

TV Intro: In the last 30 years, the childhood vaccine schedule has tripled while the US autism rate has skyrocketed from one in 10,000 to one in 50. Dozens of published research papers show that yes, vaccines and autism are linked. Yet, the debate rages on in part ...

Richard: Good evening. Welcome to another edition of Out in Left Field, a Green Monster Production for [00:00:28] Biddeford Public Access Television. I'm Richard Rhames, your sometimes host. Matt Hite, your other sometimes host is here and tonight - oh, and Dennis Hugh is behind the camera. We must acknowledge the person who is responsible for your being able to see us and hear us, so blame him.

Anyway, we're delighted this evening to be joined by Buckley Hugo, who is an advocate for special needs children. He came to our attention through a letter to the editor back in early January. Basically, a letter talking about the false economy of short changing kids with special needs and pointing to the rather tragic case of Adam Lanza down in Connecticut. Newtown may be a lovely town but it looks like maybe they skimmed a little bit on services for special needs kids and every once in awhile, that can lead to problems.

Buckley, welcome.

Buckley: Thank you, Richard.

Richard: Thanks for being here. First off, how long have you been doing what you do? What is it that you do?

Buckley: What is it that I do? Well, first and foremost, I am a parent of an 18 year old with autism. When I first embarked on this parenthood [00:02:00] journey with him, when I first started navigating the special ed maze, as a parent they hand you this thick packet called Notice of Procedural Safeguards, which is all the legalities you as a parent need to know about your child in special education.

Well, I was one of those freaky parents that actually took the time to read it and realized, wow, there's a lot of protections in here for children and for parents. I wonder how many parents know about this and how to effectively use these regulations? That's how my journey started, just as an advocate for my own son. I started my own business professionally, going on seven years now here in Maine. Helping other families advocate for their kids with special needs when they encounter problems in the public schools.

Richard: Pretty common, is it, that parents are out of their depth when it comes to navigating the best for their kids?

Buckley: Well, the Maine special education regulations are over 200 pages long. Yes, there are a lot of good protections, but there is a lot of complexity that goes with it.

Richard: Was your son, I guess you'd say on the spectrum, he had a problem when he entered school or did this become apparent later?

Buckley: He was pretty much, I would say, had autistic spectrum symptoms since he was born. We figured it out when he was in late preschool and by the time he was in kindergarten he was receiving interventions. That's what I mean, it's been a journey. I started with him when he was five and now he's 18.

Matt: What does that mean, receiving intervention?

Buckley: Well, in Maine, kids with disabilities usually start with the Child Development System, or CDS as it's known. Either parents or even [00:04:00] physicians can make a referral to CDS to receive reports and services which when they're really young, birth to toddler, it can mean developmental therapy in the home, and if they need it, physical therapy, occupational therapy, speech therapy. Then as children get older, they will either go to a CDS preschool then eventually enter public school in their kindergarten program.

Matt: Okay.

Richard: The effort generally, I think, is to ... The tendency is to mainstream kids.

Buckley: It's a federal mandate, actually.

Richard: That you should mainstream them?

Buckley: Right. For our viewers -

Richard: They can't just be thrown into the deep end of the pool without these services that you talk about, is that correct?

Buckley: That's correct. Under the federal IDEA, the Individuals With Disabilities and Education Act, the parents play a pivotal role in influencing how their children are educated. The schools are required to have parental input about the services kids will receive and it's only with parental influence, and in most cases, agreement amongst a team of professionals including the parents, that services can be provided.

Children with disabilities can't just be thrown into a regular class with no supports. They need to be receiving the services they need to get an appropriate education.

Richard: The issue that you raise in your letter to the editor and the issue that really came to the forefront in Newtown, Connecticut, a fairly well to do community, I think.

Buckley: Yes, indeed.

Richard: Is that this stuff costs money and there seems to be often this kind of structural problem in spending the money [00:06:00] to provide the services that these children need.

Buckley: Absolutely.

Richard: Talk about what led you to write this thing and I realized today, rereading it, that it actually had a lot to do with something that came to light down in Connecticut in early December.

Buckley: Yes, it did. In December, or I think late November, the Connecticut Office of the Child Advocate released a report studying the situation, the educational situation, with Adam Lanza and two very well established civil rights attorneys in Connecticut wrote an OpEd [00:06:48], which first appeared in the Connecticut Mirror, and I'm going to briefly read through it. This is an OpEd by attorneys Andrew Feinstein and Jennifer Laviano.

Richard: Before you get into it, you mentioned just in passing this Office of the Child Advocate. That's quite a work to get the Office of the Child Advocate established in the state. Maine doesn't have any such thing, right?

Buckley: No. The closest thing we have are the federally funded Disability Rights Center in Augusta. That has a narrow focus on individuals with disabilities whereas this appears to be more broad and focused on all children.

Richard: The Office of the Child Advocate - this is the entity that managed to get this information about Adam Lanza's background?

Buckley: Right.

Richard: Got that dragged out into the light.

Buckley: Yeah, they were the ones that did that. The article says, "What is the cost to society for failing our children? Is making our children go through metal detectors and lock down drills the only way to protect them? No, it is not. We

have a system in place [00:08:00] designed to support our children to contribute to learn, graduate, make friends, hold jobs, and fulfill the American dream. The law requires public schools to seek out, evaluate, identify, and provide services to children with disabilities, including children with serious emotional disturbances.

Under the Individuals with Disabilities and Education Act, public schools are the front line and it makes sense. Schools see virtually all children on a day in and day out basis. Their obligation is not just academics but education, including social, functional, and adaptive skills to allow students to become contributing members of society.

We saw that the Newtown Public Schools, in violation of state and federal law, refused to evaluate, refused to identify, and refused to provide services to Adam Lanza. We saw Newtown ignore evidence that he was a troubled, violent youth who required intensive therapeutic support. Instead, Newtown pushed him through the system as quickly as possible. Adam Lanza's needs went untreated. While we can never know whether appropriate intervention would have stopped the tragic events of December 2012, some treatment has to be better than none."

There's more, but that's the meat of it.

Richard: Yeah. They talk about how he was, they actually, when things began to get really bad, they basically threw him out of school and were doing some kind of home education, which was very sporadic. Can you talk about that?

Buckley: Yeah, one of the misreportings in the media was that he was, "home schooled," which implies that the parents decided to have him educated at home. Well, that wasn't what happened. What happened is the school district decided that they couldn't effectively educate Mr. Lanza in a public school, so they had him do home bound [00:10:00] study, which isolated him at home and had tutoring done there.

Instead of identifying his needs and trying to have him, I'd say, rehabilitated and integrated into the school environment with his peers, he became more isolated and more emotionally unstable.

Richard: Based on this piece in the Mirror, it sounds as though even that home bound thing was pretty episodic.

Buckley: Right, it was not consistent and he was not a very willing participant, it seems like. There was an evaluation done up at Yale, which I believe gave recommendations for what needed to happen for his treatment. I don't know

exactly the contents of that. The gist of it is that Newtown didn't accept those recommendations and he wasn't receiving services and this is obviously a young man who was very disturbed and his needs flew under the radar and ultimately became tragic.

Richard: Yeah, but the point is that, the situation built and the point that's made in the Mirror piece and the point that you make in your OpED [00:11:22] is that this has a financial price tag. Even a wealthy town like Newtown, there seems to be this dynamic that we just don't want to spend money on public education and this special ed stuff is probably the most expensive component in public education.

Buckley: Yeah, absolutely.

Richard: Why is that?

Buckley: Well, because in order to do it effectively, you have to have a very low teacher to student ratio. For the kids who are most profoundly disabled, there's a lot of one on one time that [00:12:00] needs to go into it. When you have children who are having trouble just talking, that they're having problems with their pronunciation, you have to have a therapist working with them one on one and showing them sometimes how to make the correct movements of their mouth to produce sounds, as one example.

With some children, it's behavioral interventions because they get emotionally upset very easily and in order for them to understand how their emotional stages effect other people, you have to specifically teach it to them. It's not something they can just pick up.

Richard: Right. Well, one of the things that seems to be happening is that there are more and more, at the same time when the political class and maybe if the press is right in the polo page, understood Maine voters, there's this kind of hatred of public institutions and an effort to shrink government 'til you can drown it in the bathtub and public education is part of that. You've got this continual battle with funding public education, at the same time it looks as though the problems that the schools are being faced with are increasing.

You brought this little chart here, tonight. It appears to be fairly well documented that autism, for instance, these cases are increasing in number. Can you talk a little bit about this chart?

## Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000-2008  
Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5 – 9.9)	1 in 150
2002	1994	14	6.6 (3.3 – 10.6)	1 in 150
2004	1996	8	8.0 (4.6 – 9.8)	1 in 125
2006	1998	11	9.0 (4.2 – 12.1)	1 in 110
2008	2000	14	11.3 (4.8 – 21.2)	1 in 88
2010	2002	11	14.7 (5.7 – 21.9)	1 in 68

Buckley: Well, yeah, I can talk about the chart. As you can see, we have a birth year for children that were born in 1992. The prevalence rate was one [00:14:00] in 150. For children that were born 10 years later in 2002, it's now one and 68.

Richard: That's male and female combined.

Buckley: Right, the vast majority of which are male.

Richard: Yeah.

Buckley: Probably 80 to 90%.

Matt: It's more than doubled.

Buckley: Yes, the diagnosis rate has more than doubled.

Richard: We're at a point now where if it's one in 68 for both genders, you're talking at least maybe one in 30 or 35 boys.

Buckley: At least, that's probably one in 50.

Richard: Yeah. Okay, so at the same time we've got this structural decrease in funding, not just in Newtown.

Buckley: Not just in Newtown.

Richard: It's right here in River City and you've got this, autism advocates talk about this as a crisis that seems to be largely unacknowledged. Diminished resources and increasing need. Enter Buckley Hugo and others, IEP MAN, you've got it on your plate. What's IEP?

Buckley: It stands for individualized education program, and it's what every student with a disability receives, or is supposed to receive, in a public school.

Richard: You say it's hard for parents to navigate this labyrinth all on their own, so that's where you come in.

Buckley: That's correct. Yeah. Often I will get phone calls from parents just saying that their child is struggling in the public schools, what can you do to help me?

It usually just starts with reviewing the paperwork that they have on their child. Sometimes the problem is very obvious. One of my real [00:16:00] things I'm campaigning for, and just something I stumbled into, is kids who have reading disabilities, kids who have dyslexia. This is a disability that can be completely remediated, it's just that schools either don't want to fund the training for their teachers to learn how to do it, and the other issue that goes with that is that our schools are not up on it. Schools that are training teachers are not up on the latest research in how to remediate this problem.

Teachers aren't equipped with the tools that they need to be able to remediate dyslexia. I often will get a child's file and all I have to do is read two or three pieces of paper to realize immediately, well this child has a reading disability and he or she is not receiving the services they need.

That's what makes my blood boil most because with disabilities such as autism, chances are it's lifelong and there's a multitude of issues that kids usually have. Sensory issues, they have emotional issues, and usually are learning disabled. With kids who just strictly have a reading disability, they usually are stellar kids in all respects. They play sports, they're involved with community services and

they're smart, so they learn how to compensate. They learn how to find context cues in what they're reading to figure out words.

They haven't really learned how to read because they're mixing up letters and things. The good news is that there are teaching methodologies out there that work to remediate these kids but they're expensive and schools don't want to spend the money. I don't mean that globally, of course there are some school districts that will, but I've been to probably more due process hearings over reading programs than I have anything else.

Richard: Really?

Buckley: Yeah.

Richard: This whole thing with [00:18:00] dyslexia, you talk about mixing it up, just for folks who don't know, what's dyslexia?

Buckley: Dyslexia is a reading disability and what in essence it is if you're trying to read the word cat, instead of seeing C-A-T, you might see C-T-A. Trying to read the words linear-ally is difficult for you. Reading is not something that comes to everyone naturally. Some people require more intensive instruction to get over those hurdles. It can be done. I've seen many success stories with kids once they do get the proper interventions.

Richard: Those are expensive and that's more one on one.

Buckley: That's right. That's correct. Yeah.

Richard: My brother, who was probably smarter than me, but he struggled in school. Back then there was no word for his problem. He didn't read well.

Buckley: Right.

Richard: He had dyslexia.

Buckley: Yeah. If you go online and look on Wikipedia, you can find a list of famous people that have dyslexia and I read an article recently saying how it can have its advantages because people with dyslexia have to learn to think outside the box. They don't know how to read properly so they have to come up with ways to teach themselves how to compensate for the fact that they're having trouble reading.

Richard: Okay, so that's an easy case.



Buckley: That's an easy case.

Richard: You talk about this business with autism and the thing we held up, autism spectrum disorder.

Buckley: Right.

Richard: Describe the whole autism thing and what's the spectrum?

Buckley: The autism spectrum, [00:20:00] what it means is that there are kids who are considered either high functioning, low functioning, or I suppose mid functioning. Usually you hear it in terms of low or high. The low functioning children, most of them are non verbal. Because of that, they have problems communicating. They have to usually have some kind of assistive technology device that helps them communicate. They might need to say they need to go to the bathroom, but they can't communicate so they'll use an electronic device and find the right picture and push it so they can show their caregiver what it is they need to do.

On the high functioning side of it, there are children who are verbal. Children or adults that were diagnosed as having Asberger's syndrome, where mostly their problems are social communication and social cues. They will find that even though they can be very bright, that they have trouble navigating society and may say things or not understand what people are saying to them because so much of our side of language is idiomatic.

Richard: What does that mean?

Buckley: Gosh I'm trying to think of a good idiom off the top of my head. Sarcasm is probably the best one. It's like if you showed up here -

Richard: Good going.

Buckley: Yeah. If Richard was late today, I would say, "Boy, you're always really on time aren't you?" Someone on the spectrum might say, "Why are you saying I was on time? I was actually five minutes late?" They don't understand. Teasing is another thing where it's hard for them to understand.

Richard: If somebody says, "Go jump [00:22:00] in a lake," there's a tendency to take that as literal.

Buckley: Right.

Richard: Not as a, "I disagree with you." "Why do you want me to jump in the lake?"

Buckley: Yeah. My son and I, there have been countless examples of being a parent of a teenager. It can be amusing enough being a parent of a typical teenager when it comes to arguments, but when you get in arguments with a teenager who's on the spectrum and doesn't understand sarcasm, it can get very interesting.

Richard: All right, so you talk about, and you said earlier, this is for life. The kids that are "low functioning," autism advocates for years have been talking about the looming cost of autism to society because it's unlikely that most of these so called low functioning kids on the spectrum are going to recover well enough to function normally.

Buckley: Right, they are most likely going to need caregivers for their entire lives.

Richard: Right.

Buckley: That's going to be expensive. Whether or not it's the state funding it or the parents. There was a story recently that came out because there are numerous adults now, young adults, that need services that were not getting them. To give you a little bit more background in that. The school systems in general are responsible for educating children/young adults until they age out, which in Maine is when they hit 21. Through age 20 or when they hit 21.

Especially for kids who are severely disabled, they're not going to be able to graduate with a regular diploma. They'll graduate with what's called a certificate of [00:24:00] completion, meaning that you've been in school as long as you possibly can. At that point, they are no longer receiving services under a child's eligibility. They have to receive services from the state under adult eligibility.

There's been a waiting list for years for some of those children. There was recently a lawsuit that was settled with the state where they've agreed that a lot of young adults who have been on these waiting lists must come off and must get services.

Matt: That's going to cost money.

Buckley: That's going to cost money. It wasn't a lot in terms of total budget, it was a few million, but it will cost the state some money to give these young adults what they need.

Richard: I would think it would cost quite a lot.

Buckley: In the long term, yes.

Richard: Reading what autism parents are writing, their fear is when they age out and either they die or they're incapable of taking care of their autistic children, what's going to happen to my kid then?

Buckley: Yeah. For severely disabled young adults who become middle aged adults that are living with their parents who are aging, becoming elderly, it is a real issue. They really need before it's too late, to be transitioned into some kind of assisted living because their parents aren't going to be able to take care of them.

The Disability Rights Center I was talking about earlier in Augusta led a similar lawsuit against the state where some young disabled men were being forced to live in a nursing home because that's all the state would [00:26:00] provide. That fortunately got overturned. The men are going to be living in some other kind of assisted living, but not in a nursing home. Definitely, funding is a huge part of it not only at the state level but what the feds will reimburse in terms of Medicare and Medicaid. In our case Maine Care. There's a lot of fighting going on between the current commissioner and at the federal level about what Maine should be required to do to earn its federal dollars.

Matt: It sure seems like with this administration, and not only this administration though. You have this playing off of one interest against the other. They're talking about, "We want to throw off young adults because we need this money for the elderly.", producing this generational conflict.

Richard: The truly needy.

Matt: Right, and then it just seems like okay, we have laws that require this, and those laws require these services but those laws could be changed. It seems like increasingly, as we've discussed, as the resources seem to be shrinking and these people with political power are brazenly pitting people against each other, it seems like it's got to be a bad outcome.

Buckley: Yeah, the outcome is that the people who are in need get lost in the shuffle. It brings to mind the move of the DHHS office in Portland.

Matt: Yeah - "Get over it."

Buckley: Yeah, just get over it. I'm in that part of town enough to know that it does make a difference. You've got the Preble Street shelter right up the street from DHHS on [00:28:00] Marginal Way and to think that those people can just hop on a bus and go to South Portland, it's just going to be impactful. It's going to make it more difficult for those people.

Richard: Right, and it's going to, if they are getting on a bus, it's going to cost them money, it's going to cost them time. Again, to save the public sector some money over 30 years, this number that he uses, and sort of [00:28:35] mentions that oh yeah, that's projected over 30 years we're going to save that. I wonder if anyone's projecting what the bus fare is going to cost over 30 years for all of the people that are going to have to go.

Buckley: Exactly. I think what's the elephant in the room that's not being said about that is a hope that some people will just give up and not apply for benefits because it's just too much trouble.

Matt: Right.

Richard: That's where you come in in the education sphere, because I think that all too often, this is exactly what happens. In the case of Adam Lanza, at some point there wasn't enough push back and so Adam fell to the mercies of the Newtown school district. Anyway, you brought along a little diagrammatic chart here. Can you talk just a little bit about that? Get a close up of it.

State - Aggregate

Special Education - Total Expenditures Used for Special Education (As of Date:12/01/2013)  
All Years

\*\* Indicates suppressed value

- Indicates no data

Organization Name	School Year	Total Expenditures	Total Expenditures for Special Education	Percentage of Total Expenditures used for Special Education
State	2012-13	\$2,082,890,601	\$315,508,927	15.2
State	2011-12	\$2,069,569,507	\$305,683,860	14.8
State	2010-11	\$2,058,178,702	\$290,519,237	14.1
State	2009-10	\$2,074,728,957	\$304,597,844	14.7
State	2008-09	\$2,085,858,086	\$304,548,098	14.6
State	2007-08	\$2,048,228,915	\$300,179,906	14.7
State	2006-07	\$1,958,474,858	\$273,009,115	13.9
State	2005-06	\$1,871,286,705	\$255,468,225	13.6
State	2004-05	\$1,781,822,683	\$240,437,243	13.5
State	2003-04	\$1,714,773,383	\$230,414,128	13.4

Buckley: First of all, this was printed, this is a report that was generated from the, if you can see down here the sources, the state Maine Department of Education and it

lists all the expenditures for education over the last 10 years, and also the amount of that which constitutes special education. In the total expenditures column, starting at the bottom, it was 1.7 billion. That's with a B, for 2003 - 2004 [00:30:00]. We go up to 10 years later, it's just a little over two billion.

Of that, in this column, is for special education so in the 2012 - 13 school year, we have two billion in education expenses. That's state, local, and federal match. Of that, 315 million is for special education. Over here you can see what percentage that is. Back in 2003 - 2004 the percentage was 13.4 and it's gone up to 15.2, which I really don't think is that dramatic considering the need and sometimes how it's portrayed.

I imagine if some of the viewers weren't aware, I wasn't aware that the state spent in the billions of dollars on education and that of that special education is 300 million dollars.

Richard: Well it's not just the state, it's combined. So, you've got local monies and you've got federal monies that are also part of this. The Title I which is shrinking. The state is supposedly picking up 55% but everybody knows that they haven't and that there's a quixotic funding formula so that there are towns like Cape Elizabeth that actually received little or no state subsidy. There are towns like Sanford which actually receive more state subsidy than Biddeford as one of my formal city counsel mates used to point out. Except for the amount of shoreline, there's not a lot that separates Biddeford and Sanford. Go figure.

It's a real minefield, trying to make sense of this and we probably [00:32:00] won't make sense of it in the context of this show which brings me to say, you are, regardless of what you intended to do, you are watching Out in Left Field, a Green Monster production for Bitterford Public Access Television. I'm Richard Rhames, Matt Hite, Dennis Hugh, hiding behind the camera. We're delighted this evening to be joined by Buckley Hugo who is the chief cook and bottle washer at Mid Coast Advocacy. Advocates?

Buckley: Advocacy.

Richard: Advocacy. Which basically is a shop that helps parents intercede for their kids and to get an education as mandated in state law.

Buckley: State and federal.

Richard: State and federal. Which doesn't always happen.

Buckley: No, it doesn't always happen. Well, and it's very wishy washy, to speak a little bit more about the education part of this. Under state and federal law, all children,

including kids without disabilities, are entitled to a free appropriate public education, or the acronym for which we call FAPE. What is deemed appropriate has been the subject of a lot of debate and has been tried in the courts a significant amount of times.

That's where things get testy because the parents, if they want a particular service for their child, the schools might come back and say, "That's going above and beyond. You just want what's best for you child. We don't have to give you what's best. We have to give you what's appropriate." Going back to a court decision way back in the 1980s, the first Supreme Court decision on special education.

It was about a deaf kindergartner named Amy Rowley, and it was determined that by the Supreme Court that schools did not need to [00:34:00] provide the best of all circumstances for children. That they just needed to provide an appropriate education and make meaningful progress. They didn't have to be optimal. That's a lot of what I do as an advocate and what attorneys in that field do is we work with parents and school districts and school district attorneys to come up with a program that everyone can live with and that we can agree is appropriate and not best.

Matt: Yeah. Are you an attorney?

Buckley: No, I'm not. I'm a lay advocate.

Richard: You are in an organization, I just discovered today, there is this consortium, this organization of folks who do what you do, some of whom are attorneys.

Buckley: Yeah, it's the Council of Parents, Attorneys, and Advocates, or COPAA, located in Townsend, Maryland. They're the national organization of special education advocates and attorneys. Really, I use the term special education but the broader issue is civil rights. We all work on the broader issue of civil rights for children with disabilities and our specialty of this special education.

Richard: Isn't that the hook that the two attorneys who wrote this Connecticut piece? They're talking about this as a civil rights, a human rights matter really.

Buckley: Right.

Richard: This gets mentioned periodically, but you talk about this level of funding, and there was federal intervention decades ago. There was a commitment made when the laws were changed to take kids out of the snake pit, where there used to be just warehoused, and to mainstream them and the federal government did make a commitment to fund 40%?

Buckley: I think yeah, I think that's it. It's below 20.

Richard: I don't think it's ever gotten much beyond 20 and sometimes it's been 15 or 16.

Buckley: Right. I was [00:36:00] privy to some correspondence between Paul Page and the former commissioner of education.

Richard: He was just in the paper today. He's gone to work for Jim Bush in his privatization crew there.

Buckley: There's correspondence going back and forth between him and also the attorney general at the time about the IDEA being an unfunded mandate. To a certain extent I can see his point because the federal government says, here is the IDEA and for this amount of money, you have to implement everything that it says. Well, the feds are giving them money but not nearly enough to effectively do what the regulations say, that the law says it's supposed to do.

Richard: Right. On the other hand, you don't have to go to Washington to find this because at the state level, the state is supposed to pick up 55%.

Buckley: Right.

Richard: They've never done that. Even after an initiative. They still aren't doing it.

Buckley: Yeah. I can walk both sides of the fence on that one because I would figure that either way it's eventually going to come out of our pocket because either our state taxes are going to go up to pay for it or our local property taxes are going to go up to pay for it. How it all balances out I don't know. I imagine that somehow if our governor is behind it, somehow the businesses are going to end up better off than the average tax payer.

Richard: Well, and that's the rub isn't it? Famously, the locals have to raise [00:38:00] money almost totally through property tax assessments whereas the state has many other much more progressive means of raising revenue, not the least of which being the state income tax, which is progressive.

It's job one to do away with. The most potentially progressive taxation mechanism he wants to do away with, which again points towards more aggressive taxation, more working class folks paying more of the cost of civilization and the people getting the best deal out of society paying less.

Buckley: Right.

Matt: That seems to be the main goal of his administration.

Buckley: One topic I'd like to turn to and so we're not focusing too much on bashing the current governor, is on charter schools. I got involved in a bit of a debate on that at the local level because school superintendents particularly, some have been outspoken about money being taken away from their local districts and being given to charter schools.

Richard: Mike Dunn in New Portland was one of the leading examples of that.

Buckley: Yeah. The point that I've been trying to make in my town of Brunswick is a few years ago I was at a mediation for a student who needed to go into one of these expensive day treatment centers to receive all the resources he needed. I worked up a spreadsheet, which everyone agreed was pretty accurate and for this one student, it was going to [00:40:00] cost over a hundred thousand dollars.

Matt: Per year?

Buckley: Per year. 12 month program but still over a hundred thousand dollars. Admittedly some of that would be picked up by the feds, Maine Care and that kind of thing. The point I was trying to make, as I had worked with the student in our town where the family was so distraught about their daughter not doing well in the public school, that they and the school district were considering sending the student to one of these expensive day treatment centers.

What ended up happening is the parents decided to give our local charter school, the Harpswell Coastal Academy, a try and the student has flourished there. Instead of having to pay a hundred thousand dollars for the student to be educated in an environment that probably wasn't really right for her, she's been able to go to a charter school which has fit her needs at a fraction, probably 10% of the cost. There are many similar students in the same situation that are going to that school right now and being successful.

Matt: What is the nature of that charter school? Are they chartered especially to deal with special needs kids?

Buckley: No, they are for experiential learning for special need kids who are higher functioning on the spectrum, they really need to get out of the classroom. Having them trying to sit still in an environment when they're expected to just pay attention and absorb and stuff, that just doesn't work for a lot of kids. The school has really filled that void and I think saved our town a gob of money by being able to serve the needs of this particular population.

Richard: It's not necessarily about the funding [00:42:00] mechanism of charter schools or the main charter school, but it's about the method used for teaching.



Buckley: Right.

Richard: It's possible to set up these experiential type school environments. I think Portland has one.

Buckley: Right.

Richard: One of our guests a few years ago, who's a USM education professor, Lynn Ross, she talked about where she grew up in Rochester and it was a big enough town so that they had many different schools within the same system. There were magnet schools that could offer different methodologies. Of course that was back when Rochester probably had an industrial base and when there was actually money around to do stuff like that.

Matt: Before consolidation had gotten as far as it's gotten now.

Buckley: Consolidation certainly hasn't been a pretty process. RSU 23, over across the river there didn't work out so well.

Richard: No. The whole matter of local control is certainly an issue and this idea that somehow you have to do this important heavy lifting for the next generation on the cheap, it's difficult under these kind of circumstances. We talked earlier in the show and I guess it's been kind of a recurring theme about increased needs and less and less money. We've done a couple, three shows over the 10 years we've been doing this about autism. It looks as though we've seen that [00:44:00] there has apparently been this increase. I think you've got another graphic. There are a number of theories about how come the autistic population seems to be increasing. There is a theory that there seems to be this coincidence of increased vaccination regimens and a spike in autism.

Buckley: Yeah. It's a very hot topic and I think we can mention some legislation to be introduced by representative Farnsworth?

Richard: Yeah. First you have this chart that shows, because it was not always thus. You didn't used to get the number of injections that kids are routinely given today.

**TABLE 2. Recommended schedule for active immunization of normal infants and children\***

Recommended age <sup>†</sup>	Vaccine(s) <sup>‡</sup>	Comments
2 mos	DTP#1 <sup>§</sup> , OPV#1 <sup>**</sup>	OPV and DTP can be given earlier in areas of high endemicity
4 mos	DTP#2, OPV#2	6-wk to 2-mo interval desired between OPV doses
6 mos	DTP#3	An additional dose of OPV at this time is optional in areas with a high risk of poliovirus exposure
15 mos <sup>††</sup>	MMR <sup>‡‡</sup> , DTP#4, OPV#3	Completion of primary series of DTP and OPV
18 mos	HbCV <sup>§§</sup>	Conjugate preferred over polysaccharide vaccine <sup>***</sup>
4–6 yrs	DTP#5 <sup>†††</sup> , OPV#4	At or before school entry
14–16 yrs	Td <sup>¶¶</sup>	Repeat every 10 yrs throughout life

\*See Table 3 for the recommended immunization schedules for infants and children up to their seventh birthday not immunized at the recommended times.

<sup>†</sup>These recommended ages should not be construed as absolute, e.g., 2 months can be 6–10 weeks. However, MMR should not be given to children <12 months of age. If exposure to measles disease is considered likely, then children 6 through 11 months old may be immunized with single-antigen measles vaccine. These children should be reimmunized with MMR when they are approximately 15 months of age.

<sup>‡</sup>For all products used, consult the manufacturers' package enclosures for instructions regarding storage, handling, dosage, and administration. Immunobiologics prepared by different manufacturers can vary, and those of the same manufacturer can change from time to time. The package inserts are useful references for specific products, but they may not always be consistent with current ACIP and American Academy of Pediatrics immunization schedules.

<sup>§</sup>DTP=Diphtheria and Tetanus Toxoids and Pertussis Vaccine, Adsorbed. DTP may be used up to the seventh birthday. The first dose can be given at 6 weeks of age and the second and third doses given 4–8 weeks after the preceding dose.

<sup>\*\*</sup>OPV=Poliovirus Vaccine Live Oral, Trivalent; contains poliovirus types 1, 2, and 3.

<sup>††</sup>Provided at least 6 months have elapsed since DTP#3 or, if fewer than 3 doses of DTP have been received, at least 6 weeks since the last previous dose of DTP or OPV. MMR vaccine should not be delayed to allow simultaneous administration with DTP and OPV. Administering MMR at 15 months and DTP#4 and OPV#3 at 18 months continues to be an acceptable alternative.

<sup>‡‡</sup>MMR=Measles, Mumps, and Rubella Virus Vaccine, Live. Counties that report ≥5 cases of measles among preschool children during each of the last 5 years should implement a routine 2-dose measles vaccination schedule for preschoolers. The first dose should be administered at 9 months or the first health-care contact thereafter. Infants vaccinated before their first birthday should receive a second dose at about 15 months of age. Single-antigen measles vaccine should be used for children aged <1 year and MMR for children vaccinated on or after their first birthday. If resources do not allow a routine 2-dose schedule, an acceptable alternative is to lower the routine age for MMR vaccination to 12 months.

<sup>§§</sup>HbCV=Vaccine composed of Haemophilus influenzae b polysaccharide antigen conjugated to a protein carrier. Children <5 years of age previously vaccinated with polysaccharide vaccine between the ages of 18 and 23 months should be revaccinated with a single dose of conjugate vaccine if at least 2 months have elapsed since the receipt of the polysaccharide vaccine.

<sup>\*\*\*</sup>If HbCV is not available, an acceptable alternative is to give Haemophilus influenzae b polysaccharide vaccine (HbPV) at age ≥24 months. Children at high risk for Haemophilus influenzae type b disease where conjugate vaccine is not available may be vaccinated with HbPV at 18 months of age and revaccinated at 24 months.

<sup>†††</sup>Up to the seventh birthday.

1989 childhood immunization schedule

Buckley: Yes, this is a chart. This is the 1983 vaccinations schedule. As you can see, there are not too many listed here. These are the ages in which they're received and this is what the children received. Some people might know that the MMR shot, measles, mumps, rubella, has received a lot of bad press but even in 1983 there it was. Children were receiving it even 30 years ago.

As you can see, compared to the chart of current vaccinations, the one from 1983 looks pretty sparse. It starts over here at birth. First dose they receive is hepatitis B and from there on out you can see there's just a lot of different ones. These are all the different vaccinations over here and this is the schedule on which they're supposed to have them. It starts at birth and goes up to 18 years old.

Vaccines	Birth	1 mo	2 mos	4 mos	6 mos	9 mos	12 mos	15 mos	18 mos	19-23 mos	2-3 yrs	4-6 yrs	7-10 yrs	11-12 yrs	13-15 yrs	16-18 yrs
Hepatitis B <sup>1</sup> (HepB)	1 <sup>st</sup> dose	2 <sup>nd</sup> dose			3 <sup>rd</sup> dose											
Rotavirus <sup>2</sup> (RV) RV-1 (2-dose series); RV-5 (3-dose series)			1 <sup>st</sup> dose	2 <sup>nd</sup> dose	See footnote 2											
Diphtheria, tetanus, & acellular pertussis <sup>3</sup> (DTaP; <7 yrs)			1 <sup>st</sup> dose	2 <sup>nd</sup> dose	3 <sup>rd</sup> dose			4 <sup>th</sup> dose				5 <sup>th</sup> dose				
Tetanus, diphtheria, & acellular pertussis <sup>4</sup> (Tdap; ≥7 yrs)													(Tdap)			
Haemophilus influenzae type b <sup>5</sup> (Hib)			1 <sup>st</sup> dose	2 <sup>nd</sup> dose	See footnote 5		3 <sup>rd</sup> or 4 <sup>th</sup> dose	see footnote 5								
Pneumococcal conjugate <sup>6a</sup> (PCV13)			1 <sup>st</sup> dose	2 <sup>nd</sup> dose	3 <sup>rd</sup> dose		4 <sup>th</sup> dose									
Pneumococcal polysaccharide <sup>6b</sup> (PPSV23)																
Inactivated poliovirus <sup>7</sup> (IPV) (<18 years)			1 <sup>st</sup> dose	2 <sup>nd</sup> dose	3 <sup>rd</sup> dose						4 <sup>th</sup> dose					
Influenza <sup>8</sup> (IV; LAIV) 2 doses for some: see footnote 8					Annual vaccination (IV only)					Annual vaccination (IV or LAIV)						
Measles, mumps, rubella <sup>9</sup> (MMR)							1 <sup>st</sup> dose					2 <sup>nd</sup> dose				
Varicella <sup>10</sup> (VAR)							1 <sup>st</sup> dose					2 <sup>nd</sup> dose				
Hepatitis A <sup>11</sup> (HepA)							2 dose series see footnote 11									
Human papillomavirus <sup>12</sup> (HPV2: females only; HPV4: males and females)														(3 dose series)		
Meningococcal <sup>13</sup> (Hib-MenCY ≥ 6 wks; MCV4-Dz9 mo; MCV4-CRM ≥ 2 yrs.)			see footnote 13										1 <sup>st</sup> dose			

Range of recommended ages for all children
  Range of recommended ages for catch-up immunization
  Range of recommended ages for certain high-risk groups
  Range of recommended ages during which catch-up is encouraged and for certain high-risk groups
  Not routinely recommended

Matt: It went from something like 10 -

Buckley: 10 to 30.

Matt: To 30, so tripled.

Buckley: Yeah, it tripled.

Matt: There is at least a correlation and we know that correlation is not causation. There is at least a [00:46:00] correlation I believe between the number of immunizations and ...

Buckley: When the diagnosis rates started to increase. The 1983 schedule is the same as the 1989 schedule and it was really in 1990 that the number of vaccinations really popped and went much higher. Speaking anecdotally, and I'll be the first one to say it's antidotal because I worked with a lot of families with children on the autism spectrum, and of course I just have a lot of friends in the community, and there are too many parents out there that are convinced that something changed in their child after they received a series of vaccinations and you're not going to, no legislator is going to change their mind on that.

At this point, the studies that have been done to debunk those theories have been sponsored either by pharmaceutical companies or the government. For a parent who is absolutely certain that their child was the victim of a vaccine injury, that's not going to allay their fears and has really led to, I think, this revolt against not having children vaccinated. It is becoming a problem in terms of the herd immunity, but I think rather than taking an approach that the solution is to legislate that everyone has to have their children vaccinated, it should instead to focus on why is it that parents don't want their children vaccinated, what's really going on here?

Richard: I want to get onto the Farnsworth bill and this whole business of herd immunity because this is late breaking news, literally. I think yesterday it was in the paper. There are a [00:48:00] number of questions, certainly without diving into it very deeply, a few years ago. They came pretty clear from the autism parents that they had noticed this correlation, there's been a lot of focus on this thimerisol, which used to be a fairly consistent, it was a preservative.

Buckley: It's a cheap preservative.

Richard: Right, which contains mercury. To begin dosing children, I don't have a PhD in biochemistry, but the mercury's impact on the central nervous system is fairly well understood. It's not good for you. Mad as a hatter, all that stuff. To be dosing, to be jabbing newborns, the new schedule, at birth you're getting a shot and apparently it was fairly common practice to dose pregnant women with flu vaccine which often contained thimerisol which passed through the placental barrier. So before the kid is even born, theoretically, he or she is getting a dose of mercury.

Matt: Right, and you can debate the merits of that or lack thereof, but my understanding is that thimerisol is largely been removed from these vaccinations and yet the ...

Buckley: The numbers still persist. Yeah.

Matt: Are increasing.

Buckley: Yeah.

Richard: The autism advocates that I've read, you've got to be careful about [00:50:00] the fine print. A couple of years ago, because now I'm getting ancient and I was told, you ought to have a flu shot, and it was a lot of hype in the media. Don't be old and get the flu. It's really, really bad. I went to a local pharmacy and there was a real run on flu shots, apparently. Anyway, before I got jabbed, I asked does this stuff have thimerisol in it? They didn't know. They had to go find the safety data sheet or something. After I got inoculated, I discovered that because it was single does, apparently it didn't have it. The whole thing with thimerisol and these preservative agents, they put them in these multi dose vials. Maybe it's not in the single does but it still could be in the multi dose vials. You really have to check.

Buckley: I think when it comes to causation, it probably is a combination of factors and that's why, fortunately, still a majority of children, it's not an issue. If it's your child, though, it becomes an issue and it's a big deal. I can tell you that I have my son, who is 18 and autistic, when we had my daughter who came along four years later, I can tell you we were a lot more discerning about the vaccination issue with her.

Richard: Did she get the prescribed vax or not?

Buckley: She has gotten the minimum for what she needs to go to school and she's been fine.

Richard: Okay. Was she inoculated at birth?

Buckley: I don't think she was inoculated at birth. I'll have to ask my wife to find an inoculation sheet.

Richard: [00:52:00] If you're following the law, if you're doing what the experts tell you to do, you're jabbing your kid right out of the womb.

Buckley: I can tell you that with our daughter, we pretty much with every shot determined what was mandatory and what was discretionary. Anything that was discretionary we passed up.

Richard: Did you ask about preservatives in the vaccines that she was given?

Buckley: Yeah, and it's just as you experienced. Sometimes they know, sometimes they don't know. Sometimes they have a stock response, they don't use that anymore. As I said, as a parent of a child with autism, you're a lot more sensitive to that than someone who hasn't been through it.

Richard: Okay. We only have a few minutes so let's talk about the liberal Richard Farnsworth, Portland representative? He's not a senator right, he's a representative?

Buckley: I think he's a representative.

Richard: Okay. He's been in the legislature a long time. He headed up a non profit for awhile. Now I guess he's back in the legislature. Anyway, he's proposing a bill for this session. Can you talk about that a little bit?

Buckley: Well, right now Maine law allows parents to have their children opt out of having vaccinations for religious or philosophical reasons. It's pretty much still firmly in the parents' control. I believe the premise of the bill is that in order for parents to opt out, the physician has to sign off on it.

Richard: You got to find a doc who will sign on the dotted line.

Buckley: Yeah. For one thing, certainly putting doctors in that position isn't fair to them. I also think, as I was starting to state earlier, I think the intent of [00:54:00] having more kids vaccinated is fine but the approach in my opinion to have to force them to do it without having as much say is not the way to go about it. It's dismissing parents' fears about the vaccinations as being misguided, is probably the nicest way I can put it. More research really needs to be done to allay parental concerns about this. As I said, I know too many families who have had the issues where their kids get vaccinated and they change, the kids change for the worse.

Matt: Like you said, the research needs to be objective and not overly influenced or controlled by the companies that are making money from these. From these products. You have this other issue of again, the government mandating that you buy these products from these private companies and put them in your children. It's disturbing.

Richard: With immunity from consequence. What's the vaccine court?

Buckley: The vaccine court was a -

Richard: It's not really a court is it?

Buckley: Yeah, it's not really a court. It was a hearing system, I guess is the way I would put it, set up to address the grievances of parents against the drug companies. I don't think there's been any decision that's come out of those hearings that is found any liability on behalf of the pharmaceutical companies. It's almost like

forced arbitration, is really what it is, where the underdogs, in this case being the parents, they just never come out on top.

Richard: I guess, which the Farnsworth bill doesn't really address [00:56:00] but parents who's kids have been, they believe damaged by these, there is no legal recourse for these folks because of this vaccine court, so called, that the Congress set up to shield the pharmaceutical industry from lawsuit.

Buckley: I think this is really the pharmaceutical equivalent of too big to fail. If parents are allowed to go through the regular court system and if a judge finds in favor of a parent against a pharmaceutical company in millions if not billions in damages, not to mention the message that it sends about the safety of vaccines, that's just not a societal risk that our national legislators are going to take a chance on.

Richard: Well, it would impede company profits and big pharma has a lot of political clout. You mentioned and in the Press Harold piece that I held up, Farnsworth talks about this herd immunity. There is a rationale for compelling parents to get their kids vaccinated. What's herd immunity?

Buckley: Herd immunity, in my non medical background, keep in mind.

Richard: This is H-E-R-D, not H-E-A-R-D.

Buckley: Yeah. Is that the more of us that get vaccinated, the disease effectively becomes eradicated. Similar to small pox which I think has not been around the United States for 50 years or so because we've all had our small pox vaccinations. What the medical professionals are telling us now is that we're starting to see the resurgence of childhood diseases because parents are now [00:58:00] forgoing vaccinations such as measles and mumps, the classic MMR, measles, mumps, and rubella. We're starting to see that again. As Richard and I were talking about earlier, people for years used to get those and yes, for some, having the measles can be quite problematic, but for others they just come through it.

Richard: Yeah, it's a childhood disease. Measles, mumps, all that stuff. I had them. I was telling you, I saw this cheat sheet that my mother had to fill out. She had all of those things. She lived to be almost 90 years old in a time when there wasn't a whole lot of autism around. I do digress. Anyway, we're out of time. You've been watching Out in Left Field, a Green Monster production. Our guest this evening has been Buckley Hugo who is the chief cook and bottle washer at Mid Coast Advocacy.

Buckley: Right.

Richard: I don't know, you in the book?

Buckley: I'm in the book.

Richard: He's in the book. Online.

Buckley: [MidCoastAdvocacy.com](http://MidCoastAdvocacy.com).

Richard: It really does apparently fall very heavily on parents to be advocates for their children. There are laws out there at least currently but you have to know what's in the law and what's behind the law and be able to navigate through the channels because apparently this economic back pressure is pretty significant.

Buckley: Well put.

Richard: Thank you Buckley for being on the show tonight. For Matt Hite, Dennis Hugh behind the camera. Good night. See you next week.