

**DISABILITY COMMISSION
ADVISORY BOARD MEETING**

Meeting Link: meet.google.com/trb-fzvv-iri
Call in Number: 1-315-599-0017

Wednesday July 14th 2021
5:30-7:00p.m.

Meeting Agenda

- Call to Order
- Introductions
- Approval of June minutes
- City Department Presentation - *Sarah Rodrigo, Arts & Culture*
- Presentation - *John Kelly, Second Thoughts MA*
- Developer Presentation
- Chair's Report - *Olivia Richard*
- Commissioner's Report - *Kristen McCosh*
- Architectural Access Report - *Patricia Mendez*
- Old Business
 - Old Action Items
- New Business
 - New Action Items
- Public Input
- Adjournment

Meeting Minutes

Attending:

Jerry Boyd
Juan Carlos Ramirez-Tapia

Olivia Richard
Carl Richardson
Elizabeth Dean-Clower
Dusya Lyubovskaya
Alice Fisher

Absent:

Yardley Sanchez
Kyle Robidoux
Zary Amirhosseini
Wesley Ireland
Paul Caron

Meeting called to order:

5:37pm

June Meeting Minutes:

Motion to approve June meeting minutes by Carl, seconded by Alice. Motion carried.

Votes Taken

- Lacking a quorum due to the early departure of Carl Richardson, no votes were taken at this meeting.

Other Decisions Made

- Taking a vote to finalize the two letters that have been drafted was postponed either to the August meeting or a special meeting, if the Executive Committee decides to call one.

Issues Discussed

City Department Presentation: Sarah Rodrigo, Arts and Culture

- The Mayor's Office of Arts and Culture works with various City partners including working closely with Patricia and Sarah of the Disabilities Commission to review projects. They hold monthly public meetings - which

are noticed - of the Boston Art Commission in order to discuss all public art projects proposed and underway in the City.

- The particular project being presented today is a community-initiated and driven project. Has been underway in this iteration for more than a decade, but has been under discussion for several decades.
- An associate from Sasaki, the firm doing the design work for the plaza, is scheduled to join the meeting.
- Douglass Plaza in Roxbury will be home to a long-planned memorial to the great orator, writer, and abolitionist Frederick Douglass. The Frederick Douglass Sculpture Committee, under the leadership of Aziza Robinson Goodnight, has been tirelessly organizing, fundraising, and managing this project. Capital funds and Community Preservation Act funds have recently been secured.
 - Presentation Slide Image Description: A clay model of the sculpture by Mario Kyoto, based on a drawing by local artist Paul Goodnight. The model is against a black background. The base is a large book with “Frederick Douglass” inscribed on the spine in capital letters. A young black boy sits on the book with a foot dangling over the spine, while his other foot supports the open book he holds and which he is reading. Behind the boy is Roxbury puddingstone. On it stands a middle-age black man in formal dress including a waistcoat and tails. This is the portrait of Frederick Douglass. He is standing tall, pointing out over the boy’s head. To the man’s left, and our right in the image, standing on the book is a young man standing in a Civil War soldier’s uniform holding a rifle. On the other side also standing is a black woman in a long full skirt and puff-sleeve blouse, holding a sign with a long handle, a protest sign, her hair tied in a bun.

- On the right side of the slide is another image, which is of a public plaza. The sculpture just described is in the center, with planters on either side, and exuberant green and yellow plantings including sunflowers. On each side is a tree with a canopy of purple blossoms. On the center is gray pavers or cobbles, and the center is the bronze version of the sculpture, and people staged around showing possible uses.
- Next slide shows the current state of the project site: between Tremont and Hammond St, at the corner, Slade's Restaurant is in the background with a black and white mural of Frederick Douglass on it
 - Slide Description: You are looking toward Hammond St with Tremont St on the left. In the background there are city buildings, in the center is a tree that is relatively healthy and will be remaining on the site. In front are cobblestones, a bus shelter to the left hand side, an electrical control box between the tree and the bus shelter. Sidewalks are running toward the tree across Hammond St, and a chain link fence is on the right.
 - The image on the right is looking the other way. You see mainly cobblestones. In the center is a circular concrete piece with sort of pie shape seams. No one knows what this is for. It is a mystery. It will be removed as part of the renovation. Around the cobblestones are black bollards which will be removed. There is also vehicle parking between the cobblestones and the taller apartment buildings on the other side.
- The Sasaki team came to this project through the artwork itself which was initially supposed to be sited in the Frederick Douglass Peace Garden which is near this site, but kind of tucked in behind the apartment building in the right hand photograph. That has become a difficult site because of maintenance. This site is very visible, gets a lot of foot traffic, and was

decided to be a better site. But it's a difficult place to site a sculpture, so the Committee brought in Sasaki to design a new plaza.

- Next Sarah presented the “initial vision” for the site, with architectural plans displayed on the slide. Received feedback from Commission about accessibility - the site has those old cobblestones, the plan was for pavers which are difficult for traveling for people on wheels or with other mobility challenges; the positioning of the various pieces and where the ramps are located, all posed potential accessibility challenges. The Sasaki team went back to the drawing board and came up with a new plan.
- Next slide included the updated plan. Most of the bones are the same, in terms of locating the planting beds and the sculpture. Added a clear pathway across the side, aligned the crosswalks better, relocated the seating elements to the edges of the planting beds. The plan got rid of the cobblestones, bringing in new pavers.
- The current vision for the site is the same rendering described from that first slide with planters, purple blossom tree canopy, and the tree that is currently on site.
- Final slide includes contact information - sarah.rodrido@boston.gov or 617-635-2424. The Office of Arts and Culture boston.gov/public-art and Sasaki Associates at www.sasaki.com
- Questions/Comments from the Board:
 - Board Member Dusya - when will the sculpture be installed?
 - Sarah - hope to be completed by the end of next summer. Big effort - Public Works owns the site, working with Sasaki, the Committee, the Community Preservation Act. Had hoped to be done this year, but looks like we'll invite you to a celebration at the end of next summer.
- Questions/Comments from the Public:

- David Viera - what is the projected cost of this project, what part is being paid by the CPA, and where is the rest of the money coming from?
- Sarah - the project has received significant funding from the Brown Fund for the artwork over the past 10 years. Capital funding to complete the artwork -- similar to the Percent for Art program that MOAC runs -- that comes directly from capital. Then some capital also for the plaza, and \$400,000 from CPA the plaza construction. CPA cannot pay for art, it's for the improvement of the public space. Then the City is supplementing \$300,000 for the plaza and the artwork. All told over time, without knowing the totals from the Brown Fund that have already funded the sculpture, Sarah estimates around \$1.3 million over more than 10 years of development. The plaza itself is \$700,000.

Between presentations, the Board discussed the technical challenges related to the virtual meeting format. There was a great deal of feedback and attendees noted that it was very hard to hear the presenters. Andrea (CPWD) reported back from discussing with Boston City TV that the issue is the amplification of your voices on the speakers in the room was being picked up by the microphone that must remain unmuted in order to make the recording for TV / YouTube. The Cable department recommends using Zoom instead of Google Meet, as the Zoom platform allows for better control of the audio. The Commission will follow up with the Cable department and the Executive Committee about making the switch.

Second City Presentation: John Kelly, Second Thoughts MA

- John introduced himself - pronouns he/him/his; a former Advisory Board member, he is now the director of Second Thoughts Massachusetts, a group of disability rights activists against assisted suicide.
- The presentation began with the group's talking points as to why Massachusetts should reject assisted suicide, beginning with the general points, including:
 - It's impossible to have real choice in a country that is run by insurance companies, whose business model is to deny treatment even if it's life saving. Offered an example of a doctor who prescribed expensive treatment for patients, who were denied access when the insurance company said they would only fund hospice or assisted suicide.
 - When one is denied treatment, their condition can worsen and they can die. As an example, 90% of people in Japan with ALS get a tracheotomy. In the US 90% of ALS patients do not receive a trach, being discouraged from doing so.
 - Legalization makes assisted suicide a medical treatment, which will always be the most profitable and "cost-effective" treatment.
 - Drugs are dispensed from a pharmacy with no follow up.
 - 1 in 10 older adults in Massachusetts are abused every year. Many people are in nursing homes with no access to home care services. Home care benefits are something we support, so that elders can receive it through Medicare rather than having to spend down their resources in order to qualify for Medicaid.
 - For those living at home, there are no protections against error, or abusive caregiver steering someone to assisted suicide. No witnesses are required for the request, picking up the dose, administering or witnessing the death itself. There's no way for anyone to know the caregiver didn't steer.

- Misdiagnosis - this puts 6 million Americans at risk of severe harm. 12-15% of people diagnosed with 6 months or less to live will outlive their diagnosis, sometimes by decades. John described a story as published in the Boston Globe by an Oregon resident who first sought assisted suicide after a cancer diagnosis, but after a second doctor convinced her to attempt treatment she is still alive more than 20 years later.
- John made an analogy to the death penalty which is a well-known progressive issue. Progressives oppose the death penalty because there is no way to prevent innocent people from dying as a result. With this issue, the challenges are even greater.
- Medical prejudice - the doctors who support assisted suicide are the same ones who rushed to create crisis standards of care. John described the fight to make sure those standards are not outright discriminatory. The initial crisis standards of care created in the pandemic were discriminatory. For example, planned to deny beds and ventilators to older ill and disabled people who doctors didn't expect to live. Such as those with "medical orders of life sustaining treatment" called MOLT. Were supposed to be given to people who doctors "would not be surprised" if they died within the next year. John received one 10 years ago. It's a questionnaire that asks things like "do you want to be taken to the hospital" and the first answer is "no," with potential "yes" options on another side, again with the least amount of care being the first option.
- Next, a slide deck with additional information was presented.
- The first slide includes a Venn diagram showing that people with terminal conditions are people with disabilities.

- Next, the results of a survey conducted in Oregon regarding the reasons people seek assisted suicide are presented. All have to do with “existential distress” at the idea of becoming disabled including:
 - Loss of autonomy (cited by 91%)
 - Decreasing ability to do things that are fun (90%)
 - Loss of dignity (74%)
 - Loss of control of bodily functions such as incontinence (43%)
 - Feeling like an emotional burden on family, friends, or caregivers (48%)
 - Inadequate pain control or concern about it (27%)
 - The first two years of the program they had pain listed on its own, but so few folks cited this reason that they added “fear”
 - Financial cost of treatment is relatively low at 5%
- Assisted suicide is presented as “individual choice” like you’re in a supermarket. But when you’re discussing dignity, that has to do with other people and our self-esteem. It relates to being deemed worthy by other people and yourself.
 - John recounted that in the early days of his spinal cord injury he experienced a lot of humiliation. The best way he found to regain dignity was to build connections with other disabled people. So for example, one would hope that ALS patients would meet with other ALS patients before declining a trach.
- A terminal diagnosis is not reliable.
- In a poll of US adults regarding who approves or disapproves of laws that allow doctor-assisted suicide for terminally ill patients. Overall 49% disapprove, 47% approve. For white people, 44% disapprove and 53% approve. For Hispanic people, 65% disapprove and 32% approve. For Black adults 65% disapprove and 29% approve.

- Next John presented a map of the Commonwealth showing which areas voted in favor of an assisted suicide law. Wealthier and whiter towns voted in favor. There is a class divide over who supports and who opposes assisted suicide. People who are disabled, or who are Black or Indigenous, are used to being disrespected by doctors and not receiving the best care.
 - A stereotype that Black people feel less pain than white people has led to Black patients receiving abysmal treatment for pain. Including a recent study that Black children with appendicitis were one-fifth as likely to receive opioid painkillers for their severe pain when in the emergency room. As recently as a survey conducted in 2016, 1/3 of white medical students and residents believed that Black people have thicker skin and a higher tolerance for pain.
- Next, John noted the controversy around, and opposition to, the movie *Me Before You*. This was a 2016 film that promoted the view that even if your life was otherwise perfect, having a spinal cord injury the same level as John meant that you would want to die. Many films present the view that “better dead than disabled.” This law would make that law in Massachusetts.
- In summary John quoted Marilyn Golden of the Disability Rights Education and Defense Fund that “If assisted suicide is legal, some people’s lives will be ended without their consent, through mistakes, coercion, and abuse. No safeguards have ever been enacted, or even proposed, that can prevent this outcome, which can never be undone.” Finally, John noted that depression is also a complicated issue, because depression is seen as a rational response to being disabled but it is not.
- Questions/Comments from the Board:
 - Alice Fisher - please share copies of these documents.
 - Andrea, CPWD - will re-send to everyone
 - Elizabeth Dean-Clower - what is the status of legislation in MA?

- John - the bill is in the Public Health Committee, which includes many assisted suicide supporters including the Chair, Jo Comerford, who has committed to her constituents that she will move the bill through. It looks like it will be difficult to persuade the Committee not to pass it out, but the group wants people to testify against it. Hearing likely to be scheduled in the fall. Don't have an exact date but usually get good notice. Also still unknown if the State House will be open for in-person testimony by that time. The large hearing room only has two elevators which can create quite a logjam and such hearings also often last all day. The Massachusetts Medical Society has done "neutral" which reveals the organization as a trade association, because their position is that some members want to be able to prescribe these drugs. In states that have passed these bills, disability rights organizations have not been strongly upfront in opposition.

Chair's Report: Olivia Richard

- Celebrate the agreement between the City of Boston and Michael Muehe and other plaintiffs to create more accessible curbs and streets.
- MassHealth is having EVV (electronic visit verification) listening sessions, check Boston Center for Independent Living's website at bostoncil.org for more info. That's for consumers of the PCA program.
- More than just BCYF for swimming. Mass.gov/topics/swimming you can get all kinds of information about the accessible pools, spray decks, etc. in the Commonwealth.

Commissioner's Report: Kristen McCosh

- ADA Day coming up a week from Thursday, July 29th in Copley Square Park. Will also have an online component. Theme this year is Reconnecting. Will have City Departments present to help folks get reconnected with City Government after a long year inside. Food, music, the Mayor will be speaking. Will be honoring our EMS department for their great work throughout COVID.
- Open Streets - a program where the City closes down streets to cars, opening just to pedestrian traffic. Have done for years with Newbury Street, and other streets are coming.
- Captioning ordinance is still planned to be announced on ADA Day, as are a number of exciting initiatives.

Architectural Access Report – Patricia Mendez

- Postponed to next month.

Public Input:

- David Viera - Regarding the settlement with Disability Law Center - would like to put out a message to all the municipal candidates (Mayor, City Council) - there's no reason why a lawsuit was required in order to reach a resolution to the equity issues around curb cuts and sidewalks.
 - Commissioner McCosh clarified that the agreement was developed not in response to a lawsuit, but rather advocates who have been working with the City for years wanted a clear statement of the plan for improvements, and for an ADA Coordinator for curbs/sidewalks to be hired. As a result of this agreement an engineer was hired to fill this role. Ultimately this was a result of decades of work within the City. As an older City with roads owned by a variety of entities it has been a difficult network to plan work for, which is not an excuse but a reality.

We have more to do and this agreement explains how we are going to carry out that work.

- Second, having been unable to attend the June meeting, interested in an update on the bike plan initiative. At this point anything that gets released will be too late for this season.
 - Commissioner McCosh responded that Public Works has been working on a series of videos internally that the Commission contributed to planning. The Commission has stepped back a bit given the demands ADA Day and a Boston Public Schools project, but will pick it up again in August.
- Third, there was a note in a recent update from the Commission about Farmer's Market Coupons. Would like to clarify whether those can be used to purchase things other than produce.
 - CPWD will confirm and follow up with David offline.
- Fourth, the feedback problem with Google is awful and the Board should switch to Zoom.
- Finally, regarding bus stops - there is a stop in Hyde Park that needs to be repainted on the street. In attempting to get this done, the MBTA has said it's a City issue, and the City says it's an MBTA issue. Who is in charge?
 - Commissioner McCosh asked David to share the specific stop. Most issues like this are relatively clear cut. Promised to be in touch individually.

Adjournment

A motion to adjourn was made by Dusya, seconded by Alice, and the motion was carried. The meeting was adjourned at 6:54pm.