputy Editor
James F Wiley, II, MD, MPH

BLOW BY — Blowing (or wafting) oxygen past a patient's face is not a reliable means of oxygen delivery and is not used in adults. However, this method can temporarily provide oxygen to infants and toddlers who become agitated and more distressed with other methods of oxygen delivery, particularly during the initial evaluation and treatment for a reversible cause of respiratory distress such as croup or bronchospasm.

Blow by oxygen is typically provided with oxygen tubing, corrugated tubing, or a simple mask. Alternatively, some young children will accept blow by oxygen more readily if the end of the oxygen tubing is poked through the bottom of a Styrofoam or paper drinking cup. Blow by oxygen is typically held at a short distance from the child's face by a parent or other caregiver. Limited evidence suggests that only low concentrations of oxygen (<30 percent fraction of inspired oxygen) can be provided using these systems [1-3].

Self-inflating (Ambu) ventilation bags do not reliably deliver oxygen to spontaneously breathing children and should not be used to provide blow by oxygen [1,4]. This type of system typically has a one-way valve to prevent rebreathing. Oxygen flows through the valve when the bag is squeezed. With a mask tightly applied to the face, some spontaneously breathing patients may be able to generate sufficient inspiratory pressure to overcome the valve. However, children cannot reliably accomplish this. In comparison, a flow-inflating (anesthesia) ventilation bag that is connected to an oxygen source provides a constant flow of oxygen. (See 'Ventilation bags' below.)

The following points should be considered when providing blow by oxygen to children:

Oxygen can be best delivered at a flow rate of at least 10 L/min through a reservoir (such as a simple mask or large cup) [1].

The reservoir must remain in proximity to the child's face.

Oxygen saturation should be monitored.

Alternative oxygen delivery systems should be considered for children who require greater than 30 percent oxygen or prolonged oxygen therapy.

SUMMARY AND RECOMMENDATIONS — Critically ill or injured patients frequently require oxygen therapy. The choice of an oxygen delivery system will depend upon the clinical status of the patient and the desired dose of oxygen. For patients who are breathing spontaneously, the appropriate delivery system depends upon the dose of oxygen that they require and how well they tolerate the system. These patients should remain in a position of comfort whenever possible. (See 'General concepts' above.)

Blow by (wafting) oxygen can be provided with oxygen tubing, corrugated tubing, or a simple mask to infants or children who require less than 30 percent oxygen for short periods of time. Self-inflating (Ambu) bags should not be used as a source of blow by oxygen. Pulse oximetry should be monitored to ensure that oxygen is being effectively delivered. (See 'Blow by' above.)

A nasal cannula can deliver 25 to 40 percent oxygen, depending on the patient's respiratory rate, tidal volume, and extent of mouth breathing. Flow rates 2 L/min or less are recommended for infants. (See 'Nasal cannula' above.)

A simple mask with 6 to 10 L/min of oxygen flow delivers 35 to 50 percent oxygen. Partial and nonrebreathing masks with oxygen reservoirs deliver maximum concentrations of 60 and 95 percent oxygen, respectively. (See 'Masks' above.)
Enclosure systems include hoods and tents and are appropriate for infants and children. Hoods can deliver up to 90 percent oxygen and may be used for infants less than one year of age. Tents deliver less oxygen (up to 50 percent). Mist that accumulates in the tent may obscure the child from view.
(See 'Enclosure systems' above.)
Ventilation bags are used to provide oxygen to patients who require assisted ventilation. A reservoir must be attached to self-inflating bags in order to provide high concentrations of oxygen.
(See 'Ventilation bags' above.)
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2) Pediatrics
Oxygen for Newborn Resuscitation: How Much Is Enough? (Norway, Spain, India ; August 2006)
Ola Didrik Saugstad, Siddarth Ramji, Max Vento

http://pediatrics.aappublications.org/content/118/2/789?sso=1&sso_redirect_count=1&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token

3)
Air versus oxygen for resuscitation of infants at birth (Cochrane group, 2005)
Authors
Tan A, Schulze A, O'Donnell CPF, Davis PG
Reviewers' conclusions
There is insufficient evidence at present on which to recommend a policy of using room air over 100% oxygen, or vice versa, for newborn resuscitation. A reduction in mortality has been seen in infants resuscitated with room air, and no evidence of harm has been demonstrated. However, the small number of identified studies and their methodologic limitations dictate caution in interpreting and applying these results. We note the use of back-up 100% oxygen in more than a quarter of infants randomised to room air. Therefore, on the basis of currently available evidence, if one chooses room air as the initial gas for resuscitation, supplementary oxygen should continue to be made available.

https://www.nichd.nih.gov/cochrane_data/davisp_05/davisp_05.html

4)
Original article
Outcomes of oxygen saturation targeting during delivery room stabilization of preterm infants (Australia, Norway, Canada, USA, Spain, 2016)
They found in their own research that low oxygen causes bleeding inside the brain and deaths for preterm babies but still did not accept the fact.
They want to repeat the same research with large number of patients and expect different results (that is called insanity: Albert Einstein).
Ju Lee Oei[1,2,3],
Neil N Finer[4,5],
Ola Didrik Saugstad[6],
Ian M Wright[7],
Yacov Rabi[8,9],
William Tarnow-Mordi[3],

Wade Rich[5],
Vishal Kapadia[10],
Denise Rook[11],
John P Smyth[1,2],
Kei Lui[1,2],
Maximo Vento[12]

Conclusion Not reaching SpO2 80% at 5 min is associated with adverse outcomes, including IVH. Whether this is because of infant illness or the amount of oxygen that is administered during stabilisation is uncertain and needs to be examined in randomised trials
http://fn.bmj.com/content/early/2017/10/07/archdischild-2016-312366

Dear Dr. Gordon,
The Respected Chairman

I really appreciated your publication on 10/24/2017 from page 20-73.

https://iacc.hhs.gov/meetings/iacc-meetings/2017/full-committee-meeting/october24/written_public_comments_102417.pdf

I need your help.
You can change the World in 2017 and help tens of millions of children in USA, Europe, Asia and rest of the World.
Hundreds of literatures from Harvard, Columbia, MIT, Yale, Kaiser Permanente, Dartmouth and other respected institutions suggest " Hypoxia before, during and after birth is causing Autism ".
Newborn blue babies are not getting oxygen they need in USA and all over the World.
Researchers are looking for the answer and the solution ASAP.
We all carry Autistic genes but we are not all autistic.
Similarly, all babies with hypoxia during and birth will not cause Autism.
Hypoxia has epigenetic effects on autistic genes.
Therefore, we should make all Highly Respected members of NRP /ILCOR / ANZCOR / European Newborn Resuscitation Committees that they should change their practice guidelines immediately and give required amount of oxygen to blue newborn innocent babies and resuscitate them quickly, aggressively, adequately and make them better ASAP.
Newborn babies with respiratory distress cannot get better on their own. The recommendation of waiting, watching and monitoring for the first 10 minutes of lives and beyond 10 minutes in Europe is preposterous.
THIS IS THE VIOLATIONS :
1) Newborn Human Rights to life
2) Illegal practice in Medicine, no consents were obtained; parents are not aware.
3) Unethical. We are supposed to help theses innocent children. Instead we are
hurting them for no reason.
I am requesting from the bottom of my heart that you take the lead and change the World forever.
GOD GAVE YOU THE ASSIGNMENT SINCE YOU JOIN IN 2016, THE POWER AND THE RESPONSIBILITY.
YOU CAN SAVE TENS OF MILLIONS OF CHILDREN AND HALF-A- BILLION POPULATION SORROW IN THIS WORLD.
I will be keep sending you emails.
" The real life is when you save other lives "

Thanks and Regards
Dr. Kanjilal
[PII redacted]

THESE ARE MORE VOICES OF CONCERN FROM THE FRONT LINE PHYSICIANS, RESIDENTS AND INTERNS

Debasis Kanjilal [PII redacted]

to lifesupport, Review.persona., info, postmaster, nobelforum, thomas.perlmann, juleen.zierath, patrik.ernfors, anna.wedell, Ole, kanjilal

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Thanks for your valuable time
Dr. Kanjilal
[PII redacted]

THESE ARE MORE VOICES OF CONCERN FROM THE FRONT LINE PHYSICIANS, RESIDENTS AND INTERNS

27)

From: AMR DAIA [PII redacted]
Subject: supporting Dr.Kanjilal for Nobel price
Date: January 15, 2017 at 7:44:29 PM EST
To: postmaster@nobel.no

My name is Amr and I am a pediatric resident .
I am supporting Dr. Kanjilal's effort to help children in this world and request you to strongly consider his nomination for the Nobel peace prize.
sincerely,
Amr daia

28)
Pradip Mukherjee

to postmaster, me

Dear Ms. Kullmann and Members of the Nobel Committee,

I have been practicing as an Obstetrician/Gynecologist for the last thirty years in New York City. I have known Dr. Kanjilal over two decades. He is a well known, and recognized Neonatologist in the City.
Dr. Kanjilal believes very strongly that supplying oxygen to newborns before resuscitation, can avert many problems,such as Autism, Cerebral Palsy, Neonatal Encephalopathy, learning difficulties, and brain damage among other things. His voiced concerns are now recognized by the New Born Resuscitation Committee, and his recommendation of administering oxygen first, has been adopted since October 2015.
I do believe that Dr. Kanjilal's efforts and sincere work in bringing this life saving fact to attention, will help many newborns in living a normal life. It is my belief, that Dr. Kanjilal's work does merit consideration for nomination, so I sincerely hope, you will give his efforts, your attention.
Thank you.

Dr. Pradip Mukherjee
Senior Attending
Dept. of Ob, Gyn at Coney Island Hospital

29)
From: [PII redacted]
Date: January 17, 2017 at 20:03:40 EST
To: <postmaster@nobel.no>

Subject: Support for Dr. Debasis Kanjilal, Nobel Prize

Dear Ms. Kullmann and Nobel Prize Committee,

My name is Ariella Barhen, and I am currently a second year Pediatric resident at Icahn School of Medicine - Elmhurst Hospital in New York. I am writing in support of Dr. Debasis Kanjilal for the Nobel Prize.

I completed my medical school training in Israel, where I was exposed to physicians constantly working to advance medicine. As I transitioned to residency, Dr. Kanjilal has been a continued source of innovation and education in my medical training. He has led residents, as well as other attendings, to question standards. He has discussed his concern for the increased rates of autism spectrum disorder and learning disabilities in the rising populations. It is Dr. Kanjilal's belief that this is due to decreased oxygen supply at birth.

While our population continues to question the reason behind the increase in Autism or learning disabilities, we remain complacent in our management during critical times - aka when a newborn's brain enters this world. Questions should be pursued, or answers will never be found.

Dr. Kanjilal is an inspiration to our facility, and I fully support his nomination for the Nobel Prize.

Ariella Barhen, MD
Pediatrics, PGY-2
Icahn School of Medicine at Mount Sinai
Elmhurst Hospital Center

30)

rashi kochhar [PII redacted]

THESE ARE MORE VOICES OF CONCERN FROM THE FRONT LINE PHYSICIANS, RESIDENTS AND INTERNS

Debasis Kanjilal [PII redacted]

to lifesupport, Review.persona., info, postmaster, nobelforum, thomas.perlmann, juleen.zierath, patrik.ernfors, anna.wedell, Ole, kanjilal

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PLEASE SAVE THE CHILDREN IN THIS WORLD NOW AND MAKE A BETTER WORLD FOR TOMORROW .

NEWBORN BABIES SUFFERING BEGAN IN 2006 AND MUST END IN 2017

Einstein said:
"The only source of knowledge is experience."
"It is the supreme art of the teacher to awaken joy in creative expression and knowledge."
"Great spirits have always found violent opposition from mediocre minds.
The latter cannot understand it when a man does not thoughtlessly
submit to hereditary prejudices but honestly and courageously uses his intelligence."

Thanks for your valuable time
Dr. Kanjilal
[PII redacted]

THESE ARE MORE VOICES OF CONCERN FROM THE FRONT LINE PHYSICIANS, RESIDENTS AND INTERNS

32)

From: [PII redacted]
Date: January 22, 2017 at 4:58:03 PM EST
To: <postmaster@nobel.no>
Cc: [PII redacted]
Subject: Support for Dr Debasis Kanjilal
Dear Ms. Kullmann and Nobel Prize Committee:
I am a second year resident in pediatrics and have worked with Dr Kanjilal, he is an experienced neonatologist with deep understanding of the physiology and pathology of the newborns, he is passionate about giving the newborn the perfect resuscitation and he is so concerned about the increasing rate of ASD and other diseases which might be caused by hypoxia in newborns.
I strongly believe that the newborn resuscitation need to be reinvestigated for the best of the newborns.

Dr Kanjilal was fighting for a long time to change the guidelines for meconium stained newborns and we were all happy to see the change finally in the new NRP.

I am writing here for his support and to consider his work for your evaluation for the Nobel Prize 2017.

Dr. Anas A. Abdul Kayoum
Pediatrics PGY-2
Elmhurst hospital center

Dear Dr. Gordon
Chairman IACC,

You and your highly respected organization have been recommended for " NOBEL PEACE PRIZE " for the year 2018 by " The highly respected organization that represent peace and humanity for millions of people ".

This organization is only few miles away from Mother Teresa's place in Kolkata, India.

I am forwarding that email.

I really appreciated your support to save the children from Autism.

THIS REPRESENT THE VICTORY FOR CHILDREN WITH AUTISM IF YOU WIN.

NOBEL PRIZE IS NOT IMPORTANT BUT TO SAVE THE CHILDREN IS !

Thanks and Regards

Dr. Kanjilal
[PII redacted]

---------- Forwarded message ----------
From: **swamidhrubananda** [PII redacted]
Date: Mon, Nov 27, 2017 at 5:16 AM
Subject: Respectfully submitting nomination for Dr. Debasis Kanjilal, Dr. Joshua Gordon (Chairman of IACC), and IACC (Interagency Autism Coordinating Committee) for The Nobel Peace Prize, 2018.
To: [PII redacted]
Cc: [PII redacted]

TO
Ms.BERIT REISS-ANDERSEN,

HIGHLY RESPECTED MADAM,

PLEASE SEE THE ATTACHMENT

CONSISTING OF FOUR PAGES ONLY FOR YOUR KIND

CONSIDERATION .

THANKS,

WITH REGARDS,

SWAMI DHRUBANANDA SARASWATI

DATED 26/11/2017

Wayne Clarke **January 17, 2018**

Dear IACC

I would like to invite you to a parent summit My Time Inc is hosting where we will bring MSC's, parent, grandparents and caregivers together. The theme of the event is "we are all in this together". Thank you.

MY TIME INC PRESENTS

PARENT SUMMIT

The Mission of My Time Inc. is to support, educate, empower, enlighten and uplift a parent of a child diagnosed with Autism and Developmental Disabilities to live a quality of life they deserve in their Community

Parents interact with providers to help them better advocate for their love ones…

"We're All in This Together"

Parent support is not a new Phenomenon but

My Time Inc. is bringing a New and Dynamic Perspective to it

Community interact with parents while awareness is spread about Autism and Developmental Disabilities.

Date: Thursday November 16, 2017
Time: 10:00 am – 1:00 pm
Place: Bayview Community Center
5955 Shore Parkway
Brooklyn NY 11236

RSVP@ 917 933-9875/ parentsummit2017@mytimeinc.org

9603 Flatlands Ave
Brooklyn NY 11236
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Michelle Guger **January 17, 2018**

Hello, I at 62 yrs of age found out I've had ASD after traveling all over the country working 75+ jobs, 45+ places to rest/sleep with homelessness a repeated issue. I now have a home and working on the emotional combination of ptsd, adhd, ocd, anxiety and more. Up until about 3 yrs. ago received no outside help dealing with these issues.

Through my own analytical gifts I've managed to defeat self abuse, alcohol, drugs, tobacco, anorexia and more. I was finally given the opportunity to get a full evaluation and have the self diagnosis of adhd, ptsd and ocd on paper.

The reason for this note is after reading some of your meeting, it seems that I might be able to shed some light or at least give food for thought on some of the areas of puzzlement.

What I have been through all these years should be of some benefit to others. I have been told by other professionals (medical) that I needed to go back to school, although that does help the self esteem due to my age and the reading problems.....

Please feel free to contact me if I can help in any way.

Thank you, Shelley

Vashti Johnson **January 17, 2018**

We in urban cities need a better understanding of your policy's and vision to improve the quality of life for our youth.

Note: Profanity has been redacted in this document

John Best **January 17, 2018**

Dear Liars,
You are hereby ordered to tell the truth about how mercury in vaccines causes autism. You are also ordered to go [profanity redacted] yourselves.
Sincerely,
John Best
Londonderry, NH

Shannon Rosa **January 17, 2018**

I am the parent of a 17-year-old high-support autistic son, and am writing regarding my concerns about his near-future integrated housing options. Those concerns are twofold: 1) I want my son to be part of his community, and 2) I am worried about ongoing efforts to erode existing civil rights safeguards that protect and guarantee integration for people with disabilities.

As this committee must be aware of the body of research supporting integrated housing options for people with disabilities, in terms of both improved quality of life and wider community disability acceptance, I will instead emphasize the basic decency factor: My son and his adult soon-to-be peers are part of their local communities, and they deserve whatever supports they need to live the lives they want to live?in those communities. I urge the committee to redouble efforts to make those options more readily available, and to identify attempts at segregated housing, veiled or outright, farm-based or "neo-institutional," as the isolating and dehumanizing options that they are.

I also urge the committee to exercise vigilance and demonstrate opposition to recent Department of Justice rollbacks on disability protections. We cannot allow civil rights for autistic people, including those integration protections upheld by Olmstead, to be decided by business interests (e.g., the sheltered workshop industry suspected to have lobbied for last month's disappointing DOJ actions). My son's housing options need to be determined by what he needs and deserves, and not by the calculations of a profit-minded entity.

I would like to thank the Committee members for their time, and their hard work.

Shannon Rosa
Redwood City, California

Note: Personally Identifiable Information (PII) has been redacted in this document.

Dr. Eileen Nicole Simon **January 17, 2018**

Eileen Nicole Simon, PhD, RN
[PII redacted]
Cambridge MA
[PII redacted]

Following are comments I would like to hear discussed by members of the IACC, at the meeting to be held on January 17, 2018:

1. Thank You

Allison Singer, thank you for discussing why parents of language-impaired autistic children must be listened to.

Difficulty learning to speak is the most serious affliction of autistic children.

The language disorder is not the result of "social disorder" or deficits in "shared attention." I remember when I first heard these euphemistic explanations in the late 1980s. I remember being shushed when I tried to point out that these were totally inaccurate descriptions of my two autistic sons.

Self-advocates may have social problems, and difficulty with shared attention, but their afflictions cannot be compared with those of people who had difficulty learning to speak in childhood.

2. Public Comments

Public comments submitted for the meeting on October 24 were especially interesting, but again only summarized in bland categories. Please discuss the distress expressed by those of us who took the time, and put considerable effort into writing the comments we submitted.

Why are parents like John Best so profanely angry? How can members of the IACC so arrogantly dismiss the suffering we are experiencing? Please remember the original mission of the IACC, and its formation in response to the Combating Autism Act.

Please discuss what we have to say. Please allocate more time for discussion of public comments, much more time. Please focus on the topics we are requesting to be discussed. Please allocate time for discussion of brain injury sites, sites most vulnerable to prenatal exposures like rubella virus and drugs like valproic acid, and to oxygen insufficiency at birth and during the neonatal period.

Allison Singer, thank you again.

3. Echolalic Speech

Echolalia is a prominent aspect of the speech disorder of autistic children. Leo Kanner had to ask parents to explain the out-of-context comments of the children he described. Kanner described the language of autistic children as "metaphorical."

Use of the pronoun "you" rather than "I" derives from the child reciting verbatim an entire phrase heard in the past, in new somewhat similar contexts.

"You want spaghetti for supper?" means "I want spaghetti for supper."

My son [PII redacted] most emphatic statement of frustration was, "What's the matter? Did your wagon get stuck?" He angrily said this one time when he was unable to squeeze the last of the toothpaste out of the tube. I had to explain to my puzzled mother that [PII redacted] was restating questions I asked him when the little wagon he liked to pull around the yard got stuck in shrubbery along the fence.

Kanner had to ask parents for the meaning of their children's metaphorical speech. Members of the IACC should also include us in conversations about the disabilities of our autistic children.

Reference: Kanner L. Irrelevant and metaphorical language in early infantile autism. 1946. *Am J Psychiatry*.1946 Sep;103(2):242-6. *Am J Psychiatry*. 1994 Jun;151(6 Suppl):161-4.

4. Umbilical Cord Clamping

I was glad to see the comment submitted to the IACC by Donna Young condemning clamping of the umbilical cord at birth.

Use of a surgical clamp on the umbilical cord has to be the most horrific medical error of all time. Clamping the cord is "bloodletting" of the worst kind. Clamping the cord at birth can leave one-third of the infant's blood in the placenta.

The American College of Obstetrics and Gynecology (ACOG) has changed the requirement of clamping the cord immediately after birth to waiting for 20 to 30 seconds. This may not be long enough for some infants, but hopefully a decline in need for special education will be seen five years from now.

5. Placenta and Lungs

Development of the placenta begins within the uterine endometrium shortly after conception. Blood cells form in proliferating blood vessels that supply embryonic organs. Within the first month after conception blood is pumped by the embryonic heart to the placenta to receive oxygen and nutrients from the mother.

Prenatal circulation to the lungs is sufficient only for differentiation of airways and the alveoli, which will take over respiration after birth.

Blood flow to the lungs begins with closure of the fetal heart valves that direct blood to the placenta before birth. This cannot be forced by clamping off circulation to and from the placenta. Traditional textbooks of midwifery and obstetrics all taught that pulsations of the cord should cease before it is severed.

6. Resuscitation at Birth

Dr. Debasis Kanjilal's concerns about resuscitation of infants should be discussed by members of the IACC. Perusing (on amazon.com) the new 7th edition of the Neonatal Resuscitation Manual, I see that clamping of the umbilical cord at birth is now recognized as controversial. Nevertheless clamping the cord continues as standard practice.

Dr. John Kattwinkel is among the most prominent authors of previous versions of the Neonatal Resuscitation Manual, and putting his name in PubMed brings up several chapters of earlier versions of the manual, published in *Pediatrics* and other journals.

Kattwinkel is co-author of an article published in 2017 on ventilation during delayed cord clamping. Dr. David Hutchon and others in the UK are using a "mobile resuscitation trolley" (a "code cart") to transport oxygen to the delivery bed. Thus resuscitation procedures can begin without clamping the umbilical cord.

Reference: Hutchon D, Bettles N. Motherside care of the term neonate at birth. *Matern Health Neonatol Perinatol*. 2016 Jun 30;2:5.

7. IACC Expertise

Not all members of the IACC are knowledgeable in the fields of embryology, respiratory physiology, or neurology. But doctors who head NIH agencies should be able to discuss these scientific topics and possible relevance to autism.

On 26 Nov 2017, keywords "apgar autism" in PubMed displayed 34 citations, and "neonatal resuscitation autism "in displayed 120+, "birth complications autism" displayed 250+, and "neonatal encephalopathy autism" 300+.

Perusing a few of these make it clear that low Apgar scores, and other clear indications that autism is associated with injury at birth, are topics to be avoided in discussing autism. This attitude needs to change. It is possible to resuscitate newborn infants without clamping the umbilical cord, and clamping the cord is a procedure that should be abandoned.

I could be wrong. But asphyxia at birth, and auditory system damage should be discussed as causes of autism.

8. Birth Injury

Both of my first two sons suffered head trauma and oxygen insufficiency at birth. Of course I searched the medical literature to understand how trauma and respiratory distress affect the brain. An article in the October 1969 issue of the *Scientific American*, by WF Windle on brain damage caused by asphyxia at birth was my starting point.

The inferior colliculi in the midbrain auditory pathway were the only visible sites of damage in monkeys subjected to asphyxia at birth.

The inferior colliculi? I was just beginning graduate school at the Boston University School of Medicine, and in our neuroanatomy class we had just been taught the components of the brainstem auditory pathway. Each way-station from cochlear nucleus to temporal lobes makes a unique contribution to processing sounds arriving at our ears.

Children learn language by ear. How might damage in the auditory pathway affect learning to speak?

9. Childhood Disorder

Autism is a neurological disorder that begins in childhood. Its neurological signs are:

(1) Language disorder,
(2) Repetitive movement disorder, and
(3) Diminished level of consciousness.

Full recovery from these signs is rare. Speech often remains stilted, repetitive movements may appear in situations of excitement, and under- or over-reaction to environmental noise is frequently evident.

My oldest son is now 55 years old. He reads and writes well; he has co-authored two memoirs with me. He remembers first hearing songs that were popular when he was three years old, and remembers movies he first saw when only a little older.

But his autism still sticks out like a sore thumb. He in no way can be compared to any of the self-advocates who have been appointed to the IACC.

10. Blood Flow

During the summer of 1970 I worked in the laboratory of Seymour Kety at the Massachusetts General Hospital. Dr. Kety told me he urged Dr. Windle to look for damage in the inferior colliculi in the monkeys subjected to asphyxia.

Kety's seminal research on blood flow in the brain had revealed that the highest blood flow in the brain was in the inferior colliculi. He took a great interest in my idea that damage in the inferior colliculi might impede language development.

Kety's paper on blood flow in the brain is free online: Kety SS. Regional neurochemistry and its application to brain function. *Bull N Y Acad Med*. 1962 Dec;38:799-812.

I urge members of the IACC to read this paper in preparing next year's Strategic Plan.

11. Aerobic Metabolism

Louis Sokoloff worked with Kety on the autoradiographic research that revealed the highest blood in the inferior colliculi. He extended this research using a carbon-14 labeled analogue of glucose (deoxyglucose). Deoxyglucose is transported into cells in the same way that glucose is.

The research on blood flow was done with a tracer that was metabolically inactive. The deoxyglucose method is a way to measure glucose utilization, and therefore aerobic metabolism.

Uptake of deoxyglucose was, like that of the tracer in the research on blood flow, highest in the inferior colliculi:

> "The highest values were clearly in the structures involved in auditory functions with the inferior colliculus the most metabolically active structure in the brain" [Sokoloff et al. p912]

Reference:

Sokoloff L, et al. The [14C]deoxyglucose method for the measurement of local cerebral glucose utilization: theory, procedure, and normal values in the conscious and anesthetized albino rat. *J Neurochem*. 1977 May;28(5):897-916.

12. Apgar and Autism

In PubMed, keywords "apgar autism" displays two pages of citations that indicate perinatal stress in infants who later develop autism. Virginia Apgar developed her scoring system for infant well-being at birth, and explained the choice of scoring one minute after birth as follows:

"In the Sloane Hospital the cord has been cut by this time, and the infant is in the hands of an individual other than the obstetrician. In many hospitals, such is not the case. Those obstetricians who practice slow delivery and delayed clamping of the cord until pulsations of the umbilical artery cease still have the infant in the sterile field. However, if the obstetrician is reminded of the passage of time by another observer, he may assign a score even though the cord is still attached" [Apgar et al. p1987].

The Sloane Hospital is at Columbia University, where by the 1950s surgical episiotomy was recommended for all women, thus the need for a sterile field. Landau et al. (1950) were obstetricians in Missouri, who practiced "slow birth" except when surgery for cesarean delivery was needed.

References:

Apgar V et al.. Evaluation of the newborn infant – second report. *JAMA* 1958; 168(15):1985-9.

Landau DB et al. Death of cesarean infants: a theory as to its cause and a method of prevention. *J Pediatr* Apr 1950; 36(4):421-6.

13. Critical Care

On Monday, December 18, I called my son on his cell phone a little after 5pm. He told me how he had spent his day, mostly riding around Boston and suburbs on buses and trolleys.

A little after 7:30 I received a phone call from his group home, and was told he had been taken by ambulance to the ER at the Good Samaritan Hospital in Brockton MA. The group home director told me she would call as soon as she had any information from the ER. I did not wait for her phone call.

When I arrived at the ER I found my son gasping for air, with the aid of a CPAP machine. I was also informed I was not his legal guardian, but could wait in the family room for further information. At 3am a nurse came into the family room and asked which patient I was there for. He told me my son had been intubated, and transferred to the Critical Care Unit.

When I arrived in the CCU the first thing I was told was that as next-of-kin I would be fully informed. No one from the group home had come to the ER or CCU.

My son was sleeping, with regular respirations, and oxygen level at 98 percent. His heart rate was regular with normal rhythm. I was told he would be kept sedated for another 12 to 24 hours. I got home at 4am, but by 7:30 I was on my way back to the hospital. He remained sedated. His vital signs looked good, CAT scans and EEG were normal. The plan was to keep him sedated another 24 hours, so I returned home; I needed sleep.

I returned Wednesday. He remained stable, but the plan was to keep him sedated until Thursday. No one wanted to predict his neurological outlook.

Thursday sedation was slowly tapered. A little after noon he woke up. He was able to speak, and respond to questions. Soon he was asking questions, "What day is it? How did I get here?" I wept, and gave thanks to God. My son was discharged back to his group home the day before Christmas.

14. Community Care

My son was discharged from Westborough State Hospital in 2003, and placed in a community group home. I was urged to take him home. I was told he was less in need of ongoing care than other patients. The state hospitals were being closed. Only a "recovery center" in Worcester would remain for inpatient care.

My son was 40 years old. He had been taken to Westborough 10 years earlier by the police; he had been repeatedly stealing cars. When interrogated in court he told the judge, "A set of wheels makes my day." Would we be able to prevent him from returning to this kind of criminal activity?

One social worker told me I might have to quit my job and stay home to guard the doors. This would be his life in the community? My husband threatened to leave if our son came home. So he was placed in a group home about 30 miles from where we lived. There were no group homes in the upscale suburb where we lived.

I was one of only two mothers who made frequent visits to the group home, and took our sons on outings. Her son had been a brilliant student in college, until he went into a coma following a binge drinking party. He had many more problems than my son (including incontinence), but his command of language was far beyond that of my son, and he was far more able to articulate goals for his future. His schizophrenic illness was severe, but very different from my son's autism.

15. Causes and Care

"Trauma-informed care" is a concept in place since at least the early 1990s. I also received training in this for my jobs in nursing. Physical and/or sexual abuse in childhood is with great assurance assumed to be the cause of persistent mental illnesses. I thought this was beginning to change, but just a few days ago I received an announcement of a job opening for a community unit in which trauma-informed care is provided.

Autism is different from depression, bipolar disorder, schizophrenia, and other "personality" disorders. And, autism is far less well understood than these other mental illnesses, none of which can be proven to be caused by physical or sexual abuse in childhood.

16. Changes in Care

"Recovery is Real" is the sickening motto of the Department of Mental Health (DMH) in Massachusetts. This means that depression is the top priority for inpatient admission to the DMH Recovery Center in Worcester, or any other hospital.

Another resident in my son's group home has tried to instruct him how to go to an ER and tell them he is working on a plan. Part of my son's chronic "leaves of absence" from his group home includes visiting hospital ERs, where he is well-known by DMH psychiatrists assigned to area hospitals.

In 2009 my son went missing from his group home for 7 weeks +2 days. He was found by the Cambridge police in Harvard Square, and they took him to Cambridge Hospital. The hospital discharged him to the Quincy Mental Health Center (QMH), one of only four remaining DMH in-patient units. QMH was closed the following year despite huge public protest meetings attended by people from as far away as Cape Cod.

In 2015 my son went missing again, and I was grateful that he could be tracked via his cell phone. I received a call from the police in Belmont (adjacent to Cambridge). They told me they were not allowed to take him to a hospital, so I took him to Cambridge Hospital. The psychiatrist at the hospital told me if he refused to return to his group home, the only alternative would be a homeless shelter.

17. Laws versus Science

My son has been assigned a legal guardian. She is an enthusiastic recent law school graduate. At a meeting a few days before my son was rushed to the ER, she informed me that there are now strict laws granting full freedom for mentally ill people in the community. This is why the group home cannot force my son to attend his day program.

What is this day program? It is supposed to prepare clients for more independent living, but there is no training for employment at all. How is anyone able to live independently without a paycheck?

Staff at the day program are quick to use strong (loud) redirection for clients who miss the mark in following program rules. My son's speech remains somewhat quirky, because he still uses many echolalic phrases. He shouts back when shouted at, and this too is part of his echolalic language.

He clearly prefers to go off on his own during the day, but he is chronically in trouble for shop lifting. He is so well known that he rarely has to go to court any more, but his social security income pays for what he takes. If he had to pay from his own paycheck, he might sooner learn not to steal.

I am ignorant of the legal system. Science, for me, is far more significant in understanding mental illnesses, and providing appropriate care.

I believe the IACC was formed to address the problem of increasing autism prevalence during the 1990s. The self-advocates on this committee have never shown any understanding at all of the kinds of problems that afflict my son.

18. Always Here?

During my graduate school days back in the 1970s, I read (among many other things) the book by Thomas Szasz, The Myth of Mental Illness. I see on amazon.com that he has now published more books, including *The Manufacture of Madness* and *Anatomy of an Epidemic* (on psychiatric drugs). I will look at these.

On amazon com I also see the books by Emil Kraepelin on dementia praecox, general paresis (syphilitic insanity), manic-depressive insanity and paranoia, and Eugen Bleuler's *Theory of Schizophrenic Negativism*. Schizophrenia was adopted as a far more exotic euphemism for premature dementia. Many people feigned schizophrenia as a means to obtain respite at mental asylums. Yes, this was a myth, described in novels like *I Never Promised You a Rose Garden*.

And, now we have the new "neurodiversity" myth, and the myth that autism is nothing new. Claims that a few historical geniuses were cases of autism have led to the recent fasciation with "social disorders" unrecognized until adolescence or early adulthood. But autism in early childhood always includes problems with language development.

Claims of a social disorder, or problems with "shared attention" are euphemistic attempts to account for failure to master the well-documented stages of speech development in childhood.

New laws are rapidly being put in place to promote full freedom for all people with a diagnosis of autism. This has led to loss of protection (since about 2009) for people like my son, who remain short of full cognitive development.

19. Broca's Aphasia

When our son went missing in March 2009, my husband (like me) was overcome with grief. Nothing else mattered except for our desperate attempts to find him.

My husband was a professor at Harvard for 45 years. He taught popular courses in literary history, including medieval court life and medieval theater. Spring semester was when his students selected plays to perform, often outdoors which attracted large audiences. He was totally distraught during the spring of 2009, and we spent a lot of time searching for our son. Few people understand how we suffered.

Our son was found by the Cambridge police on May 2, but by then my husband had decided to take early retirement. By the following fall semester he had come to regret this decision. He had three retirement projects, books he wanted to write, but he missed teaching, and his students. He consulted with a psychiatrist, who prescribed medication for anxiety.

The medicine was Xanax, which led to side effects of dizziness. My athletic husband (who ran 5 miles every morning, rode his bicycle everywhere, and spent winter weekends skiing) quickly lost it all. He became unable to move his legs during one morning run, and barely made it home. He began losing his balance.

In November 2012 he fell down the cellar steps with a laundry basket; 12 steps. I took him to the emergency room; he was badly bruised, but CAT scans and other tests were normal. Two years later he began falling and could not get himself up. I called 911 on December 15, 2014. I was told he had subdural bleeding, and I signed the agreement for surgery. I was warned that the bleed was near the speech-motor area. Following surgery he was unable to speak.

I was hopeful that he would recover, but in January 2015 we moved into an assisted living facility. Three years later we are still here. My husband has Broca's aphasia. I have come to realize that practically no one understands language disorders.

"Could he use a communication board?" someone asked me, then went on to explain that this method has been useful in reaching non-verbal autistic children.

No! Language is the defining feature of the human species. Its failure to develop in childhood or its loss in adulthood are equally tragic.

I beg the scientific members of the IACC to focus on failure of language development, the most disabling problem of autistic children.

Jonathan Mitchell **January 17, 2018**

I think the IACC should focus more on scientific research that finds a cure for autism. Neurodiversity proponents such as Samantha Crane should not be on the IACC. Instead they should appoint autistic people who regard autism as a medical condition that needs treatment and a cure and prevention. I have autism and it severely handicaps me. They should vet the neurodiversity autistic members and ask them to release medical records to Joshua Gordon, confirming an autism diagnosis. We should be doing science research to help prevent autism. Samantha Crane should explain how autism impacts her and how a graduate from harvard law school can have a diagnosis of autism.

Why has the IACC appointed 7 autistic public members who are neurodiversity proponents and zero pro-cure, pro-treatment autistics when Roger Kulp and Jake Crosby applied and were turned down and the law states that the public members will have balanced points of views. I think that's unfair

Kelly Israel and Julia Bascom, on behalf of the Autistic Self Advocacy Network January 17, 2018

Thank you for the opportunity to submit written comments.

The Autistic Self Advocacy Network is pleased to see, from the new questions and objectives in the IACC's 2016-2017 Strategic Plan, that the IACC has taken some of the abundant feedback from the autistic community into account. Nonetheless, much more needs to be done to redirect autism research away from a medicalized model of autism and towards research that benefits autistic people and enhances and respects our self-determination. We appreciate that the 2016-2017 Strategic Plan is more inclusive in its coverage of several issues that are important to the autistic community, such as: our commonly co-occurring conditions (psychiatric disabilities, sleep disorders, etc.) and the mortality rate associated with them; the individualized, person-centered, home and community-based services and supports we need to live in our communities; diagnostic and service disparities between different communities of autistic people; and autism across the lifespan. We urge the IACC to advise the federal government to fund research on these issues that actually aids the autistic community. For example, the IACC could advise the federal government to fund research on how to best help autistic people manage a co-occurring condition, rather than solely research that investigates the biological basis of the condition.

Indeed, ASAN remains concerned that funding for autism research is disproportionately concentrated in studies of the biology and causation of autism, and medical "treatment" of autistic traits. The latest data available, from the IACC and the Office of Autism Research Coordination for fiscal year 2015, states that *only 2%* of all autism research funding in 2015 went toward research on the effectiveness of services and supports. As shown in the 2014-2015 Autism Spectrum Disorder Research Portfolio Analysis Report, while the IACC reports that 6% of total autism research funding went into research on services and supports (research which falls under the 2013 Strategic Plan's Question 5, "Where Can I Turn For Services?"[1]), *61% of that funding went toward the "practitioner training" subcategory*. ASAN subtracts this funding from the total percentage because funding that goes towards practitioner training does *not* go towards understanding: what services and supports delivery models work best, what services and supports enhance our quality of life, which services and supports improve our level of integration into our communities, or anything else that may actually improve the quality and breadth of services available to us.

While overall research funding into lifespan issues increased from 1% to 2% of total funding, this funding is not remotely proportional to funding for research on the biology of autism. Research into the biology and causation of autism, research that does not aid autistic people alive today in any significant way, continued to make up more than *half* of all autism research funding as of 2015. Another 17% of funding in fiscal year 2015 went towards medical or behavioral health "treatments" for autistic traits. ASAN urges the IACC to advise funders to rebalance the autism research agenda and to take steps to direct autism research funding towards the support of our well-being, self-determination, and inclusion in society across the lifespan.

Lifespan and Quality of Life

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[1] The most recent data on federal funding for autism research, for fiscal year 2015, was released before the Strategic Plan's Questions and Objectives were updated in the 2016-2017 Strategic Plan. Thus, the Question referenced in this sentence is from the 2013 Strategic Plan, as the data in the Portfolio Analysis Report corresponds with the Questions in that Plan.

ASAN appreciates the IACC's stated interest in prioritizing research on the physical and mental health conditions that most commonly co-occur with autism, as expressed in its overviews of Questions 2, 5, and 6 in the Strategic Plan. We agree that more research needs to be done into how to best aid us in managing and treating these conditions, and that such research would reduce our high mortality and enhance our quality of life. We would benefit if the IACC advised funders to prioritize studies on which treatments, services and supports, and, where appropriate, medications for commonly co-occurring conditions would work best for us. Anecdotal reports ASAN has received suggest that common treatments and medications for some of these conditions (such as sleeping pills and psychotropic medications) work differently on autistic people than they do on non-autistic people.

ASAN strongly concurs with the IACC's statement that more research needs to be done on how these co-occurring conditions impact our transitions into adulthood and across the life course. We recommend that the IACC, when making recommendations for the use of autism research funding, prioritize the training of doctors and therapists competent in treating adults with developmental disabilities.

Many of the IACC's objectives and research priorities mention the need for autism researchers to study whether a co-occurring condition "contributes" to "ASD-related behaviors." ASAN cautions against recommending the study of our co-occurring conditions solely with respect to what causes them biologically, or prioritizing research on whether addressing co-occurring conditions impacts autistic traits. Research on the mitigation of co-occurring conditions is important in and of itself for improving the quality of life of autistic people. Whether or not a co-occurring condition alters autistic traits should always be secondary to the core goals of mitigating discomfort, alleviating distress, and improving the health and well-being of the autistic person experiencing said condition. Our health matters in and of itself. Research on our co-occurring conditions should therefore concern how they present in us and what services and supports will help us more effectively manage these conditions.

ASAN agrees with the IACC that research on aging in autism, and on autism as it presents across the lifespan, is relatively limited. The research base for autism relies too heavily on either broad, country-wide studies of autistic children and young adults, or on studies of a select number of autistic people from a mostly-White, upper-middle class background at a specific point in the lifespan. ASAN recommends that the IACC prioritize longitudinal aging-related studies of autistic people of a wide variety of backgrounds, socioeconomic statuses, genders, and ethnicities. We also recommend that the IACC prioritize the use of community-based participatory research which works directly with autistic self-advocates ourselves (including non-speaking self-advocates and self-advocates with intellectual disabilities), rather than acquiring study participants solely by contacting parent representatives or our service providers. We possess firsthand knowledge and experience of our own aging process that other stakeholders lack. High-quality research done in partnership with autistic adults ourselves is the only way to reduce the gap in the knowledge base described by the Strategic Plan.

None of these advancements will be possible if funding for lifespan issues continues to make up only a mere 2 percent of all autism research funding, and if, as the IACC mentions in its 2014-2015 Autism Spectrum Disorder Research Portfolio Analysis report, only 37 of the research projects that were funded even relate to lifespan issues in autism. We urge the IACC to direct proportionate funding for autism research on these issues of pressing importance to the many autistic people who will, or have now, reached adulthood.

Transitions to Adulthood

ASAN appreciates the IACC's growing interest in the transition of autistic people to adulthood, as indicated by the Strategic Plan. We recommend prioritizing research that uses strategies for improving transition services similar to those listed in HHS' Report to Congress, "Young Adults and Transitioning Youth with Autism Spectrum Disorder." The report recommends increased coordination between transition-age services provided under the child's IEP and adult services and supports. We also agree with the report's recommendations for comprehensive, coordinated care, in which a person's primary care, mental and behavioral health, and vocational service providers work together to develop an individualized set of services and supports. Transition services will always be less than effective if they only operate in a vacuum, rather than in conjunction with other services provided to the autistic youth.

We caution against the notion of transition-age autistic youth as a significantly different population from other youth with intellectual and developmental disabilities, who therefore require "autism-specific" transition supports. While many of us will require transition supports which must be individualized to fit our needs, we will *all* need forms of supports that make the broader community more accessible and that aid our passage into postsecondary education or competitive integrated employment. Our needs are similar to those of other transition-age youth with intellectual and developmental disabilities, who are equally heterogeneous, if not more so. The diversity of the support needs of transition-age autistic youth should never be used as a reason to restrict our access to the community, segregate us, or to have low expectations for what we can accomplish.

Supports and Services

ASAN is pleased to see that, at points, the Strategic Plan focuses on research which would improve our access to services and supports. For instance, Question 4 includes an objective which, if the government or private funders of autism research invested in it, would lead to research into technology that would help us manage our own health remotely and increase our access to high-quality preventative care for our chronic conditions.

However, ASAN strongly opposes language in the Strategic Plan which suggests that, because autism presents differently in each autistic person, some populations of autistic people will require more restrictive or segregated services. For instance, in the Strategic Plan's overview of Question 5, the IACC implies that, because of the "heterogeneity" of autism and autistic traits, some autistic people may require housing options that are not compliant with CMS' HCBS Settings Rule. ASAN reiterates that all autistic people, regardless of the form of our disability or level of support need, can live in the community with appropriate services and supports. The degree or kind of support we need should never be used as a justification for restricting the kind of homes we can live in and limiting our right to live in the community. Furthermore, the HCBS Settings Rule is designed merely to ensure that segregated residential settings cannot be funded with federal dollars meant for home and community-based services.

The Strategic Plan repeatedly describes autism as a heterogeneous disorder throughout the plan itself and indicates that, because of this heterogeneity in autism itself, different autistic people will require different supports. While it is true that we are a diverse population and that one autistic person may have substantially different support needs from another, all autistic people benefit from integration into the broader community and services and supports that facilitate this integration. ASAN reiterates that autistic people are not substantially more heterogeneous in our presentation and needs than other people with intellectual and developmental disabilities. Additionally, higher support needs do not alter the right of a person with a disability to receive services and supports in the community rather than in an institution.

ASAN also recommends that the IACC consider prioritizing research which examines what employment supports are effective for autistic adults beyond the age of transition. Many of the supported employment programs that exist today are either time-limited or only occur during an autistic student's transition into adulthood, despite significant evidence that many autistic people may continue to need some supports long after we have graduated from high school or acquired a job in the community. The IACC should recommend the funding of research on potential long term, cost-effective employment support options, such as: customized employment, job coaching and discovery, and the use of assistive technology to facilitate employment.

ASAN reiterates our interest in research on assistive technology that improves the independence and communication ability of autistic people. Many emerging technologies have the potential to vastly improve our independence, self-determination, and quality of life. We are particularly interested in the IACC recommending or prioritizing: (1) additional, more extensive research similar to that in the 2014-2015 Research Portfolio, which investigates the effectiveness of service provision models that enhance our access to augmented and assistive communication devices (AAC); as well as (2) research that investigates the effectiveness of telehealth services as a way to improve the health of autistic people and increase the accessibility of preventative care, including the role of telehealth and assistive technology in the provision of HCBS.

Diagnostic Disparities and Prevalence

ASAN appreciates the IACC's recognition of the unmet needs of autistic women and girls, as indicated by the 2016-2017 Strategic Plan's Cross-Cutting Objective and its repeated references to research on how autism presents in girls and women. Prioritizing research into the services and supports that will help autistic girls and women thrive socially and professionally is critical. Nonetheless, we caution against the IACC's assumption that there are "sex differences" in autism that cannot be explained by women and girls being socialized differently from boys, and especially that there is an underlying biology that causes these "sex differences." While the science of sex differences is complex and it is inconclusive as to whether there are neurological sex differences at all, it is well-documented that autistic girls and women are *under-diagnosed.*[2] Girls are also diagnosed at later ages than boys.[3] In addition, both a narrow focus on "sex differences" and the Strategic Plan itself make no mention of the high number of gender nonconforming, gender nonbinary, and trans autistic people in our community.

Underdiagnosis can have significant negative consequences. A recent study[4] shows that autistic children who identify as female also have reduced executive functioning and adaptive functioning skills when

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[2] Sarah Bargiela et. al., *The Experiences of Late-Diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype,* 46 J. Autism & Dev. Disorders 3281, 3281 (2016) (explaining the body of evidence showing the under-diagnosis of women and girls).

[3] Sarah Bargiela et. al., 46 J. Autism & Dev. Disorders at 3285-91 (2016); Ellen Giarelli et. al., *Sex differences in the evaluation and diagnosis of autism spectrum disorders among children*, 3 Disability & Health Journal, no. 2., April 2010, at 107-116.

[4] Note that Julia Bascom, ASAN's Executive Director, was an author on this study. We include this study for the purpose of illustrating our point. The study does not represent the specific views or opinions of the Autistic Self Advocacy Network.

compared to autistic children who identify as male.[5] This may be due to the reduced support girls and women receive. Research has consistently shown that accurate diagnosis and access to supports and services improves the quality of life of autistic people and our success in adulthood.[6] Autistic women and girls, due to being underdiagnosed, would receive support services at later ages.

With respect to the underdiagnosis of autistic people of color, low-income autistic people, and autistic people who speak English as a second language, we appreciate the Strategic Plan's acknowledgement that more research must be done on these disparities and how to reduce them. We also appreciate the Strategic Plan's recommendation that the government and/or private funders invest in research on strategies that increase the availability of autism screening procedures and services and supports for each of these populations.

Working with the Autistic Community

Meaningful advances in the scientific understanding of autism, in the knowledge of how autistic people grow and change across our lifespans, and on which services and supports best serve autistic adults, will not and cannot happen without the participation, input, and leadership of autistic people. ASAN recommends that the IACC develop and implement, in consultation with the self-advocate community, a robust outreach and engagement plan to the autistic community, particularly to non-speaking autistic adult self-advocates and autistic adults with intellectual disabilities. Beyond deliberately prioritizing research which demonstrates real partnership with the autistic community, the IACC should also (whenever the IACC has the ability to do so) promote the involvement of autistic adults in grant review and other aspects of the development process for new studies. The involvement of a wide variety of autistic people early in the development process enhances the quality of the studies and makes it more likely that the studies will investigate the subjects that matter most to the autistic community.

Again, ASAN appreciates the opportunity to provide comments on the important issue of autism research. For more information on our comments, please contact Julia Bascom, Executive Director of ASAN, at jbascom@autisticadvocacy.org.

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[5] Emily I. White et. al., *Sex differences in parent-reported executive functioning and adaptive behavior in children and young adults with autism spectrum disorder,* 10 Autism Research 1653, 1653-1662 (2017).

[6] Centers for Disease Control and Prevention, *Autism Spectrum Disorder: Treatment,* https://www.cdc.gov/ncbddd/autism/treatment.html (last visited Jan. 5, 2018).