

Child and Neurodevelopmental Disorder Care During the COVID-19 Crisis: The cases of Boston and Florence

Tuesday 21 April 2020

9.00am Boston, 5.00pm Florence, 7pm Canberra

Hosts: John Mendoza, ConNetica Consulting

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Boston Children's Hospital

Harvard Medical School

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Overview

- Situation Report on COVID-19 in Boston, Massachusetts and USA
- Social Distancing' and Lockdown of Non-Essential Services
- Shift in Hospital Functions to Telehealth
- Telehealth Interventions for Targeted Risk Groups
- Home Care of Persons with Neurodevelopmental Disorders
- Status of Residential Schools and Group Homes
- Telehealth and Health Disparities
- Covid-19 Ethics
- Window of Opportunity for Change

Harvard details coronavirus outbreak plans



"While this work has been informed by previous University planning for outbreaks such as mumps, H1N1, and Ebola, this novel coronavirus is a very different disease and presents its own unique challenges."

January 21 First Case in the US March 12, 2020

Since the initial outbreak of the coronavirus in Wuhan, China, the Gazette has been providing regular updates from Harvard specialists in epidemiology, infectious disease, economics, politics, and other disciplines. Here, the Gazette speaks with Executive Vice President Katie Lapp to learn about the extensive preparations and contingency planning that the University is undertaking to ensure the safety, health, and productivity of the Harvard community.



Harvard President and his Wife Socially Distances



Harvard University President Lawrence Bacow and his wife have reportedly tested positive for the novel coronavirus COVID-19. Informing his Harvard affiliates about the infection in an email on March 24, Bacow wrote that both he and his wife started experiencing symptoms on Sunday and were confirmed of the infection on Tuesday afternoon.

Working from home since March 14

In the email, he also revealed that it was on March 22 that both of them started coughing followed by "fever, chills, and muscle aches". The couple contacted their doctor the next day and got tested as soon as possible. Talking about the infection, Bacow said neither of them knew how they contracted the deadly virus. However, they have been working from home amid social isolation and practising social distancing since March 14.

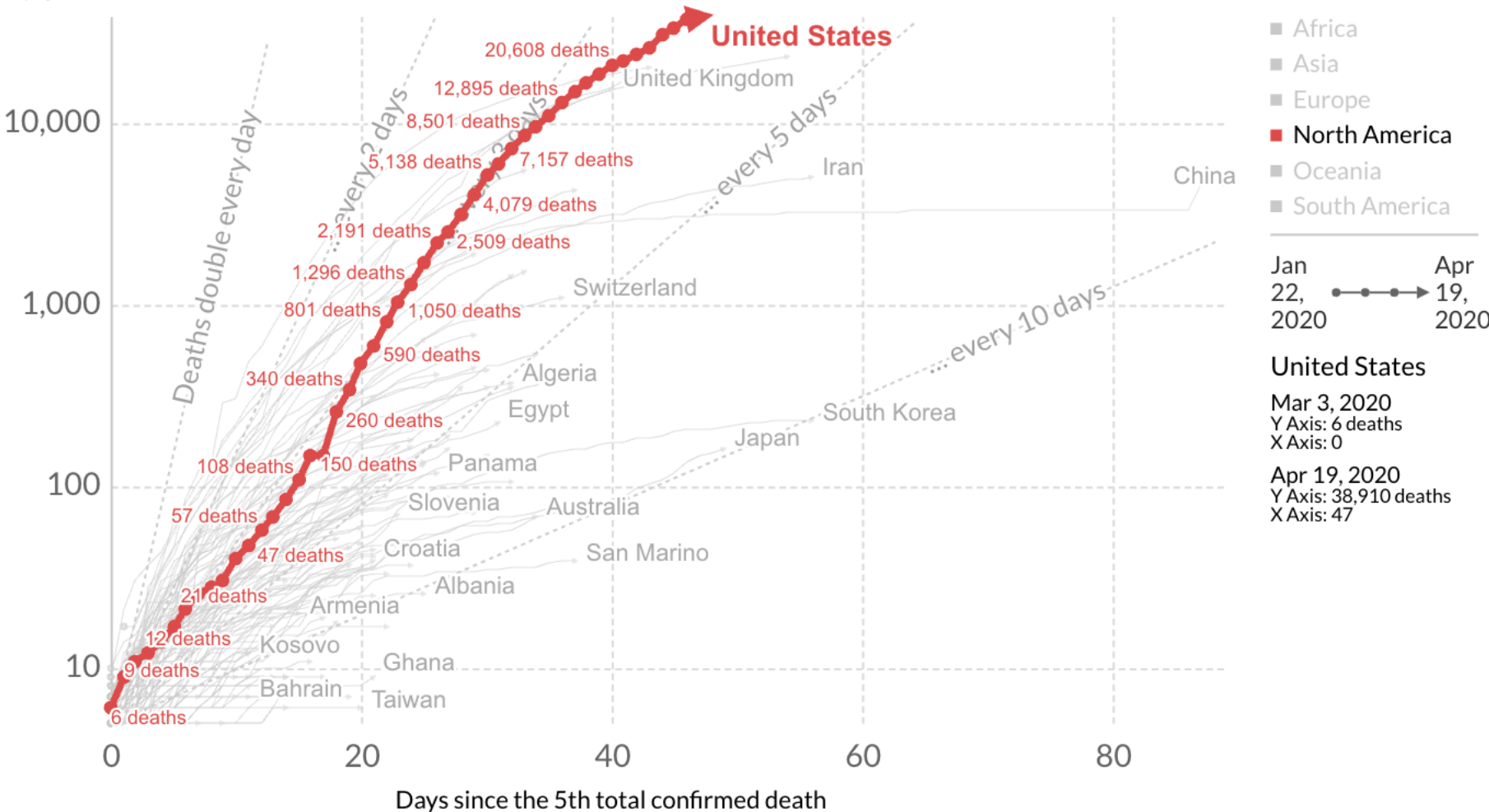
Harvard Prohibits Non-Essential University Travel Until May 31, International Travel Cancelled Until August 31



Total confirmed COVID-19 deaths: how rapidly are they increasing?

Limited testing and challenges in the attribution of the cause of death means that the number of confirmed deaths may not be an accurate count of the true number of deaths from COVID-19.

LOG



Source: European CDC – Situation Update Worldwide – Last updated 19th April, 11:00 (London time)

CC BY



April 22, 2020

| | |
|------------------------------|-------------------------|
| All beds needed* | 55,318 (11,060-190,810) |
| ICU beds needed* | 15,428 (3,968-49,618) |
| Invasive ventilators needed* | 13,527 (3,143-44,472) |

* Projected

Mar 01 Apr 01 May 01 Jun 01

Date

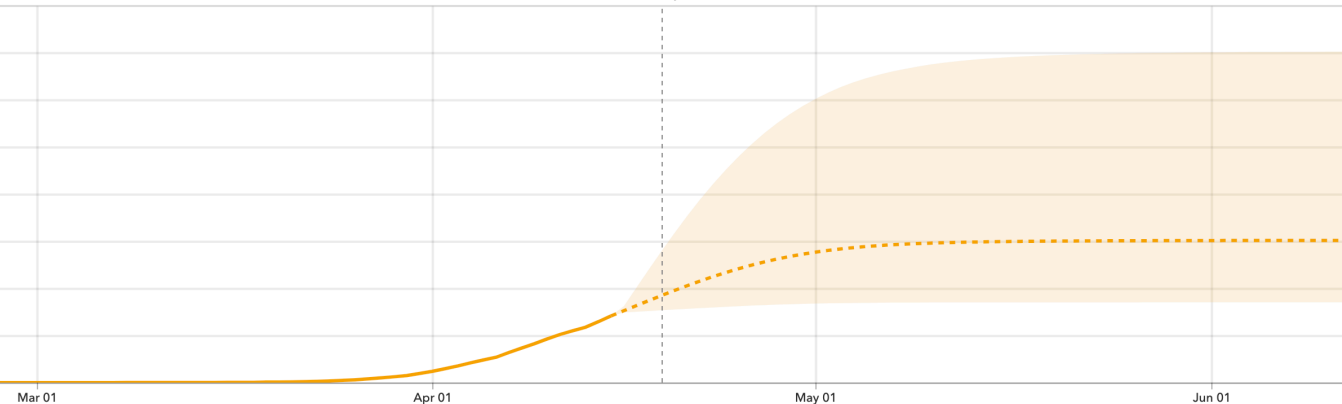
--- All beds needed (projected) --- ICU beds needed (projected) --- Invasive ventilators needed (projected)

All resources specific to COVID-19 patients.
Shaded areas indicate uncertainty ⓘ

Total deaths

60,308 COVID-19 deaths
projected by August 4, 2020

Today



— Total deaths - - - Total deaths (projected)

All deaths specific to COVID-19 patients.
Shaded area indicates uncertainty ⓘ

April 22, 2020

| | |
|------------------------------|-------------------|
| All beds available | 4,848 |
| All beds needed* | 2,618 (301-9,728) |
| ICU beds needed* | 902 (123-3,302) |
| Invasive ventilators needed* | 836 (100-3,112) |
| ICU beds available | 277 |

* Projected

Feb 01 Mar 01 Apr 01 May 01 Jun 01 Jul 01

Date

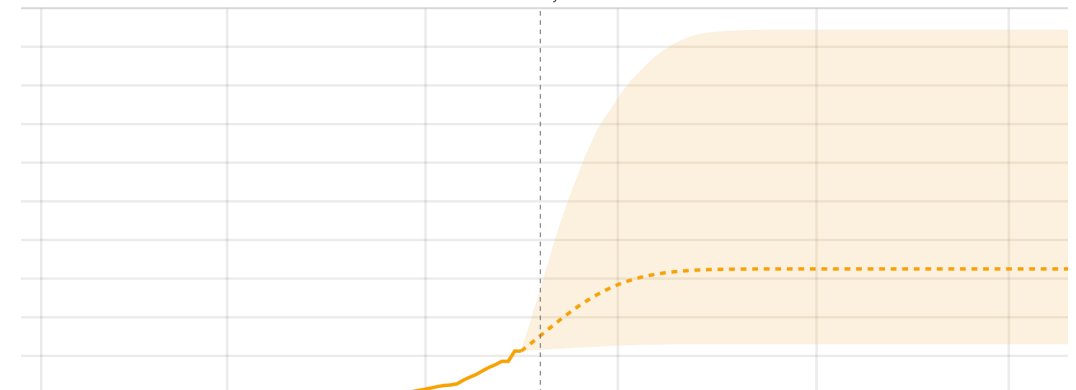
--- All beds needed (projected) --- ICU beds needed (projected) --- Invasive ventilators needed (projected)

All resources specific to COVID-19 patients.
Shaded areas indicate uncertainty ⓘ

Total deaths

3,236 COVID-19 deaths
projected by August 4, 2020

Today



— Total deaths - - - Total deaths (projected)

All deaths specific to COVID-19 patients.



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The Surge in Massachusetts - 21 April Monday Patriot's Day

US health officials watching Mass. coronavirus outbreak closely, Birx says

By **Andy Rosen** Globe Staff, Updated April 19, 2020, 12:23 p.m.



Governor Charlie Baker spoke about coronavirus on Saturday. BLAKE NISSEN FOR THE BOSTON GLOBE

Massachusetts is becoming a top concern for federal officials responding to the COVID-19 outbreak as cases here climb into what Governor Charlie Baker described on Sunday as “the middle of the surge.”

Bill Rodgers takes you through the sights, sounds and feel of what would have been Marathon Monday

By **Dan Shaughnessy** Globe Columnist, Updated April 19, 2020, 35 minutes ago



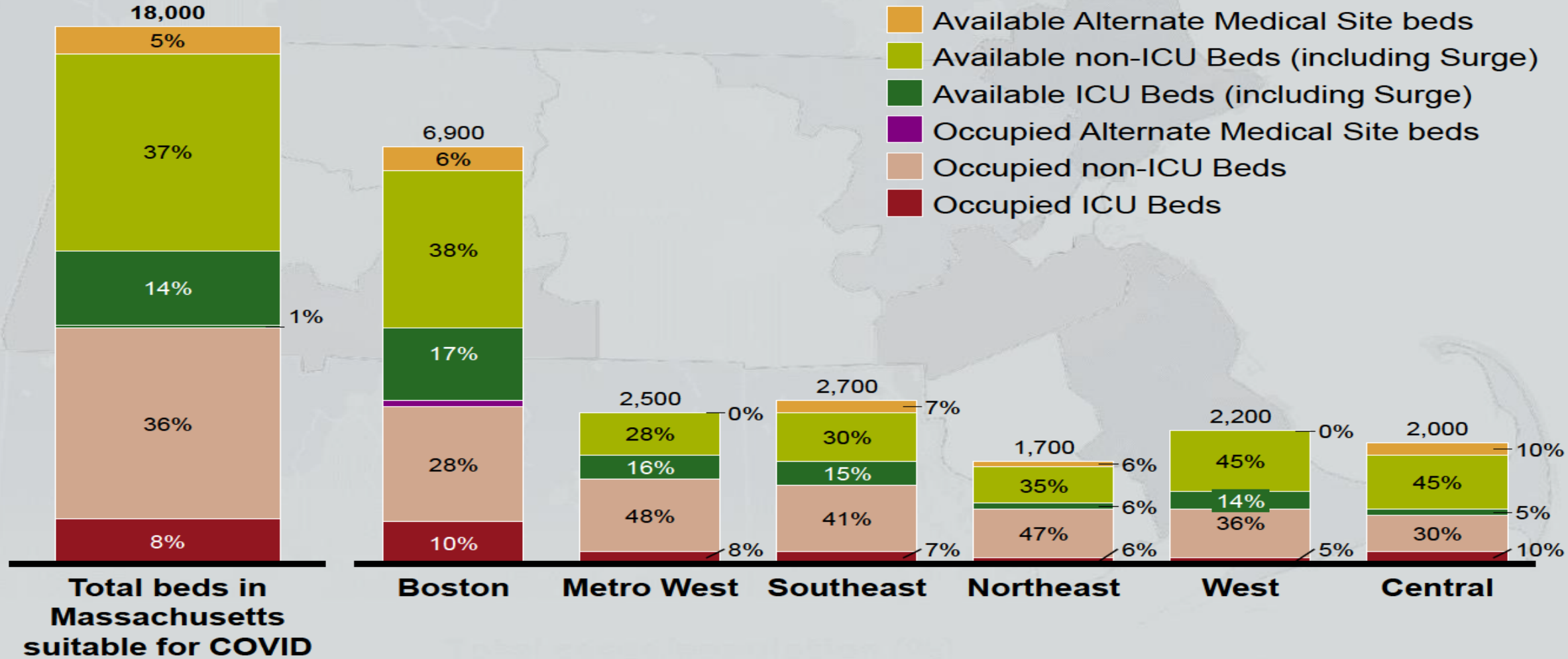
Because of the coronavirus pandemic, the Boston Marathon has been postponed until September. DAVID RYAN/GLOBE STAFF

No Marathon Monday.

No early morning buses shuttling runners to within walking range of the starting line. No piles of sweat pants and pullovers discarded on Hopkinton common. No kids along the route with orange slices and cups of water.

Total Occupancy of Beds by Region

Last Updated: April 16, 2020, 5:00pm



Occupancy/ availability as reported by hospitals to DPH.

Represent EOHHS Regions. Note that total bed estimates may change day-to-day due to hospitals updating surge planning. This data includes 5,000 unstaffed surge beds.

Boston Children's Hospital Transition to Virtual Visits for Non-Urgent Services

- Credentialing and privileging process not straightforward
 - Ins and Outs of Who can provide Telemedicine and Telehealth Services
 - Trainees excluded – a problem for a major teaching hospital
- Tackle compliance issues for telemedicine and telehealth - basics of Medicare reimbursement
 - Pace setter for other insurers
- Loss of reimbursement if wrong coding used
- Attrition in the number of visits
 - Some patients could not download the software or sign on the App
 - Some patients do not have access to faster broad band internet service
 - Immigrant patients requiring interpreter services
 - Lower functioning, non-verbal patients, poor eye contact, poor reciprocity during sessions

Some Advantages:

- Major insurers approved same rate of provider reimbursement
 - Prior to Covid-19 reimbursement rates lower, usage <1:10 visits
 - Approving services across State borders without requiring credentialing (e.g., New Hampshire, Connecticut, Vermont, Maine, New York)
- Accessible from anywhere
- Can share online resources
- Scheduling more flexible
- Emerging evidence of Efficacy

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Read the FREE Buyer's Guide at the bottom, it will help you make the right decision.



Need Telemedicine Software?

Dissemination of Evidence-based Telehealth Practice for Children with IDD

- Useful for children with both ASD and IDD
- Suitable for difficult access and rural areas
- Children with comorbid behaviors
- Coaching acceptable to parents
- Treatment can be delivered reliably by trained therapists
- Telehealth equally effective as live instruction for Early Start Denver Method (with didactic workshops supervision)
- Suitable for minorities and immigrant children – address health disparities and unmet healthcare needs in IDD
- Further research is needed

Randomized Controlled Trial

> [J Am Acad Child Adolesc Psychiatry](#). 2016 Jul;55(7):602-609.e3. doi: 10.1016/j.jaac.2016.05.001. Epub 2016 May 7.

Effect of Parent Training on Adaptive Behavior in Children With Autism Spectrum Disorder and Disruptive Behavior: Results of a Randomized Trial

Lawrence Scahill ¹, Karen Bearss ², Luc Lecavalier ³, Tristram Smith ⁴, Naomi Swiezy ⁵, Michael G Aman ³, Denis G Sukhodolsky ⁶, Courtney McCracken ⁷, Noha Minshawi ⁵, Kylan Turner ⁸, Lynne Levato ⁴, Celine Saulnier ², James Dziura ⁹, Cynthia Johnson ¹⁰

Clinical Trial

> [J Autism Dev Disord](#). 2018 Apr;48(4):1020-1030. doi: 10.1007/s10803-017-3363-2.

Feasibility of Parent Training via Telehealth for Children With Autism Spectrum Disorder and Disruptive Behavior: A Demonstration Pilot

Karen Bearss ¹, T Lindsey Burrell ^{2 3}, Saankari A Challa ⁴, Valentina Postorino ^{2 3}, Scott E Gillespie ², Courtney Crooks ⁵, Lawrence Scahill ^{2 3}

Can telehealth save cost of care and make treatment accessible?

PEDIATRICS COVID-19 COLLECTION
We are fast-tracking and publishing the latest research and articles related to COVID-19 for free. [View the collection.](#)

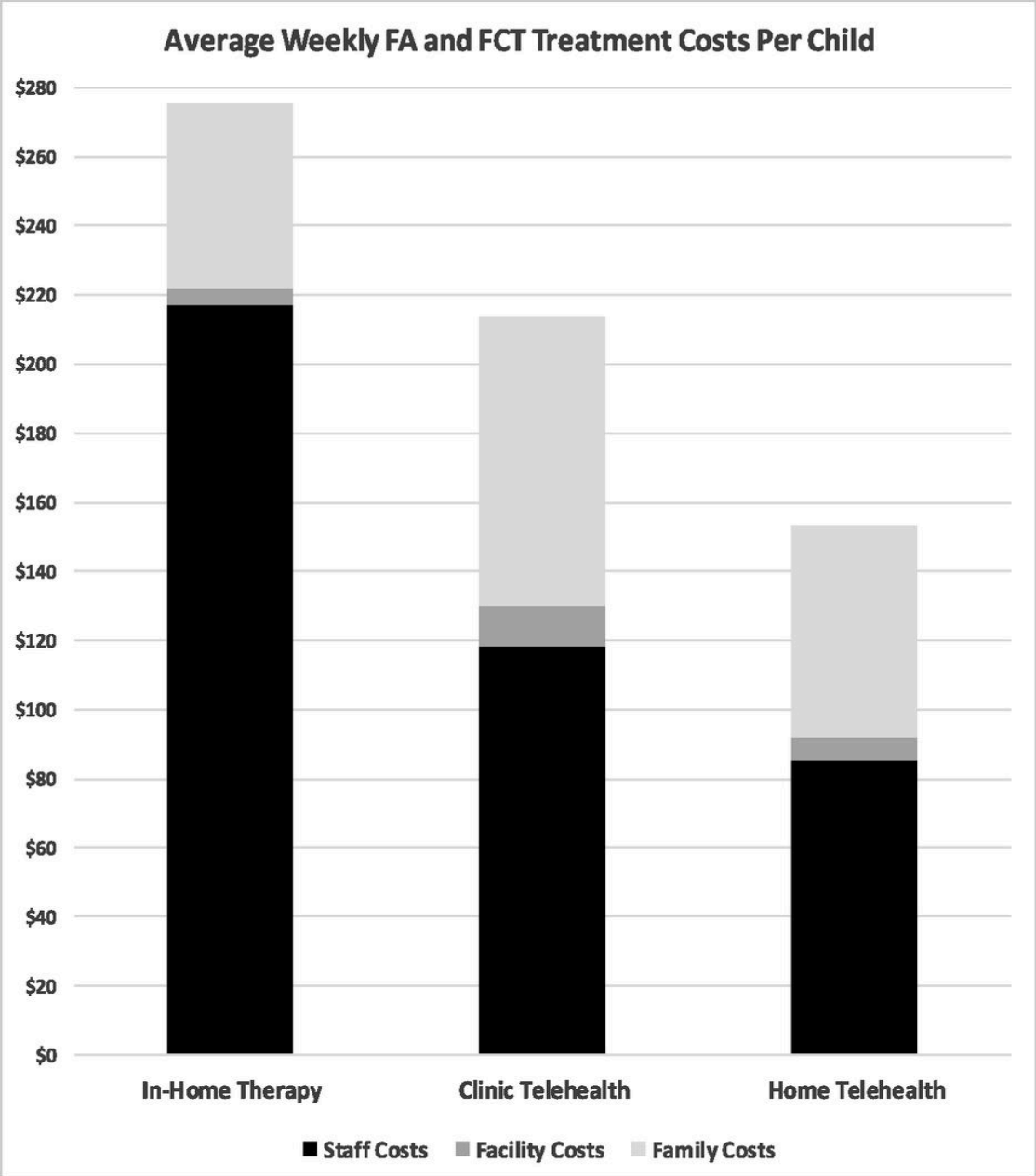
PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

SUPPLEMENT ARTICLE

Telehealth and Autism: Treating Challenging Behavior at Lower Cost

Scott Lindgren, David Wacker, Alyssa Suess, Kelly Schieltz, Kelly Pelzel, Todd Kopelman, John Lee, Patrick Romani and Debra Waldron
Pediatrics February 2016, 137 (Supplement 2) S167-S175; DOI: <https://doi.org/10.1542/peds.2015-28510>

CONCLUSIONS: This research demonstrated that parents can use ABA procedures to successfully treat behavior problems associated with autism spectrum disorders regardless of whether treatment is directed by behavior consultants in person or via remote video coaching. Because ABA telehealth can achieve similar outcomes at lower cost compared with in-home therapy, geographic barriers to providing access to ABA for treating problem behavior can be minimized. These findings support the potential for using telehealth to provide research-based behavioral treatment to any family that has access to the Internet.



Maintaining activities about the Covid-19 following closure of Schools

- Why do you wipe things?
 - We wipe things to keep them clean
 - Young children do not have understanding of transmission
- Why is that person wearing a mask? Is the mask a costume?
 - It's not a costume, they may not feel well
 - When better, they will stop
- Why can't I invite my friend? Why can't I visit grandma?
 - They will need to be away for a while
 - Use telephone and video to maintain contact
- Why can't I go to school?
 - School is closed right now; your teacher and other kids are at home like you
 - Avoid unnecessary detail on illness as younger children may develop fears about attending school
- Don't be afraid to discuss directly
 - Most children would have heard about the virus, seen people wearing masks
 - Be reassuring, positive
- Be developmentally appropriate
 - Answer questions clearly and do not overwhelm with unnecessary information
 - Take the cues from the child, let them express what they learned, provide opportunity to answer questions
- Deal with your own anxiety
 - Do not talk to your child when you are feeling anxious or upset, wait for a calmer time
 - Emphasize the safety precautions in developmentally understandable ways, e.g., washing hands during length of 2 Happy Birthday songs, etc.
- Parent-Child Play - Quiet and Physical
 - Rotate toys, use bubble play, listen to music, toss a ball, paint, play catch you, pretend to be different animals, use blocks, puzzles, coloring, stickers, tape on paper, build a fort with cushions, create an obstacle course, read or looking at books together
- Outdoor Activities
 - While physically distancing, walks, set up a blanket and use quiet and physical activities (as above), go on bicycle and car rides
- 'Real time' Household Activities:
 - preparing meal, setting the table, sorting or putting away laundry, cleaning up (be patient, as it take longer based on developmental level)
- Maintain Daily Routine:
 - Divide activities in predictable, shorter periods
 - Maintain nap and sleep routines



Residential Care and Group Home Services

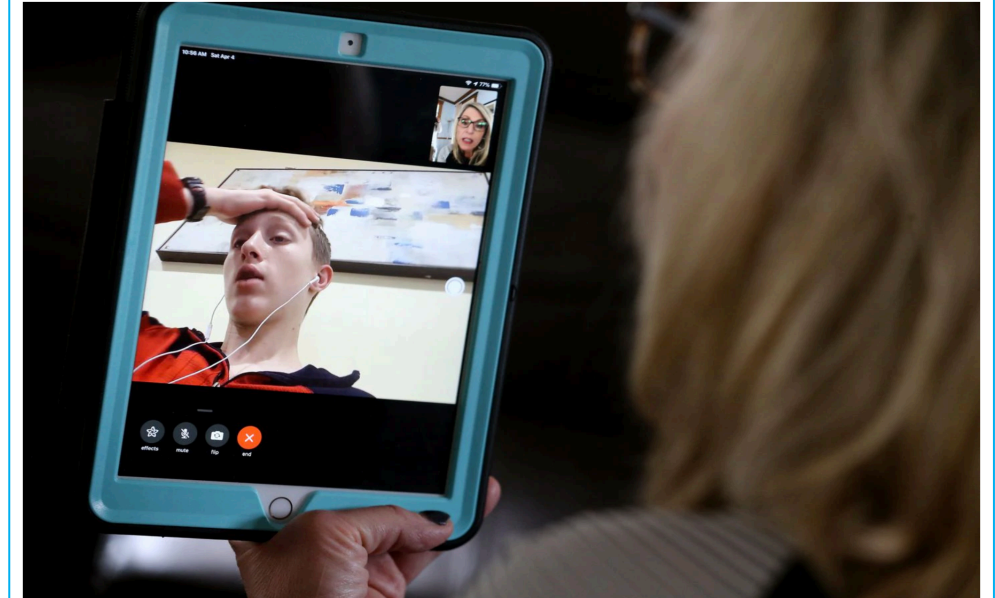
- Generally older children/adolescents and adults with more severe IDD's
- Approved placement by the Special Education and Developmental Disabilities Services
- Usually able to go home on weekends or visit with families electively (disrupted if visiting home, requiring 14-day sequestration) – or vice versa, parents unable to visit
- <https://www.boston25news.com/news/we-are-usually-forgotten-ones-people-with-disabilities-explain-how-pandemic-affects-them-differently/BV7TAB5OKNDJ5EB74IF2G3VESY/>

Berkshire County Arc, which operates 42 group homes and an apartment building for residents, ages 22 to 90, with developmental disabilities and brain injuries.

On Friday, state officials said two residents living in group homes overseen by the Department of Developmental Services have died from the coronavirus. Sixty-seven residents and 71 employees have tested positive. They declined to say where they were living or how old they were. Officials did not respond to a request Monday for the latest data.

Isolated from their families, children and adults in group homes struggle for normalcy

By [Shelley Murphy](#) and [Meghan Sorensen](#) Globe Staff and Globe Correspondent, Updated April 4, 2020, 4:31 p.m.



From her home in Wilmington, Roberta Biscan used FaceTime to talk with her son Connor, 15, who has autism and lives in a group home in Hopkinton. CRAIG F. WALKER/GLOBE STAFF

Roberta Biscan said her 15-year-old son Connor, who lives in a Hopkinton group home for children with autism, knows a virus is making people sick, but he doesn't understand why he can't come home for his usual weekend visits. On the phone, he says he misses going to school, like he used to, and tells his mother he needs a hug.

"It's extremely hard not being there to comfort or reassure him," Biscan said.

The social isolation caused by the coronavirus pandemic has fallen especially hard on families with special needs children and adults with developmental disabilities. Like Biscan's son, many may not fully understand what is happening or why, and being apart from their loved ones amid so much uncertainty has added to their burden.



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Framework: Developmental (and cognitive) understanding of change, attachment, loss, separation, death

- Age <3 years
 - Familiar attachment figure
 - Unlikely to understand difference between temporary and permanent absence
- Age 3-5 years
 - May talk about loss or death, but may still expect person to come back
 - Most children do not realize that everyone will die
- Age 5-10 years
 - Understanding death as final, irreversible, and inescapable (e.g. Worden, 1996)
- Loss of “safe haven” – loss of “*secure base function*”
- Loss of regulatory functions – close relationships help regulate sleep and eating behaviors, emotions, social interactions, sense of self, problem solving, as well as physiology, cardiovascular, immune function, temperature regulation, pain sensitivity, and epigenetics
- Avoidance behaviors of loss reminders derailing the process of adapting to the loss
- Circumstances around the death – in particular with sudden and traumatic exposures
- Secondary losses, financial standing, “changed circumstances” associated with the loss further disrupting developmental functions

15-year-old fostered and then adopted adolescent male with Down Syndrome

- Sudden loss of his mother
- Seen in follow up accompanied by his sister (often seen by his adoptive mother and father)
- Behavioral regression, agitation, aggression, including self-injuriousness
- Currently stable in group home

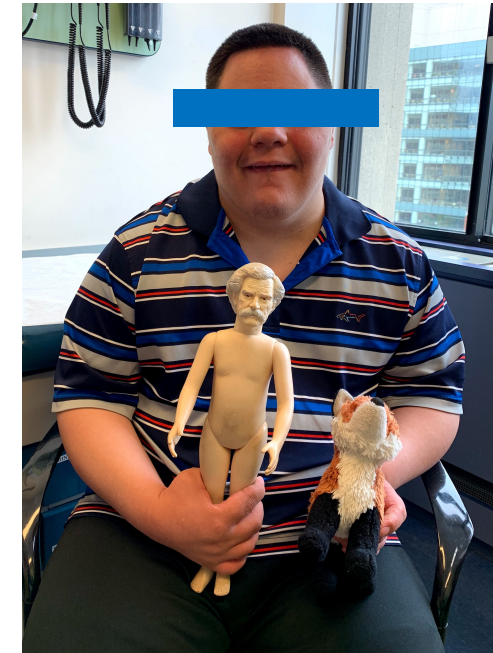
Grief and its Complications in Individuals with Intellectual Disability

Claire Brickell, BS, and Kerim Munir, MD, MPH, DSc

Bereavement and loss have significant impact on the lives of individuals with intellectual disability (ID). Although there is a growing impetus to define the symptoms of grief that predict long-term functional impairment, little is known about maladaptive grieving among individuals with ID. We examine the literature concerning the phenomenology of traumatic grief (TG) in the general population, along with what is known about the manifestations of grief in individuals with ID. We then apply modern theories of grief and grief resolution to individuals with ID in order to highlight potential areas of vulnerability in this population and to lay the groundwork for interventions that will facilitate their adaptation to loss. We provide a theoretical framework for the proposition that individuals (including children and adults) with ID are more susceptible to TG, based on an increased risk of secondary loss, barriers to communicating about the loss, and difficulty finding meaning in the loss. We conclude that individuals with ID should be considered as potential candidates for targeted bereavement interventions. Further research is required, however, in order to develop population-appropriate measurement scales for testing these hypotheses. (HARV REV PSYCHIATRY 2008;16:1-12.)

Keywords: grief, bereavement, intellectual disability

Harvard Review of Psychiatry . 2008 ; 16(1): 1-12



Linking Objects and Linking Phenomena

- Symbolic, tangible object that belonged to or represents the deceased
 - Photograph, clothing, e.g., comb, handkerchief, watch
 - Gift, note, e.g, letter from a war zone by a soldier before he is killed
- “Meeting Point” between the representation of the deceased person and the mourner (self)
- Sensations, songs, behavior patterns, memories; these can postpone or “freeze” mourning process, but also can “initiate” and “jump start” mourning
- As if the loss had just happened

Prolonged Grief Disorder (PGD) in DSM5-TR, 2020

Proposed Developmental Modifications

- A. Death of a person at least 12 month previously - for children for 6 months
- B. One or both following symptoms, nearly daily basis for past month – compound item split for children
 - 1. intense yearning/longing for the deceased person
 - 2. for children, preoccupation may focus on the circumstances of the death
- C. At least 3 of the following of the following:
 - 1. Identity disruption, feeling part of self has died - children experience discontinuity as feeling different from others and often self-conscious as a result, e.g., weird or different as a result of being motherless
 - 2. Marked sense of disbelief about the death - children may not understand the permanence of the death
 - 3. Avoidance of reminders that the person is dead – for children include efforts to avoid reminders that the person is dead
 - 4. Intense emotional pain, anger sorrow, bitterness related to the death - children may feel deprived of the person's help in responding to developmental needs
 - 5. Difficulty moving on with life, e.g., engaging with friends, pursuing interests, planning the future – for children inability to achieve developmental milestones
 - 6. Emotional numbness - children may not understand this, and adolescents may describe 'not feeling anything'
 - 7. Feeling that life is meaningless - children and adolescents may express this as 'its not worth trying' 'nothing really matters anymore' or 'my life is ruined' - Yearning to physically reunite, not SI, but wish to die, concrete thinking
 - 8. Intense loneliness (same)
- D. Disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning
- E. The duration of the bereavement reaction clearly exceeds expected social, cultural or religious norms for the individual's culture and context. The symptoms are not better explained by another mental disorder



“Extended” Attachment Supports



Are We All in This Together?

The pandemic has helpfully scrambled how we value everyone’s economic and social roles.

By Michael J. Sandel

Mr. Sandel teaches political philosophy at Harvard. His forthcoming book is “The Tyranny of Merit: What’s Become of the Common Good?”

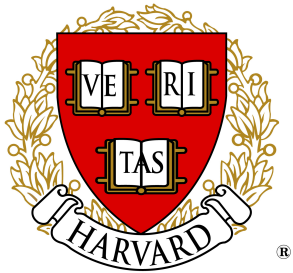
April 13, 2020





Michael Sandel led a campuswide audience in a Zoom event, “Harvard Live: Pandemic Ethics.”

Stephanie Mitchell/Harvard file photo



If Harvard were to reopen today, who should be allowed to return?



Michael Sandel poses a series of questions at a community event on ethics and the pandemic response

BY **Brett Milano**
Harvard Correspondent

DATE April 17, 2020

Suppose Harvard were allowed to reopen tomorrow. Would it be ethical to allow a limited number of students to return, provided they tested virus-free and were willing to repeat the test daily?

March 18, 2020

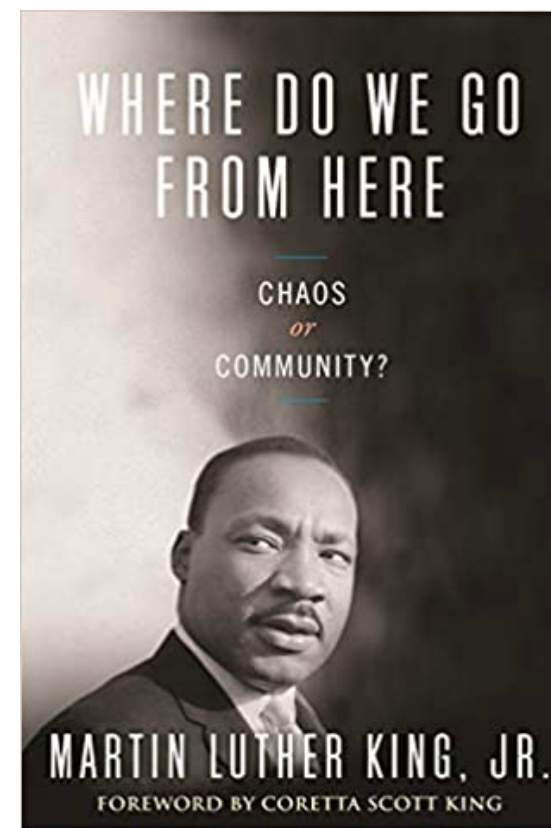
The Honorable Mitch McConnell
Majority Leader
U.S. Senate
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
U.S. Senate
Washington, DC 20515

Dear Majority Leader McConnell and Minority Leader Schumer:

- Prioritize and expand home and community-based services and supports
- Coronavirus Support for People with Disabilities Act
- Prohibition of Non-Discrimination in the Rationing of Scarce Medical Resources
- Enforcement of Non-Discrimination by HHS Office of Civil Rights

Thank you!



As the Rev. Dr. Martin Luther King said, “We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.” The fragile state of this “network of mutuality” has become all too apparent during the coronavirus outbreak. Though we may be vulnerable, we are not dispensable. In fact, we have critical experience to share in adapting to challenging and constantly changing situations affecting our health, employment, education, housing, and families--experience that all Americans will need in the days and weeks ahead. We are grateful for the urgency with which the Senate is moving to make sure that the American people never feel the worst of this pandemic, and we seek only to protect our community from the unintended but all too foreseeable impacts of discrimination. As Americans, we move forward together.

