Congratulations on making it to 9th grade! Please find enclosed a packet relating to a particular subject.

Please note: The readings and videos may challenge your perspective. That's alright. Whitman High School does not intend to push any particular agenda. Use this opportunity to expand your perspective and build a stronger foundation for your reasoning.

You are not required to subscribe to any particular perspective; feel free to respond to each reading as you see fit in your journal entries.

Best of luck!
The English Department congratulates you on reaching this milestone in your academic journey! To help prepare you for the rigors of high school, the 9th grade teachers have chosen summer reading texts that we hope will entertain and challenge you.

**Directions:**

1. Choose **ONE** of the following topics:
   - racial prejudice/race relations
   - cycle of poverty
   - gender roles
   - bullying
   - intellectual disability
   - euthanasia


3. Thoughtfully read and watch each piece.

4. Carefully select, print, and read your own interesting article or essay about the topic.

5. For **EACH** essay, article and video, write a journal entry in the chart provided. (Each entry must be ½ - 1 page, in 12 point Times New Roman, double spaced.) Include two or more of the following in your journal entries:
   - a brief summary of the piece
   - your opinion about the issue and/or the article itself. Please, note: You do not have to agree with the author’s argument.
   - connections between the piece and your life, your observations, current events, history, a piece of literature, etc.
   - revelations, insights, questions, ideas, and feelings that you have as a result of reading the piece.

***Refer to the model journal entries.

6. Print your journal entries and be prepared to hand them in on your first day of high school!

**Assessment:**

In addition to handing in your journal entries on the first day of school, you will demonstrate your understanding of the reading throughout the first month of school.
When Bill met Shelley: No disability could keep them apart

McCarthy, Ellen

“If you’re that in love, age doesn’t mean a thing. Even though my mind was young and my heart was young — somewhere inside my head I was mentally old enough.”
–Bill Ott

“You know that scene in ‘Dirty Dancing’ where Baby meets Johnny for the first time? It was kind of like that.”
–Shelley Belgard

***

BILL OTT WILL always remember the moment he met Shelley Belgard. It was in spring 1988. He was 12 and sometimes shy. Into music, sports and, suddenly, girls.

Shelley was three years older, chatty and outgoing. They’d both shown up at a Montgomery County social club looking for friends, fun and the kind of acceptance that seems so elusive during teen life.

Shelley smiled. Bill introduced himself. And that was it. “I didn’t know what love was,” he says. “Until I met her.”

He was sure it was the real thing, but nobody ever believes that coming from a 12-year-old.

Certainly not one with Down syndrome.

But Bill knew. “If you’re that in love, age doesn’t mean a thing,” he says. “Even though my mind was young and my heart was young — somewhere inside my head I was mentally old enough.”

And the feeling was mutual. “You know that scene in ‘Dirty Dancing’ where Baby meets Johnny for the first time? It was kind of like that,” remembers Shelley, a petite brunette who was also
born with a mental disability. “You’re looking at this awesome-looking guy, and you really don’t want to blow it. You kind of want to play it safe and not play it safe at the same moment.”

He lived in Silver Spring and she was in Potomac, so they exchanged phone numbers. Their parents would drive them to movies and one another’s houses. They frequently met at the social club. Throughout high school, they stayed close.

Bill took Shelley to both his junior and senior proms. Each time he rented a tux, and she picked out a fancy new dress. They wrapped their arms around each other to pose for photos and danced all night long. Bill, who grew up going to Catholic Mass every Sunday, told Shelley’s mother he would convert to Judaism if that’s what it took to be with her.

But after high school, it became more difficult to remain in each other’s lives. They moved into assisted-living programs in different parts of the county. There weren’t as many social activities to bring them together and, eventually, they lost contact.

But Bill never forgot. He had known true love — her name was Shelley.

***

THEY CALLED IT “water on the brain,” and Gail and John Belgard were told that their firstborn would die early and never be functional.

Fluid was building up inside the infant’s skull, wreaking havoc on her brain. It was 1974, CAT scans had just been invented, and there were approaches to treat hydrocephalus but certainly no cures. Doctors said the baby would live for six months.

“But she kept not dying,” recalls Gail, a psychologist who, like her husband, grew up in Louisiana.

They were living in Houston at the time, and, despite Shelley’s persistence in the world, experts at Texas Medical Center insisted Gail and John not take her home. But after nine months, they’d had enough. Their daughter was living, they reasoned, so she might as well live at home.

By the time Shelley was 10 years old, she’d had 29 surgeries. Surgeons put in shunt after shunt to drain the excess fluid from her brain. At 5, she had a craniotomy that lasted through the night and nearly caused blindness.

Despite it all, Shelley was a happy, effervescent little girl. Her verbal and motor skills were delayed, but once she started talking, she never stopped. Once, while in the hospital on her
10th birthday, she tried to bargain her doctors into releasing her for the day, but they didn’t budge.

Gail and Bill never knew what Shelley’s life would be like in a year or two years, never mind into adulthood — if, God willing, she made it that far.

“You know what was nice?” Gail remembers. “People have all these expectations of their children or wishes for their children — to go to Harvard or whatever. For us it was, ‘Shelley learned to tie her shoe! She learned to feed herself! Gee, she’s walking!’ Everything was great. Whatever she was doing was great.”

In the early 1980s, the Belgards, who by then had two younger sons, moved to Potomac. Gail had grown frustrated with the opportunities available for Shelley in Houston, so she searched the country for a place where their daughter would have the best chance to grow and make friends. They settled on Montgomery County.

All Gail and John wanted was for Shelley to have the most normal life possible. They knew she would never drive, have children or go very long without a doctor’s visit. But she had proved herself more than capable of learning and loving. So even at Shelley’s bat mitzvah, the Jewish ceremony that marked her transition to womanhood at 12, Gail insisted the rabbi recite the normal prayer that he’d meet Shelley again one day under her wedding chuppah.

In Montgomery County the Belgards found public school programs tailored to people like Shelley, high-functioning individuals with intellectual impairments. There were after-school programs and social clubs where she made dozens of friends. She went to seven proms and never lacked for weekend activities.

“I felt like I had died and gone to heaven when we moved here,” Gail recalls.

Shelley flourished at Walter Johnson High School. She took some classes with the general student population and others through a special education learning center. She loved to read and write. Math came harder, but with the help of dedicated tutors she graduated with a full diploma and stayed on to participate in a two-year job training program.

Then came the new hardest part: figuring out the rest of Shelley’s life.

The Belgards were unsatisfied with the special-needs living options available: Some provided too much assistance; others offered too little. So Gail and the mother of one of Shelley’s friends worked to set up a program that would suit their needs. They lobbied for state funding, found a company that provides services to high-functioning people with disabilities, and rented a dozen
apartments in a building in North Bethesda. Sixteen young adults picked roommates and moved in with the help of graduate students who would serve as counselors and aides.

After stints at a few other places, Shelley found a full-time job in the mailroom of a medical association. She got involved with a weekly theater program, was a fixture at the social gatherings put on by the assisted-living program and saw her family several times a week.

It was what her parents hoped for — the most normal life imaginable.

Still, it was lacking. When she was sick, no one rubbed her back until she fell asleep. Sometimes she had stories to tell, and there was no one to listen. Her roommates didn’t stay up worrying if she was late getting home from work.

Shelley was lonely.

***

BY HIS MID-20s, Bill was living with a couple of guys in an apartment on the other side of Bethesda. Aides would drop in occasionally to help the three men, who all had intellectual impairments, do chores or go shopping, but for the most part they were on their own.

Bill had held a part-time job at Giant since he was 16 and was an expert at getting himself around on public transportation. Though he didn’t walk until he was 3, he grew up to be a wrestler at Springbrook High in Silver Spring. He slogged through all the tests required to earn a full diploma, took up guitar, became an ardent Redskins fan and learned a handful of sayings in other languages so he could greet Giant customers in their native Farsi or Spanish.

“He has a tremendous memory,” says his mother, Mary Ott, who still lives in Silver Spring with her husband, Ed. “And he’s always been very concerned about people — very people-oriented.”

Bill had always been a romantic, too. He often talked to his parents about marrying someday, about having the kind of relationship they had. After losing touch with Shelley, he dated a few other young women, but nothing seemed quite right. He felt controlled by some of the women, judged by others.

For several years Bill was among a couple of dozen local people with disabilities who went on an annual Caribbean cruise with chaperones. In 2007, Shelley signed up for the trip. Gail Belgard still remembers how excited Bill was when he saw Shelley at the orientation meeting.

But once they set sail, Shelley was overcome by seasickness. Because she was unable to leave
her cabin, a chaperone asked for a volunteer to keep her company. Bill’s hand shot into the air. “I’m staying with her,” he declared.

“I want to be Shelley’s hero,” he would say later, recalling the moment. “I want to be her avenger.”

That December, he told his parents he wanted to marry Shelley.

“I just kept coming back to her,” Bill says. “Who was the woman who would not prejudge me from the outside and look inside? I knew Shel would. So I came back to her.”

He took her to dinner once, and another time they rode the bus to Montgomery Mall. They one-upped each other with puns. Sometimes Shelley struggles with balance, so she took his arm as they walked. For her birthday in January, they celebrated at a Mexican restaurant. Knowing Shelley liked to read in bed at night, Bill gave her a book light. Then he pulled out another little box. Inside was a small ruby ring he’d bought with savings from the grocery store.

“Shel, will you marry me?” he asked.

She immediately said yes and raced home to tell her roommates. When Bill announced the engagement to his parents, they weren’t sure what to think. They knew Bill was serious, “but we had to see how it would work out,” Mary says.

Shelley’s parents were equally skeptical. “I just thought, ‘This, too, shall pass,’ ” Gail remembers.

But it didn’t. Shelley and Bill stuck together for years and continued to insist their love — and engagement — were real. Bill took the bus to see her almost every week. They spent holidays together, held hands and made up pet names for each other. They pushed, again and again, to marry.

“It’s like going into a new venture — flying into the world. That’s exactly how I think of getting married,” Bill says. “It’s like two eagles flying into the sky together.”

***

HAD THEY BEEN born a few decades earlier, Bill and Shelley might have been institutionalized. Even if their parents had fought to bring them home, their life expectancy probably wouldn’t have stretched much past their 20s. But today people with intellectual impairments often live into their 60s or later, and many have lives that include jobs, active social calendars and no
small measure of independence. With increasing frequency, they seek lifelong romance.

Experts say it’s difficult to track the number of couples with intellectual impairments, because they often enter into committed relationships without getting married. In many instances, a legal marriage could interfere with Social Security or health-care benefits. But the intellectually impaired and their advocates say it should surprise no one that they often possess an abiding desire to find a partner in life.

“There is a bias in our society that is unfounded — that just because you have Asperger’s syndrome or you have Down syndrome that you automatically cannot sustain a relationship. But that’s just not true,” says Philip Davidson, a professor of pediatrics at the University of Rochester School of Medicine and Dentistry who has studied developmental disabilities. “These people are really not all that different than you and me. Their investment in the lives of other people are as significant as yours and mine.”

In the past, stigmas against people with intellectual impairments led to forced sterilization and laws prohibiting them from marriage. In some states those laws remain, though they are rarely enforced. Sexuality continues to be a complicated issue inside and outside the disabled community, especially when it comes to a disabled couple’s ability to care for children. But the value of a committed relationship can’t be overestimated, say people with developmental disabilities and their families.

Liz Weintraub, a 46-year-old Rockville woman with an intellectual impairment, married her husband, Philip, seven years ago. They met at an advocacy picnic, and it was “love at first sight.” She always wanted to wear a white dress and walk down the aisle just as her sister had done. But what came after the wedding was even more significant.

“It’s the company,” she says. “Knowing that I have someone that I can talk to every day. That I can love someone. And that somebody can love me back.”

***

AFTER TWO YEARS of dating, Bill became Shelley’s roommate. He had his own room and a separate bed, but they were together. And it wasn’t exactly easy. In the beginning, Bill would come home, say hi to Shelley and retreat to his room to watch television for hours. Shelley would get upset, sometimes so mad “that I nearly threw this ring right at him.”

“Getting used to living with Shel was a big trial for me,” says Bill, who is broad-shouldered and friendly, quick to offer a wide grin and a bear hug. His speech is sometimes slowed by a stutter but is almost unfailingly thoughtful and poignant. “That was just me trying to get from one part
of my life to another. It was a big transition for me, because I was living with guys. Guys watch sports. Guys watch TV. What guys do is what guys do. They watch TV in their underwear. Now I know to keep my pants on.”

The pair began seeing a couples therapist every week. They say the therapist helped them learn how to share, listen to each other and respect one another’s personal time and space. And he helped convince their parents they were ready for marriage. Gail Belgard was the last holdout.

“We all need to learn to be in a relationship, but it was much more severe,” she says of Shelley and Bill’s evolution as a couple. “I wanted to make sure this was the right person for Shelley.”

The couple frequently came to dinner at the Belgards’ house, and as time went on, Gail could see the warmth and depth of emotion between them. Bill learned what to do when Shelley had an epileptic seizure. Shelley helped Bill quit his fast-food habit and cook more at the apartment. They both loved board games, trivia, music and movies. They were attentive, affectionate and deeply concerned with each other’s needs.

And they complemented each other even in their disabilities. Shelley, now 38, has problems with visual perception and gets lost easily. Bill, 36, has a tremendous sense of direction. When Bill is grasping for a word, it’s often on the tip of Shelley’s tongue.

And, above all, they’re in love.

“When I see her, she’s like a bright penny,” says Bill, who tucks his T-shirts into his jeans and wears a belt beneath his round belly. “She’s like the color of orange, like a real joyful, lively spirit. Her love is like pink. There is so much good in her that I really fell in love with.”

“Awww, honey,” Shelley says, blushing and pushing up her red-framed glasses. For her, she adds, the real gift is being “with someone who understands me. When other people think I’m talking in circles, he knows what I’m talking about. I don’t have to explain it. He just gets me.”

By the end of 2011, wedding planning had begun. It was decided that this would be a commitment ceremony, rather than a legal exchange of vows, because Shelley’s health insurance could be jeopardized if she married.

But everyone involved considered it an official wedding. Shelley and her mother shopped for a wedding dress and picked out invitations. They hired the band that played at her bat mitzvah. Bill and Shelley decided the colors for the wedding would be red and white. Red symbolized passion; white evoked purity, because the two decided to hold off on sex until after the wedding.
And last Sept. 2, Shelley walked down the aisle of the Bethesda Marriott to meet Bill under her wedding chuppah. She wore a strapless dress with crystal beading, a glittering tiara and red cowboy boots as an homage to her Texas roots. Bill’s chest puffed with pride as he smiled at his bride. A rabbi and a priest presided over the ceremony, asking the pair if they would be committed to each other in good times and bad, sickness and health.

Later that day, they spun around the ballroom. For their first dance, they chose the Etta James ballad “At Last.”

***

A COUPLE OF weeks after the wedding, Bill stayed out late at a friend’s place and forgot to tell Shelley where he would be. She was worried and so furious when he came home that she was tempted to call it off. She didn’t, of course, because she understands the importance of commitment, and, besides, the anger soon passed. That night she slipped into bed next to Bill, as she has every night since they said “I do.”

Their life is one of overarching love and joy, but it is not perfect. They continue to meet with their couples therapist every week. They are still finding their comfort level with sexuality and working to strike the right balance between independence and togetherness.

But as they sat together in December, watching a video of the wedding ceremony, Bill’s eyes welled up with tears and Shelley stroked his arm. “You were so handsome, honey,” she said.

“I know,” he replied with a nod.

“Don’t worry,” she added. “You’ll always be handsome.”

Their modern apartment, with granite countertops and French doors, is filled with family photos, board games and Redskins paraphernalia. Shelley has worked at the medical association for 15 years; Bill has been with Giant for 20. In the mornings and evenings, their counselors come in to offer hugs, help with cooking and make sure Shelley has taken her pills. Often the couple gathers with friends in the building to watch movies or share a pizza in honor of someone’s birthday. Each month their calendars are marked up with happy occasions.

Still, there are moments of great sadness. Shelley, in particular, is acutely aware of her impairment in a way that many people with intellectual disabilities are not. Gail remembers riding in the car with the couple once and hearing Bill ask whether she would choose to be born without an impairment, if she had the chance. “Of course!” Shelley exclaimed.
“‘Well, I wouldn’t, because it’s fine,’” Gail remembers Bill saying. “But it’s not fine with her.” But on most days Shelley’s sunny disposition shines through and she makes the most out of life, regardless of her disability. “I didn’t choose to be born with hydrocephalus, and there’s nothing I can do to change it,” she says, shrugging.

Bill and Shelley, along with their parents, decided that Bill would get a vasectomy before the wedding. Their conditions are too severe to healthfully have a child. But Bill especially mourns the loss of children they’ll never have.

“I’m such a loving person,” he says, arms heavy on a table in the community room of their apartment building. “I have so much love to give. Shelley is such a loving person. And fatherhood is such a big thing to me.”

But he knows they are a family, even without children. To him, the best part wasn’t wearing a tuxedo to the wedding or dancing at the reception or even going on a honeymoon cruise to Mexico. The best part, he says, is just to “live with a woman who I’ve loved ever since I met her.”

And everyone in their orbit is acutely aware of how much richer their lives are because of each other. On a recent trip with the Otts to visit family in Ohio, Bill’s parents were struck by how well the two got on, even for long, boring stretches of travel. “You could see how happy they were together,” Mary Ott says. “You could really see it.”

Shelley’s father, John, is stopped short by tears when he talks about what his daughter has found with Bill.

“You want your children to be happy,” he says. “Having a mate — someone who really cares if you come home at night, someone who cares whether you’re well or sick — that makes life worthwhile.”

“Yes,” Gail adds. “She’s not lonely now.”

Welcome to Holland

Kingsley, Emily Perl

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."
And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

FANS of "Of Mice and Men", the 1937 novella by John Steinbeck, will recall the character of Lennie Small, an oafish, dim-witted man whose physical strength is ill-matched to his love of rabbits. On November 29th, in a remarkable example of law imitating art, a hearing at the Supreme Court put Lennie back in the spotlight. The question is whether the fictional man's intellectual profile should help determine the fate of Bobby Moore, a real-life Texan awaiting execution.

Mr Moore, a man with an IQ in the 70s, was sentenced to die 36 years ago for killing a store clerk during a robbery. In 2014 Mr Moore had his death sentence revoked after successfully making a claim under Atkins v Virginia, a ruling of 2002 banning the execution of intellectually disabled people. But a year later the Texas Court of Criminal Appeals (CCA) sent him back to death row. The quarrel in Moore v Texas is whether the CCA used the right standard when it decided that Mr Moore--who at 13 could name neither the days of the week nor the months of the year, nor distinguish between addition and subtraction--is too clever to qualify for an exemption.

Clifford Sloan, Mr Moore's lawyer, argued that Texas's "unique approach" to measuring intellectual disability relies on "harmful and inappropriate lay stereotypes" which are "anti-clinical" and contradict the "core holding" in Atkins. In response, Scott Keller, the Texas solicitor-general, noted that the justices largely left it to the states to decide who qualifies as mentally retarded, or, in today's parlance, "intellectually disabled". The CCA, Mr Keller maintained, dutifully applied the three-part test endorsed in Atkins: low IQ, deficits in "adaptive functioning" and onset before the age of 18. The Texas court could not be faulted, he said, for turning to one psychological manual rather than another to flesh out the first two parts.

Mr Sloan's rejoinder to this claim was embraced by the four liberal justices and, it seems, by Justice Anthony Kennedy, the fifth vote Mr Moore needs to avoid execution. In Hall v Florida, a case from 2014, the Supreme Court ruled that standards for intellectual disability must be "informed by the medical community's diagnostic framework", and may not disregard established medical practice. But in evaluating Mr Moore's case, Mr Sloan noted, the Texas appeals court bashed the district court for relying on the current manual of the American
Association on Intellectual and Developmental Disabilities. Instead, the CCA flipped back to an old standard from 1992, plus a list of seven factors springing, apparently, from the minds of the judges. None of the factors (including whether the person "can lie effectively" or "formulate plans") included a single citation.

Justices Stephen Breyer, Elena Kagan and Sonia Sotomayor zeroed in on the CCA's comment that as intellectual disability standards are "exceedingly subjective", they should be geared not to clinical standards but to the "level and degree of mental retardation at which a consensus of Texas citizens would agree that a person should be exempted from the death penalty." This idea alarmed Mr Breyer. The will of the people of Texas, he said, "has nothing to do with it." Standards for intellectual disability should be fashioned from the views of medical professionals, he implied, even if a rule that works for all 50 states is hard to come by.

Ms Sotomayor pressed Mr Keller to defend the CCA's reliance on Steinbeck's character to define who counts as intellectually disabled. One problem with fashioning standards after Lennie, Ms Sotomayor pointed out, is that the character seems just as capable as Mr Moore, who, as a teenager, made money cutting grass. "Lennie was working on a farm. How is that different from mowing a lawn?" And if Mr Moore's ability to hide weapons and lie disqualifies him from being intellectually disabled, why should Lennie be included? He sought to "hide the death of the rabbit he killed", Ms Sotomayor recalled, and yet he was held up by the Texas court as "not just mildly, but severely disabled".

Mr Keller tried to explain away the Lennie reference as a mere "aside" in a ruling that was otherwise consistent with both Atkins and Hall. But a majority of the justices seem skeptical that Texas's standards for measuring intellectual disability jibe with their precedents. Word on Mr Moore's fate should arrive in the spring.

“Novel Justice; Capital Punishment and Intelligence.” The Economist, 3 Dec. 2016, p. 23, Student Resources in Context, go.galegroup.com/ps/i.do?p=GPS&sw=w&u=beth96221&v=2.1&id=GALE%7CA472368151&it=r&asid=614325756dbb1ba4258890fb2c3b714d.
Better police training: learning to interact with people living with intellectual or developmental disabilities

Pollack, Harold

On January 12, 2013, Robert Ethan Saylor, a twenty-six-year-old man living with Down syndrome, went to see Zero Dark Thirty at a local theater in Frederick County, Maryland. He was accompanied by his attendant, Mary Crosby. When the movie ended, Crosby asked him if he was ready to go home. Saylor became angry, and Crosby called Saylor's mother for advice on managing the situation. Saylor's mother suggested that Crosby go get the car to give her son an opportunity to calm down.

While Crosby was gone, Saylor decided to go back inside the theater. He sat down in his original seat to watch Zero Dark Thirty a second time. Customers aren't supposed to do this, and he was asked to leave. Against Crosby's advice, a theater manager called three off-duty sheriff's deputies who were working security. Things got loud, and then physical as they grabbed the 300-pound Saylor and tried to drag him out. Saylor ended up on the ground in cuffs. He suffered a fractured larynx, and died. The Baltimore Chief Medical Examiner's Office ruled his death a homicide as a result of positional asphyxia.

The officers were never indicted. I believe that was the right call. I doubt these three officers had any desire to hurt Mr. Saylor, let alone to cause his death. That is precisely what makes such cases instructive and frightening. Indeed, the deputies' legal defense was that they had followed their training in their steady escalation of force.

Saylor didn't respond to the deputies' instructions in the way they wanted or expected and was clearly angry and frustrated, but he was sitting passively in his seat. They dealt with his disruptive and defiant--but non-dangerous--behavior by putting their hands on him when they could have kept their distance and waited for him to calm down or for more-experienced help to arrive. His attendant was available to assist them; his mother was en route. This situation could have been managed without force. Instead, as a judge concluded, Saylor died over a $12 movie ticket.
In this era of Black Lives Matter, protesters, ordinary citizens, policymakers, and police are trying to find common ground in improving police training and procedures to defuse potentially violent situations of all kinds. Everyone involved in policing also understands that officers require better training, policies, and procedures when they encounter people in behavioral crisis. Many police departments are raising their game to deal with crises that arise from severe mental illness. I myself am involved in two Chicago efforts to reduce the use of force by police in such situations.

Less attention is paid to men, women, and youth who experience behavioral crises involving intellectual disability, autism, communication disorders, and other disabilities. Sometimes, as with Robert Saylor, the disabilities are obvious. Sometimes they are more hidden, or are merely one element in the mix. A disturbing number of violent policing incidents involve individuals living with intellectual and developmental disabilities (IDD). Baltimore's Freddie Gray, for example, appears to have been cognitively harmed by lead paint exposure, and Chicago's Laquan McDonald experienced a complicated mix of mental health challenges and learning disabilities.

This issue is of some personal interest to me. My wife, Veronica, and I are the guardians of her brother Vincent, who lives with an intellectual disability called fragile X syndrome (FXS), the most common heritable cause of intellectual disability. Men with this disorder sometimes exhibit behaviors that may require interventions, including from law enforcement. In one national survey of caregivers of young people with FXS, one-third of parents reported that they had been injured, often repeatedly, by their sons.

Rebecca Feinstein and I recently surveyed forty middle-aged and older caregivers for individuals with fragile X syndrome. Personal safety was a common concern. One respondent had been pushed down the stairs and suffered a broken rib and punctured lung. Another reported, "He's not aggressive or violent just for the sake of it.... I know what triggers it. I spend the vast majority of my days working around knowing how to prevent something like that from happening." As long as the behavior was directed only at her, she had learned to live with it.

Some of the most poignant conversations occurred after the tape recorder was shut off. One mother described how her son had hurt someone in a random outburst and then fought with the police. I asked, "Why is he still living with you?" Her response was straightforward: The best residential placements won't take him because of these behaviors; the places that will take him include other young men who exhibit the same behavioral challenges. She was afraid for her son.
Caregivers' concerns are compounded by worry about how their sons might be traumatized, injured, or worse if they summon law enforcement help. They have good reason to be concerned; too many police departments haven't been educated on the issues associated with IDD.

Even positive or inclusive stereotypes don't always help. The population of individuals who live with IDD is diverse, experiencing conditions ranging from Down syndrome and other genetic disorders to the consequences of traumatic brain injury and fetal alcohol syndrome. Some of these disabilities are easily recognized, but others are more subtle or are accompanied by physical or psychiatric comorbidities, including some that bring them into conflict with others or into contact with police.

Basic improvements to training and procedures can make a big difference. Dr. Bruce Davis, the director of behavioral and psychological services at Tennessee's Department of Intellectual and Developmental Disabilities, and his colleagues offer useful strategies for officers to slow situations down, to use time and distance to keep everyone safe from avoidable physical confrontations. I asked Davis what he was trying to accomplish with this training. "One thing I try to do ... is to turn around the idea that the successful intervention is a collar, or an arrest," he said. "We turn it into the idea that a successful interaction is a de-escalation. We talk about quiet authority and how much more effective that can be in working with many people, particularly a person with intellectual disabilities.... It's a reconceptualization of the police officer's role."

Davis also teaches officers about some of the health problems that individuals with IDD may experience when they are physically restrained. One critical principle is to restrain resistant subjects on their sides rather than face down, and to monitor the restrained person's face for signs of distress. Many deaths occur because officers restrain someone in a prone position, and then apply pressure to the neck, back, or chest in ways that can cause lethal aspirations or positional asphyxiation. Many people with IDD experience respiratory disorders, GI reflux, or morphological defects that make prone restraints especially dangerous.

Sometimes, interpersonal conflicts occur at private residences or group homes because a staff member or caregiver has become overly controlling or has otherwise precipitated conflict. Davis related one case in which a group home resident became angry and unruly because the staff had gotten rid of his pet dog. Family caregivers and staff in residential facilities can also work with local police ahead of time, informing police of a person's specific disabilities and behavioral challenges and formulating a crisis plan.
Not long ago, Vincent wasn’t feeling well. He wanted to go to the hospital. So an ambulance was sent to his group home. As usual in such cases, a police officer arrived to help. At some point, Vincent decided that he wanted to slide from his chair onto the floor. The floor was cold and dirty, and Vincent is clumsy. So the officer tried to help by gently pushing on Vincent's shoulders to keep him in the chair. But Vincent didn't like that, and resisted. Fortunately, Veronica was there to help, and the incident was resolved peacefully. But it's scary to think about how this mundane occurrence could have instantly become life-changing for everyone. Vincent is a strong 250-pound man who doesn't always realize the consequences of what he does. My mother-in-law occasionally had marks on her arms because he would flail at her with the back of his hand when he got frustrated.

Vincent didn't pose safety issues in the three years he lived with us; he is blessed with a sweet disposition, and is wonderfully gentle with Veronica and our two daughters. Still, the possibility of behavioral crisis remains in the back of our minds, in the queue of anxieties and worries. As does our concern about whether it would even be safe or wise to summon law enforcement help.

Ending the R-word: Ban it or understand it?

Grinberg, Emanuella

Every time Ellen Seidman hears the word "retarded," she worries for her 9-year-old son, Max, who has cerebral palsy.

She wonders if people will ever respect him, or see him as an equal, if they associate that word with people like him, who have intellectual disabilities.

"I'm not saying that anyone who uses the word flippantly has something against people with special needs," said Seidman, a magazine editor and mom blogger. "But it is a demeaning word even if it's meant as a joke, because it spreads the idea that people who are cognitively impaired are either stupid or losers."

Seidman is not alone in her desire to see "the R-word" go the way of racial slurs once considered acceptable. More than 250,000 people have pledged online to take part in the Special Olympics' campaign to "spread the word to end the word." Many of them are expected to participate in Wednesday's annual day of action through pledge drives, fundraisers and individual acts to raise awareness.

For her part, Seidman created a short video that explains what the word means to her. She posted it on her blog, Love That Max, and share it through social media. Although people who know her know where she stands (and not everyone agrees), she hopes that the video will make people think about the weight of the word.

"It starts with thinking about a word, but I want it to translate into the way people treat others with disabilities," she said. "It's about helping to see people with cognitive impairments as great people, as competent people, as people who can contribute in so many ways to our society."

Launched by two college students in 2009, the campaign is gaining traction not only among the citizenry, but in the halls of government and the medical community. President Obama
passed Rosa's Law in 2010, which eliminates the use of the words "retarded" and "retardation" in federal health, education and labor laws.

The bill changed the terms "mental retardation" to "intellectual disability" and "mentally retarded individual" to "individual with an intellectual disability." This shift made the terms more consistent with language already used by the Centers for Disease Control and Prevention, the United Nations, and the White House. Currently, 43 states have passed similar legislation or have similar bills pending, according to the Special Olympics.

But policy is just one part of the strategy. The much larger goal targets social stigma and negative perceptions surrounding people with intellectual disabilities.

"You can't ban terminology any more than you can ban thought," said Dr. Stephen B. Corbin, senior vice president for community impact of the Special Olympics. "But we know that using bad language contributes to the dehumanization and stigmatization of others, which incites treating them differently."

On this point, some opponents of the movement agree with its supporters: Intellectual disability still carries a subconscious cultural taboo which attaches to the word used to describe it. But those who believe the movement is misguided and risky say the stigma will keep attaching to new terms until we purge negative connotations from the condition itself.

"All of this reflects the cycle of word taboo," said Christopher M. Fairman, a professor at the Moritz College of Law at Ohio State University and author of a book subtitled "Word Taboo and Protecting Our First Amendment Liberties." "We have witnessed this happen as the clinical diagnostic term 'mental retardation' became the offensive slur 'retard.' And so we will shift again, this time to intellectual disability."

Already, derogatory use of "ID" is starting to pop up, he said.

"By focusing on the word itself, you reinforce the negative connotation and actually strengthen the taboo," Fairman said. "The focus should be on the acceptance and inclusion of people with intellectual disabilities. This breaks down the cultural taboo that creates word taboo in the first place."

The idea of getting rid of negative perceptions is also at the top of Special Olympics' priorities. At the start of the millennium, Special Olympics President Tim Shriver began promoting the idea within the organization that stigma persists when the education system and media fail to release accurate messages about the population, Corbin said.
To get hard facts, the organization conducted a survey of 190 nations. Across all countries, more than one-third of the public believed that individuals with intellectual disabilities should work in special workshops, not in "mainstream" workplaces, the survey found. Worldwide, the vast majority of people believed that children with intellectual disabilities should be educated in special schools, separately from other children. A separate study of media portrayals determined that over time, depictions of persons with intellectual disabilities in film and TV focused more often on pity than on strength and achievements.

"Despite greater scientific knowledge, policy and societal changes, and the establishment of high-profile events such as the Special Olympics World Games, media accounts have continued to portray persons with intellectual disabilities in stereotypical, one-dimensional ways," said the authors of the study, which was released in 2005.

The organization's athletes began asking to change the language in Special Olympics policies, handbooks and literature to remove "mental retardation," which finally happened in 2004, Corbin said.

There are other signs that perceptions are changing for the better, he said. Project Unify, a partnership between the Department of Education and Special Olympics, lets special education students participate in team sports with general education teens. More than 2,000 schools in 42 states have unified athletic programs, with varying degrees of intensity. In the entertainment industry, actors like "Glee's" Lauren Potter are portraying characters with intellectual disabilities with depth and personality.

The push to cleanse the R-word from general conversation began to pick up speed in 2009, when two Special Olympics interns who were college students at the time decided to focus on the word. They engaged student leaders on college campuses to launch a day of action around pledge drives to stop using the word.

"There'd been plenty of movement within community to end the use word for years, but we decided we wanted student leaders to become the heart of the campaign," said Shriver, who was a Yale student at the time. "We recognized the pervasive use of the word among young people, but we also noticed an incredible desire among their peers to take on leadership roles and fight for the rights of people with ID."

More than 30 schools participated in the first day of action and each had its own approach, he said. Some students went classroom to classroom with posters for people to sign, others set up a fixed location with a table cloth for signing. From there, signees were directed to r-
word.org for tips on how to respond to the word when it came up in casual conversation and how to drive a conversation about it.

"One of the things we wanted to do was really simplify and strip down this message and say, our goal is to educate about consequences and lead people to a point where they can reflect and decide for themselves," said Soeren Palumbo, an MBA student at the University of Pennsylvania who has a sister with intellectual disabilities.

"To force people to change their language and conceptions might be close to impossible, and we recognize that, because in the beginning we were not as nuanced. We thought could do that, and in the beginning we got a lot of backlash. But we can tell you about how using this language keeps up walls between people and dehumanizes people with ID."

Seidman, the mother who created the video on how the R-word affects her, admits she used to use it before Max was born.

"It's hard to explain until you experience it yourself, and I think a lot of people out there just don't understand why," she said. "There's already a lot of prejudice and misunderstanding about people with cognitive impairments, and this is one small thing I can do to help."

Juicervose

Produced by Kelsey Padgett.

LISTEN TO PODCAST: http://www.radiolab.org/story/juicervose/ (45 minutes)

Ron and Cornelia Suskind had two healthy young sons, promising careers, and a brand new home when their youngest son Owen started to disappear.

3 months later a specialist sat Ron and Cornelia down and said the word that changed everything for them: Autism.

In this episode, the Suskind family finds an unlikely way to access their silent son's world. We set off to figure out what their story can tell us about Autism, a disorder with a wide spectrum of symptoms and severity. Along the way, we speak to specialists, therapists, and advocates including Simon Baron-Cohen, Barry and Raun Kaufmann, Dave Royko, Geraldine Dawson, Temple Grandin, and Gil Tippy.

TED

I’m Not Your Inspiration, Thank You Very Much

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