

“Enviably Life ~ Imagine Better”

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Good morning – it’s nice to see everyone here on a Saturday morning! The lovely introduction from Susan mentioned some of the roles I play in life, but my primary claim to fame is being the father of a soon to be 15 year old boy with autism named Elijah. This is literally true – strangers will come up to me on the street and start talking, and I’ll think “they must know me from all my work at The Arc”, or “they must want my opinion because I’m clearly a man of taste and distinction” and the first thing they say is “hey, you’re Elijah’s dad!” Yep, that’s me. I guess there are many worse things to be known for.

Elijah and his sister Sarah are the joys of our life, and Elijah in particular continues to lead Laurel and I on a long and often very strange journey. Often times all we can do is look at each other and shake our heads. I love to tell stories about Elijah, and a couple of very quick stories might help to give you a sense of our lives together. One of his current fascinations is with personal hygiene products – by the way, if anyone is ever out in the Amherst area and needs lotion, conditioner, deodorant, whatever, please stop by – we have one of the world’s definitive collections and we’re running out of storage space! One of the first phrases Elijah learned to use in a sentence was “I buy” The latest twist on this is that he’s learned to use Google very adeptly, but what he’s usually searching for is “blue Colgate mouthwash – strong anticavity protection” Another example of life with Elijah is a month or two ago we were all wrestling and tickling after dinner, which he really enjoys, and all of a sudden he stopped, looked up at the ceiling and in a weird, high pitched voice went “OOOOOOOOOOOOOOO...not good” Laurel and I started looking around for the mother ship coming in for the pick up! Obviously it’s not all roses – there are times when he cries for 2 hours in a row because some little detail wasn’t right, when he doesn’t sleep for two or three nights in a row or occasionally when he whacks or pinches one of us, but all in all we couldn’t be more pleased with life with Elijah.

In preparing for this session, I went back to a talk I gave about 8 years ago at The United Family Convention in Western MA and looked at some of the questions that we had then about Elijah and his future, questions like;

- how can we create a place for Elijah?
- how can we help him find his niche, or create supportive community around him?
- can we create or be part of a change in the service system that would give him a chance at what one presenter I heard recently calls an **“enviable life”** Isn’t that a great phrase? Not a passable life, or a minimally acceptable one, but an enviable life – one anyone would want to live.

Some things have changed since that talk 8 years ago – Elijah has gone from being non-verbal to speaking in sentences, although the experts said he would never talk. He changed from being a little skinny stick-figure boy into a 6ft 250lb young man –it’s like the joke with the gorilla - “where does a 250lb boy with autism sleep?” But as much as some things have changed, many of the questions I mentioned a minute ago about Elijah and his future remain, although some clarity seems to be emerging through the use of a lot of imagination and a little elbow grease.

The title of this opening section of the program this morning is **“Imagine Better”**, and I want to get back to this theme of the importance of imagination in both our individual lives as families and in looking at the service system in a minute, but first, before we can “imagine better” we have to take a quick look at where we are, at where we’re starting from. Let me say before I launch into this that my primary experience as both a provider and recipient of services has been in the DMR family support system, and I have only a little understanding of what those of you in the DPH or DMH or other communities might be experiencing, although I’m guessing that the landscape for you might not be too dissimilar to what I see when I look at the service system.

First, in looking at our current landscape I want to say that I feel like we're at a crossroads in the family movement in Massachusetts. I know it's fashionable to say things like that in these kinds of presentations, but in this case I really believe it's true! We're in the middle of a real and discernable lull, a time of seeming lethargy where it's become increasingly difficult to motivate people or mobilize parents – even around crucial issues which directly impact their families! Let me give you an example – as part of the budget cycle last year the legislature cut family support funding across the board by 30%, a cut that was passed along directly to families in the form of allocation cuts. That means that a family who might have gotten an allocation of \$1,000 the year before could only get \$700 in flex funds this year. Sue mentioned that I run a family support program out in the western part of the state, and we serve about 140 families a year – here's the amazing thing to me - **not one family called me to complain!** Where's the outrage? Where are the families saying "Whoa, you gotta be kidding me"! We're keeping our child with severe disabilities here at home and saving the Commonwealth hundreds of thousands of dollars a year, and now you cut my already totally inadequate respite allocation by 30%?" Luckily this cut has since been restored, but what this story reveals to me is a fundamental truth about families – that we're often so grateful for any assistance at all that it's difficult to mobilize us to ask for more or better. Don't get me wrong – there's something noble and good about gratitude and the ethic of shouldering our own burdens, but we can't let this blind us to the need for asking systemic questions about adequacy and sufficiency.

We have to somehow recover some of the drive and the passion in the family movement. Most of us in the room this morning are benefiting from the advocacy of previous generations of families – in a phrase I really like, **we're standing on the shoulders of giants** – people who fought for and passed 766, the ADA and Chapter 171 – and some of those people are in the room - I want to particularly recognize Lou and Emily Nissebaum who I think of as mentors and examples for all of us, but who's going to build on their accomplishments? Who's going to solidify their legacy? Let's face it these guys aren't getting any younger! I can't help but feel that we're not doing our part, and I want to challenge those of you who are family members this morning to get involved, step up to the plate, pull up your socks, whatever metaphor you choose, but we need your help and commitment to continue a strong and vital family movement on behalf of the people we love.

Second, in looking at our current landscape I see a chronically under funded family support system that's under an enormous amount of pressure from years of new referrals without new resources. What's even worse is that every year it seems we have to rally and fuss and write letters to the legislature to maintain the inadequate funding that we've got, and this equation has to change. Many people are getting decent supports in spite of this pressure, but the stress on the system which serves more than 13,000 families in the Commonwealth is growing every day. If you happen to be one of the few hundred families statewide with a DOE/DMR prevention grant, or one of the 80 families who will qualify for the new autism waiver resources are plentiful – if not, you're often left struggling for a couple of hundred dollars of flex funding and hopefully a case manager or advocate to talk to when things get tough. We have what I've often called a Cadillac and skateboard system – either you hit it big or you scrape along, and to keep my transportation metaphor going, we need to develop a lot more Yugos, a range of intermediate services that so many families need to be well supported.

Third, in looking at our current landscape I see a service system still struggling to give families a real voice in the design and implementation of the services which are so crucial in their lives. One of the real accomplishments of the past several years for Mass Families was the passage (with many allies) of Ch 171, also known as the Individual and Family Support bill. This legislation basically mandates that people being served by the seven named state agencies actually have some say in the shape of the services they receive. Passing this bill was a landmark achievement, but it's an open question as to how effective the implementation of this bill has been, and how much it has really served to change the culture and practice of the individual state agencies. Even within DMR, which has more of a history of including families in service planning, the pendulum seems to be swinging away from family direction and control, and back to more centrally managed services often based on the requirements of various waivers either in place or being applied for. We need to recommit to the principals of Ch 171, and recover a vision of families as experts, as the people who know what they need and when they need it, and then trust them to do the right thing.

Fourth and finally, when I look at the service system I see, inexplicably, a system which still has around 1,000 people and \$170 million dollars wrapped up in institutional settings. In looking back on my address from 8 years ago, one of the strong themes for action was the need to band together and do the advocacy necessary to facilitate the closure of these outdated and inefficient models of care, and 8 years later not much has changed. On the positive side, there is a commitment on the part of DMR and the executive branch to close at least some of the remaining sites, but the issue is now tied up in the courts which could drag the process along for years. I want to stop and say I can't imagine what it must be like for a parent or family member who was pressured and convinced to put their son or daughter in an institution in an era when that was "the thing to do", and I hear their fear as they consider a move to the community system after all these years – I don't think those of us who are also families can be hard-hearted about their experience. The fundamental truth, however, is that people belong in their communities- as long as people with disabilities are shut away and segregated as "other" they will continue to be objects of fear, or scorn or pity and those days are simply gone. We need to recommit and intensify our efforts to gently (with a compassionate eye towards these individuals and families) but firmly relegate these outdated models of care to the past where they belong.

I want to get back to the theme of imagination I mentioned a few minutes ago – one of the primary reasons we're here today is a real desire to "imagine better" for our family members and the people we love, and this tool of imagination is crucial both in creating a vision of what "better" means in our individual families, and in looking at the service system as a whole. Let's start with families – I once heard someone describe one of the key roles of families as "keepers of the vision" and I love that description – if we don't dream about successful outcomes and an enviable life for our kids, than who will? That's our job, and our imagining is crucial for our kids because the consistent message they get from our culture is that they can't do anything, that they're not worth anything and we have to be the ones to tell them over and over again **yes you can, and yes you are!** Now of course imagination needs to lead to exploration and planning and implementation if it's going to bear fruit, but the whole process begins with a vision of a life that's rich and full of possibilities. I want to go back to the Elijah story for a moment, and I use our example not to say in any way that we've arrived or got the answers – we're still very much on the journey – or to say that your vision should be anything like ours, but simply to illustrate the power of imagination.

Very soon after we started trying to answer the questions about Elijah's future that I told you about a minute ago we began to be convinced that the answers regarding an enviable life for him lay in community. In imagining a rich and full life for Elijah, we wanted him to be part of a community which cared for him (and would care for him after Laurel and I are gone), where he had a place, where his support would not primarily be based on paid staff (although that would have its place) but be a natural outgrowth of community life together. We had no idea of how to pull this together, or even where to look for examples but we had the beginnings of a vision and that's where all of us as families have to start. We spent the next 6 years talking with people, exploring options, visiting existing communities and programs and working to refine our initial vision in light of this new information we were gathering. We continued to imagine what the infrastructure would need to look like to make this vision of community a reality for Elijah, and then about a year and a half ago we had the opportunity to buy a much larger house that, while it needed a lot of work also had the space to try out some of the things we were thinking of. We had been talking for a couple of years with another family from our church about our vision for community, and it was a vision that resonated with them as well and they ended up becoming our housemates for a year along with another single friend and helping to pilot this project. This family recently moved out to buy their own place, but we had a great year together and learned an amazing amount about what it means to live in community and what it might take to do this in some sustainable way for Elijah. Many things are still really uncertain, and we have a long way to go in converting our vision into reality but we feel like we're on the way, that we're moving towards our goal of the life we imagined for Elijah. Without first imagining what an enviable life might look like, however, we would have had no idea what we were looking for or how to even get started. Everything starts with imagination!

Imagination is also crucial in looking at our system of care. It's so easy to get caught up in what is, in the way we've always done things, to be satisfied with the status quo - but my encouragement to you this morning is to have the vision and the creativity to imagine better!

Imagine a family support system with something approaching adequate funding, where new families mean new resources, where legislators and other state leaders realize the importance of these supports and where we don't have to fight every year to hold on to the little we've got.

Imagine a truly individualized and responsive service system that doesn't try to squeeze everyone into cookie cutter models, but which encourages choice and creativity, listens to people's hopes and dreams and imaginings and then giving people a place at the table as resources are allocated and their services are designed.

Imagine a family support system where families have true portability with both their core and flex resources to work with the organization that best meets their needs

Imagine an employment system for people with disabilities that focuses on real work and creating valued roles for people in their communities rather than wasting their days in segregated settings.

Imagine a family support system with a range of graduated and intermediate levels of support truly designed to offer families the support they need to keep their kids at home, rather than our current Cadillac and skateboard system.

Imagine a world in which all people with disabilities live and work in their home communities as valued and contributing members, where everyone has a place and a role, where there are no more institutions that shut people with disabilities away, either for their protection or for ours.

These things I've proposed this morning seem ambitious, to say the least! But they and many other goals can be accomplished if we have the courage and tenacity to imagine better, and then put our visions into practice. Every major accomplishment we can think of flowed from an individual or a small group of people with imagination and a dream, and I guarantee you that there were a crowd of people around each of these visionaries saying things like "you're wasting your time", or "this will never work", or "it's not practical". Our family members, the people that we love deserve a chance at an enviable life – lets commit this morning to work together to imagine better, and then do the hard work of planning and advocacy needed to make these visions a reality. Thank you.