WEBVTT

1
00:00:03.400 --> 00:00:06.600
Hello and welcome to the health and Healthcare equity and communication

2
00:00:06.600 --> 00:00:08.700
disorders research symposium.

3
00:00:09.300 --> 00:00:12.600
This Symposium is funded in part by conference Grant

4
00:00:12.600 --> 00:00:14.000
through nidcd.

5
00:00:20.600 --> 00:00:23.100
This session that you're listening to today is one

6
00:00:23.100 --> 00:00:27.200
of six sessions that comprise the 2021 research

7
00:00:26.200 --> 00:00:27.900
symposium.

8
00:00:28.500 --> 00:00:31.900
All of the sessions are available in the convention virtual

9
00:00:31.900 --> 00:00:32.800
library.

10
00:00:36.600 --> 00:00:39.900
The following are the topic areas for the upcoming research

11
00:00:39.900 --> 00:00:42.700
Symposium each year, the Symposium

12
00:00:42.700 --> 00:00:46.400
presenters write an article based on their presentation that

13
00:00:45.400 --> 00:00:48.400
is published in the Journal of speech language

14
00:00:48.400 --> 00:00:49.500
and hearing research.

15
00:00:50.200 --> 00:00:53.300
We encourage you to check out the date the future

16
00:00:53.300 --> 00:00:55.500
symposia and the related articles.

17
00:00:57.700 --> 00:00:59.400
Now on to our presentation today.

18
00:01:00.900 --> 00:01:03.800
The title of the presentation is driving towards equity

19
00:01:03.800 --> 00:01:06.700
and healthcare for persons with communication disabilities.

20
00:01:06.700 --> 00:01:10.100
My name is Megan Morris. I am an

21
00:01:09.100 --> 00:01:12.400
associate professor in the division

22
00:01:12.400 --> 00:01:16.400
of General Internal Medicine at the University of Colorado in

23
00:01:15.400 --> 00:01:18.900
the anshutes Medical Campus. I

24
00:01:18.900 --> 00:01:21.200
also am a methodologist in the

25
00:01:21.200 --> 00:01:24.700
adult and child Consortium for health outcomes research

26
00:01:25.500 --> 00:01:27.000
science or Accords

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00:01:30.500 --> 00:01:33.700

I received a speaker honorarium and Asha convention

28
00:01:33.700 --> 00:01:37.800
registration labor supported by nidcd Grant.

29
00:01:36.800 --> 00:01:39.600
You can read it

30
00:01:39.600 --> 00:01:39.700
here.

31
00:01:41.800 --> 00:01:44.200
I would like to start today with a case.

32
00:01:44.200 --> 00:01:47.600
This is a case that happened last year

33
00:01:47.600 --> 00:01:52.000
in the midst of the covid-19 pandemic.

34
00:01:50.800 --> 00:01:53.400
So on June

35
00:01:53.400 --> 00:01:56.500
5th of 2020 a physician

36
00:01:56.500 --> 00:02:00.200
in Texas had a conversation with a wife of a hospitalized covid-19

37
00:01:59.200 --> 00:02:02.500
positive patient the patient

38
00:02:02.500 --> 00:02:05.700
his name was Michael Hickson was 45 years

39
00:02:05.700 --> 00:02:08.800
old and had an ox brain injury

40
00:02:08.800 --> 00:02:11.400
due to a sudden Cardiac Arrest three years

41
00:02:11.400 --> 00:02:12.100
prior.

42
00:02:13.800 --> 00:02:16.500
As a result he had limited communication and was

43
00:02:16.500 --> 00:02:17.400
quadriplegic.

44
00:02:18.300 --> 00:02:21.700
Mr. Hixson was living in a nursing home and had developed

45
00:02:21.700 --> 00:02:24.200
pneumonia as a result of his covid-19.

46
00:02:25.900 --> 00:02:28.100
The Physician approached Mr. Hixson's wife

47
00:02:28.100 --> 00:02:32.000
to have a conversation about whether Mr. Hixson would receive the

48
00:02:31.500 --> 00:02:34.600
medication to treat his covid-19 symptoms

49
00:02:34.600 --> 00:02:36.800
and and pneumonia

50
00:02:37.700 --> 00:02:40.400
The wife decided to record the conversation.

51
00:02:41.500 --> 00:02:44.400
She recorded the conversation and then actually posted it

52
00:02:44.400 --> 00:02:47.900
online for others to see on YouTube.

53
00:02:47.900 --> 00:02:51.000
And so we're able to actually have a

54
00:02:50.500 --> 00:02:54.200

bit of the transcript of that conversation.

55
00:02:53.200 --> 00:02:56.100
I'd like to read that to you now.

56
00:02:57.300 --> 00:03:00.200
The Physician said the decision is do we want

57
00:03:00.200 --> 00:03:03.400
to be extremely aggressive with his care or do

58
00:03:03.400 --> 00:03:07.400
we want do we feel like this will be futile and

59
00:03:06.400 --> 00:03:09.400
the big question of utility is

60
00:03:09.400 --> 00:03:12.400
one we always question and the

61
00:03:12.400 --> 00:03:15.100
issue is will this help him improve this quality of

62
00:03:15.100 --> 00:03:19.000
life will this help him improve anything will It

63
00:03:18.200 --> 00:03:21.500
ultimately change the outcome and the

64
00:03:21.500 --> 00:03:24.100
thought is the answer is no to all of these.

65
00:03:25.300 --> 00:03:26.100
the wife responded

66
00:03:26.800 --> 00:03:28.800
what would make you say no to all of those?

67
00:03:30.200 --> 00:03:33.800
Physician said because of right now this quality

68
00:03:33.800 --> 00:03:34.000
of life.

69
00:03:35.300 --> 00:03:35.600
He doesn't.

70
00:03:36.500 --> 00:03:37.600
Have much of one.

71
00:03:38.400 --> 00:03:41.400
My wife responded what do you mean because he's

72
00:03:41.400 --> 00:03:44.000
paralyzed with a brain injury. He doesn't have a

73
00:03:44.500 --> 00:03:44.800
quality of life.

74
00:03:45.900 --> 00:03:47.600
And the physician responded, correct?

75
00:03:50.800 --> 00:03:53.400
After the conversation Michael Hickson was

76
00:03:53.400 --> 00:03:56.200
discharged from the hospital on hospice.

77
00:03:57.400 --> 00:04:00.700
His leading to was discontinued and he passed away on

78
00:04:00.700 --> 00:04:01.700
June 11th.

79
00:04:04.900 --> 00:04:08.200
So there are a few things that are problematic

80
00:04:07.200 --> 00:04:08.900
with this case.

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00:04:09.800 --> 00:04:12.700

And which I want to discuss today in this talk.

82
00:04:12.700 --> 00:04:15.100
I don't want to get into this specifics of

83
00:04:15.100 --> 00:04:18.300
his medical case. I don't begin to know or

84
00:04:18.300 --> 00:04:22.200
understand. What was the right choice for Mr. Hickson's

85
00:04:21.200 --> 00:04:22.300
care?

86
00:04:23.300 --> 00:04:26.600
What I want to focus instead on is what

87
00:04:26.600 --> 00:04:28.100
the physician said to the wife.

88
00:04:28.700 --> 00:04:31.700
He said that because Mr. Hickson could not

89
00:04:31.700 --> 00:04:34.100
walk or talk. He did not have a quality of

90
00:04:34.100 --> 00:04:34.500
life.

91
00:04:35.900 --> 00:04:38.900
And that this affected the treatment decisions The

92
00:04:38.900 --> 00:04:40.700
Physician made for Mr. Hixson.

93
00:04:42.100 --> 00:04:45.800
So it is really here that I want to again spend

94
00:04:45.800 --> 00:04:48.300
the rest of our time together talking through

95
00:04:48.300 --> 00:04:52.500
is assumption about quality of life assumptions

96
00:04:51.500 --> 00:04:55.400
about people with disabilities and potential

97
00:04:54.400 --> 00:04:57.600
disparities experience by individuals

98
00:04:57.600 --> 00:04:58.400
with disabilities.

99
00:05:01.400 --> 00:05:04.100
So before we get to that want to highlight

100
00:05:04.100 --> 00:05:07.600
that there are a range of different populations that

101
00:05:07.600 --> 00:05:10.800
experience disparities. So first one that

102
00:05:10.800 --> 00:05:14.300
we are all familiar with and that is has received

103
00:05:13.300 --> 00:05:17.000
a lot of attention especially lately

104
00:05:16.200 --> 00:05:19.200
is is individuals who

105
00:05:19.200 --> 00:05:22.100
are part of racial ethnic minority populations.

106
00:05:24.100 --> 00:05:27.100
Those who do not speak English here in our

107
00:05:27.100 --> 00:05:31.000
country also in constitute a

108
00:05:30.500 --> 00:05:33.300

disparity population where an individual

109
00:05:33.300 --> 00:05:36.200
lives including if they are live in

110
00:05:36.200 --> 00:05:39.700
a rural area that is also a potential disparity.

111
00:05:40.600 --> 00:05:43.700
A population sexual orientation and gender

112
00:05:43.700 --> 00:05:46.400
identity and then finally disability which

113
00:05:46.400 --> 00:05:49.200
again is what we want to be talking about today.

114
00:05:50.000 --> 00:05:50.200
and

115
00:05:51.400 --> 00:05:54.500
I bring up all these other populations not to say

116
00:05:54.500 --> 00:05:57.400
that they are lesser than or not important to

117
00:05:57.400 --> 00:06:01.100
talk about they are absolutely very important to

118
00:06:00.100 --> 00:06:03.800
talk about. I just want to today focus

119
00:06:03.800 --> 00:06:07.200
on disability and there's a few different reasons why we're

120
00:06:06.200 --> 00:06:09.800
focusing on disability. I'm

121
00:06:09.800 --> 00:06:12.500
not just this talk, but the this Symposium

122
00:06:12.500 --> 00:06:15.400
the range of talks and that's really to highlight

123
00:06:15.400 --> 00:06:18.400
the disability experience it often is

124
00:06:18.400 --> 00:06:21.800
not discussed in terms of disparity populations

125
00:06:21.800 --> 00:06:24.400
as an example. NIH does

126
00:06:24.400 --> 00:06:27.200
not include disability as a disparity population.

127
00:06:28.200 --> 00:06:31.200
As such I believe that more attention needs to

128
00:06:31.200 --> 00:06:34.500
be drawn to disability and their experiences

129
00:06:34.500 --> 00:06:39.200
and I am very grateful to Asha

130
00:06:37.200 --> 00:06:40.400
for allowing us and

131
00:06:40.400 --> 00:06:42.900
nidcd to do this symposium.

132
00:06:46.100 --> 00:06:49.600
I also want to bring up the issue of intersectionality of

133
00:06:49.600 --> 00:06:52.200
disability and racemethnicity because this is a very

134
00:06:52.200 --> 00:06:55.500
important topic and unfortunately, it

135
00:06:55.500 --> 00:06:58.500

is one where we don't have much data and so won't

136
00:06:58.500 --> 00:07:01.200
be spending a whole lot of time talking about but again, I

137
00:07:01.200 --> 00:07:04.500
want to bring our attention to and highlight this

138
00:07:06.800 --> 00:07:09.300
and for example to start

139
00:07:09.300 --> 00:07:13.400
off with it's important to remember that the

140
00:07:12.400 --> 00:07:15.500
experience of those who both

141
00:07:15.500 --> 00:07:18.300
have a disability and might belong to a racial

142
00:07:18.300 --> 00:07:22.900
and ethnic minority population. For example, Michael Hixson

143
00:07:22.900 --> 00:07:25.600
was an influential who was black

144
00:07:25.600 --> 00:07:29.000
and we don't know about his experience after

145
00:07:28.500 --> 00:07:31.500
his amoxic brain injury and

146
00:07:31.500 --> 00:07:34.500
what type of Rehabilitation Services he had

147
00:07:34.500 --> 00:07:37.500
access to that might have affected his

148
00:07:37.500 --> 00:07:40.600
disability and thus his disability

149
00:07:40.600 --> 00:07:41.200
experience.

150
00:07:42.200 --> 00:07:45.200
And on the other side we want to

151
00:07:45.200 --> 00:07:48.300
be careful not to equate race-methnicity with

152
00:07:48.300 --> 00:07:53.000
disability. Unfortunately many individuals in

153
00:07:52.200 --> 00:07:56.300
our country who belong to racial ethnic minority populations

154
00:07:55.300 --> 00:07:59.600
are overrepresented in

155
00:07:59.600 --> 00:08:03.500
some disability diagnoses. So

156
00:08:03.500 --> 00:08:06.300
for example, they might be

157
00:08:06.300 --> 00:08:09.600
more likely children who belong to rational

158
00:08:09.600 --> 00:08:12.600
ethnic minority communities might be more likely to

159
00:08:12.600 --> 00:08:17.100
be labeled as having problematic behavior

160
00:08:16.100 --> 00:08:19.500
and that this reaches

161
00:08:19.500 --> 00:08:23.700
the level of a disability. Whereas perhaps

162
00:08:23.700 --> 00:08:26.400

they're not those some students

163
00:08:26.400 --> 00:08:29.600
who actually have disabilities might be overlooked.

164
00:08:29.600 --> 00:08:34.100
And so we want to make sure that we recognize the

165
00:08:33.100 --> 00:08:36.700
uniqueness and the difference

166
00:08:36.700 --> 00:08:39.000
between race and ethnicity and disability.

167
00:08:42.200 --> 00:08:45.500
I'd like to first start off talking about the medical versus social

168
00:08:45.500 --> 00:08:46.600
model of disability.

169
00:08:47.800 --> 00:08:50.500
First on the medical model which is one. We're all

170
00:08:50.500 --> 00:08:53.700
very familiar with I believe this

171
00:08:53.700 --> 00:08:56.300
is really what is is the

172
00:08:56.300 --> 00:08:58.700
foundation for rehabilitation and

173
00:09:00.300 --> 00:09:04.500
I also have a degree in public health and it's also a core

174
00:09:03.500 --> 00:09:07.300
component of Public Health is that disability

175
00:09:06.300 --> 00:09:09.600
is a part of an individual and so

176
00:09:09.600 --> 00:09:12.900
because of that to the solution

177
00:09:12.900 --> 00:09:15.400
or to address the challenges of a disability

178
00:09:15.400 --> 00:09:19.100
is to fix the individuals. So this means someone who

179
00:09:18.100 --> 00:09:22.200
had a stroke you have difficulty communicating we

180
00:09:21.200 --> 00:09:24.800
will provide them rehabilitation services

181
00:09:24.800 --> 00:09:27.400
to improve their communication abilities.

182
00:09:28.400 --> 00:09:31.500
Or on the public health side is

183
00:09:31.500 --> 00:09:35.200
we Embark in public health campaigns such

184
00:09:34.200 --> 00:09:37.600
as encouraging people to wear

185
00:09:37.600 --> 00:09:41.600
helmets. Well writing a bike to minimize or

186
00:09:41.600 --> 00:09:44.400
avoid brain injuries in

187
00:09:44.400 --> 00:09:47.500
case of a bicycle accident and this is

188
00:09:47.500 --> 00:09:51.500
to again avoid a bicycle accident to avoid

189
00:09:50.500 --> 00:09:53.600

a brain injury to avoid a

190
00:09:53.600 --> 00:09:53.900
disability.

191
00:09:55.700 --> 00:09:58.600
The other side or the other

192
00:09:58.600 --> 00:10:01.400
side of a Continuum is the social model of disability

193
00:10:01.400 --> 00:10:04.200
was which was introduced in their early

194
00:10:04.200 --> 00:10:08.100
1980s and this states that while impairments

195
00:10:07.100 --> 00:10:11.200
are present that disability only

196
00:10:10.200 --> 00:10:13.400
occurs when a society does

197
00:10:13.400 --> 00:10:16.800
not include people regardless of their individual

198
00:10:16.800 --> 00:10:17.500
differences.

199
00:10:18.900 --> 00:10:21.700
So in the social model of disability

200
00:10:21.700 --> 00:10:25.300
if someone has a

201
00:10:24.300 --> 00:10:27.900
disability and is experiencing challenges of

202
00:10:27.900 --> 00:10:30.600
that. We need to look at the environment and

203
00:10:30.600 --> 00:10:34.300
say what in the environment can change so

204
00:10:33.300 --> 00:10:36.600
that we can ensure that this individual

205
00:10:36.600 --> 00:10:40.400
has maximum ability to participate in

206
00:10:39.400 --> 00:10:42.500
their daily lives in school

207
00:10:42.500 --> 00:10:44.100
in work, etc.

208
00:10:47.100 --> 00:10:50.400
And both the medical model and the social model. I would

209
00:10:50.400 --> 00:10:54.300
say it are a part of the Whos

210
00:10:53.300 --> 00:10:56.500
ICF model of disability

211
00:10:56.500 --> 00:10:59.100
and health and this again might be very

212
00:10:59.100 --> 00:11:02.800
familiar to to many of you and this

213
00:11:02.800 --> 00:11:05.600
model states that disability results from

214
00:11:05.600 --> 00:11:08.600
these multiple factors that interact

215
00:11:08.600 --> 00:11:11.800
together and it's not really one simple

216
00:11:11.800 --> 00:11:14.400

thing. And so how I see

217
00:11:14.400 --> 00:11:17.600
both the medical model and the social model in

218
00:11:17.600 --> 00:11:21.200
in this who model

219
00:11:20.200 --> 00:11:23.900
is that the health condition disorder

220
00:11:23.900 --> 00:11:26.500
disease at the top and then on the left, we

221
00:11:26.500 --> 00:11:30.500
have the body functions and structure those represent

222
00:11:29.500 --> 00:11:32.500
the the medical model of again

223
00:11:32.500 --> 00:11:35.300
to address a disability you intervene on

224
00:11:35.300 --> 00:11:38.600
those pieces, whereas the social model focuses

225
00:11:38.600 --> 00:11:41.800
more at the bottom of this model is the environmental

226
00:11:41.800 --> 00:11:44.300
and personal factors. So if someone

227
00:11:44.300 --> 00:11:46.300
who has a communication disability,

228
00:11:47.100 --> 00:11:50.600
Having difficulty obtaining a job.

229
00:11:50.600 --> 00:11:53.100
Well, we need to look at

230
00:11:53.100 --> 00:11:56.800
maybe there are some biases in the

231
00:11:56.800 --> 00:12:00.600
job market and that is an interfering

232
00:12:00.600 --> 00:12:03.400
with them being able to to work. And so

233
00:12:03.400 --> 00:12:07.200
we again need to look at those contextual factors in

234
00:12:06.200 --> 00:12:07.700
address those.

235
00:12:08.600 --> 00:12:11.300
So I bring this all together to say

236
00:12:11.300 --> 00:12:14.400
that neither the medical or the social model is

237
00:12:14.400 --> 00:12:17.400
right and they exist together and they

238
00:12:17.400 --> 00:12:20.000
both are important factors to think about.

239
00:12:24.400 --> 00:12:27.200
I would like to argue that and this really comes more

240
00:12:27.200 --> 00:12:32.000
from a medical model. Is that oftentimes? There

241
00:12:31.200 --> 00:12:35.400
is this underlying belief that disability isn't

242
00:12:34.400 --> 00:12:37.500
inherently unhealthy state

243
00:12:37.500 --> 00:12:40.600

of being and that because disability is

244
00:12:40.600 --> 00:12:43.100
unhealthy this leads to poor health

245
00:12:43.100 --> 00:12:43.800
outcomes.

246
00:12:45.100 --> 00:12:48.800
I would like to argue though. It's much more complicated than that that

247
00:12:48.800 --> 00:12:51.500
it's disability plus social personal and

248
00:12:51.500 --> 00:12:54.400
environmental factors that really lead to

249
00:12:54.400 --> 00:12:57.900
poor health and health outcomes for individuals with disabilities

250
00:12:57.900 --> 00:13:01.200
and the social personal environmental factors.

251
00:13:00.200 --> 00:13:03.200
I've listed just a few

252
00:13:03.200 --> 00:13:06.600
here. So we have decreased access to

253
00:13:06.600 --> 00:13:09.600
exercise opportunities. So for example,

254
00:13:09.600 --> 00:13:14.600
if someone who is deaf has has

255
00:13:12.600 --> 00:13:16.100
challenges running

256
00:13:15.100 --> 00:13:18.900
outside because their

257
00:13:18.900 --> 00:13:21.800
neighborhood doesn't have have sidewalks

258
00:13:21.800 --> 00:13:25.000
and they're worried about not hearing cars

259
00:13:24.100 --> 00:13:28.000
home behind them poor social

260
00:13:27.400 --> 00:13:31.500
support lack of accessible housing low

261
00:13:30.500 --> 00:13:34.000
socioeconomic status

262
00:13:33.100 --> 00:13:37.100
decrease access to employment and

263
00:13:36.100 --> 00:13:39.300
then disparities and quality and access to

264
00:13:39.300 --> 00:13:42.900
health care, which will be spending more time speaking out

265
00:13:42.900 --> 00:13:43.200
today.

266
00:13:44.800 --> 00:13:47.600
So in thinking about the social personal environmental

267
00:13:47.600 --> 00:13:50.300
factors, this looks that I've listed here. This

268
00:13:50.300 --> 00:13:53.400
looks very familiar to a concept that

269
00:13:53.400 --> 00:13:57.000
is very hot and popular right

270
00:13:56.100 --> 00:13:59.800

now, which is social determinants of health. So

271
00:13:59.800 --> 00:14:02.900
social determinants of Health state that there

272
00:14:02.900 --> 00:14:06.400
are these other factors that exist in

273
00:14:06.400 --> 00:14:09.600
a person's environment that

274
00:14:09.600 --> 00:14:12.400
affects their health and Health Care

275
00:14:12.400 --> 00:14:13.200
outcomes.

276
00:14:13.900 --> 00:14:16.200
And a classic example of

277
00:14:16.200 --> 00:14:19.400
this is you know, historically if a

278
00:14:19.400 --> 00:14:23.200
patient let's say has diabetes and they're diabetes is uncontrolled

279
00:14:22.200 --> 00:14:25.200
and they go to the doctor and the doctor

280
00:14:25.200 --> 00:14:28.500
says well, why aren't you eating healthy foods?

281
00:14:28.500 --> 00:14:32.900
Why aren't you exercising and to

282
00:14:32.900 --> 00:14:35.200
to control your

283
00:14:35.200 --> 00:14:39.100
diabetes or why aren't you taking your medication to

284
00:14:39.100 --> 00:14:44.000
control your diabetes? Well, perhaps that individual is

285
00:14:42.100 --> 00:14:45.600
lower income

286
00:14:45.600 --> 00:14:49.000
and can't afford their diabetes medication or cannot

287
00:14:48.400 --> 00:14:51.800
afford fresh fruits and vegetables. Maybe they

288
00:14:51.800 --> 00:14:55.800
live in a neighborhood where it's a

289
00:14:55.800 --> 00:14:58.900
food desert and they don't have access to to

290
00:14:58.900 --> 00:15:01.400
create grocery stores

291
00:15:01.400 --> 00:15:04.600
with again healthy foods. So again,

292
00:15:04.600 --> 00:15:08.200
it's recognizing that to really address

293
00:15:07.200 --> 00:15:10.100
the the health needs of

294
00:15:10.100 --> 00:15:13.000
a population. We need to be looking at

295
00:15:13.900 --> 00:15:16.700
Individuals in a population as and society

296
00:15:16.700 --> 00:15:19.400
as a whole not just looking at the

297
00:15:19.400 --> 00:15:20.700

health and Healthcare System.

298
00:15:22.900 --> 00:15:25.500
And this model that I have listed here

299
00:15:25.500 --> 00:15:28.900
is from healthy people 2020. If

300
00:15:28.900 --> 00:15:31.800
you're not familiar with this healthy people 2020 and

301
00:15:31.800 --> 00:15:35.500
there's healthy people 2010 and 2030

302
00:15:34.500 --> 00:15:37.500
is what we're now on and this

303
00:15:37.500 --> 00:15:40.300
is published by the Department of Health and

304
00:15:40.300 --> 00:15:44.000
Human Services and it sets goals for the upcoming decade

305
00:15:43.700 --> 00:15:46.700
on how to improve health and well-being

306
00:15:46.700 --> 00:15:48.600
for the population.

307
00:15:51.300 --> 00:15:55.200
Again, here's some more examples within

308
00:15:54.200 --> 00:15:57.700
the different categories of social determinants of

309
00:15:57.700 --> 00:16:00.800
health. So we have again economic stability

310
00:16:00.800 --> 00:16:04.400
access to employment housing poverty

311
00:16:03.400 --> 00:16:07.000
education High School

312
00:16:06.600 --> 00:16:09.300
graduation for social and

313
00:16:09.300 --> 00:16:13.800
Community context. We have discrimination incarceration for

314
00:16:12.800 --> 00:16:15.300
the neighborhood and built environment.

315
00:16:15.300 --> 00:16:18.400
We have access to

316
00:16:18.400 --> 00:16:21.300
foods that support healthy eating patterns crime and

317
00:16:21.300 --> 00:16:24.100
violence quality of Housing. And then last we have

318
00:16:24.100 --> 00:16:27.400
health and health care and access to to health

319
00:16:27.400 --> 00:16:30.600
care and access to primary care and we

320
00:16:30.600 --> 00:16:33.800
could spend probably the rest of our time talking

321
00:16:33.800 --> 00:16:36.900
about how individuals with disabilities um,

322
00:16:36.900 --> 00:16:39.400
oftentimes are at

323
00:16:39.400 --> 00:16:43.000
risk for many of these things and many of our these categories.

324
00:16:42.700 --> 00:16:45.700

So again, just I want

325
00:16:45.700 --> 00:16:48.300
us to to remember and keep

326
00:16:48.300 --> 00:16:50.400
this in mind moving forward, but

327
00:16:51.300 --> 00:16:54.400
Again, we cannot talk about all of these things. And

328
00:16:54.400 --> 00:16:57.300
so we'll be focusing on health and health care.

329
00:16:59.300 --> 00:17:02.800
Just a few statistics on individuals with communication disabilities.

330
00:17:02.800 --> 00:17:05.100
And this I'm going to

331
00:17:05.100 --> 00:17:08.500
be focusing on individuals with

332
00:17:08.500 --> 00:17:12.100
speech language in our voice disabilities in

333
00:17:11.100 --> 00:17:14.300
this data comes from what is called the National Health

334
00:17:14.300 --> 00:17:17.100
interview survey or enhance and

335
00:17:17.100 --> 00:17:20.600
his is published or it's a survey that

336
00:17:20.600 --> 00:17:24.900
is administered every single year by by

337
00:17:23.900 --> 00:17:26.600
the government to measure

338
00:17:26.600 --> 00:17:30.100
basic health and access

339
00:17:29.100 --> 00:17:32.400
to healthcare services and use of

340
00:17:32.400 --> 00:17:35.900
Health Care Services. It's a ministered to to individuals

341
00:17:35.900 --> 00:17:38.400
in their homes, and it is

342
00:17:38.400 --> 00:17:40.500
nationally represented.

343
00:17:42.200 --> 00:17:45.900
So in 2012 the and his

344
00:17:45.900 --> 00:17:48.500
actually had a supplement and the

345
00:17:48.500 --> 00:17:51.800
supplement was asking questions about speech

346
00:17:51.800 --> 00:17:54.400
language and voice disabilities. And this was

347
00:17:54.400 --> 00:17:58.100
a gold mine of information for

348
00:17:57.100 --> 00:18:00.300
us because it really gave us

349
00:18:00.300 --> 00:18:05.800
the first look into self-reported communication

350
00:18:04.800 --> 00:18:08.700
disabilities a gave

351
00:18:08.700 --> 00:18:11.600

us a view on who these individuals

352
00:18:11.600 --> 00:18:15.000
are and which I'll go through in a second and in the

353
00:18:14.200 --> 00:18:17.200
upcoming slides. I will show some data

354
00:18:17.200 --> 00:18:18.600
about their health and health care.

355
00:18:19.600 --> 00:18:23.100
So according to enhance and

356
00:18:22.100 --> 00:18:25.300
again the respondents 10% of the

357
00:18:25.300 --> 00:18:28.400
US population has a speech language and/or voice

358
00:18:28.400 --> 00:18:31.300
disability and you can see that there are higher rates

359
00:18:31.300 --> 00:18:35.800
in black and other other races

360
00:18:35.800 --> 00:18:38.900
and including American Indian and Alaska

361
00:18:38.900 --> 00:18:40.500
native populations.

362
00:18:41.200 --> 00:18:45.200
That between 36 and 50% of

363
00:18:44.200 --> 00:18:47.200
individuals communication disabilities are

364
00:18:47.200 --> 00:18:50.600
married. The 36 is individuals with

365
00:18:50.600 --> 00:18:53.500
just voice disabilities and the 50% or

366
00:18:53.500 --> 00:18:57.000
the the larger number is individuals

367
00:18:56.300 --> 00:19:00.300
with multiple communication disabilities. And

368
00:18:59.300 --> 00:19:04.100
this is compared to sorry. I

369
00:19:03.100 --> 00:19:06.600
flipped that the 36 is those

370
00:19:06.600 --> 00:19:09.100
with multiple communication disabilities the 50% is

371
00:19:09.100 --> 00:19:12.400
those with just voice disabilities and this is compared

372
00:19:12.400 --> 00:19:15.700
to individuals without communication disabilities,

373
00:19:15.700 --> 00:19:19.900
which is 54% are married between

374
00:19:18.900 --> 00:19:22.000
36 and 57% are

375
00:19:21.400 --> 00:19:24.600
employed compared to 62% of

376
00:19:24.600 --> 00:19:28.400
individuals who don't have communication disabilities 13

377
00:19:27.400 --> 00:19:31.300
to 25% of

378
00:19:30.300 --> 00:19:33.900

individuals with communication disabilities live

379
00:19:33.900 --> 00:19:36.600
below the federal poverty line, and

380
00:19:36.600 --> 00:19:39.700
this is compared to 13% of those without communication

381
00:19:39.700 --> 00:19:40.300
disabilities.

382
00:19:41.100 --> 00:19:45.600
And then those 24 to

383
00:19:45.600 --> 00:19:49.100
65 percent of individuals with communication disabilities

384
00:19:48.100 --> 00:19:51.700
also have another disability such

385
00:19:51.700 --> 00:19:54.400
as a vision loss or a

386
00:19:54.400 --> 00:19:57.500
Mobility disability or cognitive or a

387
00:19:57.500 --> 00:20:00.700
mental health disability. So again, I

388
00:20:00.700 --> 00:20:03.500
bring that up is I think it's a really

389
00:20:03.500 --> 00:20:06.300
important to remember that individuals who had

390
00:20:06.300 --> 00:20:09.100
communication disabilities who are talking about the disparities. They

391
00:20:09.100 --> 00:20:12.900
experience they might be experiencing it due

392
00:20:12.900 --> 00:20:15.300
to multiple factors related to a range

393
00:20:15.300 --> 00:20:16.600
of disabilities. They might have

394
00:20:19.700 --> 00:20:22.600
I also want to talk about the difference between health and

395
00:20:22.600 --> 00:20:25.600
versus Healthcare disparities Health disparities

396
00:20:25.600 --> 00:20:28.400
are disparities in health outcomes,

397
00:20:28.400 --> 00:20:31.400
which can result from a wide range

398
00:20:31.400 --> 00:20:34.500
of medical social and environmental factors.

399
00:20:35.100 --> 00:20:38.700
On the other hand Healthcare disparities are disparities

400
00:20:38.700 --> 00:20:43.100
in access to high quality health care and Healthcare

401
00:20:41.100 --> 00:20:44.500
disparities can lead

402
00:20:44.500 --> 00:20:47.300
to health disparity. So Health disparities is much

403
00:20:47.300 --> 00:20:50.900
wider and Broad reaching. There's a much

404
00:20:50.900 --> 00:20:53.500
right wider range of factors that contribute to

405
00:20:53.500 --> 00:20:56.200

health disparities as compared to Health

406
00:20:56.200 --> 00:20:57.200
Care disparities.

407
00:20:58.400 --> 00:21:02.200
Um and again for the sake of time we'll be talking today

408
00:21:01.200 --> 00:21:04.000
about Healthcare disparities.

409
00:21:06.100 --> 00:21:09.800
So Amy Kilbourn and colleagues published this model

410
00:21:09.800 --> 00:21:13.000
in American Journal of Public Health back in

411
00:21:13.300 --> 00:21:16.600
2006. And these are the phases of healthcare

412
00:21:16.600 --> 00:21:19.400
disparities research. And I think this is a great model

413
00:21:19.400 --> 00:21:22.000
to think through. So first we have to

414
00:21:22.600 --> 00:21:25.400
detect the the disparities, so we needed

415
00:21:25.400 --> 00:21:28.600
to find the disparity and design our vulnerable

416
00:21:28.600 --> 00:21:29.100
population.

417
00:21:30.100 --> 00:21:34.500
Next we need to understand and identify the determinants that

418
00:21:33.500 --> 00:21:36.800
contribute to the disparities

419
00:21:36.800 --> 00:21:39.600
and then finally our third and final phase is

420
00:21:39.600 --> 00:21:43.500
to reduce the disparity. So we need to intervene and

421
00:21:42.500 --> 00:21:46.100
we need to evaluate interventions and

422
00:21:46.100 --> 00:21:49.400
when you translate into some meat and then work on changing policy.

423
00:21:50.400 --> 00:21:53.200
So I'm going to spend today talking a little

424
00:21:53.200 --> 00:21:56.700
bit about research within each of these three

425
00:21:56.700 --> 00:21:57.800
different domains.

426
00:21:58.700 --> 00:22:01.700
So first detecting so disability and

427
00:22:01.700 --> 00:22:05.100
Healthcare disparities. Those are relatively new but growing

428
00:22:04.100 --> 00:22:05.900
body of literature.

429
00:22:07.400 --> 00:22:10.700
Most of this literature has been in the area of

430
00:22:10.700 --> 00:22:13.600
physical and cognitive disabilities particularly with

431
00:22:13.600 --> 00:22:16.400
women with physical or cognitive disabilities.

432
00:22:17.600 --> 00:22:20.400

Um, multiple Studies have demonstrate that

433
00:22:20.400 --> 00:22:23.400
these individuals have decreased rates of cancer

434
00:22:23.400 --> 00:22:25.800
screenings and prevention conversations.

435
00:22:26.600 --> 00:22:29.300
So you can see there. They have much lower rates and

436
00:22:29.300 --> 00:22:32.400
mammograms much lower rates of receiving and

437
00:22:32.400 --> 00:22:35.100
Pap smear and much less likely to be asked about

438
00:22:35.100 --> 00:22:38.900
contraception those with physical disabilities

439
00:22:38.900 --> 00:22:41.500
are less likely to receive evidence-based treatment

440
00:22:41.500 --> 00:22:44.300
when they are diagnosed with

441
00:22:44.300 --> 00:22:47.600
early stage lung cancer, and there's much

442
00:22:47.600 --> 00:22:50.200
much more research in this area, but I will

443
00:22:50.200 --> 00:22:53.400
move on and talk specifically about

444
00:22:53.400 --> 00:22:56.900
communication disabilities. So patients

445
00:22:56.900 --> 00:22:59.400
with communication disabilities are three times more

446
00:22:59.400 --> 00:23:02.500
likely to experience medical event

447
00:23:02.500 --> 00:23:05.400
when they are hospitalized they have

448
00:23:05.400 --> 00:23:06.500
higher rates of

449
00:23:09.100 --> 00:23:12.600
They sorry they write the satisfaction with the

450
00:23:12.600 --> 00:23:15.700
quality of care lower as compared to those without communication

451
00:23:15.700 --> 00:23:18.500
disabilities and in multiple qualitative

452
00:23:18.500 --> 00:23:22.000
studies. They describe negative experiences interacting with

453
00:23:21.600 --> 00:23:23.000
healthcare providers.

454
00:23:23.800 --> 00:23:26.800
So this is a quote from a man with ALS

455
00:23:26.800 --> 00:23:29.400
who was a part of a research study I conducted.

456
00:23:30.600 --> 00:23:33.400
He was saying he The Physician was only using

457
00:23:33.400 --> 00:23:36.300
the medical data to decide whether to

458
00:23:36.300 --> 00:23:39.400
keep me or not and I was saying send me home send

459
00:23:39.400 --> 00:23:43.000

me home and they wouldn't listen at all and that

460
00:23:42.600 --> 00:23:44.300
was extremely frustrated.

461
00:23:45.400 --> 00:23:48.500
Because of that I will never allow myself an overnight

462
00:23:48.500 --> 00:23:49.500
in the hospital again.

463
00:23:50.400 --> 00:23:53.700
I think it falls down to people my condition are not viewed

464
00:23:53.700 --> 00:23:56.600
as people at the same level as healthy people.

465
00:24:00.100 --> 00:24:03.300
As I mentioned before using the National

466
00:24:03.300 --> 00:24:06.300
Health interview survey some colleagues and

467
00:24:06.300 --> 00:24:06.800
I have published.

468
00:24:08.200 --> 00:24:11.200
Data on the health and Healthcare outcomes of

469
00:24:11.200 --> 00:24:15.200
individuals with communication disabilities. And so I want to share some

470
00:24:14.200 --> 00:24:17.500
of that data here. So just to

471
00:24:17.500 --> 00:24:21.000
orient you on the left. We have no communication disability

472
00:24:20.600 --> 00:24:24.100
and then we have different voice only

473
00:24:23.100 --> 00:24:26.200
then speech language only and

474
00:24:26.200 --> 00:24:29.300
then speech language plus voice disability and you

475
00:24:29.300 --> 00:24:33.400
can see there in the top dark purple

476
00:24:32.400 --> 00:24:35.500
blue is the number

477
00:24:35.500 --> 00:24:39.000
of chronic conditions. So those without communication disabilities

478
00:24:38.500 --> 00:24:41.200
about a quarter of them have two or more

479
00:24:41.200 --> 00:24:45.700
chronic conditions. But if you go to the very right almost

480
00:24:44.700 --> 00:24:47.600
63% of those with

481
00:24:47.600 --> 00:24:50.500
speech language plus voice disability have multiple

482
00:24:50.500 --> 00:24:51.600
chronic conditions.

483
00:24:52.400 --> 00:24:56.700
And The Chronic conditions that we're talking about include hypertension

484
00:24:55.700 --> 00:24:59.100
stroke and emphysema

485
00:24:58.100 --> 00:25:02.000
asthma cancer diabetes arthritis and

486
00:25:01.300 --> 00:25:04.700

you can see really across all of

487
00:25:04.700 --> 00:25:07.900
these chronic conditions that again on

488
00:25:07.900 --> 00:25:10.600
the left is the no communication disabilities

489
00:25:10.600 --> 00:25:13.200
and then it goes all the

490
00:25:13.200 --> 00:25:16.800
way to the right of different levels of communication disabilities and

491
00:25:16.800 --> 00:25:20.500
you can see the star are significantly different

492
00:25:19.500 --> 00:25:22.900
differences again higher

493
00:25:22.900 --> 00:25:26.300
rates of those conditions in

494
00:25:25.300 --> 00:25:28.700
our disabled population. And this

495
00:25:28.700 --> 00:25:31.900
is actually I want to highlight this all of

496
00:25:31.900 --> 00:25:35.400
this data is controlling for other demographic information

497
00:25:34.400 --> 00:25:38.800
such as age race gender

498
00:25:38.800 --> 00:25:41.900
where they live in the country Etc.

499
00:25:44.600 --> 00:25:47.700
Next we have access to healthcare. So the

500
00:25:47.700 --> 00:25:50.500
first two graphs on the left are having a

501
00:25:50.500 --> 00:25:53.400
usual source of care when ill and having a usual

502
00:25:53.400 --> 00:25:56.100
source of care for routine care and you can

503
00:25:56.100 --> 00:25:59.800
see we have very high levels and none of this these results

504
00:25:59.800 --> 00:26:01.400
are statistically significant.

505
00:26:02.200 --> 00:26:05.700
But on the very right we see the category of

506
00:26:05.700 --> 00:26:08.000
trouble finding providers. So, you know, they have

507
00:26:08.100 --> 00:26:11.400
a usual source of care when they go to try to find a

508
00:26:11.400 --> 00:26:14.300
provider. They had more difficulty. So it's between

509
00:26:14.300 --> 00:26:18.100
five and ten percent of individuals

510
00:26:17.100 --> 00:26:20.500
with communication disabilities have trouble finding a

511
00:26:20.500 --> 00:26:23.700
provider who is willing to see them. And again,

512
00:26:23.700 --> 00:26:26.200
this is this is in contrast to

513
00:26:26.200 --> 00:26:28.400

only two and a half percent of the general population.

514
00:26:31.200 --> 00:26:34.500
Next we have unmet means for healthcare. So

515
00:26:34.500 --> 00:26:37.400
we have delayed Medical Care due to

516
00:26:37.400 --> 00:26:40.200
cost on the left. Then we

517
00:26:40.200 --> 00:26:42.400
have forgone medical care due to cost.

518
00:26:43.100 --> 00:26:47.300
Next we have delayed care due to availability and

519
00:26:46.300 --> 00:26:50.000
then on the right we have foregone healthcare

520
00:26:49.300 --> 00:26:53.900
services and this could be prescription medications

521
00:26:52.900 --> 00:26:56.000
or an eye

522
00:26:55.300 --> 00:26:58.200
exam due to cost and

523
00:26:58.200 --> 00:27:02.000
again, you can see individuals with communication disabilities

524
00:27:01.400 --> 00:27:04.500
have much higher rates of

525
00:27:04.500 --> 00:27:05.700
unmet needs.

526
00:27:08.700 --> 00:27:11.100
So that's just a little bit into the area of

527
00:27:12.900 --> 00:27:15.600
Again it detecting the disparity now.

528
00:27:15.600 --> 00:27:18.200
I would like to move and talk

529
00:27:18.200 --> 00:27:21.600
a little bit about understanding the factors or

530
00:27:21.600 --> 00:27:24.700
the determinants that could be contributing or

531
00:27:24.700 --> 00:27:26.100
causing this disparities.

532
00:27:28.400 --> 00:27:31.800
I would like to start with the iom Institute of medicine now known

533
00:27:31.800 --> 00:27:34.900
as National Academy of Medicine, they

534
00:27:34.900 --> 00:27:37.900
published a report title unequal

535
00:27:37.900 --> 00:27:40.800
treatment. And in this report on

536
00:27:40.800 --> 00:27:43.900
unable treatment, they published a disparity model

537
00:27:43.900 --> 00:27:46.700
and I think this is a really important model to

538
00:27:46.700 --> 00:27:50.900
think through. So here you have are non-minority

539
00:27:50.900 --> 00:27:54.400
population in the on

540
00:27:53.400 --> 00:27:56.300

the left and our minority on the right

541
00:27:56.300 --> 00:27:59.300
and this bar graph imagine that

542
00:27:59.300 --> 00:28:02.200
why access being any any outcome that

543
00:28:02.200 --> 00:28:05.100
is important to you. So again, it could be

544
00:28:05.100 --> 00:28:09.300
diabetes. It could be access to speech language

545
00:28:09.300 --> 00:28:13.100
Services following a stroke and so

546
00:28:12.100 --> 00:28:13.500
you can see

547
00:28:14.900 --> 00:28:17.400
There's a difference so the difference between

548
00:28:17.400 --> 00:28:20.100
again the outcome for whatever outcome you

549
00:28:20.100 --> 00:28:23.700
pick between our minority and minority population can

550
00:28:23.700 --> 00:28:26.800
be contributed to three different things. So

551
00:28:26.800 --> 00:28:29.600
first as clinical appropriateness and

552
00:28:29.600 --> 00:28:32.900
need and additionally a

553
00:28:32.900 --> 00:28:33.900
patient preferences.

554
00:28:34.600 --> 00:28:37.300
And then we have the operations of the

555
00:28:37.300 --> 00:28:40.600
Healthcare systems and the legal and Regulatory climate and

556
00:28:40.600 --> 00:28:44.800
then discrimination biases and prejudices stereotyping

557
00:28:43.800 --> 00:28:46.600
and uncertainty. So the

558
00:28:46.600 --> 00:28:49.900
authors of the report say that these two last categories

559
00:28:49.900 --> 00:28:52.600
are what makes up disparities and

560
00:28:52.600 --> 00:28:55.500
that there are sometimes it is appropriate if

561
00:28:55.500 --> 00:28:59.200
a patient has a preference for a different

562
00:28:59.200 --> 00:29:02.300
type of treatment or you know

563
00:29:02.300 --> 00:29:06.300
for going care for

564
00:29:06.300 --> 00:29:09.600
a bit and that is their preference we need

565
00:29:09.600 --> 00:29:12.300
to respect that and that's appropriate but

566
00:29:14.200 --> 00:29:18.300
But I would say oftentimes when we talk about disability when

567
00:29:17.300 --> 00:29:20.700

our populations in

568
00:29:20.700 --> 00:29:23.700
The graft are non-disability and disability. We

569
00:29:23.700 --> 00:29:27.000
often shock that up to clinical appropriateness and

570
00:29:26.400 --> 00:29:30.000
need and patient preferences. But my I

571
00:29:29.400 --> 00:29:33.100
would contend probably clinical appropriateness

572
00:29:32.100 --> 00:29:35.900
and need is the bigger category. And

573
00:29:35.900 --> 00:29:38.200
well absolutely it is

574
00:29:38.200 --> 00:29:42.400
sometimes appropriate for them to to get

575
00:29:41.400 --> 00:29:44.300
a difference in care and they'll have

576
00:29:44.300 --> 00:29:47.400
a difference in outcomes that we haven't spent enough time

577
00:29:47.400 --> 00:29:50.500
talking about these last two categories that really

578
00:29:50.500 --> 00:29:52.300
make up the disparity.

579
00:29:54.800 --> 00:29:57.200
So first talking just for

580
00:29:57.200 --> 00:30:00.700
a second about the operations of the healthcare system and

581
00:30:00.700 --> 00:30:02.700
our legal and Regulatory climate.

582
00:30:03.600 --> 00:30:06.400
So many of you probably are aware of

583
00:30:06.400 --> 00:30:09.800
the Americans with Disabilities acts which was passed in 1990s.

584
00:30:09.800 --> 00:30:12.800
So 30 years ago as a

585
00:30:12.800 --> 00:30:15.800
part of the Ada. They actually state that

586
00:30:15.800 --> 00:30:18.400
Healthcare organizations are required to provide what

587
00:30:18.400 --> 00:30:21.700
they have called effective communication to all

588
00:30:21.700 --> 00:30:23.300
patients with disabilities.

589
00:30:24.200 --> 00:30:28.000
This was then strengthened with Section 1557 of

590
00:30:27.600 --> 00:30:30.700
the Affordable Care Act, which was passed in

591
00:30:30.700 --> 00:30:33.300
2010 that specifically stated that

592
00:30:33.300 --> 00:30:37.100
Healthcare organizations need to provide effective communication

593
00:30:36.100 --> 00:30:40.100
which includes provision of auxiliary AIDS

594
00:30:39.100 --> 00:30:43.200

and services such as hearing assistive

595
00:30:42.200 --> 00:30:46.100
devices. So they specifically call out

596
00:30:45.100 --> 00:30:48.500
as an example hearing assistive devices

597
00:30:48.500 --> 00:30:51.300
like pocket Talkers in in the law.

598
00:30:52.800 --> 00:30:55.600
So despite this mandate. So again, we have it

599
00:30:55.600 --> 00:30:58.700
starting in 1990 and it was reinforced in 2010.

600
00:30:58.700 --> 00:31:01.800
Many Healthcare systems are still not

601
00:31:01.800 --> 00:31:04.600
providing effective communication to

602
00:31:04.600 --> 00:31:06.000
patients with disabilities.

603
00:31:07.100 --> 00:31:10.800
As evidence for this according to the Department of justices

604
00:31:10.800 --> 00:31:14.000
website or the dojs website the most

605
00:31:13.600 --> 00:31:16.300
frequent Ada lawsuit in the

606
00:31:16.300 --> 00:31:19.300
healthcare setting is related to the lack

607
00:31:19.300 --> 00:31:21.100
of providing effective communication.

608
00:31:22.100 --> 00:31:25.300
One of the challenges of the Ada and

609
00:31:25.300 --> 00:31:28.000
perhaps at some argue. One of the

610
00:31:28.300 --> 00:31:31.600
reasons why we have not seen more movements in

611
00:31:31.600 --> 00:31:34.800
hospitals and Health Systems to be more accommodating

612
00:31:34.800 --> 00:31:37.300
to patients with disabilities is that

613
00:31:37.300 --> 00:31:40.400
the Ada is primarily enforced through

614
00:31:40.400 --> 00:31:43.500
patient complaints and lawsuits. So it requires

615
00:31:43.500 --> 00:31:46.700
a patient to have the means

616
00:31:46.700 --> 00:31:49.700
and abilities to file a lawsuit

617
00:31:49.700 --> 00:31:52.700
against their their health system

618
00:31:52.700 --> 00:31:55.600
and against their physician which puts patients in

619
00:31:55.600 --> 00:31:58.600
a very awkward spot and so many say

620
00:31:58.600 --> 00:32:01.400
that because this is our main enforcement strategy

621
00:32:01.400 --> 00:32:04.300

this really weakens the teeth behind the law.

622
00:32:04.900 --> 00:32:07.500
And we have also heard from some

623
00:32:07.500 --> 00:32:10.500
Healthcare Systems who say that it actually is

624
00:32:10.500 --> 00:32:14.100
cheaper to settle they occasional

625
00:32:13.100 --> 00:32:16.400
patient lawsuits, then actually

626
00:32:16.400 --> 00:32:20.300
do work to become systematically accessible

627
00:32:19.300 --> 00:32:23.000
to their patients with disabilities. So

628
00:32:22.300 --> 00:32:26.000
again this new example of both the

629
00:32:25.200 --> 00:32:30.000
legal and Regulatory climate and maybe

630
00:32:29.400 --> 00:32:32.900
the lack thereof of of the regulatory climate

631
00:32:32.900 --> 00:32:35.500
and the operations of

632
00:32:35.500 --> 00:32:40.100
the healthcare system and how this might be impeding of

633
00:32:39.100 --> 00:32:42.500
the access to high quality healthcare

634
00:32:42.500 --> 00:32:45.200
for individuals with communication disabilities.

635
00:32:46.900 --> 00:32:49.900
So the next section of the iom report

636
00:32:49.900 --> 00:32:52.400
was discrimination biases and

637
00:32:52.400 --> 00:32:55.700
Prejudice stereotyping and uncertainty and I

638
00:32:55.700 --> 00:32:58.000
want to induce the term ableism.

639
00:32:58.800 --> 00:33:01.100
I hope that many of you

640
00:33:01.100 --> 00:33:04.200
have heard the term before for those who are not

641
00:33:04.200 --> 00:33:07.200
familiar with ableism. It is just like

642
00:33:07.200 --> 00:33:10.200
the other isms and such as racism in

643
00:33:10.200 --> 00:33:13.500
sexism. It's discrimination and social social

644
00:33:13.500 --> 00:33:17.000
prejudice against persons with disabilities and

645
00:33:16.200 --> 00:33:19.500
it's in favor of those who are able-bodied.

646
00:33:20.300 --> 00:33:22.500
and there there's

647
00:33:23.500 --> 00:33:26.600
Small amount of data on this and again, it's growing and

648
00:33:26.600 --> 00:33:30.000

I'll talk a little bit about this here, but I

649
00:33:29.200 --> 00:33:32.500
will draw your attention to some of the other talks

650
00:33:32.500 --> 00:33:35.800
that are part of the Symposium.

651
00:33:35.800 --> 00:33:39.100
Well when they will dive a little bit deeper into these

652
00:33:38.100 --> 00:33:41.100
this topic, but first,

653
00:33:42.700 --> 00:33:45.700
in a study that I currently lead funded by

654
00:33:45.700 --> 00:33:48.600
nidcd, we are recruiting medical students

655
00:33:48.600 --> 00:33:52.100
and we've given them the disability implicit

656
00:33:51.100 --> 00:33:54.400
association test, which is through the

657
00:33:55.900 --> 00:33:58.100
Through Harvard and anyone can go

658
00:33:58.100 --> 00:34:01.600
online and take this test but we have have medical

659
00:34:01.600 --> 00:34:04.400
students take this test and have found that

660
00:34:04.400 --> 00:34:07.400
at 85% of the medical students who

661
00:34:07.400 --> 00:34:11.100
have completed the disability IIT. I

662
00:34:10.100 --> 00:34:13.900
have a preference for able-bodied individuals and

663
00:34:13.900 --> 00:34:17.800
this isn't actually a higher preference than the

664
00:34:16.800 --> 00:34:19.200
statistics in the

665
00:34:19.200 --> 00:34:20.000
general population.

666
00:34:21.700 --> 00:34:25.000
Recently, Dr. Lisa isoni

667
00:34:24.100 --> 00:34:27.200
and colleagues published a survey of

668
00:34:27.200 --> 00:34:30.600
a national survey of Physicians. It was

669
00:34:30.600 --> 00:34:33.500
just published this last March in the journal

670
00:34:33.500 --> 00:34:37.300
Health Affairs and they found that the Physicians

671
00:34:36.300 --> 00:34:39.400
reported that only 50

672
00:34:39.400 --> 00:34:42.600
7% reported strongly

673
00:34:42.600 --> 00:34:45.500
welcoming patients with disabilities into

674
00:34:45.500 --> 00:34:49.000
their practice. So that's means over 40%

675
00:34:48.900 --> 00:34:51.500

said that they did not

676
00:34:51.500 --> 00:34:54.000
strongly welcome patients with disabilities.

677
00:34:55.300 --> 00:34:58.400
Only 41% reported feeling very confident about

678
00:34:58.400 --> 00:35:02.000
providing the same quality of care for people with

679
00:35:01.000 --> 00:35:02.700
disabilities.

680
00:35:03.900 --> 00:35:07.200
And then last 82% right

681
00:35:06.200 --> 00:35:09.500
the quality of life for persons with significant

682
00:35:09.500 --> 00:35:12.900
disabilities as worse than those without disability.

683
00:35:13.800 --> 00:35:16.200
And this the last statistic here,

684
00:35:16.200 --> 00:35:20.000
this last rate is really important research has

685
00:35:19.300 --> 00:35:22.400
shown that actually you give quality

686
00:35:22.400 --> 00:35:25.600
of life measures to individuals with disabilities. They actually

687
00:35:25.600 --> 00:35:28.300
report very similar levels of quality of life

688
00:35:28.300 --> 00:35:31.600
as people without disabilities and some have

689
00:35:31.600 --> 00:35:33.500
debt this the disability paradox.

690
00:35:34.200 --> 00:35:37.700
so it's quite problematic if there is a discrepancy between

691
00:35:37.700 --> 00:35:40.400
how a patient rates their

692
00:35:40.400 --> 00:35:43.500
quality of life and how a provider who's making

693
00:35:43.500 --> 00:35:46.900
medical decisions rates the quality of life of that

694
00:35:46.900 --> 00:35:49.300
individual as you saw in the case

695
00:35:49.300 --> 00:35:53.900
at the beginning of this talk that perceptions of

696
00:35:53.900 --> 00:35:56.600
quality of life can enter into and

697
00:35:56.600 --> 00:35:59.500
decisions that that Healthcare Providers make

698
00:36:02.500 --> 00:36:05.300
now I'm going to move on to the third and

699
00:36:05.300 --> 00:36:10.000
final area which is reducing intervening evaluating

700
00:36:09.800 --> 00:36:11.700
translating and changing.

701
00:36:13.500 --> 00:36:17.100
So unfortunately, we don't actually have much data

702
00:36:16.100 --> 00:36:19.600

or studies in this final

703
00:36:19.600 --> 00:36:21.800
area. We're still very

704
00:36:23.600 --> 00:36:27.200
Junior, or young in this this area and as

705
00:36:26.200 --> 00:36:29.900
a demonstration of this colleagues and

706
00:36:29.900 --> 00:36:32.900
I recently did a scoping review of disability

707
00:36:32.900 --> 00:36:35.600
Health Care disparities. So we looked for

708
00:36:35.600 --> 00:36:38.300
all types of studies in in medical

709
00:36:38.300 --> 00:36:42.200
journals published and around disability and

710
00:36:41.200 --> 00:36:44.700
Healthcare disparities published. We

711
00:36:44.700 --> 00:36:48.200
started in 1990 and went through 2019. So

712
00:36:47.200 --> 00:36:50.400
you can see there is an absolute

713
00:36:50.400 --> 00:36:53.200
Trend up over the years of published articles.

714
00:36:54.300 --> 00:36:57.600
We took all of those articles those 190 and

715
00:36:57.600 --> 00:37:01.200
we actually categorized those into our three areas that

716
00:37:00.200 --> 00:37:03.800
we've been discussing so detecting understanding

717
00:37:03.800 --> 00:37:07.400
and intervening or reducing. So 50%

718
00:37:06.400 --> 00:37:09.600
of the Articles identified. We

719
00:37:09.600 --> 00:37:13.100
categorized in the phase of detecting or defining

720
00:37:12.100 --> 00:37:14.300
that disparity.

721
00:37:15.500 --> 00:37:18.700
41% of the studies fell into

722
00:37:18.700 --> 00:37:22.000
the category of understanding and understanding the

723
00:37:21.400 --> 00:37:25.100
factors that contribute to those disparities and

724
00:37:24.100 --> 00:37:28.000
then finally nine percent of the studies

725
00:37:27.400 --> 00:37:30.500
were intervention studies. So

726
00:37:30.500 --> 00:37:34.700
this equaled out to 18 Interventional

727
00:37:33.700 --> 00:37:35.600
studies and

728
00:37:36.800 --> 00:37:39.200
one piece that was interesting and

729
00:37:39.200 --> 00:37:43.000

important to note that of these 18 Interventional studies

730
00:37:42.700 --> 00:37:45.900
14 were medical education.

731
00:37:45.900 --> 00:37:47.000
So focused on

732
00:37:48.200 --> 00:37:51.700
On intervening and in improving the

733
00:37:51.700 --> 00:37:54.400
the knowledge and attitudes of

734
00:37:54.400 --> 00:37:58.300
medical students towards individuals with disabilities. So that

735
00:37:58.300 --> 00:38:01.800
really leaves us with only four published studies

736
00:38:01.800 --> 00:38:06.200
that address are aimed

737
00:38:05.200 --> 00:38:08.500
at reducing the spirits in healthcare experience

738
00:38:08.500 --> 00:38:11.300
by people with all types of disabilities. This

739
00:38:11.300 --> 00:38:14.100
is not specific to communication disabilities. This is

740
00:38:14.100 --> 00:38:17.700
all disabilities, which again is about 25% of

741
00:38:17.700 --> 00:38:20.700
the US population who is experienced disparities,

742
00:38:20.700 --> 00:38:25.000
but we only have four published studies about interventions.

743
00:38:23.400 --> 00:38:27.000
So again, this

744
00:38:26.100 --> 00:38:29.200
is to demonstrate there's a lot of work to be

745
00:38:29.200 --> 00:38:33.100
done. I want to give an example of something

746
00:38:32.100 --> 00:38:35.300
myself and colleagues have been

747
00:38:35.300 --> 00:38:38.700
working on to to address this

748
00:38:38.700 --> 00:38:42.400
Gap and start moving this area forward and

749
00:38:41.400 --> 00:38:44.700
it is an example of how

750
00:38:44.700 --> 00:38:47.900
as researchers I've partnered with

751
00:38:48.200 --> 00:38:51.500
Different policy makers and those who are also in

752
00:38:51.500 --> 00:38:51.800
practice.

753
00:38:53.700 --> 00:38:56.500
So I'll start by telling the story

754
00:38:56.500 --> 00:38:56.600
of

755
00:38:58.700 --> 00:39:01.900
Of some of my research so about a

756
00:39:01.900 --> 00:39:04.500

decade ago a little less than a decade ago. I started

757
00:39:04.500 --> 00:39:07.900
thinking about documenting disability status in

758
00:39:07.900 --> 00:39:10.100
the electronic health record. I became

759
00:39:10.100 --> 00:39:13.900
interested in this because I was interested in studying at

760
00:39:13.900 --> 00:39:16.800
an organization level the quality of care delivered

761
00:39:16.800 --> 00:39:19.800
to patients with communication disabilities. But

762
00:39:19.800 --> 00:39:22.400
what I found was that there was no good way

763
00:39:22.400 --> 00:39:25.700
of identifying patients with communication disabilities.

764
00:39:25.700 --> 00:39:28.400
So that really led me to start talking about

765
00:39:28.400 --> 00:39:31.300
documenting disability status. So I started

766
00:39:32.400 --> 00:39:35.500
writing about it. I received some grants started publishing

767
00:39:35.500 --> 00:39:39.300
on the topic and then I started receiving calls

768
00:39:38.300 --> 00:39:41.300
from different Health Systems

769
00:39:41.300 --> 00:39:43.800
across the country who were interested in

770
00:39:45.100 --> 00:39:48.500
In implementing collection of disability status in

771
00:39:48.500 --> 00:39:51.100
their electronic health record and wanted to

772
00:39:51.100 --> 00:39:54.400
chat with me get my advice and get my

773
00:39:54.400 --> 00:39:57.100
thoughts on what they are working on and what was

774
00:39:57.100 --> 00:40:00.700
interesting about those calls was that who I

775
00:40:00.700 --> 00:40:03.200
was talking to so many of the people who

776
00:40:03.200 --> 00:40:06.500
was talking to we're new in

777
00:40:06.500 --> 00:40:09.400
their position. And what was also going

778
00:40:09.400 --> 00:40:12.800
on at a similar time was the

779
00:40:12.800 --> 00:40:15.400
ACA was was passed the horrible

780
00:40:15.400 --> 00:40:19.500
year and again going back to section 1557 it

781
00:40:18.500 --> 00:40:21.400
prohibits Healthcare organizations from

782
00:40:21.400 --> 00:40:24.300
discriminating against patients based off

783
00:40:24.300 --> 00:40:27.500

on race color national origin sex age or

784
00:40:27.500 --> 00:40:30.300
disability and it's specifically states that

785
00:40:30.300 --> 00:40:34.100
organizations with 15 or more employees. They're

786
00:40:33.100 --> 00:40:36.500
required to designate an employee to leave these

787
00:40:36.500 --> 00:40:36.900
efforts.

788
00:40:37.200 --> 00:40:41.100
So what was happening is health systems were beginning

789
00:40:40.100 --> 00:40:44.000
to hire individuals who

790
00:40:43.400 --> 00:40:48.300
were in charge of overseeing section

791
00:40:47.300 --> 00:40:50.300
1557 for the organization

792
00:40:50.300 --> 00:40:54.700
and making sure that persons all

793
00:40:53.700 --> 00:40:56.500
persons weren't discriminated against and

794
00:40:56.500 --> 00:40:59.200
many of the people I was I was speaking

795
00:40:59.200 --> 00:41:02.800
with were really focused on disability, but often

796
00:41:02.800 --> 00:41:05.200
they were at the new person in their in their role

797
00:41:05.200 --> 00:41:08.300
and I would say the other

798
00:41:08.300 --> 00:41:12.400
piece that was I think prompting organizations

799
00:41:11.400 --> 00:41:14.500
to hire these individuals was that

800
00:41:14.500 --> 00:41:19.300
there was an epic in patient lawsuits according

801
00:41:17.300 --> 00:41:20.800
to the Ada

802
00:41:20.800 --> 00:41:23.200
again and violations of

803
00:41:23.200 --> 00:41:27.200
the Ada in healthcare setting and so organizations

804
00:41:26.200 --> 00:41:29.600
were hiring these individuals and they were

805
00:41:29.600 --> 00:41:32.300
saying here's your desk. Make sure

806
00:41:32.300 --> 00:41:35.900
we don't get sued and make sure we're following federal law,

807
00:41:35.900 --> 00:41:37.000
but they didn't quite

808
00:41:37.200 --> 00:41:38.600
know what to do in their roles

809
00:41:39.400 --> 00:41:43.200
somewhere further ahead than others and unfortunately

810
00:41:42.200 --> 00:41:46.100

many of these conversations that the

811
00:41:45.100 --> 00:41:49.100
individuals would Express their

812
00:41:48.100 --> 00:41:51.900
frustration and how they felt alone. And

813
00:41:51.900 --> 00:41:55.700
so what I decided in and we

814
00:41:54.700 --> 00:41:58.300
started in May 2018 is

815
00:41:57.300 --> 00:42:00.100
to actually get these individuals together.

816
00:42:01.500 --> 00:42:04.500
They would ask me. Well, what's the evidence? What's the research to help

817
00:42:04.500 --> 00:42:07.200
me and I would say unfortunately, we're just

818
00:42:07.200 --> 00:42:10.400
early and we don't know a whole lot of research yet to

819
00:42:10.400 --> 00:42:14.200
tell you exactly how to do your job how to make sure Health

820
00:42:13.200 --> 00:42:16.500
Care is accessible. But let's get everyone together

821
00:42:16.500 --> 00:42:19.400
and put our minds together and share strategies

822
00:42:19.400 --> 00:42:22.500
share our challenges with each other give each

823
00:42:22.500 --> 00:42:25.700
other advice and then also share in our successes. So we

824
00:42:25.700 --> 00:42:28.400
started meeting and we started slowly growing

825
00:42:28.400 --> 00:42:31.700
and then in January of 2019.

826
00:42:31.700 --> 00:42:34.600
I received a from before

827
00:42:34.600 --> 00:42:37.600
the patient center outcomes Research Institute and engagement

828
00:42:37.600 --> 00:42:40.100
award and this allowed me to do a few things

829
00:42:40.100 --> 00:42:43.500
one is to formalize the group. It also

830
00:42:43.500 --> 00:42:46.800
allowed me to do key stakeholder interviews

831
00:42:46.800 --> 00:42:49.300
with 55 individuals. And

832
00:42:49.300 --> 00:42:53.400
the point of these interviews was to identify the research

833
00:42:52.400 --> 00:42:56.100
priorities for

834
00:42:55.100 --> 00:42:58.400
advancing disability equity and

835
00:42:58.400 --> 00:43:00.500
it was the stakeholders. I talked to

836
00:43:01.900 --> 00:43:05.700
range from Advocates to researchers to policymakers

837
00:43:04.700 --> 00:43:08.900

to to professional

838
00:43:07.900 --> 00:43:10.600
societies to health

839
00:43:10.600 --> 00:43:13.700
insurance organizations Etc. And then

840
00:43:13.700 --> 00:43:16.400
we also can mean a meeting of stakeholders in the fall of

841
00:43:16.400 --> 00:43:17.200
2020.

842
00:43:18.200 --> 00:43:22.000
So I'm going to go through a subset of our interviews. We're

843
00:43:21.100 --> 00:43:24.300
with these disability accessory coordinators.

844
00:43:24.300 --> 00:43:26.900
So people who worked within Healthcare organizations.

845
00:43:28.600 --> 00:43:31.700
And of our 55 interviews 21 of

846
00:43:31.700 --> 00:43:34.500
them were these individuals with with these

847
00:43:34.500 --> 00:43:35.200
dacs.

848
00:43:35.900 --> 00:43:39.300
They represent an 18 different community

849
00:43:38.300 --> 00:43:41.600
and academic Healthcare organizations or

850
00:43:41.600 --> 00:43:45.200
hospitals across the United States and Healthcare

851
00:43:44.200 --> 00:43:47.200
organizations ranged in size. And

852
00:43:47.200 --> 00:43:50.800
we're again geographically dice

853
00:43:50.800 --> 00:43:54.300
dispersed overall. They

854
00:43:53.300 --> 00:43:55.400
the

855
00:43:56.700 --> 00:43:59.900
these individuals represented over

856
00:43:59.900 --> 00:44:02.600
200 hospitals and again our

857
00:44:02.600 --> 00:44:05.800
organization range from just having one hospital to active 40

858
00:44:05.800 --> 00:44:06.200
hospitals.

859
00:44:08.500 --> 00:44:11.700
One of the things we found whereas that many of them had very

860
00:44:11.700 --> 00:44:14.500
different job titles. And so we

861
00:44:14.500 --> 00:44:17.400
started writing down the job titles. So we

862
00:44:17.400 --> 00:44:20.400
have section 504 coordinator, which

863
00:44:20.400 --> 00:44:23.400
is relates to the rehab act. You see

864
00:44:23.400 --> 00:44:26.200

their section and 1557 coordinator and then

865
00:44:26.200 --> 00:44:30.000
the ADA compliance manager and ago

866
00:44:29.300 --> 00:44:32.800
it goes on and on we have a patient

867
00:44:32.800 --> 00:44:36.400
advocate. We have geriatric Services director. We

868
00:44:35.400 --> 00:44:39.000
have language access program manager. We

869
00:44:38.100 --> 00:44:41.400
have interpreter services coordinator. So again,

870
00:44:41.400 --> 00:44:44.500
they had a wide range of titles. I will

871
00:44:44.500 --> 00:44:47.400
say that it was common for

872
00:44:47.400 --> 00:44:50.800
these individuals to have a background in occupational therapy.

873
00:44:50.800 --> 00:44:54.200
We did have a few people who actually had

874
00:44:53.200 --> 00:44:56.600
a background in and we're previously

875
00:44:56.600 --> 00:44:58.300
speech language pathologist.

876
00:45:01.200 --> 00:45:04.500
Almost all of the participants. We talked to you were the first person in

877
00:45:04.500 --> 00:45:07.800
a position and been in their position between six months to

878
00:45:07.800 --> 00:45:10.400
nine years again many reported that

879
00:45:10.400 --> 00:45:13.400
their position began as a result of a patient

880
00:45:13.400 --> 00:45:16.400
lawsuit or a doj or Department of Justice

881
00:45:16.400 --> 00:45:19.700
and consent decree and then some Heather

882
00:45:19.700 --> 00:45:23.100
position as a result of again section 1557 of

883
00:45:22.100 --> 00:45:24.200
the portable Care Act.

884
00:45:25.800 --> 00:45:28.500
The mission of their position was

885
00:45:28.500 --> 00:45:31.800
they stated was to meet the requirements and remain

886
00:45:31.800 --> 00:45:34.800
compliant with the laws and regulation, but

887
00:45:34.800 --> 00:45:37.500
they also talked about having a mission of

888
00:45:37.500 --> 00:45:40.700
creating a culture focused on equal access to healthcare

889
00:45:40.700 --> 00:45:41.900
for people with disabilities.

890
00:45:42.800 --> 00:45:46.200
What I have identified as a researcher, I have

891
00:45:45.200 --> 00:45:48.500

really enjoyed working

892
00:45:48.500 --> 00:45:51.000
with these individuals because they're the people

893
00:45:51.300 --> 00:45:54.300
who are on the front lines who

894
00:45:54.300 --> 00:45:57.800
are implementing initiatives to ensure equal

895
00:45:57.800 --> 00:45:58.200
care.

896
00:46:00.400 --> 00:46:03.400
Some individuals their positions were abroad and

897
00:46:03.400 --> 00:46:06.500
focused on all disparities and all populations. So

898
00:46:06.500 --> 00:46:09.100
rice and ethnicity sexual orientation and gender

899
00:46:09.100 --> 00:46:12.400
identity and disability. But some are very focused

900
00:46:12.400 --> 00:46:15.600
on specific initiatives like interpretive Services.

901
00:46:15.600 --> 00:46:18.400
We actually had it interesting number of

902
00:46:18.400 --> 00:46:21.600
individuals who started off as the

903
00:46:21.600 --> 00:46:24.300
Director of ASL interpreting for

904
00:46:24.300 --> 00:46:28.400
their hospital or their home system and be because

905
00:46:27.400 --> 00:46:30.100
they said oh

906
00:46:30.100 --> 00:46:33.100
you're you know ASL you work with people who are

907
00:46:33.100 --> 00:46:36.500
deaf and hard here, you know death and and so

908
00:46:36.500 --> 00:46:39.900
because of that, you know, all things disability. And

909
00:46:39.900 --> 00:46:42.200
so you're now in charge of all things disability for

910
00:46:42.200 --> 00:46:45.800
your organization. And so those individuals who again

911
00:46:45.800 --> 00:46:48.500
might be very immersed in

912
00:46:48.500 --> 00:46:52.500
the Deaf culture and and ASL

913
00:46:51.500 --> 00:46:54.700
they might not be as familiar

914
00:46:54.700 --> 00:46:57.100
with the broader disability community and so

915
00:46:57.100 --> 00:46:59.500
have had to educate themselves on how to

916
00:47:00.900 --> 00:47:02.100
now do their new role.

917
00:47:03.900 --> 00:47:06.900
Their activities within their position range from

918
00:47:06.900 --> 00:47:09.200

developing and implementing policies and procedures

919
00:47:09.200 --> 00:47:12.500
responding to Patient requests and complaints and

920
00:47:12.500 --> 00:47:16.200
they did trainings and they again ensure

921
00:47:15.200 --> 00:47:18.900
that their organization was compliant with legal and

922
00:47:18.900 --> 00:47:20.400
requirements.

923
00:47:21.600 --> 00:47:24.700
The initiatives that they worked on fell into

924
00:47:24.700 --> 00:47:27.500
these seven different categories. So

925
00:47:27.500 --> 00:47:30.300
first you see there was documenting disability status.

926
00:47:31.300 --> 00:47:34.800
Next is training and then you see effective communication.

927
00:47:34.800 --> 00:47:38.100
This is a very hot and popular topic

928
00:47:37.100 --> 00:47:40.400
is is effective communication and

929
00:47:40.400 --> 00:47:43.300
different accommodations and supports they can

930
00:47:43.300 --> 00:47:47.600
provide patients. So they talked about building and implementing

931
00:47:46.600 --> 00:47:49.900
affected communication toolkits to

932
00:47:49.900 --> 00:47:52.700
their outpatient clinics and inpatient units and

933
00:47:52.700 --> 00:47:54.300
then also sensory toolkits.

934
00:47:55.900 --> 00:48:00.100
Then we have accessible medical equipment because facilities

935
00:47:58.100 --> 00:48:01.500
and physical access

936
00:48:01.500 --> 00:48:05.700
service animals as a very interesting topic

937
00:48:05.700 --> 00:48:08.900
and then finally electronic materials or

938
00:48:08.900 --> 00:48:10.000
website and patient portal.

939
00:48:13.100 --> 00:48:16.500
So that is a little bit of a description of again

940
00:48:16.500 --> 00:48:19.100
what we heard from individuals who are

941
00:48:19.100 --> 00:48:22.700
boots on the ground working on disability Equity initiatives

942
00:48:22.700 --> 00:48:26.900
in hospitals and Healthcare organizations. So again,

943
00:48:25.900 --> 00:48:28.600
as I said, we started in 2018

944
00:48:28.600 --> 00:48:32.300
we have now formalized ourselves we meet

945
00:48:39.300 --> 00:48:44.400

If sorry

946
00:48:42.400 --> 00:48:46.200
my zoom decided

947
00:48:45.200 --> 00:48:48.400
to restart itself, and so there was

948
00:48:48.400 --> 00:48:49.500
a pause in our recording.

949
00:48:51.700 --> 00:48:54.600
All right. Sorry about that. Um,

950
00:48:54.600 --> 00:48:58.200
so we meet every other week via

951
00:48:57.200 --> 00:49:00.100
zoom on Friday and it's a safe space

952
00:49:00.100 --> 00:49:03.900
in which participants can exchange ideas share solutions

953
00:49:03.900 --> 00:49:06.600
to problems and we Champion their

954
00:49:06.600 --> 00:49:11.400
successes. We do invite subject matter experts as

955
00:49:10.400 --> 00:49:13.300
guest speakers to that. And so

956
00:49:13.300 --> 00:49:16.300
we've grown we have 40 to

957
00:49:16.300 --> 00:49:19.700
50 members and who again represent Health

958
00:49:19.700 --> 00:49:20.800
Systems across the country.

959
00:49:22.200 --> 00:49:25.500
We also have an online platform for them in which they're able

960
00:49:25.500 --> 00:49:29.300
to engage in real time discussions and also share a

961
00:49:28.300 --> 00:49:30.900
variety of resources with each other.

962
00:49:33.300 --> 00:49:37.200
As I said the the other part of the the

963
00:49:36.200 --> 00:49:39.600
grant the award

964
00:49:39.600 --> 00:49:43.000
we received from bakori was to host a

965
00:49:42.200 --> 00:49:46.500
meeting which was the disability Equity collaborative Summit

966
00:49:45.500 --> 00:49:48.500
is what we call it. And

967
00:49:48.500 --> 00:49:51.400
this the goal of this Summit was to identify a practice

968
00:49:51.400 --> 00:49:54.600
policy and research priorities for advancing equity

969
00:49:54.600 --> 00:49:58.000
and care for people with all types of disabilities. This

970
00:49:57.500 --> 00:50:00.800
occurred in Fall of 2020 was virtual

971
00:50:00.800 --> 00:50:04.000
over to half day sessions and we

972
00:50:03.600 --> 00:50:07.000

started inviting people and just groom to

973
00:50:06.900 --> 00:50:09.100
over 80 participants.

974
00:50:11.100 --> 00:50:15.300
And and these 80

975
00:50:14.300 --> 00:50:17.400
participants represented people from

976
00:50:17.400 --> 00:50:21.800
who are displayed coordinators Advocates researchers

977
00:50:20.800 --> 00:50:23.900
policymakers people from

978
00:50:23.900 --> 00:50:26.300
industry cares Etc.

979
00:50:27.300 --> 00:50:30.600
And the format is we had presentations and

980
00:50:30.600 --> 00:50:33.100
these were based off of again our interviews with

981
00:50:33.100 --> 00:50:36.100
our 55 different key stakeholders. And then we

982
00:50:36.100 --> 00:50:40.200
had breakout groups for people to have some smaller

983
00:50:39.200 --> 00:50:41.000
group discussions.

984
00:50:43.600 --> 00:50:46.200
So in these discussions, we were really

985
00:50:46.200 --> 00:50:49.600
focused on being tangible and focusing on

986
00:50:49.600 --> 00:50:52.600
Solutions and concrete steps. And

987
00:50:52.600 --> 00:50:55.900
so I'm happy to report that we have taken

988
00:50:55.900 --> 00:50:58.100
some of those initial steps that

989
00:50:58.100 --> 00:51:01.300
we're discussed in that in that meeting almost a

990
00:51:01.300 --> 00:51:04.100
year ago. And so we have developed a website. So this

991
00:51:04.100 --> 00:51:06.800
is our disability Equity collaborative website.

992
00:51:07.500 --> 00:51:10.500
So I'll highlight a few pieces here.

993
00:51:10.500 --> 00:51:13.700
So first we have in the middle our Healthcare

994
00:51:13.700 --> 00:51:16.500
resources. So this and

995
00:51:16.500 --> 00:51:19.800
I encourage you to check this out. If you're interested, we have

996
00:51:19.800 --> 00:51:22.700
collated information from

997
00:51:22.700 --> 00:51:25.600
a wide variety of sources across the

998
00:51:25.600 --> 00:51:28.800
internet from our federal Partners CMS

999
00:51:28.800 --> 00:51:31.700

to different advocacy organizations and put

1000
00:51:31.700 --> 00:51:34.900
together an organized library of resources on

1001
00:51:34.900 --> 00:51:37.400
for Healthcare systems on how

1002
00:51:37.400 --> 00:51:40.200
to be accessible to patients again with a range

1003
00:51:40.200 --> 00:51:43.200
of disabilities. Next. You can see to the right of that

1004
00:51:43.200 --> 00:51:46.400
we have research so we have what our current

1005
00:51:46.400 --> 00:51:49.800
research projects that are going on in research opportunities and

1006
00:51:49.800 --> 00:51:51.000
also publish results.

1007
00:51:51.800 --> 00:51:54.100
And then I also want to highlight the our work

1008
00:51:54.100 --> 00:51:57.700
group Tab. And so we have four work groups.

1009
00:51:57.700 --> 00:52:02.300
One is our our what we call our disability leaders

1010
00:52:00.300 --> 00:52:03.300
our Healthcare leaders. And

1011
00:52:03.300 --> 00:52:06.300
this is again, the there are disability accessibility

1012
00:52:06.300 --> 00:52:09.200
coordinators who meet every other Friday and then

1013
00:52:09.200 --> 00:52:12.400
we have a few other work groups

1014
00:52:12.400 --> 00:52:15.400
that we are just in the beginning stages of

1015
00:52:15.400 --> 00:52:18.500
launching. So our first one that's most developed is our

1016
00:52:18.500 --> 00:52:21.600
our documentation work Group

1017
00:52:21.600 --> 00:52:24.500
which is documenting disability status and we're

1018
00:52:24.500 --> 00:52:27.600
Focus right now in the electronic health record. We

1019
00:52:27.600 --> 00:52:32.400
have partnered with different emrs

1020
00:52:30.400 --> 00:52:33.900
including epic and

1021
00:52:33.900 --> 00:52:37.000
have worked done some

1022
00:52:36.100 --> 00:52:39.300
work together to really narrow down

1023
00:52:39.300 --> 00:52:42.100
what ours some of the priorities in that

1024
00:52:42.100 --> 00:52:45.400
area. Then we also have our research work group

1025
00:52:45.400 --> 00:52:48.400
and then we have finally our

1026
00:52:48.400 --> 00:52:51.200

standards and guidelines work group. So the goal of

1027
00:52:51.200 --> 00:52:51.700
that group.

1028
00:52:51.800 --> 00:52:54.800
Is to develop some guidelines

1029
00:52:54.800 --> 00:52:57.600
but also implementation guides for

1030
00:52:57.600 --> 00:53:00.100
health system. So if someone's new to an

1031
00:53:00.100 --> 00:53:03.700
organization or they're smaller organization who is

1032
00:53:03.700 --> 00:53:06.900
interested in in getting started with being

1033
00:53:06.900 --> 00:53:10.400
accessible and launching accessibility initiatives.

1034
00:53:09.400 --> 00:53:12.400
Where where do they start and what

1035
00:53:12.400 --> 00:53:15.500
are and how do we actually make these

1036
00:53:15.500 --> 00:53:17.900
initiatives make these policies happen?

1037
00:53:21.200 --> 00:53:24.800
So I'd like to end today with just going over a few

1038
00:53:24.800 --> 00:53:27.800
of the research priorities that were identified by

1039
00:53:27.800 --> 00:53:30.100
by both our

1040
00:53:30.100 --> 00:53:33.900
key informants stakeholder interviews, but also in our

1041
00:53:33.900 --> 00:53:37.300
our meeting of 80 80 and

1042
00:53:36.300 --> 00:53:39.400
visuals at this Summit. So the first

1043
00:53:39.400 --> 00:53:42.600
one is recognizing disability as a disparity population.

1044
00:53:43.500 --> 00:53:46.300
As I mentioned at the beginning disability is not

1045
00:53:46.300 --> 00:53:49.500
at NIH designated disparity populations. So

1046
00:53:49.500 --> 00:53:52.900
if you submit a grant and focused on a disparities

1047
00:53:52.900 --> 00:53:55.400
and you submit it to for example National Health

1048
00:53:56.500 --> 00:53:59.300
and the institute for minority health and health

1049
00:53:59.300 --> 00:54:02.800
disparities. They would reject your your application

1050
00:54:02.800 --> 00:54:04.700
if it was only focused on disability.

1051
00:54:05.500 --> 00:54:08.600
Other different federal agencies do

1052
00:54:08.600 --> 00:54:12.300
include disability as a disparity population, which is encouraging and

1053
00:54:11.300 --> 00:54:14.500

then also disability is often excluded

1054
00:54:14.500 --> 00:54:17.900
from diversity Equity inclusion conversations.

1055
00:54:19.500 --> 00:54:22.700
Next is to improve data. So like I

1056
00:54:22.700 --> 00:54:26.200
said, I presented data earlier in

1057
00:54:26.200 --> 00:54:29.800
this presentation from the National Health interview survey.

1058
00:54:30.100 --> 00:54:33.600
So that was a one-time supplement And So

1059
00:54:33.600 --> 00:54:36.200
It produced really rich data, but

1060
00:54:36.200 --> 00:54:39.800
unfortunately, we do not have any follow-up data for that and

1061
00:54:39.800 --> 00:54:42.500
many of the other National Health

1062
00:54:42.500 --> 00:54:46.000
and Healthcare surveys do not include specific

1063
00:54:45.500 --> 00:54:48.700
questions about communication disabilities,

1064
00:54:48.700 --> 00:54:52.700
which really limits our understanding of the

1065
00:54:51.700 --> 00:54:55.000
population of individuals with

1066
00:54:54.500 --> 00:54:57.500
communication disabilities at a population level and

1067
00:54:57.500 --> 00:55:02.000
for Trends and again outcomes

1068
00:55:01.200 --> 00:55:03.300
their health and Health Care outcomes.

1069
00:55:04.400 --> 00:55:08.400
And then additionally we need to require and improve

1070
00:55:07.400 --> 00:55:10.600
our our documentation of

1071
00:55:10.600 --> 00:55:13.800
disability status and electronic health records so

1072
00:55:13.800 --> 00:55:16.600
we can identify who requires a combinations and

1073
00:55:16.600 --> 00:55:20.100
then also track what populations

1074
00:55:19.100 --> 00:55:22.700
are experiencing disparities. And as well

1075
00:55:22.700 --> 00:55:25.700
as if we Implement and initiative how

1076
00:55:25.700 --> 00:55:29.100
to make sure that the the intervention

1077
00:55:28.100 --> 00:55:31.200
is actually making change.

1078
00:55:32.800 --> 00:55:37.500
The third recommendation or requirement

1079
00:55:35.500 --> 00:55:38.700
is to engage

1080
00:55:38.700 --> 00:55:41.000

in multi-stakeholder pragmatic research.

1081
00:55:41.600 --> 00:55:44.400
So in all the work that I've done and

1082
00:55:44.400 --> 00:55:45.200
I've talked about today.

1083
00:55:47.100 --> 00:55:50.600
I've really made sure that people with disabilities are front and centered and have

1084
00:55:50.600 --> 00:55:53.700
persons with disabilities as my research Partners.

1085
00:55:53.700 --> 00:55:56.400
That's really important. There's the

1086
00:55:56.400 --> 00:55:59.600
saying nothing about us without us which was the rallying

1087
00:55:59.600 --> 00:56:02.600
Cry of the disability rights movement in the 1970s. And

1088
00:56:02.600 --> 00:56:05.400
it's something that I think we need to hold true

1089
00:56:05.400 --> 00:56:08.200
to in our research. We need more

1090
00:56:08.200 --> 00:56:11.200
research to really identify the extent of

1091
00:56:11.200 --> 00:56:14.100
and it determines of the disparities. We also need to focus on

1092
00:56:14.100 --> 00:56:17.700
evidence-based solutions that became be rapidly

1093
00:56:17.700 --> 00:56:19.500
translated to the real world setting.

1094
00:56:21.700 --> 00:56:24.500
And then finally, our fourth one is I mentioned

1095
00:56:24.500 --> 00:56:27.700
this earlier is to recognize intersectionality that

1096
00:56:27.700 --> 00:56:31.300
this will be rates do differ by racemativity and

1097
00:56:30.300 --> 00:56:34.200
we need to acknowledge that and acknowledge

1098
00:56:33.200 --> 00:56:36.400
how persons multiple

1099
00:56:36.400 --> 00:56:39.600
identities can intersect and compound.

1100
00:56:42.700 --> 00:56:45.500
So I will just end today with a

1101
00:56:45.500 --> 00:56:48.300
quote from Martin Luther King

1102
00:56:48.300 --> 00:56:51.200
Jr. Of all the forms of inequity.

1103
00:56:51.900 --> 00:56:54.700
or inequality Injustice in healthcare

1104
00:56:54.700 --> 00:56:57.500
is the most shocking and the most inhumane and

1105
00:56:57.500 --> 00:56:58.300
so it is

1106
00:57:00.200 --> 00:57:03.700
sediments like this that really drive drive my work in and

1107

00:57:03.700 --> 00:57:07.700
my colleague's work. So thank you for for listening

1108
00:57:06.700 --> 00:57:09.200
in to this

1109
00:57:09.200 --> 00:57:12.200
session. I encourage you to check out the rest

1110
00:57:12.200 --> 00:57:15.600
of the sessions for this Symposium, and and

1111
00:57:15.600 --> 00:57:18.400
I've put up information about our display Equity

1112
00:57:18.400 --> 00:57:21.500
collaborative. If you're interested, please check it out and please

1113
00:57:21.500 --> 00:57:24.000
let me know. I look forward

1114
00:57:24.200 --> 00:57:27.800
to hearing from you and have a great rest of your

1115
00:57:27.800 --> 00:57:29.400
Symposium and Conference.