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4 HELPING FAMILIES IN MENTAL HEALTH CRISIS ACT OF 2013

5 THURSDAY, APRIL 3, 2014

6 House of Representatives,

7 Subcommittee on Health

8 Committee on Energy and Commerce

9 Washington, D.C.

10 The subcommittee met, pursuant to call, at 10:31 a.m.,
11 in Room 2322 of the Rayburn House Office Building, Hon. Joe
12 Pitts [Chairman of the Subcommittee] presiding.

13 Present: Representatives Pitts, Burgess, Murphy,
14 Blackburn, Gingrey, Lance, Cassidy, Guthrie, Griffith,
15 Bilirakis, Ellmers, Upton (ex officio), Pallone, Capps,
16 Schakowsky, Green, Butterfield, Barrow, Christensen,

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17 Sarbanes, DeGette, Tonko and Waxman (ex officio).
18 Staff present: Clay Alspach, Chief Counsel, Health;
19 Mike Bloomquist, General Counsel; Sean Bonyun, Communications
20 Director; Karen Christian, Chief Counsel, Oversight; Noelle
21 Clemente, Press Secretary; Brenda Destro, Professional Staff
22 Member, Health; Brad Grantz, Policy Coordinator, Oversight
23 and Investigations; Sydne Harwick, Legislative Clerk; Robert
24 Horne, Professional Staff Member, Health; Katie Novaria,
25 Professional Staff Member, Health; Sam Spector, Counsel,
26 Oversight; Heidi Stirrup, Health Policy Coordinator; Tom
27 Wilbur, Digital Media Advisor; Ziky Ababiya, Democratic Staff
28 Assistant; Karen Lightfoot, Democratic Communications
29 Director and Senior Policy Advisor; Karen Nelson, Democratic
30 Deputy Committee Staff Director for Health, Anne Morris Reid,
31 Democratic Senior Professional Staff Member; and Matt
32 Siegler, Democratic Counsel.

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|
33 Mr. {Pitts.} The subcommittee will come to order. The
34 Chair will recognize himself for an opening statement.

35 Millions of Americans suffer with severe mental
36 illnesses, such as bipolar disorder, schizophrenia and major
37 depression, and many of them, and their families, struggle to
38 find the treatment and help they desperately need.

39 I would like to commend my colleague from Pennsylvania,
40 Dr. Murphy, for his yearlong investigation into mental health
41 issues and for proposing H.R. 3717, the Helping Families in
42 Mental Health Crisis Act. Briefly, this bill would reform
43 the Community Mental Health Services Block Grant program by
44 changing administration, improving data collection, and by
45 requiring treatment standards to facilitate care. It would
46 enhance Medicaid payments to Federally Qualified Community
47 Behavioral Health Centers (FQCBHCs), make adjustments to
48 HIPAA and FERPA--the Family Education Rights and Privacy Act--
49 -privacy regulations, and expand access to certain medical
50 records for qualifying caregivers; create an Assistant
51 Secretary for Mental Health who will be responsible for
52 coordinating spending at all federal agencies on mental

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53 health, including at the Substance Abuse and Mental Health
54 Services Administration (SAMHSA). It would make changes to
55 key Justice Department regulations that impact at-risk or
56 imprisoned individuals with mental illness. It would
57 increase federal funding for certain Medicaid providers and
58 research at the National Institutes of Health. It would
59 institute liability protections for physician volunteers at
60 FQCBHCs, and it would reform existing mental health programs
61 at SAMHSA.

62 I would like to welcome all of our witnesses here today.
63 We look forward to learning from your expertise and
64 experience.

65 [The prepared statement of Mr. Pitts follows:]

66 ***** COMMITTEE INSERT *****

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|

67 Mr. {Pitts.} I will yield the balance of my time to the
68 gentleman from Pennsylvania, Dr. Murphy.

69 Mr. {Murphy.} I thank the chairman for convening this
70 hearing, and I want to thank the witnesses for being here as
71 well.

72 In light of yesterday's tragic shooting at Fort Hood
73 involving a soldier under treatment for a behavioral health
74 disorder, and news this week out of Pittsburgh of a mother
75 who said she heard voices commanding her to drown her two
76 young children in a bathtub, today's hearing has a sad
77 element of timeliness to it. But let us keep in mind, most
78 persons with mental illness are not violent, and tragically,
79 are more frequently the victims of violence, but you will
80 never hear the breaking news of a homeless man being robbed
81 or beaten or a person with mental illness losing their job.

82 Over the last year, the Oversight and Investigations
83 Subcommittee I chair held a series of forums and hearings to
84 review our Nation's mental health system, and this bill, the
85 Helping Families in Mental Health Crisis Act, is a result of
86 those hearings, and with anything, there is misinformation

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87 about this legislation, which is why I am glad you have
88 convened this hearing so we can continue to work forward on
89 perfecting it.

90 Fifty years ago, our Nation confronted the atrocities of
91 asylums, warehouses for those whose illnesses medical science
92 could not yet treat, and at that time this committee moved
93 legislation to close those places and help individuals live
94 in the community. Many were getting treatment and many were
95 not, and for half a century operated under the illusion that
96 having done something, we did the right thing. We didn't.

97 Unfortunately, that illusion has been shattered by the
98 heartbreaking daily tragedies that prove our mental health
99 system is broken and failing the very people who need help
100 most. The stories are haunting and the numbers are
101 staggering. Three point six million people with serious
102 mental illness don't get treatment. There is over 40,000
103 suicides a year, 20 soldier suicides each day. Another 1.3
104 million attempted suicide.

105 There is only one child psychiatrist for every 2,000
106 children with a mental health disorder. It is a system where
107 the three largest mental health hospitals are actually jails,

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108 and there is a shortage of 100,000 psychiatric beds
109 nationwide for those who are in acute crisis.

110 A rule to protect privacy needs clarification because it
111 has frustrated a countless number of physicians and members
112 and generated over 70,000 complaints, and the mental health
113 agency that until recently employed as many dentists as it
114 did psychologists and psychiatrists, and this is what the
115 American taxpayer buys for \$125 billion.

116 That is why we introduced this bill, to engage in
117 meaningful reform. It has several of those elements that
118 just presented by the chairman in empowering parents and
119 caregivers by breaking down the barriers that prevent
120 communication, increases access to acute care psychiatric
121 beds, provides alternatives to inpatient care through
122 assisted outpatient treatment, and expands access to the
123 underserved and rural populations; creates an Assistant
124 Secretary of Mental Health to scrutinize federal programs and
125 promote evidence-based care; ensures mental health patients
126 enrolled in Medicare and Medicaid have access to the full
127 range of medications that keep them healthy and out of the
128 hospital; advances critical research at the National

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129 Institutes of Mental Health like the Brain Research
130 Initiative; promotes promising evidence-based care like the
131 recovery after initial schizophrenic episode; improves
132 quality and expands access to integrated medical and mental
133 health care at community mental health providers, extends
134 health information technologies so mental health providers
135 can communicate and work with primary care physicians, and
136 ensures greater accountability from the Substance Abuse and
137 Mental Health Service Administration.

138 For far too long, those who need help have been getting
139 it the least, and where there is no help, there is no hope.
140 We can, must and will take mental illness out of the shadows
141 of ignorance, despair, neglect and denial and into that
142 bright light of hope, and it starts with the Helping Families
143 in Mental Health Crisis Act.

144 I look forward to hearing the comments of our witnesses
145 today. I yield back.

146 [The prepared statement of Mr. Murphy follows:]

147 ***** COMMITTEE INSERT *****

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|
148 Mr. {Pitts.} The chair thanks the gentleman and now
149 recognizes the ranking member of the subcommittee, Mr.
150 Pallone, for 5 minutes for an opening statement.

151 Mr. {Pallone.} Thank you, Chairman Pitts.

152 This is our subcommittee's first proceeding on mental
153 health during this Congress, and while I am thankful to you
154 for finally convening a panel to talk about this critically
155 important issue, I remain conflicted and disappointed that
156 you have decided to move straight to a legislative hearing.

157 For over a year we have had personal and staff
158 discussions about the importance of the Health Subcommittee
159 examining mental health in light of some heartbreaking events
160 in the past couple of years, and despite this today, I and
161 other members of the subcommittee are at a significant
162 disadvantage because we haven't been afforded an opportunity
163 to be at the forefront of evaluating and focusing on mental
164 illness. As the Health Subcommittee, we should be the ones
165 putting a full-scale effort into reviewing this and
166 understanding it better.

167 Mental illness is an important public health issue.

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168 According to numbers from the National Alliance on Mental
169 Health, it is estimated that one in four adults experience a
170 mental illness during the course of a given year. That is
171 about 55.7 million people. Meanwhile, only about 60 percent
172 of people with mental illness get treatment each year. Of
173 these people, approximately 11.4 million adults in the United
174 States live with a serious mental illness, which includes,
175 among others, major depression, schizophrenia and bipolar
176 disorder. Individuals with serious mental illness can be
177 treated effectively, but unfortunately, it has been so
178 difficult for those who need services to break through the
179 stigma and weigh the obstacles associated with mental health,
180 even though we know how important mental health is and how
181 interlinked it is to all aspects of health and quality of
182 life.

183 What some people may not realize is that mental illness
184 is not an isolated public health problem. Cardiovascular
185 disease, diabetes and obesity often coexist with mental
186 illness and treatment of the mental illness can reduce the
187 effects of these disorders. So it is proven that people,
188 families and communities will benefit from increased access

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189 to mental health services. Despite recent vigorous debate
190 about America's mental health policies, there has been no
191 clear solution yet. However, we made some significant steps
192 over recent years. The first significant milestone was the
193 Paul Wellstone Mental Health Parity and Addiction Equity Act,
194 which makes sure that large employer-based insurers cannot
195 charge more or place greater restrictions on mental health
196 benefits that they do for medical benefits. This parity law
197 marked a dramatic and historic step for the rights of
198 Americans with mental health and addition illness. When I
199 was the chairman of the Health Subcommittee, I was proud to
200 help play a critical role in enacting this bipartisan
201 legislation.

202 Of course, the parity struggle is not over. The
203 implementation of this law is critical. Specifically, we
204 need to ensure that there are measures in place for
205 meaningful reporting on compliance with the law.

206 Another significant milestone was passage of the
207 Affordable Care Act. It includes a number of provisions
208 aimed at improving coverage for and access to mental health
209 services. So let me point out some of the critical details

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210 in the ACA. First, people can no longer be denied coverage
211 because of preexisting conditions, and this includes mental
212 health illness; more access to the Medicaid program, which
213 has always provided a number of mental health treatments.
214 Mental health treatment now comes standard. Every health
215 plan sold through an exchange has to cover a variety of
216 medical services, which includes mental health and substance
217 abuse treatments. And finally, the ACA extends mental health
218 parity to all Americans, not just those who are covered by
219 large employers, again, building upon the Paul Wellstone law.

220 Mr. Chairman, these are just the highlights of the law
221 the Republicans aim to repeal. The ACA also includes a
222 number of provisions that specifically list mental health and
223 substance abuse as priority topics in programs like the
224 National Prevention Council, health workforce development
225 initiatives and medical homes, and there is still a lot more
226 to do. People will only benefit from the progress we have
227 made if services are available and if those who need help are
228 not afraid to seek it. We need to build from these laws to
229 support the continuum of mental health services at all levels
230 of government.

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231 That is why I believe we must support efforts to
232 increase awareness about mental health and reduce the fear,
233 shame and misperceptions that often prevent people from
234 getting the help they need, and I am committing to spreading
235 the message that it is okay to talk about mental health
236 because treatment is effective and people do recover. We
237 must find out which treatments are the right treatments and
238 how we can best identify Americans who need help, and that is
239 why agencies such as the Substance Abuse and Mental Health
240 Services Administration and NIMH are so important.

241 So Mr. Chairman, there are a number of Democrats on the
242 committee who have introduced legislation and expressed
243 interesting in working together to improve mental health in
244 this country. I hope that if you choose to move forward on
245 the bill under consideration today that we can find common
246 ground and pass bipartisan legislation. I have some serious
247 concerns about some of the provisions of H.R. 3717 but I
248 remain committed to working with you and my other colleagues
249 on the committee as we make mental health a priority.

250 Thank you, Mr. Chairman.

251 [The prepared statement of Mr. Pallone follows:]

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252 ***** COMMITTEE INSERT *****

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|
253 Mr. {Pitts.} The chair thanks the gentleman and now
254 recognizes the chairman of the full committee, the gentleman
255 from Michigan, Mr. Upton, for 5 minutes for an opening
256 statement.

257 The {Chairman.} Well, thank you, Mr. Chairman.

258 Mental illness affects millions of Americans and their
259 families, yet sadly it is a subject often left unmentioned in
260 Congress and in communities across the country, and we are
261 working to change that. Yes, we are. Ensuring treatments
262 and resources are available and effectively used for those
263 suffering with mental illnesses has been a priority of this
264 committee throughout the 113th Congress.

265 Since January of last year, Oversight and Investigations
266 Subcommittee Chairman Tim Murphy has spearheaded a thorough
267 review of all federal mental health programs. The
268 subcommittee and the committee held a series of public
269 forums, briefings and investigative hearings to discern how
270 federal dollars devoted to research and treatment into mental
271 illness are being prioritized and spent. I want to commend
272 him and those of efforts, and those of the ranking member of

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273 the Oversight and Investigations Subcommittee, Diana DeGette,
274 to ensure a bipartisan focus on these vital issues.

275 To address the gaps discovered in the extensive and
276 wide-ranging examination, Chairman Murphy introduced H.R.
277 3717 last year, the Helping Families in Mental Health Crisis
278 Act of 2013. The bill addresses issues that are important in
279 diagnosing and treating individuals with serious mental
280 illness. It would reorient federal funding for mental health
281 to improve the delivery of mental health services and help
282 improve the lives of mental health patients and their
283 families.

284 I am pleased that two important provisions of that bill
285 were included in H.R. 4302 that the President signed earlier
286 this week, which was sponsored, of course, the overall bill
287 by Chairman Pitts. The first provision will help local
288 jurisdictions implement assisted outpatient treatment grant
289 programs, and the second will improve access to community
290 mental health services, bipartisan and bicameral support for
291 both of those provisions.

292 I would just like to add that to those families who have
293 been impacted by mental illness in some form, Congress is

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294 aware of your plight and we can do better.

295 I yield the balance of my time to the vice chair of the
296 subcommittee, Dr. Burgess.

297 [The prepared statement of Mr. Upton follows:]

298 ***** COMMITTEE INSERT *****

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|
299 Dr. {Burgess.} Well, I thank the chairman for yielding.
300 I really do not have prepared comments this morning but I did
301 feel obligated to respond.

302 I am the vice chairman of this subcommittee as well as
303 the vice chairman of the Oversight and Investigations
304 Subcommittee, and in total, the committee through its
305 subcommittees, this represents the eighth dedicated hearing
306 to mental health and mental health issues between the
307 Oversight and Investigations Subcommittee and the
308 Subcommittee on Health and the full committee in general. So
309 it is not from lack of attention. Chairman Murphy has made
310 this the centerpiece of his chairmanship of the Oversight and
311 Investigations Subcommittee, which is appropriate but that is
312 not a legislative committee, so today we are in the Health
313 Subcommittee, and Chairman Pitts is encouraging us to have
314 this legislation hearing on Congressman Murphy's efforts.

315 And then as a Texan, I just have to say across the
316 country, our hearts are heavy because of what we saw down in
317 Fort Hood last evening. When the news stories began to
318 break, I am sure I felt the same as everyone else across the

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319 country felt: oh, no, not again. It seems like just a few
320 months ago that we were down for the memorial service for the
321 13 soldiers who were lost in November of 2009, and now we are
322 facing another series of questions surrounding another
323 incident yesterday.

324 We know there will be an investigation. We know there
325 will be answers to the questions that are forthcoming, but
326 right now please let us keep in our thoughts the soldiers at
327 Fort Hood, their general officer corps, of course the people
328 in Killeen, Texas, Harker Heights, Coppers Cove, those
329 communities. I will tell you from firsthand experience
330 during the memorial service 4-1/2 years ago, those
331 communities came together and embraced the soldiers at Fort
332 Hood and let them know they were not acting alone. Our
333 military has been under great stress for the last decade.
334 Surely this is something they didn't need but we can all
335 stand in their support.

336 Thank you, Mr. Chairman. I will yield back.

337 [The prepared statement of Dr. Burgess follows:]

338 ***** COMMITTEE INSERT *****

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|

339 Mr. {Pitts.} The chair thanks the gentleman and now
340 recognizes the ranking member of the full committee, Mr.
341 Waxman, 5 minutes for an opening statement.

342 Mr. {Waxman.} Thank you, Mr. Chairman.

343 One in four adults has a diagnosable form of mental
344 illness in any given year. More than 10 million Americans
345 are living with serious mental illness, conditions like
346 schizophrenia and major depression. But even as the demand
347 for mental health services has increased, there has been an
348 unprecedented decline in state public mental health spending.
349 The Federal Government has stepped in to help fill the gap.
350 The increased coverage provided by the Affordable Care Act
351 and the mental health benefits it requires will make a
352 substantial improvement in the lives of Americans who need
353 these services. Already more than 7 million Americans signed
354 up for insurance coverage through the marketplaces that
355 includes mental health and substance use disorder services at
356 parity with medical and surgical benefits.

357 The expansion of Medicaid in many states, but not all
358 unfortunately, has also made a huge difference, giving

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359 millions more comparable behavioral health coverage. But
360 there is certainly more that can be done.

361 Today's hearing is focused on one bill, legislation
362 introduced by Congressman Murphy, H.R. 3717, the Helping
363 Families in Mental Health Crisis Act of 2013. There are some
364 provisions in H.R. 3717 that I strongly support. I support
365 reauthorization of programs with strong bipartisan backing
366 like the Garrett Lee Smith Suicide Prevention program and
367 National Child Traumatic Stress Initiative. I support the
368 provisions recognizing the important work of the National
369 Institute of Mental Health on brain research that will help
370 us better understand the causes of mental illness. I support
371 the campaign to raise awareness regarding mental illness
372 among our young people, and I support the proposal that would
373 extend electronic health record meaningful use incentive
374 payments to mental health providers.

375 But I must express deep concern about other provisions
376 in this bill. I think the bill broadly redefines the privacy
377 rights of individuals with a diagnosed mental illness. This
378 could discourage many people who need to come forward for
379 care from seeking necessary treatment if they fear their

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380 privacy won't be protected. The bill cuts federal support
381 for mental health services administered through the Community
382 Mental Health Services Block Grant and conditions States'
383 ongoing support on the adoption of new federal standards for
384 involuntary treatment that would displace current law. So
385 you have the Federal Government cutting the funds but saying
386 if you are going to get funds that are left, you have to do
387 it the way we tell you to do it. This has always been a
388 State responsibility. This is a one-size-fits-all response.
389 I am not sure if that is the best way for us to approach it.

390 It proposes a dramatic reorganization of mental health
391 authorities in the Department of Health and Human Services
392 that would minimize the role of the main agency on mental
393 health--the Substance Abuse Mental Health Services
394 Administration--and would reverse efforts to better
395 coordinate mental health and substance abuse activities.
396 Separation of these two programs--I can't understand the
397 reasoning behind it. And the bill undermines the important
398 work of the protection and advocacy programs that protect the
399 rights of people with mental illness from abuse and neglect.

400 The bill has an important provision in it that I think

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401 we need to look very carefully at, and that is the expansion
402 of Medicaid coverage that we are going to mandate under
403 Medicaid, and I think the responsibility of the states that
404 have been paying for it and shifting those costs to the
405 Federal Government. This could be billions and billions and
406 billions of dollars at a time when we hear so often from the
407 other side of the aisle we can't afford the entitlements of
408 Medicaid the entitlements of poor people, and a lot of poor
409 people have the greatest problem in accessing mental health
410 services.

411 Last year, I and other Democrats introduced mental
412 health legislation but key provisions from that legislation
413 are absent in Congressman Murphy's bill. Any bill we advance
414 should include investments in mental health first aid, mental
415 health in the schools, and mental health provider workforce
416 development. We should be looking at all ideas that have
417 been put forward and working in a bipartisan manner on
418 legislation to achieve our shares the goal of improving our
419 system.

420 I want to thank all of the witnesses for appearing
421 before us today. In particular, I want to take a moment to

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422 recognize Ms. Jensen, who will share her own personal history
423 with mental illness and road to recovery. I also want to
424 acknowledge Ms. Thompson, who is a constituent of mine, and
425 will discuss her experience as the daughter of a mother with
426 serious mental illness. And Ms. Zdanowicz, I know family
427 members close to you also have a history of mental illness,
428 and that is true of Dr. Shern as well. It takes a great deal
429 of courage for you to come here and speak out publicly about
430 such difficult experiences, but it is important for the
431 Subcommittee to hear your perspectives and to share it with
432 our other colleagues in the Congress.

433 Thank you, Mr. Chairman.

434 [The prepared statement of Mr. Waxman follows:]

435 ***** COMMITTEE INSERT *****

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436 Mr. {Pitts.} The Chair thanks the gentleman. That
437 concludes opening statements. All members' opening
438 statements will be made a part of the record.

439 I have a UC request. At this time I would ask unanimous
440 consent to enter these documents into the record, one by the
441 American Psychiatric Association, a Wall Street Journal
442 article titled ``The Definition of Insanity: How a Federal
443 Agency undermines treatment for the Mentally Ill,' ' a
444 statement by Robert Bruce, another Wall Street Journal
445 article dated December 26, 2013, and an op-ed by Congressman
446 Murphy that appeared in the Philadelphia Inquirer January 26,
447 2014. Without objection, so ordered.

448 [The information follows:]

449 ***** COMMITTEE INSERT *****

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450 Mr. {Pitts.} We have one panel today with five
451 witnesses. I will introduce them in the order that they
452 speak. Unfortunately, our first witness, Dr. Michael Welner,
453 is still on a train delayed. He will be coming in at any
454 minute. He is Founder and Chairman of the Forensic Panel.
455 Ms. Sylvia Thompson, Patient Advocate and President of the
456 National Alliance on Mental Illness; Dr. David Shern, Interim
457 President and CEO of Mental Health America; Ms. Nancy Jensen,
458 a person with lived experience, and Ms. Mary Zdanowicz,
459 Attorney and former Executive Director of the Treatment
460 Advocacy Center.

461 Thank you all for coming. Your written testimony will
462 be made a part of the record. You will each be given 5
463 minutes to summarize your written testimony, and we will
464 begin with Ms. Thompson. Ms. Thompson, you are recognized
465 for 5 minutes.

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|
466 ^STATEMENTS OF SYLVIA THOMPSON, PATIENT ADVOCATE AND
467 PRESIDENT, NATIONAL ALLIANCE ON MENTAL ILLNESS, WEST SIDE LOS
468 ANGELES; DR. DAVID L. SHERN, INTERIM PRESIDENT AND CEO,
469 MENTAL HEALTH AMERICA, ALEXANDRIA, VIRGINIA; NANCY JENSEN,
470 PERSON WITH LIVED EXPERIENCE, WICHITA, KANSAS; AND MARY T.
471 ZDANOWICZ, ATTORNEY, NORTH EASTHAM, MASSACHUSETTS

|
472 ^STATEMENT OF SYLVIA THOMPSON

473 } Ms. {Thompson.} Thank you, Mr. Chairman and members of
474 the committee, Representative Waxman. My name is Sylvia
475 Thompson and I am a Professional Care Manager as well as
476 President of NAMI's West Side Los Angeles affiliate, but that
477 is not why I am here today.

478 Today I am my mother's daughter. My mother was severely
479 mentally ill from as far back as I can remember. So growing
480 up in my family was like living in a combat zone. It never
481 felt safe because of her drastic mood changes, paranoia,
482 grandiose ideas, impulsivity, delusions, depression and
483 inappropriate anger often directed at me. As much as we

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484 loved our mother, my family was powerless to help her because
485 she did not believe she was ill. It is called anosognosia.
486 It affects up to 40 percent of those with schizophrenia and
487 bipolar disorder, and that is a conservative estimate.
488 Because she didn't believe she was ill, she would not stay in
489 treatment so she could not take care of herself nor could she
490 take care of me. She had suicidal ideation, delusions,
491 hospitalizations, believed I was possessed, and would
492 disappear for days or weeks.

493 I am a firm believer in self-determination but for those
494 that are capable. We must recognize there is a whole group
495 of people like my mother who are too ill to self-direct their
496 own care. Just take a look at the news. We can't pretend
497 these people don't exist. These tragic stories like this
498 morning, they are not the face of mental illness. They are
499 the face of mental illness that is severe mental illness that
500 is left untreated.

501 Our helpline is flooded with calls from family members
502 of individuals who are imprisoned by their delusions and
503 hallucinations. Parents beg for treatment and cannot get it.
504 The current mental health system doesn't help them because

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505 their child is too ill to volunteer for treatment. The
506 police can't help until after they become dangerous. It
507 can't be a recovery model or a medical model. We must
508 embrace both because one size does not fit all.

509 Sometimes the recovery model works but sometimes
510 assisted outpatient treatment or involuntary hospitalization
511 is initially necessary to get somebody on the recovery path.
512 AOT would help the few who have a past history of multiple
513 arrests, violence or hospitalizations caused by refusing to
514 stay in treatment. Studies show AOT reduces homelessness,
515 incarceration, suicide, arrest, and yes, violence. It saves
516 money. It reduces force and it saves lives. We need more
517 hospital beds. California has only five state hospitals with
518 less than 7,000 beds. Because of that, Californians with
519 severe mental illness are four times more likely to be
520 incarcerated than hospitalized--four times. That would never
521 be tolerated for cancer for Alzheimer's disease. Even at its
522 best, California would be short over 10,000 hospital beds to
523 help the most severely mentally ill get stabilized. We can't
524 pretend that hospitals are not needed.

525 We have to free family caretakers from HIPAA handcuffs

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526 so they can provide care to loved ones. How can someone
527 ensure their loved one has transportation to an appointment
528 if they don't know when the appointment is, or ensure they
529 stay on their medications if they don't know what the
530 medicines are. We have to prioritize the most severely ill
531 and stop funding non-evidence-based programs and groups that
532 impede care for the most seriously ill.

533 Congress created SAMHSA to target mental health services
534 to the people most in need. Only four in the 288 programs in
535 SAMHSA's national registry of evidence-based practices focus
536 on severe mental illness. That is four out of 288.

537 I urge you to pass H.R. 3717. I am not a politician, I
538 am not a legislator, but I am someone who has spent her life
539 in the trenches personally and now professionally. It is
540 wonderful to want to improve mental health for everyone but
541 in the process we absolutely cannot ignore the most severely
542 ill. They are the most vulnerable and they need your help.

543 My mother struggled my whole life. Before we gained
544 guardianship, she was living in a state of squalor surrounded
545 by stacks of newspaper, rotten food, human feces, dead
546 rodents. That was how she self-directed her care. No one

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547 chooses that life. But you should also know, she spoke seven
548 languages fluently. She knew every opera libretto and she
549 was a gifted pianist. She was passionate, she was creative
550 and she was loving. She was someone's daughter, she was
551 someone's sister, she was someone's wife, and she was the
552 mother to six amazing children who were desperate for her to
553 be well again.

554 My mother's inability to acknowledge her illness was not
555 a choice. It was a symptom that trapped her and robbed all
556 of us of her greatness, robbed me of my mother. I am proud
557 to be my mother's daughter. I inherited her passion, her
558 creativity, her outside-the-box thinking. In her memory and
559 to prevent others from going through what she and our family
560 did, I implore you all to please work together to pass H.R.
561 3717. Thank you.

562 [The prepared statement of Ms. Thompson follows:]

563 ***** INSERT 1 *****

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|

564 Mr. {Pitts.} The chair thanks the gentlelady and now
565 recognizes Dr. Shern five minutes for his opening statement.

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|
566 ^STATEMENT OF DAVID L. SHERN

567 } Mr. {Shern.} Thank you, Mr. Pitts, members of the
568 committee. I am the Interim President and CEO of Mental
569 Health America, which is the Nation's oldest mental health
570 advocacy organization. We are 105 years old this year. We
571 were founded by a person who had bipolar illness and have
572 throughout our history stood very firmly for the full
573 inclusion of people with mental illnesses in every aspect of
574 American life. We have 240 affiliates around the country,
575 approximately, and are very concerned with America's mental
576 health from a public health perspective.

577 Prior to joining Mental Health America, I was a tenured
578 Professor and Dean at the University of South Florida and a
579 mental health researcher, a psychologist by training, and I
580 spent my professional career really studying systems of care
581 for people with severe mental illnesses, and of particular
582 relevance, I think, for our discussion today was a program,
583 an NIMH-funded program that we conducted in New York City, an
584 experimental program using psychiatric rehabilitation

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585 technology to engage and serve persons with severe mental
586 illnesses who are homeless, living on the streets of New York
587 City, about 60 percent of whom also had very serious
588 addiction disorders. We were able through the use of peer
589 counselors who are involved in the program and a very well
590 understood technology, psychiatric rehabilitation technology
591 developed by Boston University to engage this very difficult
592 to treat, most in need group of individuals. We did that by
593 emphasizing the fact that they had choices in terms of how
594 they could organize their recovery and empowered them to
595 express those choices and empowered our team, our treatment
596 team, to enact those choices.

597 Through that process, we successfully housed the
598 majority of clients. We significantly reduced their level of
599 psychiatric symptomatology. We improved their quality of
600 life.

601 The important point is, I thought about these issues a
602 lot, and it is clear to me that we have technologies that can
603 be used to engage individuals in care. We don't always do
604 it, but those technologies are available to us and our
605 challenge is to try to implement them more effectively.

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606 I am also a family member. I think everyone here is a
607 family member. I have a feeling if we queried the committee,
608 we would find out that there is not one degree of separation
609 between many of us and a family member who has a mental
610 health problem. My nephew had severe bipolar disorder,
611 particularly when he was in high school, and even though I
612 knew all the people in the United States who developed the
613 evidence-based practices for this because of the inadequate
614 system of care, in this case in Pueblo, Colorado, we couldn't
615 get Kyle what he needed. Fortunately, my family had the
616 resources to get him into residential care and he is doing
617 fine now, but we went through a very difficult time, a time
618 when he was confused about what was going on with him and so
619 I am very sensitive to these issues.

620 The reason that I left academia and entered advocacy was
621 to try to close this gap between what we know and what is
622 routinely available to people, and there are many aspects, as
623 many of you have commented already, many aspects of this
624 legislation that are very important and that will seek to do
625 that, to expand coverage, and as many people have expressed,
626 we are very enthusiastic and supportive of those.

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627 There are, however, some aspects about which we are very
628 concerned. We are concerned with the emphasis on assisted
629 outpatient treatment. It is very clear to us that the issue
630 is having a full engagement-oriented system of care for
631 individuals and making those services available to those
632 individuals. We are concerned with expansion of the IMD
633 exclusion, focusing only on one type of care when we realize,
634 as Dr. Arthur Evans testified last week, that is in fact a
635 continuum of care which is most important.

636 We are concerned with what we conceive as an attack on
637 the protection and advocacy system and what we conceive as
638 some very fundamental misunderstandings about the role of the
639 Substance Abuse and Mental Health Services Administration in
640 leading the Nation's health. From our perspective, SAMHSA
641 has led every major mental health reform during the last 50
642 years. Is our system what we think it should be? No, it is
643 fragmented, it is broken and it is not responding to people.
644 Do we have the technology to make a difference? Yes, we do.
645 Are we implementing that technology? No, we are not. There
646 are several aspects of this bill which will help with that.
647 However, there are some premises and some assumptions that

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648 are very concerning for us and that we feel ultimately will
649 damage the system and will make it in fact more difficult for
650 people to access the services that they need.

651 We have made big progress with the Parity Act and
652 enacting that as part of the Affordable Care Act, which was
653 bipartisanly adopted by the Senate Finance Committee in the
654 initial markup of the bill. It is a chance for us to live
655 into the possibility of that Act to get people the services
656 that they need.

657 Thank you, Mr. Chairman.

658 [The prepared statement of Mr. Shern follows:]

659 ***** INSERT 2 *****

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|

660 Mr. {Pitts.} The Chair thanks the gentleman and now

661 recognizes Ms. Jensen 5 minutes for an opening statement.

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|

662 ^STATEMENT OF NANCY JENSEN

663 } Ms. {Jensen.} My name is Nancy Jensen, and I am the
664 author of ``The Girl Who Cried Wolf,`` which tells the story
665 of my lived experienced as a person with mental illness and a
666 survivor of the terrible place called Kaufman House in
667 Newton, Kansas.

668 The story of Kaufman House vividly shows why parts of
669 this bill destroying the funding and effectiveness of both
670 PAIMI and recovery programs must be removed. This bill
671 slashes funding for PAIMI's program and takes away their
672 ability to combat evil and protect the rights of people with
673 mental illness including the right to choose their treatment.

674 If this bill is law, the Kaufman House would still be
675 terrorizing, abusing and enslaving people with mental
676 illness. As a former resident, I know how terrible Kaufman
677 House was. They called what they were doing therapy. It was
678 not therapy. It was sexual and emotional abuse. The
679 Kaufmans forced their so-called patients to be nude and do
680 bizarre acts, sex acts, while they videotaped it. I was

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681 forced to be naked, to sleep on a filthy floor and use a
682 bucket for a toilet. I was degraded and told I should never
683 get married, never have a child, never join a church, and
684 that I would never get a job. Well, as a proudly married
685 mother with both faith in God and a job, I proved Kaufman
686 wrong.

687 The PAIMI program shut down this house of horrors when
688 no one else would or could. The PAIMI program freed my
689 friends and helped get us justice. I was the first former
690 resident to tell the State about the evil. Eleven other
691 Kansans made reports after me but the State did absolutely
692 nothing.

693 How did PAIMI programs shut down Kaufman House when the
694 State adult protective services could not? Well, first, the
695 PAIMI Act gives protection and advocacy agencies powers and
696 independence to gain access in places like Kaufman House to
697 investigate and shut them down. Without a court order, the
698 APS was turned away. Second, PAIMI programs provided the P&A
699 enough funding so that it could properly investigate the
700 Kaufmans, and PAIMI freed us and got us the right treatment
701 and then pressed for policy changes. Third, and perhaps the

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702 most important, with PAIMI, the victim is the client. The
703 client is in charge. With the APS, they serve the interests
704 of the provider and the State.

705 Long story short, thanks to PAIMI and its special powers
706 and funding, the Kaufman House was shut down and we obtained
707 the right type of treatment, and Arlan and Linda Kaufman were
708 found guilty of over 60 charges. The Kaufmans are in prison
709 today and I am here testifying. How cool is that?

710 This bill also takes away the PAIMI program's ability to
711 educate policymakers. The PAIMI program worked with me as a
712 survivor to change policy so future Kaufman Houses can never
713 happen again. Licenses are now required, guardianship laws
714 are fixed, and now there is an abuse and neglect unit.

715 PAIMI does not just help victims of abuse. This bill
716 makes it harder for people with mental illness to find
717 housing, employment and education. It prevents individuals
718 with mental illness from receiving the treatment they choose.

719 Another important lesson from Kaufman House is the need
720 for recovery programs like alternatives conference. You must
721 have recovery programs to have recovery.

722 Finally, I believe this bill is misnamed. The Helping

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723 Families in Mental Crisis Act? Well, I want to respectfully
724 point out to the subcommittee that the focus needs to be on
725 helping the individual with mental illness and crisis and
726 through recovery. Yeah, families are really important
727 support but the focus needs to be on the person and their
728 recovery.

729 Thank you.

730 [The prepared statement of Ms. Jensen follows:]

731 ***** INSERT 3 *****

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|

732 Mr. {Pitts.} The Chair thanks the gentlelady and now
733 recognizes Ms. Zdanowicz for 5 minutes for an opening
734 statement.

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|

735 ^STATEMENT OF MARY ZDANOWICZ

736 } Ms. {Zdanowicz.} Thank you, Mr. Chairman, members of
737 the subcommittee.

738 I have been involved in advocacy for people with severe
739 mental illnesses and their families for many years, and I
740 really have no hope that some of the things that have created
741 barriers to treatment would be addressed until Congressman
742 Murphy introduced the Helping Families in Mental Health
743 Crisis Act.

744 I too want to talk about the protection and advocacy
745 program, and while I think the original intent of the program
746 and the original practice of the program was very important,
747 it has lost its way, and I will share a personal experience
748 that is very difficult to talk about. My sister has
749 schizophrenia. She has been ill since she was 18 years old.
750 She has spent most of her adult life in state psychiatric
751 hospitals. For the most part she has received good medical
752 care and they have protected my sister, who is very
753 vulnerable. But in 1998, the State hospital that she was in

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754 closed. She was moved to a hospital that had less than 500
755 patients, but because of the loss of beds due to the hospital
756 closure, the patient population grew from 500 to 750 patients
757 by 2007. I knew what was happening at the hospital to some
758 extent, and I was able to get her moved to a facility that
759 was safe, but a few years later I was able to get her medical
760 records, and I found out what was really happening and just
761 how bad things were, and I am still haunted to this day by
762 what happened to patients that didn't have a family to
763 protect them, and the protection and advocacy organization
764 was nowhere to be found.

765 The problem is that the bill that created protection and
766 advocacy was enacted in 1986. The first finding in that bill
767 is that patients or persons with mental illness are
768 vulnerable to abuse and serious injury, and so it created a
769 federally funded organization independent of States to
770 monitor care of patients in hospitals and facilities. Now,
771 at that time there were 250,000 people in State psychiatric
772 hospitals. Now there are fewer than 35,000, and the
773 protection and advocacy organizations have changed course as
774 a result, and not necessarily in a good way.

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775 I will give you an example from Massachusetts, which is
776 the State where I live. That organization reported spending
777 more than \$250,000 on lobbying, federal funding on lobbying
778 against State measures, and more than \$100,000 actually went
779 to professional lobbyists, but it isn't just lobbying that is
780 the problem. In Massachusetts, that organization got
781 government funding to conduct a study of community services,
782 which to me is very important because I have a brother with
783 schizophrenia who lives in a group home and I am his
784 guardian, and I work very closely with staff and the
785 management of that group home to make sure he is safe in the
786 community. But I was appalled when I read the report, and
787 one of the findings was that guardians should not be involved
788 in protective measures that should be used for individuals
789 living in the community, and a finding that GPS devices that
790 are used for people who have a history of wandering and
791 getting injured are a violation of individual rights. It is
792 just a perversion. If you look and compare with the
793 Alzheimer's Association view on that, they find it an
794 appropriate use of electronic devices to have a comprehensive
795 safety program for people who need it and may be unsafe in

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796 the community.

797 So I want to say that Congressman Murphy's bill really
798 will do what it is named, and that is, it will help families
799 who are in mental illness crisis.

800 Thank you.

801 [The prepared statement of Ms. Zdanowicz follows:]

802 ***** INSERT 4 *****

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|
803 Mr. {Pitts.} The Chair thanks the gentlelady, and notes
804 that Dr. Welner still has not been able to get here. If he
805 comes in during the panel, we will permit him to give his
806 testimony at that time, but I will begin the questioning now
807 and recognize myself for 5 minutes for that purpose.

808 Ms. Thompson, in your experience, has the HIPAA privacy
809 rule been misapplied to the effect that it serves as a
810 barrier for helping the very people responsible for providing
811 care in the community?

812 Ms. {Thompson.} Absolutely.

813 Mr. {Pitts.} Could you expound on that?

814 Ms. {Thompson.} What my experience was with HIPAA was
815 that my family was consistently kept separate from my
816 mother's medical needs, health care needs, psychiatric needs.
817 We were unable to talk to physicians until we got
818 guardianship at the end, which we weren't able to get
819 guardianship until the last 9 months of her life because of
820 the difficulty in gaining access to physicians telling us
821 what was going on. As a professional advocate, I learned how
822 to communicate with doctors. Most family members don't have

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823 that knowledge. I was fortunate enough to have gone through
824 the training and professional experience to be able to tell a
825 doctor he doesn't have to say anything to me but he has to
826 listen to me. Most family members don't know that that is
827 their right to say something. And so there is a lack of
828 education on both sides, and the continued hiding behind
829 HIPAA has got to stop.

830 Mr. {Pitts.} Ms. Zdanowicz, in your opinion, how has
831 the legacy of deinstitutionalization of the mentally ill
832 worked out over the past half century?

833 Ms. {Zdanowicz.} Well, this is one of my most
834 passionate issues because I have seen the effect of closure
835 of state psychiatric hospitals, and that is why I think the
836 IMD exclusion is so important. I view it as discriminatory
837 provision because it is the only population that is precluded
838 from Medicaid coverage in hospitals.

839 A perfect example is when the hospital is closed where
840 my sister was and she was moved to the other hospital, and
841 there were not enough hospital beds left, which created this
842 overcrowding, which just prevented people from getting
843 treatment. Now, on the other hand, I do want to recognize,

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844 Congressman Pallone, Congressman Lance, that New Jersey has
845 what is a gem in terms of psychiatric hospital treatment, and
846 that is the Greystone Psychiatric Hospital, and that is where
847 my sister is now and she is receiving just superior
848 treatment. So it can be done correctly. But if you continue
849 to close hospitals, there won't be enough beds, and people
850 will end up where they are now: in jails and prisons. I
851 just finished a survey of all the jails and prisons across
852 the country, and I can tell you, they are the new psychiatric
853 hospitals.

854 Mr. {Pitts.} Ms. Thompson, back to you. If you could
855 choose one thing that the government could have done to help
856 your family, what would it be?

857 Ms. {Thompson.} Just one?

858 Mr. {Pitts.} Well, you can name more than one.

859 Ms. {Thompson.} It would be that my mother was
860 protected from herself. I come at this from so many
861 different angles. I understand patients' rights. I
862 wholeheartedly believe in them. I help fight for them. But
863 when someone lacks the capacity, there is no shame in lacking
864 capacity. When someone lacks the capacity, we need to take

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865 care of them, and that did not happen with my mother. She
866 fell through the cracks over and over and over again, and if
867 there had been more support for her, there would have been
868 ongoing treatment for her. When my mother went through
869 treatment, she would come back and everything would go back
870 the way it was because there was no follow-up. She came
871 home, and we didn't have the ability to do what we do.

872 I see it with families now. A family member, you know,
873 a son or daughter is hospitalized for a 72-hour hold and gets
874 discharged home and the parents don't know how to create the
875 right environment to keep that person on the road to
876 recovery. They don't have the skills. There needs to be
877 ongoing support. There needs to be more IMD beds. There
878 needs to be this ongoing system of support for family members
879 and for the person with the diagnosis.

880 Mr. {Pitts.} My time is expired. The Chair recognizes
881 the ranking member, Mr. Pallone, 5 minutes for questions.

882 Mr. {Pallone.} Thank you, Mr. Chairman. I am trying to
883 get two topics in with Dr. Shern, so if I cut you off a
884 little bit, it is because I am trying to get to the second
885 set of questions.

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886 The first relate to ACA and compliance with parity laws.
887 As I said, Mr. Chairman, I am pleased we are having this
888 hearing but I am troubled by a number of provisions in this
889 bill, but it is a wide-ranging effort to address some
890 important issues.

891 I wanted to discuss again the Affordable Care Act and
892 the Mental Health Parity and Addiction Equity Act. The
893 Mental Health Parity can enshrine in law the principle that
894 mental health care is just as important as physical health
895 care, and then the Affordable Care Act not only extended this
896 principal to the individual health insurance market but also
897 required that all expanded Medicaid programs as well as
898 individual and small group health insurance plans cover
899 mental health and substance abuse services as part of the
900 essential benefits package. I hope my Republican colleagues
901 understand that they are voting to repeal these advancements
902 for mental health when they support the Ryan budget or vote
903 to repeal the ACA.

904 So questions. Dr. Shern, what is your view of the
905 importance of health insurance coverage and mental health
906 parity and expanding access to treatment and improving

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907 health?

908 Mr. {Shern.} It is absolutely critically important.

909 Because of the development of the mental health treatment

910 system in the United States, we have systematically

911 discriminated against individuals with mental illnesses.

912 That was largely repaired with the parity bill and further

913 extended into markets that the parity bill didn't apply to by

914 its unanimous incorporation into the Affordable Care Act.

915 Getting to people sooner with effective care is critically

916 important in terms of trying to stem these problems.

917 Insurance access is a major impediment for individuals with

918 mental health and addiction conditions is critically

919 important.

920 Mr. {Pallone.} And then secondly, these laws were

921 clearly major steps forward but effective implementation and

922 enforcement are essential. What more can Congress do to

923 ensure health insurers are fully complying with the letter

924 and the spirit of both the ACA and the parity law?

925 Mr. {Shern.} I think that this House bill that is under

926 consideration provides an excellent opportunity to provide

927 resources to the Department of Labor and to the Department of

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928 Health and Human Services to assess the degree to which the
929 parity bill is being effectively implemented across the
930 United States and to provide ongoing guidance to insurers and
931 payers and primary consumers about what they should expect to
932 be their rights under this bill and the appropriate
933 boundaries with regard to insurance coverage. So it is a
934 complex bill. Equity in coverage is not something that is
935 easily determinable. It has a large State influence, so I
936 think it is very important that we systematically monitor it,
937 and that would be a very helpful addition to this
938 legislation.

939 Mr. {Pallone.} All right. Thank you. Now, I want to
940 get to this Wall Street Journal editorial, which I think the
941 chairman introduced into the record. They ran an editorial
942 that sharply criticized SAMHSA's effort to provide services
943 that help individuals prevent, treat and recover from mental
944 health disorders, and they called SAMHSA the vanguard of the
945 legacy advocacy and anti-psychiatry movement, accused the
946 agency of wasting taxpayer dollars on programs that do not
947 help those with the most serious mental illnesses. Obviously
948 these are very serious allegations. How would you respond to

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949 this editorial's characterization of SAMHSA?

950 Mr. {Shern.} It is, from my perspective, almost
951 entirely inaccurate. If you look at the major--you know, we
952 talked about the deinstitutionalization and the problems with
953 deinstitutionalization, and that surely was a policy that was
954 well intended but very poorly implemented. If you look at
955 every major reform since deinstitutionalization in terms of
956 improving services for people with mental illnesses, many of
957 the things we talked to you about today, SAMHSA has been the
958 champion of the reform. They started the Community Support
959 program, which is the first effort to try to build an
960 adequate community treatment system for people with severe
961 mental illnesses. They started the Child and Adolescent
962 Support program. With Congress's support, they implemented
963 the Assistance with Care Act. They have implemented acts
964 around people with dual disorders. We could go on and on and
965 on.

966 I think one of the things that is unfair is this
967 characterization of SAMHSA as an entity that is anti-
968 psychiatry, anti-treatment, anti-medication. That is just
969 not true.

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970 Mr. {Pallone.} The editorial also claims that very few
971 of SAMHSA's evidence-based programs focus on individuals with
972 serious mental illnesses. Can you comment on SAMHSA's work
973 in that area?

974 Mr. {Shern.} Our estimate is that over 80 percent of--
975 no one remembers that SAMHSA is an agency that addresses both
976 mental health and substance use issues. If you look at the
977 mental health portion, our estimate is about 80 percent to 85
978 percent of their resources are spent on issues related to and
979 persons who have severe mental illnesses. So again, I just
980 feel this is a gross mischaracterization of the SAMHSA
981 program.

982 Mr. {Pallone.} Thank you.

983 Mr. {Pitts.} The Chair thanks the gentleman and now
984 recognizes the vice chairman of the full committee, Ms.
985 Blackburn, for 5 minutes for questions.

986 Mrs. {Blackburn.} Thank you, Mr. Chairman. I thank
987 each of you who are witnesses for being here and for adding
988 to the work that we have done. I do want to thank Dr. Murphy
989 for the work he has done with our committee. I think that
990 because of the work he has done and concerns that we are

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991 hearing from our constituents, especially now that we are
992 highlighting this issue, we have learned about the size and
993 the scope of untreated mental illness and exactly where it
994 affects families and individuals.

995 We have also, and Ms. Thompson, this speaks to some of
996 yours, we have talked about the privacy laws and the impact
997 that that has on public safety and also looked at federal
998 resources and how those are utilized, and you are certainly
999 adding to that discussion today and we appreciate it, and we
1000 are pleased with the components that the new legislation
1001 would put in place, some redirection, some refocusing, and we
1002 think that those are good and they are appropriate.

1003 I do have a couple of questions that I wanted to ask,
1004 and I will be brief on these.

1005 Ms. Thompson, I did want to come to you first. I want
1006 to thank you for sharing your story. As we looked at HIPAA
1007 and FERPA and the privacy issues. What I would like to hear
1008 from you, as we look at reforms, through what you have
1009 experienced firsthand and what you have learned through your
1010 caregiving and your advocacy, give me maybe the top three or
1011 four things that you would say this is what you need to

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1012 change as you look at HIPAA and FERPA reforms. Do you have
1013 that laundry list? Could you give that to us?

1014 Ms. {Thompson.} I don't know if I have a laundry list
1015 but I can tell you that I think what is important is that
1016 when somebody is--if somebody--I work with the
1017 developmentally disabled population as well. It is
1018 automatic. They have a condition before the age of 18, so
1019 there is no HIPAA violation. The parents are clearly the
1020 guardian. They become the guardian. They go through what is
1021 legally necessary.

1022 Mrs. {Blackburn.} Been through the qualification?

1023 Ms. {Thompson.} Correct. What happens with mental
1024 illness is that oftentimes that doesn't present until after
1025 the child is no longer a child, so at that point you are
1026 trying to shut the barn door after the horse has left, if you
1027 will forgive the analogy. There need to be some
1028 qualifications in place with HIPAA that make it clear when
1029 somebody is not able to make decisions when there is a
1030 question as to their safety or the safety of others, that
1031 relinquishes professionals, that doesn't allow them to keep
1032 their hands tied.

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1033 Mrs. {Blackburn.} Okay. So almost like a revisit of a
1034 power of attorney?

1035 Ms. {Thompson.} Yes. Right now you can try to get the
1036 individual to sign off but if somebody doesn't think they are
1037 ill, they are not going to sign off permission. That doesn't
1038 mean they are not ill and not in need of help.

1039 Mrs. {Blackburn.} So you would encourage us to have
1040 some type of allowance or avenue that that oversight you
1041 could negotiate?

1042 Ms. {Thompson.} Like a waiver, and maybe that--I don't
1043 know. As I said before, I am not a legislator. I don't
1044 know. Maybe having--if the physician deems it necessary or
1045 maybe getting two physicians to deem it necessary that HIPAA
1046 can be broken in this instance. It can't just be because
1047 somebody is going to commit a crime or they are going to kill
1048 themselves. There needs to be--they need to get help before
1049 that.

1050 Mrs. {Blackburn.} Okay. Ms. Zdanowicz, I can tell you
1051 want to weigh in on this. I see you nodding your head.

1052 Ms. {Zdanowicz.} I have to agree completely. I
1053 actually would say the same thing. I was unable to get

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1054 information about treatment for my brother and sister until I
1055 got guardianship, and I paid \$5,000 to get guardianship for
1056 my sister, who was in agreement. She did not object to it.
1057 But I had that in order to get information, but even with
1058 that, for example, when I know my brother is in a hospital, a
1059 particular hospital, I have been told he was transferred
1060 there, and I call and they say we can't tell you if he's
1061 here, and then I will fax my guardianship papers and they'll
1062 still say HIPAA prevents us from talking with you, and then I
1063 learn later that they have changed his medication in a way
1064 that I already know is not helpful and there is nothing I can
1065 do about it, it is too late.

1066 People don't understand HIPAA, and I often tell
1067 families, if you are told that they cannot tell you anything
1068 about your family member, you are still free to tell them
1069 what they need to know about your family member. It is a
1070 terrible obstacle for families to help, and I totally support
1071 the revisions to that portion of the bill.

1072 Mrs. {Blackburn.} Thank you. Yield back.

1073 Mr. {Pitts.} The Chair thanks the gentlelady and now
1074 recognizes the ranking member of the full committee, Mr.

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1075 Waxman, 5 minutes for questions.

1076 Mr. {Waxman.} Thank you, Mr. Chairman. I want to
1077 apologize to the panel because there is another subcommittee
1078 meeting at the same time, and I have been required to go back
1079 and forth.

1080 Ms. Jensen, I want to start by thanking you for being
1081 here today and telling us your story. It is a deeply
1082 personal one, and I was struck by the utter failure and
1083 inability of authorities in your State to bring an end to the
1084 terrible abuses of people with mental illness, including
1085 yourself, at the Kaufman House, that is, until the P&A became
1086 involved. Can you elaborate on whether or not Kansas was an
1087 outlier and not adequately addressing complaints about the
1088 Kaufman House prior to the P&A's involvement? Do you think
1089 it is unique?

1090 Ms. {Jensen.} All I can say is that there was 12
1091 complaints to the Adult Protective Services, and he even sued
1092 Adult Protective Services, and so they quit coming to the
1093 door. And so I believe that I know for a fact if it wasn't
1094 for PAIMI, Kaufman House would still be going on.

1095 Mr. {Waxman.} We have heard from witnesses today that

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1096 P&As lobby, and in fact, in the testimony, you worked with
1097 the P&A to change laws that would prevent future Kaufman
1098 Houses through licensure requirements, guardianship laws and
1099 the establishment of an abuse and neglect unit. Can you
1100 clarify whether the federal funding was used for these
1101 activities and any other lobbying activities? Do you know?

1102 Ms. {Jensen.} No, there was no federal funding. I and
1103 my friend, we just never wanted it to happen again, so we
1104 were volunteers. We did it ourselves, and it was educating
1105 us on the issue but there was no financial spending of
1106 federal funds to get these laws passed.

1107 Mr. {Waxman.} Proponents of the PAIMI proposals in H.R.
1108 3717 claim these provisions will return the program to its
1109 roots but it seems to me that an 85 percent reduction in
1110 federal funding would do much more than that. How would a
1111 funding reduction of this magnitude impact the ability of the
1112 P&A in Kansas and P&As around the country to protect the
1113 rights of people with mental illness?

1114 Ms. {Jensen.} I am so scared that if you take PAIMI
1115 away, and that is what would happen, there wouldn't be any
1116 protection for us if we were being abused, neglected or

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1117 exploited. There wouldn't be anyone coming in and taking us
1118 out of that situation in order to talk to us and investigate
1119 the situation, and I just ask you not to do that.

1120 Mr. {Waxman.} Well, your testimony is very persuasive
1121 and I think quite valuable to us to hear that point of view.

1122 I want to ask Ms. Thompson and Dr. Shern, I am pleased
1123 that my colleagues and I have some points of bipartisan
1124 agreement on issues before us. We all believe that mental
1125 health care is an essential part of our health care system.
1126 We agree that we need to work to end the stigma that
1127 surrounds seeking treatment, and we agree that we need to
1128 invest in community-based approaches for care so that
1129 individuals who need help are able to get it. I think
1130 everybody here on the panel would agree with these goals as
1131 well. But I also believe that witnesses invited by both
1132 Republicans and Democrats today agree that expanding access
1133 to health insurance and improving health coverage of mental
1134 health services are critical.

1135 Ms. Thompson, as a general matter, do you think
1136 individuals who have health insurance have a better chance of
1137 getting into treatment for their mental health conditions?

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1138 Ms. {Thompson.} I am sorry. Can you--

1139 Mr. {Waxman.} If you have health insurance, don't you
1140 have--

1141 Ms. {Thompson.} Oh, absolutely.

1142 Ms. {Waxman.} And do you think including mental health
1143 coverage as an essential health benefit and requiring it be
1144 covered at parity with physical health were important steps
1145 forward?

1146 Ms. {Thompson.} Yes.

1147 Mr. {Waxman.} And Dr. Shern, do you agree with that?

1148 Mr. {Shern.} Absolutely.

1149 Mr. {Waxman.} I think, Mr. Chairman, we could learn a
1150 lot from these witnesses. There is a lot more to the ACA
1151 than we can fit into 30-second attack ads. But it advances a
1152 number of essential priorities that both sides agree on, and
1153 I hope we can agree that it is here to stay, that we should
1154 build off of these things that we agree on in the law rather
1155 than constantly focus on repealing or undermining it.

1156 I see my time is over and I will yield back the balance.

1157 Mr. {Pitts.} The Chair thanks the gentleman and now
1158 recognizes the vice chairman of the subcommittee, Dr.

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1159 Burgess, 5 minutes for questions.

1160 Ms. {Zdanowicz.} Mr. Chairman, if I may?

1161 Mr. {Pitts.} Go ahead.

1162 Ms. {Zdanowicz.} I did want to just elaborate on one
1163 point that was made, and that is about the money that is
1164 used, the federal funding to lobby, and that is documented.
1165 You can find that in IRS reports and State lobbying reports
1166 that in fact federal funding is being used to lobby, and
1167 professionally, I have seen it done. I have been up against
1168 lawyers of protection and advocacy organizations lobbying in
1169 State capitals against State legislation. So it does happen,
1170 and it is not the original mission, and it takes away from
1171 what they are supposed to be doing.

1172 Mr. {Waxman.} And it is in violation of the rules that
1173 say that they cannot use that money for lobbying.

1174 Ms. {Zdanowicz.} And so I think that in order for them
1175 to be able to do what they are supposed to do, which is
1176 monitor like they did when you were being abused, I think
1177 that would be a significant improvement. So thank you.

1178 Mr. {Pitts.} The Chair thanks the gentlelady and now
1179 recognizes Dr. Burgess 5 minutes for questions.

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1180 Dr. {Burgess.} And please let the record reflect the
1181 generosity and time that I gave to the ranking member of the
1182 subcommittee. We don't often have areas of commonality, so I
1183 thought that was important to have that follow-up.

1184 The majority of my questions were for Dr. Welner. One
1185 of my big objections to these types of hearings is we never
1186 have an M.D. Thank you for calling an M.D. Unfortunately,
1187 because of travel issues, he has not been able to join us, so
1188 I am going to submit my questions to Dr. Welner for the
1189 record.

1190 Dr. Shern, your discussion with Ranking Member Pallone
1191 brought some things to mind, and really, this is more of just
1192 reminding people of the process, yes, the budget process, the
1193 legislative process, process in the agencies. Go back just
1194 for a little bit to the Mental Health Parity Act, and I don't
1195 know how many people now remember, the Mental Health Parity
1196 Act, introduced by one of our colleagues, Patrick Kennedy,
1197 indeed, we had hearings in this subcommittee many, many years
1198 ago. The Mental Health Parity Act was used as the vehicle to
1199 pass the Troubled Asset Relief Program, two absolutely
1200 unrelated proposals. Now, I just want to be clear. I

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1201 actually opposed both of them, so that no vote actually did
1202 double service that day, but to think that we passed
1203 something of the magnitude of the Mental Health Parity Act
1204 and its effect upon caregivers and third-party payers as a
1205 vehicle to bail out banks, I am still bothered by that nexus.
1206 But nevertheless, that is what happened. The Mental Health
1207 Parity Act had not actually been scored, to the best of my
1208 recollection, by the Congressional Budget Office. I think it
1209 estimated some significant budgetary outlays over a 10-year
1210 period but be that as it may, now the Affordable Care Act
1211 actually passed sometime after that, about a year and a half
1212 after that, and was signed by the President in March of 2010.
1213 The part of the Affordable Care Act dealing with essential
1214 health benefits was actually subject to a rule. The rule was
1215 supposed to be published and concluded in August of 2012. I
1216 don't want to seem cynical here but the actual rule was
1217 delayed until a couple days after Election Day in 2012. I
1218 don't know why the Administration would see an advantage to
1219 doing that but apparently there was. And if you will recall,
1220 much of the difficulty that subsequently happened to the
1221 Affordable Care Act was because of that delay. The governors

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1222 were required to disclose whether or not they would
1223 participate in state exchanges on November 18th. The
1224 essential health benefit rule was published on November 8th.
1225 So that gave them precious little time to actually evaluate,
1226 is this a good idea or a bad idea for my State. To be fair,
1227 they were given two extensions but finally by January 2013
1228 the governors had to declare. Twenty-six States said no,
1229 thank you, we are not doing an exchange. Four States said
1230 well, maybe we will do one but we will let the Federal
1231 Government set it up. So the fact that so many States were
1232 not doing their own exchanges and that task then fell to the
1233 Federal Government and clearly the Center for Consumer
1234 Information and Insurance Oversight was not up to the task of
1235 standing up a massive new information technology project in
1236 the 8 months that they had available, and I think we all know
1237 the story on that.

1238 But here is the issue. Okay, Mr. Pallone is right. The
1239 Mental Health Parity Act and the ACA, the nexus of those two
1240 things does affect stuff. None of that--because the way the
1241 Congressional Budget Office works, we only get information
1242 about bills before we pass them. Sometimes we don't even get

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1243 that. But we only get that budgetary information as the
1244 legislation is coming through the process. We don't get a
1245 rescore by the Congressional Budget Office when the
1246 rulemaking happens. So if you take the combination of the
1247 Affordable Care Act and the essential health benefits, when
1248 the Mental Health Parity Act was passed it said we are not
1249 requiring you, Mr. Private Insurance Company or Mrs. Private
1250 Insurance Company, to offer mental health benefits, but if
1251 you do, they need to be on a par with other medical services
1252 that you offer. So I am concerned that there were companies
1253 that were going to drop out of the mental health business. A
1254 year later, we had the Affordable Care Act passed and it says
1255 this is part of your essential benefit package.

1256 You know, I am from Texas. I will never attribute to
1257 coincidence that that can be adequately explained by
1258 conspiracy, but the Mental Health Parity Act was passed in
1259 2008 and the rule was not published until last November, and
1260 I can't help but wonder if the reason the rule was not made
1261 public until all of the Affordable Care Act stuff was in
1262 place was because this is going to blow the cost way beyond
1263 anything that anyone projected for the Mental Health Parity

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1264 Act or for the ACA. I don't know the answer to that
1265 question. I think it is one that we are going to have to ask
1266 our Congressional budget writers to help us with but it just
1267 underscores the difficulty of making budgetary decisions on
1268 these types of issues. There are always things in the future
1269 that will affect them.

1270 Thank you, Mr. Chairman. I have rambled enough, and I
1271 will yield back.

1272 Mr. {Pitts.} The Chair thanks the gentleman and now
1273 recognizes the gentleman from Texas, Mr. Green, 5 minutes for
1274 questions.

1275 Mr. {Green.} Thank you, Mr. Chairman, and Dr. Shern, I
1276 think we are in agreement that our country has a long way to
1277 go to improve mental health systems. I am also from Texas
1278 but in an earlier life I actually did probate work, and one
1279 of my judges, who was a friend, appointed me to do mental
1280 health work, do the probable cause hearings and the
1281 commitment hearings, and it opened my eyes to the Texas
1282 mental health code, and actually as a State senator, we were
1283 able to change some of it.

1284 I appreciate Dr. Murphy's leadership for many years on

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1285 this issue. I have some concern about part of the
1286 legislation, the Medicaid IMD exemption. My concern is cost
1287 shifting from the State if the State does it to the Federal
1288 Government.

1289 But I want to get to the follow-up on my colleague from
1290 north Texas. Dr. Shern, the Affordable Care Act included
1291 demonstration in 11 States to test whether undoing the IMD
1292 exemption for emergency psychiatric care and letting federal
1293 funds pay for the care in IMDs that States would concurrently
1294 provide would improve service to the population. It is my
1295 understanding we don't yet have enough information to know
1296 whether this demonstration is successful. My question is, it
1297 seems to me that before we move ahead and spend billions to
1298 supplant the State funds, we ought to see if this
1299 demonstration yields any positive results. Can you update us
1300 on any of those demonstration projects?

1301 Mr. {Shern.} I am not aware that evaluations have been
1302 completed. Our position would be quite consonant with yours.
1303 When that provision was discussed and been made part of the
1304 Affordable Care Act, there was a concern that looking at only
1305 one element in a system of care just really wasn't the

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1306 appropriate way to think about how to build an effective
1307 community care system. And so we maintained and the law was
1308 enacted that this had to be evaluated as part of a system of
1309 care initiative. Our recommendation is that there be no
1310 changes to the IMD law until the results of that evaluation
1311 are complete.

1312 Mr. {Green.} Okay. The Congressional Budget Office,
1313 they haven't officially scored the provision. My
1314 understanding is, it is quite expensive, tens of billions
1315 possibly. If we had tens of billions of dollars to spend on
1316 improving the mental health system in the United States, how
1317 would we direct it and where should we really be looking to
1318 invest that money to see the greatest improvements?

1319 Mr. {Shern.} Well, you know, I think that we have heard
1320 a lot this morning about the importance of assertive
1321 engagement-oriented outreach. Ms. Thompson talked about how
1322 important some of that was for her mom and how it would have
1323 been helpful had that continued when her mom came home. The
1324 committee heard in testimony from Dr. Arthur Evans, who runs
1325 the Philadelphia mental health system, about how critically
1326 important that there be funds available for crisis

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1327 alternative services, for peer engagement and outreach
1328 services. We know a lot about what we can and should do, and
1329 I would much prefer to see those funds spent on fully
1330 developing a continuum of care in communities with assertive
1331 outreach and engagement.

1332 Mr. {Green.} Well, I am familiar at least in Houston,
1333 Harris County, with some of the substantial reforms that have
1334 been made in the last 20 years, for example, our Harris
1335 County Hospital District. When I would first go see a client
1336 or a patient, it was literally dismal. It looked like a
1337 holding cell in the hospital. But they have created a
1338 diversion now to where you actually have committed to mental
1339 health treatment, and it is a partnership between the
1340 University of Texas where we have a psychiatric hospital in
1341 Houston, but it is doing better but we have less psychiatric
1342 beds in Houston, Harris County than we did in the 1980s. So
1343 that is our big concern.

1344 I am pleased with Dr. Murphy's bill. It includes a
1345 provision to extend the liability for doctors who volunteer
1346 in behavioral health clinics. He and I have had legislation
1347 for a number of years. It has passed this committee and

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1348 somehow the Senate doesn't do it. It would expand for our
1349 FQHCs and not just behavioral mental health clinics but our
1350 FQHCs where volunteer physicians could go in and be under the
1351 Federal Torts Claims Act, and that makes so much sense.
1352 While it is a good step forward in increasing the mental
1353 health workforce, much needs to be done to develop
1354 professionals.

1355 Mr. Chairman, both on our Health Subcommittee and I know
1356 on our Oversight Committee Dr. Murphy is doing, there are a
1357 lot of examples of things happening all over the country
1358 based on local community success, and I think this panel
1359 shows that, that maybe we should, since we do have the
1360 Affordable Care Act and mental health parity issues, then
1361 maybe we ought to look at some of those examples from around
1362 the country and see what we can do to make sure we get the
1363 best bang for our federal dollar to help our States and the
1364 local communities, because, again, oftentimes it is our
1365 hospital districts that are providing some of that care.

1366 So I appreciate it, and I yield back my time.

1367 Mr. {Pitts.} The Chair thanks the gentleman and now
1368 recognizes the gentleman from Pennsylvania, Dr. Murphy, 5

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1369 minutes for questions.

1370 Mr. {Murphy.} Thank you. I want to thank all the panel
1371 for being here. I really appreciate your time.

1372 A quick question to start off with. I am just going to
1373 ask each one of you if you have read the bill. Ms. Thompson?
1374 It is a yes or no.

1375 Ms. {Thompson.} Not the whole bill.

1376 Mr. {Murphy.} All right. Dr. Shern?

1377 Mr. {Shern.} Not the entire bill.

1378 Mr. {Murphy.} Ms. Jensen?

1379 Ms. {Jensen.} I didn't hear the question.

1380 Mr. {Murphy.} Have you read the bill we are talking
1381 about?

1382 Ms. {Jensen.} Yes, I read the bill.

1383 Mr. {Murphy.} The whole thing?

1384 Ms. {Jensen.} Yes, the whole thing.

1385 Mr. {Murphy.} Thank you. Ms. Zdanowicz?

1386 Ms. {Zdanowicz.} And yes, I have read the whole thing.

1387 Mr. {Murphy.} Thank you. Ms. Jensen, did anybody else
1388 in your testimony today advise you on things to say?

1389 Ms. {Jensen.} Of course not.

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1390 Mr. {Murphy.} So I am not sure where you got this
1391 statement from, that it would make it harder to get housing
1392 and education. If there is a point in that bill where you
1393 feel that is, will you make sure you let me know? Because I
1394 want to fix that. Would you let me know?

1395 Ms. {Jensen.} I don't understand what you are saying,
1396 sir.

1397 Mr. {Murphy.} You had said in your statements that the
1398 bill would make it harder to get housing and education. If
1399 there is a place in the bill where that occurs, would you let
1400 me know, because I want to--

1401 Ms. {Jensen.} If you take PAIMI away, we have a hard
1402 time getting help with housing and education.

1403 Mr. {Murphy.} I don't agree, but thank you.

1404 Dr. Shern, I am just not clear. Are you a clinician
1405 that treats patients?

1406 Mr. {Shern.} No, I am a research psychologist.

1407 Mr. {Murphy.} Okay. Thank you. You said SAMHSA does
1408 not support programs that are anti-treatment. Are you
1409 familiar with the Alternatives Conference?

1410 Mr. {Shern.} I am.

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1411 Mr. {Murphy.} Are you aware that Alternatives is short
1412 for Alternatives to Treatment?

1413 Mr. {Shern.} My interpretation of Alternatives, it not
1414 alternatives to treatment, it is alternatives available for
1415 people to make choices about how to best engineer their
1416 recovery.

1417 Mr. {Murphy.} Do you think everybody is capable of
1418 making that choice?

1419 Mr. {Shern.} I think everybody is capable of
1420 understanding what is important to them.

1421 Mr. {Murphy.} Ms. Thompson referred to something called
1422 anosognosia. Do you know what that is?

1423 Mr. {Shern.} I have heard it described, yes.

1424 Mr. {Murphy.} Okay. I am disappointed you don't know
1425 what it is. It is critically important, so I have to go into
1426 a little lesson here. If a person has a stroke on the right
1427 side of their brain, and on the left side, their arm doesn't
1428 work, a characteristic of that is if you say to this person
1429 try and move your left arm and they don't and you say I think
1430 you are having a stroke, you need to go to the hospital, that
1431 person may say it is no big deal, I don't know what that is

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1432 all about, that is anosognosia.

1433 About 40 to 50 percent of people with severe mental
1434 illness, schizophrenia, if shown a videotape of them
1435 hallucinating, delusional, they don't know who they are, they
1436 think they are the angel Gabriel, Jesus, whatever else, and
1437 if you say do think that is okay, they will say sounds okay
1438 to me, I don't understand the problem.

1439 What Ms. Thompson is referring to for those people who
1440 are not capable of making decisions on their own to have
1441 someone else assist them so that they have a right to get
1442 better. Would you agree that such persons may need some
1443 assistance that they are not capable of making on their own?

1444 Mr. {Shern.} I think the way that you specifically have
1445 characterized the situation, people would meet the criteria
1446 for not being competent and--

1447 Mr. {Murphy.} Good. We are in agreement there. And do
1448 you think in the Alternatives Conference, which spends about
1449 \$600,000 a year of taxpayers' money, do you think we should
1450 be paying for conferences that have things called unleash the
1451 beast: primal movement workshop, how to make collages,
1452 dancing, interpretive yoga or how to stop taking your

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1453 medication? Do you think taxpayers should pay for that?

1454 Mr. {Shern.} I think it is very important that we have
1455 an open--

1456 Mr. {Murphy.} I am asking, do you think taxpayers
1457 should pay for those items when we are so short on funds? Do
1458 you think we should be paying for that for people who have
1459 severe mental illness?

1460 Mr. {Shern.} I think that it is very important that we
1461 have an open forum to discuss the various--

1462 Mr. {Murphy.} I appreciate that. I didn't ask you
1463 about an open forum. So I am going to take that as a yes and
1464 you are afraid to say yes.

1465 Do you know in SAMHSA's--no, it is true. Come on. I
1466 want to have an open discussion. In SAMHSA's documents that
1467 describe their strategic plan, it is about 40,000 words, how
1468 many times does it mention the word ``schizophrenia''?

1469 Mr. {Shern.} You know, I have not had an opportunity to
1470 count them.

1471 Mr. {Murphy.} Well, it is easy to count because the
1472 answer is zero. Do you know how many times it mentions the
1473 word ``bipolar''? Zero. So when you say SAMHSA is focused

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1474 on severe mental illness, my problem is, it is not, and when
1475 I had the leader of SAMHSA in my office and I said would you
1476 change anything, she said no.

1477 So what I see here is, I think SAMHSA plays a very
1478 important role. I want to see it keep on doing that. But I
1479 want to make sure we get back to evidence-based care, and I
1480 am assuming you would be okay with that.

1481 Mr. {Shern.} Absolutely.

1482 Mr. {Murphy.} That if a program shows that it can work,
1483 make it work.

1484 Mr. {Shern.} Absolutely.

1485 Mr. {Murphy.} And let us do that, and why I am
1486 concerned here is that throughout the Federal Government, we
1487 have got money in the Department of Defense, Veterans
1488 Affairs, Education, HHS, who knows where else, and we have to
1489 make sure we have got programs that work, and the ones that
1490 work, expand them, and if they don't, eliminate them, and if
1491 they are redundant, merge them, and that is what I want to
1492 have happen with this bill.

1493 On the parity issue, real quick, I just want to say that
1494 there is parity for people who have private insurance in the

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1495 Affordable Care Act. There is not parity with Medicaid, so
1496 if you have more than 16 beds, you are not going to get it,
1497 and if you see two doctors on the same day, you are not going
1498 to get it.

1499 The last question I want to address to Ms. Zdanowicz.
1500 Dr. Shern called the Journal editorial a gross
1501 mischaracterization of SAMHSA for leading an anti-psychiatry
1502 movement. Do you have any comments on that with regard to
1503 SAMHSA and providing money or grants to groups that fight
1504 treatment or discourage treatment?

1505 Ms. {Zdanowicz.} Yes, and in fact, I have read many of
1506 the State applications for grants from SAMHSA, CMHS, and when
1507 you read those, you find very little reference to the most
1508 severely ill. Much of it is about, this is how we are going
1509 to get people out of State psychiatric hospitals. It is
1510 about how we are going to--if we just offer people, you know,
1511 what they want and make sure that we are really nice to them,
1512 that they are going to be just fine and it is going to settle
1513 their symptoms. But the question is, well, what if the
1514 person wants is a semiautomatic machine gun to shoot you
1515 because they think that you are the devil? Well, then what

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1516 do you do? Well, then you call the police and you get them
1517 into jail, and if there was ever a form of coercion, that is
1518 it.

1519 Mr. {Murphy.} Thank you. I have to yield back.

1520 Mr. {Pitts.} The Chair thanks the gentleman and now
1521 recognizes the gentlelady from California, Ms. Capps, 5
1522 minutes for questions.

1523 Mrs. {Capps.} Thank you, Mr. Chairman, and I would like
1524 to thank all of our panelists for your testimony today. I
1525 want to single you out, Ms. Jensen, because yours was so
1526 personal, and I appreciate that you are willing to tell your
1527 story.

1528 Dr. Shern, mental health is an important issue that
1529 members of this committee on both sides of the aisle have a
1530 shared interest in addressing. I worked in our community in
1531 public schools before coming to Congress as a public health
1532 nurse and so I have had experience with this topic, and I am
1533 really pleased that today it is being discussed.

1534 We heard from the testimony that there are some
1535 provisions in this bill that have widespread support and
1536 others that are perhaps problematic. I know that other

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1537 members of the committee have also expressed interest in the
1538 topic and introduced legislation on mental health, and I hope
1539 that moving forward we can have an open dialog--the chairman
1540 just mentioned that--about all of the proposals and ideas.

1541 That being said, Dr. Shern, are there any provisions not
1542 included in H.R. 3717 that you feel are important to the
1543 improving mental health system?

1544 Mr. {Shern.} Well, you know, as we have said on a
1545 number of occasions, I think that understanding that a full
1546 continuum of engagement-oriented and assertive outreach
1547 services are critically important for effective services for
1548 people with severe mental illnesses. Additionally, and I
1549 think that Dr. Murphy mentioned this in his remarks or Mr.
1550 Pitts, you know, we are continuing to learn about the
1551 importance of early identification for people who are going
1552 to develop disorders that have psychotic features, and I
1553 think it is critically important that we do a much better job
1554 at early identification of people who are going to have the
1555 more severe illnesses, and we are developing a reasonable
1556 evidence base about the things that are helpful to them
1557 because that can stem disability. I am also very excited

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1558 about the peer movement, the use of persons who themselves
1559 are in recovery to help with these engagements and follow a
1560 long process, and also with appropriate supervision to
1561 provide the kind of extension of the mental health workforce
1562 that is going to be required.

1563 Mrs. {Capps.} Yes. Well, that is the point I wanted to
1564 pick up on because Dr. Welner in his written testimony that I
1565 read, he noted the importance of having enough mental health
1566 professionals. Maybe that is a whole other hearing,
1567 particularly it seems to a hole in this bill and one that I
1568 think we should be addressing with more specificity.

1569 Dr. Shern, one of the key principles both sides of the
1570 aisle agree on is that we need to do everything possible to
1571 encourage individuals, and you talked about outreach,
1572 struggling with mental illness to seek treatment. That is
1573 actually part of the stigma, recognition and the clear sort
1574 of lack of understanding that we have about our brain and
1575 issues that affect it. Treatment does prove to be very
1576 helpful, as we heard today, and is more successful I think
1577 than some of the public seems to recognize, and early
1578 detection, just as you said, and regular treatment are so

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1579 essential for preventing those rare and tragic cases where
1580 individuals become violent toward themselves or others, and
1581 we know people with mental illness are actually more likely
1582 to be victims, so that is a piece of the story that needs to
1583 be clearly said as well.

1584 But the stigma demands, I think, and we should be
1585 desirous of ways to address the stigma. Privacy concerns are
1586 also intimately related. That is why I am concerned about
1587 the changes to our health privacy law that this bill
1588 proposes. It creates entire new standards for individuals
1589 who have what the bill loosely defines as serious mental
1590 illness, and that is a loose definition, unfortunately, and I
1591 know these are difficult areas to find the right path but
1592 that is something we really need to get to.

1593 Dr. Shern, first, can you help us clear up a key point
1594 of fact? Does HIPAA always require patients to give their
1595 permission before information is shared or do providers have
1596 flexibility if there is a threat or if they believe the
1597 patient lacks capacity?

1598 Mr. {Shern.} It is my understanding that there is
1599 flexibility. You know, I was thinking also the Virginia Tech

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1600 shooting, and when people looked at FERPA and HIPAA then, it
1601 was clear that there was a lot of misunderstanding about the
1602 bill and in emergency situations that can be found.

1603 Mrs. {Capps.} Yes.

1604 Mr. {Shern.} So part of the thing I think we need, and
1605 I think Ms. Thompson would agree, is just better public
1606 education about what those laws actually mean.

1607 Mrs. {Capps.} I am glad you put that on the record.

1608 What impact will the changes proposed in the bill have
1609 on people's willingness? Is that a concern to you, people's
1610 willingness to seek treatment for mental illness?

1611 Mr. {Shern.} It is a concern of mine, a concern of my
1612 organization, given the coercive nature of some of the
1613 outpatient treatment programs.

1614 Mrs. {Capps.} Thank you. I yield back.

1615 Mr. {Pitts.} The Chair thanks the gentlelady and now
1616 recognizes the gentleman from New Jersey, Mr. Lance, 5
1617 minutes for questions.

1618 Mr. {Lance.} Good morning, and thank you, Mr. Chairman,
1619 and thank you for your leadership on this issue, and thanks
1620 to Dr. Murphy as well for his leadership.

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1621 Earlier this week, a bill on which I had worked with
1622 Congresswoman Matsui of this committee, the Excellence in
1623 Mental Health Act, was included in a larger piece of
1624 legislation, and I am pleased that the President has signed
1625 that into law and I certainly want to work with all members
1626 of this subcommittee and the full committee as we move
1627 forward on this challenging issue.

1628 Ms. Zdanowicz, as I understand it, your sister spent
1629 quite a few years in New Jersey facilities including the now-
1630 closed Hagedorn Psychiatric Hospital in Hunterdon County. I
1631 grew up in Glen Gardner where that facility was located.
1632 Before it was related to psychiatric concerns, it was related
1633 to tubercular concerns.

1634 It is clear from your testimony that many mental health
1635 facilities in this country are currently unable to meet the
1636 needs of their communities. In your judgment, would passage
1637 of legislation in this regard help in States across the
1638 country including States like New Jersey?

1639 Ms. {Zdanowicz.} Absolutely, and the closing of
1640 Hagedorn Hospital was a travesty. That is the hospital I
1641 mentioned that was a safe hospital that she was transferred

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1642 to. She got excellent care there. And it was closed. And
1643 she then moved to Greystone which, as I mentioned before, is
1644 a gem. It is a wonderful hospital. But as a result of the
1645 closure of Hagedorn, it is virtually impossible to get anyone
1646 into a State psychiatric hospital now, and in fact, the State
1647 has implemented what I will call a gatekeeping process that
1648 prevents people--when a psychiatrist says this person needs
1649 to be in a psychiatric hospital because they need more than
1650 two weeks of treatment, they can be shut down by a nurse who
1651 is reviewing the process just because the State is trying to
1652 keep the population down.

1653 Mr. {Lance.} Before your sister was at Hagedorn, what
1654 was the State hospital before that where she was?

1655 Ms. {Zdanowicz.} That was Ancora in south Jersey.

1656 Mr. {Lance.} In southern New Jersey, yes.

1657 Ms. {Zdanowicz.} And it was a very bucolic setting. It
1658 was a very nice hospital when she first went there. There
1659 were less than 500 patients, and the care was very good until
1660 because of the closure of the previous hospital the
1661 population grew to 750 and it was truly bedlam because the
1662 hospital, the staff were not able to handle it and that was

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1663 when I was able because I had the resources to get her moved
1664 to a safer hospital. But it wasn't until the Department of
1665 Justice came in at the request of the State and investigated
1666 it, protection and advocacy was nowhere to be found, and in
1667 fact, I called them at one point, but that was not on their
1668 radar screen. They were more concerned with other issues
1669 like legislation for AOT and fighting that.

1670 Mr. {Lance.} Thank you. Let me say that I was honored
1671 as a child to know Garrett Hagedorn, who was a State senator
1672 from Bergen County, and I had the privilege of being the
1673 minority leader in the State senate before I came here, and I
1674 have worked on these issues and hope to be able to continue
1675 to work on these issues here in Washington, and thank you for
1676 being with us today.

1677 Let me say that there are, Mr. Chairman, community
1678 mental health facilities in the district I represent such as
1679 the Richard Hall Community Health Center in Bridgewater,
1680 Township, in Somerset County, and I hope that these fine
1681 efforts can continue and that we can work in a bipartisan
1682 capacity on this very important issue and we are reminded yet
1683 again so tragically of the importance of this issue based on

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1684 what happened at Fort Hood yesterday.

1685 Mr. Chairman, I yield back the balance of my time.

1686 Mr. {Murphy.} Would the gentleman yield?

1687 Mr. {Lance.} I certainly would.

1688 Mr. {Murphy.} I just want to point out, there is
1689 misunderstandings in the HIPAA law, and Dr. Shern, you have
1690 never been involved in a case and you shouldn't already have
1691 an on it.

1692 This bill does not undo HIPAA laws. It clarifies them,
1693 and we want to work on language. I have been talking with
1694 Representative DeGette on this too. We want to make it so
1695 that all those things that are also in the regulations that
1696 go along with the law are clarified. It doesn't change
1697 anything, but there are a lot of misunderstandings.
1698 Clinicians misunderstand this all the time, so we want to
1699 make sure work to clarify that, but it doesn't change the
1700 law. Thank you.

1701 Mr. {Pitts.} The Chair thanks the gentleman and now
1702 recognizes the gentlelady from Virgin Islands, Dr.
1703 Christensen, for 5 minutes for questions.

1704 Dr. {Christensen.} Thank you, Mr. Chairman. I want to

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1705 ask some questions to Dr. Shern about the bill and its impact
1706 on SAMHSA because the bill makes some significant changes to
1707 the way the Federal Government's mental health investment is
1708 structured within the Department of Health and Human
1709 Services, particularly in Substance Abuse and Mental Health
1710 Services Administration. I want to make sure that I
1711 understand the impact these changes could have, particularly
1712 to the Community Mental Health Services Block Grant and
1713 programs of regional and national significance.

1714 Dr. Shern, starting first with the mental health block
1715 grant, how would H.R. 3717 impact this program?

1716 Mr. {Shern.} Well, it is my understanding that the
1717 block grant would be moved to the Assistant Secretary's
1718 office and would have a different type of oversight than it
1719 currently has now, providing less flexibility to States, for
1720 example, in terms of how those funds are used.

1721 Dr. {Christensen.} So do you support provisions in this
1722 bill that would condition States' receipt of block grant
1723 funding on newly established federal involuntary patient or
1724 outpatient treatment standards and specific criteria for
1725 outpatient treatment?

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1726 Mr. {Shern.} No, we wouldn't support that.

1727 Mr. {Murphy.} Could the gentlelady ask him to clarify
1728 what that means because I am not sure.

1729 Dr. {Christensen.} What do you mean? I asked if he
1730 would support the provisions that would condition the receipt
1731 of block grants on newly established federal involuntary
1732 inpatient or outpatient standards, and he said no, he would
1733 not.

1734 Mr. {Murphy.} But I am not sure he read or understood
1735 the section there. It would simply say that States--and I
1736 appreciate the--

1737 Dr. {Christensen.} Is this not on my time?

1738 Mr. {Murphy.} I am sorry, ma'am. I was asking to
1739 yield. I was just trying to clarify. Thank you.

1740 Dr. {Christensen.} If I have time, I will yield at the
1741 end.

1742 As I am sure you are aware, SAMHSA has general
1743 authorities to conduct programs of regional and national
1744 significance in mental health and substance abuse prevention
1745 and substance abuse treatment. I understand funding through
1746 these authorities accounts for approximately 35 percent of

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1747 SAMHSA's mental health budget and 25 percent of substance
1748 abuse spending. Title XI of H.R. 3717 would terminate any
1749 program by the end of the fiscal year that is not explicitly
1750 authorized or required by statute shall be terminated. So
1751 how will this impact SAMHSA's ability to continue initiatives
1752 pursuant to PRNS authorities like the Minority Fellowship
1753 program and National Suicide Prevention Hotline?

1754 Mr. {Shern.} It is my understanding that through the
1755 appropriation process, Congress can direct and influence
1756 SAMHSA's agenda. So in many ways, those kinds of
1757 relationships between the legislative and executive branch
1758 are already in place. The programs of regional and national
1759 significance are extremely important. Most of the innovative
1760 processes, particularly around systems of care issues and
1761 many of the things we are talking about today, have come
1762 through that program. So anything that would further
1763 constrain that, we would oppose.

1764 Dr. {Christensen.} And in your testimony, you convey
1765 support for an initiative to improve interagency coordination
1766 of mental health and substance abuse programs within the
1767 Department but you seem to have some reservations about the

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1768 way H.R. 3717 approaches coordination of HHS programs in
1769 mental health through the establishment of that new Secretary
1770 position. Could you elaborate on the reservations you might
1771 have about that?

1772 Mr. {Shern.} Well, our sense is that the Administrator
1773 for SAMHSA is a direct report to the Secretary of Health and
1774 Human Services, and so in some sense, interposing another
1775 layer of government between SAMHSA and the Secretary doesn't
1776 seem to us to be particularly helpful. Additionally, we
1777 believe, and I think this was mentioned earlier in testimony
1778 today, that it is a lot more than HHS that is involved in
1779 mental health care. Housing is involved, Justice is
1780 involved, Labor is involved, et cetera, et cetera, and we
1781 would concur with Drs. Richard Frank and Sherry Gleed in
1782 their analysis of the mental health system in this country
1783 saying that coordination needs to occur literally at the
1784 White House level because it is those interdepartmental
1785 issues which are important. Additionally, I think since
1786 President Bush's commission and its findings, there has been
1787 increasingly interdepartmental cooperation without imposing
1788 any additional structural changes to the government.

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1789 Dr. {Christensen.} Is there anything else you would
1790 like to add about any other areas the bill could negative
1791 impact SAMHSA?

1792 Mr. {Shern.} Well, I think that sort of
1793 overbureaucratizing and overregulating and trying to more
1794 narrowly focus the agenda of SAMHSA around a particular set
1795 of concerns or issues which, generally, I think, are well
1796 represented already in their portfolio will not be helpful.
1797 Certainly, as in any human endeavor or any area of
1798 government, there are ways that things can be improved. I
1799 think that the organization has been mischaracterized in
1800 editorials and publicity surrounding that and that anything
1801 that can further those kinds of issues will be harmful to the
1802 people of this country and their mental health.

1803 Dr. {Christensen.} Thank you. I yield back my time.

1804 Mr. {Pitts.} The Chair thanks the gentlelady and now
1805 recognizes the gentleman from Louisiana, Dr. Cassidy, 5
1806 minutes for questions.

1807 Mr. {Cassidy.} I yield to Dr. Murphy.

1808 Mr. {Murphy.} I thank the gentleman.

1809 Dr. Shern, you already mentioned you didn't read the

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1810 bill so is there a specific place in this bill that you can
1811 make reference to where you have these concerns about the
1812 Secretary of Mental Health and what that person will do to
1813 limit care? Is there some specific page or paragraph you can
1814 reference to clarify your conclusions?

1815 Mr. {Shern.} I am sorry, Dr. Murphy. I am not
1816 understanding the question.

1817 Mr. {Murphy.} Well, you made a statement to the
1818 gentleman that this person who would be the Secretary of
1819 Mental Health would over bureaucratize and complicate some of
1820 these issues. Is there a specific place in the bill you can
1821 tell me where it says that? I need a specific. I don't need
1822 concepts or philosophy. Because what we are trying to do at
1823 this hearing is work to improve the bill. So if you think
1824 there is something in there, it is important this committee
1825 has accurate information and not impressions. Is there
1826 something in the bill? If you don't, you can get back to me
1827 on that. That is okay.

1828 Mr. {Shern.} The question I was responding to had to do
1829 with conditioning the receipt of block grant funds based on
1830 States have effective assisted outpatient treatment, and it

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1831 is my understanding, and correct me if I am wrong, that that
1832 is in fact a provision of the bill.

1833 Mr. {Murphy.} There is a provision of the bill. That
1834 is not the issue with the Secretary of Mental Health.

1835 Mr. {Shern.} That wasn't the question, though.

1836 Mr. {Murphy.} Well, part of it. You said it would over
1837 bureaucratize. The person who now hands SAMHSA, do you know
1838 what her degree is in, what her background is?

1839 Mr. {Shern.} She is an attorney.

1840 Mr. {Murphy.} Exactly. Haven't we done enough with
1841 treating people with mental illness as legal cases? We have
1842 closed our hospitals and filled our prisons. We close our
1843 treatment centers. We have not given adequate funding to
1844 community mental health centers and we have replaced the
1845 hospital bed with a flophouse or a blanket over some steam
1846 grate. That is wrong. I think it is immoral. That puts us
1847 in a third-world category.

1848 Mr. {Shern.} I agree with you completely. I think it
1849 is one thing--

1850 Mr. {Murphy.} I want for the record--yes, there is a
1851 lot to do. A person's background should meet their role.

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1852 Now, I respect that you are here, but also, it is important
1853 to understand, you don't treat patients. You have never been
1854 involved in a patient case. You have never been involved in
1855 a HIPAA discussion. You haven't, and that is important. You
1856 are here as a citizen. But I want to make it very--

1857 Mr. {Shern.} I am here as a research psychologist.

1858 Mr. {Murphy.} I understand, sir, but you haven't read
1859 the bill, okay? Sir, along these lines, let me clarify for
1860 the committee, the Federal Government spends \$125 billion a
1861 year across many agencies. The Department of Defense has
1862 spent \$100 million and the group just said that they money
1863 they spent on resilience programs and other things doesn't
1864 work. DOD has to go back and say what did we do wrong.
1865 Well, we found out that some of the things they are doing are
1866 in clearly good programs with regard to evidence-based
1867 programs, and some of is not, and they need to make sure
1868 people are following the program. The VA spends a lot of
1869 money in mental health but unfortunately, a study said that
1870 about 20 percent of the time when someone goes into a VA
1871 hospital for mental health services for PTSD, they get
1872 appropriate care. The rest of the time they don't. That is

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1873 wrong. Judiciary spends a heck of a lot of money and in many
1874 States on jails. That is wrong. We should be treating these
1875 people.

1876 We have had many witnesses before this committee that do
1877 that. The purpose of the Secretary of Mental Health--and I
1878 think you are demeaning the quality of this. I don't want
1879 someone who is dealing with 60 million Americans that one out
1880 of five or one of four people who deal with it in life to be
1881 some back bench low-level person. I want this person to have
1882 some power and mojo. I want this person to be a clinician of
1883 an M.D., Ph.D. or D.O. level. I want this person to be one
1884 who has access behind their title, Assistant Secretary of
1885 Mental Health, to be able to walk into the office of
1886 Judiciary, Defense, the VA, Education, HHS and say we want
1887 your information, we need to know if your programs work or
1888 don't work or if they are redundant. We have got to make
1889 this system work.

1890 Sir, for the last 20 years that SAMHSA has been around,
1891 it has gotten worse. Now, SAMHSA has done a lot of great
1892 things, and I applaud them for that, and we want to keep them
1893 going. I am not interested in getting rid of them. I am

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1894 interested in beefing them up. But I am also saying we need
1895 evidence-based programs around this country.

1896 There is a lot of misinformation being thrown out today,
1897 so I am frustrated, but I also know, you know what? That is
1898 the nature of the mental health community. For the first
1899 time since Kennedy was President, for the first time in the
1900 last 50 years we have an opportunity in this Congress to say
1901 we need to overhaul this system. There have been some great
1902 programs that have come through. I applaud Congressman
1903 Kennedy and Senator Wellstone. Some of those things have
1904 been marvelous. But it has been piecemeal, and I want us to
1905 really approach this in a comprehensive way but sometimes in
1906 the mental health community, we are so used to dealing with
1907 dysfunction in ourselves, we don't understand when we have an
1908 opportunity.

1909 So here is what I am recommending. When you are given a
1910 comment and you haven't read the bill, say I haven't read the
1911 bill, okay? And with regard to this, what we want, what I
1912 want is from everybody and all the agencies throughout
1913 spreading rumors about this bill too to my colleagues and
1914 other people, send me ideas for amendments. Let us work on

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1915 this, but let us not play this game.

1916 Thank you. I yield back.

1917 Mr. {Pitts.} The Chair thanks the gentleman and now

1918 recognizes the gentleman from North Carolina, Mr.

1919 Butterfield, 5 minutes for questions.

1920 Mr. {Butterfield.} Thank you very much, Mr. Chairman,

1921 and thank the witnesses for their testimony today. I will

1922 try to look around Mr. Tonko and see all four of you. That

1923 is the advantage of being on the bottom tier. That is fine,

1924 Paul. That is fine.

1925 But thank you for holding today's hearing. Certainly,

1926 mental health is a very important issue. It is an important

1927 issue to all four of you. It is an important issue to us and

1928 certainly to the people that I represent in North Carolina,

1929 and so that means that we have to do all that we can at the

1930 federal level to ensure that people who are living with a

1931 mental illness receive the treatment and support they

1932 deserve.

1933 Some of my colleagues certainly know in my prior life I

1934 was a trial judge in North Carolina, served for 15 long years

1935 in 32 counties in my State, and so I have seen firsthand what

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1936 mental illness can do not only to families but to
1937 communities, and so I thank you for your passion.

1938 I have read most of Mr. Murphy's bill, and I think it is
1939 a good step, a step in the right direction. Certainly, there
1940 are many improvements that we can make, and I thank the
1941 chairman for offering us an opportunity to offer amendments
1942 to the legislation and there will be several.

1943 There are many different people involved in the
1944 continuum of care for mental illness and it is important that
1945 we recognize another category, and that is the role of social
1946 workers in the continuum of care and the important role that
1947 they play in mental and behavioral health infrastructure in
1948 our country. The importance of the social work profession
1949 will continue to increase as the mental and behavioral health
1950 challenges impact a growing percentage of the population.
1951 According to the U.S. Bureau of Labor Statistics, the need
1952 for social workers specializing in mental health and
1953 substance abuse is expected to grow by 23 percent from 2012
1954 to 2022. That is 10 years. That rate is much faster than
1955 the average for all other occupations. Social work is built
1956 on a foundation of integrated care working directly with

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1957 patients, but in settings including hospitals and schools and
1958 substance abuse prevention and treatment programs and family
1959 service settings and long-term care facilities. Social
1960 workers have a history of working with and across disciplines
1961 including psychiatrists, pharmacists, nurses and others and
1962 will play a central role as we seek to improve health
1963 outcomes for people with mental and behavioral issues.

1964 I understand that part of the goal of this hearing is to
1965 identify and fill gaps that exist in the health care
1966 workforce in an effort to meet the unique needs of different
1967 populations such as our veterans and people living in urban
1968 or rural communities or adults.

1969 Let me go to Dr. Shern if I can very quickly. We know
1970 that health professions other than M.D.'s and Ph.D.'s have a
1971 growing role in meeting the mental health needs in the United
1972 States. Can you talk about your experiences and/or best
1973 practices working with other professionals in an integrated
1974 and team-based approach?

1975 Mr. {Shern.} Yeah, well, I think that that integrated
1976 team-based approach that involves several different
1977 disciplines is essentially the state of the art in terms of

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1978 how services are best delivered, particularly for people who
1979 have complex conditions or have, in this case, severe mental
1980 illnesses, and I think that there are real opportunities and
1981 real challenges that we confront in terms of adequate health
1982 care workforce in general and trying to understand and
1983 articulate different roles, particularly roles for
1984 paraprofessionals, peers and others and certainly including
1985 social work. You know, all of this that we are talking about
1986 in terms of the integration of care, understand that people
1987 live in communities, interact with complex systems, that is
1988 the hallmark of social work's approach to these issues. So I
1989 think many disciplines are involved. I think the best
1990 treatment involves a multidisciplinary team and I think that
1991 is basically considered state of the art in terms of services
1992 for people with severe mental illness.

1993 Mr. {Butterfield.} How do you see an integrated team-
1994 based approach involving social workers and pharmacists and
1995 nurses and others in addition to psychiatrists contributing
1996 to the success of this legislation and addressing mental
1997 health needs?

1998 Mr. {Shern.} Well, you know, it is clear from research

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1999 actually that was done in the 1970s that multidisciplinary
2000 teams can both save money in terms of decreasing utilization
2001 of the most expensive resources and improve outcomes, and the
2002 disciplines that you mentioned in your question would be the
2003 disciplines that typically would be involved in those kinds
2004 of multidisciplinary teams.

2005 Mr. {Butterfield.} Finally, let me go to you, Ms.
2006 Thompson, and thank you very much for your very passionate
2007 day. On another day I will share with this committee my
2008 personal story. I too grew up in a home with a mother who
2009 had mental illness. It was paranoia. She was not a harm or
2010 threat to anyone except herself, but it had a significant
2011 impact on her family and her work. So thank you for your
2012 testimony.

2013 Do you think this legislation does enough to recognize
2014 and encourage an integrated team-based approach to addressing
2015 mental health needs of patients and their families?

2016 Ms. {Thompson.} As I said earlier, I haven't read the
2017 entire bill. From my understanding, it addresses--the issue
2018 I have with what has happened in my experience was that there
2019 was no quality of life for my mother, so whatever it takes to

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2020 create an ability for people to have a better quality of
2021 life, whether they know what it is or not, whether they are
2022 able to recognize it for themselves or not, that I feel we
2023 have an obligation to do that.

2024 Mr. {Butterfield.} Thank you. My time is expired. I
2025 am sorry.

2026 Mr. {Pitts.} The Chair thanks the gentleman and now
2027 recognizes the gentlelady from North Carolina, Ms. Ellmers, 5
2028 minutes for questions.

2029 Mrs. {Ellmers.} Thank you, Mr. Chairman, and thank you
2030 to our panel. Each one of you have very important
2031 information for us today, and I would also like to
2032 congratulate and thank my colleague, Mr. Murphy, for the work
2033 that he has done on this issue, especially in relation to the
2034 HIPAA situation. As a nurse before coming to Congress, I
2035 know that much of the misinformation that is there is
2036 parochial and essentially what happens is, it is
2037 misinterpreted or overinterpreted and the clarifications are
2038 necessary so that each health care professional can
2039 understand what can be relayed because it is a very crucial
2040 time.

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2041 So with that, I do have a question for Ms. Zdanowicz and
2042 for Ms. Thompson. Both of you are doing important work, and
2043 your stories are compelling on a personal level as well. In
2044 North Carolina, you know, the past 10 years, the suicide rate
2045 has spiked significantly from about 18 percent to 22 percent.
2046 I represent Fort Bragg, and this affects our military, as you
2047 know, and our soldiers as well. In fact, a statistic that I
2048 am reading here that is provided for me says that actually
2049 this year into 2014, there have been more soldiers who have
2050 died by their own hand than those on the battlefield. Now,
2051 death in itself is not to be embraced. However, when we look
2052 at that statistic, we know the effects are incredible and
2053 that we need to deal with this issue.

2054 Obviously, medical beds, you know, patient beds,
2055 psychiatric beds are so essential, and we are in more need
2056 today than ever. Today North Carolina has only eight beds in
2057 a State psychiatric hospital per 100,000 people. So I
2058 believe we are at the lowest ratio. And one of our largest
2059 hospital systems in my area in North Carolina, Wake Med, is
2060 basically struggling with this issue. They treat an average
2061 of 314 patients a month whose primary diagnosis is psychosis,

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2062 and this is up one-third over the last 2 years. Any given
2063 time, there are 25 to 50 patients with a diagnosis of mental
2064 illness of some form that are not necessarily in a dedicated
2065 psychiatric unit but are having to be placed in other areas
2066 of the hospital, and as you can imagine, that is difficult
2067 for the patient, the family and then also the health care
2068 professionals who are taking care of them.

2069 Ms. Zdanowicz, can you give us some points and guidance
2070 on how we can improve this mental health bed situation?

2071 Ms. {Zdanowicz.} Well, I would love to tell you that we
2072 could convince States to increase the number of beds and
2073 increase the number of long-term and intermediate-care beds
2074 that are just disappearing but that is not going to happen,
2075 and that is why assisted outpatient treatment is so important
2076 because it is a way of keeping individuals who are not safe
2077 in the community without medication on treatment, and there
2078 is empirical evidence to show that it reduces
2079 hospitalization, reduces incarceration, which, as I mentioned
2080 before, the jails and prisons are the new State psychiatric
2081 hospitals. If we don't have those kinds of facilities, we
2082 have to have a way of ensuring that people who don't realize

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2083 that they are ill, that won't take their medication any other
2084 way have a means of getting that support, and it is not just
2085 a court order of somebody telling them. It comes with
2086 services. And I know people who have experienced it, and it
2087 does not scare people away and in fact it improves their
2088 lives. So unless we can get more beds, this is a solution
2089 with the population we are talking about, not everyone but
2090 the population we are concerned about.

2091 Mrs. {Elmers.} Thank you.

2092 And Ms. Thompson, I just want to thank you for the work
2093 that you are doing. In Randolph County, which is one of my
2094 counties that I represent, the crisis intervention training
2095 for law enforcement is making a significant difference.
2096 Basically this is sponsored by you and NAMI, and it has done
2097 incredible work in the ability to have those law enforcement
2098 officers in the situation, know when they have to react and
2099 be able to engage and deescalate the situation, and it has
2100 made a huge difference. However, we need to continue to show
2101 that this program is working and we need greater coverage and
2102 reaching out to some of the other law enforcement. How can
2103 we extend this program? Do you know of the barriers? And I

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2104 know I am running out of time, but can you identify the
2105 barriers that we can address that might actually be able to
2106 help this situation?

2107 Ms. {Thompson.} The situation in terms of getting more
2108 people informed?

2109 Mrs. {Ellmers.} Yes, or getting this program in place
2110 for more law enforcement to learn about--

2111 Ms. {Thompson.} This program is vital. You need to
2112 give people the tools on how to deal with people in crisis,
2113 because if you don't, that is where the abuse comes from.
2114 That is really the abuse in the police department. That is
2115 where all of that comes from is because you are asking them
2116 to deal with something that they have no knowledge, that is
2117 not their skill set, and it is not fair to them and it is not
2118 fair to the individual.

2119 But that needs to be funded. I mean, there is no way--
2120 we can't do it alone. NAMI is trying desperately. We are a
2121 volunteer-based organization. We are a nonprofit
2122 organization. We try to reach out to law enforcement as much
2123 as we can. We need help. We need funding.

2124 Mrs. {Ellmers.} Thank you so much, and again, thank you

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2125 to our entire panel.

2126 Thank you. I yield back the remainder of my time.

2127 Mr. {Pitts.} The Chair thanks the gentlelady and now

2128 recognizes the gentleman from Florida, Mr. Bilirakis, 5

2129 minutes for questions.

2130 Mr. {Bilirakis.} Thank you so very much, Mr. Chairman.

2131 I want to thank the panel for their testimony and of course

2132 coming to Washington and sharing with us.

2133 In addition to being on the E&C Committee, I also serve

2134 as vice chairman of the Veterans Affairs Committee, and we

2135 have held several hearings over the years on the mental

2136 health issues and of course, it is an extremely important

2137 issue. As a matter of fact, Time magazine wrote back in 2012

2138 that more U.S. military personnel have died by suicide since

2139 the war in Afghanistan began than have died fighting. When

2140 they take their own lives, these deaths diminish us as a

2141 whole. It leaves behind spouses, children, parents and

2142 siblings who must deal with the loss and their own grief.

2143 So when I look at H.R. 3717, and thank you,

2144 representative Murphy, for filing the bill, of course,

2145 Helping Families in Mental Health Crisis Act, I look at it

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2146 from the viewpoint of our veterans and their families in
2147 addition to the general population.

2148 I want to thank the witnesses again for coming here
2149 today and talking about these issues. It is so very
2150 important. It is an invisible wound that millions grapple
2151 with each day. It carries a stigma, as you said, and we need
2152 to help remove the stigma so people aren't afraid to seek
2153 help. Mental health issues are just as serious as visible
2154 physical wounds, in my opinion. We must responsibly address
2155 this problem. Too many Americans and their families are
2156 suffering and they deserve proper care, in my opinion.

2157 Your experiences dealing with family members with mental
2158 health issues or living with it or treating it helps inform a
2159 lot of us in the debate. Again, thank you for being here. I
2160 really appreciate it. And I would like to yield the rest of
2161 my time to Representative Murphy.

2162 Mr. {Murphy.} I thank the gentleman for yielding.

2163 A couple other clarifying points I want to make for
2164 members. This bill does not cut 85 percent of federal
2165 funding for the programs. It does not. There are multiple
2166 sources for that federal funding. This is one of them. And

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2167 so it is very important that people are dealing with the
2168 facts.

2169 Also, Dr. Shern, you referred to a coercive feature of
2170 assisted outpatient treatment that would make people seek
2171 treatment. Are you aware of the programs Ms. Zdanowicz is
2172 talking about here with regard to the evidence on when AOT
2173 can work to reduce incarceration, et cetera?

2174 Mr. {Shern.} Yes, I am.

2175 Mr. {Murphy.} So what I am trying to find out here, and
2176 I recognize not all States do things the same way.

2177 Mr. {Shern.} Right.

2178 Mr. {Murphy.} For example, California has one county
2179 that does this; the rest don't. And some States do it better
2180 than others. I think New York does a pretty good job on
2181 that.

2182 But in this bill, are you aware of how we define who
2183 would qualify for assisted outpatient treatment?

2184 Mr. {Shern.} Generally, yes.

2185 Mr. {Murphy.} Well, we very narrowly defined that.
2186 They to be incarcerated before, had multiple
2187 hospitalizations, but the rest we leave up to the States

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2188 because I think States should decide a lot of this too. So I
2189 want to make sure we are making it clear. There is no
2190 coercion involved here but we are saying States have to have
2191 something on the books.

2192 But let me ask the panelists this--

2193 Mr. {Shern.} Can you clarify that a bit, the no
2194 coercion involved in assisted outpatient treatment?

2195 Mr. {Murphy.} I am saying with regard to the States,
2196 they can put this together any way they want but we are
2197 saying--

2198 Mr. {Shern.} Coercion of the States?

2199 Mr. {Murphy.} Yes. What we are saying here is that as
2200 an alternative to just waiting until someone is in imminent
2201 danger, until someone has a knife to their head or someone
2202 else's. We want to provide a mechanism by which people are
2203 not just waiting for that ``someone is about to die''
2204 standard. That is something established in the 1700s. We
2205 need to be doing more.

2206 So what I want to ask here is, I am open to other ideas,
2207 and what else could we do to make sure people--we have this
2208 integrated care, this wraparound care. I mean, we know when

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2209 someone is in an acute crisis, that they need a lot of help
2210 and long term. What would be a couple of those things? Ms.
2211 Thompson, can you think of anything that we should make sure
2212 we include here?

2213 Ms. {Thompson.} Well, I think how HIPAA is addressed is
2214 vital because, you know, waiting until somebody is at a risk
2215 to themselves and others is waiting way too long to help
2216 them. We are waiting way too long to step in.

2217 Mr. {Murphy.} So making sure we have some way that
2218 families can participate more would be helpful?

2219 Ms. {Thompson.} That is correct.

2220 Mr. {Murphy.} Dr. Shern, do you have any
2221 recommendations of ways we could help provide some integrated
2222 wraparound services? I mean, we have some in here now under
2223 the Excellence in Health Care. You don't have to answer now
2224 but if you can provide us some ideas, I would love to hear
2225 them.

2226 Mr. {Shern.} Sure, and I think we have a pretty good
2227 evidence base with regard to that and I think that where AOT
2228 has been shown to be successful is in New York where there
2229 was a \$125 million appropriation to enhance services.

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2230 Mr. {Murphy.} Zdanowicz, do you have any other
2231 suggestions we can do? I know you are in support of AOT by
2232 any other things States should be doing?

2233 Ms. {Zdanowicz.} Well, I mentioned earlier, I just
2234 finished a survey of jails and prisons around the country,
2235 and this is where we need more help, and it is something that
2236 is being overlooked. I think it is coming to the forefront
2237 now. But that is where are so many people with mental
2238 illnesses who are refusing treatment, and what happens to
2239 them in those situations, I have talked to jails and learned
2240 just how horrible and dangerous and heartbreaking it is, and
2241 I think it is something that we have to focus on and not only
2242 just providing treatment in the institutions but keeping them
2243 out of the institutions, and I have talked to police officers
2244 trained to deal with people with mental illness. I was in a
2245 meeting where they asked, after hearing all the evidence, you
2246 know, the recovery-based peer support programs the State
2247 provides, a police officer stood up and said well, when I
2248 call the State, I can't get any help for this homeless person
2249 who is psychotic and delusional. So I think those are the
2250 areas that we need to have more integrated services.

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2251 Mr. {Murphy.} Mr. Chairman, for the record, I just want
2252 to point out that in support of what Dr. Shern is saying, a
2253 report says that ACT works but a report says we also found
2254 evidence in the case manager data that receiving AOT combined
2255 with ACT services--assertive community treatment--
2256 substantially lowers risk of hospitalization compared to
2257 receiving ACT alone. So we will work with you on that.
2258 Thank you.

2259 Mr. {Pitts.} The gentleman yields back. The chair now
2260 notes that the subcommittee members have concluded their
2261 questions, and without objection, the Chair recognizes the
2262 gentleman from New York who is also on the full committee,
2263 Mr. Tonko, 5 minutes for questions.

2264 Mr. {Tonko.} Thank you, Mr. Chair.

2265 Preliminarily, I state to our colleague and my friend,
2266 Mr. Murphy, that many of us are engaged in regard to this
2267 bill. We have read the bill and have sent you specific
2268 suggestions on how we believe the bill can be improved. We
2269 all agree that there are serious issues that need to be
2270 addressed but there are also serious reservations out there
2271 to some provisions in the instant bill. I think your intent

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2272 is right, and we want to continue to work with you, but it
2273 needs to be a collaborative process. I commit to keeping an
2274 open dialog here so as to exchange on behalf of the issues
2275 and to recognize the importance of the issues here, the
2276 people most importantly impacted by mental health disorders
2277 and mental illnesses are of high need. So we need to
2278 recognize that and move forward with the sense that more than
2279 one point of view needs to be exchanged here in order for us
2280 to move forward most effectively.

2281 I also want to make the record clear that the protection
2282 and advocacy organizations are already precluded, prohibited
2283 by federal law from using any federal funds for lobbying
2284 purposes. Any lobbying activities conducted by these
2285 organizations, most notable organizations, are done with
2286 private dollars. Certainly, this would be restricted as
2287 lobbying activities with private funds which as I am sure my
2288 colleagues on the other side of the aisle would agree with in
2289 the way of yesterday's Supreme Court ruling could raise
2290 significant free-speech concerns, and I think those free-
2291 speech concerns are essential here for these organizations
2292 using private dollars.

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2293 With that being said, I thank you again, Mr. Chair, for
2294 the opportunity. This issue is near and dear to my heart. I
2295 served in the New York State Assembly before coming to
2296 Congress. One of my proudest achievements in 25 years of
2297 service in that body was Timothy's Law. I was the prime
2298 sponsor of mental health parity in New York. I have the
2299 utmost respect for the mental health community and for those
2300 who advocate. Their resilience, their determination is
2301 stellar, and I recognize that, and I recognize the work done
2302 by the Oversight and Investigations Subcommittee to examine
2303 issues surrounding mental health.

2304 While there are many aspects of this bill with which I
2305 strongly disagree in its current form, I think that the
2306 intent is right on and it is in the right place, and I hope
2307 that we can continue to have bipartisan discussions to
2308 improve the bill. Those struggling with mental illnesses
2309 deserve nothing less.

2310 So Mr. Shern, in your testimony you speak to the fact
2311 that our treatment systems should be welcoming rather than
2312 frightening. I couldn't agree more. And I think everyone in
2313 this room recognizes that voluntary community-based treatment

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2314 is always preferable and leads to better outcomes in the long
2315 run.

2316 One of the more difficult questions we are weighing as a
2317 panel is what circumstances more coercive forms of treatment,
2318 whether this is assisted outpatient treatment or inpatient
2319 hospitalization might be necessary. In your opinion, when is
2320 it appropriate, if ever, to resort to these more coercive
2321 forms of treatment when dealing with an individual with
2322 serious mental illness?

2323 Mr. {Shern.} Well, I think, you know, in situations in
2324 which a person doesn't have the capacity to make the
2325 decisions necessary to preserve their safety or is a threat
2326 to another person, which is the standard sort of commitment
2327 that laws that exist across the country. At that point in
2328 time we have provisions for involuntarily treating
2329 individuals. I personally have--when we implemented our New
2330 York City program, our Manhattan program for people who had
2331 severe mental illnesses and were living on the streets of New
2332 York, I personally witnesses people literally running from
2333 our program because of--literally running, jumping onto the
2334 Staten Island Ferry by slipping under the door right before

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2335 the ferry took off rather than be engaged by our program. So
2336 I personally have experienced people running from care
2337 because of coercive interventions.

2338 Mr. {Tonko.} And Mr. Shern, does the evidence show that
2339 assisted outpatient treatment programs are more effective
2340 than similarly resourced assertive community treatment
2341 programs?

2342 Mr. {Shern.} It is my understanding that those
2343 situations in which AOT has been shown to be effective both
2344 in the Duke trials and in the New York State experience were
2345 situations in which there were enhanced services available.
2346 Compelling people into a service system that doesn't exist is
2347 not going to make a difference.

2348 Mr. {Tonko.} And when States have adopted more
2349 expansive need-for-treatment standards for civil commitment,
2350 have we seen an impact on individuals seeking care
2351 voluntarily?

2352 Mr. {Shern.} Coercive interventions can chase people
2353 from care.

2354 Mr. {Tonko.} Thank you very much, and with that, I
2355 yield back as I see I have exhausted my time.

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2356 Mr. {Pitts.} The Chair thanks the gentleman. The Chair
2357 overlooked one member of the subcommittee, so at this time
2358 yields 5 minutes to Mr. Griffith from Virginia.

2359 Mr. {Griffith.} Thank you very much, Mr. Chairman, and
2360 I apologize to both you, Mr. Chairman, and to our panelists.
2361 I have been involved in another hearing as well and so I have
2362 been running up and down the stairs trying to make sure I got
2363 here.

2364 I want to agree with Representative Tonko in saying that
2365 putting this forward by Dr. Murphy is a big step. Somebody
2366 has to put it forward. We have been studying it for a little
2367 while. He decided to take that leap, and I commend him for
2368 that because that is very, very important. There are things
2369 in a bipartisan fashion that we can work on to improve the
2370 bill, and I heard Dr. Murphy say earlier he is looking for
2371 those suggestions.

2372 That being said, I also want to underscore that HIPAA
2373 does have to be addressed. It doesn't mean we want to undo
2374 the principles of HIPAA. It doesn't mean we want to, you
2375 know, let everybody have access. But we heard so much
2376 testimony from so many family members who wanted to help,

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2377 people who loved the individual with mental health problems
2378 who wanted to be there for them, and in many cases were not
2379 able to be there to take care of them because they were
2380 blocked. They were blocking from having the necessary
2381 knowledge to know whether or not they were a risk to
2382 themselves or to others. They were blocked because they
2383 didn't know exactly what was going on. So we have to improve
2384 that.

2385 Where I would like to see improvements in this bill is
2386 in figuring out how to define that because when you look at
2387 Section 301, we have a real opportunity to work on that
2388 across the board, all parties coming together and figuring
2389 out how we do that. My concerns particularly relate to two
2390 groups of individuals. You have got the elderly. It is
2391 pretty obviously that with an elderly person, you know, if
2392 you have competing children--I used to do divorce work in my
2393 small town private practice. I did a lot of criminal work.
2394 People will fight over all kinds of things and particularly
2395 when it becomes mom or dad, family members get into a fight.
2396 So we have to figure out a system where if you have got a
2397 child who hasn't been involved in mom's life for 20 years,

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2398 that they don't come waltzing in and knock Ms. Thompson out
2399 because all family members get it.

2400 Also, I worry in that same situation, that young men, we
2401 have heard so much testimony that young men particularly in
2402 that suspect group, 14 to 18 is a problem but 14 to, I think
2403 it was 28--Dr. Murphy can correct me on my ages--where there
2404 is a lot of onset of first signs of mental illness and they
2405 don't get treatment. Fourteen to 18, parents are still
2406 involved. On that 18th birthday, they get knocked out. And
2407 whether that is what HIPAA is supposed to do or not, it is
2408 the way it is interpreted, and if you are worried about
2409 lawyer suing you for giving away the information, you are not
2410 going to do it as a doctor. No matter what different people
2411 may think it means, Dr. Murphy is right. We have got to
2412 clarify it. But then I also worry if you have too big a door
2413 for people to get information, does that estranged father
2414 come back in, never having participated in his son's life and
2415 now the son is 22 and he decides he wants to come in and
2416 knock mom out.

2417 So that is the scenario that I am looking at. I think
2418 we can make improvements. And with that, Mr. Chairman, I

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2419 yield to Dr. Murphy.

2420 Mr. {Murphy.} I thank the gentleman. I also thank you
2421 for your commitment to help us improve that language. It is
2422 important. We have had too many people raise concerns so we
2423 have to do it the right way.

2424 Dr. Shern, you had mentioned that you are aware--well,
2425 let me ask you, are you aware of any study at all, empirical,
2426 published study, that supports your understanding that
2427 broader commitment standards drive people away from seeking
2428 treatment? Are you aware of any particular study offhand or
2429 can you provide that for us?

2430 Mr. {Shern.} I can look into it. I am not aware of any
2431 offhand.

2432 Mr. {Murphy.} Okay. I appreciate that, because you
2433 made the statement. I want it backed up with evidence.

2434 I also want to say that what I was reading before, the
2435 quote I forgot to reference is where it said that AOT
2436 combined with ACT services substantially lowers risk of
2437 hospitalization compared to receiving ACT alone. This is in
2438 the study done by Duke University Policy Research Associates
2439 and the University of Virginia School of Law on the New York

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2440 State assisted outpatient treatment program evaluation. So
2441 there is a lot we can learn from New York.

2442 One other thing I want to mention, when I refer to some
2443 of the concerns I have, and Ms. Jensen, you brought a very
2444 compelling story forward on what happened with that horrible
2445 place you were in, and I am glad you fought hard to shut it
2446 down, but also some of these groups also cause some problems
2447 too. A case we heard was from Joe Bruce. His son William
2448 was diagnosed with some psychosis. He was in Maine. And
2449 these advocates came in. This family was completely cut off
2450 from being able to talk to their son, which is a HIPAA issue,
2451 yet these advocates could talk to him, coached him during a
2452 hearing on this, and told him to say when he was asked if he
2453 was going to be a harm to himself or someone else say no. He
2454 listened to their coaching. He was dismissed from the
2455 hospital. He went home. He took a hatchet and chopped his
2456 mother to pieces.

2457 This was very moving testimony this committee heard. We
2458 don't think a group like this has any business telling
2459 someone get them out of treatment altogether. We want
2460 professionals involved who are looking out for the best

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2461 interest of the patients all the way through.

2462 Mr. Chairman, I want to thank you for this hearing
2463 today. We have heard some powerful information. I look
2464 forward to working with my colleagues on both sides of the
2465 aisle on this. The good news is, we have elevated this to
2466 the level of Congressional discussion instead of keeping it
2467 in the dark shadows. We have understood that this isn't just
2468 an issue of violent mentally ill. We have to work together.
2469 I am excited about this, and I want to leave with a message
2470 of hope for the many people who are struggling with mental
2471 illness. We will continue to listen to you. We want to work
2472 together. We have got to change this system and help you
2473 all.

2474 With that, I yield back.

2475 Mr. {Pitts.} The Chair thanks the gentleman, and thanks
2476 him for his leadership on this issue. This has been a very
2477 important hearing, very compelling testimony, very
2478 informative. Thank you very much to the witnesses for
2479 coming.

2480 Now, we have members who may have follow-up questions
2481 who were not able to attend. They are in other hearings. We

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2482 will send you the written questions. We ask that you please
2483 respond promptly. Do you have something?

2484 Mr. {Tonko.} Yes, Mr. Chair. We ask that these
2485 documents be included in the record.

2486 Mr. {Pitts.} We have a unanimous consent request to
2487 include in the record testimony of the National Disability
2488 Rights Network, a letter from the American Psychiatric
2489 Association, testimony by the National Coalition of Mental
2490 Health Recovery, testimony titled Helping Families in Mental
2491 Crisis Act, H.R. 3717 by the Citizen Commission on Human
2492 Rights, a letter by Consortium for Citizens with
2493 Disabilities, and testimony by Judge David Bazelon Center for
2494 Mental Health Law. Without objection, so ordered.

2495 [The information follows:]

2496 ***** COMMITTEE INSERT *****

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|

2497 Mr. {Pitts.} I remind members that they have 10
2498 business days to submit questions for the record. That means
2499 members should submit their questions by the close of
2500 business on Thursday, April 17.

2501 Thank you again very much for attending. Without
2502 objection, the subcommittee is adjourned.

2503 [Whereupon, at 12:48 p.m., the subcommittee was
2504 adjourned.]