

Belonging Matters' Podcast

Transcript

Series 2 Episode 3: Big Dreams, High Hopes, Great Expectations

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Welcome to Belonging Matters Podcast, Series Two, Employment. Also available on Apple podcasts, Google podcasts, Spotify, and www.belongingmatters.org. You can email Belonging Matters on info@belongingmatters.org, and please, subscribe and share. Series Two, Episode Three, "Big dreams, high hopes, great expectations." Kathy Snow is a wife and mother as well as an author, public speaker, trainer, consultant, and host of the website, "Disability is Natural". Her son Benjamin was born in 1987 in Texas, and diagnosed with

Cerebral Palsy. She took Benjamin to therapy, welcomed therapists and early intervention people and would have won, hands down, the therapy 'Mom of the Year award', but within a year, she began to question the conventional wisdom of disability world. In this podcast, Kathy shares many of Benjamin's achievements attained on his journey from childhood and teenage years, through to adulthood, including community participation, literary accomplishments, and award winning short film and a master's degree. The podcast was published as an article by Belonging Matters in their periodical, issue 15, 'Thinking About Life After School'.

If we as parents don't believe in our children, who will? It's critically important that parents have the same dreams for their child with a disability that they have for the other children and family; the same dreams they had before the child was diagnosed. None of us can know what's possible for any of our children. But if we don't dream for our children, they cannot learn to dream for themselves. When Emily and Benjamin were very young, we routinely said things like, "One day when you kids grow up and go to university, get a job, marry...", and so on. In turn, our children talk the same way, "Mommy, when I grow up and..." [fill in the blank]. At age 11, Benjamin said he wanted to be an actor, the first James Bond who used a power wheelchair, he wanted his chair to be like Bonds' car, with weapons attached. And he wanted to, quote, "Kiss the sexy

babes", unquote. I asked if he knew anything about acting. "No.", he said, "I'll just do it". I told him that people who become actors need to know something about acting, so would he like to take drama lessons, he said, "Yes." We enrolled him in drama classes for the next three years, and he was a star. Many people think we should be, quote, unquote, "realistic" with children who have disabilities. Why? We're not realistic with children who do not have disabilities. If a child without a disability says he wants to be a doctor or an astronaut, or something similar, we don't tell him that he doesn't have the intellectual capacity to do so. We might think that, but we keep it to ourselves. Because if you crush a child's dreams once, you've probably crushed him forever, the child won't risk speaking up again. So if a child's dream seems outrageously unrealistic, at least remain neutral, and say, "Hmm, that's interesting." And then wait and see if the child brings it up again, or be more supportive and say, "Let's learn more about that." You and your child can read a book about it or research it on the internet. Your child can spend time with someone who knows about it, or take a class in it. Your child's interest may increase, or she may realise this isn't for her after all. Allowing her to figure this out is much better than an adult saying, "You can't do this." And yes, our children may experience disappointment, but they'll recover and bounce back. That's what builds character.

We need to focus on strengths, abilities and interest. As a young child, Benjamin was routinely assessed and experts focused on what he could not do, crawl, sit up, walk and more. When he started talking at age three, he demonstrated a remarkable auditory memory and gift for mimicry. He could memorise dialogue from his beloved 'Thomas the Tank Engine' videos and books, and could mimic the British accents. Professionals ignored these skills because they weren't listed on their assessment forms. But we valued these marvellous abilities. They served Benj well in drama classes, and fuelled his love of words and writing. He would like a career as a writer or as voice talent. When Benjamin was very young, I was fortunate to learn from adults with developmental disabilities. They helped me realise that you don't have to walk or talk, or do any so called functional skills to live a good life. But you might need a power wheelchair, or a communication device, or other supports. In addition, these adults had spent their childhood receiving traditional therapies, and they shared powerful stories about how therapy made them feel that they were not okay. They also believe they disappointed their parents, because they couldn't do what therapy was supposed to fix, walk, talk and so on. Their personal stories broke my heart, and caused us to rethink traditional therapies. When Benjamin was six, he resigned from his therapy career, and we supported his decision. We replaced traditional therapy with techniques learned from therapists incorporating beneficial

activities throughout Benjamin's day, to help him do what he wanted to do. We no longer focused on what Benjamin could not do. We focused on what he could do, and build on those strengths. Therapists are not "bad people;" they're well intentioned (as are we). It's how traditional therapy is practised that's the issue! Instead of "doing therapy" to children, therapists can become consultants, and help parents and others learn how to assist a child by way of helpful everyday activities that are meaningful and relevant to the child. When Benjamin was a three year old, we ended formal assessments, enough of the doom and gloom focus on our son's perceived "deficits". If eligibility for services required assessments, professionals could informally assess Benjamin by playing with him, observing him, talking to us and more. When a focus is on a child's problems, so called, we are unable to see the positives, his strengths, abilities and interest. We wanted to focus on our son's positives and build on those, and no amount of therapy could cure him of Cerebral Palsy. Dr. Margaret Steinman, a medical doctor, was born with bone deformities. And she endured many surgeries and years of therapies as a child. In an interview, she said, "I felt as a child, they kept trying to fix me. But nobody was helping me learn how to live with the way I was." Can we learn from the experiences of adults who have been there and done that? Focusing on our children's interest can lead to wonderful outcomes. In kindergarten, Benjamin couldn't keep up in math, when the teacher led the

class in 'one to one counting', as the children picked up their beans to learn to count. By the time Benjamin struggled to pick up bean number one, the teacher was on bean number six. At home, one of his favourite toys was a set of 12 pirates, each about three inches tall. I took them to his teacher, and asked that Benjamin used those for counting, he could easily and quickly pick them up in his fist. Tapping into this interest led to a valuable solution, and other known boys wanted to be his friend, and math partner. When we focus on the positives, we'll spend less time talking about so called problems or deficits, and that, in turn, can lead to using more respectful, accurate descriptors. Using people first language is a good beginning. Our children are not autistic, retarded, etc. A child has autism, or has a cognitive disability and so on. And let's eliminate special needs. It can generate pity, and lead to segregation. If we say a child has special needs, that can trigger placement in a special segregated programme.

We need to think about chronological age, not developmental age. Children with disabilities may be evaluated across a variety of domains, fine motor, gross motor, receptive language, expressive language, intellectual, social and more. Then, a professional may label a child with a developmental age in one domain or another if there's a difference between the child's chronological age and the criteria on the test, we may then generalise the results of one test to the whole child.

Parents have said, "My child is 15 but he functions at the level of a 10 year old..." Then, how do we treat a child? Like a 10 year old, we won't let him be a 15 year old. This is patently unfair, and can lead to disastrous consequences. Certain tests may be needed in order for the child to qualify for services, but the results should have limited release, and should never be used to define or describe the child. A physical therapist classified five year old Benjamin as quote, "Functioning at the level of an eight month old.", unquote, because he didn't sit up or crawl the right way, at the right time. When the kindergarten teacher heard this during the IEP meeting, she almost fell out of her chair. She couldn't have an eight month old in her class. Luckily, Benjamin was at the meeting, more about this later. And he appeared to be reading one of his 'Thomas the Tank Engine' books out loud, complete with British accent. He wasn't like an eight month old. I assured the teacher that the physical therapist was talking about a measurement on a gross motor scale. But imagine if Benjamin had not been at the meeting, the teacher would have refused to have an eight month old in her class. In reality, Benjamin wasn't reading. He had memorised many Thomas books. And if you didn't know any better, it looked like he was reading. I didn't tell the teacher this. I knew she'd figure it out the first day of school. But didn't he look great that day! We need to make our children look good instead of making them look bad. We need to provide tools for success, assistive technology, supports and

accommodations. Benjamin would not be where he is today, without the tools he needs; power wheelchair, computer, and many other supports and accommodations. People without disabilities can get through the day without their cell phones, microwave ovens, day planners, etc. as well as supports and accommodations. Why would we deny these tools to a child with a disability? If we don't provide the right tools at the right time, we create more developmental delays, since the child is prevented from doing ordinary age appropriate activities, and learning from those experiences. For example, if a child is carried or pushed in a stroller or wheelchair, because she cannot walk, she also cannot learn how to get around on her own, like she could in a power wheelchair. And being pushed keeps her in an 'infantalized' powerless state. If a child cannot write with a pencil, we may hold the child back in school and or place a child in a special education classroom, preventing him from learning the academic and social lessons in the general education environment. Instead, the child should be allowed to write using a computer or tablet. If a child is unable to speak or be understood by others, he needs a communication device or some other form of effective communication. If a child is not reading, she should be provided with books on a tablet, computer or on tape. Think of other examples. Whatever tools a child needs should be provided at the right age, to enable the child to be a two year old, or a 10 year old, and so on. If I could do it over again, maybe one would have had a power

wheelchair as an 18 month old, so he could run around the house and explore and learn like his sister did at that age. Regarding communication, the first thing most mothers want to hear a child say is 'Mama'. And the second thing is, 'Mommy, I love you'. I routinely ask parents, would you rather hear your two year old say, 'Mommy I love you.' with a communication device or not at all. The answer 100% of the time is the same, with a communication device. It's vitally important for a child to be able to communicate that to his mommy. It's vitally important that his mommy hear that from her child. Yet few professionals give much thought to the really important things in the lives of children and families.

So the supports and accommodations can be anything that enables a child or young person to be more successful, engaged in chronologically age appropriate activities, and so on. We arranged Benjamin's bedroom so he could master his environment. His toys and books were in bands on countertops, so we could reach them in his wheelchair. Other changes in our home allowed Benjamin the same access and freedom enjoyed by other members of the family. Spend some time thinking about how different a child's life and a family's life could be when a child has the tools she needs for success, from a low tech digital watch, if she can't tell time on a regular watch, to a high tech power wheelchair, and everything in between. And if government programmes or services won't find

assistive technology devices, we need to do whatever it takes to get what is needed; buy on credit, borrow the money, ask for donations, or any other way, our children are counting on us. We need to expect and encourage self direction and personal responsibility. Too often, children and young people with disabilities are given a pass. We don't expect or encourage it to be self directed or responsible. We don't let them do things because they can't do it the right way, or at all, or we can do a better and faster. Thus, many children learn to be helpless and dependent, and we've been great teachers! When Emily and Benjamin were young, both were expected to do chores, pick up after themselves and more. As mentioned previously, changes were made in our home, so he could be more responsible for himself, including rearranging kitchen drawers and shelves, so Benjamin could get dishes and utensils out to help set the table. We gave both children an allowance, even though understanding math and handling money were difficult for Benjamin. But how else would a child learn the value of money and being responsible unless the child has money to spend. One Christmas when our children were preschoolers, Emily wanted to help decorate the Christmas tree, you probably know the outcome, all the ornaments were down low and in the same area, and you have to leave it that way, so you don't hurt the child's feelings. She also wanted to pass out the wrapped presents. Since she couldn't read yet, she showed us each present, re-read the recipients name, and she proudly

handed it to the person. The following year in anticipation of Christmas, Benjamin wanted to follow in big sister's footsteps. But sitting in his wheelchair, he could not get up close to the tree as easily, and he couldn't reach the presents under the tree. So that year, and since then, we bought a smaller tree and placed it and the presents on a table so both children could be Santa's helper. Self direction and responsibility need to be practised in school and community settings too. Parents may need to share their beliefs about this with teachers and others, who may presume that children with disabilities are inherently incompetent and unable. And if we've encouraged our children to speak up and be self directed at home, they'll have the skills to do the same in other settings. Thus, our children need to attend their special-ed planning meetings, and be involved in making decisions about goals, accommodations, assistive technology and more. Whose education, whose life is it any way? Parents, along with input from the child, can decide if the child should attend the entire meeting, or certain parts of it. But by middle school and above, a child should essentially be in charge of the meeting. Some parents want their child at meetings, because of the negative ways teachers talk about the child. But if the child or young person is present, we don't talk about them anymore, we talk to them. The child's participation can change the dynamics and the outcomes of the meeting, and the skills learned will serve them for the rest of their lives. All children want to be responsible. And yes,

they'll occasionally balk at chores, adults complain too. When we don't expect children to be self directed and responsible, we're sending the unspoken message; we don't believe in you, we don't trust you, and we don't think you're competent. Children will live up or down to our expectations. When we provide children with opportunities to be responsible and self directed, along with whatever tools they need, they'll master these skills. And if they don't learn these skills under our guidance, what will happen when we're gone? Do we want to raise helpless children who will end up in the hands of a government programme? Is that what our children want?

We need to presume inclusion. Every child is born included. Inclusion is a natural state of affairs. Our daughter would always be included, and we wanted to same for Benjamin. So we never asked permission for inclusion. Being included prepares the child for success in the real world. Segregation prepares the child only for more segregation as an adult. When we enrol Benjamin in karate, drama lessons and other activities, we never announced that he had Cerebral Palsy. Instead, we casually mentioned that he would need wheelchair access, low vision accommodations, and so on. If we don't make a big deal about our children's disabilities, others won't either. A positive attitude is critical. The path to ensuring Benjamin's success involved changing ourselves, our words, attitudes and actions, not trying to change Benjamin. I've

detailed some of our strategies, but it's Benjamin who created his wonderful life. We simply opened the door to opportunities, and Benjamin had the desire and the tools he needed to make it happen. Your child can too.

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