

1
00:00:15,530 --> 00:00:18,113
[Ken Richman] Shall we start?

2
00:00:18,113 --> 00:00:20,699
[Dien Ho] Yes. Let me just
go ahead and thank you

3
00:00:20,699 --> 00:00:22,979
again, Ari, for coming
today and thank you

4
00:00:22,979 --> 00:00:25,559
everybody for coming
to this talk.

5
00:00:25,559 --> 00:00:28,139
I'm super excited about
it and I'm grateful

6
00:00:28,139 --> 00:00:31,079
also for Ken organizing this event.

7
00:00:31,079 --> 00:00:32,999
It was his outreach that allowed us

8
00:00:32,999 --> 00:00:35,309
to have Ari's visit today.

9
00:00:35,309 --> 00:00:38,280
I won't do the formal
introduction for Ari.

10
00:00:38,280 --> 00:00:40,500
I'll give that, leave that
up to Ken to do,

11
00:00:40,500 --> 00:00:42,864
but I do want to say that

12
00:00:42,864 --> 00:00:45,935
I'm the chair of the Center
for Health Humanities

13
00:00:45,935 --> 00:00:48,530
and also a professor
of philosophy at MCPHS.

14
00:00:48,530 --> 00:00:51,290
We have just

15
00:00:51,290 --> 00:00:55,040
started a new major in
Health Humanities at MCPHS.

16
00:00:55,040 --> 00:00:57,770
It's a Bachelor of Arts degree.

17
00:00:57,770 --> 00:01:00,454
It is the first ever stand-alone

18
00:01:00,454 --> 00:01:03,545
health humanities major
in all of New England.

19
00:01:03,545 --> 00:01:05,465
So I'm super excited about it.

20
00:01:05,465 --> 00:01:07,220
We already started
to have a number

21
00:01:07,220 --> 00:01:09,560
of majors in our program.

22
00:01:09,560 --> 00:01:11,554
If you are interested
in the program,

23
00:01:11,554 --> 00:01:13,159
or if you know people

24
00:01:13,159 --> 00:01:14,810
who might be interested
in the program,

25

00:01:14,810 --> 00:01:16,084
please reach out to me.

26

00:01:16,084 --> 00:01:17,539
I'll be more than
happy to talk about

27

00:01:17,539 --> 00:01:19,520
it and point them to
the right direction and

28

00:01:19,520 --> 00:01:21,860
hopefully have you be
a part of our cohort.

29

00:01:21,860 --> 00:01:24,949
So with that said, I'm going
to hand the baton over

30

00:01:24,949 --> 00:01:26,060
to Ken so that he can do

31

00:01:26,060 --> 00:01:28,799
the proper introduction.
Thanks, Ken.

32

00:01:29,080 --> 00:01:31,355
[Ken Richman] All right, great.

33

00:01:31,355 --> 00:01:35,840
Thank you so much. This is just fantastic. I've stopped the [screen]
share so that

34

00:01:35,840 --> 00:01:40,489
I can look at my notes because
I could go on and on,

35

00:01:40,489 --> 00:01:42,860
I'm so excited about this event.

36

00:01:42,860 --> 00:01:45,125

But I want to give some welcomes,

37

00:01:45,125 --> 00:01:46,775
talk about how we're
going to handle

38

00:01:46,775 --> 00:01:51,890
the session, and then introduce Ari Ne'eman.

39

00:01:51,890 --> 00:01:54,125
So I want to welcome those

40

00:01:54,125 --> 00:01:56,119
many of you who are learning about

41

00:01:56,119 --> 00:01:58,880
neurodiversity for really the first time.

42

00:01:58,880 --> 00:02:01,430
And I also want to
welcome those who are

43

00:02:01,430 --> 00:02:03,739
with us who engage very regularly

44

00:02:03,739 --> 00:02:05,600
with neurodiversity in

45

00:02:05,600 --> 00:02:07,550
their academic writing and research and advising

46

00:02:07,550 --> 00:02:09,679
government agencies. We have people who

47

00:02:09,679 --> 00:02:12,649
are engaged in community
organizing and training,

48

00:02:12,649 --> 00:02:14,899
even performing on stage.

49

00:02:14,899 --> 00:02:16,460
And so many of us

50
00:02:16,460 --> 00:02:19,760
who are engaging with these
issues in order to do our

51
00:02:19,760 --> 00:02:21,980
best to respect and love

52
00:02:21,980 --> 00:02:23,149
the people we care about

53
00:02:23,149 --> 00:02:25,309
sometimes
including ourselves.

54
00:02:25,309 --> 00:02:28,159
I want to welcome, we
had registrations

55
00:02:28,159 --> 00:02:29,974
from the two previous

56
00:02:29,974 --> 00:02:32,090
Health Humanities speakers,
both from Europe.

57
00:02:32,090 --> 00:02:33,890
I want to welcome those
who are joining us

58
00:02:33,890 --> 00:02:36,109
from west of Boston--we have
people from California,

59
00:02:36,109 --> 00:02:39,139
Michigan, Minnesota,
Pittsburgh, Alberta.

60
00:02:39,139 --> 00:02:43,009
And those several of
you from England,

61
00:02:43,009 --> 00:02:44,959
Sweden in the
Netherlands, and Denmark.

62
00:02:44,959 --> 00:02:47,480
And that's a group who
are very dear to me

63
00:02:47,480 --> 00:02:50,194
because of who they are,

64
00:02:50,194 --> 00:02:51,980
and also because they've

65
00:02:51,980 --> 00:02:54,455
contributed in very
important ways to

66
00:02:54,455 --> 00:02:58,430
my own understanding
of autism and just

67
00:02:58,430 --> 00:03:00,950
what it is
to be in the world.

68
00:03:00,950 --> 00:03:04,190
So thank you so much
for everybody being here.

69
00:03:04,190 --> 00:03:07,100
It's a really important group.

70
00:03:07,100 --> 00:03:10,024
Here's how we're
going to progress.

71
00:03:10,024 --> 00:03:13,520
We're going to have--
the chat will be open.

72

00:03:13,520 --> 00:03:16,309
You can send questions
to me at any time.

73
00:03:16,309 --> 00:03:17,540
It won't bother anybody else.

74
00:03:17,540 --> 00:03:19,175
It's not going to pop up.

75
00:03:19,175 --> 00:03:21,740
And that that'll help us streamline things.

76
00:03:21,740 --> 00:03:23,990
It also
means that if you

77
00:03:23,990 --> 00:03:26,209
don't exactly know how
to ask your question,

78
00:03:26,209 --> 00:03:28,850
that's okay because it'll
come to me and I will try to

79
00:03:28,850 --> 00:03:31,835
formulate it in an
appropriate way.

80
00:03:31,835 --> 00:03:33,050
I'll try to be accurate about it,

81
00:03:33,050 --> 00:03:35,780
but you don't need
to be shy and think

82
00:03:35,780 --> 00:03:37,535
oh, I don't know,
this isn't quite right.

83
00:03:37,535 --> 00:03:39,440
It's okay. Just send it to me.

84
00:03:39,440 --> 00:03:42,020
And it also means that

85
00:03:42,020 --> 00:03:44,150
you don't have to remember
your question for very long.

86
00:03:44,150 --> 00:03:45,680
You can type it into the chat and

87
00:03:45,680 --> 00:03:48,020
send it off, and I'll
have a record on it.

88
00:03:48,020 --> 00:03:50,899
And you can do that at any time

89
00:03:50,899 --> 00:03:53,029
during the session.

90
00:03:53,029 --> 00:03:56,029
Our usual practice is to
start with questions

91
00:03:56,029 --> 00:03:59,209
from our MCPHS students.

92
00:03:59,209 --> 00:04:01,085
And for those of
you who don't know,

93
00:04:01,085 --> 00:04:02,900
MCPHS stands for

94
00:04:02,900 --> 00:04:06,949
Massachusetts College of Pharmacy
and Health Sciences.

95
00:04:06,949 --> 00:04:09,050
Some of you are
joining us who may

96

00:04:09,050 --> 00:04:12,889
have no previous connection
with the University.

97

00:04:12,889 --> 00:04:16,430
Okay, so now it's time to
talk about Ari Ne'eman.

98

00:04:16,430 --> 00:04:17,930
For many of

99

00:04:17,930 --> 00:04:21,319
us Ari Ne'eman doesn't
need any introduction.

100

00:04:21,319 --> 00:04:24,515
We've read about him in Neurotribes
[holds up book by Steve Silverman],

101

00:04:24,515 --> 00:04:31,759
And we're not surprised to see him listed in
this book [holds up book titled Autism],

102

00:04:31,759 --> 00:04:35,179
Sue Fletcher Watson's revision
of Happé's Autism book as

103

00:04:35,179 --> 00:04:39,620
one of the key proponents
of neurodiversity.

104

00:04:39,620 --> 00:04:43,669
And we know about
the Autistic Self Advocacy Network

105

00:04:43,669 --> 00:04:47,210
that Ari founded.

106

00:04:47,210 --> 00:04:50,209
And we know that he has served

107

00:04:50,209 --> 00:04:53,150

on boards and advisory committees

108

00:04:53,150 --> 00:04:54,830
at the state and federal level.

109

00:04:54,830 --> 00:04:57,229
What I didn't know
until recently is that he

110

00:04:57,229 --> 00:05:00,649
did all of that are pretty
much before he was 21.

111

00:05:00,649 --> 00:05:03,770
That's what really
got me in preparing

112

00:05:03,770 --> 00:05:07,009
for this session.
Amazing stuff.

113

00:05:07,009 --> 00:05:10,430
He continues in his advanced age

114

00:05:10,430 --> 00:05:14,480
(ha ha) to have wonderful
contributions

115

00:05:14,480 --> 00:05:17,014
and just really important stuff.

116

00:05:17,014 --> 00:05:19,039
Some of those have
appeared recently in

117

00:05:19,039 --> 00:05:21,980
the New York Times (and I have
especially appreciated reading

118

00:05:21,980 --> 00:05:24,890
those myself), and he's working on

119

00:05:24,890 --> 00:05:28,265
a new paper on this
particular topic,

120
00:05:28,265 --> 00:05:31,264
which is important to the everyday
lives of a lot of

121
00:05:31,264 --> 00:05:33,769
people. And so I'm

122
00:05:33,769 --> 00:05:35,930
going to hand it over to
him and I look forward,

123
00:05:35,930 --> 00:05:38,149
like everybody else,

124
00:05:38,149 --> 00:05:41,099
to hearing what he has to say. Thanks.

125
00:05:42,580 --> 00:05:46,920
[Ari Ne'eman] Thank you so much. Are
my slides coming up?

126
00:05:48,310 --> 00:05:50,705
[Ken Richman] Yes.
[Ari Ne'eman] Great.

127
00:05:50,705 --> 00:05:51,949
[Ari Ne'eman] Well, thank you so much for

128
00:05:51,949 --> 00:05:53,659
having me and thank you for that

129
00:05:53,659 --> 00:05:57,860
great introduction, Ken,
and thank you to MCPHS

130
00:05:57,860 --> 00:05:59,779
for hosting what I

131

00:05:59,779 --> 00:06:02,405
hope will be a very
interesting conversation.

132
00:06:02,405 --> 00:06:05,030
So first, just a
little bit about me.

133
00:06:05,030 --> 00:06:08,779
As Ken mentioned, I
was the co-founder of

134
00:06:08,779 --> 00:06:11,150
the Autistic Self Advocacy
Network and ran

135
00:06:11,150 --> 00:06:15,799
the organization
from 2006 to 2016.

136
00:06:15,799 --> 00:06:19,880
I'm not quite as
young as I once was.

137
00:06:19,880 --> 00:06:26,339
32 now, so I'm no longer knee
high to a grasshopper.

138
00:06:27,520 --> 00:06:29,659
I served as one of

139
00:06:29,659 --> 00:06:31,370
President Obama's appointees to

140
00:06:31,370 --> 00:06:33,484
the National Council
on Disability.

141
00:06:33,484 --> 00:06:36,260
I'm currently a doctoral
student in health policy at

142
00:06:36,260 --> 00:06:39,739

Harvard and do research
on disability policy,

143

00:06:39,739 --> 00:06:43,744
long-term services and
supports and bioethics.

144

00:06:43,744 --> 00:06:45,949
And, you know, I really see

145

00:06:45,949 --> 00:06:49,114
this conversation as reflecting

146

00:06:49,114 --> 00:06:53,195
an interesting
opportunity to integrate

147

00:06:53,195 --> 00:06:57,980
the values of a social movement,

148

00:06:57,980 --> 00:07:00,110
the neurodiversity movement,

149

00:07:00,110 --> 00:07:06,409
with the concrete
questions of measurement

150

00:07:06,409 --> 00:07:09,290
and clinical practice that come

151

00:07:09,290 --> 00:07:12,590
up in the context of
autism service provision,

152

00:07:12,590 --> 00:07:14,959
and really in many ways

153

00:07:14,959 --> 00:07:17,659
in disability service-
provision as a whole,

154

00:07:17,659 --> 00:07:19,339

in that many of the ideas of

155

00:07:19,339 --> 00:07:20,899
the neurodiversity movement have

156

00:07:20,899 --> 00:07:25,865
found interest outside
of autism, as well.

157

00:07:25,865 --> 00:07:27,500
So I want to begin as

158

00:07:27,500 --> 00:07:30,559
so many presentations
do with a quote

159

00:07:30,559 --> 00:07:33,410
"Civil Rights practice is

160

00:07:33,410 --> 00:07:36,935
fundamentally about
who has to change."

161

00:07:36,935 --> 00:07:41,284
This quote comes from
Professor Kenji Yoshino,

162

00:07:41,284 --> 00:07:45,725
who has written an
absolutely fantastic book

163

00:07:45,725 --> 00:07:48,680
about the concept of covering.

164

00:07:48,680 --> 00:07:53,615
Covering, very much related
to the concept of passing.

165

00:07:53,615 --> 00:07:57,004
Passing is hiding

166

00:07:57,004 --> 00:08:00,889

an aspect of--hiding
marginalized identity.

167
00:08:00,889 --> 00:08:05,299
When someone who is gay
pretends to be straight,

168
00:08:05,299 --> 00:08:07,055
they are passing for straight.

169
00:08:07,055 --> 00:08:10,759
When someone who is Jewish
pretends to be a gentile,

170
00:08:10,759 --> 00:08:13,639
they are passing for Christian

171
00:08:13,639 --> 00:08:17,390
or whatever non-Jewish religion's

172
00:08:17,390 --> 00:08:20,285
in the majority of the,
in any given culture.

173
00:08:20,285 --> 00:08:24,694
When someone who is disabled
pretends to be non-disabled,

174
00:08:24,694 --> 00:08:27,245
they are passing as non-disabled.

175
00:08:27,245 --> 00:08:30,395
Covering is a
very related concept.

176
00:08:30,395 --> 00:08:32,704
It refers to not hiding

177
00:08:32,704 --> 00:08:36,665
the existence of
marginalized identity,

178

00:08:36,665 --> 00:08:44,945
but instead hiding any
overt characteristic of it.

179
00:08:44,945 --> 00:08:48,064
So a covering demand,

180
00:08:48,064 --> 00:08:50,870
which is something we see
very often in society,

181
00:08:50,870 --> 00:08:54,499
would be to say, we
accept the idea that you

182
00:08:54,499 --> 00:08:58,385
can be Jewish and be
in our workplace.

183
00:08:58,385 --> 00:09:00,230
But if you're wearing

184
00:09:00,230 --> 00:09:03,890
a yarmulke or if you're
taking off Saturdays,

185
00:09:03,890 --> 00:09:05,929
that might be a problem.

186
00:09:05,929 --> 00:09:07,909
We accept the idea
that you can be

187
00:09:07,909 --> 00:09:11,675
gay and be a part of
our social group.

188
00:09:11,675 --> 00:09:15,379
But if you invite
your same-sex spouse

189
00:09:15,379 --> 00:09:20,585
to a social gathering

or company party,

190

00:09:20,585 --> 00:09:24,440
or are too obviously gay,

191

00:09:24,440 --> 00:09:26,720
then that represents a problem.

192

00:09:26,720 --> 00:09:29,689
And covering is a very--passing

193

00:09:29,689 --> 00:09:30,949
and covering are both

194

00:09:30,949 --> 00:09:33,425
very relevant concepts when we

195

00:09:33,425 --> 00:09:36,530
talk about the neurodiversity movement.

196

00:09:36,530 --> 00:09:40,205
Because neurodiversity
really originated

197

00:09:40,205 --> 00:09:44,630
as a response from
autistic people to

198

00:09:44,630 --> 00:09:47,810
passing and covering
demands both from

199

00:09:47,810 --> 00:09:49,940
the larger society and

200

00:09:49,940 --> 00:09:54,619
specifically from the world
of autism service provision.

201

00:09:54,619 --> 00:09:58,384
Autism has existed really in,

202

00:09:58,384 --> 00:10:00,530
I think, growing opinion of

203

00:10:00,530 --> 00:10:03,410
many researchers and
certainly my own,

204

00:10:03,410 --> 00:10:07,250
going back indefinitely,

205

00:10:07,250 --> 00:10:11,420
but the diagnosis was
documented first in

206

00:10:11,420 --> 00:10:14,495
the 1940s and began to

207

00:10:14,495 --> 00:10:19,804
be popularized in the 1970s and 80s.

208

00:10:19,804 --> 00:10:21,950
And by the early nineties,

209

00:10:21,950 --> 00:10:24,440
you began to see the
emergence of really

210

00:10:24,440 --> 00:10:30,140
the first community of
autistic adults who understood

211

00:10:30,140 --> 00:10:33,889
themselves to be autistic
and began to seek each other

212

00:10:33,889 --> 00:10:38,690
out and really form a sense
of collective identity,

213

00:10:38,690 --> 00:10:41,630
and start to discuss their opinions

214
00:10:41,630 --> 00:10:44,810
about where autism policy,

215
00:10:44,810 --> 00:10:47,720
service provision and
research and all kinds of

216
00:10:47,720 --> 00:10:51,094
other things going
on in our name

217
00:10:51,094 --> 00:10:52,490
were going. And there was

218
00:10:52,490 --> 00:10:54,710
a great deal of
concern at that time

219
00:10:54,710 --> 00:10:57,589
in this emergent
autistic adult community

220
00:10:57,589 --> 00:10:59,270
coming together really on

221
00:10:59,270 --> 00:11:02,030
the sidelines of autism
parent conferences

222
00:11:02,030 --> 00:11:05,434
and on this newfangled
thing called the internet

223
00:11:05,434 --> 00:11:10,159
that autism research policy,

224
00:11:10,159 --> 00:11:13,099
advocacy, service provision,
and so on was something

225
00:11:13,099 --> 00:11:16,805
that was happening

about us without us.

226

00:11:16,805 --> 00:11:20,240
Jim Sinclair, who is generally

227

00:11:20,240 --> 00:11:24,080
considered the founder of the
neurodiversity movement,

228

00:11:24,080 --> 00:11:26,479
wrote an iconic essay,

229

00:11:26,479 --> 00:11:29,165
called Don't Mourn for Us,

230

00:11:29,165 --> 00:11:31,969
that really laid out the idea of

231

00:11:31,969 --> 00:11:36,065
rejecting this concept
of autism is a tragedy,

232

00:11:36,065 --> 00:11:38,989
and pushing back against
this narrative that

233

00:11:38,989 --> 00:11:41,839
the objective of autism
service provision and

234

00:11:41,839 --> 00:11:46,010
research should be to try
and cure autistic people by

235

00:11:46,010 --> 00:11:51,200
making us look as normal or
as non-autistic as possible.

236

00:11:51,200 --> 00:11:53,749
Sinclair founded an
organization called

237

00:11:53,749 --> 00:11:56,480
Autism Network
International, ANI,

238
00:11:56,480 --> 00:11:59,614
which proved
tremendously influential

239
00:11:59,614 --> 00:12:01,040
in laying the foundation

240
00:12:01,040 --> 00:12:02,389
for what

241
00:12:02,389 --> 00:12:04,909
are many autistic-
run organizations

242
00:12:04,909 --> 00:12:07,085
today, including ASAN,

243
00:12:07,085 --> 00:12:09,499
the Autistic
Self Advocacy Network,

244
00:12:09,499 --> 00:12:13,565
the Autistic Women and
Nonbinary Network,

245
00:12:13,565 --> 00:12:16,849
and many, many others
throughout the world.

246
00:12:16,849 --> 00:12:19,009
One of the most exciting
things I think we've

247
00:12:19,009 --> 00:12:21,199
seen over the last decade is

248
00:12:21,199 --> 00:12:26,045
neurodiversity and
autistic advocacy

249

00:12:26,045 --> 00:12:29,179
proliferate around the world.

250

00:12:29,179 --> 00:12:31,130
That was always an
international movement,

251

00:12:31,130 --> 00:12:33,560
but it's become even more so in

252

00:12:33,560 --> 00:12:37,489
very impressive sophisticated
ways in recent years.

253

00:12:37,489 --> 00:12:43,744
And the focus of the neurodiversity movement was to try

254

00:12:43,744 --> 00:12:46,879
and articulate the views

255

00:12:46,879 --> 00:12:50,450
of autistic people with
respect to autism,

256

00:12:50,450 --> 00:12:53,269
policy, research and
service provision,

257

00:12:53,269 --> 00:12:55,850
and in particular
to critique some of

258

00:12:55,850 --> 00:12:59,015
the ways in which the larger,

259

00:12:59,015 --> 00:13:02,630
more prominent parent-
and researcher-

260

00:13:02,630 --> 00:13:08,285
dominated organizations

were approaching autism

261

00:13:08,285 --> 00:13:12,005
service provision,
research, and advocacy.

262

00:13:12,005 --> 00:13:13,579
There are a lot of
different components of this.

263

00:13:13,579 --> 00:13:14,870
Some of this related

264

00:13:14,870 --> 00:13:17,779
to representations of
autism in the media.

265

00:13:17,779 --> 00:13:22,249
Some of this related to
conversations around different

266

00:13:22,249 --> 00:13:25,400
modes of service provision.

267

00:13:25,400 --> 00:13:27,890
A lot of discussion around
pushing back against

268

00:13:27,890 --> 00:13:31,819
the emphasis on
institutionalization, and so on.

269

00:13:31,819 --> 00:13:34,834
But I want to focus in particular

270

00:13:34,834 --> 00:13:39,215
on the neurodiversity
movement's critique of

271

00:13:39,215 --> 00:13:43,309
autism interventions designed to

272

00:13:43,309 --> 00:13:47,600
make autistic people look
and act more normal.

273
00:13:47,600 --> 00:13:50,719
One of the most common
of those interventions,

274
00:13:50,719 --> 00:13:55,040
especially today, is applied
behavioral analysis.

275
00:13:55,040 --> 00:13:58,880
Applied behavioral analysis
is an intervention

276
00:13:58,880 --> 00:14:03,050
that is often considered
synonymous with autism

277
00:14:03,050 --> 00:14:06,320
in a lot of clinical circles
in the United States.

278
00:14:06,320 --> 00:14:08,510
There has been a very
heavy emphasis over

279
00:14:08,510 --> 00:14:13,700
the last 20 years or so to
secure insurance coverage

280
00:14:13,700 --> 00:14:19,385
for ABA for autism. There has been
a very heavy emphasis to

281
00:14:19,385 --> 00:14:22,940
press providers to
refer autistic children

282
00:14:22,940 --> 00:14:27,455
and sometimes autistic
adults to receive ABA.

283
00:14:27,455 --> 00:14:29,990
And there are a great deal of

284
00:14:29,990 --> 00:14:33,589
concerns that the neurodiversity
movement has.

285
00:14:33,589 --> 00:14:34,879
There's a great deal of concern

286
00:14:34,879 --> 00:14:38,615
the neurodiversity movement
has with regards to ABA.

287
00:14:38,615 --> 00:14:43,399
There are really two
broad critiques of ABA.

288
00:14:43,399 --> 00:14:46,999
The first is that ABA has

289
00:14:46,999 --> 00:14:52,655
historically made use of
aversive interventions--

290
00:14:52,655 --> 00:14:53,840
the use of pain and

291
00:14:53,840 --> 00:14:57,169
noxious stimuli in order
to modify behavior.

292
00:14:57,169 --> 00:14:58,550
I would say proponents of

293
00:14:58,550 --> 00:15:01,894
ABA would say that's
no longer the case.

294
00:15:01,894 --> 00:15:03,499
I think we have
some evidence that

295

00:15:03,499 --> 00:15:05,359
that's not in fact true,

296

00:15:05,359 --> 00:15:07,699
which I'll discuss briefly later.

297

00:15:07,699 --> 00:15:09,829
But I don't want to get
into too much because it's

298

00:15:09,829 --> 00:15:13,009
not the main focus
of my arguments.

299

00:15:13,009 --> 00:15:17,330
The second critique is
that the emphasis of

300

00:15:17,330 --> 00:15:22,385
ABA is to try and make
autistic children,

301

00:15:22,385 --> 00:15:23,839
in the words of

302

00:15:23,839 --> 00:15:25,400
Ole Ivar Lovaas,

303

00:15:25,400 --> 00:15:27,799
the founder of applied
behavioral analysis

304

00:15:27,799 --> 00:15:29,570
in the context of autism--

305

00:15:29,570 --> 00:15:33,515
the most prolific or
prominent practitioner--

306

00:15:33,515 --> 00:15:37,714
indistinguishable

from peers.

307

00:15:37,714 --> 00:15:40,985
ABA service provision is
very focused on the idea

308

00:15:40,985 --> 00:15:46,190
that the goal of autism
intervention should be

309

00:15:46,190 --> 00:15:50,689
to reduce autistic
traits and promote

310

00:15:50,689 --> 00:15:55,645
behaviors that are consistent
with typical appearance.

311

00:15:55,645 --> 00:15:59,269
Here we have the website from

312

00:15:59,269 --> 00:16:03,499
one prominent ABA provider
that represents to families

313

00:16:03,499 --> 00:16:06,455
that in fact ABA can recover

314

00:16:06,455 --> 00:16:10,939
their autistic children and
make them non-autistic.

315

00:16:10,939 --> 00:16:14,495
And this is a claim that
some ABA providers make,

316

00:16:14,495 --> 00:16:18,589
some ABA providers do not
make, but regardless

317

00:16:18,589 --> 00:16:20,029
it's really embedded in

318
00:16:20,029 --> 00:16:23,600
the underlying goals of
applied behavioral analysis.

319
00:16:23,600 --> 00:16:26,689
The reduction of
autistic traits and

320
00:16:26,689 --> 00:16:30,095
the promotion of
non-autistic appearance.

321
00:16:30,095 --> 00:16:32,990
If we were to scroll
down on this website

322
00:16:32,990 --> 00:16:37,805
we would see exactly
what ABA providers

323
00:16:37,805 --> 00:16:43,355
mean when they talk about
the idea of recovery.

324
00:16:43,355 --> 00:16:47,329
First, that individuals have

325
00:16:47,329 --> 00:16:49,910
test scores that are
in the average range

326
00:16:49,910 --> 00:16:52,460
or higher on tests
of intelligence,

327
00:16:52,460 --> 00:16:55,985
language, socialization,
and daily living skills.

328
00:16:55,985 --> 00:16:58,489
And, you know, we
could quibble about

329

00:16:58,489 --> 00:17:01,460
what some of those tests
of socialization say,

330

00:17:01,460 --> 00:17:04,339
but this is not the most
objectionable component.

331

00:17:04,339 --> 00:17:06,319
I think we generally do see

332

00:17:06,319 --> 00:17:09,560
language acquisition and
cognitive development

333

00:17:09,560 --> 00:17:13,129
and daily living skill
development as positive things.

334

00:17:13,129 --> 00:17:16,249
That person is earning
passing grades in

335

00:17:16,249 --> 00:17:18,619
a regular education classroom

336

00:17:18,619 --> 00:17:22,174
with no specialized
supports whatsoever.

337

00:17:22,174 --> 00:17:24,620
And certainly we want to see

338

00:17:24,620 --> 00:17:28,685
autistic children in a
regular education classroom.

339

00:17:28,685 --> 00:17:31,639
[I am a] very big believer in
inclusive education.

340

00:17:31,639 --> 00:17:33,484

I think there are some

341

00:17:33,484 --> 00:17:37,280
interesting and
important questions

342

00:17:37,280 --> 00:17:40,159
to ask about whether or
not we should in fact

343

00:17:40,159 --> 00:17:44,089
be prioritizing the idea
that our definition of

344

00:17:44,089 --> 00:17:46,880
success is that a child or

345

00:17:46,880 --> 00:17:50,389
adult receive no specialized
supports whatsoever.

346

00:17:50,389 --> 00:17:52,730
In fact, someone can be perfectly

347

00:17:52,730 --> 00:17:56,000
successful in the general
education classroom or in

348

00:17:56,000 --> 00:17:58,369
life with the receipt of

349

00:17:58,369 --> 00:18:01,979
some form of specialized
supports or accommodations.

350

00:18:01,979 --> 00:18:04,790
I think there is
something to be said for

351

00:18:04,790 --> 00:18:08,510
that bullet being a
little concerning.

352
00:18:08,510 --> 00:18:10,579
But the most concerning
component to

353
00:18:10,579 --> 00:18:13,039
this idea of recovery is

354
00:18:13,039 --> 00:18:17,660
the idea that individuals

355
00:18:17,660 --> 00:18:21,035
should lose their
autism diagnosis,

356
00:18:21,035 --> 00:18:25,055
that we should be working to make

357
00:18:25,055 --> 00:18:29,525
autistic children and
adults look non-autistic,

358
00:18:29,525 --> 00:18:31,999
such that they no longer meet

359
00:18:31,999 --> 00:18:34,940
the diagnostic
criteria for autism.

360
00:18:34,940 --> 00:18:37,969
And we can sort of
see how that plays

361
00:18:37,969 --> 00:18:41,975
out in a wide variety
of different places.

362
00:18:41,975 --> 00:18:45,289
Many autistic people have
expressed frustration

363
00:18:45,289 --> 00:18:49,054
with the tendency on the

part of many providers to

364

00:18:49,054 --> 00:18:52,429
suppress stimming behavior like

365

00:18:52,429 --> 00:18:54,559
hand flapping or rocking back and

366

00:18:54,559 --> 00:18:57,604
forth and other things
that autistic people do

367

00:18:57,604 --> 00:19:01,459
because they are
personally beneficial,

368

00:19:01,459 --> 00:19:03,169
because we like doing them,

369

00:19:03,169 --> 00:19:06,170
because they may help
us manage anxiety.

370

00:19:06,170 --> 00:19:09,365
There's also a
concerning emphasis on

371

00:19:09,365 --> 00:19:12,589
eye contact as a goal in and of

372

00:19:12,589 --> 00:19:16,369
itself. This is an article from, and it

373

00:19:16,369 --> 00:19:20,539
looks like the headline is
a little cut off there,

374

00:19:20,539 --> 00:19:22,610
but it says,

375

00:19:22,610 --> 00:19:27,065
BYU students make glasses

to help autistic kids'

376

00:19:27,065 --> 00:19:28,729
eye contact.

377

00:19:28,729 --> 00:19:30,739
And it talks about

378

00:19:30,739 --> 00:19:37,714
a technology project at the
Brigham Young University

379

00:19:37,714 --> 00:19:40,580
designed to try and encourage

380

00:19:40,580 --> 00:19:45,230
eye contact by projecting
images of things

381

00:19:45,230 --> 00:19:49,790
that autistic people are
interested in on glasses in

382

00:19:49,790 --> 00:19:55,025
locations that autistic people
are supposed to look at.

383

00:19:55,025 --> 00:19:58,895
And the provider
working on this project

384

00:19:58,895 --> 00:20:03,230
argues that eye
contact is necessary.

385

00:20:03,230 --> 00:20:07,054
That it is necessary to
build this device to

386

00:20:07,054 --> 00:20:08,719
superimpose an image of

387

00:20:08,719 --> 00:20:12,440
Mickey Mouse on a
child's mother's face

388
00:20:12,440 --> 00:20:14,450
not just because the mother

389
00:20:14,450 --> 00:20:19,115
wants her child to look at
her in a particular way,

390
00:20:19,115 --> 00:20:21,440
which we might argue
is or isn't a

391
00:20:21,440 --> 00:20:23,420
legitimate goal of
service provision,

392
00:20:23,420 --> 00:20:24,995
but the provider argues that

393
00:20:24,995 --> 00:20:30,740
eye contact is necessary for
autistic people to develop

394
00:20:30,740 --> 00:20:34,024
joint attention and to

395
00:20:34,024 --> 00:20:37,130
have the ability to
communicate socially.

396
00:20:37,130 --> 00:20:41,165
And so you basically have
a model of thinking about

397
00:20:41,165 --> 00:20:44,460
autism and autistic challenges

398
00:20:44,460 --> 00:20:47,104
that is very straightforward,
very linear.

399
00:20:47,104 --> 00:20:50,884
It says autistic children
don't make eye contact.

400
00:20:50,884 --> 00:20:54,169
As a result of that lack
of making eye contact

401
00:20:54,169 --> 00:20:56,855
they have social
communication challenges.

402
00:20:56,855 --> 00:21:00,364
By making autistic
children make eye contact,

403
00:21:00,364 --> 00:21:03,814
we can address their social
communication challenges.

404
00:21:03,814 --> 00:21:05,450
Part of the problem with

405
00:21:05,450 --> 00:21:07,310
that mode of thinking is
that we actually have

406
00:21:07,310 --> 00:21:10,430
a fair amount of
research that shows that

407
00:21:10,430 --> 00:21:12,950
autistic people can display

408
00:21:12,950 --> 00:21:15,890
joint attention and can
communicate socially--

409
00:21:15,890 --> 00:21:18,049
and of course, autistic
people ourselves

410
00:21:18,049 --> 00:21:19,519
would tell you
this and we have for

411
00:21:19,519 --> 00:21:24,635
years--via means other
than eye contact.

412
00:21:24,635 --> 00:21:27,515
And that in fact

413
00:21:27,515 --> 00:21:30,680
autistic people pick
up on directional cues

414
00:21:30,680 --> 00:21:34,459
from eye gaze even when
not making eye contact.

415
00:21:34,459 --> 00:21:37,069
And of course, crucially,

416
00:21:37,069 --> 00:21:41,300
eye contact is unpleasant
for many autistic people.

417
00:21:41,300 --> 00:21:43,310
Many of us don't like to do it.

418
00:21:43,310 --> 00:21:44,869
And so this

419
00:21:44,869 --> 00:21:47,375
this very heavy emphasis

420
00:21:47,375 --> 00:21:49,489
in service provision on promoting

421
00:21:49,489 --> 00:21:56,525
something that is essentially,
we would argue, cosmetic,

422

00:21:56,525 --> 00:22:01,895
that is unpleasant for
autistic people at any age,

423

00:22:01,895 --> 00:22:05,210
and that is unnecessary because

424

00:22:05,210 --> 00:22:09,514
autistic people can
accomplish the same ends

425

00:22:09,514 --> 00:22:13,190
of joint attention and
social communication

426

00:22:13,190 --> 00:22:17,930
via different means
other than eye contact--

427

00:22:17,930 --> 00:22:20,615
this, all of this taken together,

428

00:22:20,615 --> 00:22:25,219
suggests that the demand for

429

00:22:25,219 --> 00:22:29,495
eye contact in autism
service provision

430

00:22:29,495 --> 00:22:32,449
is a passing demand.

431

00:22:32,449 --> 00:22:35,119
I'm going to use the
phrase passing demand

432

00:22:35,119 --> 00:22:39,094
here to encompass both
passing and covering demands

433

00:22:39,094 --> 00:22:40,880
for simplicity's sake. But

434
00:22:40,880 --> 00:22:44,090
basically what we are
seeing in the emphasis on

435
00:22:44,090 --> 00:22:51,784
eye contact is a clinical
goal whose purpose is to try

436
00:22:51,784 --> 00:22:55,640
and make autistic persons

437
00:22:55,640 --> 00:23:02,090
look and act normal to
pass as non-autistic.

438
00:23:02,090 --> 00:23:04,894
Passing, as I mentioned earlier,

439
00:23:04,894 --> 00:23:07,444
is the management of undisclosed,

440
00:23:07,444 --> 00:23:09,710
discrediting information
about the self.

441
00:23:09,710 --> 00:23:14,075
Irving Goffman's
seminal book on stigma

442
00:23:14,075 --> 00:23:17,675
goes into this and covering
in considerable detail.

443
00:23:17,675 --> 00:23:20,029
Again, I'm going to use
the word passing here

444
00:23:20,029 --> 00:23:22,445
to refer to both
passing and covering.

445

00:23:22,445 --> 00:23:28,370
Really any demand that, in our
instance autistic people

446
00:23:28,370 --> 00:23:31,025
but really people from
any marginalized group,

447
00:23:31,025 --> 00:23:33,500
suppress a trait because it is

448
00:23:33,500 --> 00:23:39,320
associated with a
marginalized identity.

449
00:23:39,320 --> 00:23:42,064
Audre Lord, the poet,

450
00:23:42,064 --> 00:23:45,289
puts this somewhat
more eloquently.

451
00:23:45,289 --> 00:23:48,020
"Am I to be cursed
forever with becoming

452
00:23:48,020 --> 00:23:51,230
someone else on my way to myself?"

453
00:23:51,230 --> 00:23:54,469
And this really captures

454
00:23:54,469 --> 00:23:58,114
something that we also see
in the political literature.

455
00:23:58,114 --> 00:24:04,264
Namely that passing efforts
harm autistic people.

456
00:24:04,264 --> 00:24:06,289
Camouflaging, which
is a word that

457

00:24:06,289 --> 00:24:09,064
we see used in
clinical literature [and]

458

00:24:09,064 --> 00:24:11,540
really corresponds to what

459

00:24:11,540 --> 00:24:13,399
we would consider as passing or

460

00:24:13,399 --> 00:24:15,620
covering, is a risk marker for

461

00:24:15,620 --> 00:24:18,169
suicidality in autistic adults.

462

00:24:18,169 --> 00:24:20,330
Camouflaging is also associated

463

00:24:20,330 --> 00:24:22,895
with poor mental health, burnout,

464

00:24:22,895 --> 00:24:25,369
depression, functional
challenges,

465

00:24:25,369 --> 00:24:28,549
exhaustion and
self-esteem problems.

466

00:24:28,549 --> 00:24:30,770
And again, going back to the 1990s,

467

00:24:30,770 --> 00:24:32,840
before we had much
of this literature,

468

00:24:32,840 --> 00:24:36,350
autistic people through the
neurodiversity movement were

469

00:24:36,350 --> 00:24:40,475
very clearly communicating
that passing

470

00:24:40,475 --> 00:24:43,789
and that clinical
demands to pass

471

00:24:43,789 --> 00:24:49,565
were burdensome and harmful
for autistic people.

472

00:24:49,565 --> 00:24:51,680
There's a great resource on

473

00:24:51,680 --> 00:24:54,485
this topic for
first-person perspectives.

474

00:24:54,485 --> 00:24:58,475
Amanda Vivian, who's a
fantastic autistic

475

00:24:58,475 --> 00:25:02,840
writer produced in 2011 a

476

00:25:02,840 --> 00:25:06,395
resource called the
Autistic Passing Project.

477

00:25:06,395 --> 00:25:10,745
The web address for it is on the
bottom of the page right there.
[\[Autistic Passing Project \(tumblr.com\)\]](https://www.autisticpassingproject.com)

478

00:25:10,745 --> 00:25:14,120
And it includes a number of
quotes from autistic people

479

00:25:14,120 --> 00:25:17,210
talking about their
experiences with passing.

480
00:25:17,210 --> 00:25:19,970
"It made me angry and sad and

481
00:25:19,970 --> 00:25:23,449
frustrated because I never
stopped being autistic.

482
00:25:23,449 --> 00:25:25,440
I just learned how to
get around in

483
00:25:25,440 --> 00:25:26,840
an NT [neurotypical] world better.

484
00:25:26,840 --> 00:25:28,909
These days, I am pretending to be

485
00:25:28,909 --> 00:25:31,325
normal for them, not myself.

486
00:25:31,325 --> 00:25:33,260
And that's what hurts."

487
00:25:33,260 --> 00:25:36,680
"I am actually at a point
now where I rarely

488
00:25:36,680 --> 00:25:40,055
leave the house because I
don't have the energy to pass."

489
00:25:40,055 --> 00:25:41,420
And these are quotes from

490
00:25:41,420 --> 00:25:43,069
the Autistic Passing Project.

491
00:25:43,069 --> 00:25:44,825
I encourage you
to take a look at it.

492

00:25:44,825 --> 00:25:48,409
I think it really illustrates
the human stakes in

493
00:25:48,409 --> 00:25:52,519
a way that complements
the literature

494
00:25:52,519 --> 00:25:56,690
and that helps reinforce
the underlying critique

495
00:25:56,690 --> 00:25:59,269
at the heart of the neurodiversity movement

496
00:25:59,269 --> 00:26:03,514
namely, that the goal
of autism intervention,

497
00:26:03,514 --> 00:26:06,049
service provision,
research, et cetera,

498
00:26:06,049 --> 00:26:12,395
should not be to make autistic
people look or act normal,

499
00:26:12,395 --> 00:26:15,605
but should be instead to improve

500
00:26:15,605 --> 00:26:18,844
autistic people's
lives consistent

501
00:26:18,844 --> 00:26:21,979
with our own desires
and preferences.

502
00:26:21,979 --> 00:26:25,070
This is the case for the
neurodiversity movement.

503
00:26:25,070 --> 00:26:27,949

Now, we've also seen

504

00:26:27,949 --> 00:26:30,800
some very strong backlash

505

00:26:30,800 --> 00:26:33,290
to neurodiversity
over the years.

506

00:26:33,290 --> 00:26:36,349
Here's an article
that ran recently--

507

00:26:36,349 --> 00:26:38,839
well not so recently
a few years ago,

508

00:26:38,839 --> 00:26:41,045
but there are plenty
others like it--

509

00:26:41,045 --> 00:26:45,260
in Aeon magazine, called
Against Neurodiversity,

510

00:26:45,260 --> 00:26:47,944
arguing that neurodiversity movement

511

00:26:47,944 --> 00:26:51,619
favors the quote, unquote,
"high functioning"

512

00:26:51,619 --> 00:26:54,949
(which, by the way, is a term
with no clinical definition,

513

00:26:54,949 --> 00:26:56,480
but it's one that we see thrown

514

00:26:56,480 --> 00:26:58,250
around a lot along
with the term 'low

515
00:26:58,250 --> 00:27:02,645
functioning' in discourse
around autism)

516
00:27:02,645 --> 00:27:04,489
and overlooks those

517
00:27:04,489 --> 00:27:06,305
who struggle with severe autism and,

518
00:27:06,305 --> 00:27:07,819
and this, this critique of

519
00:27:07,819 --> 00:27:09,799
the neurodiversity
movement, very,

520
00:27:09,799 --> 00:27:14,209
very common in autism
politics, argues that

521
00:27:14,209 --> 00:27:16,205
neurodiversity

522
00:27:16,205 --> 00:27:21,139
harms individuals with
severe impairments,

523
00:27:21,139 --> 00:27:24,544
harms autistic people
with severe impairments

524
00:27:24,544 --> 00:27:28,460
because there are
many people who have

525
00:27:28,460 --> 00:27:32,089
autistic traits that
are harmful to them,

526
00:27:32,089 --> 00:27:33,544
that they do struggle with,

527
00:27:33,544 --> 00:27:36,680
and that they do in
fact want to see,

528
00:27:36,680 --> 00:27:41,030
or often that their family
members want to see

529
00:27:41,030 --> 00:27:45,620
addressed, suppressed,
mitigated, or ameliorated,

530
00:27:45,620 --> 00:27:47,869
whatever terminology
you want to use.

531
00:27:47,869 --> 00:27:49,549
And there's been
a lot of back and

532
00:27:49,549 --> 00:27:51,109
forth over this
critique which has

533
00:27:51,109 --> 00:27:52,850
existed really as long as

534
00:27:52,850 --> 00:27:55,505
the neurodiversity
movement has existed.

535
00:27:55,505 --> 00:27:58,999
It often comes from some of

536
00:27:58,999 --> 00:28:01,309
the more traditional parent and

537
00:28:01,309 --> 00:28:03,349
professional organizations

538
00:28:03,349 --> 00:28:05,374

that the neurodiversity movement,

539

00:28:05,374 --> 00:28:08,060
which has historically been

540

00:28:08,060 --> 00:28:10,309
run by autistic people ourselves,

541

00:28:10,309 --> 00:28:13,564
emerged in response to.

542

00:28:13,564 --> 00:28:17,149
I don't think it's actually
accurate to say that it's

543

00:28:17,149 --> 00:28:23,359
a parents versus autistic
people divide because

544

00:28:23,359 --> 00:28:26,299
you actually do see
a large number of

545

00:28:26,299 --> 00:28:30,289
families on the side of the
neurodiversity movement.

546

00:28:30,289 --> 00:28:32,690
I think parents are
not a monolith,

547

00:28:32,690 --> 00:28:35,749
but there's certainly
a dedicated group

548

00:28:35,749 --> 00:28:38,630
of some parents who reject

549

00:28:38,630 --> 00:28:40,414
the neurodiversity movement

550

00:28:40,414 --> 00:28:42,380

because they believe
that it doesn't

551

00:28:42,380 --> 00:28:44,269
account for the needs of

552

00:28:44,269 --> 00:28:47,434
autistic people with
severe impairments.

553

00:28:47,434 --> 00:28:52,400
Some researchers and
a few autistic people

554

00:28:52,400 --> 00:28:55,114
have argued that the
way to address this

555

00:28:55,114 --> 00:28:59,764
is to split autism

556

00:28:59,764 --> 00:29:03,410
and really think about it
in two distinct groups.

557

00:29:03,410 --> 00:29:06,515
This is an article from
Simon Baron-Cohen,

558

00:29:06,515 --> 00:29:09,664
a very prominent, famous
autism researcher,

559

00:29:09,664 --> 00:29:12,559
arguing that in order to resolve

560

00:29:12,559 --> 00:29:17,734
the controversy surrounding
neurodiversity, we,

561

00:29:17,734 --> 00:29:20,210
all we need to do is
just acknowledge that

562
00:29:20,210 --> 00:29:22,790
autism is a diagnosis that

563
00:29:22,790 --> 00:29:24,830
contains a lot of

564
00:29:24,830 --> 00:29:27,649
very significant differences

565
00:29:27,649 --> 00:29:30,439
between different
autistic people,

566
00:29:30,439 --> 00:29:31,819
and once we

567
00:29:31,819 --> 00:29:34,445
acknowledge that
heterogeneity of autism

568
00:29:34,445 --> 00:29:36,409
we won't have a controversy

569
00:29:36,409 --> 00:29:38,779
over neurodiversity
anymore because we'll have

570
00:29:38,779 --> 00:29:43,250
one group of autistic
people who we'll consider

571
00:29:43,250 --> 00:29:47,360
the neurodiversity approach
relevant to and will

572
00:29:47,360 --> 00:29:49,459
apply neurodiversity
model to and

573
00:29:49,459 --> 00:29:51,919
we'll have another group

of autistic people

574

00:29:51,919 --> 00:29:53,719
who we'll consider the traditional

575

00:29:53,719 --> 00:29:56,329
medical model relevant for,

576

00:29:56,329 --> 00:29:59,270
and we'll apply it
over there and we'll

577

00:29:59,270 --> 00:30:02,600
just separate out
the autism diagnosis

578

00:30:02,600 --> 00:30:06,230
between those who we apply

579

00:30:06,230 --> 00:30:08,239
neurodiversity to
and those who we

580

00:30:08,239 --> 00:30:10,805
apply the medical cure model to.

581

00:30:10,805 --> 00:30:14,749
And this is an idea
that has some super,

582

00:30:14,749 --> 00:30:17,045
is superficially very compelling.

583

00:30:17,045 --> 00:30:18,905
A lot of people like this.

584

00:30:18,905 --> 00:30:21,320
It seems to offer a way to

585

00:30:21,320 --> 00:30:24,635
resolve a very
acrimonious conflict.

586

00:30:24,635 --> 00:30:27,425

There are a couple
problems with it, though.

587

00:30:27,425 --> 00:30:33,500

The first is, there is no
clear dividing line in autism.

588

00:30:33,500 --> 00:30:37,490

In fact, the DSM-5
moved away from

589

00:30:37,490 --> 00:30:41,450

the three distinct
autism diagnoses to

590

00:30:41,450 --> 00:30:44,314

a single unified autism diagnosis

591

00:30:44,314 --> 00:30:45,919

because they recognized that at

592

00:30:45,919 --> 00:30:47,825

different points in
a person's life

593

00:30:47,825 --> 00:30:50,390

they might receive all
of these diagnoses

594

00:30:50,390 --> 00:30:52,790

and that they were
applied wildly unevenly.

595

00:30:52,790 --> 00:30:54,860

And we actually, with

596

00:30:54,860 --> 00:30:59,690

very rare exceptions
relating to the small,

597

00:30:59,690 --> 00:31:02,179
tiny minuscule percentage
of instances of

598

00:31:02,179 --> 00:31:05,329
autism where we have a
clear genetic etiology,

599

00:31:05,329 --> 00:31:07,100
we don't really have

600

00:31:07,100 --> 00:31:09,679
any clear understanding of

601

00:31:09,679 --> 00:31:12,980
the different phenotypes
within the autism diagnosis.

602

00:31:12,980 --> 00:31:14,734
In addition,

603

00:31:14,734 --> 00:31:18,950
although neurodiversity
advocates are painted

604

00:31:18,950 --> 00:31:21,844
by their opponents
as representing

605

00:31:21,844 --> 00:31:25,474
only the, quote, unquote,
"high-functioning"--

606

00:31:25,474 --> 00:31:27,589
and I will say I don't love the term

607

00:31:27,589 --> 00:31:29,510
high-functioning because it has

608

00:31:29,510 --> 00:31:31,279
no definition and because it has

609

00:31:31,279 --> 00:31:34,189
its roots
in the high-grade/

610
00:31:34,189 --> 00:31:37,970
low-grade terminology of
institutionalization--

611
00:31:37,970 --> 00:31:40,639
but because that is,

612
00:31:40,639 --> 00:31:43,699
despite the fact that neurodiversity advocates are

613
00:31:43,699 --> 00:31:46,340
painted as universally

614
00:31:46,340 --> 00:31:48,500
presenting those with
less severe impairments,

615
00:31:48,500 --> 00:31:51,244
there are in fact
many autistic people

616
00:31:51,244 --> 00:31:52,939
and many family members of

617
00:31:52,939 --> 00:31:56,764
autistic people with
more severe impairments

618
00:31:56,764 --> 00:31:59,404
that support the neurodiversity movement.

619
00:31:59,404 --> 00:32:02,254
And then finally, crucially,

620
00:32:02,254 --> 00:32:07,039
the neurodiversity
perspective argues that

621

00:32:07,039 --> 00:32:11,420
the emphasis on
indistinguishability from peers,

622
00:32:11,420 --> 00:32:12,440
that the emphasis on

623
00:32:12,440 --> 00:32:18,005
typical adherence
harms autistic people

624
00:32:18,005 --> 00:32:21,709
even if you are not able to talk.

625
00:32:21,709 --> 00:32:23,450
Even if you also have

626
00:32:23,450 --> 00:32:26,030
a co-occurring
intellectual disability.

627
00:32:26,030 --> 00:32:30,650
I'm going to talk a
little bit about how

628
00:32:30,650 --> 00:32:35,149
that point of view is actually
consistent with seeking

629
00:32:35,149 --> 00:32:38,884
service provision, support,
and even amelioration

630
00:32:38,884 --> 00:32:43,234
of impairments and intrinsically
harmful characteristics.

631
00:32:43,234 --> 00:32:47,659
But the approach of again,

632
00:32:47,659 --> 00:32:50,660
segmenting out autism is one

633
00:32:50,660 --> 00:32:53,839
that neurodiversity activists

634
00:32:53,839 --> 00:32:57,679
reject as the compromise

635
00:32:57,679 --> 00:33:01,040
to resolve the divides
in the autism world.

636
00:33:01,040 --> 00:33:04,669
So I'm gonna skip forward a

637
00:33:04,669 --> 00:33:08,960
little bit just in
order to maintain time.

638
00:33:08,960 --> 00:33:12,260
But the traditional approach,

639
00:33:12,260 --> 00:33:14,240
as we talked about earlier,

640
00:33:14,240 --> 00:33:21,784
is to equate autistic
traits with autistic challenges.

641
00:33:21,784 --> 00:33:26,090
And the way this thinking
goes more or less is

642
00:33:26,090 --> 00:33:28,970
autistic people
display unusual traits

643
00:33:28,970 --> 00:33:32,360
such as repetitive behavior
and lack of eye contact.

644
00:33:32,360 --> 00:33:35,810
Autistic people also
experienced challenges like

645
00:33:35,810 --> 00:33:37,939
social communication difficulties

646
00:33:37,939 --> 00:33:40,475
and self-injurious behavior.

647
00:33:40,475 --> 00:33:43,129
Non-autistic people don't display

648
00:33:43,129 --> 00:33:46,055
these traits or experience
these challenges.

649
00:33:46,055 --> 00:33:49,790
Therefore, the way to
mitigate these challenges is

650
00:33:49,790 --> 00:33:51,500
to suppress autistic traits

651
00:33:51,500 --> 00:33:53,884
and promote non-autistic ones.

652
00:33:53,884 --> 00:33:57,289
And part of the concern
with this logic is it

653
00:33:57,289 --> 00:34:01,490
seems to place the form of

654
00:34:01,490 --> 00:34:05,849
certain behaviors
over their function.

655
00:34:06,700 --> 00:34:11,089
Neurodiversity argues that there

656
00:34:11,089 --> 00:34:14,809
are unusual autistic traits

657

00:34:14,809 --> 00:34:18,019
and there are
autistic challenges.

658
00:34:18,019 --> 00:34:20,990
And they're both
caused by autism.

659
00:34:20,990 --> 00:34:24,784
But one does not necessarily
cause the other.

660
00:34:24,784 --> 00:34:29,599
That suppressing
stimming behavior

661
00:34:29,599 --> 00:34:34,685
or promoting eye contact does not

662
00:34:34,685 --> 00:34:37,370
actually correspond to improving

663
00:34:37,370 --> 00:34:39,574
social communication
skills because

664
00:34:39,574 --> 00:34:42,320
social communication
challenges are not

665
00:34:42,320 --> 00:34:46,010
caused by lack of eye contact,

666
00:34:46,010 --> 00:34:48,230
but they're caused by

667
00:34:48,230 --> 00:34:52,534
the underlying
neurological differences

668
00:34:52,534 --> 00:34:55,565
that represent the
disability of autism,

669
00:34:55,565 --> 00:34:58,955
which may also cause eye contact.

670
00:34:58,955 --> 00:35:00,320
But you can't form

671
00:35:00,320 --> 00:35:03,769
a direct causal relationship
from the fact that

672
00:35:03,769 --> 00:35:05,990
someone doesn't
make eye contact to

673
00:35:05,990 --> 00:35:08,720
the fact that they have social
communication challenges.

674
00:35:08,720 --> 00:35:12,439
Autistic people may find

675
00:35:12,439 --> 00:35:14,719
that there are other
ways to address

676
00:35:14,719 --> 00:35:17,899
social communication
challenges other than

677
00:35:17,899 --> 00:35:21,815
making eye contact that
are more effective for us

678
00:35:21,815 --> 00:35:24,260
because autistic people are in

679
00:35:24,260 --> 00:35:27,710
a meaningful way different
than non-autistic people.

680
00:35:27,710 --> 00:35:29,599

So endeavoring to imitate

681

00:35:29,599 --> 00:35:32,840
non-autistic behavior
may not lead to

682

00:35:32,840 --> 00:35:35,299
the same results that it would if

683

00:35:35,299 --> 00:35:39,770
that same behavior was applied
in a non-autistic person.

684

00:35:39,770 --> 00:35:42,289
And we've tried to operationalize

685

00:35:42,289 --> 00:35:44,629
this in a number of different ways.

686

00:35:44,629 --> 00:35:47,359
I'll show you
some screenshots from

687

00:35:47,359 --> 00:35:49,939
the DSM-5 autism criteria.

688

00:35:49,939 --> 00:35:52,730
And I had the
pleasure of advising

689

00:35:52,730 --> 00:35:56,120
the DSM-5 Neurodevelopmental
Disorders Taskforce.

690

00:35:56,120 --> 00:35:59,794
I worked with Dr. Steven Kapp and a

691

00:35:59,794 --> 00:36:04,294
number of other folks at
ASAN to produce advice.

692

00:36:04,294 --> 00:36:05,750

There are a number
of things that were

693

00:36:05,750 --> 00:36:07,940
incorporated based
on our feedback.

694

00:36:07,940 --> 00:36:11,960
One was the new DSM-5 criteria

695

00:36:11,960 --> 00:36:13,850
for autism. I shouldn't say new.

696

00:36:13,850 --> 00:36:15,154
They're seven years old now.

697

00:36:15,154 --> 00:36:16,939
But the DSM-5 criteria for

698

00:36:16,939 --> 00:36:21,620
autism acknowledges
that autistic people,

699

00:36:21,620 --> 00:36:23,600
because of passing demands from

700

00:36:23,600 --> 00:36:26,630
clinicians or from
the larger society,

701

00:36:26,630 --> 00:36:31,219
may be camouflaging or
masking autistic traits,

702

00:36:31,219 --> 00:36:32,599
but that they are still

703

00:36:32,599 --> 00:36:35,510
autistic and that
they shouldn't lose

704

00:36:35,510 --> 00:36:40,354

their diagnosis by virtue
of learned behavior

705

00:36:40,354 --> 00:36:43,564
that lets them look non-autistic.

706

00:36:43,564 --> 00:36:48,470
We also were very concerned
by early proposals

707

00:36:48,470 --> 00:36:52,820
to add a severity scale
to the autism diagnosis.

708

00:36:52,820 --> 00:36:55,670
And early versions of
the severity scale

709

00:36:55,670 --> 00:37:01,820
included as instances
of greater severity

710

00:37:01,820 --> 00:37:05,674
individuals who had

711

00:37:05,674 --> 00:37:10,369
excessively focused
or fixated interests.

712

00:37:10,369 --> 00:37:11,840
And we worked with

713

00:37:11,840 --> 00:37:15,605
the DSM-5 committee to in fact
change the severity scale.

714

00:37:15,605 --> 00:37:17,389
These are the two instances,

715

00:37:17,389 --> 00:37:19,699
what's present within
it currently.

716
00:37:19,699 --> 00:37:23,375
To instead focus on

717
00:37:23,375 --> 00:37:25,969
the level of support
someone requires

718
00:37:25,969 --> 00:37:30,410
and to really be oriented
towards things that

719
00:37:30,410 --> 00:37:35,030
autistic people might find
personally distressing

720
00:37:35,030 --> 00:37:38,269
rather than autistic traits

721
00:37:38,269 --> 00:37:40,894
that many of us would
find pleasurable,

722
00:37:40,894 --> 00:37:45,665
like our focused
interests or even neutral,

723
00:37:45,665 --> 00:37:48,050
like stimming or rocking.

724
00:37:48,050 --> 00:37:49,820
We generally do not want to see

725
00:37:49,820 --> 00:37:52,099
a severity scale which has

726
00:37:52,099 --> 00:37:55,519
the sizeable possibility
of being used as

727
00:37:55,519 --> 00:37:59,884
a proxy for treatment outcomes

728
00:37:59,884 --> 00:38:02,360
be defined in such a way that

729
00:38:02,360 --> 00:38:04,535
tells providers that they should

730
00:38:04,535 --> 00:38:09,170
seek to reduce pleasurable
or neutral autistic traits.

731
00:38:09,170 --> 00:38:10,399
Instead, we want it

732
00:38:10,399 --> 00:38:13,429
organized, if we have to have
a severity scale at all,

733
00:38:13,429 --> 00:38:15,214
which I think some
of us question,

734
00:38:15,214 --> 00:38:17,119
we want it organized

735
00:38:17,119 --> 00:38:20,810
around need for
support and areas of

736
00:38:20,810 --> 00:38:24,710
difficulty where
autistic people and

737
00:38:24,710 --> 00:38:27,424
the neurodiversity
critique does accept

738
00:38:27,424 --> 00:38:32,190
the need for some service
provision and intervention.

739
00:38:32,380 --> 00:38:34,610
And if you want to

read more about

740

00:38:34,610 --> 00:38:36,500
our work with the
DSM-5 committee,

741

00:38:36,500 --> 00:38:38,600
there's a fantastic book chapter

742

00:38:38,600 --> 00:38:40,759
Stephen and I wrote
about this available in

743

00:38:40,759 --> 00:38:43,009
a new anthology called

744

00:38:43,009 --> 00:38:46,620
Autistic Community in the
Neurodiversity Movement.

745

00:38:46,690 --> 00:38:49,429
Now, what if we want to go

746

00:38:49,429 --> 00:38:52,969
beyond the diagnostic
criteria for autism?

747

00:38:52,969 --> 00:38:58,594
Because in general,
service providers rely

748

00:38:58,594 --> 00:39:01,549
on many tools other than

749

00:39:01,549 --> 00:39:03,229
the diagnostic criteria to

750

00:39:03,229 --> 00:39:06,335
decide how they're going
to deliver services.

751

00:39:06,335 --> 00:39:09,829

There's the old saying
"In God we trust, others

752
00:39:09,829 --> 00:39:11,255
must provide data."

753
00:39:11,255 --> 00:39:15,439
That saying has in
some positive and in

754
00:39:15,439 --> 00:39:17,419
some very negative ways really

755
00:39:17,419 --> 00:39:19,895
dominated in the autism world.

756
00:39:19,895 --> 00:39:21,890
There has been a
very heavy emphasis

757
00:39:21,890 --> 00:39:25,670
on data collection.

758
00:39:25,670 --> 00:39:28,849
That presents both a challenge and

759
00:39:28,849 --> 00:39:32,450
an opportunity for neurodiversity advocates

760
00:39:32,450 --> 00:39:35,794
in that we can look at
some of the measures,

761
00:39:35,794 --> 00:39:39,739
the outcome measures
being used to evaluate

762
00:39:39,739 --> 00:39:44,299
autism interventions, and really

763
00:39:44,299 --> 00:39:48,170
deconstruct which

components of them

764

00:39:48,170 --> 00:39:50,570
do or don't align with

765

00:39:50,570 --> 00:39:53,330
the principles of the
neurodiversity movement.

766

00:39:53,330 --> 00:39:56,449
And I'm going to show you some
examples here that really

767

00:39:56,449 --> 00:39:59,359
get into some of the
nitty gritty of

768

00:39:59,359 --> 00:40:03,169
how we can begin to define
what neurodiversity

769

00:40:03,169 --> 00:40:07,445
might mean for service
provision and research,

770

00:40:07,445 --> 00:40:09,409
both contexts in which

771

00:40:09,409 --> 00:40:14,989
these clinical instruments
are frequently utilized.

772

00:40:14,989 --> 00:40:18,844
This is the Social
Reciprocity Scale.

773

00:40:18,844 --> 00:40:20,449
This is an example of a

774

00:40:20,449 --> 00:40:23,524
few items from the Social
Reciprocity Scale.

775

00:40:23,524 --> 00:40:26,089

And one of the things you
see very clearly here

776

00:40:26,089 --> 00:40:28,700

is the Social Reciprocity Scale,

777

00:40:28,700 --> 00:40:31,220

which is very frequently utilized

778

00:40:31,220 --> 00:40:36,215

in both clinical trials,

779

00:40:36,215 --> 00:40:38,435

a wide variety of
research studies,

780

00:40:38,435 --> 00:40:40,460

and in some clinical practice

781

00:40:40,460 --> 00:40:43,190

in autism, includes a number of

782

00:40:43,190 --> 00:40:48,020

items in assessing
social reciprocity

783

00:40:48,020 --> 00:40:51,680

that from the neurodiversity perspective

784

00:40:51,680 --> 00:40:54,439

we might find
somewhat concerning.

785

00:40:54,439 --> 00:40:59,059

For example, Item
16: does a child,

786

00:40:59,059 --> 00:41:00,919

and this is the
children's version

787

00:41:00,919 --> 00:41:02,795
of the Social Reciprocity Scale,

788

00:41:02,795 --> 00:41:06,935
avoid eye contact or have
unusual eye contact.

789

00:41:06,935 --> 00:41:09,874
If someone does then they receive

790

00:41:09,874 --> 00:41:13,309
a score of greater severity.

791

00:41:13,309 --> 00:41:16,189
And one of the things
that the SRS is

792

00:41:16,189 --> 00:41:19,250
used for in clinical
trials is in evaluating

793

00:41:19,250 --> 00:41:22,819
whether an intervention
results in

794

00:41:22,819 --> 00:41:25,355
a reduction of severity

795

00:41:25,355 --> 00:41:28,429
or an increase in
social reciprocity.

796

00:41:28,429 --> 00:41:30,440
And from that standpoint,

797

00:41:30,440 --> 00:41:32,329
it becomes very concerning if you

798

00:41:32,329 --> 00:41:34,639
have items within the SRS,

799

00:41:34,639 --> 00:41:37,879
within the tool used to
measure social reciprocity,

800
00:41:37,879 --> 00:41:40,489
that assumes that the only way

801
00:41:40,489 --> 00:41:43,385
by which autistic
people can measure,

802
00:41:43,385 --> 00:41:47,840
can express social reciprocity
and can be successful

803
00:41:47,840 --> 00:41:50,419
in social communication
is through

804
00:41:50,419 --> 00:41:53,690
the same ways as
non-autistic people.

805
00:41:53,690 --> 00:41:55,819
And so the fact that

806
00:41:55,819 --> 00:42:00,334
the SRS--and there are other
examples throughout the SRS--

807
00:42:00,334 --> 00:42:06,289
embeds essentially a
passing demand into how it

808
00:42:06,289 --> 00:42:09,109
evaluates progress in

809
00:42:09,109 --> 00:42:13,640
autism interventions
becomes very concerning.

810
00:42:13,640 --> 00:42:16,010
Again, looking at whether or not

811
00:42:16,010 --> 00:42:18,050
someone is avoiding
eye contact is

812
00:42:18,050 --> 00:42:19,879
a perfectly legitimate
thing to do

813
00:42:19,879 --> 00:42:22,115
if you're trying to
diagnose autism.

814
00:42:22,115 --> 00:42:24,470
It's true autistic
people do avoid

815
00:42:24,470 --> 00:42:28,669
eye contact. That is
characteristic of autism.

816
00:42:28,669 --> 00:42:31,069
It's a much more
problematic thing to

817
00:42:31,069 --> 00:42:33,770
do if what you're trying
to do is evaluate

818
00:42:33,770 --> 00:42:35,554
whether or not an intervention

819
00:42:35,554 --> 00:42:39,184
is working and
working in the sense

820
00:42:39,184 --> 00:42:45,185
of delivering additional
value to people's lives

821
00:42:45,185 --> 00:42:47,600
because it defined success

822
00:42:47,600 --> 00:42:50,374
as the reduction of
autistic traits.

823
00:42:50,374 --> 00:42:53,300
Of course, not all items

824
00:42:53,300 --> 00:42:56,194
within the SRS-2
have these problems.

825
00:42:56,194 --> 00:42:58,700
So let's see: difficulty
and making friends.

826
00:42:58,700 --> 00:43:01,460
I think we can all
agree that improving

827
00:43:01,460 --> 00:43:02,990
the ability to make friends

828
00:43:02,990 --> 00:43:05,600
and improving social
relationships

829
00:43:05,600 --> 00:43:08,090
that people have access to is

830
00:43:08,090 --> 00:43:12,665
a goal that we can all get
behind. No critique there.

831
00:43:12,665 --> 00:43:15,229
But again, you do see, and

832
00:43:15,229 --> 00:43:17,870
here we have the young
adult version of the SRS,

833
00:43:17,870 --> 00:43:20,059
a number of items that

834
00:43:20,059 --> 00:43:22,805
are concerning from the
neurodiversity perspective.

835
00:43:22,805 --> 00:43:26,300
"I have repetitive behaviors
that others consider odd."

836
00:43:26,300 --> 00:43:29,869
It's really, I think, very
questionable ethically

837
00:43:29,869 --> 00:43:33,410
if it is the
appropriate province of

838
00:43:33,410 --> 00:43:38,495
service providers to
define success as

839
00:43:38,495 --> 00:43:42,964
reducing behaviors that others
consider odd just because

840
00:43:42,964 --> 00:43:48,695
they are associated with and
characteristic of autism.

841
00:43:48,695 --> 00:43:53,014
Similarly, monotone voice and

842
00:43:53,014 --> 00:43:57,859
efforts to modify autistic
prosody, and so on.

843
00:43:57,859 --> 00:44:01,099
These are traits that may
be socially stigmatized,

844
00:44:01,099 --> 00:44:05,340
but they are not in any
sense intrinsically harmful.

845
00:44:05,340 --> 00:44:09,970
This is the CYBOCS-ASD.
CYBOCS itself is

846
00:44:09,970 --> 00:44:14,799
a measure of obsessive
compulsive behavior designed for

847
00:44:14,799 --> 00:44:21,309
OCD. The CYBOCS-ASD,
and I should have noted at

848
00:44:21,309 --> 00:44:24,459
the bottom it was developed
by Lawrence Scahill and

849
00:44:24,459 --> 00:44:26,139
his research group
was kind enough

850
00:44:26,139 --> 00:44:28,305
to provide me with a copy.

851
00:44:28,305 --> 00:44:32,499
CYBOCS-ASD is an
adaptation of the CYBOCS

852
00:44:32,499 --> 00:44:37,044
specifically designed for
use with autistic people.

853
00:44:37,044 --> 00:44:40,449
And it's been utilized
in clinical trials.

854
00:44:40,449 --> 00:44:43,449
A few colleagues of mine
and I actually had a letter

855
00:44:43,449 --> 00:44:46,585
earlier this year in the
Journal of American Medicine [JAMA]

856
00:44:46,585 --> 00:44:49,789
critiquing a recent
drug trial for

857
00:44:49,789 --> 00:44:52,130
relying on the CYBOCS-ASD

858
00:44:52,130 --> 00:44:54,679
as its primary outcome measure

859
00:44:54,679 --> 00:44:58,189
because the CYBOCS-ASD,

860
00:44:58,189 --> 00:45:01,219
like the previous
example I provided

861
00:45:01,219 --> 00:45:03,095
although to an even
greater extent,

862
00:45:03,095 --> 00:45:08,390
defined success as the
reduction in autistic traits.

863
00:45:08,390 --> 00:45:09,950
And again, you can see here,

864
00:45:09,950 --> 00:45:12,530
there are a lot of
instances where when

865
00:45:12,530 --> 00:45:15,200
we actually look at the items

866
00:45:15,200 --> 00:45:17,060
we find that the traits in

867
00:45:17,060 --> 00:45:19,925
question are not in
any sense harmful.

868
00:45:19,925 --> 00:45:21,799
You know, there
are some instances--

869
00:45:21,799 --> 00:45:24,109
repetitive
self-injurious behavior,

870
00:45:24,109 --> 00:45:27,949
repetitive sexual behavior--that

871
00:45:27,949 --> 00:45:30,605
we can make a pretty
strong argument

872
00:45:30,605 --> 00:45:33,860
that these may be appropriate
targets for intervention.

873
00:45:33,860 --> 00:45:37,954
But informing
providers and families

874
00:45:37,954 --> 00:45:42,694
that they should define
success by reducing echolalia,

875
00:45:42,694 --> 00:45:46,039
reducing the need to

876
00:45:46,039 --> 00:45:50,314
repeat routine activities,
hand or arm flapping,

877
00:45:50,314 --> 00:45:55,459
repetitive play with certain
objects, trucks, trains, dinosaurs--

878
00:45:55,459 --> 00:46:01,565
these may be appropriate
diagnostic things to look for.

879
00:46:01,565 --> 00:46:04,279
They are not appropriate
in any sense of

880
00:46:04,279 --> 00:46:09,124
the term for targeting
for intervention.

881
00:46:09,124 --> 00:46:10,820
And if you look at how this

882
00:46:10,820 --> 00:46:13,325
plays out in the CYBOCS-ASD,

883
00:46:13,325 --> 00:46:15,814
the CYBOCS-ASD actually

884
00:46:15,814 --> 00:46:20,839
scores a child as more
severe if they would

885
00:46:20,839 --> 00:46:24,050
react with distress
if being prevented from

886
00:46:24,050 --> 00:46:28,430
performing repetitive behaviors
such as repetitive play,

887
00:46:28,430 --> 00:46:30,544
hand flapping, arm flapping.

888
00:46:30,544 --> 00:46:34,385
Similarly, a child is
scored as more severe

889
00:46:34,385 --> 00:46:41,750
if they do not try and
stop repetitive behavior.

890
00:46:41,750 --> 00:46:43,160
And again, these

are in part

891

00:46:43,160 --> 00:46:45,050
concepts that really come from

892

00:46:45,050 --> 00:46:47,629
applying a model that

893

00:46:47,629 --> 00:46:50,524
was really developed
for use in OCD

894

00:46:50,524 --> 00:46:53,119
and really only
modestly adapting it

895

00:46:53,119 --> 00:46:55,864
into the very different
context of autism.

896

00:46:55,864 --> 00:46:57,799
Autistic people
generally like our

897

00:46:57,799 --> 00:46:59,405
repetitive behaviors.

898

00:46:59,405 --> 00:47:02,089
In OCD, repetitive behaviors are

899

00:47:02,089 --> 00:47:04,685
distressing for the people
who experience them;

900

00:47:04,685 --> 00:47:07,160
really not in any
sense comparable.

901

00:47:07,160 --> 00:47:11,419
Similarly, if behaviors
are more peculiar

902

00:47:11,419 --> 00:47:15,350
they're scored as more severe
on the CYBOCS-ASD.

903
00:47:15,350 --> 00:47:17,329
And this is again,

904
00:47:17,329 --> 00:47:22,370
not just a matter of, for
lack of a better word

905
00:47:22,370 --> 00:47:25,264
I'm going to say
political correctness or

906
00:47:25,264 --> 00:47:28,985
terminology or social niceties.

907
00:47:28,985 --> 00:47:32,269
This has concrete impacts on

908
00:47:32,269 --> 00:47:36,020
how we evaluate what forms
of service provision,

909
00:47:36,020 --> 00:47:38,315
what forms of intervention,

910
00:47:38,315 --> 00:47:43,114
what forms of really almost
everything we do in autism

911
00:47:43,114 --> 00:47:44,885
whether or not they work.

912
00:47:44,885 --> 00:47:49,099
And it provides clear
instructions to providers and

913
00:47:49,099 --> 00:47:53,435
to families as to what
their goals should be.

914
00:47:53,435 --> 00:47:56,089
So from the CYBOCS-ASD

915
00:47:56,089 --> 00:47:57,799
and other similar
instruments, wheat,

916
00:47:57,799 --> 00:48:01,459
we really see families
and providers receiving

917
00:48:01,459 --> 00:48:03,320
the instruction that
they should reduce

918
00:48:03,320 --> 00:48:07,234
the peculiarity of
autistic behaviors.

919
00:48:07,234 --> 00:48:13,115
That autistic people should
be told to try and resist

920
00:48:13,115 --> 00:48:15,860
these behaviors which are
not harmful and may be

921
00:48:15,860 --> 00:48:18,934
pleasurable and that
come naturally to them.

922
00:48:18,934 --> 00:48:21,860
And I think it would be very
difficult to come up with

923
00:48:21,860 --> 00:48:23,510
a more clear instance about

924
00:48:23,510 --> 00:48:26,570
passing or a covering
demand than that.

925

00:48:26,570 --> 00:48:30,290
And that families
and providers should

926
00:48:30,290 --> 00:48:34,595
intervene to try and
prevent hand flapping,

927
00:48:34,595 --> 00:48:37,520
rocking, lack of eye contact and

928
00:48:37,520 --> 00:48:39,980
other perfectly
natural things for

929
00:48:39,980 --> 00:48:41,540
an autistic person to be doing

930
00:48:41,540 --> 00:48:44,285
that really don't harm anyone.

931
00:48:44,285 --> 00:48:47,690
And so that has a great
deal of relevance.

932
00:48:47,690 --> 00:48:49,700
And I believe that when we talk

933
00:48:49,700 --> 00:48:53,629
about operationalizing the
neurodiversity movement,

934
00:48:53,629 --> 00:48:57,600
taking it from something that
has shown up quite a bit in

935
00:48:58,090 --> 00:49:02,690
social criticism and
media criticism,

936
00:49:02,690 --> 00:49:05,119
and turning it into
something that can have

937
00:49:05,119 --> 00:49:07,610
very concrete impacts on

938
00:49:07,610 --> 00:49:11,044
the world of autism
service provision,

939
00:49:11,044 --> 00:49:14,029
research, and intervention,
which is really what

940
00:49:14,029 --> 00:49:16,010
neurodiversity was initially

941
00:49:16,010 --> 00:49:18,395
designed to try and influence,

942
00:49:18,395 --> 00:49:20,360
we really need to look at

943
00:49:20,360 --> 00:49:23,719
these outcome
measures and pressure

944
00:49:23,719 --> 00:49:26,705
and urge their revision

945
00:49:26,705 --> 00:49:30,749
in order to try and
shift clinical practice.

946
00:49:30,760 --> 00:49:33,514
One other thing I'll
highlight here.

947
00:49:33,514 --> 00:49:38,000
We have seen, I think
even some researchers,

948
00:49:38,000 --> 00:49:40,625
even some traditional

autism researchers

949

00:49:40,625 --> 00:49:43,699
are recognizing that this
is a little problematic,

950

00:49:43,699 --> 00:49:46,414
although not necessarily
for ethical reasons.

951

00:49:46,414 --> 00:49:48,290
We've seen the ADOS-2,

952

00:49:48,290 --> 00:49:49,550
which is one of the major

953

00:49:49,550 --> 00:49:51,979
diagnostic instruments
for autism,

954

00:49:51,979 --> 00:49:54,649
utilized as a measure
of clinical outcomes.

955

00:49:54,649 --> 00:49:56,299
And this really goes back to

956

00:49:56,299 --> 00:50:00,770
that concept that we
saw on that CARD page

957

00:50:00,770 --> 00:50:02,989
and that's really
embedded within ABA and

958

00:50:02,989 --> 00:50:05,629
a lot of other thinking in
autism service provision

959

00:50:05,629 --> 00:50:08,584
that the goal of intervention
should be to try

960
00:50:08,584 --> 00:50:12,080
and make an autistic
person a look and

961
00:50:12,080 --> 00:50:15,695
act as non-autistic
as possible, to

962
00:50:15,695 --> 00:50:18,350
reduce traits associated with

963
00:50:18,350 --> 00:50:21,425
the diagnosis independent
of whether or not they are

964
00:50:21,425 --> 00:50:25,399
harmful or distressing
to the individual.

965
00:50:25,399 --> 00:50:28,550
So really the underlying
message here is we

966
00:50:28,550 --> 00:50:31,550
have to separate diagnosis and

967
00:50:31,550 --> 00:50:33,664
outcome measurement and recognize

968
00:50:33,664 --> 00:50:35,030
that some of these tools may be

969
00:50:35,030 --> 00:50:39,095
perfectly appropriate
in diagnosing autism

970
00:50:39,095 --> 00:50:42,229
because they do accurately
describe ways in which

971
00:50:42,229 --> 00:50:46,490
autistic people are different

from non-autistic people,

972

00:50:46,490 --> 00:50:50,150
but they are highly inappropriate

973

00:50:50,150 --> 00:50:52,820
for defining what the goals

974

00:50:52,820 --> 00:50:54,980
of service provision should be

975

00:50:54,980 --> 00:50:56,614
because autistic people will

976

00:50:56,614 --> 00:50:58,760
continue to be different from

977

00:50:58,760 --> 00:51:02,929
non-autistic people even
after intensive intervention,

978

00:51:02,929 --> 00:51:07,359
and that passing
demands imbedded within

979

00:51:07,359 --> 00:51:10,030
clinical practice may result in

980

00:51:10,030 --> 00:51:13,119
autistic people
that appear typical

981

00:51:13,119 --> 00:51:16,899
but this ignores the
considerable personal

982

00:51:16,899 --> 00:51:21,130
distress, harm, and effort that is

983

00:51:21,130 --> 00:51:23,860
imposed upon autistic people that

984

00:51:23,860 --> 00:51:27,070
autistic people are burdened
with as a result of

985

00:51:27,070 --> 00:51:32,170
these passing demands that
have been, that have become

986

00:51:32,170 --> 00:51:35,349
pervasive in the culture

987

00:51:35,349 --> 00:51:39,040
of autism service provision
and intervention.

988

00:51:39,040 --> 00:51:44,889
So I want to take a few minutes
here before I wrap up.

989

00:51:44,889 --> 00:51:46,849
I think I can take
another--what do you

990

00:51:46,849 --> 00:51:49,069
think, Ken--10 minutes before I

991

00:51:49,069 --> 00:51:51,689
wrap up and then
we'll have time for questions?

992

00:51:51,689 --> 00:51:53,750
[Ken Richman] That sounds fine. We
all want to hear

993

00:51:53,750 --> 00:51:58,205
what you have to say, and although
people may have other places to go

994

00:51:58,205 --> 00:52:03,209
my Zoom is pretty much unlimited, so we can hang out until you're
exhausted.

995

00:52:03,580 --> 00:52:06,529
[Ari Ne'eman] I think we'll probably
still hit the 2:30 mark,

996
00:52:06,529 --> 00:52:10,100
but I'll take
another ten minutes

997
00:52:10,100 --> 00:52:13,094
to wrap up.
[Ken Richman] Sounds good.

998
00:52:13,094 --> 00:52:17,870
[Ari Ne'eman] A couple of additional things here.
Now, I think it is

999
00:52:17,870 --> 00:52:20,840
important to acknowledge
that there may be

1000
00:52:20,840 --> 00:52:26,690
some circumstances
where instruction

1001
00:52:26,690 --> 00:52:29,600
in passing might be legitimate.

1002
00:52:29,600 --> 00:52:32,089
We should maintain a
strong presumption

1003
00:52:32,089 --> 00:52:35,765
against the use of passing
demands in clinical practice.

1004
00:52:35,765 --> 00:52:38,675
But there might be
some circumstances

1005
00:52:38,675 --> 00:52:45,149
where a service provider
might legitimately and

1006

00:52:45,149 --> 00:52:50,090
ethically provide service
provision that has

1007
00:52:50,090 --> 00:52:53,389
the effect of reducing

1008
00:52:53,389 --> 00:52:56,390
a trait that is
associated with autism.

1009
00:52:56,390 --> 00:52:58,940
But I think we should
have a very high bar.

1010
00:52:58,940 --> 00:53:00,860
I'm going to try and
illustrate some of

1011
00:53:00,860 --> 00:53:02,959
the relevant ethical
considerations

1012
00:53:02,959 --> 00:53:06,379
here with examples outside
of the world of autism

1013
00:53:06,379 --> 00:53:12,079
because I think in many
ways the culture of

1014
00:53:12,079 --> 00:53:15,139
emphasizing indistinguishability
from peers is so

1015
00:53:15,139 --> 00:53:17,060
intense in the
autism world that it

1016
00:53:17,060 --> 00:53:19,354
can be useful to
step outside of it

1017

00:53:19,354 --> 00:53:21,800
in order to illustrate some of

1018
00:53:21,800 --> 00:53:23,644
the general principles we may

1019
00:53:23,644 --> 00:53:26,839
extrapolate back into
the world of autism.

1020
00:53:26,839 --> 00:53:30,109
So here's an instance that I find

1021
00:53:30,109 --> 00:53:33,199
very concerning. It's a news story

1022
00:53:33,199 --> 00:53:39,695
from 2012 about a family

1023
00:53:39,695 --> 00:53:41,840
whose 15-year-old son with

1024
00:53:41,840 --> 00:53:45,665
Down Syndrome has gotten cosmetic surgery

1025
00:53:45,665 --> 00:53:51,830
to make his ears look more normal.

1026
00:53:51,830 --> 00:53:54,934
And this is, this is
cosmetic surgery.

1027
00:53:54,934 --> 00:53:59,900
It's very similar to surgery
that used to be done,

1028
00:53:59,900 --> 00:54:02,945
generally considered
unethical now,

1029
00:54:02,945 --> 00:54:08,029
to modify the eyes of people

with Down Syndrome to

1030

00:54:08,029 --> 00:54:09,739
make them look more

1031

00:54:09,739 --> 00:54:13,414
like more typical,
typically appearing.

1032

00:54:13,414 --> 00:54:15,380
And the frame that's

1033

00:54:15,380 --> 00:54:17,300
that's provided
here is this person

1034

00:54:17,300 --> 00:54:21,274
was bullied because
of their ears.

1035

00:54:21,274 --> 00:54:26,060
They received cosmetic surgery
and now they're thrilled.

1036

00:54:26,060 --> 00:54:28,670
And so what's the problem?

1037

00:54:28,670 --> 00:54:30,904
And I think many of us,

1038

00:54:30,904 --> 00:54:32,764
again, going back to that

1039

00:54:32,764 --> 00:54:34,309
Kenji Yoshino quote at

1040

00:54:34,309 --> 00:54:36,094
the beginning of
our presentation,

1041

00:54:36,094 --> 00:54:38,615
"who has to change,"

1042
00:54:38,615 --> 00:54:42,274
would find this to be
somewhat concerning.

1043
00:54:42,274 --> 00:54:45,769
That the idea that we
are going to respond to

1044
00:54:45,769 --> 00:54:51,139
social stigma solely by
modifying the individual,

1045
00:54:51,139 --> 00:54:52,789
and that we are

1046
00:54:52,789 --> 00:54:54,650
essentially
going to accept

1047
00:54:54,650 --> 00:54:59,119
the legitimacy of that
bullying by saying we are

1048
00:54:59,119 --> 00:55:03,079
going to change a
person's appearance

1049
00:55:03,079 --> 00:55:06,319
in a way that
has no underlying,

1050
00:55:06,319 --> 00:55:11,000
no other purpose other
than to make them try and

1051
00:55:11,000 --> 00:55:13,489
pass as normal is

1052
00:55:13,489 --> 00:55:15,109
something that should raise

1053

00:55:15,109 --> 00:55:17,345
real ethical red flags for us.

1054
00:55:17,345 --> 00:55:18,890
So that's, that's actually

1055
00:55:18,890 --> 00:55:20,705
helpful and a lot
of ways because it

1056
00:55:20,705 --> 00:55:23,719
highlights one initial question

1057
00:55:23,719 --> 00:55:25,444
that we might want to ask

1058
00:55:25,444 --> 00:55:31,580
when subjecting
any form of instruction or

1059
00:55:31,580 --> 00:55:33,635
intervention that may have

1060
00:55:33,635 --> 00:55:38,630
the effect of increasing
passing to evaluation.

1061
00:55:38,630 --> 00:55:41,000
Namely, does it serve

1062
00:55:41,000 --> 00:55:44,449
any purpose other than
promoting passing?

1063
00:55:44,449 --> 00:55:48,065
Cosmetic surgery really doesn't.

1064
00:55:48,065 --> 00:55:50,600
Does an intervention serve

1065
00:55:50,600 --> 00:55:53,690
any purpose other than

promoting typical appearance?

1066

00:55:53,690 --> 00:55:56,239
There are interventions that

1067

00:55:56,239 --> 00:55:58,700
may make someone
look more typical,

1068

00:55:58,700 --> 00:56:04,130
but actually have other
underlying purposes.

1069

00:56:04,130 --> 00:56:06,409
One example that comes up

1070

00:56:06,409 --> 00:56:08,975
and I'm going to come
back to this in a moment,

1071

00:56:08,975 --> 00:56:15,830
is you have many
people who may have

1072

00:56:15,830 --> 00:56:19,084
mobility impairments and may

1073

00:56:19,084 --> 00:56:22,895
opt to use crutches
rather than a wheelchair.

1074

00:56:22,895 --> 00:56:24,560
And I'll talk a little bit more

1075

00:56:24,560 --> 00:56:25,939
about the pros and cons that

1076

00:56:25,939 --> 00:56:27,830
many people with
mobility impairments

1077

00:56:27,830 --> 00:56:30,020

go through in
thinking about that.

1078
00:56:30,020 --> 00:56:33,380
One reason why they
might opt to do that is

1079
00:56:33,380 --> 00:56:36,499
to look or appear more typical.

1080
00:56:36,499 --> 00:56:39,950
But another reason why they
might opt to do that is

1081
00:56:39,950 --> 00:56:44,000
to have the ability
to traverse stairs.

1082
00:56:44,000 --> 00:56:47,959
And I think you get into a
very interesting discussion

1083
00:56:47,959 --> 00:56:52,640
there as to if you are
a service provider

1084
00:56:52,640 --> 00:56:54,620
and you're talking to someone

1085
00:56:54,620 --> 00:56:57,890
about their desire to select

1086
00:56:57,890 --> 00:57:01,490
a particular mobility aid
or their desire to select

1087
00:57:01,490 --> 00:57:03,829
some other intervention that has

1088
00:57:03,829 --> 00:57:06,980
both passing a
non-passing purposes,

1089

00:57:06,980 --> 00:57:09,710
why is someone seeking

1090

00:57:09,710 --> 00:57:11,720
a particular goal? Is it solely

1091

00:57:11,720 --> 00:57:14,449
because they went to look
as normal as possible?

1092

00:57:14,449 --> 00:57:16,264
While if it's an adult,

1093

00:57:16,264 --> 00:57:18,170
they have the right to
make their own decisions

1094

00:57:18,170 --> 00:57:19,939
but you still might want
to have a conversation

1095

00:57:19,939 --> 00:57:22,055
with them, if it's a child,

1096

00:57:22,055 --> 00:57:25,490
especially if it's a demand

1097

00:57:25,490 --> 00:57:28,025
being placed on the
child by their parents--

1098

00:57:28,025 --> 00:57:29,780
I don't want you to
use a wheelchair.

1099

00:57:29,780 --> 00:57:32,780
I want you to use a crutch
because it looks more

1100

00:57:32,780 --> 00:57:35,960
normal--then that might
be more concerning.

1101
00:57:35,960 --> 00:57:40,130
Alternatively, if the primary
reason someone is seeking

1102
00:57:40,130 --> 00:57:46,130
an intervention that may have
incidental passing effects

1103
00:57:46,130 --> 00:57:49,400
but is primarily

1104
00:57:49,400 --> 00:57:53,105
being sought for
non-passing purposes,

1105
00:57:53,105 --> 00:57:57,034
that might conceivably
be legitimate. And

1106
00:57:57,034 --> 00:58:01,220
it's not necessarily by
itself sufficient reason.

1107
00:58:01,220 --> 00:58:03,019
Not every passing demand with

1108
00:58:03,019 --> 00:58:05,119
a non-passing
purpose is ethical.

1109
00:58:05,119 --> 00:58:06,679
There might be multiple means

1110
00:58:06,679 --> 00:58:08,510
of accomplishing the same goal.

1111
00:58:08,510 --> 00:58:12,199
But I would argue
that the existence of

1112
00:58:12,199 --> 00:58:14,179

a non-passing purpose is

1113

00:58:14,179 --> 00:58:16,640
an important prerequisite in

1114

00:58:16,640 --> 00:58:19,324
evaluating whether
or not a passing,

1115

00:58:19,324 --> 00:58:22,774
whether or not
instruction in passing,

1116

00:58:22,774 --> 00:58:24,560
rather than the passing demand,

1117

00:58:24,560 --> 00:58:27,604
might conceivably be legitimate.

1118

00:58:27,604 --> 00:58:32,349
I'd also highlight whether
or not a trait is

1119

00:58:32,349 --> 00:58:36,999
personally distressing.
In the context of autism

1120

00:58:36,999 --> 00:58:40,014
we're usually talking
about specific traits.

1121

00:58:40,014 --> 00:58:44,754
So if we were to see the
neurodiversity

1122

00:58:44,754 --> 00:58:47,109
movement's critique taken more

1123

00:58:47,109 --> 00:58:48,939
seriously in clinical practice,

1124

00:58:48,939 --> 00:58:50,485

one of the things that we would

1125

00:58:50,485 --> 00:58:53,050
find ourselves doing
is going through

1126

00:58:53,050 --> 00:58:55,810
instruments like the
CYBOCS and the SRS-2

1127

00:58:55,810 --> 00:58:59,109
and many others and
saying, all right,

1128

00:58:59,109 --> 00:59:01,540
at least for the purposes of this

1129

00:59:01,540 --> 00:59:04,194
instrument's use in
outcome measurement,

1130

00:59:04,194 --> 00:59:07,000
we need to pick out
those things that are

1131

00:59:07,000 --> 00:59:11,610
legitimate to incorporate.
and are legitimate

1132

00:59:11,610 --> 00:59:13,665
to make goals of
service provision,

1133

00:59:13,665 --> 00:59:16,410
and those things that
are not legitimate.

1134

00:59:16,410 --> 00:59:20,190
And one of the questions
we might find is,

1135

00:59:20,190 --> 00:59:25,004
is somebody distressed

by the existence of a trait?

1136

00:59:25,004 --> 00:59:30,315

But here we come back to
this example previously.

1137

00:59:30,315 --> 00:59:33,209

Someone may be distressed by

1138

00:59:33,209 --> 00:59:35,340

their atypical appearance for

1139

00:59:35,340 --> 00:59:36,869

reasons that really have nothing

1140

00:59:36,869 --> 00:59:38,430

to do with very
typical appearance,

1141

00:59:38,430 --> 00:59:40,530

but more have to do with
how other people in

1142

00:59:40,530 --> 00:59:43,410

society respond to
that appearance.

1143

00:59:43,410 --> 00:59:49,125

And we usually don't accept
it as ethical to enforce

1144

00:59:49,125 --> 00:59:52,979

essentially cosmetic
behavior modification

1145

00:59:52,979 --> 00:59:58,335

or surgery or any number of
other things on children.

1146

00:59:58,335 --> 01:00:00,884

And often,

1147

01:00:00,884 --> 01:00:05,309
when they're incorporated
as a standardized part of

1148
01:00:05,309 --> 01:00:07,515
clinical practice rather than

1149
01:00:07,515 --> 01:00:11,789
a choice an adult makes
in a fully informed way,

1150
01:00:11,789 --> 01:00:13,514
even on adults

1151
01:00:13,514 --> 01:00:17,144
solely because of reasons
of societal stigma.

1152
01:00:17,144 --> 01:00:20,280
So the question of
whether or not something is

1153
01:00:20,280 --> 01:00:24,190
personally distressing
is relevant

1154
01:00:24,560 --> 01:00:27,689
but it's not sufficient.

1155
01:00:27,689 --> 01:00:29,655
And I think you get into

1156
01:00:29,655 --> 01:00:33,210
really interesting
discussion here as

1157
01:00:33,210 --> 01:00:36,165
to why a trait is
personally distressing.

1158
01:00:36,165 --> 01:00:39,299
And there are different
approaches that one might take

1159

01:00:39,299 --> 01:00:41,940

if one is thinking
about teaching someone

1160

01:00:41,940 --> 01:00:44,985

to engage in
situational passing--

1161

01:00:44,985 --> 01:00:47,925

You're about to go
into a job interview.

1162

01:00:47,925 --> 01:00:50,685

Here are some useful
job interview skills.

1163

01:00:50,685 --> 01:00:54,059

Making eye contact may be one of them

1164

01:00:54,059 --> 01:00:57,690

if you decide not to disclose
that you're autistic--versus

1165

01:00:57,690 --> 01:01:00,390

ongoing passing demands.

And instruments

1166

01:01:00,390 --> 01:01:03,179

like the CYBOCS and the SRS-2

1167

01:01:03,179 --> 01:01:05,370

which are often utilized in

1168

01:01:05,370 --> 01:01:08,714

the context of evaluating
early intervention,

1169

01:01:08,714 --> 01:01:11,100

drug trials and
other similar things

1170

01:01:11,100 --> 01:01:14,160
really represent ongoing
passing demands.

1171
01:01:14,160 --> 01:01:17,759
The forms of intensive
behavioral intervention

1172
01:01:17,759 --> 01:01:22,139
and other forms of
intervention that are

1173
01:01:22,139 --> 01:01:25,105
associated with these
instruments are

1174
01:01:25,105 --> 01:01:30,239
really designed to
be used to create

1175
01:01:30,239 --> 01:01:34,290
an expectation of behavior
modification that is

1176
01:01:34,290 --> 01:01:36,899
lasting and permanent and gets

1177
01:01:36,899 --> 01:01:39,855
internalized on the
part of the individual.

1178
01:01:39,855 --> 01:01:41,550
And that really is
something we should

1179
01:01:41,550 --> 01:01:43,560
find more concerning and apply

1180
01:01:43,560 --> 01:01:48,330
a very high bar before deciding

1181
01:01:48,330 --> 01:01:52,304
we consider it to be acceptable.

1182

01:01:52,304 --> 01:01:55,230

There's also the question of
whether or not a trait causes

1183

01:01:55,230 --> 01:01:58,169

intrinsic harm and in the objections

1184

01:01:58,169 --> 01:01:59,310

to the neurodiversity movement

1185

01:01:59,310 --> 01:02:03,284

we often see folks refer to
self-injurious behavior

1186

01:02:03,284 --> 01:02:07,169

as an example of "how can you say

1187

01:02:07,169 --> 01:02:09,360

that we shouldn't
be trying to make

1188

01:02:09,360 --> 01:02:12,270

someone less autistic?

1189

01:02:12,270 --> 01:02:16,994

My autistic
child self-injures.

1190

01:02:16,994 --> 01:02:18,570

Obviously, we should
be dealing with

1191

01:02:18,570 --> 01:02:20,310

self-injurious behavior.

1192

01:02:20,310 --> 01:02:22,230

And so the neurodiversity
argument is

1193

01:02:22,230 --> 01:02:25,485

invalid for that

particular child."

1194

01:02:25,485 --> 01:02:28,499
And I think it is certainly
the case that dealing with

1195

01:02:28,499 --> 01:02:30,735
self-injurious behavior is

1196

01:02:30,735 --> 01:02:33,720
a legitimate goal
of intervention.

1197

01:02:33,720 --> 01:02:37,140
I think the difficulty
here is that

1198

01:02:37,140 --> 01:02:42,000
that does not justify
the wide variety of

1199

01:02:42,000 --> 01:02:46,830
other non-intrinsically
harmful autistic traits

1200

01:02:46,830 --> 01:02:48,854
that are subject to
interventions.

1201

01:02:48,854 --> 01:02:50,804
I would say, and

1202

01:02:50,804 --> 01:02:53,700
there has been some
research on the views of

1203

01:02:53,700 --> 01:02:57,180
neurodiversity proponents in
case you don't believe me,

1204

01:02:57,180 --> 01:03:00,060
but as someone with a very long
history in the movement

1205
01:03:00,060 --> 01:03:03,180
I can confirm that
neurodiversity proponents have

1206
01:03:03,180 --> 01:03:04,979
no issue with interventions

1207
01:03:04,979 --> 01:03:07,740
designed to address
self-injurious behavior.

1208
01:03:07,740 --> 01:03:09,900
Now I think there's
going to be a lot of

1209
01:03:09,900 --> 01:03:12,945
interesting
discussions in item by

1210
01:03:12,945 --> 01:03:15,330
item analyses of
these instruments

1211
01:03:15,330 --> 01:03:18,869
as to what constitutes
intrinsic harm.

1212
01:03:18,869 --> 01:03:22,320
Often I've seen providers,

1213
01:03:22,320 --> 01:03:24,149
when presenting
these ideas to them,

1214
01:03:24,149 --> 01:03:25,650
say to me, "well,

1215
01:03:25,650 --> 01:03:29,115
you know, the parents I talk to

1216
01:03:29,115 --> 01:03:31,110

are very distressed that

1217

01:03:31,110 --> 01:03:33,615
their child won't make
eye contact with them.

1218

01:03:33,615 --> 01:03:36,345
And I consider that
intrinsicly harmful.

1219

01:03:36,345 --> 01:03:39,509
So in order to respond to
the family preference,

1220

01:03:39,509 --> 01:03:42,764
I'm going to encourage
eye contact." Or similarly,

1221

01:03:42,764 --> 01:03:46,979
"the service
provider finds

1222

01:03:46,979 --> 01:03:48,689
it very inconvenient that

1223

01:03:48,689 --> 01:03:51,465
the child keeps on
flapping their hands.

1224

01:03:51,465 --> 01:03:53,999
So I consider that
intrinsicly harmful."

1225

01:03:53,999 --> 01:03:57,990
Or "the atypical appearance
sparks bullying,

1226

01:03:57,990 --> 01:03:59,670
and so that's
intrinsicly harmful."

1227

01:03:59,670 --> 01:04:00,809
And I think we should be very

1228

01:04:00,809 --> 01:04:03,119
skeptical of those arguments,

1229

01:04:03,119 --> 01:04:04,709
in large part because

1230

01:04:04,709 --> 01:04:08,369
they ignore the harm that
passing demands cause.

1231

01:04:08,369 --> 01:04:10,019
And so they really think only in

1232

01:04:10,019 --> 01:04:12,135
terms of one side
of the equation.

1233

01:04:12,135 --> 01:04:15,974
They assume that passing only
has benefits and they give

1234

01:04:15,974 --> 01:04:20,910
no credence to both the
perspectives of autistic adults,

1235

01:04:20,910 --> 01:04:23,070
but also a growing body of

1236

01:04:23,070 --> 01:04:24,930
research literature showing that

1237

01:04:24,930 --> 01:04:27,539
passing demands do
in fact cause harm.

1238

01:04:27,539 --> 01:04:29,249
So there may be a,

1239

01:04:29,249 --> 01:04:31,050
there certainly are
going to be a lot

1240
01:04:31,050 --> 01:04:32,910
of cases in the middle of

1241
01:04:32,910 --> 01:04:35,189
self-injury and violence that

1242
01:04:35,189 --> 01:04:37,575
are obviously
intrinsically harmful,

1243
01:04:37,575 --> 01:04:42,150
and lack of eye contact and
stimming and odd prosody

1244
01:04:42,150 --> 01:04:44,669
that I would argue are just

1245
01:04:44,669 --> 01:04:47,474
stigmatized and not
intrinsically harmful.

1246
01:04:47,474 --> 01:04:49,200
But this illustrates

1247
01:04:49,200 --> 01:04:52,350
the underlying ethical
principles at play.

1248
01:04:52,350 --> 01:04:57,389
And I want to come back to
that question of a person with

1249
01:04:57,389 --> 01:04:59,669
a mobility impairment
deciding between

1250
01:04:59,669 --> 01:05:03,660
a wheelchair and crutches.

1251
01:05:03,660 --> 01:05:09,780
Because it's certainly the

case that crutches offer

1252

01:05:09,780 --> 01:05:12,660
some advantages in
terms of navigating

1253

01:05:12,660 --> 01:05:17,205
the built environment that
a wheelchair does not.

1254

01:05:17,205 --> 01:05:19,380
But also, a wheelchair offers

1255

01:05:19,380 --> 01:05:21,839
many advantages that
crutches do not.

1256

01:05:21,839 --> 01:05:23,310
And in fact, many of my friends

1257

01:05:23,310 --> 01:05:25,725
with mobility disabilities report

1258

01:05:25,725 --> 01:05:27,750
that the first time they got

1259

01:05:27,750 --> 01:05:31,170
their powered chair and the
first time they decided,

1260

01:05:31,170 --> 01:05:34,739
despite the urging of family
members and providers,

1261

01:05:34,739 --> 01:05:35,760
that they were not going to

1262

01:05:35,760 --> 01:05:37,589
organize their life to try and

1263

01:05:37,589 --> 01:05:40,935
retain the ability to walk

for as long as possible

1264

01:05:40,935 --> 01:05:42,959
but in fact were going to

1265

01:05:42,959 --> 01:05:45,614
begin relying on a wheelchair,

1266

01:05:45,614 --> 01:05:47,670
that their mobility dramatically

1267

01:05:47,670 --> 01:05:50,400
increased. Their ability to
do things in the world

1268

01:05:50,400 --> 01:05:54,839
dramatically increased. That
the costs associated with

1269

01:05:54,839 --> 01:05:59,039
even the legitimate
non-passing benefits

1270

01:05:59,039 --> 01:06:01,725
of crutches as opposed
to a wheelchair

1271

01:06:01,725 --> 01:06:07,079
were just not worth the
the burden associated with

1272

01:06:07,079 --> 01:06:11,519
crutches and sacrificing
the benefits

1273

01:06:11,519 --> 01:06:14,819
associated with having
access to a power chair.

1274

01:06:14,819 --> 01:06:17,640
I would finally add
that we really need to

1275
01:06:17,640 --> 01:06:19,590
evaluate whether or not something

1276
01:06:19,590 --> 01:06:21,300
represents the least burdensome

1277
01:06:21,300 --> 01:06:25,845
means of accomplishing
that non-passing purpose.

1278
01:06:25,845 --> 01:06:30,629
I've got a fairly initial framework

1279
01:06:30,629 --> 01:06:35,364
for evaluating the ethics
of passing instruction here.

1280
01:06:35,364 --> 01:06:37,664
And I'm going to

1281
01:06:37,664 --> 01:06:43,304
close by making two
additional points.

1282
01:06:43,304 --> 01:06:46,680
First is, many people
will say, "Well,

1283
01:06:46,680 --> 01:06:48,030
a lot of people, a lot of

1284
01:06:48,030 --> 01:06:49,889
autistic people
don't communicate.

1285
01:06:49,889 --> 01:06:53,114
So it's going to be
very difficult to

1286
01:06:53,114 --> 01:06:57,180
evaluate if somebody finds
something distressing or not."

1287
01:06:57,180 --> 01:07:00,090
And I would push back
on that a little bit.

1288
01:07:00,090 --> 01:07:02,040
Everyone communicates.

1289
01:07:02,040 --> 01:07:05,535
We just don't always
understand all communication.

1290
01:07:05,535 --> 01:07:07,920
And I think actually
even if you spend

1291
01:07:07,920 --> 01:07:09,869
some time with some
of the families

1292
01:07:09,869 --> 01:07:11,249
that bring up this concern

1293
01:07:11,249 --> 01:07:13,619
initially, outside of

1294
01:07:13,619 --> 01:07:16,559
the highly politicized
nature of these arguments,

1295
01:07:16,559 --> 01:07:18,060
they would agree with you.

1296
01:07:18,060 --> 01:07:21,569
A non-speaking autistic
person generally will find

1297
01:07:21,569 --> 01:07:24,930
some way of communicating,
distress or pleasure.

1298
01:07:24,930 --> 01:07:27,119

It's often their family
members that are

1299

01:07:27,119 --> 01:07:30,989
especially good at
evaluating that.

1300

01:07:30,989 --> 01:07:34,589
So, you know, I think we do
need to give some credence to

1301

01:07:34,589 --> 01:07:38,700
the fact that autistic
people have inner lives,

1302

01:07:38,700 --> 01:07:41,969
even if they aren't always able

1303

01:07:41,969 --> 01:07:45,554
to communicate that in
very sophisticated ways.

1304

01:07:45,554 --> 01:07:48,255
And begin to start thinking about

1305

01:07:48,255 --> 01:07:51,839
how we can to the
greatest extent possible

1306

01:07:51,839 --> 01:07:55,829
parse these principles throughout

1307

01:07:55,829 --> 01:07:57,930
the totality of the
autism spectrum

1308

01:07:57,930 --> 01:07:59,369
rather than

1309

01:07:59,369 --> 01:08:01,920
conceding the point
that Baron-Cohen

1310
01:08:01,920 --> 01:08:04,799
and some other people

1311
01:08:04,799 --> 01:08:07,469
make that neurodiversity
should be something that

1312
01:08:07,469 --> 01:08:10,529
applies only to those who
can talk or only those

1313
01:08:10,529 --> 01:08:13,109
who don't have an
intellectual disability.

1314
01:08:13,109 --> 01:08:15,210
I think conceding
that point would be

1315
01:08:15,210 --> 01:08:16,979
a real failure of solidarity

1316
01:08:16,979 --> 01:08:19,299
on the part of the
neurodiversity movement.

1317
01:08:19,340 --> 01:08:21,450
As I've stated earlier,

1318
01:08:21,450 --> 01:08:23,129
we should have a
strong presumption

1319
01:08:23,129 --> 01:08:25,890
against passing demands
in clinical practice.

1320
01:08:25,890 --> 01:08:27,390
It should be very, very,

1321
01:08:27,390 --> 01:08:31,109
very difficult for us to justify

1322

01:08:31,109 --> 01:08:35,805
any ongoing passing demands
in clinical practice.

1323

01:08:35,805 --> 01:08:38,804
And I think when we think
about outcome measures,

1324

01:08:38,804 --> 01:08:42,254
we really are talking about
ongoing passing demands.

1325

01:08:42,254 --> 01:08:44,669
If something is embedded
in an outcome measure

1326

01:08:44,669 --> 01:08:47,595
like the CYBOCS
or the SRS -2,

1327

01:08:47,595 --> 01:08:48,810
you don't really have

1328

01:08:48,810 --> 01:08:51,030
the opportunity in
any meaningful way

1329

01:08:51,030 --> 01:08:53,640
to make an
individualized decision--

1330

01:08:53,640 --> 01:08:55,410
Does it make sense
for this person?

1331

01:08:55,410 --> 01:08:58,589
How do you weigh the costs
and benefits for this person?

1332

01:08:58,589 --> 01:09:00,360
You know, and so on.

1333
01:09:00,360 --> 01:09:06,284
It really is defined as,
at a very basic level,

1334
01:09:06,284 --> 01:09:10,320
how we consider progress
in autism intervention.

1335
01:09:10,320 --> 01:09:15,599
And so a very big part of the
neurodiversity movement's

1336
01:09:15,599 --> 01:09:18,944
work in the coming
years really should

1337
01:09:18,944 --> 01:09:22,859
be to make the case that the
use of outcome measures

1338
01:09:22,859 --> 01:09:25,049
like the CYBOCS, the SRS-2,

1339
01:09:25,049 --> 01:09:27,719
and a number of others
that incorporate

1340
01:09:27,719 --> 01:09:30,690
passing demands is unethical

1341
01:09:30,690 --> 01:09:32,730
and that we should be working to

1342
01:09:32,730 --> 01:09:35,789
revise these measures
in order to make them

1343
01:09:35,789 --> 01:09:40,259
ethical prior to continuing
to allow their use

1344
01:09:40,259 --> 01:09:45,270

in clinical practice
and in research

1345

01:09:45,270 --> 01:09:49,950
that has the
purpose of evaluating

1346

01:09:49,950 --> 01:09:52,769
interventions as
opposed to simply

1347

01:09:52,769 --> 01:09:56,055
diagnosing or
characterizing autism.

1348

01:09:56,055 --> 01:09:58,800
Many of these measures
are totally legitimate

1349

01:09:58,800 --> 01:10:02,175
for exploring the
characteristics of autism.

1350

01:10:02,175 --> 01:10:03,780
They do a relatively good job

1351

01:10:03,780 --> 01:10:06,014
characterizing what autism is.

1352

01:10:06,014 --> 01:10:08,084
They don't do such a good job of

1353

01:10:08,084 --> 01:10:11,470
characterizing how we
should respond to that.

1354

01:10:11,540 --> 01:10:14,909
As we think about the effort to

1355

01:10:14,909 --> 01:10:18,854
revise autism outcome
measures, we should

1356
01:10:18,854 --> 01:10:21,269
look to participatory action and

1357
01:10:21,269 --> 01:10:24,284
community-based participatory
research models

1358
01:10:24,284 --> 01:10:26,460
that involve autistic adults,

1359
01:10:26,460 --> 01:10:29,024
both those with
research backgrounds

1360
01:10:29,024 --> 01:10:31,769
and those without
as full partners

1361
01:10:31,769 --> 01:10:37,515
in the process of revision.
And the AASPIRE project--

1362
01:10:37,515 --> 01:10:39,284
the Academic Autism

1363
01:10:39,284 --> 01:10:41,249
Spectrum Partnership
in Research and

1364
01:10:41,249 --> 01:10:42,870
Education--has been doing

1365
01:10:42,870 --> 01:10:47,025
some really fantastic work
along those lines.

1366
01:10:47,025 --> 01:10:49,905
They currently have
a project regarding

1367
01:10:49,905 --> 01:10:54,569
evaluating patient-

reported outcome measures

1368

01:10:54,569 --> 01:10:57,705
to align them with,

1369

01:10:57,705 --> 01:11:01,560
identify those that measure

1370

01:11:01,560 --> 01:11:04,650
the outcomes that matter
most to autistic adults.

1371

01:11:04,650 --> 01:11:07,094
I think we really need to expand

1372

01:11:07,094 --> 01:11:08,934
that emphasis on patient-reported

1373

01:11:08,934 --> 01:11:10,499
outcome measures where there

1374

01:11:10,499 --> 01:11:12,374
often is a recognition

1375

01:11:12,374 --> 01:11:16,259
that autistic people
and others who will be

1376

01:11:16,259 --> 01:11:17,640
doing the reporting
need to be in

1377

01:11:17,640 --> 01:11:19,229
the room to also look at

1378

01:11:19,229 --> 01:11:22,710
clinician- and parent-
reported outcome measures.

1379

01:11:22,710 --> 01:11:25,830
In part because
the ethical issues

1380
01:11:25,830 --> 01:11:27,779
are very relevant there.

1381
01:11:27,779 --> 01:11:32,069
Even if a measure is going to
be utilized by providers,

1382
01:11:32,069 --> 01:11:34,829
it's going to be utilized
on autistic people.

1383
01:11:34,829 --> 01:11:38,099
And so you really do need
autistic people in the room and

1384
01:11:38,099 --> 01:11:39,809
a meaningful partnership to

1385
01:11:39,809 --> 01:11:42,134
tackle these ethical questions.

1386
01:11:42,134 --> 01:11:43,740
And I think this,

1387
01:11:43,740 --> 01:11:47,220
this idea of operationalizing

1388
01:11:47,220 --> 01:11:48,569
the neurodiversity movement--

1389
01:11:48,569 --> 01:11:51,690
one of the reasons why it's
so promising is it opens up

1390
01:11:51,690 --> 01:11:53,729
a whole universe of

1391
01:11:53,729 --> 01:11:57,075
additional research that we can
and should be doing.

1392

01:11:57,075 --> 01:11:58,860
First, there's, there's
a great deal of

1393

01:11:58,860 --> 01:12:00,794
ethics work that
will need to be done

1394

01:12:00,794 --> 01:12:05,069
evaluating the ethics of trait-
specific passing demands.

1395

01:12:05,069 --> 01:12:09,689
And I imagine that we will
see some of our friends and

1396

01:12:09,689 --> 01:12:13,680
colleagues who do publish

1397

01:12:13,680 --> 01:12:16,725
in the ethics
research literature

1398

01:12:16,725 --> 01:12:18,389
put together

1399

01:12:18,389 --> 01:12:21,689
some truly excellent articles
evaluating the ethics

1400

01:12:21,689 --> 01:12:23,264
of the demand for

1401

01:12:23,264 --> 01:12:26,730
eye contact, the demand
to suppress stemming,

1402

01:12:26,730 --> 01:12:31,560
and I'm sure we will see some
of the folks out there in

1403

01:12:31,560 --> 01:12:33,914

the autism service
provision world

1404

01:12:33,914 --> 01:12:37,514
really argue that everything
is fine just the way it is

1405

01:12:37,514 --> 01:12:41,175
and put forward very intense
rebuttals to those arguments,

1406

01:12:41,175 --> 01:12:43,619
which we may find a
little frustrating.

1407

01:12:43,619 --> 01:12:45,059
But at least we'll
be talking about

1408

01:12:45,059 --> 01:12:47,579
the same things and at least
we will move away from

1409

01:12:47,579 --> 01:12:50,430
this normative
assumption that anything

1410

01:12:50,430 --> 01:12:55,005
autistic is legitimate
to try and suppress,

1411

01:12:55,005 --> 01:12:57,750
and instead argue
that providers must

1412

01:12:57,750 --> 01:13:00,689
make an affirmative case meeting

1413

01:13:00,689 --> 01:13:03,930
a relatively high
ethical bar prior to

1414

01:13:03,930 --> 01:13:07,710

trying to modify behavior
in support of passing.

1415
01:13:07,710 --> 01:13:10,679
There's a great deal of
clinical work to be done

1416
01:13:10,679 --> 01:13:12,630
revising outcome measures and

1417
01:13:12,630 --> 01:13:15,570
revising autism service
provision methods.

1418
01:13:15,570 --> 01:13:17,100
And I think there's also some,

1419
01:13:17,100 --> 01:13:19,874
some interesting
observational research.

1420
01:13:19,874 --> 01:13:23,820
I mentioned earlier that
the other major critique of

1421
01:13:23,820 --> 01:13:26,669
ABA is the use of aversives--

1422
01:13:26,669 --> 01:13:29,609
pain as a means of
behavior modification.

1423
01:13:29,609 --> 01:13:33,315
And often in modern arguments around ABA,

1424
01:13:33,315 --> 01:13:34,980
ABA providers will say, "well,

1425
01:13:34,980 --> 01:13:37,665
we don't really do that anymore."

1426
01:13:37,665 --> 01:13:43,529

And in fact, if you look at
the code of ethics for BCBAs

1427

01:13:43,529 --> 01:13:46,289
(Board Certified
Behavior Analysts),

1428

01:13:46,289 --> 01:13:49,799
it does permit punishment
and aversive

1429

01:13:49,799 --> 01:13:51,660
interventions. It states it

1430

01:13:51,660 --> 01:13:53,489
should be utilized
as a last resort,

1431

01:13:53,489 --> 01:13:55,260
but it does still permit it.

1432

01:13:55,260 --> 01:13:58,380
And there's been some
interesting research--

1433

01:13:58,380 --> 01:14:01,755
Frieda Brown at CUNY has
done some of the best of it--

1434

01:14:01,755 --> 01:14:07,769
looking at surveying
ABA and PBIS experts

1435

01:14:07,769 --> 01:14:11,655
regarding their perceptions
of treatment acceptability,

1436

01:14:11,655 --> 01:14:17,355
the acceptability of
particular interventions

1437

01:14:17,355 --> 01:14:19,470
in their fields that find

1438
01:14:19,470 --> 01:14:22,439
ABA providers do
in fact continue,

1439
01:14:22,439 --> 01:14:25,859
a significant, substantial
minority does in fact

1440
01:14:25,859 --> 01:14:29,730
continue to view aversive
interventions as legitimate.

1441
01:14:29,730 --> 01:14:32,085
It continues to be a
problem in the field.

1442
01:14:32,085 --> 01:14:34,590
Even some practitioners of

1443
01:14:34,590 --> 01:14:36,360
very harsh aversive

1444
01:14:36,360 --> 01:14:39,704
interventions like
contingent electric shock,

1445
01:14:39,704 --> 01:14:45,284
which is rare, continue
to be welcome at ABAI,

1446
01:14:45,284 --> 01:14:48,194
the association's
professional conference.

1447
01:14:48,194 --> 01:14:50,369
So the reason I bring
that up, and you know

1448
01:14:50,369 --> 01:14:51,930
the discussion about ABA and

1449

01:14:51,930 --> 01:14:54,539
aversives is really a
separate conversation,

1450
01:14:54,539 --> 01:14:59,595
is it helps us empirically to
actually look at

1451
01:14:59,595 --> 01:15:01,410
what providers are doing.

1452
01:15:01,410 --> 01:15:03,629
And as we begin to get a sense as

1453
01:15:03,629 --> 01:15:06,990
to which modes of
autism intervention--

1454
01:15:06,990 --> 01:15:10,470
which priorities of autism
intervention, I should say,

1455
01:15:10,470 --> 01:15:12,480
rather than modes--
which priorities in

1456
01:15:12,480 --> 01:15:15,735
autism intervention we
consider illegitimate,

1457
01:15:15,735 --> 01:15:19,080
we really should be
surveying both experts and

1458
01:15:19,080 --> 01:15:22,290
frontline providers
in a wide variety of

1459
01:15:22,290 --> 01:15:26,805
different modalities to
understand whether or not

1460
01:15:26,805 --> 01:15:28,500

they are still using

1461

01:15:28,500 --> 01:15:31,920
those particular goals
for intervention.

1462

01:15:31,920 --> 01:15:34,530
Because these dialogues and

1463

01:15:34,530 --> 01:15:37,544
these these arguments back
and forth--"You do this."

1464

01:15:37,544 --> 01:15:39,779
"No, I don't."

1465

01:15:39,779 --> 01:15:41,549
"Your field says you do."

1466

01:15:41,549 --> 01:15:43,574
"Well, that's not what it means."

1467

01:15:43,574 --> 01:15:48,060
--are often very frustrating
and unproductive.

1468

01:15:48,060 --> 01:15:50,310
We would really benefit
from bringing more of

1469

01:15:50,310 --> 01:15:52,790
an empirical lens to

1470

01:15:52,790 --> 01:15:55,370
study not just what
autistic people do,

1471

01:15:55,370 --> 01:15:58,549
but also what service
providers do, as well.

1472

01:15:58,549 --> 01:16:02,614

Finally, I'm just going
to say that an emphasis

1473

01:16:02,614 --> 01:16:06,875
on outcome measurement
and looking at autism

1474

01:16:06,875 --> 01:16:09,320
outcome measurement as where

1475

01:16:09,320 --> 01:16:11,149
the rubber meets the road

1476

01:16:11,149 --> 01:16:13,100
in the neurodiversity
movement's critique of

1477

01:16:13,100 --> 01:16:16,039
autism intervention I think

1478

01:16:16,039 --> 01:16:17,629
has the potential to turn down

1479

01:16:17,629 --> 01:16:19,759
the temperature in the autism, in

1480

01:16:19,759 --> 01:16:23,059
the ideological conflicts
in the autism world.

1481

01:16:23,059 --> 01:16:26,030
I'm not of the
belief that we need

1482

01:16:26,030 --> 01:16:29,809
peace or truce in the
quote, unquote "autism wars,"

1483

01:16:29,809 --> 01:16:31,490
having spent
considerable part of

1484

01:16:31,490 --> 01:16:34,854
my career working to
politicize autism

1485
01:16:34,854 --> 01:16:39,434
and to heighten the contradictions

1486
01:16:39,434 --> 01:16:43,619
between the different
perspectives in the autism world,

1487
01:16:43,619 --> 01:16:46,260
I actually think that
it's better that we

1488
01:16:46,260 --> 01:16:50,370
are litigating these
conflicts and values

1489
01:16:50,370 --> 01:16:53,610
and we're getting these
problems out in the open. In

1490
01:16:53,610 --> 01:16:55,650
the olden days
where it was really

1491
01:16:55,650 --> 01:16:58,800
only parent and professional
voices that predominated,

1492
01:16:58,800 --> 01:17:02,339
and autistic people largely
had an advisory opinion,

1493
01:17:02,339 --> 01:17:06,570
at best that often was
limited to talking about

1494
01:17:06,570 --> 01:17:08,880
our personal
experiences rather than

1495

01:17:08,880 --> 01:17:12,120
our opinions on values,

1496
01:17:12,120 --> 01:17:15,330
ethics, research or any
number of other things.

1497
01:17:15,330 --> 01:17:17,310
We don't want to go
back to those days.

1498
01:17:17,310 --> 01:17:20,669
So the ideological conflicts
on autism are going to

1499
01:17:20,669 --> 01:17:24,794
continue because they reflect
real differences in values.

1500
01:17:24,794 --> 01:17:28,185
But I think once we
start to look at

1501
01:17:28,185 --> 01:17:32,025
item by item evaluations and
outcome measurement,

1502
01:17:32,025 --> 01:17:35,939
we can at the very least
begin to mitigate some of

1503
01:17:35,939 --> 01:17:40,199
the misrepresentations of the
neurodiversity movement

1504
01:17:40,199 --> 01:17:43,040
that are put out to families.

1505
01:17:43,040 --> 01:17:45,930
I think many families
who are concerned about

1506
01:17:45,930 --> 01:17:49,830

neurodiversity are
misinformed that this,

1507

01:17:49,830 --> 01:17:52,170
that the movement wants to

1508

01:17:52,170 --> 01:17:53,790
make it so that they can't get

1509

01:17:53,790 --> 01:17:57,299
service provision to
address self-injury or they

1510

01:17:57,299 --> 01:17:59,625
can't get service
provision to promote

1511

01:17:59,625 --> 01:18:02,865
language or cognitive
development.

1512

01:18:02,865 --> 01:18:05,115
And that's just
really not the case.

1513

01:18:05,115 --> 01:18:06,180
And by the same token,

1514

01:18:06,180 --> 01:18:09,465
I think family,
Members, by and large,

1515

01:18:09,465 --> 01:18:13,350
do often find themselves
wondering why on earth

1516

01:18:13,350 --> 01:18:17,010
is there such an emphasis that
my child make eye contact?

1517

01:18:17,010 --> 01:18:19,889
What's so wrong with the
fact that my child flaps

1518
01:18:19,889 --> 01:18:23,609
their hands or rocks
back and forth?

1519
01:18:23,609 --> 01:18:27,150
So I think the more
that we can really

1520
01:18:27,150 --> 01:18:30,884
focus on the concrete
implications of neurodiversity

1521
01:18:30,884 --> 01:18:36,029
in addition to some of these
more hot-button debates

1522
01:18:36,029 --> 01:18:38,039
around modes of intervention

1523
01:18:38,039 --> 01:18:41,520
and conflicts in public policy,

1524
01:18:41,520 --> 01:18:44,340
the more that we can better
understand each other

1525
01:18:44,340 --> 01:18:46,350
and, I think, advance the ideas of

1526
01:18:46,350 --> 01:18:50,400
the neurodiversity
movement to new audiences.

1527
01:18:50,400 --> 01:18:53,880
All right, I think that
brings me to the end of

1528
01:18:53,880 --> 01:18:56,774
my discussion or end of
my presentation rather.

1529

01:18:56,774 --> 01:18:59,144
And I look forward to
taking your questions.

1530
01:18:59,144 --> 01:19:01,539
Thank you all so much.

1531
01:19:01,560 --> 01:19:06,620
[Ken Richman] Well, that is awesome. Thank you, Ari.
You can't share [see] the applause.

1532
01:19:06,620 --> 01:19:09,435
There's already been a lot of applause
in the chat, actually.

1533
01:19:09,435 --> 01:19:15,209
There are several people who have sent chat just saying "this is
brilliant," "this is awesome,"

1534
01:19:15,209 --> 01:19:18,105
"I'm so glad I'm here."
Two people said,

1535
01:19:18,105 --> 01:19:19,740
"I am so upset that I have to

1536
01:19:19,740 --> 01:19:21,720
leave to pick up my
kid from school"

1537
01:19:21,720 --> 01:19:22,920
(apparently some schools are still

1538
01:19:22,920 --> 01:19:26,400
open), and things like that.

1539
01:19:26,400 --> 01:19:28,590
So there's so much,
so much going on.

1540
01:19:28,590 --> 01:19:32,760
I do have and

1541

01:19:32,760 --> 01:19:36,240
and some of these compliments
are from people I don't know.

1542

01:19:36,240 --> 01:19:38,745
And some of them are
from people I know and,

1543

01:19:38,745 --> 01:19:43,140
and I absolutely can

1544

01:19:43,140 --> 01:19:45,779
tell you you should value
when they compliment you.

1545

01:19:45,779 --> 01:19:48,879
It's a big deal and should mean a lot.

1546

01:19:48,879 --> 01:19:52,849
I do have some questions, and they
come from a variety of

1547

01:19:52,849 --> 01:19:57,110
different people. That is, people

1548

01:19:57,110 --> 01:20:00,469
with different perspectives. Some who
who I know are autistic

1549

01:20:00,469 --> 01:20:03,560
and have experiences personally,

1550

01:20:03,560 --> 01:20:06,379
and some who I believe are not, although I don't know.

1551

01:20:06,379 --> 01:20:09,679
So one of our students asked

1552

01:20:09,679 --> 01:20:12,919
about ABA. And of course there are concerns with

1553

01:20:12,919 --> 01:20:18,135
ABA, and this I believe is a student who's read Daniel Wilkenfeld's and

1554
01:20:18,135 --> 01:20:22,070
McCarthy's paper raising some concerns.
I know you are aware of

1555
01:20:22,070 --> 01:20:26,255
that paper. And the student asks, well

1556
01:20:26,255 --> 01:20:30,924
can someone still accept ABA
therapy even if they know

1557
01:20:30,924 --> 01:20:36,179
there are lots of problems with
it? Could they benefit?

1558
01:20:36,179 --> 01:20:38,670
I'm I repeat the
question like, well,

1559
01:20:38,670 --> 01:20:39,990
you know, do we have to

1560
01:20:39,990 --> 01:20:42,149
throw the baby out
with the bathwater?

1561
01:20:42,149 --> 01:20:45,509
Is there some way that somebody
could say "I want ABA even though I

1562
01:20:45,509 --> 01:20:49,154
know that in a lot of forms
it can be harmful but

1563
01:20:49,154 --> 01:20:51,314
I can still get some benefit from it."

1564
01:20:51,314 --> 01:20:54,180
[Ari Ne'eman] But I think one of the
problems is it's generally

1565
01:20:54,180 --> 01:20:57,930
not people seeking
ABA for themselves,

1566
01:20:57,930 --> 01:21:00,059
they're seeking it
for their children.

1567
01:21:00,059 --> 01:21:02,384
And I think you do see

1568
01:21:02,384 --> 01:21:06,539
a very different
circumstance in terms of

1569
01:21:06,539 --> 01:21:09,225
the ethical acceptability of

1570
01:21:09,225 --> 01:21:10,889
imposing a passing demand on

1571
01:21:10,889 --> 01:21:15,270
a child, especially
a all-pervasive--

1572
01:21:15,270 --> 01:21:19,920
Remember, this is the,
ABA providers argue for

1573
01:21:19,920 --> 01:21:21,630
applying it 30, 40 hours a

1574
01:21:21,630 --> 01:21:25,739
week on a child from
a very young age.

1575
01:21:25,739 --> 01:21:28,215
Do I think it's certainly

1576
01:21:28,215 --> 01:21:30,749
possible that adults in

1577

01:21:30,749 --> 01:21:33,404
a fully informed way might say,

1578

01:21:33,404 --> 01:21:36,749
"I want to get instruction
on how to look more normal"?

1579

01:21:36,749 --> 01:21:38,130
You know, I think it's possible.

1580

01:21:38,130 --> 01:21:39,690
I think you still
need to really have

1581

01:21:39,690 --> 01:21:41,880
a meaningful conversation about

1582

01:21:41,880 --> 01:21:43,950
what's motivating that.

1583

01:21:43,950 --> 01:21:48,390
If it, in fact, is coming from
things in the broader society

1584

01:21:48,390 --> 01:21:50,699
that might be better
addressed through

1585

01:21:50,699 --> 01:21:54,480
social change than through
behavior modification.

1586

01:21:54,480 --> 01:21:55,860
But that's really

1587

01:21:55,860 --> 01:21:58,469
very rarely what
we're talking about here.

1588

01:21:58,469 --> 01:22:01,740
Now, you know, part of

the challenge that I

1589

01:22:01,740 --> 01:22:04,919
think we face in these
discussions is families

1590

01:22:04,919 --> 01:22:10,275
are presented with only a very
limited range of options.

1591

01:22:10,275 --> 01:22:12,359
You know, groups like

1592

01:22:12,359 --> 01:22:15,149
Autism Speaks and others have
very aggressively promoted

1593

01:22:15,149 --> 01:22:19,095
ABA as the only
option and ensures

1594

01:22:19,095 --> 01:22:21,330
in response to laws that have been

1595

01:22:21,330 --> 01:22:24,884
passed mandating ABA have
responded accordingly.

1596

01:22:24,884 --> 01:22:28,230
And so families may have ABA

1597

01:22:28,230 --> 01:22:29,624
presented to them as

1598

01:22:29,624 --> 01:22:32,174
their only choice for
early intervention.

1599

01:22:32,174 --> 01:22:36,045
And sometimes families will
make very ad hoc decisions.

1600

01:22:36,045 --> 01:22:38,789
Even families that sort of

1601
01:22:38,789 --> 01:22:40,829
want to see the neurodiversity

1602
01:22:40,829 --> 01:22:42,930
perspective practiced, about trying

1603
01:22:42,930 --> 01:22:46,289
to work closely with

1604
01:22:46,289 --> 01:22:49,410
a specific provider to get
them to change the way

1605
01:22:49,410 --> 01:22:53,279
that they do their
work, and so on.

1606
01:22:53,279 --> 01:22:56,310
You know, I'm not
going to critique

1607
01:22:56,310 --> 01:22:58,965
individual choices of
individual families,

1608
01:22:58,965 --> 01:23:01,109
especially when families don't

1609
01:23:01,109 --> 01:23:03,239
have access to
other intervention.

1610
01:23:03,239 --> 01:23:05,010
But I do think that

1611
01:23:05,010 --> 01:23:06,630
you're always going to

1612
01:23:06,630 --> 01:23:10,349

face an uphill battle trying to

1613

01:23:10,349 --> 01:23:15,000
retrofit a mode of
service provision

1614

01:23:15,000 --> 01:23:19,979
that has this emphasis on
indistinguishability from peers

1615

01:23:19,979 --> 01:23:23,235
really very heavily in its DNA.

1616

01:23:23,235 --> 01:23:26,849
And you know, I think you

1617

01:23:26,849 --> 01:23:30,869
do see in part because ABA
is so heavily embedded

1618

01:23:30,869 --> 01:23:32,639
lot of folks that say, "Well,

1619

01:23:32,639 --> 01:23:35,085
let's change ABA instead."

1620

01:23:35,085 --> 01:23:36,600
The problem is that when you

1621

01:23:36,600 --> 01:23:38,729
talk to the ABA providers,

1622

01:23:38,729 --> 01:23:41,849
you generally find folks who say,

1623

01:23:41,849 --> 01:23:45,929
"Well, you know, the
problem doesn't exist."

1624

01:23:45,929 --> 01:23:50,715
You know? Or, you know,

1625
01:23:50,715 --> 01:23:53,864
usually you will hear from them

1626
01:23:53,864 --> 01:23:56,939
either, "Doing these things
isn't in fact the problem.

1627
01:23:56,939 --> 01:24:00,540
It's appropriate to suppress
autistic traits. It's necessary,"

1628
01:24:00,540 --> 01:24:03,539
or you will hear, "We are not
in fact trying to suppress

1629
01:24:03,539 --> 01:24:04,920
autistic traits," which are

1630
01:24:04,920 --> 01:24:07,800
quite sometimes
contradictory responses.

1631
01:24:07,800 --> 01:24:11,220
So I don't rule out the
possibility of reform in ABA,

1632
01:24:11,220 --> 01:24:14,834
but I think it has to
actually start before we,

1633
01:24:14,834 --> 01:24:16,830
we tend to take it seriously.

1634
01:24:16,830 --> 01:24:18,464
I think on balance,

1635
01:24:18,464 --> 01:24:21,150
I think the, the emphasis really

1636
01:24:21,150 --> 01:24:23,460
needs to be on critiquing
the intervention,

1637

01:24:23,460 --> 01:24:26,535
pushing for the availability
of alternatives,

1638

01:24:26,535 --> 01:24:29,700
and if there's a faction
in ABA, among

1639

01:24:29,700 --> 01:24:33,360
ABA providers that decides
to seriously work on reform,

1640

01:24:33,360 --> 01:24:36,704
we're articulating principles
here they can use for that.

1641

01:24:36,704 --> 01:24:38,459
They don't need our
permission to try

1642

01:24:38,459 --> 01:24:40,839
and fix their broken field

1643

01:24:41,000 --> 01:24:44,100
In the meantime, we're
not going to

1644

01:24:44,100 --> 01:24:48,284
validate the legitimacy
of the intervention

1645

01:24:48,284 --> 01:24:51,090
when we believe these
severe ethical problems

1646

01:24:51,090 --> 01:24:52,590
still exist.

1647

01:24:52,590 --> 01:24:55,649
[Ken Richman] Right. Fair enough. That's a great answer.

1648

01:24:55,649 --> 01:24:58,860
That makes a lot of sense. I've got
another question here, which

1649
01:24:58,860 --> 01:25:01,360
I think you may have answered, but

1650
01:25:01,640 --> 01:25:04,199
this person asks

1651
01:25:04,199 --> 01:25:07,110
are there any circumstances
where you'd

1652
01:25:07,110 --> 01:25:10,259
think it would be a good
outcome, or an acceptable outcome

1653
01:25:10,259 --> 01:25:12,089
to reduce repetitive behaviors?

1654
01:25:12,089 --> 01:25:13,500
And I think your answer was

1655
01:25:13,500 --> 01:25:15,640
sure, when they're injurious or when

1656
01:25:15,640 --> 01:25:19,889
there is intrinsic harm.

1657
01:25:19,889 --> 01:25:21,630
Is that? [Ari Ne'eman] Yes, that's correct. And that's why I think it's
useful to

1658
01:25:21,630 --> 01:25:23,504
articulate these
broad principles.

1659
01:25:23,504 --> 01:25:27,705
Because you will see when
these things come up.

1660

01:25:27,705 --> 01:25:31,199
I have a paper undergoing
review right now,

1661
01:25:31,199 --> 01:25:35,370
which got comments back recently.

1662
01:25:35,370 --> 01:25:39,840
One of the
comments was, "Well,

1663
01:25:39,840 --> 01:25:43,259
what if you have a
child who is stimming

1664
01:25:43,259 --> 01:25:47,760
such that they cannot be
examined in the doctor's office

1665
01:25:47,760 --> 01:25:49,230
and as a result,

1666
01:25:49,230 --> 01:25:50,850
you've got to suppress stimming."

1667
01:25:50,850 --> 01:25:53,444
Well, you know, maybe,
I mean, you know,

1668
01:25:53,444 --> 01:25:56,219
you might find other
adaptive mechanisms

1669
01:25:56,219 --> 01:25:59,489
to examine that child,

1670
01:25:59,489 --> 01:26:02,174
but maybe you've
got to momentarily

1671
01:26:02,174 --> 01:26:05,895
suppress stimming for a 15-
minute doctor appointment.

1672
01:26:05,895 --> 01:26:10,590
But that doesn't really
justify embedding

1673
01:26:10,590 --> 01:26:13,574
this as a normative
expectation and

1674
01:26:13,574 --> 01:26:15,405
outcome measurement and as

1675
01:26:15,405 --> 01:26:18,509
a standard part of early
intervention, as it is now.

1676
01:26:18,509 --> 01:26:20,219
So I think it's
certainly the case

1677
01:26:20,219 --> 01:26:24,630
you will have edge cases with
certain kinds of stimming,

1678
01:26:24,630 --> 01:26:26,685
certain contexts and stimming,

1679
01:26:26,685 --> 01:26:29,820
but we articulate these
principles and we talk

1680
01:26:29,820 --> 01:26:33,134
about the problems in part
because at the moment

1681
01:26:33,134 --> 01:26:36,270
we believe that in
autism intervention,

1682
01:26:36,270 --> 01:26:39,809
in large segments of
autism intervention

1683

01:26:39,809 --> 01:26:45,300
the problems outweigh, the
problems are more common

1684

01:26:45,300 --> 01:26:49,380
than the edge cases of acceptability.
[Ken Richman] Fair enough.

1685

01:26:49,380 --> 01:26:52,649
So, again these are coming from very
different perspectives--

1686

01:26:52,649 --> 01:26:55,275
some people who have engaged
with these issues a lot,

1687

01:26:55,275 --> 01:26:56,730
others not so much,
and I have

1688

01:26:56,730 --> 01:27:00,720
a very interesting
question which I,

1689

01:27:00,720 --> 01:27:02,010
think I know one part
of the answer,

1690

01:27:02,010 --> 01:27:04,349
but I can complicate it a little

1691

01:27:04,349 --> 01:27:07,034
bit and make it
really quite,

1692

01:27:07,034 --> 01:27:12,644
maybe quite interesting. So a psychologist
among us asks

1693

01:27:12,644 --> 01:27:15,180
whether it makes a difference

1694

01:27:15,180 --> 01:27:19,274
what the etiology
of autistic symptoms are.

1695
01:27:19,274 --> 01:27:21,689
Now, I'm pretty sure
you would say, well,

1696
01:27:21,689 --> 01:27:23,675
it doesn't matter what
story we tell, if

1697
01:27:23,675 --> 01:27:25,409
we tell if it comes
from the genes or

1698
01:27:25,409 --> 01:27:27,509
comes from epigenetics
or whatever.

1699
01:27:27,509 --> 01:27:32,145
But the particular
question focuses

1700
01:27:32,145 --> 01:27:39,569
on autistic symptoms that
might come up from PANDA, the

1701
01:27:39,569 --> 01:27:42,870
Pediatric Autoimmune
Neuropsychiatric Disorders

1702
01:27:42,870 --> 01:27:45,180
associated with streptococcal infection.

1703
01:27:45,180 --> 01:27:46,380
The reason I think that that's

1704
01:27:46,380 --> 01:27:48,509
an interesting
question, is this:

1705
01:27:48,509 --> 01:27:50,925

one of the reasons
that we might give

1706
01:27:50,925 --> 01:27:54,300
for not trying to

1707
01:27:54,300 --> 01:27:55,679
make people not autistic

1708
01:27:55,679 --> 01:27:57,659
is because they're autistic,
and if we make them

1709
01:27:57,659 --> 01:27:59,564
not autistic they're
not the same person.

1710
01:27:59,564 --> 01:28:01,470
But if we think about

1711
01:28:01,470 --> 01:28:04,904
some change coming
on someone, right?

1712
01:28:04,904 --> 01:28:07,410
I mean, obviously we
want to avoid the story that says

1713
01:28:07,410 --> 01:28:09,495
"somebody took my
kid away and replaced

1714
01:28:09,495 --> 01:28:11,640
it with this autistic fake,"

1715
01:28:11,640 --> 01:28:14,730
which is that
kind of story.

1716
01:28:14,730 --> 01:28:17,700
But if you have
somebody who then has

1717

01:28:17,700 --> 01:28:18,869
some kind of accident or

1718

01:28:18,869 --> 01:28:21,074
something, and now it has changed.

1719

01:28:21,074 --> 01:28:24,699
I think that the kind of
question that's being asked here,

1720

01:28:25,070 --> 01:28:27,405
what about an
intervention that would

1721

01:28:27,405 --> 01:28:29,204
kind of put them back,

1722

01:28:29,204 --> 01:28:32,400
restart them, put them back

1723

01:28:32,400 --> 01:28:36,630
to having the
neurology that they had before.

1724

01:28:36,630 --> 01:28:41,720
Now it doesn't, you don't need to say that
the autistic traits are bad,

1725

01:28:41,720 --> 01:28:44,458
you just need to say they
just happen not to be the traits

1726

01:28:44,458 --> 01:28:46,195
that this person came with.

1727

01:28:46,195 --> 01:28:46,860
[Ari Ne'eman] Okay, let's, so, let's

1728

01:28:46,860 --> 01:28:48,885
interrogate that a little
bit because I think

1729
01:28:48,885 --> 01:28:50,250
a couple of points I would make here.

1730
01:28:50,250 --> 01:28:53,925
First, very much an edge
case in terms of autism.

1731
01:28:53,925 --> 01:28:57,329
Autism is generally not
an acquired disability.

1732
01:28:57,329 --> 01:28:59,820
Overwhelming

1733
01:28:59,820 --> 01:29:01,575
research shows that it's

1734
01:29:01,575 --> 01:29:04,244
almost always present from birth.

1735
01:29:04,244 --> 01:29:07,334
You know, what we
refer to as autism,

1736
01:29:07,334 --> 01:29:11,549
I would say present from
birth. And it's genetic.

1737
01:29:11,549 --> 01:29:15,284
I think sometimes there
are autistic traits that

1738
01:29:15,284 --> 01:29:17,340
can be referred to as autism that

1739
01:29:17,340 --> 01:29:19,470
are associated with
acquired disabilities,

1740
01:29:19,470 --> 01:29:21,225
but that's pretty rare.

1741

01:29:21,225 --> 01:29:23,235
But, but in terms of kind of

1742

01:29:23,235 --> 01:29:26,010
ethical analysis and
in those edge cases,

1743

01:29:26,010 --> 01:29:29,369
I think I would go
back to the question of

1744

01:29:29,369 --> 01:29:32,895
is there a non-passing
purpose involved?

1745

01:29:32,895 --> 01:29:35,520
And I think usually
when you're talking about

1746

01:29:35,520 --> 01:29:38,789
acquired disability,
it's pretty rare

1747

01:29:38,789 --> 01:29:42,735
that you have an acquired disability
that,

1748

01:29:42,735 --> 01:29:50,595
whose characteristics are
entirely limited to neutral

1749

01:29:50,595 --> 01:29:53,684
or pleasurable characteristics.

1750

01:29:53,684 --> 01:29:56,070
I think usually you're going

1751

01:29:56,070 --> 01:29:58,425
to see with an acquired
disability of that nature

1752

01:29:58,425 --> 01:30:00,270

something that we would put into

1753

01:30:00,270 --> 01:30:03,219
the category of intrinsic harm.

1754

01:30:03,230 --> 01:30:06,134
Difficulties with
cognitive development,

1755

01:30:06,134 --> 01:30:08,850
difficulties with
communication

1756

01:30:08,850 --> 01:30:11,640
that fall into that category.

1757

01:30:11,640 --> 01:30:13,650
And again, even then,

1758

01:30:13,650 --> 01:30:15,270
I don't know that it's

1759

01:30:15,270 --> 01:30:18,660
presumptively legitimate,
if you show intrinsic harm

1760

01:30:18,660 --> 01:30:23,490
you automatically find an
intervention to be legitimate.

1761

01:30:23,490 --> 01:30:25,889
You have to still then
weigh the costs and benefits

1762

01:30:25,889 --> 01:30:28,980
and crucially the preferences
of the individual.

1763

01:30:28,980 --> 01:30:32,040
But I, the reason I'm
reluctant to just

1764

01:30:32,040 --> 01:30:34,140
draw a bright line and say,

1765
01:30:34,140 --> 01:30:37,949
you know, from birth

1766
01:30:37,949 --> 01:30:40,515
passing demands bad; acquired

1767
01:30:40,515 --> 01:30:42,419
you can
get away with them,

1768
01:30:42,419 --> 01:30:44,010
is that in fact, many of

1769
01:30:44,010 --> 01:30:47,340
these issues apply beyond autism.

1770
01:30:47,340 --> 01:30:49,470
and are very
relevant,

1771
01:30:49,470 --> 01:30:51,000
as I discussed with the mobility

1772
01:30:51,000 --> 01:30:52,529
impairment example, to some of

1773
01:30:52,529 --> 01:30:57,060
our friends in the acquired
disability world, too.

1774
01:30:57,060 --> 01:31:01,125
So I think
in autism contexts,

1775
01:31:01,125 --> 01:31:04,154
that's not a super
relevant question because

1776
01:31:04,154 --> 01:31:08,340

the idea of acquired autism,

1777

01:31:08,340 --> 01:31:10,620
usually we wouldn't refer

1778

01:31:10,620 --> 01:31:12,449
to something like that as autism.

1779

01:31:12,449 --> 01:31:15,209
We might refer to it as
autistic-like traits,

1780

01:31:15,209 --> 01:31:18,224
but you may disagree
as to whether or not

1781

01:31:18,224 --> 01:31:19,530
that's a difference

1782

01:31:19,530 --> 01:31:21,179
that may not matter.

1783

01:31:21,179 --> 01:31:23,039
But regardless, you know,

1784

01:31:23,039 --> 01:31:24,930
part of the reason
why I tried to,

1785

01:31:24,930 --> 01:31:27,149
in articulating an
ethical framework,

1786

01:31:27,149 --> 01:31:30,435
apply it more broadly
than autism is because I,

1787

01:31:30,435 --> 01:31:34,005
I do think that the
underlying analysis

1788

01:31:34,005 --> 01:31:37,469

would be relevant even if it
was an acquired condition.

1789

01:31:37,469 --> 01:31:44,459
[Ken Richman] Okay. That's also, that's,
as usual, a very smart answer.

1790

01:31:44,459 --> 01:31:46,680
Here's a question from someone

1791

01:31:46,680 --> 01:31:49,275
who has thought about this a lot,

1792

01:31:49,275 --> 01:31:53,670
I happen to know, and
asks about whether

1793

01:31:53,670 --> 01:31:55,649
helping autistic
individuals prepare

1794

01:31:55,649 --> 01:31:58,665
situational scripts
is objectionable.

1795

01:31:58,665 --> 01:32:00,820
Reading the question:

1796

01:32:00,830 --> 01:32:03,914
"Can it be considered
active promotion of

1797

01:32:03,914 --> 01:32:07,814
passing? To me," this person writes,
"stimulating a,

1798

01:32:07,814 --> 01:32:08,970
stimulating the creation of

1799

01:32:08,970 --> 01:32:11,895
situational scripts
focuses on providing

1800
01:32:11,895 --> 01:32:17,970
predictability for the autistic
person and thereby decreases discomfort.

1801
01:32:17,970 --> 01:32:23,040
But on the other hand,
the situational script can be

1802
01:32:23,040 --> 01:32:28,830
like crutches for passing."
So what's your response?

1803
01:32:28,830 --> 01:32:31,365
[Ari Ne'eman] I think it really
depends on the circumstance,

1804
01:32:31,365 --> 01:32:32,820
the individual and the,

1805
01:32:32,820 --> 01:32:34,919
you know, the nature of

1806
01:32:34,919 --> 01:32:38,745
the script and how
it's being applied.

1807
01:32:38,745 --> 01:32:41,370
I realize 'it depends'

1808
01:32:41,370 --> 01:32:44,009
is the worst possible
answer to give

1809
01:32:44,009 --> 01:32:46,079
when having ethical debates, but

1810
01:32:46,079 --> 01:32:50,384
some relevant considerations
I would put out there.

1811
01:32:50,384 --> 01:32:52,409
I think situational passing is

1812
01:32:52,409 --> 01:32:54,390
often appropriate
when it's a choice

1813
01:32:54,390 --> 01:32:57,119
of the individual. The example I

1814
01:32:57,119 --> 01:33:01,019
provided earlier of a job
interview is a good one.

1815
01:33:01,019 --> 01:33:03,509
I think you often have to

1816
01:33:03,509 --> 01:33:05,985
consider the degree
to which individuals

1817
01:33:05,985 --> 01:33:11,219
have the autonomy

1818
01:33:11,219 --> 01:33:12,659
in the situation to make

1819
01:33:12,659 --> 01:33:15,269
that choice in a
free way,

1820
01:33:15,269 --> 01:33:17,520
and that's obviously
more the case

1821
01:33:17,520 --> 01:33:21,630
the older they get, the less
power people have over them,

1822
01:33:21,630 --> 01:33:25,319
the more they have the
opportunity to exit a situation.

1823
01:33:25,319 --> 01:33:28,620

Those are all considerations
that come up in

1824

01:33:28,620 --> 01:33:31,034
the context of
educational environments

1825

01:33:31,034 --> 01:33:33,180
that have to be weighed
very carefully.

1826

01:33:33,180 --> 01:33:35,400
I think it's also
important to try

1827

01:33:35,400 --> 01:33:37,920
and distinguish in the process of

1828

01:33:37,920 --> 01:33:41,145
instruction between
passing demands

1829

01:33:41,145 --> 01:33:45,600
and situational or contextual
passing instruction.

1830

01:33:45,600 --> 01:33:49,950
By which I mean, often because

1831

01:33:49,950 --> 01:33:51,719
these ideas are embedded in

1832

01:33:51,719 --> 01:33:53,460
outcome measurements, they're

1833

01:33:53,460 --> 01:33:56,265
part of the definition
of success

1834

01:33:56,265 --> 01:34:00,150
in many forms of
early intervention,

1835
01:34:00,150 --> 01:34:03,974
you do not see children taught,

1836
01:34:03,974 --> 01:34:06,510
"Well, you know, you
might want to make

1837
01:34:06,510 --> 01:34:10,379
eye contact or you might not.

1838
01:34:10,379 --> 01:34:12,764
But if you don't, here's
what people will think.

1839
01:34:12,764 --> 01:34:16,655
If you do,

1840
01:34:16,980 --> 01:34:18,960
here's what people
will think, and here's

1841
01:34:18,960 --> 01:34:21,540
some things you might want
to explain, and so on."

1842
01:34:21,540 --> 01:34:23,549
And you get into an
interesting discussion

1843
01:34:23,549 --> 01:34:25,140
of how much nuance you can or

1844
01:34:25,140 --> 01:34:28,964
can't communicate to a
three-year-old there and so on,

1845
01:34:28,964 --> 01:34:32,130
but that's rarely done.

1846
01:34:32,130 --> 01:34:33,689
I mean, usually what
you will see is

1847
01:34:33,689 --> 01:34:35,369
this very intensive effort

1848
01:34:35,369 --> 01:34:38,819
around saying this is
the way to behave.

1849
01:34:38,819 --> 01:34:41,009
We will reward you if
you behave this way.

1850
01:34:41,009 --> 01:34:42,600
We will not reward you,

1851
01:34:42,600 --> 01:34:48,194
or in some ways punish
you if you do not.

1852
01:34:48,194 --> 01:34:51,165
So, I think if you are
you are trying to teach

1853
01:34:51,165 --> 01:34:55,170
especially older children
situational passing skills

1854
01:34:55,170 --> 01:34:57,840
it can be very important
to do it in a way

1855
01:34:57,840 --> 01:35:00,840
that affirms their autonomy
to use them or not

1856
01:35:00,840 --> 01:35:03,179
and to be very cognizant
of the power you

1857
01:35:03,179 --> 01:35:05,474
may have over them
in that situation

1858

01:35:05,474 --> 01:35:08,309
and really reinforce
their ability

1859

01:35:08,309 --> 01:35:09,560
to make that choice.

1860

01:35:09,560 --> 01:35:16,245
[Ken Richman] Right. I think that the power, the power both with respect
to parents

1861

01:35:16,245 --> 01:35:18,734
and the, and autistic individuals

1862

01:35:18,734 --> 01:35:21,240
and providers, that the
power relations are

1863

01:35:21,240 --> 01:35:23,984
really, really quite significant.

1864

01:35:23,984 --> 01:35:26,279
I've got a number of
questions coming in,

1865

01:35:26,279 --> 01:35:30,285
as well as some more
compliments, and a couple,

1866

01:35:30,285 --> 01:35:31,769
more than one person said,

1867

01:35:31,769 --> 01:35:33,360
oh my goodness, I have so much.

1868

01:35:33,360 --> 01:35:34,979
I'm gonna get back to the paper

1869

01:35:34,979 --> 01:35:36,839
I was writing or
the project or

1870
01:35:36,839 --> 01:35:38,010
at least two people have

1871
01:35:38,010 --> 01:35:40,770
already been saying,
I've got to go

1872
01:35:40,770 --> 01:35:43,094
and this is going to
change my practice

1873
01:35:43,094 --> 01:35:46,455
with my clients, which
is absolutely awesome.

1874
01:35:46,455 --> 01:35:48,045
And here's an
interesting question

1875
01:35:48,045 --> 01:35:50,250
from a philosopher. Suppose

1876
01:35:50,250 --> 01:35:51,929
we assume that the most

1877
01:35:51,929 --> 01:35:55,319
vulnerable and
marginalized individuals

1878
01:35:55,319 --> 01:35:58,409
are also most often
the ones who are

1879
01:35:58,409 --> 01:36:02,004
petitioning strongly for
passing instruction. Right,

1880
01:36:02,004 --> 01:36:05,144
so they're asking, "How do I pass?"

1881
01:36:05,144 --> 01:36:07,049
You can imagine people

1882

01:36:07,049 --> 01:36:08,609
getting very frustrated
with their lives,

1883

01:36:08,609 --> 01:36:11,670
and they go, a kid or teenager saying,
"How do I make friends?"

1884

01:36:11,670 --> 01:36:14,790
Help me be like the other kids."

1885

01:36:14,790 --> 01:36:16,829
If that were the situation,

1886

01:36:16,829 --> 01:36:18,749
if that's true, how

1887

01:36:18,749 --> 01:36:21,659
should service providers
or clinicians or parents

1888

01:36:21,659 --> 01:36:25,829
think self-critically about how
to respond, whether they

1889

01:36:25,829 --> 01:36:30,009
should satisfy that request
or deny the request?

1890

01:36:30,009 --> 01:36:33,870
[Ari Ne'eman] A very interesting question, and
I think a lot of it, you know,

1891

01:36:33,870 --> 01:36:39,075
goes--I'm trying to think of
the right way to frame this.

1892

01:36:39,075 --> 01:36:41,040
Going back to the conversation

1893

01:36:41,040 --> 01:36:43,200

around acquired disability

1894

01:36:43,200 --> 01:36:46,514
and to the extent to which
these principles apply,

1895

01:36:46,514 --> 01:36:49,499
I once read a very
interesting analysis

1896

01:36:49,499 --> 01:36:52,680
of this exact question
in discussing

1897

01:36:52,680 --> 01:36:56,444
the ethics of cosmetic surgery

1898

01:36:56,444 --> 01:36:59,129
with regards to
facial deformation.

1899

01:36:59,129 --> 01:37:01,529
And there was a
lot of back and forth in

1900

01:37:01,529 --> 01:37:05,030
very similar ways
regarding it, and I don't

1901

01:37:05,030 --> 01:37:07,160
think it's exactly the
same thing in part

1902

01:37:07,160 --> 01:37:10,385
because I do think the
fact that these are

1903

01:37:10,385 --> 01:37:13,790
natural traits present from

1904

01:37:13,790 --> 01:37:16,340
birth that are often
very much a part of

1905
01:37:16,340 --> 01:37:20,150
someone's self
identity and that are

1906
01:37:20,150 --> 01:37:24,709
imbedded neurologically in
certain ways is relevant.

1907
01:37:24,709 --> 01:37:27,049
But I think there are
certain,

1908
01:37:27,049 --> 01:37:28,310
there's certain, there are

1909
01:37:28,310 --> 01:37:30,860
certain principles
you can extrapolate.

1910
01:37:30,860 --> 01:37:32,870
So, you know, what I would

1911
01:37:32,870 --> 01:37:34,609
say here is I think you need to

1912
01:37:34,609 --> 01:37:38,720
have a very in-depth
counseling process.

1913
01:37:38,720 --> 01:37:41,510
If someone
comes to you and

1914
01:37:41,510 --> 01:37:44,570
says, "Everybody

1915
01:37:44,570 --> 01:37:48,300
treats me

1916
01:37:48,300 --> 01:37:51,479
badly because I don't

make eye contact with them,

1917

01:37:51,479 --> 01:37:53,099
and I don't have

1918

01:37:53,099 --> 01:37:56,205
any friends because I
don't make eye contact."

1919

01:37:56,205 --> 01:38:00,270
I don't know that the most
ethical response you can make,

1920

01:38:00,270 --> 01:38:02,880
you can give to that
person is. "Great,

1921

01:38:02,880 --> 01:38:04,889
let's teach you how
to make eye contact.

1922

01:38:04,889 --> 01:38:06,374
Then you'll have friends.

1923

01:38:06,374 --> 01:38:08,805
Then people won't
treat you badly."

1924

01:38:08,805 --> 01:38:13,875
I don't know that that is the
most appropriate response.

1925

01:38:13,875 --> 01:38:19,664
Now someone is saying in a
very targeted way,

1926

01:38:19,664 --> 01:38:24,060
"I am struggling in
this workplace because

1927

01:38:24,060 --> 01:38:26,130
I'm being treated
badly, and I know it's

1928

01:38:26,130 --> 01:38:29,145
wrong for them to treat
me badly that way,

1929

01:38:29,145 --> 01:38:32,700
but if I

1930

01:38:32,700 --> 01:38:35,160
sort of act more confidently and

1931

01:38:35,160 --> 01:38:39,330
talk with more typical
prosody while I'm at work.

1932

01:38:39,330 --> 01:38:41,490
I know that'll cost me something.

1933

01:38:41,490 --> 01:38:43,409
I know I shouldn't
have to do that.

1934

01:38:43,409 --> 01:38:45,029
I know that's not right,

1935

01:38:45,029 --> 01:38:47,279
but I'm going to
make the decision to

1936

01:38:47,279 --> 01:38:49,620
do it contextually

1937

01:38:49,620 --> 01:38:51,840
from the hours of
09:00 AM to 05:00 PM

1938

01:38:51,840 --> 01:38:54,209
because I really need to get

1939

01:38:54,209 --> 01:38:55,259
ahead in this job for

1940

01:38:55,259 --> 01:38:56,999
the next few years before I

1941

01:38:56,999 --> 01:38:59,250
can take the next
step in my career."

1942

01:38:59,250 --> 01:39:01,484
That might be more appropriate.

1943

01:39:01,484 --> 01:39:03,315
The key, though, is,

1944

01:39:03,315 --> 01:39:06,030
and here we bring it back
to outcome measurement,

1945

01:39:06,030 --> 01:39:09,629
you can't make that kind
of individualized decision

1946

01:39:09,629 --> 01:39:14,190
in a standardized clinical
outcome measure.

1947

01:39:14,190 --> 01:39:18,450
So we're talking about
revising the measures that

1948

01:39:18,450 --> 01:39:22,470
are really designed to

1949

01:39:22,470 --> 01:39:26,655
define progress across
the board for everyone.

1950

01:39:26,655 --> 01:39:31,724
And so there's, there are
fascinating

1951

01:39:31,724 --> 01:39:34,244
back and forth

discussions regarding

1952

01:39:34,244 --> 01:39:37,769
what individual providers
should do in individual cases,

1953

01:39:37,769 --> 01:39:39,119
and I think it's worth

1954

01:39:39,119 --> 01:39:41,370
exploring, interrogating
that, and

1955

01:39:41,370 --> 01:39:43,230
I hope this lecture and some of

1956

01:39:43,230 --> 01:39:45,450
the papers I intend
to produce from it

1957

01:39:45,450 --> 01:39:47,489
produce a really robust

1958

01:39:47,489 --> 01:39:49,695
research literature
on this topic.

1959

01:39:49,695 --> 01:39:52,019
But I think the
first step needs to

1960

01:39:52,019 --> 01:39:54,870
be getting these things out of

1961

01:39:54,870 --> 01:39:58,140
these outcome measures which
are used as the default

1962

01:39:58,140 --> 01:40:02,355
for defining
intervention success.

1963

01:40:02,355 --> 01:40:05,790
[Ken Richman] Alright, that's
really important.

1964
01:40:05,790 --> 01:40:07,229
We've some other questions,

1965
01:40:07,229 --> 01:40:09,510
a couple of other questions.
One particularly focused

1966
01:40:09,510 --> 01:40:12,089
on quality of life measures.

1967
01:40:12,089 --> 01:40:16,800
And eventually, I'd like to,

1968
01:40:16,800 --> 01:40:22,919
maybe offline, ask you
about the role of impairment,

1969
01:40:22,919 --> 01:40:25,919
but I don't want you to respond
right now because

1970
01:40:25,919 --> 01:40:28,844
there are a couple other things that
I think we should get to

1971
01:40:28,844 --> 01:40:32,025
first that will have
broader interest.

1972
01:40:32,025 --> 01:40:38,774
But there are a couple
of questions about this:

1973
01:40:38,774 --> 01:40:41,130
about advocacy

1974
01:40:41,130 --> 01:40:44,100
or alliance
in some ways.

1975

01:40:44,100 --> 01:40:49,919

One person asks "How
can others," I guess

1976

01:40:49,919 --> 01:40:53,889

NTs--neurotypical people--
"support

1977

01:40:54,440 --> 01:40:58,889

this effort that
you're talking about

1978

01:40:58,889 --> 01:41:03,055

and the changes that
you are trying to,

1979

01:41:03,055 --> 01:41:05,264

to make or advocate for?"

1980

01:41:05,264 --> 01:41:08,294

And I'm going to ask

1981

01:41:08,294 --> 01:41:09,780

another question at the same time,

1982

01:41:09,780 --> 01:41:12,270

and you don't have to answer
them in the same order.

1983

01:41:12,270 --> 01:41:14,130

If you want to answer one
and ask me to repeat

1984

01:41:14,130 --> 01:41:16,319

the other one, that's
fine, too.

1985

01:41:16,319 --> 01:41:18,704

There's one person who asks, Well, wait--

1986

01:41:18,704 --> 01:41:21,465

"if I start

1987

01:41:21,465 --> 01:41:24,419
taking about neurodiversity
and apply it to

1988

01:41:24,419 --> 01:41:27,389
another type of disability

1989

01:41:27,389 --> 01:41:30,674
another sort of neurological
disability, am I

1990

01:41:30,674 --> 01:41:34,139
is that unfair, am I
appropriating?

1991

01:41:34,139 --> 01:41:36,735
Would that be inappropriate?
Would that be misappropriation?

1992

01:41:36,735 --> 01:41:38,100
If I take this idea from

1993

01:41:38,100 --> 01:41:41,684
the autism community and
apply it somewhere else?"

1994

01:41:41,684 --> 01:41:44,774
[Ari Ne'eman] I certainly don't think
it's misappropriation.

1995

01:41:44,774 --> 01:41:46,169
I encourage you to do so.

1996

01:41:46,169 --> 01:41:49,690
I tend to think of it as
exporting the revolution.

1997

01:41:51,350 --> 01:41:54,030
So by all means. In fact,

1998

01:41:54,030 --> 01:41:56,550
there has been some very
interesting research

1999
01:41:56,550 --> 01:41:58,049
recently on applying,

2000
01:41:58,049 --> 01:42:00,045
very
interesting writing,

2001
01:42:00,045 --> 01:42:01,499
I should say, on applying

2002
01:42:01,499 --> 01:42:03,059
the neurodiversity framework to

2003
01:42:03,059 --> 01:42:06,329
stuttering that I've been
quite excited about.

2004
01:42:06,329 --> 01:42:08,520
And there's longstanding
discussions around

2005
01:42:08,520 --> 01:42:10,829
neurodiversity in the
context of dyslexia,

2006
01:42:10,829 --> 01:42:15,060
ADHD, various forms
of mental illness.

2007
01:42:15,060 --> 01:42:17,129
Sort of an interesting
discussion and

2008
01:42:17,129 --> 01:42:18,839
the mental illness conversation

2009
01:42:18,839 --> 01:42:22,574
because historically one of

2010

01:42:22,574 --> 01:42:27,600
the frames of the mental
health consumer community

2011

01:42:27,600 --> 01:42:31,830
is the idea of recovery
as a positive good.

2012

01:42:31,830 --> 01:42:34,349
Mental health consumers
have generally

2013

01:42:34,349 --> 01:42:37,619
framed recovery is
something that they

2014

01:42:37,619 --> 01:42:42,060
want as equivalent to
no longer being subject

2015

01:42:42,060 --> 01:42:45,269
to coercion and

2016

01:42:45,269 --> 01:42:48,389
being able to live in
the community, and so on.

2017

01:42:48,389 --> 01:42:50,070
So in some ways that

2018

01:42:50,070 --> 01:42:53,205
conflicts with the
neurodiversity framework,

2019

01:42:53,205 --> 01:42:55,635
at the very least
semantically in that,

2020

01:42:55,635 --> 01:42:57,385
you know, we would very much

2021

01:42:57,385 --> 01:43:00,335

refer to ourselves
as still autistic

2022

01:43:00,335 --> 01:43:03,484
even when we're quite
happy and doing well.

2023

01:43:03,484 --> 01:43:09,410
I once had an interesting
conversation with Will Hall,

2024

01:43:09,410 --> 01:43:12,079
who's part of the psych survivor,

2025

01:43:12,079 --> 01:43:13,699
mental health consumer community,

2026

01:43:13,699 --> 01:43:14,990
and very much part of

2027

01:43:14,990 --> 01:43:16,970
that vision of recovery

2028

01:43:16,970 --> 01:43:19,025
and mental illness
where he asked me,

2029

01:43:19,025 --> 01:43:22,730
"Do you think autism
is a real thing?"

2030

01:43:22,730 --> 01:43:24,889
I said "What do you mean
do I think it's

2031

01:43:24,889 --> 01:43:26,599
a real thing? I run an

2032

01:43:26,599 --> 01:43:29,719
organization. It's been relevant

2033

01:43:29,719 --> 01:43:31,459

in my life in all kinds of ways.

2034

01:43:31,459 --> 01:43:32,659
Yes, I think it's neurological--

2035

01:43:32,659 --> 01:43:34,129
We've got, you know,

2036

01:43:34,129 --> 01:43:37,429
MRIs. Look at the studies."

2037

01:43:37,429 --> 01:43:38,810
So I think you do

2038

01:43:38,810 --> 01:43:41,999
sometimes--the one risk
that I sometimes do see

2039

01:43:41,999 --> 01:43:45,510
in applying the neurodiversity
frame beyond autism

2040

01:43:45,510 --> 01:43:49,050
is there are some communities
where the self-advocates

2041

01:43:49,050 --> 01:43:50,939
there very much
don't want that.

2042

01:43:50,939 --> 01:43:54,015
They've bought into a very
different conception.

2043

01:43:54,015 --> 01:43:57,254
Mental health, consumer,
psych survivor world--

2044

01:43:57,254 --> 01:43:59,879
some elements of it
are still challenging

2045

01:43:59,879 --> 01:44:03,195
the neurological basis
for mental illness.

2046
01:44:03,195 --> 01:44:05,970
The neurodiversity movement
very much accepts

2047
01:44:05,970 --> 01:44:09,494
and confirms the neurological
basis of autism.

2048
01:44:09,494 --> 01:44:14,369
So I think you do see a
little tension there.

2049
01:44:14,369 --> 01:44:16,350
But in general, we
want to see folks

2050
01:44:16,350 --> 01:44:18,945
accept the neurodiversity
frame. We welcome it.

2051
01:44:18,945 --> 01:44:22,139
And I encourage folks to bring

2052
01:44:22,139 --> 01:44:26,129
it into any context in which
they feel it's relevant.

2053
01:44:26,129 --> 01:44:30,134
The question, another
question was about allies.

2054
01:44:30,134 --> 01:44:32,039
Well, first I
encourage you to check

2055
01:44:32,039 --> 01:44:33,510
out ASAN's website,

2056
01:44:33,510 --> 01:44:36,734

www.autisticadvocacy.org.

2057

01:44:36,734 --> 01:44:40,050

And lots of opportunities to get

2058

01:44:40,050 --> 01:44:41,970

involved either via donating or

2059

01:44:41,970 --> 01:44:44,279

signing up for our

email list and so on.

2060

01:44:44,279 --> 01:44:47,370

I also think there are unique
opportunities that you

2061

01:44:47,370 --> 01:44:50,670

may have as professionals.

2062

01:44:50,670 --> 01:44:53,235

Many of you are

service providers.

2063

01:44:53,235 --> 01:44:57,119

And I think you can work to use

2064

01:44:57,119 --> 01:45:00,930

the role that you

have and sometimes

2065

01:45:00,930 --> 01:45:02,400

the privilege that

you have within

2066

01:45:02,400 --> 01:45:04,740

your field as someone who's on

2067

01:45:04,740 --> 01:45:07,529

the acceptable side of

2068

01:45:07,529 --> 01:45:12,644

the provider-consumer

line to encourage reform.

2069

01:45:12,644 --> 01:45:14,789
You know, somebody asked earlier,

2070

01:45:14,789 --> 01:45:17,915
"Is there any
way to reform ABA?"

2071

01:45:17,915 --> 01:45:22,169
I just, I would find it really--I

2072

01:45:22,169 --> 01:45:24,075
probably would
would be a lot more

2073

01:45:24,075 --> 01:45:26,925
optimistic about the
answer to that question

2074

01:45:26,925 --> 01:45:29,400
if a lot of the people asking it

2075

01:45:29,400 --> 01:45:31,380
were applying their
efforts to reforming

2076

01:45:31,380 --> 01:45:35,520
ABA rather than asking if
there was a way to do so.

2077

01:45:35,520 --> 01:45:37,739
Because to date, I haven't really

2078

01:45:37,739 --> 01:45:40,034
seen very much in that space.

2079

01:45:40,034 --> 01:45:42,944
I've seen much more defending

2080

01:45:42,944 --> 01:45:45,150
an ABA that could exist

2081

01:45:45,150 --> 01:45:47,310
rather than the ABA
that does exist.

2082

01:45:47,310 --> 01:45:48,810
And I, I'm

2083

01:45:48,810 --> 01:45:51,900
understandably skeptical
about the process of

2084

01:45:51,900 --> 01:45:55,185
change given where that
investment has taken place.

2085

01:45:55,185 --> 01:45:57,210
But even here in
another field,

2086

01:45:57,210 --> 01:45:58,349
there are lots of ways

2087

01:45:58,349 --> 01:46:01,539
that neurodiversity
principles could be relevant

2088

01:46:01,539 --> 01:46:03,180
to clinical psychology,

2089

01:46:03,180 --> 01:46:06,120
to occupational therapy,
to speech pathology,

2090

01:46:06,120 --> 01:46:08,789
to lots of fields that

2091

01:46:08,789 --> 01:46:11,039
autistic people or people with

2092

01:46:11,039 --> 01:46:13,379
other neurological

disabilities interact with.

2093

01:46:13,379 --> 01:46:17,249

So leverage whatever
standing you have to advance

2094

01:46:17,249 --> 01:46:19,050

these ideas and work with

2095

01:46:19,050 --> 01:46:21,690

autistic people in
partnership to do so.

2096

01:46:21,690 --> 01:46:24,480

One of the really exciting things is we're seeing

2097

01:46:24,480 --> 01:46:27,765

a growing generation of
autistic researchers.

2098

01:46:27,765 --> 01:46:29,730

And so I think there
are a lot of folks to

2099

01:46:29,730 --> 01:46:32,235

partner with towards
those ends.

2100

01:46:32,235 --> 01:46:38,039

[Ken Richman] Fantastic. I would say, I
would add, if I may,

2101

01:46:38,039 --> 01:46:39,839

there are ways of
talking that

2102

01:46:39,839 --> 01:46:43,589

are, and referring to diversity

2103

01:46:43,589 --> 01:46:46,919

and autistic people
and autistic traits

2104

01:46:46,919 --> 01:46:50,534
that are more and
less respectful.

2105

01:46:50,534 --> 01:46:54,750
And, we sometimes can
learn how to express ourselves

2106

01:46:54,750 --> 01:46:56,849
in a way that's more

2107

01:46:56,849 --> 01:46:59,969
respectful when we
don't know otherwise.

2108

01:46:59,969 --> 01:47:02,355
Here's a question,
and of course we're going on

2109

01:47:02,355 --> 01:47:06,600
and most people have had to go, and don't,

2110

01:47:06,600 --> 01:47:11,924
nobody should feel
guilty about, for fading,

2111

01:47:11,924 --> 01:47:14,940
fading away by their
attention or needing to go.

2112

01:47:14,940 --> 01:47:16,650
Here's an interesting
question from someone

2113

01:47:16,650 --> 01:47:19,095
who has a lot of
experience working with

2114

01:47:19,095 --> 01:47:24,765
autistic people in the community
and this person asks: well,

2115

01:47:24,765 --> 01:47:26,940
there may be
a lot of autistic people

2116
01:47:26,940 --> 01:47:30,629
who've learned to suppress

2117
01:47:30,629 --> 01:47:38,970
their autistic behavior, to cover,
or pass for practical

2118
01:47:38,970 --> 01:47:41,340
reasons, right, at
work or whatnot,

2119
01:47:41,340 --> 01:47:46,379
and how can we support
those people who,

2120
01:47:46,379 --> 01:47:49,710
who've already learned
to do that and learned that

2121
01:47:49,710 --> 01:47:54,825
this is the way they have to,
or feel like they have to live their lives.

2122
01:47:54,825 --> 01:47:58,289
[Ari Ne'eman] I mean, I think a
lot of the value

2123
01:47:58,289 --> 01:48:00,240
of autistic community is

2124
01:48:00,240 --> 01:48:02,069
really to create spaces where

2125
01:48:02,069 --> 01:48:05,564
people can let go of
that to some extent.

2126
01:48:05,564 --> 01:48:08,460
At the various autistic

community conferences

2127

01:48:08,460 --> 01:48:10,050
and the social gatherings

2128

01:48:10,050 --> 01:48:11,955
there's often a tremendous,

2129

01:48:11,955 --> 01:48:13,649
tremendous feeling of relief

2130

01:48:13,649 --> 01:48:15,300
on the part of people, of

2131

01:48:15,300 --> 01:48:18,060
of letting go of a burden
that they carry with

2132

01:48:18,060 --> 01:48:21,599
them every day in their
day to day lives

2133

01:48:21,599 --> 01:48:25,499
by virtue of entering
a space without

2134

01:48:25,499 --> 01:48:30,299
the oppressive passing demand

2135

01:48:30,299 --> 01:48:31,860
that can be so pervasive.

2136

01:48:31,860 --> 01:48:36,734
So, you know, I think it's
very tricky because of course

2137

01:48:36,734 --> 01:48:39,029
people do learn to pass
and often they

2138

01:48:39,029 --> 01:48:42,104
have no reason to do so.

2139
01:48:42,104 --> 01:48:45,734
Thinking about the professional
or personal consequences

2140
01:48:45,734 --> 01:48:48,059
of what will happen to
them if they don't.

2141
01:48:48,059 --> 01:48:50,010
I don't know that we

2142
01:48:50,010 --> 01:48:52,305
should be second-
guessing their judgment.

2143
01:48:52,305 --> 01:48:55,424
But the more that we can a)

2144
01:48:55,424 --> 01:48:57,210
try and connect autistic people

2145
01:48:57,210 --> 01:48:58,919
with other autistic
people so that

2146
01:48:58,919 --> 01:49:01,649
there are spaces
where we don't feel

2147
01:49:01,649 --> 01:49:05,340
that demand, and b) try and
change our workplaces,

2148
01:49:05,340 --> 01:49:08,039
try and change our
schools, and so on

2149
01:49:08,039 --> 01:49:12,090
to make those passing demands

2150
01:49:12,090 --> 01:49:14,399

go away
or become less severe,

2151
01:49:14,399 --> 01:49:16,950
I think the better
off we'll be and

2152
01:49:16,950 --> 01:49:21,315
the more accommodating and
inclusive our communities will be.

2153
01:49:21,315 --> 01:49:25,710
[Ken Richman] Alright, that's fantastic. One of the,

2154
01:49:25,710 --> 01:49:28,605
one of the key
organizers of Autescape

2155
01:49:28,605 --> 01:49:30,870
was here, had to leave a few minutes ago,

2156
01:49:30,870 --> 01:49:33,689
but she helps to provide

2157
01:49:33,689 --> 01:49:39,584
one of those spaces where
autistic people can go and drop,

2158
01:49:39,584 --> 01:49:42,180
drop the mask.

2159
01:49:42,180 --> 01:49:45,224
And it's interesting to,

2160
01:49:45,224 --> 01:49:47,730
it's interesting to hear

2161
01:49:47,730 --> 01:49:50,190
from people how
comfortable they are

2162
01:49:50,190 --> 01:49:53,099

there and how that's
a place where

2163

01:49:53,099 --> 01:49:56,490
they have learned to accept themselves

2164

01:49:56,490 --> 01:49:59,144
and more.

2165

01:49:59,144 --> 01:50:01,640
[Ari Ne'eman] We should probably wrap up at the hour.

2166

01:50:01,640 --> 01:50:03,190
[Ken Richman] Yeah.

2167

01:50:03,190 --> 01:50:07,769
[Ari Ne'eman] I'm hoping you can save the chat transcript and send it
over to me.

2168

01:50:07,769 --> 01:50:12,090
[Ken Richman] Yes. I will highlight it.
I lost the last one,

2169

01:50:12,090 --> 01:50:14,535
so I'm going to,
before close out,

2170

01:50:14,535 --> 01:50:18,539
I'm going to copy it over
into a Word document.

2171

01:50:18,539 --> 01:50:22,034
Good.

2172

01:50:22,034 --> 01:50:27,195
I'm not sure that I have
questions left.

2173

01:50:27,195 --> 01:50:29,954
I may have a new topic

2174

01:50:29,954 --> 01:50:35,834

that hasn't been pretty
well covered. I may have.

2175
01:50:35,834 --> 01:50:37,734
My joint attention is not

2176
01:50:37,734 --> 01:50:40,770
entirely functional,
so going back and

2177
01:50:40,770 --> 01:50:44,890
forth between the
talk and, and the chat.

2178
01:50:49,400 --> 01:50:54,100
Good. Here is one

2179
01:50:54,410 --> 01:51:02,760
from --I think you've actually
answered this at the end of your talk, but

2180
01:51:02,760 --> 01:51:06,915
it was sent earlier
by Cecilia, who says 'hi,'

2181
01:51:06,915 --> 01:51:12,030
and is asking about what
meaningful health outcomes

2182
01:51:12,030 --> 01:51:14,099
for autistic individuals

2183
01:51:14,099 --> 01:51:16,624
would be, and which
you would prioritize.

2184
01:51:16,624 --> 01:51:19,004
I think you kind of

2185
01:51:19,004 --> 01:51:22,050
punted that to
the empirical work--

2186

01:51:22,050 --> 01:51:24,329
well, let's see what
autistic people care about.

2187

01:51:24,329 --> 01:51:26,459
Is that my understanding?

2188

01:51:26,459 --> 01:51:28,529
[Ari Ne'eman] Yeah. I mean, I think
there are definitely

2189

01:51:28,529 --> 01:51:29,849
a lot of, there's a lot of

2190

01:51:29,849 --> 01:51:34,170
empirical work that needs
to be done in that space.

2191

01:51:34,170 --> 01:51:36,990
I think that that is
certainly very

2192

01:51:36,990 --> 01:51:41,384
relevant as an area
for future work.

2193

01:51:41,384 --> 01:51:43,649
I would also say that
I think often we

2194

01:51:43,649 --> 01:51:47,219
undervalue the process of

2195

01:51:47,219 --> 01:51:48,540
looking at outcomes that

2196

01:51:48,540 --> 01:51:54,075
are relevant to the
general public, as well.

2197

01:51:54,075 --> 01:51:57,480
Which is to say that there's

2198

01:51:57,480 --> 01:52:02,910
remarkably little work
looking at, for example,

2199

01:52:02,910 --> 01:52:07,830
the effect of various modes of

2200

01:52:07,830 --> 01:52:10,155
service provision in autism on

2201

01:52:10,155 --> 01:52:13,724
educational inclusion or
academic achievement.

2202

01:52:13,724 --> 01:52:16,140
It sometimes seems that we are so

2203

01:52:16,140 --> 01:52:18,824
obsessed with getting people

2204

01:52:18,824 --> 01:52:22,559
to imitate typical
appearance that we

2205

01:52:22,559 --> 01:52:24,480
forget that the
purpose of schools

2206

01:52:24,480 --> 01:52:26,954
is for children to learn
something, as well.

2207

01:52:26,954 --> 01:52:31,244
And then similarly, when we
talk about health outcomes

2208

01:52:31,244 --> 01:52:35,190
we often don't give enough
emphasis to some of

2209

01:52:35,190 --> 01:52:39,675

the same outcomes regarding
chronic conditions,

2210

01:52:39,675 --> 01:52:42,315
co-occurring mental
health issues,

2211

01:52:42,315 --> 01:52:46,889
and wellness regarding

2212

01:52:46,889 --> 01:52:50,610
physical health that exist
in the general population.

2213

01:52:50,610 --> 01:52:53,069
And there are obviously
unique ways that

2214

01:52:53,069 --> 01:52:55,080
those things need
to be pursued for

2215

01:52:55,080 --> 01:52:57,194
autistic people. But I think

2216

01:52:57,194 --> 01:53:00,780
we're going to simultaneously
need to see a process of

2217

01:53:00,780 --> 01:53:05,370
revising a lot of these autism-
specific outcome measures

2218

01:53:05,370 --> 01:53:07,770
and we're going to need
to remind the fields

2219

01:53:07,770 --> 01:53:14,265
that autistic people
still are going to need

2220

01:53:14,265 --> 01:53:20,114
the same kinds of

primary care and

2221

01:53:20,114 --> 01:53:25,019
educational academic
achievement outcomes

2222

01:53:25,019 --> 01:53:28,770
that we care about with the
non-disabled population.

2223

01:53:28,770 --> 01:53:33,390
[Ken Richman] Right, right which reminds me of some of the way that your
personal story is

2224

01:53:33,390 --> 01:53:39,075
told by Steve Silverman, about
looking around saying

2225

01:53:39,075 --> 01:53:42,309
wait a second, what happened
to the school part?

2226

01:53:42,620 --> 01:53:46,529
I'm here to learn, and people can

2227

01:53:46,529 --> 01:53:50,774
look at how that's
told in Neurotribes.

2228

01:53:50,774 --> 01:53:54,555
I, I it took me a couple
tries to understand

2229

01:53:54,555 --> 01:53:57,210
a question that's come back

2230

01:53:57,210 --> 01:54:00,344
from one of the
philosophers who's here,

2231

01:54:00,344 --> 01:54:05,100
who's interested in
exploring this idea of--

2232
01:54:05,100 --> 01:54:07,934
well, that's
something like this:

2233
01:54:07,934 --> 01:54:10,080
If autistic
people are capable of

2234
01:54:10,080 --> 01:54:12,900
passing and then they
choose not to,

2235
01:54:12,900 --> 01:54:15,239
if we make this into
an optional thing,

2236
01:54:15,239 --> 01:54:19,439
then we have an
interesting situation

2237
01:54:19,439 --> 01:54:23,070
where somebody who chooses
not to might be seen as uncooperative

2238
01:54:23,070 --> 01:54:25,259
and therefore
causing trouble.

2239
01:54:25,259 --> 01:54:30,114
Right? And sort of
like the person who could walk

2240
01:54:30,114 --> 01:54:31,590
but decides

2241
01:54:31,590 --> 01:54:33,615
I'm going to, I'm going to be,

2242
01:54:33,615 --> 01:54:37,140
I'm going to say I have a
mobility impairment.

2243

01:54:37,140 --> 01:54:42,089

And so I wonder if
that sort of touches

2244

01:54:42,089 --> 01:54:44,249

anything for you.

2245

01:54:44,249 --> 01:54:47,399

[Ari Ne'eman] Yes absolutely. I'm
so glad you raised

2246

01:54:47,399 --> 01:54:48,810

that because it connects back to

2247

01:54:48,810 --> 01:54:50,819

the very first thing
I talked about,

2248

01:54:50,819 --> 01:54:53,700

which is the concept of
covering which I,

2249

01:54:53,700 --> 01:54:55,620

for the purposes of simplicity,

2250

01:54:55,620 --> 01:54:58,395

rolled into the word 'passing,'

2251

01:54:58,395 --> 01:55:00,689

but they're actually
very different things.

2252

01:55:00,689 --> 01:55:03,329

Kenji Yoshino's book,

2253

01:55:03,329 --> 01:55:05,249

I believe it's called "Covering:

2254

01:55:05,249 --> 01:55:07,139

The Hidden Assault
on our Civil Rights,

2255

01:55:07,139 --> 01:55:10,769
I really could not
recommend it enough,

2256

01:55:10,769 --> 01:55:15,180
really goes into this that
there is an expectation that

2257

01:55:15,180 --> 01:55:21,134
immutable characteristics
are considered legitimate,

2258

01:55:21,134 --> 01:55:25,049
and you aren't allowed

2259

01:55:25,049 --> 01:55:26,699
to discriminate against someone

2260

01:55:26,699 --> 01:55:28,919
based on immutable
characteristics,

2261

01:55:28,919 --> 01:55:31,665
but characteristics
that can be changed

2262

01:55:31,665 --> 01:55:35,129
there is a strong expectation
in our society that you're

2263

01:55:35,129 --> 01:55:36,629
supposed to line them with

2264

01:55:36,629 --> 01:55:39,180
typical appearance,
with normalcy.

2265

01:55:39,180 --> 01:55:41,744
And that's really something
we should challenge.

2266

01:55:41,744 --> 01:55:45,045

The covering demand, the
expectation that you can,

2267

01:55:45,045 --> 01:55:46,380
you can be autistic,

2268

01:55:46,380 --> 01:55:48,879
but you can't look autistic

2269

01:55:48,950 --> 01:55:52,335
or any number of
other variants on it,

2270

01:55:52,335 --> 01:55:54,959
is a tremendously harmful one

2271

01:55:54,959 --> 01:55:56,820
and gets at the core of what

2272

01:55:56,820 --> 01:56:00,344
the neurodiversity movement
is trying to address.

2273

01:56:00,344 --> 01:56:04,590
So I see that really
as an area in which

2274

01:56:04,590 --> 01:56:08,159
the neurodiversity critique has

2275

01:56:08,159 --> 01:56:11,654
the opportunity to make
common cause with many,

2276

01:56:11,654 --> 01:56:13,934
many other parts of not
just the disability

2277

01:56:13,934 --> 01:56:16,440
rights movement and the
disability community,

2278

01:56:16,440 --> 01:56:19,440
but with other aspects of
marginalized identity in

2279

01:56:19,440 --> 01:56:22,289
pushing back against those
forms of covering demands.

2280

01:56:22,289 --> 01:56:25,829
We have to challenge
the idea that you have

2281

01:56:25,829 --> 01:56:30,430
to be as normal as it is
possible for you to be.

2282

01:56:31,430 --> 01:56:37,109
[Ken Richman] Fantastic. That is a wonderful summary of your

2283

01:56:37,109 --> 01:56:42,179
position, and your presentation
right there, which I love.

2284

01:56:42,179 --> 01:56:45,460
It's fantastic to end on that note.

2285

01:56:45,740 --> 01:56:47,775
[Ken Richman] [Ari Ne'eman] Thank you very much.

2286

01:56:47,775 --> 01:56:50,204
It's been a pleasure and
thank you for having me.

2287

01:56:50,204 --> 01:56:53,535
I hope this is interesting
food for thought.

2288

01:56:53,535 --> 01:56:56,159
Have a good one, everyone.
[Dien Ho] Thank you so much.

2289

01:56:56,159 --> 01:56:58,600
[Ken Richman] Amazing.

