A Man’s Search for Meaning in the Lives of Children with Intellectual Disability

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To my wife Ann, who always believed in my story.

And to everyone who taught me so much,
without using words.
Table of Contents

Introduction ................................................................................................................................. 1
Chapter 1 Resilience in Families with Intellectually Disabled Children .................................... 5
Chapter 2- My Reconstructed Narrative .................................................................................. 13
Chapter 3 Applying the Story: Medicine ................................................................................... 22
Chapter 4. Applying the Story: Education and Society ............................................................. 31
Chapter 5 Sharing a Vision ....................................................................................................... 43
Conclusion: A Vision for Society ............................................................................................. 49
Introduction

Nevertheless, if we look on man's whole mental life as it exists, on the life of men that lies in them apart from their learning and science, and that they inwardly and privately follow, we have to confess that the part of it of which rationalism can give an account is relatively superficial. It is the part that has the prestige undoubtedly, for it has the loquacity, it can challenge you for proofs, and chop logic, and put you down with words. William James

As I write this, it has been almost eight years to the day since we found out our son has Down syndrome. He was five days old when our family doctor, with the ever present medical student in tow, met with my wife and me and told us that regretfully the chromosome test had confirmed trisomy-21. With my full support, my wife had adamantly refused invasive prenatal diagnostic tests that were indicated because of her age, and the non-invasive tests were negative for all deformities. My initial response was the natural denial of the results of the chromosome test, anger at the arbitrariness of life, and grief over the loss of the son that could be the valedictorian, starting point guard, or world-defining scholar. That vision of his future was now replaced with uncertainty about what his health and capabilities would be, as well as an unarticulated fear that he would somehow not belong because of his uniqueness. After a few minutes our doctor asked us, with unmistakable kindness and concern, a question that has become one of the crystalline moments in my life. “Do you now regret not getting the amniocentesis?” The question hung in the air for a few minutes as my wife sobbed gently and I looked deep into my life and into the future.

Ludwig Wittgenstein presented a thought experiment in which a number of dinner guests each have a box that only they can see into (100). While each person has a different object in their box they have all learned to call the contents of the box a “beetle.” Disconnection would inevitably arise as each spoke of a beetle but meant something different. In this situation we were
talking to our trusted family physician who certainly meant no harm in either promoting the
amniocentesis or questioning us about it later. Yet, when I recall the conversation, it always has a
disjointed feeling much like that of Wittgenstein’s dinner guests. We were each using or thinking
terms such as Down syndrome or Intellectual Disability (ID) but not really meaning the same
things. I’ve felt this disconnect many times when talking with doctors, teachers and therapists
about the intellectually disabled people who have been part of my family life—my younger sister
and my two biological children. I also felt this disconnection many times in the years I worked
providing care and training to adults with ID. The relationships I had with the individuals being
served seemed to exist in parallel to the body of regulations that guided our conduct as
professionals. While I agree with much of the advice that parent’s advocacy organizations offer,
that advice has always seemed incomplete or artificially focused. The source, and hopes of
reconciling, this disconnection in my perceptions has lingered with me throughout my life.

The purpose of this thesis is to reconcile some of these disconnections by analyzing my
experiences as a parent and sibling of individuals with Intellectual Disability in the context of
modern American society. My intent is also to suggest to interested parties a paradigm of how to
respond to, and include, people with ID in society. My general approach is to compare particular
situations or processes from the professional perspective and from the perspective of my lived
experience. A professional such as a doctor, teacher, or social worker generally works from
frameworks that are thought to be universal and rational, e.g., a code of professional knowledge
and conduct or various governmental rules and regulations. The art of these professions is using
experience and judgment to apply these frameworks to particular contexts or individuals.
Conversely, the non-professional individual in these situations is living a multi-faceted life and
experiences that life more broadly and holistically than the professional involved. (Of course, the
professional experiences their own life broadly and holistically). The lay individuals involved
may not understand, or even be aware of these professional paradigms, and are certainly not
bound by them. I believe that these differing approaches to knowledge are the crux of the
disconnections I have felt over the years. The general design of this paper is to look at specific
aspects of my experiences and find contrast and reconciliation with the frameworks or guidelines
of the professions that intersect with those experiences.
The first chapter will discuss some of the key processes in familial resilience to the losses that occur when children have Intellectual Disabilities (ID). Resilience theory is a body of work primarily in the fields of sociology, family science and psychology that explores how individuals and social systems adapt to loss and challenging circumstances. Central to these processes is what I call a reconstructed self-narrative. A self-narrative is an often unspoken story we have about ourselves that tells who we are, what is most important to us, and how we contribute to the good of others in our society. A reconstructed narrative is a term I use to describe the process of learning a new story about ourselves when exigent circumstances require one—such as the birth of a child with severe disabilities. A prominent aspect of this reconstructed narrative is the overriding sense of purpose and meaning that both creates and motivates changes in social roles, identities and values. The second chapter is written not from an academic perspective, but instead as a father explaining my hopes and visions for how my children have a place in society despite their significant limitations.

The middle chapters look at how the narrative explored in chapter two has affected decisions my wife and I have made in regards to our children. Chapter three investigates the bioethical question of prenatal testing for Down syndrome and chapter four explores an educational decision we made on behalf of my daughter. Understanding both the perspective of the professionals involved and our personal narrative will illustrate the centrality of narrative in making life-affecting or ethical decisions. Chapter five will suggest ways to develop understanding and reconciliation of the perspectives of the families and professionals. The concluding chapter will suggest an aspirational vision of what the future of those with ID in society can be.

I believe this discussion is important to most readers because all but the most fortunate will have to reconstruct or adjust their own self-narrative at some point in their lives. Dreams are lost due to acquired disability, family problems, illness and a host of other misfortunes. My hope is that some understanding of how resilience can work and bring about growth will be of some benefit to all. Specific to the case of disabilities, it is also true that a host of factors are leading to the increased prevalence of people in our society with disabilities at a time when the overall
population growth remains steady.¹ This increases the need for an ethical and manageable response to the question of how to define societal membership for those who cannot contribute as others do. One place to look for an answer is where those with disabilities are most frequently included, that is to say, their individual family system.

¹ This includes the unexplained rise of autism spectrum disorders, the general aging of the American population, Gulf war veterans, survival of extremely premature babies, and the trend toward later in life babies.
Chapter 1: Resilience in Families with Intellectually Disabled Children

This summer, in one particular patch of my garden, only a couple of the dozen or so plantings have thrived. To investigate this, I could either look into why the ten plants failed, or else focus on the factors that led to the success of the thriving plants. The latter is analogous to the social science concept of resilience theory, which seeks to understand why some people are affected in less negative ways than others by the occurrence of unfortunate events or circumstances. It seeks to find protective factors that might reduce the impact of the unfortunate circumstances or events. An example would be studying victims of systematic child abuse. Many children in this unfortunate circumstance grow up to be exemplary citizens and parents rather than repeating the cycles of abuse. Resilience theory attempts to find what influences or internal characteristics contributed to the more desirable outcomes for their lives.

The last two decades have seen a growing body of literature on resilience research specific to families with children with ID. In that research I see three themes that can be distilled as components of resilience in families with special needs children: comprehending and learning to manage the situation, developing new values or self identity, and finding meaning. In practice these themes do not exist as separate entities, but they influence and interact with each other: comprehension informs the new identities while the identity change focuses what and how comprehension occurs. The search for meaning motivates and illuminates the other two components. Despite these dependencies and interconnectedness, for the sake of clarity I will look at each of these in turn.

The search for comprehension

Comprehension usually begins with the acknowledgement and naming of the disability through a professional diagnosis. The time frame can range from a prenatal test that gives a definitive diagnosis that the child will have a syndrome known to cause developmental disability,

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2 Early theory is best represented by Aaron Antonovsky. For one example of researchers expanding on these ideas see Gordon Grant and collaborators.
to a mother with unease that something is not right with their toddler, to the adult who found their differentness had a name such as autism, dyslexia or depression. Graungaard and Skov have studied the responses of parents with infant children who were known to have clear developmental delays. Half of the children in this study had been given a formal diagnosis, and half had no diagnosis but were displaying clear developmental delays along with other issues such as seizures. The parents of both groups of children were interviewed on several occasions in a grounded theory methodology.\(^3\) The researchers found that parents generally saw a formal diagnosis of their child’s condition to be helpful. The research suggests a formal diagnosis provides some idea of what the future of the child might be, as well as suggesting courses of action that may be helpful to the child. This knowledge empowers the parents to respond to the unexpected situation because they were able to start seeing the possibilities for the future of the child. The parents of undiagnosed children were not bereft of hope but were unsure of what to hope for and relied on medical experts to provide orientation.

The medical perspective will naturally provide information on potential problems and limitations that need to be addressed and establishes a target for information gathering. For example, if the child has Down syndrome one can begin to find out what a future for a person with that condition might be like. Parents and older siblings seek information and ideas about the disability as steps to managing the changes in their lives.

Both Retzlaff and Grant noted that as families develop knowledge and confidence about managing the changed circumstances, they may “….purposefully insist on not relying too much on experts from the realization that they can only give limited answers” (Retzlaff 252). Parents realize that professionals can give a diagnosis, perhaps provide a probabilistic assessment of future possibilities, give advice on interventions or treatments to pursue, but cannot explain the child in their totality and essence. A professional can tell a parent what effects may occur given a particular diagnosis, but cannot predict with any precision how the day-to-day life of the child will be affected by those effects. This idea will be developed further in later chapters of this paper but for now it is enough to say that the importance of the form of knowing represented by a medical diagnosis fades as the individual family lives and grows.

\(^3\) Grounded theory is a method that involves a researcher doing a structured interview using open-ended questions. The answers of the subjects are analyzed for common themes and unique perspectives or connections. The strength of the method is considered to mitigate researcher bias.
Changes in Identity

I use the term identity to mean how we see ourselves in relation to the social groups we are in, and our relative status or social competence within those groups. I believe this is more than a summation of the roles we fulfill in our daily lives such as employee, automobile driver or customer. It includes the roles we have that define for us how we belong and contribute to whatever society or groups we are part of. One’s vocational role may or may not be part of one’s identity; some people do a job in which they have no interest or passion, and yet it allows them the resources to fulfill other roles or identities they value such as a parent or a philanthropist. For many people, being a parent is an identity that gives them a valued place in a given society because the outcome of that relationship is a child who becomes a contributing member of society. A child with ID naturally affects that identity to a degree because it is doubtful or at least uncertain how the child will become a contributing member of society.

Several researchers and theorists have mentioned the ability to form or alter one's identity in response to the new reality of raising a child with disabilities as a key to resilience (Grant; Hastings; Dykens). The parental identities change but also their role in forming the identity of the child changes based on the information they have acquired about individuals similar to their own child. As with any new parent, this issue arises when there is a lack of awareness of what the new role entails. This is where the initial and ongoing search for information is key. From medical experts and therapists a parent learns procedural or practical knowledge about living and caring for the child with a disability and from that information the parent begins to embrace the new role of parent of a child with disabilities. Essential for this is the connection with other parents who are playing the same role that the new parent is embracing and learning. The fact that the new parent sees other parents living out their new narrative is more important to the identity formation than the details of how they are coping. The Down Syndrome Association of Minnesota will send trained parents to meet new parents of Down syndrome children whenever the parents feel ready, even before the mother and baby have left the hospital. Knowing other parents in the same circumstance makes the role of parenting the child real and helps the parent to begin forming a new set of expectations, values and dreams that will form a new identity. The next section discusses what some of these changes in values and dreams can entail.
Positive Attributions and Value Changes.

In the early part of the past decade, Dr. Richard Hastings sent out a questionnaire to parents of children with developmental disabilities. One father wrote back with the complaint that there was no place on the survey to describe parents’ positive experiences with their children. Hastings did a literature review and found that although parents universally acknowledge problems and challenges, there were 14 positive attributions mentioned frequently by parents:

- Pleasure/satisfaction in providing care for the child.
- Child is a source of joy/happiness.
- Sense of accomplishment in having done one’s best for the child.
- Sharing love with the child.
- Child provides a challenge or opportunity to learn and develop.
- Strengthened family and/or marriage.
- Gives a new or increased sense of purpose in life.
- Has led to the development of new skills, abilities, or new career opportunities.
- Becoming a better person (more compassionate, less selfish, more tolerant)
- Increased personal strength or confidence
- Expanded social and community networks
- Increased spirituality
- Changed one’s perspective on life (e.g., clarified what is important in life, more aware of the future)
- Making the most of each day, living life at a slower pace (118).

Julie Poehlmann's team interviewed the mothers of older children and teenagers with Down syndrome or Fragile X syndrome and found their responses were similar to those in the Hastings study: parents valued the child’s ability to connect with others as well as the child's sense of humor and thoughtfulness. Positive perceptions are also reported by those with a professional involvement in the intellectually disabled. Dr. Wolf Wolfensberger was a psychologist at a Midwestern state hospital for the developmentally disabled for over 30 years. He was an influential force in the deinstitutionalization movement and process in the 1970s and
1980s. Near the end of a prodigious academic publishing career he wrote a summary of what he saw as positive attributes he came to associate with individuals with intellectual disabilities. The experiences of Dr. Wolfensberger involve mostly individuals who were institutionalized at some point in their life; he knew many of them in a non-professional role in a faith-based community group. Some of the positive perceptions he noted were:

- Diminished intellectual capacity results in focus on relationship qualities such as loyalty.
- Natural spontaneity irrespective of social customs.
- Relate to individuals rather than social positions. Treat everyone the same.
- Frequently detached from worldly possessions.
- Bring out positive qualities in others such as gentleness and compassion (1988).

These lists of positive attributions are not meant to deny struggles and challenges with the child. Instead, they are meant to accentuate the positives that have often been ignored for a variety of historical and conceptual reasons. These positive attributions are the building blocks of the new view the parents take of how their story as parents and the lives of their children play out. The question is whether these blocks are being supported or obstructed by the professionals in their lives. It is worth noting and this point that few of them have anything to do with overcoming a disability per se; they are things that happen because of the disability rather than despite the disability.

I think of these processes of learning new values and identities as foundational elements of the parents reconstructed story. I believe we all have some internal stories we tell ourselves that reflects our central identity, values and sense of how we belong to the world. My paternal grandfather had a story relayed to me that he worked hard at manual and repetitive jobs, saved and invested meticulously and skipped vacations and new cars so his son and grandchildren could have college educations and not have to work the kind of jobs available to him. He had an identity as a laborer, valued frugality, and connected these aspects with a higher purpose of a better future for his descendents. Such stories can be disrupted by a variety of events such as illness, economic catastrophe, natural disaster and, in the case of my families, children with disabilities. As I wrote earlier, a whole slew of possible stories and dreams of how my son’s life could be died when I saw his chromosome test. The process of grieving that loss never really ends, but it fades as new identities, values and connections form around his life. The most important part of these stories is how we become a valued part of the larger good of the groups
we identify with such as family, church, town, country or world. That is what gives our life meaning. Meaning is a term used more often than it is defined so it warrants a closer look.

**Meaning and purpose.**

Viktor Frankl developed a philosophy that holds that the essential drive of humans is to find purpose or meaning. He also developed a method of psychological therapy based on this idea that he called logotherapy, which basically helps people overcome problems by realizing their purpose in life. To a great extent, these ideas were developed from his observations while he was a prisoner in a Nazi concentration camp; he noticed that prisoners who survived were usually those who could identify meaning and purpose rather than focus on their loss. While it seems trite for me to compare having a child with disabilities to imprisonment in a concentration camp, his observation about how people survive extreme loss is enlightening. He compared asking the meaning of a person's life to asking a chess master “What is the best move on the board?” (113). The question has no answer without considering where all the pieces are on the board as well as what phase of the game the match is in. In other words meaning is dependent on the social and historical circumstances of the involved parties and cannot be externally defined or imposed.

Frankl talked of finding meaning by taking action rather than being paralyzed by grief and by questions that have no answer, finding transcendent love and beauty both in relationships and the physical world, and most centrally by “overcoming.” Overcoming did not mean altering one’s circumstance but instead altering oneself to choose how to interpret and respond to the circumstance. Stated in the terms I have been using, an effective new story would include what is beautiful in the new circumstance, what I find valuable, and how I might now belong to the greater good.

The idea of a new story or narrative is reflected in the practice of logotherapy Frankl developed after the war. He once treated a rabbi who had lost his wife and six children in the Auschwitz concentration camp and now found out that his new wife was sterile. Frankl reframed his loss by telling him his suffering could have the purpose of purifying him to prepare for the higher place in heaven he believed his martyr children had already attained. His identity as childless man was unalterable, but he was able to create a unique story about what the loss meant, so that he himself could become a better person because of the loss. Frankl gave him a new story that involved not removing or denying the suffering, but creating new values based on
the personal growth that comes from the suffering. It is recorded that the rabbi obtained some relief from his suffering, but what impact he then had on those around him is not known.

The story you tell about yourself and your family is a working theory that will influence how you interpret subsequent events. The key to resilience is to recognize when circumstances have rendered your interpretation of the world untenable and in need of change. In my own story, our family recognized that the dreams we had for our children’s future were never going to happen. We needed to find a new story for our family that focused not on altering the circumstance, but rather on finding coherence and purpose in the circumstance. The next section of this chapter develops the idea of what is gained in narrative forms of knowledge.

**Narrative knowledge**

Central to the idea of a self-narrative or story is emplotment—the idea that we make sense of new information about our lives by placing it into a framework or story that has cohesion and purpose (Charon). The town I live in has recently endured a series of untimely deaths of young people due to accident or suicide. Observing the response of the townspeople on social media, conversations in the grocery store and talks in our own family reveal something about how people seem to process these events. The first thing that many people want to know is the details of what happened. Regarding the traffic accident: The objective fact that a young father or teenager has died is easy enough to understand, but how, for example, the traffic accident happened seems to be important. People seem to want to be able to picture where and how the accident happened. After finding out the basic facts of the accident there begins theorizing about the cause. Speculation begins to discover if speed, alcohol or being distracted by a cell phone caused the accident. A story emerges that allows us to feel we have made sense of the random and the senseless. The driver was speeding and talking on the cell phone so they got into an accident. Based on the facts of the situation and our previous experience, we construct a story in our minds that allows us to believe that we understand what happened.

What we all know upon honest reflection is that we don’t know why events such as car accidents. In the case of a traffic accident, even if it could have been avoided by dispensing with the cell phone, it also could have been avoided by leaving home thirty seconds later. Our stories are constructed of the elements we can control; in the case of an accident that would be things like alcohol or cell phone use. We focus on what we can control because it we then can compose
a story about how these things happen, and so they can be avoided in the future. In other words, many give meaning to the tragedy by finding ways it can be an example to better the lives of others. Families of accident or suicide victims regularly appear on the local news and other media to tell their story to inform the others in our society about what controllable items led to this tragedy. Movements such as Mothers Against Drunk Driving are largely driven by families trying to add meaning to their loss by contributing to the greater good of society.

The death of a child is an almost unimaginable tragedy, but I believe there are parallels in how the story-making sequence helps us develop coherence in the circumstance. Initially, the medical facts of what caused this defect and what we have learned about the condition are important to know. Genetic counselors ask detailed questions about the extended family history regarding disabilities or miscarriages to try to find a pattern that could provide a form of explanation. How we might be able to remediate the disability through various therapies and other interventions is helpful information, but in my view they don’t provide a complete sense of purpose. What provides purpose is a story that includes how the lives of the people experiencing these unfortunate circumstances can in some fashion help the greater good of our society.
Chapter 2: My Reconstructed Narrative

*What right have we to believe Nature under any obligation to do her work by means of complete minds only? She may find an incomplete mind a more suitable instrument for a particular purpose.*  William James

**Search for meaning**

Like most students of the social sciences, I can find support in the social science literature for almost any idea I need to support; but because the research of others is not central to my search for meaning, I will largely forgo that exercise. The main ideas of this section apply to both my children, my sister and others I know with ID; but I will focus on my daughter Kelsey for two reasons. One is that among my relatives she has the greatest degree of disability; what I say about Kelsey projects in shades of gray to her brother, her aunt and the others I know with ID. Secondly, her Unknown Disability minimizes what the reader can project onto her based on the formal classification or diagnostic systems. If I say Zachary is a higher functioning child with Down syndrome, most people can place him in some frame of reference; Kelsey you will just have to listen to and try to experience. This is the story I tell myself about what her life means to me and what her purpose is for the greater good. It is a glimpse of my search for meaning for her and for me as her father.

**The beginning—did my sister know how to talk?**

Before getting to the specifics of the story I tell about Kelsey, in the interest of reflexivity I will share a story I’ve told many times about an incident involving my younger sister Karen, who has intellectual disabilities. It’s a story I’ve now held onto for a matter of decades, most likely because it tells me something about myself. The literal truth cannot really be verified but my memory of the event helps explain how I interpret my children’s disability and my roles.

When I was about sixteen I took part in a meeting to determine if my younger sister could actually talk, and that experience has left me with nagging qualms all these decades later. About

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4 Reflexivity is the idea that an investigator needs to aware of, and open about, how their personal experience affects their interpretation of events or data as well as how the investigation is affecting them.

5 My college friends recall me telling this story while in college, which would be about five years after this story.
four years prior to these events, the chronic seizures that had impeded her development since birth had stopped and we began to see improvements in many areas of intellectual functioning including some rudimentary elements of speech: songs, single-word phrases, and occasional profanity began to emerge. For whatever reason, the teacher and speech therapists at her middle school never heard any of what we considered talking, and they were concerned that this was either echolalia or wishful thinking on the part of the family. Echolalia is the mimicking of sounds without any genuine understanding of the words, something like a parrot repeating phrases. My parents arranged a meeting with sister’s speech therapist at our family home to see if she would vocalize within earshot of the therapist. If the therapist could hear what we heard, she would be able to validate that either this was early speech development or a family creating inordinate meaning in these vocalizations.

I was closest in age to her and the person most able to elicit these vocalizations that we presumed to be words. Much of it was quite routine yes/no questions or our private jokes. I would ask, “Who’s the best big brother in the world?” She would reply, “you”. I later determined any question that began with “Who’s the best…” would be answered in the same way. The arrangement on this day was that Karen and I would sit at the dining room table and work on our usual assortment of puzzles and lego projects that occupied our time together. In the adjacent room her speech therapist and my parents were waiting and listening. I went through our usual questions, jokes, songs or whatever else I could think of to encourage her to respond with spoken words. While she happily responded with her usual rich and expressive facial gestures and body language, she carefully did not say a word. The therapist did not seem impressed with our demonstration and left being reassured Karen was not actually talking.

From an academic perspective, the issue being addressed is defining functional communication. Karen’s collection of eye gazes, nods and vocalizations would not be considered functional if they could not be commonly understood. The therapist wanted to know if Karen was doing anything that could help her communicate her needs or ideas to others—in particular non-familiar others such as teachers. If she was non-purposefully making sounds or imitating her favorite brother, the answer is no. There is nothing particularly functional about learning to identify your brother as the best at everything, except to the brother being identified as such. At the time I was irritated by what I took to be an insinuation that our communication was somehow less than valid. As a now educated adult, I have a better understanding of the point of view of the
therapist and the teachers, but I believe my younger self also had a valid point in that the communication meant something to us and strengthened a connection between us. Our array of rituals that included her vocalizations, not to mention the range of facial expressions and gestures she used to communicate her needs and wishes, were understood within our family in general and in particular by me. Even if they are not verbal or written communication, they are part of my history and narrative because they have influenced how I emplot future events.

After the speech therapist left, I asked Karen why she didn’t say anything and she replied with the longest, clearest sentence we had ever heard, “I don’t know how to talk”. This, of course, proved the point we were trying to make that she was capable of functional speech. I have no idea if our parents ever communicated this to the school or therapist; I suspect the latter wouldn’t have believed Karen really said that. At present, I usually describe her as essentially non-verbal. She can still come up with short sentences relevant to the context, but they are only muttered under her breath to familiar people. She continues to be a maestro at communicating with facial expressions, body language and pointing at pictures in magazines or on TV.

My daughter Kelsey and her aunt Karen share some non-verbal communication strategies but are otherwise quite dissimilar in personality and level of disability. The interest in sharing this story is that it serves as a prequel to how I construct the story of Kelsey’s life and purpose. Essential to my role as Karen’s brother is being her interpreter or proxy—the one person who understands communication and takes the role of helping others understand her. After I graduated from college and was unsure what to do with my life, my life with Karen was highly influential in my having a career working with adults with ID. This is the story I had lived out before beginning our journey with Kelsey, and it has no doubt influenced the following narrative I have for her.

Kelsey and Daddy.

In summary form, my hope lies not in what Kelsey can learn but in what she can teach. Actually, teaching and learning seem too rationalistic; it would be more accurate to say Kelsey presents certain things that others then experience and process. We can start with what I have learned from her. One such time was a beautiful fall afternoon at a park on the bluffs overlooking the St. Croix River. We were sitting on the grass in the prairie section of the nature area, near
the trees where the raptors perched looking for prey. Off in the distance was the confluence
where the pristine blue waters of the St. Croix met the brownish hue of the mighty Mississippi.
We just sat on the grass and took in the scene, Kelsey humming the note of C-sharp, which we
have come to understand means she is content.

I have come to understand conscious perception as something akin to stencils over a
sheet of paper. The paper represents the summation of all the sensory inputs present in a
particular scene: in this case, the breeze, the sounds of nature, the feel of the grass, the view of
the St. Croix river, and so forth. Our individual neurological make-up and experiences lead us to
perceive and notice different things about this scene: an autistic child could be overwhelmed by a
breeze I don’t notice; an ornithologist would notice much more about the birds than I would; or a
landscape artist would enjoy the riparian beauty in a way I might not. All the same, there is likely
some resemblance between what each of these people perceives and brings to mind about the
scene. We could all agree on the most general statements about that scene, but people with
neurological abnormalities such as my daughter can notice some unique details others usually
miss.

Because of the unusual way her nervous system processes tactile input, Kelsey’s is highly
focused on the feeling of the grass and sticks. She can be endlessly fascinated with textures
others consider mundane, and overwhelmed by textures they consider pleasant. A similar effect
occurs with sound, as she will listen intently to the sound of a small engine on the next block or
the music in a store rather than, for example, her father’s voice. On this particular day I started
playing with the grass with her, and I studied its texture as never before. For a while I tried to
forget how I was accustomed to perceiving this park and tried to infer her perspective and share
this prelapsarian scene. The feel of the grass, the view of the St. Croix, breezes, sunlight, sounds
were the sensory inputs we shared that needed no templates or their derivative ideas and words to
be enjoyed. The people walking by each had their own thoughts of divergent complexity, beauty
and mood, but we all shared the scene on a certain phenomenological level.

While I never enjoyed the grass as much as she, I did start to see her point in playing
with grass, and she seemed to like that I tried to feel the grass as she did. I’m being only slightly
facetious because the fact is her lack of movement and depth at which she perceives certain
sensory inputs that I ignore causes me to slow down and notice more and different details about
an environment, and as a result think in a different way. Finding a way to connect with her moves me beyond the patterns through which I have learned to see the world, and move into another pattern with its own coherence and beauty. There are many things Kelsey has pointed out to me in this way; to her large stores are sources of joy and laughter while they provoke in me a primeval urge to get through our list of gatherings and return home. For another example, I cannot begin to describe the joy that covers her face and spreads to others when she listens to live music. I don’t know what losses or changes one may have to process, but I believe that if one can let go of how one is used to thinking and framing the world, and just look or listen rather than think, the beauty there lies in plain view.

It is important to note here that I am not claiming to pay no attention to the limitations of her disability. While sitting at that park I was aware of other families who were hiking down a non-wheelchair-accessible trail that leads to the bottom of the bluff—exactly the sort of trail I would have enjoyed a great deal had I not my responsibility to Kelsey. It is also true that my younger sister is capable of some extremely challenging behaviors that have been disagreeable to deal with or even hear about. Resilience is not ignoring what is lost; it is seeing what remains. As Frankl wrote, “When we are unable to change the situation ….we are challenged to change ourselves” (83). We first need to find the transcendent beauty and love in the new circumstance, but beyond that see how our new discoveries can affect the greater good of our society and humankind. For that, we must leave our grassy hill and look at how we can affect others in the community.

Kelsey and others

In the previous chapter, I reported on a list of positive attributes of those with ID as reported by parents and others. My belief is that these relationship positives are not exclusive to a child’s relationships with family and other adults, but Kelsey’s disability in fact brings opportunities for positive growth to everyone she interacts with, especially in the context of modern American society.

Since pre-school there has never been a dearth of children wanting to have a turn helping Kelsey. We’ve seen over and over both as workers and parents that there is always a percentage of children in a classroom eager to find a way to help a child with a disability. This started in
pre-kindergarten with the children arguing over whose turn it was to help her hang her coat. In elementary school, she usually spent homeroom and non-academic class time such as library or music with her mainstream classmates. Again, there needed to be a schedule established of whose turn it was to drive her wheelchair and whatever else they could do to help. On the last day of elementary school for Kelsey’s class, they had a field day where a variety of activities were set up in the school playground and fields, including an inflatable jumping house commonly seen at fairs and such. She can’t stand without assistance so her turn consisted of sitting on the bouncing surface laughing as others jumped and bounced her around. Her classmates, apparently on their own, decided it was so much fun entertaining her that she could just stay in the activity while they took turns jumping around to make her laugh. While around town, she is frequently greeted by children she went to elementary school with who know the rudiments of her non-verbal communication methods.

In many instances the children’s interactions with Kelsey are reinforced both by the school and usually the parents, but I can’t help wondering how this care-giving would be nurtured without her. Using my sociological imagination, it seems to me that at one point in our history it was likely that families would be larger and have elderly or otherwise impaired relatives living with them. At least for the older children in such a family, helping skills might be more of an expectation than in modern society. Researchers have found that, perhaps surprisingly, an important ally in the question of mainstreaming children with ID has been the parents of the typically developing children (Turnbull and Turnbull). My son Zachary does not behave all that well in his mainstream class, but I am impressed at how tolerant the children and their parents are of him. (I actually think the children are more patient than they need to be.) I realize that learning to care and help is not part of the curriculum, but I can’t help thinking that some of these children could be the nursing home aides of the future.

It is thought by some that children have an inordinate amount of pressure to be busy and accomplish goals compared to previous generations. William Doherty, a professor of family social science at the University of Minnesota, has done research and workshops on the problems of what he calls “overscheduled children”. These are children who lack free time to play, engage in unstructured creative activities, or just relax. Dr. Doherty and other are concerned that achieving measurable mastery of life in the form of grades, musical excellence and all activities
possible has replaced just learning about and exploring life. For most of my life I’ve heard my father, who taught middle school for 37 years, bemoan the “death of childhood”. He eventually stopped assigning homework because he strongly believed a large number of children were already too busy. The first page of a handbook of the Boy Scouts of America offers scouting as a contrast to “… a society where your son is often taught that winning is everything”. To whatever degree this pressure to perform is true for the children Kelsey interacts with, I have a hope that she can be an antidote. She can accomplish little of measurable value; however, a number of children seem to be gaining something from her. If nothing else, the fact that our society has decided she belongs sends a message I can hope will be heard.6

Kelsey has had impact on other people as well. One of the greatest joys of our life with her is two neighbor children about her age who have spent most of their childhood finding ways to be Kelsey’s friend and helper. Our family has been extended with several “pseudo-daughters”—from middle adolescent to young adult helpers who have worked in our home with Kelsey over the years. Our relationships with them, both as employers and as the extra adults in their lives, are something positive Kelsey has brought to our lives and hopefully to theirs. Some of the helpers who are now young adults still require their new boyfriends to meet Kelsey as sort of a character test. (She is an impeccable judge of character.) Without knowing the individual narratives of all these people, I won’t presume to know what they gain or learn from Kelsey; but I think it’s safe to assume that she has taught her young friends, classmates and helpers what a real difficulty is, that they are competent to help others without relying on professionals, that a good heart means more than intellect, and that they belong even if they have limitations and frustrations. In summary, I believe she teaches them community. In our society that I believe has too much of many things—such as possessions, competition, rising sectarianism—she is completely competent to send a different message to those who have ears to hear. My hope for her is her ability to build community, cohesion rather than competition, acceptance rather than labels, relationships rather than things.

6 There are parallels between this and the bioethical theory known as Ethics of Care. The idea being that being a caregiver requires developing a particular form of moral and practical thinking that should be valued (Lindemann, 88-98). My belief is that learning to accept and interact with someone such as Kelsey also develops a particular set of ideas and values that counteract deficits in American society.
In my story, while I’m out at the store with Kelsey, I don’t just see a princess and her Dad. I’m the interpreter who can understand an arcane language of eye-gazes and facial expressions as well as drive a wheelchair with one hand and a shopping cart with the other. She is not just shopping but is part of a decades long struggle for acceptance and normalization, an ambassador of belonging, so that she can belong and so that others can face their eventual disabilities in a better way. She is someone who squeals with delight at the music playing in the background so others can learn to notice it, and she is overjoyed at a new pillow so others can remember to appreciate it. I challenge her to remember what we have or have not picked up on our shopping list. This is a good training exercise I learned back in my days as a group home worker, but that is not why she is at the store with me. She is at the store because a trip to Walmart is more fun and interesting if she is with me. Beyond that, a trip to the store is also more challenging and purposeful if she is there. I cannot calculate all the possibilities she brings to the interactions with others; none of us can, and it is absurd to pretend we can.

**Important disclaimer**

I have said nothing in this story of hope about Kelsey overcoming her disability. It is obviously a dream of mine; and, with the amazing technologies being worked on there is a possibility to mitigate some of her limitations. However that is not central to my hope and purpose. A core postulate I start with is that the worst thing about disability is not the lack of ability; it is the secondary effect on social relationships. It’s hard to quantify how I came to hold this so fervently. A memory comes to mind from my days as a training staff for a fifty-year-old woman with Down syndrome. She had a sort of hobby of writing her name over and over with no apparent purpose other than to show passing staff that she could. Her pride was wonderful to see, but I always wondered how such a basic academic task came to be such a central part of her life and interactions. Someone in her past had spent a great deal of time teaching her to make a series of letters; but it doesn’t seem that this skill meant much to her. Nor do I see it creating any sort of authentic connection with others. While I will never stop working with Kelsey to develop whatever independence she desires and is capable of, what she does or does not learn or accomplish has nothing to do with my sense of hope or purpose for her. I’m happy for those with disabilities in the upper percentiles of ability who appear on ads for children’s hospitals and Special Olympics and whose parents seem to dominate the policy discussions in certain quarters.
However, the promotion of potential closeness in ability to typical people as the sole source of hope makes little sense to me. My friends with typical children dream about the rare Rhodes Scholar or Olympic athlete but don’t have an identity-forming expectation placed on that hope. It’s alluring to think that if I just pushed the school, doctors, social workers, and politicians harder we would be able to construct a life for her with minimal impact of her disabilities. The more functional adaptation is to look at what she can bring to the world as she is, not as we hope she can be in our greatest dreams. Actually, that would be a valuable adaptation for everyone regardless of their ability level.  

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\[\text{For a similar resilience narrative from the perspective of an extremely articulate adult with Multiple Sclerosis, see the works of Nancy Mairs.}\]
Chapter 3: Applying the story in Medicine

“The human mind, however, is constituted on an entirely different plan....Its finiteness obliges it see but two or three things at a time. If it wishes to take wider sweeps it has to use ‘general ideas,’ as they are called, and in so doing to drop all concrete truths.”  William James

General and scientific forms of knowledge

In the previous chapter I shared some of the key stories in the narrative I have constructed of my life as Kelsey’s father. Those stories reveal the most authentic meaning that can be told of the unique concept “Kelsey-daughter” has for me. I say most authentic because anything I write or say about a topic as complex as the experience of a human relationship is but a subset of that experience. Out of the constellation of things that I could remember and write about in my life with Kelsey, what came into my consciousness and became a narrative were the experiences that captured my sense of purpose for her life. Having shared some of our experiences, I can more confidently share a statement of purpose for her life that I have distilled from these experiences. Stated most succinctly, I find meaning in how her new perspectives and dependency create opportunities for growth both for her immediate family and for the other social groups in which we are embedded. Furthermore, these opportunities are especially important in our particular American society.

Narrative, like anything we can produce, does have its limitations. By its nature, it focuses on concrete details that leave the knowledge gained difficult to transpose to other situations. The development and growth of society required us to form and share abstract and generally understood ideas. Sharing abstract meaning allowed us to use language to coordinate the efforts of the social group. Human societies have many layers and types of abstractions that have many uses. Examples relevant to this particular discussion include ethical principles, governmental rules or regulations, scientific or medical facts, and formally articulated societal values such as inclusiveness. All share the characteristic of moving away from the concrete reality in order to make statements about how we collectively act, share resources, or understand

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8 The phrase “most authentic meaning” is conceptually similar to the term “thick description” used by anthropologist Clifford Geertz or “rich description” used by some narrative ethicists such as Margaret Urban-Walker.
and control our environments. And the larger in scope these ideas become, the more they must leave behind the first-person experience of the person(s) they aspire to guide or describe.

I think this is the crux of the disconnect I wrote about in the introduction. As I rebuild a narrative that includes the uniqueness of my children, those outside my family must employ a host of generalities that are not incorrect per se, but they omit the concrete truths of the reality I live in. William James wrote:

> It is true that we instinctively recoil from seeing an object to which our emotions and affections are committed handled by the intellect as any other object is handled. The first thing the intellect does with an object is to class it along with something else. But any object that is infinitely important to us and awakens our devotion feels to us also as if it must be sui generis and unique. Probably a crab would be filled with a sense of personal outrage if it could hear us class it without ado or apology as a crustacean, and thus dispose of it. “I am no such thing, it would say; I am MYSELF, MYSELF alone.” (1055)

In context, James was writing about the reactions people had to his nascent investigations into the psychology of religion, but this describes many of my reactions to interactions with people of medicine, education or government in regards to my children. I recoil when my children, who are so close to my heart and sense of purpose in life, are being categorized and furthermore assigned to categories not universally valued in society. I recently had to send a fairly large amount of documentation to the State of Minnesota to validate the fact that my son is still disabled enough to be eligible for a particular government program. All the documentation from all the professionals was technically accurate but felt as null and void as an empty tomb because none of it was pertinent to who he is.

Professionals guide their conduct by experience and judgment but ultimately have abstract rules or standards that guide their conduct. A legislator or bureaucrat writing regulations to guide the allocation of shared societal resources must communicate in abstract propositions regardless of the precise emotional meanings these words might have to each individual reading them. In a similar fashion, teachers, doctors, therapists and other professionals have a bewildering array of regulations and guidelines to adhere to as well as the onus of using scientific knowledge to guide their actions. They have adopted a set of terms and ideas that for

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9 The State of Minnesota has determined Zachary is disabled through 2016, at which time his disability status will be reviewed.
the most part are clear because by training and experience the users of these terms have similar understandings of these terms. However, when there is disagreement or disconnect, it is useful to look at the meanings of these terms to the individuals involved. The experiences of an individual or a family will add nuances of meaning to ideas that on the surface seem to have universal meanings. The next section of this chapter finishes the story I started in the introduction about the day we found out Zachary has Down syndrome. As we continue this story, pay attention to how the bioethical concepts my doctor was working from contained concepts that meant something different to me because of my history and identity.

Testing for Down syndrome

Zachary was born when Kelsey had just turned five years old. Both Kelsey’s disability and wonderful personality were evident while we were pregnant with Zachary. As it happened, she was completely opposed to the new baby, a fact we learned by her vigorously signing “finished” whenever we talked about the new brother that was coming. Both children were delivered by planned c-section by our trusted family doctor who is also an obstetrician. There was nothing obviously wrong with Kelsey at birth but the lack of normal development was noticeable by the time she was six months old.

There are several methods for diagnosing fetal anomalies ranging from ultrasounds to chorionic villus sampling and amniocentesis. There is a general progression of risk of complications from these procedures from minimal side effects to a small chance of spontaneous miscarriage. When carrying Zachary, my wife was told the risk of spontaneous miscarriage from an amniocentesis was around 1% to 2%. A variety of defects can be detected genetically but the most common is Down syndrome or Trisomy 21. The chances of a mother the age of my wife having a child with DS is about .27%, although the chances of a fetus with DS are unclear as only births are tracked. We did do a number of prenatal ultrasounds which can detect many birth defects. Depending on how Down syndrome manifests itself in the fetus, at times it can be detected, but not confirmed by ultrasound. Zachary’s ultrasounds showed no reason to suspect Down syndrome.
The bioethics of prenatal testing

One of the leading paradigms for bioethics is the four principles approach proposed originally by Tom Beauchamp and James Childress in their 1979 book *Principles of Biomedical Ethics*. The first principle is autonomy, the patient’s right to make decisions about their health care. This arose in part in reaction to the historical practice of doctors making decisions on behalf of their patients, and, at times, withholding information about diagnosis such as cancer. The principle of autonomy implies that the medical professionals have provided the patient with complete and accurate information and the ability to make choices free of coercion. In application this is identified with the practice of providing informed consent. The principle of beneficence implies that the medical profession must provide “benefits” to the patient. This also implies that benefits and deficits are evaluated by the medical professional and the most beneficial result to the patient is chosen. Providing treatment not proven to be of any benefit to the condition of the patient could be seen as violating beneficence, although the patient can autonomously choose treatments regardless. The third principle is non-malevolence, summarized by the famous Hippocratic aphorism “First, do no harm”. One form that harm may take is failure to notify patients of the potential side effects of clinical trials, or even of the fact that they were in a clinical trial. Suggesting or performing a procedure in which the likely risks are incongruent with the potential beneficence of the outcome could be a violation of non-malevolence. The fourth principle, of justice, deals with the equitable allocation of resources. Treating a patient differently because they have poor insurance or are socially marginalized would be examples that could be construed as violations of justice. In recent years the principle of autonomy and informed consent seems to be taking a primary role with the belief that if people are given enough information they will be able to make the best choice.

Most of the discussion regarding the ethics of testing for genetic conditions prenatally has centered on the principles of autonomy, although others are important to the discussion as well. The first two principles exist in tension in this topic as the “good” of diagnosing genetic conditions is weighed against the potential side effects of both the procedures used to obtain this information and the implications of obtaining that knowledge. Justice is not mentioned explicitly other than the question of how to make access to these tests available equitably. The overriding

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10 See Report A-A-91 of the AMA’s Council on Ethical and Judicial Affairs [CEJA]
principle cited when discussing genetic testing is autonomy, which is highly dependent on access to information (van den Berg). An autonomous decision about the pregnancy requires that any available information about the health of the fetus be made available. Naturally the more complete this information is the more authentic the decision becomes.

Absence of information in decision making is analogous to lacking a map in an unfamiliar town. A traveler who woke up in an unfamiliar town would certainly recognize the existence of streets and sidewalks and know how to use them, so technically they would have the ability to choose which street to walk down. However, a map enables them to find out what the streets are called, where they go and what the future consequences of walking in a particular direction might be. In short, information is the first step to autonomy in decision-making. A map with a clear legend and markings allows a traveler to find their bearings and make relatively informed decisions about the direction they should choose. At the same time, the lines and markings on the map can never give the reader as much information as someone who has lived in that town. A resident in the town can give advice about a host of factors about what is in that town that a map simply cannot.

The analysis of whether to offer any diagnostic test is a balance of the information it can provide (autonomy), in relation to the potential unintended effects of the test or procedure (malevolence or harm), along with the potential good the knowledge can provide (beneficence). Having my blood pressure checked provides useful information that can be of benefit to me (offered treatment), and carries minimal risk of unintended effects (false positives, discomfort). For this reason I am offered blood pressure checks at the doctors, fairs, drug stores and even church. A test such as colonoscopy can detect a serious condition but can have serious side effects, so it is usually not offered until a patient reaches an age at which the statistical risk of cancer is higher. The reason for offering prenatal testing for conditions such as Down syndrome follows a similar formulation. The knowledge of the ideal health or potential issues with the fetus is greater than the potential for unintended side effects; which in the case of the most accurate tests are spontaneous miscarriage or the rare false positive or negatives. Knowing that a fetus has the genetic markers for Down syndrome is seen as beneficial as the parents can either terminate the pregnancy or make various practical and emotional preparations for the new reality, and thus avoid or mitigate the challenges of the child with a disability. This calculation is the reason
physicians routinely promote and at times pressure mothers to accept the risks of amniocenteses.\textsuperscript{11} However there are some assumptions about the variables in this calculation that are left unconsidered—specifically about the value of the information being obtained and the gravity of the conditions being tested for. I am cognizant of the medical profession’s scientific understanding of Down syndrome—this genetic pattern indicates statistically that a particular set of characteristics could develop in this fetus, including almost inevitably intellectual disability. The scientific truth of that is incontrovertible; however on a personal level the concepts of Down syndrome and ID have a richer meaning because of my life experiences. This truth is reflected in the stories I tell about that day and how I came to respond as I did.

Our story of Zachary’s Down syndrome diagnosis

This story picks up when our doctor told Ann and me that Zachary had Down syndrome—a fact I had accepted the night before but had not discussed with Ann. Our doctor had asked us if we regretted not having the amniocentesis or other invasive prenatal tests; and she seemed to really want an answer. My answer was: “The worst thing I can think of is not a son with Down syndrome. The worst thing is losing a child because you are afraid of a disability”. Both of these sentences contain clauses that I believe can only be understood in terms of one’s personal histories; the one I can speak most directly to is the concept of Down syndrome and intellectual disability.

This story begins with my younger sister, specifically the day I realized she had a disability. When I was about ten years old and she was six, I protested our father’s request that I pull her in her now undersized Red Ryder wagon because I felt she was too old. He replied that I could still be pulling her when she was my age, and I suddenly understood she had a disability. Despite having her medical diagnosis explained to me, and feeling the disruption in the house as our parents found out about her disability and witnessing hundreds of seizures, nonetheless this was the moment when I understood what mental retardation meant. The main point is that because of my sister, intellectual disability is just another form of normality in my framework.

\textsuperscript{11} Brian Stotko has done some formalized research into the experiences of mothers regarding the process of testing for Down syndrome and making choices based on the test results. For an impassioned parental narrative, see Martha Beck.
There are dozens of stories involving the at least 125 individuals with ID that I knew before even considering having children. In our mid twenties, my wife Ann and I met as staff at a vocational program for individuals with severe disabilities. One of the plethora of personalities and disabilities at my workplace was a man my age I will call Viktor. His intelligence measured at about a six-month-old level and he could only move his face and neck. He communicated only by a loud vocalizations and facial grimaces when he was in pain and smiles when he was happy. Despite his complete dependency and limited ability to interact, I enjoyed being around Victor and caring for him. I remember one afternoon we sat a park overlooking a lake. Viktor reclined in his wheelchair as I lounged on a park bench. We just enjoyed the silence of nature and the simple pleasure Viktor took in the breeze that occasionally blew. A breeze I didn’t noticed until I saw him smile as it cooled his face. My memories of Viktor serve to illustrate two points. First in our frame of reference, Down syndrome is not a severe disability; compared to Viktor’s limitations it barely even registers. Second, even with his almost complete disability he was important to me at that time in my life. He connected with the staff around him and his existence in the moment influenced me to take time to live in the moment. In short, at least in his relationship with me, Viktor had a purpose.

The most valuable experience of the kind above was knowing Sam. Sam has Down syndrome and was in the same class as our daughter Kelsey for much of their early childhood. We frequently ran into him and his family around town and always stopped to talk and catch up. I still see him occasionally and he never fails to bring a smile to my face.

The evening before the Trisomy 21 diagnosis was confirmed, I was at home with our daughter Kelsey while Ann and Zachary were still in the hospital. I set up Kelsey with a cartoon DVD and looked through the rapidly growing collection of digital pictures of Zachary on my computer. I looked closely at Zachary’s face and I recalled the last time I saw Sam. The faces merged together in my mind’s eye and I accepted that Zachary had Down syndrome. (I did not share this insight with Ann at the time). Hurt and anger at the arbitrariness of life were my predominant responses; they never really disappear but by the next morning had already begun to recede. This was because my initial association with DS was not at all the facts of the disability but my memories of watching Sam play with his dad at the community pool. He is fearless around water and everything else and while he was creating some challenges, he was having fun
with his dad. My connection with intellectual disability in general was not the loss of capability but my beloved sibling, angelic daughter, and the dozens of people with ID who have enriched my life. Stated more directly, my sense of purpose and belonging that I developed is incompatible with the idea that I should accept any risk to our pregnancy to avoid such a disability. What made my interpretation of the situation different was not disagreement with the principles of bioethics per se, nor do I have any overriding principle of my own that states medical risk should never be taken. It was the meaning I had learned to attach to DS and intellectual disability as they relate to my sense of identity and purpose. It would be incongruent for me to accept an implied definition of ID that was ominous and senseless; in my authentic definition it is challenging but meaningful.

Informed consent and the narrative

Medical facts are certainly important; it would be folly to not tell parents what is known to be statistically true about a particular condition such as DS. As we saw in the first chapter, medical knowledge such as a diagnosis can provide a starting point for resilience and a new narrative. Knowing what to call a diagnosis at least allows one to search for the generalized knowledge about that category of experience. That knowledge might include medical complications to be aware of and a starting point for reaching out to other parents who have had the same experiences. However, from my experiences with Kelsey I would say that a diagnosis is not an absolute requirement because the reality is that Down syndrome or any other medical condition is more than a set of statistical probabilities; it is a form of life full of the same beauty and purpose as any other.

Medical doctors are not able to provide information about the beauty and sense of purpose parents will find because it is different for each person and every set of circumstances; it is not generalizable scientific knowledge. Who made my decision to accept the risk of having a baby with Down syndrome truly informed was my sister, Sam and all the other people and families I have known who have experienced ID and other challenges. Likewise my family can help to inform other people about what is there with ID rather than what is obviously missing. I leave unchecked Zach’s exuberant outgoingness because he has a remarkable ability to find the person in the room most uncomfortable with his disability and apply his considerable charm until they warm up to him. When I bring him with me on errands to the store or library, even though
he will likely create some challenges, I am creating opportunities for people to learn a truth about Down syndrome. If nothing else, teaching others our truth about Down syndrome is part of what gives his life a purpose.
Chapter 4: 
Applying the story in Education and Society

The principles of bioethics serve fairly well to provide a general goal for ethical decisions; it is in the application that they become muddled because of the complexity of our lived experiences. This is largely true of many of our social enterprises that are involved with guiding human conduct, including education. Part of education is charged with providing the tools to abstract and summarize basic experience so that we can communicate what has been learned effectively. The scientific method allows us a means to validate propositions about how the world operates so that over time we, humanity, can learn to understand, predict, and control what is happening in our lives. I would not care to live in a world devoid of the benefits we have accrued from abstract reasoning and science, but at the same time these are forms of knowledge that my children, younger sister and friends with ID struggle with the most. This makes for some interesting questions that arise regarding how and when those with ID belong in a typical school setting. There are numerous laws and regulations to guide the answer to these questions as well as some outstanding academic programs designed to interpret and apply these regulations. The following section describes one way in which these guidelines create an ambiguity that can best be addressed by considering the individual narrative and sense of purpose.

Kelsey in Kindergarten

We had a disagreement with the school district representatives during my daughter Kelsey’s kindergarten year. Similar to our conversation with the doctors about genetic testing, there was no real acrimony between the individuals involved; we just seemed to be talking past each other. The arrangement we negotiated for her kindergarten year was that she would spend each morning in a special education classroom with children having disabilities similar to hers. In this classroom, in addition to meeting other children with significant needs, she would have access to individualized instruction as well as occupational, speech and physical therapists. Her afternoons, Monday through Thursday, were spent with a more traditional pre-school or pre-kindergarten classroom. She was actually with two groups of children; one group attended school
Monday and Wednesday and the other Tuesday and Thursday. Only Kelsey went every day of the week. These were children considered at risk of future educational problems for a variety of reasons other than intellectual disability, but overall they were a fairly typical group of four and five-year-olds. All reports were that this was working well and the reaction of the other children to Kelsey ranged from tolerance to fascination. The parents of one typically developing girl allowed her to pick five friends from school for her birthday party, and Kelsey was one of the five.

We came to respect both her special education and pre-school program teacher a great deal. Her special education teacher understood her abilities and limitations well and had obvious skill in working with her. It was also clear that the pre-school teacher and assistants had set a tone that Kelsey was part of the class despite the additional help she needed. The disagreement arose around the Christmas break when her special education teacher had a few conversations with us to recommend that she only go to the pre-school program two days a week. After all, she was doing the same activities both Monday and Tuesday afternoon; the only change was a different group of children.

I don’t have crystalline memories of these conversations but the general flow was that the teacher was intent on making sure I understood the situation accurately. (Incidentally, this teacher has a child with ID so she likely had been on both sides of these conversations). Was I aware she was replicating activities and was that of any benefit to her? I was aware of that fact and I did think there was a benefit. Could she make more progress with more individualized time with the special education teacher? I acknowledged that was likely true. Did I think she could keep up with the children who were not intellectually impaired? When asked tactfully, this is a fair question because I have seen parents of younger children sometimes need years to truly accept the degree of their children’s impairment. I had no hope that she would demonstrate an understanding of letters, numbers, and the days of the week in the same way as the other children. I just replied that I was quite happy with how her year was going and I did not want to make any changes right now.

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12 Fridays were spent in her special education class. The program for preschool children only met four days a week.
Although I did not particularly enjoy these exchanges, the teacher was actually doing her job quite well within the frames of reference she was working in. These include the United States disability policy, the Individuals with Disabilities Education Act (IDEA), and the No Child Left Behind education reform (NCLB). These regulations are interpreted and applied by various layers of state, county and school district policies; but understanding them at a high level is illustrative of the professional perspective the teachers and others were working from.

There are four basic elements of the United State’s disability policy, as reflected in the relevant federal laws (Turnbull and Turnbull). They are:

- Equal opportunity to participate in life’s activities.
- Full participation or freedom from segregation by ability, often referred to as inclusion.
- Independent living decisions or empowerment.
- Economic self-sufficiency through work or otherwise contributing to the community.

These are generalized principles that, in part, arose in reaction to past policies or understandings of those with disabilities; specifically the physical or metaphorical institutionalization in the latter part of the 20th century. It also reflects the disabilities rights movement as being a subset of the civil rights movements with concepts like desegregation and empowerment. Since 1975, successive iterations of the IDEA have set standards and practices for the special educational system to reflect these elements.

The IDEA has six identified principles that guide the implementation of the special education system across the nation. They are a set of ideals and statements of values that are meant to guide decisions that are largely applied by thoughtful and caring individuals. These principles must be followed to insure continued federal money to subsidize the local special education systems. State education departments write additional guidelines based on the IDEA and often additional rules or procedures that can expand but not contradict what is in the IDEA. Finally, local school districts and their employees learn and apply this host of guidelines, rules and principles. Parents are not necessarily trained in these per se, but by law are made aware of their rights and responsibilities. The six principles are as follows.
• Zero reject. Everyone has access to public education regardless of ability. An application of the equal opportunity ideal.

• Nondiscriminatory evaluation. Refers to impartial assessment of disability. These rules seek to address issues such as the overrepresentation of minority groups in special education and cases where an individual displays disparate abilities in different environments.

• Appropriate education. The education program of those identified with disabilities must be individualized according to the needs identified in the aforementioned assessments.

• Least Restrictive Environment. Children should be in mainstream classrooms with non-disabled peers unless “…the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily” (IDEA, 31). The assumption is that everyone belongs in a mainstream class and exceptions to this must be documented. This is the IDEA implementation of the freedom from segregation ideal of our national policy.

• Procedural Due Process. A complicated system where teacher and parents hold each other accountable for implementing these guidelines. Basically there are means for both the parent and teacher to appeal if agreement cannot be reached on what should be done.

• Parent participation. Parents are involved in all decisions, have access to all records and can serve on special education advisory committees. In short, I may well have more control over my disabled children’s education than I would over a typical child’s. Since parents would normally make decisions for minor children, empowering parents is considered largely the same as of empowering the children with ID.

The No Child Left Behind (NCLB) federal law enacted in the last decade has provided another layer of influence in special education. Schools are expected to show progress toward achieving certain aggregate scores in standardized testing. Children with disabilities are a priori
not excluded from the testing; however, testing accommodations can be made in certain circumstances. It was thought that schools were quick to treat children with issues by applying disability labels and then lowering expectations. The result is that even children with severe disabilities are given the opportunity to demonstrate progress measurably. The key here is that progress must be objectively measurable so it can be included in the aggregate score for the school.

Looking over this brief summary of the principles of special education, it is clear that the teachers did an excellent job both in arranging Kelsey’s school schedule and in questioning me about the amount of time she was spending in the preschool program. NCLB was not applicable to her at this age, although I have no doubt this school would have found a reasonable solution to its requirements if needed. Kelsey was being educated in a highly individualized fashion, parents were being given decision-making authority, and our district always makes us quite aware of our procedural due process. Even on the dividing issue of the application of Least Restrictive environment the teacher was technically correct. Kelsey probably could make more measurable progress with specialized instruction in her special education classroom than repeating a pre-school day that possibly was over her ability level. She was not being disruptive in the mainstream class, and at this point in her life, it was hard to say definitively what she did or did not understand. Since the assumption is she belongs in mainstream unless proven otherwise, the teacher probably was right not to continue to pursue removing her from the class when we did not concur. The reason this has stuck with me all these years is that the point that was missed in our exchange has come up many times over the ensuing years both in school and other environments. What was missed is our differing understanding of the concept of benefiting from being in the class; or in a larger sense, what does it mean to be part of a class?

Inclusion and Integration- What does it mean to belong?

In the last decade there has been an active core of researchers in adult populations regarding community integration. Two caveats to this discussion are: 1) they are mostly looking at individuals who formerly lived in institutions and now have moved to community based homes or apartments and 2) most of this research took place in Westernized nations other than the United States such as Australia and New Zealand. The former point is a more valid caution because of the ages and circumstances of the populations are so different, but the questions
raised are valid regardless of age or place. Policy and practice have focused on promoting
community presence because it is perceived to be beneficial to the individual, beneficial to
society, and at least a symbolic means of redressing past systematic exclusion (Cummins and
Lau). However, what exactly is meant by inclusion is often not precisely defined. Thorn,
Pittman, Myers and Slaughter begin a discussion of training residential staff to promote
community involvement by defining four types or levels of community involvement. These are
meant as progressive categories of inclusion, although an individual may not necessarily proceed
through them sequentially. The initial category is the basic “community presence” which means
that a person with an intellectual disability is physically proximate to those with no disability. A
person with an ID riding to work on some form of public transit is physically located with non-
disabled individuals during the ride so they have a community presence. However, if they
silently ride the bus without interacting with anyone, they are present in the community but not
participating. The next level of “community participation” involves some interaction with
others. If our rider jokes with the driver, greets regular passengers and perhaps shares a cup of
coffee with them they are now engaging in both community presence and participation. The next
category is “community integration”. To be categorized as integrated, our rider must have
multiple aspects of their life involved in community participation, in particular the living setting.
If our rider interacts with others in the community at home, work and in recreational activities
they are considered to be integrated. In contrast to the other categories that can be measured
relatively easily, the final category of “community inclusion” is a perception on the part of the
individual that they are connected to the community. This is the sense of belonging that occurs
when we participate in shared activities and communication with the larger society, when we
unquestioningly accept that we belong in our social group. The individual’s perception that they
are included in the larger social group is the ultimate goal of promoting community involvement,
but it is especially difficult to ascertain when communication and self-expression are limited by
severe intellectual impairment. The main point is that the key concept in this formulation,
include, can have many different meaning depending on how an individual’s sense of
belonging is focused.

Consider a civic group such as the Lions Club, Boy Scouts, or a local church. Some may
find a sense of belonging attending only a few times a year. The knowledge that they are on the
membership rolls and have others who share their beliefs or values is enough. Others scoff at this
and think attending weekly is the best way to belong, while others scoff at this and insist
belonging is most authentic when one is involved on various committees or ministries. My
suggestion is that from the individual’s perspective there is not a single “correct” way to belong,
because it depends on the individual’s values and perceptions about how belonging in the group
operates. My decision was made on my own sense of what it meant for Kelsey to belong in that
classroom, and this sense was in no way related to her competence with the alphabet.

The reason I wanted Kelsey in a mainstream classroom was not for her to learn her letters
but to learn that she belonged there. She had inarguably developed some self-awareness of her
uniqueness by this age and I wanted to reinforce that she belonged with the children who could
walk, talk, climb and write despite her needing an adult helper as a proxy. As she developed her
understanding of the larger world, I wanted the idea of being “normal” for her to be sometimes
with people such as herself and sometimes not. I also seem to remember saying, or at least
thinking, that even if she can’t learn there she can teach. Two groups of children could in some
way grow up as I did—seeing ID as an alternative way of being rather than as a not-like-us. I
imagined a little girl growing up and looking at pictures of her fifth birthday party and seeing
how oblivious she was to such an obvious disability. Without knowing the life story of these
children I have no way of knowing what they gained from Kelsey, or if this is just a passionate
father’s rambling hopes. However, as long as she is with other children she can provide new
experiences and suggest new ways to experience a field of grass. That is why I could not fathom
agreeing to cutting in half her time with what the regulations call her non-disabled peers. In my
story, they are her students.

The idea of Kelsey having a positive social influence because of, not despite of, her
disability is a powerful part of my sense of purpose for her. There have been two situations over
the years where I have been upset—and admittedly overreacted—to things that happened at
school. I’ve spared the reader the cantankerous details, but in both cases I felt my sense of
purpose for her, and by extension my own purpose and identity, were being threatened.

**Teachers and parents using narrative**

The principles of special education as they have evolved do not have any ideas or
characteristics objectionable to me; other than the ubiquitous problem of terms and ideas not
having precisely the same shared meanings. I think that defining these terms in the context of each family is part of why the current revision of the IDEA places a strong emphasis on parents and families making informed decisions about what goals the child will have and what opportunities will be presented. Another weakness, which is partially acknowledged by some, is that much of the information being provided is being given by people in positions of some authority, be they teachers, therapists or parent advocacy experts. These are almost invariably good, caring people who have been charged with producing measurable results which in some cases could affect the funding the school receives. How to focus the interventions on what is most important to the family, and hopefully the child, is part of the difficulty of developing an educational plan. I think this is especially true in the early intervention (1-3 years old) phase where the family is still recovering from the loss and trying to find coherence and purpose.

One solution being explored in early intervention is known as the Routines Based Interview method develop by Robin McWilliam. This is a systematic method of helping the parents create a “rich and thick” description of the child’s day that is intended to focus the training on the deficits most frustrating to the child or the most meaningful to the family unit. Teachers ask about the daily routine of the child’s eating, dressing, bathing, hanging out with family, who they interact with and how, favorite activities and so forth. Similar interviews can be done with extended family members, caregivers, and school personal. The interviewer gains access to several narratives about the child’s day that reveals the kinds of frustrations and difficulties that are encountered throughout the day. More to the point, I believe it helps the interviewer and the parents understand what the reconstructed narrative entails. Had someone interviewed me about Kelsey when she was a toddler, they no doubt would have learned how she encouraged her older brother’s music lessons by her joyous response to their nervous attempts at playing the violin. Whether or not this led to a formal goal, the interviewer now knew something about how Kelsey connected to someone else in the world—as an exuberant audience for musicians. Whether parents are at the point of being aware of it, they are the experts on their children’s inclusion. The children are part of the family before they are part of anything else and how that plays out given the unique circumstances provides information about how they can connect to the larger society.
Applying the story to the Cub scouts

Midstream of the process of writing this paper, we had some experiences with Zachary that illustrates the question of inclusion, or rather the question of what it means to be included. During the summer after Zach’s 1st grade year, he played baseball in an adapted league called the Miracle League. This league was utterly non-competitive, outs were not counted, everyone scored at every at bat, and only a few players had the ability to hit or field independently. Each player had individual assistance from a typically developing player from the local Little League teams. For example, Zach can’t quite seem to grasp how to catch the ball in his glove so his helper would field the ball for him and then hand him the ball so he could at least theoretically throw it to the first baseman. He can hit the ball off of a tee or an occasional pitched waffle ball, but at no point in the whole summer did he run directly to first base without considerable direction from me. He preferred to detour to third base or just chase the ball he just hit.

Zach learned almost nothing about how to play baseball, and is no closer to being part of a typical baseball team, but he loved his baseball team. He was quite proud of his uniform and told many random strangers that he was “number 2” on the “Iron Birds”. He began to pay more attention to the baseball games on TV and we also called his Grandpa, who played quite a bit of baseball, to tell him about the games. Fairly regularly when watching or talking about this baseball team he would mention “Eddie”—a typically developing child from his school who had twice invited him to his baseball-themed birthday parties. In summary, despite little progress in learning the correct way to play baseball, he enjoyed the sense of being part of a team, had more to talk to his grandpa about, and at least anecdotally seemed to have some connection to a typically developing child that he knew from school. Kelsey went to his game as a spectator and, despite never having shown any interest in any sports activity not involving horses, was quite upset we didn’t sign her up for baseball. She did get a chance to play in the short fall season. The term “play baseball” means something quite different to both of them compared to the generally shared idea that it involves catching, throwing, hitting a ball, and running bases counter-clockwise. It seems to just mean that they are part of a group having fun.

Recognizing how powerful his sense of belonging to a group was provoked us to take another look at him joining Cub Scouts. For about a year we had been encouraged by friends of ours to look into scouting as a good activity for Zach. We had some trepidation because at this
point he had a history of not behaving well around typical children; e.g., starting wrestling matches during library time in school. Zach’s behavioral issues were less common in his special education classroom and with his older sister his only issue was some misguided attempts at helping her.

We planned to do some of the summer activities with the local scout troop that included a picnic, day camping and the town parade—where he was to walk with the other scouts and hand out candy to the crowd. As we waited for the parade to start, one of the scoutmasters greeted Zach warmly and then suggested I meet the area director for scouting because he ran a quite successful scout group of boys who had Down syndrome and/or intellectual disability. I don’t think he meant to imply that Zach necessarily belonged in that troop rather than his local troop, but it did get me thinking about what choice we would make given the opportunity. Would he be better with a group of scouts who were more like him or mostly typically developing?

As we began walking in the parade it became apparent quickly that Zach could not walk at fast as the other boys. As with most children with DS he has proportionally short legs and lower muscle tone that limits his walking speed. He is on the large size of the growth chart for boys with DS, so if he was in a special needs pack he would probably be able to keep up. I could see the other scouts ahead tossing candy underhanded to the children in the crowd. Meanwhile Zach scanned the crowd for infants so he could hand the candy to them and say “hi” to them—he likes babies more than any child I have ever seen. If I pointed out other people who wanted candy he would give them some cheerfully and try to talk to them, but his focus remained on finding babies, and this slowed him down further.

There are good reasons to have someone with DS in social groups such as scouts with similarly disabled individuals. One mother pointed out to me the reality that typical friends that children make in school will eventually grow up, move away to college, get married and start families. Zach’s friends with similar disabilities will be more likely to experience similar life arcs and perhaps maintain lifelong friendships. We also knew from his experiences with the baseball team that he still gained an important sense of belonging from being part of the group, irrespective of the amount of disabilities in that group. If the sense of belonging is the most
important part of an experience, why was I making him go on this long walk that his uniqueness was making longer?

Zach was now about 150 feet behind his troop and in danger of being passed by the float behind him. That float was a dance school that was periodically stopping to perform so that gave us some extra space. Surrounded by a few hundred observers on each side, I contemplated how to get him to catch up without making a noticeable scene. Tossing him over my shoulder would be the quickest. He would usually think that was funny but might not in this circumstance. We could just slip into the crowd and call it a day, but that would send a message about quitting that it didn’t seem parentally responsible to do. I elected to give him a shoulder ride, which he always loves but is almost too big to do. That seemed to fit with the zeitgeist of a parade as well.

The problem some would see with joining a troop of only special needs scouts is the message that you belong only with others with a disability. Separate but equal has been suggested as a solution many times in history but never seems to end up being quite equal. The scouts by policy and practice are most welcoming to anyone with any disability. The scoutmaster and I are free to make accommodations to any requirements we see fit, so Zach has the same ability to earn merit badges and awards as anyone else. Based on the joy he finds from his baseball and cub scout uniforms, I’m sure he will enjoy earning patches and so forth from these activities. What I do not know is what will happen when he and the other boys notice he is not doing the same work they are to earn the same award. Will he feel as if he belongs less?

We made it through the whole parade with a few more delays. Three times Zach stopped to talk to girls he knew from one of his classes at school. One girl from his mainstream class walked into the parade to give him a hug and say she hoped he was having a good summer. The parents of another girl gave him a flag to carry. After we ran out of candy, he walked down the edge of the street high-fiving everyone who would extend their hand. He survived but started asking me to “get the car” at about the one-mile mark—his way of telling me he was tired. Afterwards his scoutmaster asked how he did, and I told him I’m pretty sure Zach got the most hugs and attention from the girls, a fact the other scouts might appreciate more in a few years.

How have I resolved the question of whether he would be better served in a pack with typical or special-needs scouts? I thought about the story of his life and how he has fit in to other
groups, and how I hope he fits into the world in the future. At home he is much less handicapped than his sister. He is the child in our family who can walk, talk, help dad with chores, and help his older sister. At school, to this point, he has always been among the least disabled in his special education classes. Especially among children with DS, with whom he identifies strongly, he is one of the most fortunate I know as far as health and intellectual functioning. He does well in that role, but my hope for both my children is what they can do outside of our family and away from others like him; I want him to understand he has a place even when his disability is most evident. What I intended to teach him by walking in that parade and all the other things he will later struggle with in scouting is that even when he is 150 feet behind, he is still part of that parade, and he is still wearing that uniform. He is not doing exactly what the other scouts are doing, but he is still bringing a smile to the face of the parents of the babies; and together with his friends from school who greeted him, he is showing a street-full of parade viewers that things are changing rapidly and positively for those with ID.
The previous chapters have provided insight into how the processes of resilience have made a difference in my life and hopefully in the lives of my children. The ability to comprehend, classify and describe what has happened to them through diagnosis and formalized assessments provided but a starting point. The ultimate task of resilience is to reconstruct a story for their lives that includes love, beauty and purpose, all of which contribute to the larger society. When professionals such as doctors and therapy specialists interact with families in such circumstances, they are most valued in the early stages of this process where the concrete details of genetic tests and MRI’s provide orientation as to what has happened to the child who was hoped for. The results of a chromosome test or an MRI image showing evidence of a prenatal stroke give a manner of explanation of what has caused this child to be born this way. The options for therapy and other treatments can provide some hope for mitigating the lost hopes for the child with disabilities, but there usually is no actual cure that will remove the disability completely.

Schools and other formal support systems of our society provide professionals who possess impressive technical knowledge about remediating disabilities and including people with disabilities in society, but there seems to be an assumption that overcoming the disability is the only goal that will lead to being part of society. Even when such professionals are at their best, they are still applying generalized knowledge to the highly individualized, personalized and emotional situation of raising children. My belief is that this latter point causes much of the disconnection and the occasional discord that arises. Parents insist that other people just don’t understand, while the professional believes the parent is not listening, trusting, or is just delusional. So is there a way to resolve or at least mitigate this discord?
Narrative Medicine

Dr. Rita Charon is a primary care doctor who also holds a doctorate in English. She has written and spoken about the program in narrative medicine she has developed at the College of Physicians and Surgeons of Columbia University. The idea of narrative medicine is to train doctors to think of their patients in terms of the stories of their lives, and likewise to think of themselves as professionals in terms of the narrative they themselves are living out. One particular exercise is the Parallel Journal. This is a journal the doctors keep that includes everything that does not fit on the medical chart, including what they know about the patient’s history, what they learn from the patient’s silences and facial expressions, and they are feeling and intuiting as a result of the interactions. These journals invariably read like narratives, and the doctors participating in this exercise meet to share their stories. Dr. Charon is able to use her knowledge of writing and storytelling to further analyze these stories for what their literary qualities reveal. For example, why did the doctor switch from third-person to first-person at a certain point in the story? Some of the literary analysis is beyond the scope of this discussion, and I don’t expect my children’s doctors to be as fond of writing about them as I am, but the idea she has developed about the purpose of medicine is salient. In a speech available on the TED website she asked,

“What is medicine for? To donate the expertise, to an act of fidelity to give someone company. And to form staunch sturdy affiliations within our clearings, within our dyads … so no one has to be in the glare of sickness, or even death alone.” (Charon, 2011)

She is talking mainly about extremely ill individuals, but the paradigm extends to all the doctor-patient relationships and beyond. Saying that the doctor becomes your friend is going too far, but framing the doctors as allies in your story who “donate their expertise” to the cause creates a more personal dynamic than medicine has historically done. I imagine that parallel charts are one way to do this, but it is of benefit to all parties when doctors are able to communicate by attitude and attention that they value the entirety of the patients story.

I don’t know if my family doctor has ever heard of narrative medicine, but I believe the question she asked about whether we regretted not doing the amniocenteses was her attempt to
let us complete a narrative. We made a decision that had some consequence, but her question let us consider the alternative narrative. My suggestion for a follow up question a doctor could ask would be “Do you know anyone with Down syndrome?” Knowing someone with Down syndrome is quite different from knowing about Trisomy-21. Most local Down syndrome advocacy organizations have volunteer parents who will visit families with newborns with DS to address this informational deficit. I would also suggest something the parents may not be ready to hear but need to hear, the words: “Congratulations on your baby”.

Eventually a doctor will probably need to tell parents or the child something they don’t want to hear; and hearing such news from an ally who knows your story is beneficial. Last month I took Kelsey for her annual visit with a well-regarded orthopedist at the children’s clinic we frequent. This gentleman also teaches at the local land-grant university, and I understand has authored several textbook chapters on the topic of children’s orthopedic problems. In short, of all the doctors we have seen he has the highest credentials to be allowed latitude to be aloof and dismissive. When we sat down he began with his customary inquiry, addressed to Kelsey, about what’s been going on. From experience we know what she likes to tell people about, so I engaged the doctor in conversation on Kelsey’s behalf.\textsuperscript{13} The doctor and I talked about her newly pierced ears, her recent first haircut, and how she donated her hair to a girl who got sick and lost her hair.\textsuperscript{14} He remembered that she likes horses and asked if she rode this past summer, to which she responded with an enthusiastic non-verbal affirmative expression that he understood. From a purely scientific perspective this is trivial information, but I felt much better when he later told me the X-ray confirmed she had mild scoliosis. The fact that he knew she loved to ride horses meant he could understand one of our fears about such a diagnosis. From the conversation about the hair and earrings he knew she was aware of her appearance and would be concerned about changes in how she looked. Even though none of this was discussed, the fact that he knew a little bit about my daughter meant he was more of an ally who cared about her horses and earrings in addition to his professional expertise.

\textsuperscript{13} Families and close caregivers usually develop a relationship where they act as a communication proxy for the person with severe disabilities. See Hostyn and Maes for a literature review of this communication process.
\textsuperscript{14} This was through the “Locks of Love” program which makes wigs for individuals who have lost their hair due to chemotherapy or illness. These wigs are made from donated human hair.
The doctor told us the curvature was mild and unchanged since last year, and it would be something that we would need to monitor. I mentioned that Ann and I both had worked as support staff for adults with severe scoliosis and knew it could be serious. The doctor jumped right into my story and realized I was imagining surgeries, metal rod implants, and full torso braces used to treat severe cases of this condition. He re-iterated that she was quite a ways away from needing such interventions and provided some specific facts to reinforce that idea, including the most relevant fact that she had experienced no loss of mobility or function. The point is that knowing a bit about our lives helps this doctor be able to place what he is telling us in our context and intuit the personal meanings of what he is telling us.

Dr. Charon tells the story of a patient who, without an appointment, interrupted her busy day with an abrupt and rather inappropriate request to sign a particular disability form. Following her intuition, Dr. Charon brusquely signed the form and hurried along on her day. That evening she constructed a possible story that explained why the patient needed that form signed so expeditiously—the patient needed the disability payments to start a new life as an actress. This forced Dr. Charon to see the patient differently, as someone with a dream for a better future and as someone worthy of an ally rather than just as a demanding patient. Dr. Charon later found out the patient desperately needed the disability payments to escape an abusive relationship. Commenting on this anecdote, she writes “Although I did not know what had preceded her visit that day, I had wordlessly registered her urgency and need to leave home. Until my impressions were expressed in language, I did not know what, in fact, I knew about the patient” (24). In my view, Dr. Charon already knew what she needed to know as soon as she decided to sign that form. To help alleviate this disconnection between families and medical professionals, I suggest that medical doctors, occupational therapists, nurses and other specialists pay attention to what they already know intuitively about the people and families they work with.

In education: finding a vision

There are some similarities in the paradigm of how parents tend to interact with school and how they interact with medical personnel. Both are people with training and expertise in a variety of areas who are seeking how to apply that training to individual circumstances or contexts. An important distinction is that usually those with severe disabilities will not interact with doctors without family members or others being present, whereas special education teachers
and others spend hours every week with the individual with disabilities. Kelsey and Zach’s teachers are around them in social situations difficult to replicate outside of school, and as a result their teachers have their own ideas or stories about how Kelsey and Zach belong and what they can accomplish. The narrative the teachers work from must be balanced between both complying both with what the regulators expect and what the parents reconstructed narrative is hopeful for. I think this balance is best achieved when the parents and school are able to communicate and share a vision for the child’s life.

A vision is different from a story of purpose in that it orients towards the future. It is not how I see Kelsey and Zach now, but it is the wisps of imagination of what they could be. A vision is a story everyone can come to enough agreement about that it gives a direction to move toward. It then makes the daily decisions easier because everyone is moving toward the same goal. If hikers all agree they are moving west they will keep moving toward the sunset regardless of the details of the terrain.

As I’ve shared, part of my vision is the growth others can experience because of their interactions with Kelsey and Zachary. Suppose there is a school assembly and Kelsey is attending and making an inordinate amount of noise—(when she becomes excited she has a hard time containing herself). There is no hard and fast rule agreed upon regarding what to do in this situation, so the helper or teacher must make a decision about whether she should stay, leave, or just try to calm down. To be congruent with my vision, the question of what to do is not based on whether she is acting like the typical children around her are, but on how they are responding to her. If it is clear she is annoying or frightening them—she does kick her feet when excited—she should probably leave. Annoying and frightening her classmates, and allowing them to think she has the right to do so, does not create the kind of experience that seems congruent with my vision. If they are amused by her antics and she is not critically disturbing anyone she should probably stay and be helped to calm herself. The details of what is happening on a particular day are not as important as the hope that everyone understands what our story for her life is and our hopes for who she will be.

There are many chances for parents to share this vision and also glimpse the vision that the teacher and others might have. The regular conferences and educational plan meetings are one opportunity. Regulations require that teachers report progress on measurable goals, but the
entire conversation need not revolve around that. The stories you tell about home, the questions you ask, the silences you share, and the excitement you show all paint a picture of the story you have constructed for your child. Likewise what the professionals talk about and the way they talk reveals something about the story they have developed from knowing your child and others like them. As parents, you should always make statements about the hopes you have for the future and keep the focus on the vision rather than on the immediate situation. It is safe to assume that most professionals working with children with disabilities only want the best for them, and it is the parent’s role to help everyone discover what “best” means for their child and family.
Conclusion: A Vision for Society

There is one story or vision that hasn’t been addressed: the overall story of our society and their responses to disability. There have been some unfortunate episodes in American history regarding the treatment of those with ID—e.g. the eugenics movement, institutionalization, and blaming the parents for their child’s disability. There is an older vision, however, one from the Middle Ages in the Belgium town of Geel. In the 13th century, pilgrims began to flock to the shrine of St. Dympha—the patron saint of the mentally ill—to seek healing for their family members suffering from what we now call mental illness and intellectual disability. The shrine became overwhelmed with pilgrims, and so the parish priests arranged for the ill persons to stay with the townsfolk. Until the present day, families in Geel have provided what we would call foster care for those with such disabilities. Hundreds of years before medicine, education and social work addressed caring for those with such conditions, a parish in Belgium found a place for those with ID working on their farms and in their homes (Roosens). An ethnography done in the 1970’s reported that those with disabilities moved freely around the town with little note being taken of unusual behaviors such as hallucinations or seizures. Many of the host families had been taking in boarders for centuries and had developed methods of both managing difficulties and creating connections without the benefit of formal training about disabilities.

The information on Geel is regrettably incomplete or in a language I cannot read, but it is the seed of the vision I have for our society. It would be similar to Geel in so far as everyone is comfortable with intellectual and other disabilities, and yet at the same time the expertise of the professional would be valued but understood in its proper role—as a guide on a difficult journey. I dream of a Geel, USA, where it is assumed that everyone has a place regardless of their apparent limitations. A place where those without disabilities come to learn that it is everyone’s responsibility to help those with disabilities belong to society, and not just something best left solely to the experts. We will live in my metaphorical Geel when my children’s disabilities are noted no differently than their Irish heritage—a characteristic of note but not an attribute that has much to say about who they are. I have seen glimpses of this in my life—starting with my early years before I understood what my sister’s disability meant. Another glimpse came when I sat
with Kelsey on a grassy bluff and enjoy sharing the world as she sees it—irrespective of what others are accustomed to seeing. I saw Geel again when we moved to our new neighborhood when two sisters knocked on our door and asked to play with Kelsey. It does not require any special training to greet someone with a disability, ask about the weather, or to let them and their family know you appreciate that they are all an integral part of our society.
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