

TESTIMONY OF RON SUSKIND

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HEARING ON

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Introduction

Thank you, Chairman Smith, Ranking Member Bass and Members of the Subcommittee. And thank you for this opportunity to discuss the global challenge autism presents and how we might respond to it, as engaged governments and citizens in the 21st century.

For the past 25 years, I've been writing about the ideals of public policy and the challenge of effective governance, education, race, and how we value – and reward – human capacity. As a journalist, predominantly at the Wall Street Journal, and in six books, I've attempted to understand how governments can do more, most effectively, for those in need.

A great deal of my work has focused on the left behind, here and abroad – from America's blighted urban core to Pakistan and Afghanistan, Europe and Africa. As I searched the world, seeking those separated from dignity and opportunity by poverty and by bigotry in their many forms, and documenting our era's scourge of tribalism supported by violence, I discovered that the most dramatically left-

behind person I'd encountered was living in my own home.

That would be my son, Owen. Just before his third birthday, a chatting, playful boy was struck silent. Crying, inconsolable, he soon lost his few hundred-word, two-and-a-half year-old's vocabulary. By three, he was down to one word: "Juice." Soon enough, we received a diagnosis of regressive autism.

This story, of children trapped inside an unreachable world of autism, is all too common, for reasons we still don't understand, as today's distinguished guests and experts have so effectively described. The growth in diagnosed cases is startling, with three million in America and an estimated 70 million worldwide. The most bracing number from this year's CDC report is as follows: one out of 42 boys in the U.S. is on the autism spectrum. That's a rate of 2.5% of our male population.

I'm here today, though, to speak of hope. As a lifelong investigative reporter, I breathe skepticism. I am contrary by nature. I need proof, or I don't budge.

But what I'm finding now are outlines of a surprising and hopeful equation.

It starts with my family's own experience across 20 years of wrestling with my son's affinity. Virtually everyone on the autism spectrum has an affinity: a deep and special interest, a passion, that often appears to crest into obsession. That's the way most specialists have seen these affinities over recent decades, as perseverative, unproductive, a wheel in the ditch. The idea has long been to wean children off their affinity, even though that rarely works. My son's affinity is Disney animated movies. Don't worry, I won't start singing. Not yet, at least. From the earliest age, when he could not speak, we found he was memorizing the dialogue and song lyrics from his favorites – Dumbo, Pinocchio, the Lion King – by rewinding them over and over. Eventually we learned that he'd memorized about 20 of them – all the classics – and that if you threw him a line, he'd throw you back the next one. Of course, just about everything is found in the 55 Disney features since Snow White in 1937. We picked scenes – one for every occasion -- and began conversing in Disney dialogue. We became animated characters. Over years, this is how he got his speech back. He then created an interpretive, emotional language using Disney dialogue and, eventually, a powerful philosophy of life.

In other words, once we gently engaged his affinity, and began to

exchange and share the fundamental emotions found in every family, he let us in deeper. Over a decade-plus, we realized he was using his affinity like the Enigma machine in WWII – to crack the codes of the wider world. We helped, certainly, as my wife worked with him round the clock, assisted by me, his older brother, Walt, and eventually teachers and therapists. But the key was the way his self-directed energies were channeled through his passion: he used Disney to broaden his knowledge of the real world, learn to read, widen his vocabulary, teach himself to draw masterfully and, most importantly, to manage his emotional growth.

We called it “Disney Therapy,” and eventually skilled psychologists helped us hone it. Now, we call it “Affinity Therapy,” because we’ve found there are many affinities – probably 20 major ones in this period, covering much of the ASD population – that growing evidence indicates can be used in the same way.

Thomas Insel, who heads the National Institute of Mental Health, calls affinity therapy a “reversal of the telescope,” that may herald a new pathway to understand autism and help those with ASD. Since the publication of my book, neuroscientists at MIT, Yale and Cambridge University have joined to launch an international trial to study affinities. The protocol is to have children lock onto their affinity and, then using fMRI, seeing how their brains respond. The view – one affirmed by clinical observation – is that underlying neuronal capacities will be revealed. These capacities might be called the compensatory gifts of those with autism, evidence of how the brain, with its vast plasticity, finds a way; neural pathways – heavily weighted from birth or built because a traditional pathway is blocked – that can then be harnessed and nourished by therapists and educators.

Eventually, these will be the special skills and capacities tapped by employers.

Because that is our shared goal – finding productive lives for those with ASD. They want it, we want it. Society wants it. And, certainly, those who watch federal budgets want it.

How do we get there?

First, we must begin to change the way this population is viewed. More than half the ASD population is of normal or above-normal intelligence. With the difficulty in measuring their often subtle or shrouded abilities, and the deficits of using a one-size-fits-all yardstick

for those with such specialized profiles, that percentage is surely higher. I would go further: as the neuroscientists at MIT and Yale secure funding and begin their trials, I would submit that for every visible deficit, there is an equal and opposing strength. This population is just like the rest of us, only less so and more so. The "less so" parts are conspicuous, and we focus on them intently, trying to fix them, to help them the individual be more like the blended average, and manage in the world. The "more so" parts are often subtle, opaque, hard to find and measure. But why is that a surprise – all our most important qualities are hard to measure. The question increasingly is not "if" these "more so" qualities exist, but "where?"

We're beginning to get answers displayed on the LifeAnimated.net website, where parents, therapists and those with ASD have recently posted videos of the often startling abilities housed in this population, each video showing how affinities are used to find a way into the sunlight of communication and human interaction. One parent I recently spoke with told me of how her nonspeaking son became fascinated with bees. The family pushed all available education – science, history, geography, math – through that fulcrum. The child's skills grew, as did his ability to connect to others. As a teenager, he secured a job at a bee-farm in California, using his deep knowledge. Until he typed out to his mother that it was no longer bees that fascinated him. . . it was now flowers. That's where his self-directedness then led. He is now an expert on flora and is working successfully at a large organic nursery, a star employee. Another child is an expert in wind chimes, showing more expertise than the leading maker of wind chimes in America (as demonstrated by a chime-identification contest between he and the company's CEO.) A third – a small boy – speaks through logos and commercial jingles, which he's memorized utterly. As parents, siblings, therapists and friends celebrate these affinities – the children are affirmed and respected. And emotionally deepened by that human contact, each one is progressing, on their way to become deeply specialized and expert adults.

Expertise – that's what businesses want. I have recently formed an Affinity Foundation, to act as a clearinghouse and data-sharing destination for research, as well as the beginnings of an affinity network, where special skills can be displayed and employers can shop for what they need: eBay meets Monster.com.

But, as my friend Thorkil Sonne has found, a valuable specialized skill is not enough, even if it can be identified and turned into an

occupational path. ASD folks need social supports to manage in most workplaces. That's one place where funding can and should be focused: shoring up the bridges to traditional workplaces, allowing for sustainable and productive occupational engagements, or helping to create specialized workplaces where ASD achievers can work in a comfortable environment. Every public dollar spent here brings a return many times over.

One area of immediate need – and also federal support – is for a new generation of socially augmentative technology. In that regard, I've recently tapped the inventors of voice recognition technology and Siri, the personal assistant on your iPhone. Bringing them together with leading autism specialists, we're crafting a specialized app to fit the needs of ASD folks as they venture into the world. This app will be adaptable to fit an array of needs that are commonly shared in this community, but can be also be specialized by ASD individuals and their supporters – including job trainers and employers – to fit specific needs. The artificial intelligence functions will help the device get smarter and more supportive of each user. For years, my wife and I – experts on our son's needs and strengths and inclinations --dreamed of following him out the door each morning to school, to be a voice in his head, to remind him, reinforce behaviors, and give him the few prompts he'd need to get through the day. Now my son, at 23, knows the prompts that help him, the regular reminders and answered questions he needs to navigate the shifting terrain of daily life.

Soon, he'll have an app, which he can carry in his iPhone without stigma. Some people talk to themselves. My son's been doing that for years. Now, he can do it under his breath to his electronic "sidekick." Disney, as you know, has scores of sidekicks – Jiminy Cricket, Merlin, Rafiki. Owen often says the sidekick's job is to help the hero fulfill his destiny. This app will help with his hero's journey.

All together, these steps forward create that hopeful equation – hopeful, in that it fits with the way we know the world really works. We build skills and character through adversity, earn hard won insights, develop muscles, from walking into a strong headwind. I find this among "left behind" people throughout the world. What's changing in this connected age is that they're realizing this . . . and we, so often graced by opportunity and advantage, are realizing it. That's what, at day's end, binds my son to the many people I've reported about across the world; many of them unlettered and deeply disadvantaged, who have built powerful capacities to simply survive. Compensatory muscles? The greatest human trait is adaptability. We find a way to

get what we need, to bend toward the sunlight.

What's coming next, or should be, is a validation of this basic human verity. There should be federal support for a new set of yardsticks to measure many forms of intelligence and capacity, rather than the gold-plated, one-size-fits-all yardsticks that now mostly reward the already advantaged or the traditional, generalized learner. Once these yardsticks are developed, educators and employers can more easily embrace the wide varieties of inclination and ability that is the underlying truth of human diversity. This incentive – enlightened self-interest – will drive change . . . change that, in the case of ASD folks, can be buoyed by the social supports and new generation of technologies to help them manage in the world. The bottom line: we cannot survive with so much human capacity, ability and passion being discarded. Unleashing the potential of vast "left behind" communities, including those with ASD other forms of neurological distinctiveness, is our only path forward.

And, with each passing day, the journey of my son – and countless folks like him – will get a touch easier, as people begin seeing him the way he increasingly sees himself: as not less, but different.

In the past few years, in his college program on Cape Cod, he's run Disney Club, where students of shared affinity gather each week to mediate over their favorites. Because they use this affinity as their form of communication, their expressive abilities are heightened, just as their identities are affirmed. A favorite, they all agree is Dumbo. Any one of these kids – all of whom have lived in life's discard pile – can explain why. The elephant was an outcast, because of his conspicuous difference – those giant ears – but he learned eventually that what made him different helped him soar. At a recent meeting, the members said they'd all learned that in their own lives – and discussed their "hidden ears." This trenchant insight puts them ahead of most of us, and society at large.

They're just waiting for the rest of us to catch up.

I thank the committee for its time and attention and would be glad to answer any questions.