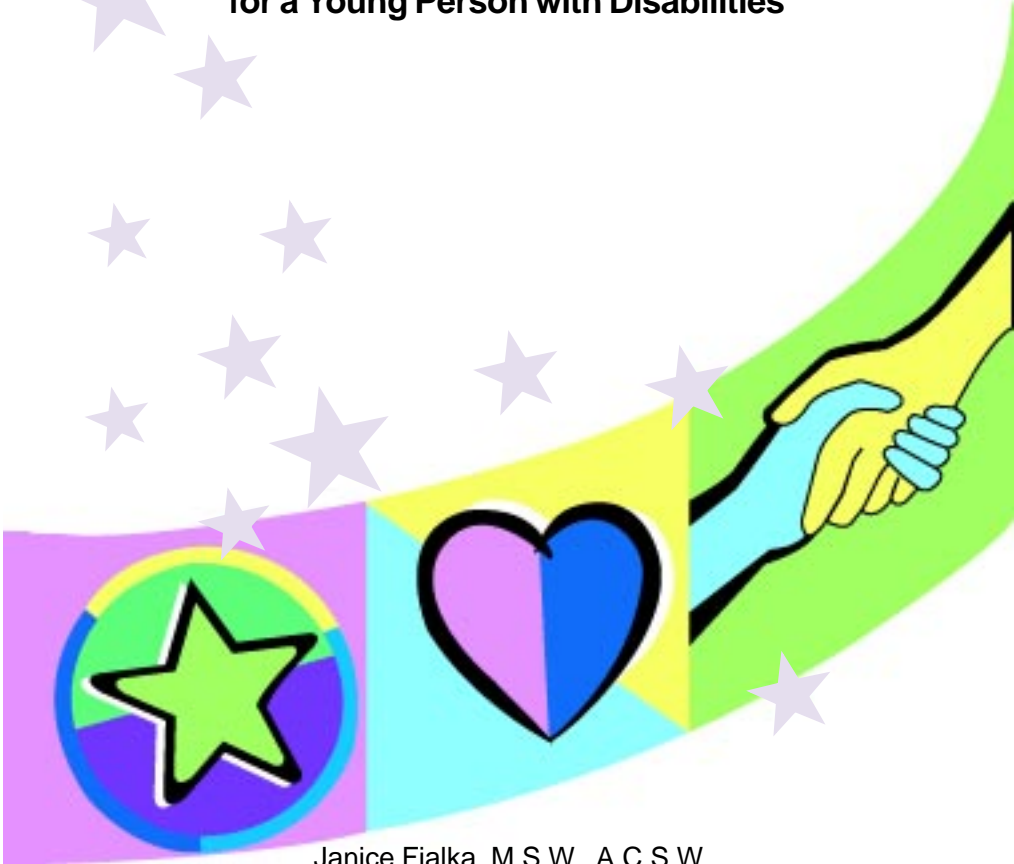


Wisconsin Healthy & Ready to Work:  
A Series of Materials Supporting Youth  
with Special Health Care Needs

# Whose Life Is It Anyway?

How One Teenager, Her Parents, and Her Teacher  
View the Transition Process  
for a Young Person with Disabilities



Janice Fialka, M.S.W., A.C.S.W.  
Martha Mock, Ph.D.  
Jennifer Wagner Neugart, M.S.



Waisman Center  
University of Wisconsin–Madison  
University Center for Excellence in Developmental Disabilities



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# Dedication

To the young adults in transition who remind us that ALL human beings want to be heard, want a sense of belonging, and want to be valued in their community.

To the parents and professionals who believe in these big dreams with respect, determination, and love.



**I believe we can change the world if we start listening to one another again. Simple, honest, human conversation. Not mediation, negotiation, problem-solving, debate, or public meetings. Simple, truthful conversation where we each have a chance to speak, we each feel heard, and we each listen well.**

**Margaret J. Wheatley**





# Table of Contents

Foreword .....	1
Introduction .....	3
About the Title: <i>Whose Life Is It Anyway?</i> .....	5
About Becky .....	7
Scene 1 .....	9
Scene 2 .....	21
Scene 3 .....	35
Scene 4 .....	47
Scene 5 .....	59
How This Book Came To Be .....	72
About the Authors .....	75
Resources .....	77
How You Might Use This Book .....	85
Order Form .....	86

| Whose Life Is It Anyway?

# Foreword

For all people, huge shifts in our lives—transitions—present both opportunity and challenge with the accompanying feelings of hope and excitement as well as fear and anxiety. Perhaps no transition is more momentous than when we move from being a child to an adult as we move from high school into the next stages of our lives.

For students with disabilities and their families, this transition from school to adult life is particularly filled with both hope and anxiety. Getting through school successfully was a great challenge, but seeking a valued place in the community isn't easy and often is confusing. The plethora of adult human service agencies, each with their own requirements, programs, and eligibility criteria are daunting. Often the waiting lists are long and supports for true community inclusion are limited.

The Individuals with Disabilities Education Act, since 1990, has required that transition planning occur as early as age 14 for students with disabilities. Each reauthorization of the law has strengthened and extended the requirements for an Individual Transition Program, in which educators and adult human service agencies collaborate to assist students with disabilities in making this great leap forward from school to adult life. Yet each professional brings his or her own experiences, feelings, and backgrounds to this process. For educators who have worked in schools for many years, they, like parents, face the challenge of interacting with numerous agencies and professionals in organizations at first unfamiliar to them. Everyone works in their own bureaucratic system and getting the rules and resources of each to mesh together to provide meaningful support is challenging. However, with the right collaboration, the right kind of listening and paying attention to feelings and facts, and the right team work, amazing transition plans do get created with and for young adults.

As students, parents, special educators, agency case managers, vocational rehabilitation counselors, and others sit together to discuss goals, supports, and services to work towards making life

dreams come true, relationships that are formed are critical. How do the groups come together as teams? How are tensions and fears addressed? How do the backgrounds, past experiences, and life circumstances of each person impact the team work? How can these feelings and perceptions be honored and used to build truly collaborative working teams?

These are the important questions that *Whose Life Is It Anyway?* addresses. We get to peek beneath the surface to understand three key people in the transition planning process—the student (Becky), her mother, and a teacher. Reading and reflecting on these stories can help all involved in transition learn the skills of understanding how to listen, how to validate one another in a team building process. We desperately need resources to help us think about how we can be together as people, working together to develop partnerships to meaningfully support an individual. This book provides a flash of light in the dark, a knowing smile of understanding, a view of the depths underneath that help us understand the surface. It helps us think about the many complexities in any simple human interaction. *Whose Life Is It Anyway?* gives us an enormously valuable resource for engaging in planning and action for transition as a meaningful human activity rather than just another form to complete.

Use this book as a tool to consider your own feelings and relationships that you bring into such planning meetings. Use it to help you think about questions to be asking and sharing that you can elicit from others in the meeting. Use the book to help you strengthen an understanding of how to build a real sense of community in your planning team. The difference this can make in your enjoyment of coming together during transition with others to support a student in envisioning his or her life may surprise you. Moreover, the impact that may occur regarding real outcomes in the lives of students like Becky may amaze you. May we all use the insights here to strengthen our capacity to work together and build better lives for people in this process.

by Michael Peterson, Ph.D.  
Professor, Wayne State University  
Coordinator, Whole Schooling Consortium  
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# Introduction

*Whose Life Is It Anyway?* is a composite from actual events experienced by several families and youth with disabilities as they transition into life after high school. It is written in five scenes, beginning just as Becky is entering her senior year in high school and is preparing for the next phase of her life after high school. Becky receives special education services within an inclusive setting and has an Individualized Education Program (IEP), which she will continue to be supported by until she is 21 years of age. She has a diagnosis of cognitive disability and a seizure disorder. The story is about her transition and is told from three points of view: Becky, her mother, and her teacher.

Each of the five scenes gives the reader a glimpse into the inner world of the feelings, thoughts, worries, hopes, and dreams of all three characters. In each scene we “listen in” on their thoughts typically not revealed out loud. We delve into the emotions that get stirred as Becky, her parents, and her teacher plan for the next phase. We hear Becky delighting in going to her senior prom. We listen to her mother wrestle with worry. We feel the pull of the teacher wanting to support both Becky and her parents.

In the real world, these internal stirrings, thoughts, and feelings are rarely voiced, seldom discussed and are likely to remain hidden from the outside world. Our hope is that by bringing the buried thoughts and the private feelings to the surface in each scene—for each character—the reader will be reminded that there is a fuller script to what teens, parents, and professionals experience in their relationships with each other during the transition planning process. By paying attention to the inner world of Becky, her mother, and her teacher, we hope to encourage a stronger appreciation for the complexity of these interactions. We believe this appreciation—this awareness—can lead to a greater sensitivity and consideration for all persons involved in the transition process. Needless to say, not all students, parents, and teachers will experience what Becky, her mother, and teacher experience in these five scenes. Our hope is that the story presented in this book will raise awareness and spark conversations about what each person might bring to the experience

of transition. At the end of each scene, there is a set of questions called “Talking Points” which encourage reflection about the events occurring in each scene.

In writing this book, we hope to encourage all of the partners to take time to get to know each other as they move forward in the future planning process. In addition, in telling the story of Becky’s transition, we offer the reader some “out of the box” possibilities for young people, especially those with cognitive disabilities. The new frontiers of assistive technology and college experiences are being realized for youth with cognitive disabilities across the country. We are seeing young people with cognitive disabilities who could never read or write, now reading and writing independently with their software programs. We are seeing young adults with such disabilities actively participating on college campuses with their same age peers: sitting in on college classes, studying with their peers, and joining student organizations. It is happening across this country and right here in our book with Becky. We invite our readers to dream big, live with great expectations, know the meaning of hard work, and commit to building trusting relationships with each other.

# About The Title: Whose Life Is It Anyway?

The immediate answer to the question *Whose Life Is It Anyway?* seems easy. Any one of us might confidently respond, “It’s the teen’s life—the life of the youth who is transitioning into adulthood. That’s whose life it is.” But if we dig deeper and more honestly into the question, we begin to feel the complexity of transition. Transitioning into adulthood is a total life change (Hanley-Maxwell, Whitney-Thomas & Mayfield Pogoloff, 1995), encompassing more than just the life of the young adult leaving high school. “No one person is fully competent in all of life’s decisions and domains.” (Kim and Turnbull, 2004). Of course, transition plans should be grounded in the dreams, strengths, interests, and abilities of the young adult. This is a fundamental principle that must never be compromised. But in reality, transition into adulthood also impacts the lives of the family and professionals who support the young adult. Transition is not a singular event involving only one main actor. There is a marvelous, though complex, cast of characters supporting the young person: parents, other family members, peers, teachers, health care and other key professionals, and the community.

Perhaps the more accurate and honest answer to the question *Whose Life Is It Anyway?* is “It is many lives intertwined.” The three of us who wrote the book believe that youth must have their own voice and it should be nurtured, celebrated, and respected. However we cannot discount others. We believe that the most effective transition planning involves the participation of the lives of many people, or at least a few key people. Each plays a significant role in the young person’s development as an adult. Often parents have a long, rich history of knowing what works and what motivates the young adult. Teachers often are aware of new resources and emerging abilities. Young adults can share what they dream for, what passions they have, and what brings meaning and joy to their lives.

Hanley-Maxwell, C., Whitney-Thomas, J. & Mayfield Pogoloff, S. (1995). The second shock: A qualitative study of parent's perspectives and needs during their child's transition from school to adult life. *The Journal of the Association for Persons with Severe Handicaps*, 20(1), 3-15.

Kim, K-H., & Turnbull, A. (2004). Transitioning to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research & Practice for Persons with Severe Disabilities*, 29(1), 53-57.





## About Becky

Becky is a vibrant young lady who is fully included in school. She has many interests, including attending high school football games with her friends, listening to music, and searching for music on the Internet. Becky receives supportive services to accommodate her cognitive disability and a seizure disorder. She has recently learned how to take care of her seizure disorder by regulating her medications, eating properly, and exercising regularly. She also receives transportation services and is learning to use the city bus system. She is working on finding the right assistive technology that will help compensate for her difficulties with reading and writing by “trying out” voice activated software.

The three main characters in *Whose Life Is It Anyway?* have explored career options focusing on Becky’s interests and thought about where she will live after she leaves high school. Becky is on a waiting list for residential services through the county, and are connected to recreational activities in the area. Becky also volunteers her time planning community activities with her church group. She especially enjoys the bake sales and decorating for the monthly youth dances with her friends.

The following scenes address some of the primary areas of transition with a renewed focus on employment and post-secondary education because she is in her senior year. Even though we cannot address all transition issues in this book, we do present some of the issues and emotions from each character’s perspective that are often overlooked.





# SCENE 1

**Early August**

Becky's last year in high school:

Three different points of view.



### Becky Stratton, the youth

Ooh! I'm sooo excited! I'm a senior now. I'm going to do all kinds of things my cousin Heather got to do. I can't wait for Senior Skip day. I'm gonna skip school with my friend, Tina. I hope my mom doesn't find out that I'm gonna skip school. Heather's going to do my hair for my senior pictures AND the prom. I wish I could drive like my friends. Then I could go to Heather's any time I want.

My senior prom. Oh, I can't wait! I hope Danny asks me to dance. He's so cute! I'm going in a limo with my friends, Michelle, Sarah, and Marta. Heather's purple dress looks pretty on me. Mom said with my red hair, I looked like a princess. I love twirling and hearing my dress swoosh around to my favorite song. Mom's going to teach me to dance—in case Danny asks me. He's sooo cute. He said "Hi" to me at the store yesterday. I think he likes me too. Sarah and Marta will be here soon to go to the football game that Danny is playing in tonight. Mom says I can only have one soda and not too much junk food at the game. I have to watch what I eat. After the game, we're going to have a sleepover. I'm going to tell my friends how much I like Danny. I hope my stupid brother leaves us alone! Whose room is it anyway?



### Anne Stratton, her mother

Holding two over-stuffed grocery bags I struggle to open the back door. I manage to get my key in the lock, shove my way in, and the bags split open. Cans of tuna fish, a carton of ice cream, and bow tie noodles scatter everywhere. Why did I ever think I could carry two bags AND open the door?

My shouts for help bring no children or husband to the rescue. They must not be home. I'm doomed to pick up the consequences of trying to do too much, too quickly. I take a deep breath. Slow down, Anne, I say to myself. Take the huge gallon of chocolate ice cream lying under the coffee table to the refrigerator. Everything else can wait.

I put the ice cream in the freezer compartment and notice how empty it is. Tom's recent layoff from the plant has really made it hard to make ends meet, but I've learned to keep a few treats here at home for everyone's morale. As I close the door I glance at the calendar hanging on the front of the refrigerator. It still says July. I'm two days late turning the page to the new month. How can it be August second already? The end of summer? "Not yet!" I cry out to my empty house. I'm not ready to move ahead. I love summer. No heating bills, no yelling at my kids to "PLEASE get your homework done now!" and no car pool. Come September all those things will be back, but for a couple of days I can talk myself into believing that "now" will last forever.

In three weeks, school starts and my three kids will occupy their new classrooms: second, eighth, and twelfth grades. Yikes! I'll be the mother of a HIGH SCHOOL SENIOR! I'm not ready for this! There's so much unknown about Becky's future. I'm sure most moms of seniors ride the feelings roller-coaster, looping through happy, sad, relieved, worried, proud, and excited. But it's different for me. The future is different because Becky is different.

My throat tightens when I think about Becky's "issues." I rip off July and see August, and my mind flies back to thirteen Augusts ago when the psychologist sat Tom and me down in an office decorated with large plants and colored medical charts of the brain and nervous system. That day I didn't want to learn where the cerebral cortex was, or the frontal lobes. That day, I didn't want to hear the results of the tests she'd done on our daughter. Becky wasn't doing what all the other kids were doing. We couldn't control her seizures and our doctor thought she ought to be "assessed." But that day in August I wanted to be anywhere but in that office, with my fingers gripping the sides of the chair, holding me down so I wouldn't run out of the room.

I don't remember most of what Dr. Thompson said. I only remember that she cleared her throat and said the one word that would change my life forever: "DISABILITY." My ears suddenly stopped hearing, as if a hundred cotton balls had been shoved into them, blocking all sounds from entering my ears and my heart. The room started rocking; I thought I might faint. Only "disability" echoed through my head, jangling from side to side. Tom and I left her office silent, not saying one word to each other on our long ride home. I didn't think then I could last more than 24 hours with this devastating news. How do you raise a child who might always have to deal with seizures and medications, might never read, never work, never marry? HOW DO YOU DO THAT? I felt totally unqualified for that role and completely overwhelmed.

But we survived. I no longer feel devastated, although I haven't managed to squelch the feeling of being overwhelmed every once in awhile. Through the years, we've rebuilt new dreams. Our families helped. Other parents who had children with disabilities helped. Some great teachers and doctors helped. Becky has now accomplished much more than any of us thought possible. She's a whiz on the computer and she loves to surf the net for her favorite music. She's friendly, stubborn more times than I'd like, and loves being a part of whatever's happening at school. She has been fully included since third grade. She's proud of the fifteen green plants she waters every day. And the family grapevine tells me she's even interested in a boy. Hard to believe that for several years we didn't know if she would ever talk. Now it seems I can't get her to stop!

Don't get me wrong. Becky's life isn't easy. Kids can be cruel, and some of them tease her. Many of them wouldn't dream of including her in their activities. Schoolwork is hard, too. Becky knows many sight words but can't read. She can use a calculator for addition, but counting change seems light-years away for her. She's learning to take her medication without constant reminders from me. But she needs a lot of help planning her day-to-day life. She will always need some help, and Tom and I won't always be here to help her.

I sigh, look at the mess I made when I came in, get the broom and dustpan, and begin sweeping up the bowtie noodles. There on the coffee table is the Polaroid photo of Becky smiling, dressed in her cousin's purple prom dress with the scooped neck. Last Saturday night Becky wanted to rehearse being a senior at the Homecoming dance. Her cousin came over and the two of them pranced around our living room, transforming the space into Cinderella's ballroom. I pull the photo closer to my heart and think how gorgeous she looked twirling in that dress with her wild red hair piled high on her head!

She's excited about being a senior and doing what seniors do: Homecoming. Senior pictures. Senior skip day. Prom. And yes, walking across the stage on graduation day.

Tom and I never thought we'd see that day, especially thirteen years ago this August, when we sat in Dr. Thompson's office. We're proud of Becky; we're proud of how we've supported her; but we're also scared. It's hard enough to think about how we'll get Becky to the Prom, let alone what she'll do after high school. All those questions we had no answers for thirteen years ago have come back to haunt us. Work? Friends? Transportation? Home? Marriage and family? Yes, the questions are back. And to my surprise, so are those feelings—like being sad, scared, and alone. When Becky walks off that graduation stage, where will her next step take her? Is there something out there other than a bottomless pit? We've faced dark holes before, but this one feels huge. Frankly, I wonder if I am up to it.

Toward the end of last year, Becky's inclusion teacher, Ms. Lewis, phoned and scheduled us for a September meeting to continue in our planning for Becky's future, or "transition" as she called it. A part of me doesn't want to go to this meeting—or any other meeting. I am tired of meetings, starting with our first meeting many years ago with Dr. Thompson. Some days I think I cannot go to one more IEP meeting, one more consultation, one more speech therapy evaluation, one more anything. . .

I glance back at the calendar on the fridge, which now correctly reads August. Today is one of those days when I don't want to go forward. I want to tape July back. In one year almost everything about Becky's life will be different, from morning to night—where she goes each day, who she sees, what she does. Everything.

How will her days be filled? What will she do? And how will we make it all happen?



### **Maya Lewis, her teacher**

As I turn the corner toward the high school, I experience *déjà vu*. Wasn't it just last week I was leaving this same parking lot after another year completed? Here I am again with a mixture of excitement, familiarity, and dread. When I crawled out of bed this morning to take my son Darryl to his first day of basketball camp, I realized this means it will soon be the start of another school year. I'm stopping by school to drop off some boxes; hopefully this will help me ease into the year.

I pop the trunk and pick up a worn box filled with books and students' goal summaries. I'll need the goal summaries later today before I make calls to my families; first things first, though. I've got to talk to my assistant principal about missing the teacher inservice. I'm never sure: how does he expect me and the other special educators to attend inservices AND complete all the follow-up IEP meetings that are inevitably scheduled the week before school starts? And doesn't my Director of Special Ed communicate with the school administrators about my IEP responsibilities? As I think about this, I feel the back of my neck tightening up. I sigh and reflect that every year it's the same thing. At least this year I'm getting a head start by coming in early.



As I open the heavy glass door and enter the office area, the presence of the security guard reminds me how much my job has changed since I began teaching seven years ago. Even in our town, we must have “How to Handle Violent Behavior” seminars for staff. Now there’s talk that we’ll be required to report any of our students we overhear speak belligerently about teachers or bullying other students. I couldn’t believe it when my co-teacher, Sondra, told me this last week when I saw her at the grocery store. I raised my voice after hearing her news. “You’ve got to be kidding, Sondra! Even if those students aren’t able to understand the full consequences of what they’re saying!? Pretty soon they will have an undercover security guard in every bathroom reporting on ALL student comments and school gossip!”

This lack of understanding of the issues surrounding students with disabilities drives me crazy. How do I explain a rule forbidding students to speak the least bit negatively about their teachers to students who have a hard time understanding consequences? Sometimes I feel as if the policies at Anthony High have not been completely thought through with ALL students in mind. While we have made progress towards becoming an inclusive school, school wide discipline is one area we are still working on.

I enter the small resource room I share with two colleagues and flip on the light. I think back to my first year here at Anthony High. Each of us special educators had a separate class for our students—and to think that now even the incoming ninth graders know about having students with disabilities in their classes. Although I enjoy co-teaching with the “regular ed” teachers, this is not the job I started out doing. While I value what my students are learning by being included in “regular ed,” there are times when I miss having enough time to meet with students one-on-one and focus on some of the content knowledge and skills I think they need.

Change of this magnitude is hard. I don’t always feel as confident as I did when I had my own classroom. I had so much more control over what the students did back then; now my students are all over the building in many different classrooms receiving instruction with other

high school students. This is great progress, but in some ways, collaborating with regular ed teachers and other professionals is a whole new career. Not to mention that keeping up with the county human services and vocational rehabilitation counselors is harder than I ever anticipated. It seems like every time I tell a family what I think one of these agencies can do for them, I find out I'm only half right. As both transition coordinator and educator, how am I supposed to keep up with the policy changes at other agencies like voc rehabilitation and county human services when I can't even keep up with the ones at my own school?

I toss my box down on the small wooden table next to my filing cabinet and begin to unpack. As I pull the top file drawer open I come across a small pink sculpture in the shape of a flower. Becky made it for me when she was assigned to me last year. The art instructor told me she labored on it for days. Becky's so thoughtful.

While Becky enjoys art, her interest in plants and gardening became clear to me last year. She and I talked about places she could work with plants and discussed a few of the county parks in our area. If only her parents were willing to look ahead a little—were willing to think about her future. At times when I look at Becky's mom's face, I think I see resistance. It's strange, but on more than one occasion I have expected Mrs. Stratton to throw her hands over her ears so she can't hear me.

Perhaps the Strattons think if we don't talk about it that somehow Becky's future will magically appear. Certainly there are parents who are angry with me because I bring them into the future they don't want to face. How can people NOT want to think about what is in the best interest of their son or daughter? Or in Becky's case, how can her parents NOT want to think about her future? On the other hand, I am sure it must be difficult; I know that I cannot fully understand what their family has to consider.

I must call Becky's parents. I wasn't able to reach them when I phoned last week, and I didn't want to leave a message. It's times like this when I'm not sure what would be most helpful to parents—

and to the student too, of course. I just don't know. What I do know is that I care—a lot.

We've lost two of our star community employers for the transition program due to their dissatisfaction with the amount of support we were able to provide at the time, and I'm not sure what we will come up with for Becky this year. I wander into the empty teachers' lounge and pick up the phone; my palms are starting to feel damp. Thinking about starting the "transition conversation" with another family makes my stomach churn. How will Mr. and Mrs. Stratton react when I tell them that at Becky's upcoming IEP we need to really focus on what Becky will do next year? Some parents want to talk about this the moment their teen enters high school, but I know Mr. and Mrs. Stratton are not those people. Mr. and Mrs. Stratton: what will you say?

It must be difficult for them; I can only begin to imagine what's going on in their minds. Last year, we spent a great deal of time focusing on Becky's interests and planning what her senior year would include. While Becky's high school teachers began talking with her and her family when she turned fourteen, I'm not sure how much was really discussed. Did anyone talk with Becky and her family about how important it was for Becky to be exploring personal interests and careers? Did they discuss building Becky's confidence and making choices and decisions in her daily life? I know transition conversations should begin as early as middle school, but it is so hard to communicate that to middle school teachers when there are so many day-to-day issues to work through.

Now I say the word "transition" yet again, but this time it's with a big "T"—THE Transition that will help Becky move into the "Real World." Ugh. Why does this conversation never seem any easier to begin? I hope I can get past any apprehension Becky's parents may be having, and help them feel positive about the opportunities we can create for their daughter. I know transition is supposed to be a "team" effort, and sometimes I'm not sure if forming a team with the Strattons is possible, but I have to try. The phone begins to ring.

## Talking Points

1. After reading Scene One from the three perspectives, what new insights or increased awareness do you have about what Becky, her mother, and her teacher are experiencing during Becky's senior year of high school?
2. What thoughts and feelings did you experience as you heard each person describe their story?
3. From your perspective, what are some of the challenges faced by Becky, her parents, and her inclusion teacher/transition coordinator in this story? What can be done to address these challenges? What other challenges and possible solutions can you envision for students, parents, and teachers in your community?
4. What can make it difficult or easy for parents and teachers to readily communicate during this transition phase of a student's life?
5. In this book, Becky is described in many ways; one aspect of that description is that she has a cognitive disability and a seizure disorder. What is the significance of these terms, or other labels people with disabilities in your community receive? What happens when parents, teachers, students, and community members use terms that you are not comfortable with?
6. While Becky is experiencing her senior year at age eighteen, she is going to continue to receive support from her school district until she is twenty-one. What types of programs exist for students with disabilities and special health care needs between the ages of eighteen and twenty-one in your school system and community?
7. What do you anticipate might happen in Becky's senior year?

## **A Place for Your Thoughts and Questions . . .**





## **SCENE 2**

**Late September**

We talk more about Becky's life after high school.



## Becky

I love my teacher, Ms. L. She's the best. She smiles at me when she talks. She helps me be in class with everyone else. She's fun, not serious all the time. She thinks I can do lots of things. She lets me help her in class and she's teaching me to learn the computer. It's so cool—when I talk, the words pop up on the screen.

Ms. L. is going to find me a job—working with plants! I'm so excited! I'm really good at that. Then I'll have my own money and I can buy anything I want. I really want new shoes to match my pretty Homecoming dress.

Oh, I really hope Danny will ask me to dance. I've practiced A LOT! I love him. I told Ms. L. I hope she keeps my secret.



## Anne Stratton, her mother

I swerve into the only remaining parking space directly in front of Becky's high school. If I was superstitious, I might think, "This is a good omen. It means my meeting about Becky is going to go well." At the very least it means I won't have to park two blocks from the school and walk in the pouring rain!

It wasn't easy leaving work early. My boss gave me one of those 'not again' looks, but I knew that Becky's future was right in front of me. I appreciated Ms. Lewis's recent phone call inviting Tom, Becky, and me to talk about senior year. She said, "Let's not call it a meeting. That sounds so formal. Why don't we just get together and continue in our planning for Becky's senior year and what might come next?" I liked the sound of her suggestion and the tone of her voice. It helped me get over the panic I felt a while ago.



Over the years, so many of the typical school meetings about Becky have been way too big. It seems that everyone who's ever smiled at Becky has been sitting at a mammoth conference table, usually in the library. At these meetings, I'm never sure exactly what to say, who to make eye contact with, or what is really supposed to happen. I worry they'll think I'm either the overly protective mother or the cold, distant mother from the North Pole. To tell the truth, I've probably been both at times. Maybe today's small "get together" with Ms. Lewis and Becky will be calmer and less confusing.

I enter the school, sign in at the office, smile at the high school secretary, and brace myself as I enter the hallways crammed with boisterous kids yelling out answers to tests and plans for the weekend. I wonder if Becky is ever included in these hallway conversations. I am most of the way to Ms. Lewis's classroom when I hear Becky giggle. The sound of her laugh is a splash of sunlight. Then I hear Becky say, "No way, Ms. L. I CAN'T do that." Ms. Lewis gently urges: "Yes, you can. You did it yesterday and you were awesome. Remember how you saw your words on the screen? Wasn't that neat?"

I lean against the doorframe and look in. Becky and Ms. Lewis are enjoying each other. I want to stay right in this spot all day long listening to this wonderful music between student and teacher. I relax my shoulders and feel some of my nervous tension float down the clearing hallways.

Ms. Lewis sees me, straightens up, and comes toward me, her hands extended in greeting. She leads me by my elbow and I feel welcomed. "I'm glad you could come today. I'm sorry Mr. Stratton couldn't be here. I felt we could talk more easily if it was just us. No formal meeting. Nothing like that." I nod. "This is such an important year and involves so much planning. I want to hear what you're thinking."

I cling to her words, hoping she really does want to hear what we're thinking. "I'm sorry Tom couldn't get off, too," I say in response. I know he wants to be here, but it's never been easy for Tom to come into a school building. Walking into the hallways brings up bad

memories from his own school days. All of those hours and hours when he was in detention and in the principal's office come right back to haunt him when he enters Becky's school. It's like the past and the present get all rolled into one moment in time.

Ms. Lewis gestures toward three chairs in front of her desk. I like it that she doesn't hide behind it. She begins talking. She seems pleased, and I think she's outlining what we can expect this coming year. Some of what she says are things we've been talking about over the last couple of years. Phrases like "agency involvement," "transition meetings," and "next steps" swirl through the air. I believe I'm paying attention, but I'm getting lost in some of the details. Is "voc" the same as "rehab"? Why is community mental health coming to the next meeting? What does it really mean that Becky will WALK in the graduation ceremony, but really not get a diploma or graduate from the public school system? Will she work? Go to school? Where will she live?

Then Ms. Lewis leans forward slightly and asks the question that knocks the wind out me: "Mrs. Stratton, what are some of your dreams for Becky? Where do you think she might be one year from now?" Tears well up in my eyes. My brain shouts, "Anne, DO NOT CRY IN FRONT OF YOUR DAUGHTER'S TEACHER! Stop it right now, Anne!" But the tears come. Becky covers her face with her hands and mumbles, "Awww, Mom!"

I tighten my fists as if they are control knobs that will turn off my unwelcome tears. It doesn't work; they continue to slide down my face. I mumble an awkward apology and grope under my chair for my purse and a Kleenex. Ms. Lewis reaches over to her desk, picks up a box of Kleenex, holds it toward me, and I take one. Silence invades the room once filled with Becky's giggles. I wonder what Ms. Lewis thinks of me. She shifts in her chair and tilts her head to one side. I think to myself, "Why can't I keep it together?"

Then something I don't expect happens. Ms. Lewis says, "These aren't easy things to think about, Mrs. Stratton. Of course you have strong feelings." I sniffle and blow my nose. She looks at me. "What kind of mother would you be if you couldn't shed a few tears about your child?" She checks to see how I'm doing, and puts the Kleenex box back on the desk. She's smiling! She's not impatient or angry with me. She's telling me crying is okay, not weird. She then turns to Becky and jokes with her.

So I share a couple of my worries with Ms. Lewis. Tom and I worry about what type of work she'll have. Will she ever be able to make change at the store? What happens if she has a grand mal seizure at work? How will she keep learning about the computer? I know she has a cognitive disability, but that doesn't mean she has to stop learning. How long will she live at home?

Ms. Lewis listens, and today I feel heard. Together we three decide on a few "next steps," including making contact with the job assessment agency, and Ms. Lewis jots down our ideas. Before we leave she asks Becky to photocopy the list so I can take it home with me.

I can't say I enjoyed crying at the first meeting of Becky's senior year. But there was something about today that was important, reassuring, even hopeful. Ms. Lewis encouraged my daughter to try out a brand new computer software program, she made Becky giggle, and Ms. Lewis and I connected on some deeper level, if only for a moment. One of the lessons that I keep having to relearn as Becky's mom is that I can feel scared, worried, sad, and happy all in the same hour. I also know that it helps so much when I don't feel judged by all the professionals who are part of our family's life. It helps when I feel heard. Today, I didn't feel quite as alone as I usually do at these meetings. When I get home, I think I will mark this day on my refrigerator calendar as a pretty good day in September.



## **Maya Lewis, her teacher**

Thank goodness. The first few hectic weeks of school are behind us. At long last, Becky and I have some time together to work on the new voice-activated software. I think Becky will enjoy learning how to put her thoughts down on paper by speaking directly into the computer and having the words pop up on the page. This will take some pressure off of her as spelling and typing are difficult for Becky.

I've asked Becky's parents to come in for an informal chat, a conversation about the future. When I talked to Mrs. Stratton on the phone last week, it was almost as if I could hear her pulling away, but she agreed to today's meeting. I don't think I've done anything to offend her, but who knows. Why is it so challenging to interact with parents sometimes? All I want to know is what they want for Becky after this year, so we can offer her the support she needs in the community until she's twenty-one. If we can just begin this conversation, I believe that will help us all.

Introducing Becky to the new software is a success. She needed encouragement, but pretty soon I have her giggling. Everything is a little harder for Becky, but I have to admit—she works hard for every step she takes, no matter how small. That's something I really respect.

And here is Mrs. Stratton, in my doorway and slightly out of breath. As I step forward to welcome her, I remember that it may not always be so easy to come to another meeting. I make sure I greet her warmly and gesture toward the chairs by my desk. It's too bad Mr. Stratton can't be here. I always feel better if I can talk to the important people in a student's life all at once and get everybody's input. Then I am certain we have all been part of the discussion and the process of planning for the future.

I begin outlining some of my ideas for Becky, some of our transition services, what I can do as her transition coordinator, and other agencies that offer transition-related services. I use this same format with all my parents, so everyone hears the same information and I don't miss anything. But Mrs. Stratton doesn't seem to be paying attention. She has a deer-in-the-headlights look, glancing everywhere except at me. Perhaps even this informal meeting is too much for her. I decide to go directly to what is, after all, the crux of this meeting. "Mrs. Stratton," I say, "what are some of your dreams for Becky? Where do you think she might be one year from now?"

I think I may have surprised her. Am I seeing tears in her eyes? Isn't this the purpose of our get-together? Isn't this what "transition" is all about? She begins to cry. I feel my neck tighten—a knot begins to develop in my stomach. This is not what I had envisioned. What should I do now? I pause for a moment, then I reach for the box of tissues on my desk and offer it to her. We sit in silence for what seems like ages, but is only moments. Mrs. Stratton sniffles into her tissue.

I want to say something helpful, but dealing with tears isn't easy for me. Even though other parents have cried during meetings I always feel a little uneasy; but despite this I try to reassure her that crying is okay. Transition is an emotional process—after all it means Becky is growing up.

Becky is visibly embarrassed and puts her head down on the computer desk. I try to give her a reassuring glance, but with her head down she can't see. So I joke with her instead and this seems to lighten the mood.

Mrs. Stratton begins to dry her tears and tells me how much she and her husband have worried about this question and all the others we might discuss today: Where will Becky live? Will she have the supports she needs? How will she get to a job? Will she even have a job? The words rush out.

I suggest we make a list of her top ten concerns and chose three for us to focus on between now and the upcoming IEP meeting. I ask Becky to write down each number as I write down Mrs. Stratton's questions of concern. As I begin to listen and write, I can feel some of the tension in the air dissipate. We write down the concerns Mrs. Stratton has just expressed. 1. Where will Becky live? 2. Where will she work? 3. Who will help her do things she needs to do? 4. How will she get around town? 5. How will she communicate with her doctor without me? When we get to Number 8, Becky interrupts: "Ms. L., I'm going to Homecoming!" That seems a good cue for us to stop for today.

As she prepares to walk out the door, Becky is anxious to share information with me about her Homecoming dress. Becky's focus on teenage concerns lightens the room. I put out my hand to Mrs. Stratton to say goodbye and give Becky a quick hug.

It's been a long day. As I get into my car I think about Mrs. Stratton's tears. It's after I've driven ten minutes that I realize I've left the papers I needed to grade tonight in one of the numerous piles on my desk. I sigh and keep driving anyway. I review tomorrow's calendar: first period, general math; second and third periods, English; fourth period, staff meeting. Perhaps I can squeeze grading in there if our meeting doesn't go too long.

I dash into the grocery store to shop for tonight's dinner. As I glance at my watch, I see it's already 5:30. My boyfriend, Keith, was expecting me fifteen minutes ago, and hopefully he remembered to pick up my son Darryl from his after-school program. Maybe I should call him and check . . . No, he's always so reliable. He remembered. Besides, I'll be home shortly.

I grab a cart and head toward the frozen food section for french fries. My mind races back to Mrs. Stratton. I'm not sure what I expected, but the thought she might cry hadn't entered my mind. There was such uncertainty and vulnerability in the air. I've

stopped telling parents “It’s okay” and “Don’t worry.” It sounds ridiculous! Of course there’s plenty of anxiety and uncertainty! My job is to help ease some of that, but I can’t take it away. I know Becky is part of a family, but I’ll admit, sometimes it’s easier to simply think about her.

As I grab the french fries, I replay portions of our discussion. Will I be able to find a job placement that Becky likes? I start a mental list of stores beside the greenhouse that sell plants. I make a note to myself, “Call Harris Hardware.” I think they have a garden section and a small greenhouse they’re starting. I’ll call Sid from the county extension, too; he might have some ideas. Do we need chicken? I don’t think I took the chicken out of the freezer. I grab a package, glance at the price, and give the chilly pack a toss into the cart.

“Mrs. Stratton,” I say, “what are some of your dreams for Becky? Where do you think she might be one year from now?”

When I pull into the driveway, my boyfriend comes out to help with the groceries. He’s annoyed: I can tell by the way he moves the bags from the trunk to his hands. “You know I’ve got to leave for my meeting in an hour, right?” he says. I stare at him and take a deep breath. He pauses and looks at my face. “Oh, I’m sorry, Maya. How did your meeting go?”

“Fine,” I respond curtly.

“Darryl,” he calls to the passenger’s seat. “What’d you do in after-school today?” My heart skips a beat. “Darryl?” I say. “KEITH! You were gonna pick him up!”

“No,” he says. “That’s Monday. This is Tuesday.”

“Oh my gosh!” I cry, and run into the house. The phone is ringing in the kitchen and I race to answer it. It’s Darryl’s after-school teacher.

Stammer as my mind races, envisioning Darryl standing on the steps of the school alone. What's wrong with me? Life seems a little much these days.

"One of us will be there in five minutes," I say. "I'm really sorry. Somehow I got my wires crossed . . ."

Keith appears in the doorway. "I can run down there and get him before my meeting," he offers, which means he's forgiven me for the late arrival. "It'll be fine." He kisses me good-bye and hands me the bag of french fries from the grocery bag. As I flip them over to see how long they cook, I can't help wondering: what's going on in the Strattons' kitchen tonight?



## Talking Points

1. How can teachers handle situations when they think parents are pulling away or appear reluctant to deal with the next phase of their child's life?
2. PATH and MAPS are two person-centered planning tools that can be used to plan for the future. What other person-centered planning tools or processes are available that could have been used to help Becky's team in this situation? What are the advantages and disadvantages of using formal tools and processes to assist with planning? (See references for PATH and MAPS page 32.)
3. What is the teacher, Ms. Lewis, experiencing when Becky's mother, Mrs. Stratton, begins to cry?
4. What are other scenarios you can imagine that could have happened at this meeting that would have resulted in less favorable results?
5. Do you think that Mrs. Stratton's reaction is typical? What is happening for her at this point in her daughter's life? How might other parents react and what might other parents be experiencing during this informal discussion about the future for their son or daughter?
6. What did Ms. Lewis do that was helpful or not so helpful? What suggestions do you have for Ms. Lewis or other inclusion teachers/transition coordinators who are discussing transition with parents?
7. What can parents do when they are experiencing worries and fears about life after high school?
8. Becky likes and respects her teacher. How do you think that relationship was built?

9. What are some experiences youth with disabilities need to participate in to improve their self-determination and self-advocacy skills?
  
10. In Becky's scene she mentions that she talks to her teacher about having a crush on Danny. What role can teachers and parents play when a student raises issues surrounding relationships, social skills, or sexuality (including sexual orientation)?

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## **A Place for Your Thoughts and Questions . . .**





## **SCENE 3**

**Late October**

We sort through our worries and responsibilities.



## Becky

This picture's perfect. I'll use it in my PowerPoint when I talk at my IEP meeting. Here's another picture with me and my mom at the greenhouse we visited. I'm holding a big geranium. It's got pretty red flowers on it. I'm going to tell everyone how much I want to work at the greenhouse.

Here's a picture of me and my friends at Homecoming. I can tell everyone how much I like doing things with my friends and listening to music. I won't tell them about Danny. He never even asked me to dance. No more!

It's fun looking through these pictures. I can't wait to run my own meeting. Ms. L. says that means everyone will listen to me. Everyone looks at me. Ms. L. is going to show me how to put these pictures in the PowerPoint. She said that way everyone will see the pictures real big. Ms. L. is helping me practice starting the meeting and she helped me do the invitations. I was going to invite Danny, but not anymore!



## Anne Stratton, her mother

I drop onto our frayed beige couch. Work today was a nightmare. The new software crashed off and on all day, and it felt like I had to ring up every other sale twice. More than one customer stomped off with a parting message like, "Just forget it! I'll shop somewhere else!" Oh well! At least I have a job, and we certainly need the money.

No particular trouble with the kids tonight, thankfully. Jay-Jay wants a raise in allowance and Lisa says she wants a pet rabbit. I wish we had a bit more money to provide the kids with some of these things. It's good that Tom is working again, but being on the afternoon shift leaves me, and only me, fixing dinner, helping with homework, and bribing kids into their beds. Today, I'm exhausted.

I look around and suppose I ought to do some picking up. I glance to my right and spot piles of unopened mail and unfolded laundry. It's been at least three days since I last opened the mail, and I decide to do that first. My fingers flip through the envelopes: bill, bill, coupons for a new pizza place, another bill. Then I pause at an envelope stamped with the familiar return address "Anthony High School" and printed on the familiar pale blue envelope with the soaring eagle. The envelope is thick. Do I really want to open this tonight?

It's been over a week since Becky and I met with Ms. Lewis. I wonder what she thinks of a grown woman crying. I guess the meeting went pretty well, but I've learned that anything and everything can change at the last minute. Maybe this is the letter that will announce that the high school Special Ed Department has a new concern about Becky and they need to meet right away. Or that a new teacher has been assigned to Becky. Or there's been a huge budget cut and Becky's transportation will be eliminated next week.

It's too late and I'm too tired to open anything that is bad news. It can wait. Or here's an idea. I can pretend this letter never came. I try to imagine telling Becky's teacher, "No, Ms. Lewis. I never got a letter about Becky's new teacher assignment. Gosh, I feel terrible about missing the chance to meet her. I guess you just can't trust the mail these days!"

I practice these words and cringe at how I sound. What kind of a mother am I? I try to reassure myself. It isn't that I don't care. It isn't that I don't want to know what's happening to Becky and her world. It's just that I hate having to deal with systems, forms, people, changes, programs . . . all that stuff that seems to take me away from just enjoying my daughter. Sometimes, when I'm really honest

with myself, I can admit I feel like a giant ping-pong ball bouncing back and forth, back and forth, between wanting to be the best mom ever and wanting to be no one's mom. Most people wouldn't understand that—not wanting to be anyone's mom. It sounds mean and cold. But being a mom sometimes means thinking about a future that feels unknown, a future that might mean more work, more frustration, more meetings, more agencies, more everything. Of course, the future can hold lots of hope for Becky, but we don't know. It's the not knowing that feels scary.

Okay, Anne, I say to myself. Pull yourself together and open the letter. I cautiously tear open the end of the envelope. There are several pieces of photocopied paper and a blue Post-It note from Ms. Lewis: "Dear Mrs. Stratton: Thanks again for meeting with me last week. After you left I searched through my files and found this article written by a father whose son was transitioning out of high school. I thought that you might find it interesting. Don't hesitate to contact me. I look forward to seeing you again soon." Maybe my crying didn't send her running the other way.

I peel off the Post-It note and stare at the photocopied pages. The heading reads: "From a Parent's Perspective." And the title? "I'm Not Ready for This."

I can relate to this title. This could be the title of my entire life! I drop the article into my lap. It was thoughtful of Ms. Lewis to send this to me. Over the years I have come to appreciate how important it is to meet other parents who have children with disabilities. Tom and I have learned about some of the most practical resources from other parents. One mother told me how her son uses PowerPoint at his IEP meetings. We brought the idea to Becky's teacher and soon Becky will be doing this very thing. Another father told Tom about how to start the application process for SSI benefits. We had no idea how to tackle this intimidating process.

It's not just ideas that come from these parents. It's that they . . . understand. When Tom and I meet new parents, we often feel this instant connection, like we are members of the same secret club I



who greet each other with our special handshake. There's an immediate bond. But I've noticed that it seemed easier to find parents in those early days when Becky was in pre-school and elementary school. Lately I haven't connected with many people. Maybe . . . maybe I've been avoiding parents—all parents. Maybe I'm not sure I want to hear them tell me what their kids are doing next year.

"I look down at the article in my lap and decide to read the opening paragraphs before I commit to reading the whole thing."

## From A Parent's Perspective

### I'm Not Ready For This

*by Michael's Dad*

One of the first lessons I had to learn as a father of a child with a disability was to live one day at a time. Sounds simple, right? But it was and still is the hardest thing I've ever had to do.

In those first years of adjusting to my son, to Michael's physical and cognitive disabilities, I was tormented by questions about his future. Would kids tease him? Would he ever have friends? Would he be able to play baseball or read my favorite book, *The Life of Jackie Robinson*? Would he work? Marry? Enjoy life? Have a decent place to live? Those worries haunted me, kept me up all night, led me to sob in my basement when no one was home, and just about stopped me from falling in love with my son.

With the help of other parents and a kind social worker, I gradually learned that if I was to survive, even

thrive as Michael's dad, I had to focus most of my attention on his Here and Now. I learned to put most of my energy into being in the moment with Michael enjoying doing what he could do, rather than worrying about what he couldn't do.

This change in how I thought about the present was tough, but I knew I was making progress with my "one-day-at-a-time" lesson a few years back when I took my son to a Detroit Tigers baseball game. He was about seven years old. I splurged and got great seats behind home plate. I knew Michael didn't understand all of the ins and outs of the game, but when my favorite player hit a much-needed home run, Michael and I leapt up from our seats, shouted with joy, and landed in each other's arms. Not once during our father-son time was I distracted by my worries of where he would live when he was thirty-five years old. I was beginning to learn.

gently set the article down. This dad's words are hitting me like a ton of bricks. He has described my life with Becky perfectly. Learning to live one-day-at-a-time is how Tom and I have managed to be as successful as we have been with Becky over the years.

I'm beginning to understand why I've been so anxious about Becky's senior year. Ms. Lewis and the school want us to think about Becky's Future, meaning the next few years. My way of

Over the years I have come to appreciate how important it is to meet other parents who have children with disabilities.

handling life with Becky—taking a few small steps every day—will no longer fit. Someone has ripped off my life jacket, and I'm being thrown overboard into the stormy sea. "Give me back my life jacket!" I cry. "Give me back my few-small-steps-at-a-time way of coping!"

I flip through the other papers from Ms. Lewis and see a flier announcing an "Information Night for Young Adults with Disabilities and their Families." I see the list of workshops: what's after high school, a job fair, employment readiness, self-determination, public transportation.

Okay, Ms. Lewis! I get the hint! She is trying to send us out into this new world—the world of Becky's Future. She's nudging us along, helping us through this maze of agencies, acronyms, and anxiety.

Maybe I can attend Information Night. I know Tom is concerned about what kind of work Becky might do, so maybe this is a place to start. I lift my weary body off of the couch and walk toward the refrigerator that holds our family calendar—the calendar that seems to propel us closer to the last day of Becky's senior year. I mark the date of Information Night on it. I can do this, I think. Like they say, "One day at a time." I add, "With a glance in the direction of the future."



## Maya Lewis, her teacher

Darryl is in bed at last, exhausted from his day at school, and I hope I can grab a few moments to catch up on schoolwork. It has been several weeks now since I met with Mrs. Stratton and, in spite of everything I hear and am supposed to believe about “professional detachment,” I can’t get Becky and her mom out of my mind.

I sit down on the living room floor amongst books, file folders, and articles. I pick up the remote, flip on the evening news, and grab the soda I pulled out of the refrigerator an hour ago. Warm. Oh, well.

One of the things I love most about my job is finding resources. Organizing the resources I find and figuring out how and when to share them, on the other hand, is always a challenge. As I begin to tune out the announcer’s voice, I glance through the titles of articles I’ve gathered over the past few months: “How to Assist Parents with SSI and Medicaid Applications.” “Using Person-Centered Planning Tools in Transition.” “Supported Employment: What Does This Mean For My Teen?” “From a Parent’s Perspective: I’m Not Ready for This.” I pause. This is the one I sent to Becky’s mom.

I wonder if Mrs. Stratton has read it. Over the summer I sent her one article about transition; did she find another one helpful? Annoying? Overwhelming? It’s hard to say after last week’s meeting. I’m never sure how much information is enough, and how much is too much. Every time I send parents clippings, articles, or fliers, I make the same mistake: I picture them opening the envelope, reading whatever I mailed them, saying, “Wow! This is so helpful!” and finding their lives have changed.

And equally foolishly, at some level I expect they will phone me right away and say, “Ms. Lewis, you are a glorious teacher! Thank you, thank you! Everything will be all right from now on! Our anxieties have melted away!” I know it’s not that simple and this is totally unrealistic, but I still dream.

My mind flashes to Becky, and her mother's tears. I wonder what went on when they got home and Mrs. Stratton shared our discussion with her husband. Becky has been her usual bubbly self at school, talking about Homecoming and her current crush, Danny. As we began to put together her PowerPoint slides that she will present during her upcoming IEP meeting to share her thoughts on her future, she kept asking me, "Will Danny be in his football jersey today? I hope I see him in the cafeteria today. Sometimes he goes to the gym when I'm there." I couldn't help but get drawn into her teenage angst and wonder with her.

I've brought home some of Becky's goals and objectives from the past few years that I have jotted down; the list is long, but no longer than the list from any other student in our special education system. I still wonder, even after teaching all this time,

...in spite of everything I hear and am supposed to believe about "professional detachment," I can't get Becky and her mom out of my mind.

do we do students a favor by giving them a label? It's often the case that once you have a label, it's with you for a lifetime. Is Becky going to be forever seen in our town as that girl with the red hair who has a cognitive disability and seizures?

Of course I know that students must have a label to receive the services they need, but I'm still not comfortable with it. I think the day I'm comfortable with it will be the day I throw in the towel. When I was getting my special ed. certification, I used to overhear conversations of a few of the teachers. It wasn't pretty. I thought then I would find a new career if I ever hear myself saying things like, "Oh, you know you can't work with his parents; they just don't understand," or "I tell the parents of eighteen-year-olds, 'At eighteen you're out, that's all there is to it. We are listening to what your daughter wants, not what YOU say she wants.'"

I know I'm not a saint, but I refuse to let the system get the best of me, leaving nothing for the parents or the students I really care about.

I shake these thoughts from my head and pick up the stack of fliers I brought home to fold. Transition Info Night for students and their families is coming up. My other colleagues have contacted the Department of Vocational Rehabilitation, human services, the local Office of Social Security, the technical college, and the university that's about an hour away. I am organizing the job fair portion of the night.

I've lined up six employers who are coming to meet students and parents. I've only worked with three of them before. I'm just getting to know the other three and would have preferred a little more time to build relationships, but I don't have that luxury. Since we lost two of our star employers from last year, we're hurting for job opportunities. It took me a few years to realize that I should invite employers. I used to just go out myself and meet with them, but it's great that they want to attend our Transition Info Night. Sometimes I still feel like a salesperson when I'm talking to them, like I'm selling them on the idea of hiring someone they should be hiring anyway.

I glance over at the phone. I wonder if I should call Mrs. Stratton tomorrow to check in before the IEP meeting. I don't know if that would help or not. Did Becky tell her mom that she is going to start the IEP meeting with her PowerPoint presentation? I hope so, because Becky certainly has been excited about working on it, and seems proud of it. I can't imagine that the Strattons ever look forward to IEP meetings; who would as a parent?

## Talking Points

1. What were some of your feelings that you experienced as you read Scene 3?
2. What do you think about the idea of “living one day at a time” for parents with children with disabilities and special health care needs? What are the pros and cons of this approach?
3. What are some other ways youth can be involved in their own IEP meetings? Why is it important to include students in all aspects of the IEP meeting, including the planning phase?
4. Often teachers or other professionals don't receive direct feedback from parents about what was helpful (as in the case of Ms. Lewis sending Becky's mother the article). How can teachers gauge their impact on families?
5. What are the pros and cons of offering articles or other resources to parents, especially if the materials focus on the emotional aspects of parenting?
6. How can teachers balance their role between parents' needs and students' needs?
7. What insights did Mrs. Stratton receive when she read the article written by the father?

## **A Place for Your Thoughts and Questions . . .**







## **SCENE 4**

**April**

We all rediscover IEP meetings can be challenging.



## Becky

I used to hate IEP meetings. So boring. This one will be different. I practiced A LOT. I know I can do a good job. I'm nervous, but it's really cool—everyone has to listen to me for a change. It's MY meeting—all about me! I'm going to tell them about my trip to the greenhouse. I want to work there so bad. Ms. L. said I probably could. There are so many plants there. I know I could do a good job taking care of them just like I do at home. Ms. L. smiled at me. It's my turn to start. Uh Hmm. "Hi to all my teachers and my mom and dad and everybody else too. This meeting is all about me and I'm going to tell you about what I need and what I want to do. . . ." I pushed the button on the computer and there I was in my favorite green shirt. I was really big. I took up the whole screen!

The meeting was good—now it's bad, really bad. What happened? I thought I did good. Mom and Dad are mad. Ms. L. and Mr. Frank look mad. Why is everyone mad? Are they mad at me? Did I say something wrong? They're asking a lot of questions. Am I going to get to work at the greenhouse? Maybe the boss at the greenhouse is scared I'll have a seizure at work, but I can tell him what to do if I have a seizure. I know what to do. Why don't they ask me what they want to know? Why don't they just listen to me? Whose IEP is it anyway?



## Anne Stratton, her mother

I like sitting at my kitchen table when the kids return from school. It's so rare for me to be home and be able to hear my kids' stories about their day. Jay-Jay's telling me about the new pet goldfish his teacher brought in to class, at the same time that Becky's pointing

to the photo of the new CD she wants for her birthday. At this moment it is hard for me to hear or see anything in my kitchen. My mind is back at the school library where we met earlier this morning for Becky's IEP conference. I force a smile and nod to Jay-Jay and Becky, looking as if I am listening but my mind's left the kitchen completely.

Why don't they ask me what they want to know? Why don't they just listen to me? Whose IEP is it anyway?

I'm back at the high school, reliving every second of that meeting. We were seated around a large conference table in the back room of the high school library. I glanced around a long table filled with ten people, most of whose names I kept forgetting. I knew the assistant principal and the language arts teacher's name for sure, but the others? Then my eyes connected with Ms. Lewis, and she nodded cheerfully and seated herself directly across the table from Tom and me. I made sure to smile back. Her phone call to us last week asking us if we had any last-minute concerns really surprised us. It was a nice surprise, though, sort of what a friend does when they know you have an appointment with your doctor to hear the results of a test that will determine your future.

"So can I, Mom?" Jay-Jay says. Becky is giggling.

"I'm sorry, Jay-Jay. I've got something on my mind. Uh, could you ask me again when you've finished your homework?"

The IEP conference . . . that's what's on my mind.

At the meeting, I watched Becky situate herself proudly at the head of the long table, ready to begin. Every night last week I heard her in her bedroom practicing her opening lines. I was right about insisting that Becky be more active in her IEPs this year. Using PowerPoint really boosted her self-esteem. She loved learning how to turn her photos into slides. It was so different from two years ago when Becky dreaded IEP meetings, kept her eyes to the floor, and never said anything except "Don't know" when she was asked a question.

Tom and I believe that it's a good thing that Becky is doing more at school. We are glad that her teachers have high expectations for her. We really are . . . but that doesn't mean we don't worry . . . a lot. Just thinking about Becky taking public transportation makes me feel that I've been dropped into the middle of a stormy sea. Of course we want her to try new things but how do we deal with our fears? What if something happens to Becky on the bus or at work? Will the teachers be there for her, for us? This world can be a very dangerous place, especially for kids with disabilities.

IEP meetings are never easy. There's something so public—so formal—about them. Why can't we make them more comfortable? Since Becky's birth it seems like we've lost all rights to our privacy. Time and time again, Tom's and my relationship has been on stage for all these people to examine. I bet they have their disagreements with their spouses, but they can argue in the privacy of their own homes, not in public for all to see. Thinking about the steady procession of professionals in our lives made my foot under the library table begin to tap incessantly.

At the IEP meeting everyone greeted everyone else. Ms. Lewis looked at Becky and smiled. This was the sign for Becky to begin her well-rehearsed welcome. She pushed her chair back, stood up, tucked her red braids behind her ears, glanced at her computer, and hit the button which brought up the first slide of her PowerPoint presentation. There was Becky standing in the greenhouse with a big smile! Her well-rehearsed words matched the slide, and she didn't seem to be one bit frightened. "Hi to all my teachers and my Mom and Dad, and everybody else, too. This is about me."

I was so proud. There was my daughter, all eyes on her, showing us through pictures what she'd been doing, showing us her life. In this one moment, this one photo, all the hard work seemed to have paid off. Becky's performance caught my breath; Tom squeezed my hand. Maybe this meeting would be different. Maybe this time everything would go smoothly.

“This is me,” Becky said, and showed us the next slide, of her standing next to a flaming red geranium at the nursery we visited a month ago. Ms. Lewis had encouraged us to tour the nursery, as it might qualify for an internship or future job for Becky next September.

“The lady on the tour was real nice.” Becky said. I was watching my daughter and feeling so proud of what she was saying and doing with the computer. But I think it was then I noticed a change in Ms. Lewis’s face. Her pleasant and confident expression seemed to have faded. After the last slide, Becky said, “Thank you for learning about my dreams.” She sat down and everyone smiled, except Mr. Frank, the assistant principal. He seemed uneasy and asked some questions about the nursery and its relationship with the work-study program. Someone said something in response. Ms. Lewis took off and put on her glasses, and fumbled with some papers in her folder.

I didn’t know what to think. There was tension in the air, but no one commented on it. Everyone seemed to have lost eye contact with everyone else, yet words kept filling the air. Was I imagining this? Was this about Becky? About us? What was going on? I looked at Tom and he looked at me.

I was so proud. There was my daughter, all eyes on her, showing us through pictures what she’d been doing, showing us her life.

Then the assistant principal used his “lecturing voice” and went on and on using letters and jargon about following protocols, appropriate work sites, and memorandums of understanding.

All of a sudden, this didn’t feel like Becky’s meeting. Her wants, needs, and dreams flew out the window. I knew my face was beginning to flush as the anger rose from my tapping foot. It

seemed as if the assistant principal had simply “tolerated” Becky’s PowerPoint. His stiff body language seemed to say “It’s time to move on to the real issues here. . . This was a nice thing to see Becky, but now we have to get on with the real meeting” and “do” transition based on the standard practice and procedure.

I wanted to shout out, “What is happening?”

The meeting today started out so well. It was about Becky. It was about her PowerPoint, her dreams, her pride. Now suddenly it felt like it had nothing to do with her. Why was this meeting so impossible, so frustrating?

When Ms. Lewis suggested that we end the meeting and reconvene in two weeks, we leaped at this opportunity. I needed time. I needed to talk with Ms. Lewis.

I wondered if the calendar on my fridge had room for one more meeting.



## **Maya Lewis, her teacher**

As I roll over I see it’s only 4:30 am. I must try to go back to sleep before the alarm goes off or I’ll be useless at school today. I can’t seem to turn my mind off. There’s a misconception among new teachers that as years pass, IEP meetings get easier. That simply isn’t true. Yesterday’s meeting, for example. I play and replay yesterday’s meeting of Becky’s IEP in my head.

Becky practiced her lines and reviewed her presentation all afternoon. She seemed excited to be participating in her IEP meeting and printing her name on the IEP this year. One day last

week as we were discussing the upcoming meeting Becky said “But what will mom and dad do if I’m doing the talking and signing?” She was relieved when I reassured her that they would have time to share their thoughts and sign the IEP as well.

I remembered some of my first IEP meetings and cringed when I thought of how unwelcome and confused the students must have felt when I and the other teachers did most of the talking.

I’m not sure what other teachers did to involve her in years past, but I got the impression from Becky that this type of involvement was a new event. At first when Mrs. Stratton suggested Becky do a PowerPoint presentation I was hesitant. But then I realized this was the perfect way to include Becky in the IEP meeting; after all, it is her meeting. Becky was excited that her math, social studies, and English teachers accepted her invitation to attend the meeting. I remembered some of my first IEP meetings and cringed when I thought of how unwelcome and confused the students must have felt when I and the other teachers did most of the talking. In the past few years I’ve found ways to have students participate that were comfortable with both of us.

Becky and I walked down the hall together and opened the heavy, metal doors to the library. We were the first ones to arrive. Becky moved in a few more chairs and organized them. “Becky, we’ll need one more because your science teacher stopped me in the hall today and said she could come to the meeting after all.”

“Oh, good! Lots of my teachers will hear me talk.” Becky said enthusiastically.

I reflected on how much Becky had grown over the time I had gotten to know her here at Anthony High. When I first met Becky she was pretty shy about expressing her thoughts and feelings; that was no longer an issue for her. I think the encouragement

and support she gets from her parents and being involved in classes and connecting with other students her age has made all the difference in her life. Having friends to share your inner thoughts and fears with is so important.

It's 4:43 am. This is getting ridiculous. Breathe, breathe, relax. My assistant principal's words pop unexpectedly in my head, "To my knowledge, Ms. Lewis, The Green Thumb is not part of our work-study program. Am I correct?" That Mr. Frank—ooooo.

As Becky started the meeting off for us, she seemed proud and confident. Then Mr. Frank interrupted her and turned to me. "To my knowledge, Ms. Lewis, The Green Thumb is not part of our work study program. Am I correct? We don't have an MOU with them, do we?" He continued his little speech about needing to be continually kept informed by his staff; his words drifted off in my head. He had done it again. The way I saw it, Mr. Frank has two gifts in life, neither of which I have ever found valuable or entertaining: 1) pulling the rug out from under his students and teachers; and 2) saying the wrong thing at the wrong time. I cleared my throat and put on my glasses and searched for the draft Memorandum of Understanding I drew up with The Green Thumb. Where was it?!? Why did he have to bring this up just now? It wasn't the time or the place. I felt my face heating up and the back of my neck tightening.

5:12 am. I give up and roll myself out of bed. As I pull on my robe and leave the room, I stop by Darryl's door to check on him; I am envious of his sleepy breathing. I stroll into the kitchen and turn on the low kitchen light. As I find the bag of coffee in the cupboard, I remember Becky's face as the assistant principal interrupted her.

Did Becky think she had done something wrong? Did he think using acronyms like MOU were going to impress the Strattons? I didn't even want to look at Mr. or Mrs. Stratton. Becky seemed confused. I could only hope: maybe it wasn't as bad as I thought it was.



While I was mortified by Mr. Frank's behavior, maybe it's not the end of the world. If that's true, then why do I find myself wondering, "Are the Strattons ever going to forgive me?" Maybe they didn't even pay attention to what he was saying or my attempts to address his interruption, even though I did not feel the timing was right. I'm hoping this was a bump in the road and not the end of the road for them, because we have a long way to go before we get where we need to be.

When I finally looked at the Strattons, they looked stunned. Mrs. Stratton had that same vulnerable, hurt, and angry look she had the day she joined Becky and me to begin our discussion about transition.

It was after looking at them that I remembered a suggestion my colleague, Jeannine, had made about having a facilitator, someone other than me to facilitate the IEP meeting. It was difficult to imagine adding one more person to the already crowded table, but it seemed like it might not be such a bad idea. As they were, things were not going well. So after Mr. Frank finished his remarks, I cleared my throat and said, "I think we've accomplished a lot this afternoon, and perhaps this would be a good place to stop." There was an uncomfortable pause. "I'd like to suggest that a smaller group of us might come back together in three weeks after we've had a chance to explore some of the ideas and services we've talked about today. How does that sound?"

I turned toward the Strattons and waited to see what would happen next. The Strattons nodded and my assistant principal gave his okay. Becky looked bewildered; she, like the rest of us, must have thought things would be a little clearer at the end of the meeting. Our disappointment, unfortunately, was the only thing that was clear.

## Talking Points

1. Put yourself in the place of Ms. Lewis. What did she want to have happen in the IEP meeting? Why did she seem disconcerted and tense at the IEP meeting? What do you think was going on behind the scenes?
2. What might parents think and do to prepare for IEP meetings? How can parents help shape the role they want to have in an IEP meeting?
3. What is the role of professionals in addressing the concerns of parents and students before, during, and after the meeting?
4. Discuss strategies that teachers can use to decrease the discomfort and increase the sense of trust during these meetings.
5. What did you think about Becky's use of the PowerPoint? How has Becky helped to shape her role in this and future IEP meetings?
6. What is your experience with actively involving students in the planning of their IEP meetings? What methods have you used to encourage their participation in a meaningful way?
7. What could happen to improve the flow before, during, and after this meeting?
8. Becky talks about the meeting as if she is puzzled by its outcome. What feelings do you imagine she is experiencing?
9. How would you handle a disagreement with an administrator? How can differences of opinion be addressed in helpful ways? What happens when these differences arise abruptly during a meeting with a student and parents?

## **A Place for Your Thoughts and Questions . . .**





## **SCENE 5**

**April, One Year Later**

We reflect on the past year.



## Anne Stratton, her mother

I'm sitting in my car and I'm stuck in traffic, right here in my own neighborhood. It's 6:30 p.m., too, which makes this backup very strange. If things don't clear up fast I'll be late picking Becky up from her job at the Pizza Palace. I continue to creep, straining my head to see in front of me. I notice four stretch limousines, the size of small ocean liners, blocking the street! What are they doing here in our humble neighborhood? Then it dawns on me. It's Prom night. Prom! I think back to one year ago tonight when Becky, in her fancy purple dress, giggled as she and six loyal friends waved to me from the tiny window of their immense limo.

An entire year has passed. We are now officially living in Becky's-Future-After-High-School. I could write a thick book about everything we've been through during these twelve months.

A year ago, sitting in that awful IEP meeting where nothing seemed to happen according to plan, was not the best of times. For awhile after that meeting, we felt a bit guarded with the whole system, but we continued to meet with Ms. Lewis during the remainder of Becky's senior year and into the next year. Tom and I have learned that you can't give up. You have to find the right people to work with and you have to be persistent. We have learned to trust a few people, and Ms. Lewis was one of them. The bottom line was she cared.

In the next few meetings she worked hard, bringing in new ideas and resources. She never gave up. She believed in Becky's dream to work with plants. We soon realized how heavily she was invested in Becky's dream. She actually talked with our local community college about a horticulture class focused on growing plants in commercial greenhouses! It met three afternoons a week.

A long, loud car honk startles me from my stuck-in-traffic reverie. I notice the ocean liners on wheels have pulled to the side of the street. I quickly press on the gas and lunge forward. There's

Kimberly Johnston and a couple of her friends, tugging on the scooped necklines of their satin dresses. They want so much to look like they fit in these unfamiliar fashions. I'm glad Becky could do typical senior year things, even if we had to do some behind-the-scenes work to get her invited to parties. I turn onto the busy six-lane street out of our neighborhood.

I remembered the one day last September when Becky came home with a college catalog she got from Ms. Lewis. Becky pointed to the highlighted horticulture class she wanted to take. We were stunned. After Becky left the kitchen Tom bellowed, "That teacher has lost her mind! They won't let Becky in a college class. SHE CAN'T READ! They don't let kids with cognitive disabilities in college. Becky still has an IEP. What is this teacher thinking?"

It wasn't that we didn't want Becky to have experiences like her friends. Since third grade we'd fought for Becky to be included in regular classrooms and regular experiences. But COLLEGE? At the next meeting, we didn't hesitate to inundate Ms. Lewis with our worries and questions: Would the college actually let Becky take a class? How would she read the materials? How would she get to class in the first place?

In spite of our skepticism and our fears, Ms. Lewis never gave up on us. She didn't dismiss our worries and didn't get defensive, not even when Tom asked her if she'd forgotten that Becky couldn't read! "No, Mr. Stratton, I haven't," she reassured us patiently. She informed us that "there is a new inclusive initiative starting at the local community college for students with cognitive disabilities. Becky can work on her IEP goals and most importantly her dreams while being on the college campus with her same age peers." She explained more about how peer tutors would support the learning needs of Becky. Needless to say, we went home from that meeting with all sorts of feelings, including being cautiously excited, almost soaring . . . as high as the kites we use to sail with our three kids on the windy Lake Michigan beach. Becky in college! The winds of possibility took our hopes for Becky to greater heights. Maybe this was a way that Becky could continue to learn, be with kids her age, and eventually get a job.

Of course, later that night, my fears returned and robbed me of all sleep. What if the college administration regretted including Becky, or unwelcoming college students rudely ignored or teased her? The image of kites flying over Lake Michigan returned, but this time I saw us empty-handed. Right before our eyes the thin kite string slipped through our fingers and Becky's dreams plummeted to the ground. Would the worries ever leave us alone?

In spite of our worst fears then, Becky is now taking two buses and her cell phone to Parkside Community College every Monday, Wednesday, and Friday. She is one of the new students on campus. She's proud; we're proud. I marvel at her courage.

I can't wait to tell the world about her courage. I've been asked to write an article for our State's newsletter for parents and professionals about what our family experienced during Becky's transition. I chuckled when they asked me to write an article. Never thought that would happen!

I remembered back a year ago when Ms. Lewis sent me the article written by the father whose son was going through transition. It was helpful to read about the feelings, thoughts and experiences of another parent. His title, "I'm Not Ready for This" matched my feelings exactly. As I read it I felt normal, reassured, less alone. Now it is my turn to reach out to other parents.

As I think about what I want to include in the article I know I will write about the importance of having great expectations for our children – I mean really great expectations! I also want to remind professionals to take some time with parents to get to know them and to be open to talking about their fears, worries, and dreams for their child. It is really hard to go forward if you can't talk about the worries. That's something Ms. Lewis did. She didn't seem to be judgmental. She seemed to want to listen and help us sort through the various feelings we were having about Becky and her future. Ms. Lewis was really there for our family. I know that she didn't always agree with us. I guess we didn't always agree with her either but she seemed interested in what we were thinking, what we were worrying about.



She took her time and really valued our input, even when it wasn't easy for her or clear to us.

We know that this is BECKY'S LIFE especially as she hits adulthood. But Becky's life involves our lives too. She isn't totally independent of us. We sometimes can read Becky in ways that no one else can. We have nudged her along at times when others seem to settle for less. We have learned how to support her, get her going. When it comes down to it, all of the professionals, as helpful as they can be, are not going to be a part of Becky's life forever. We have to be involved. Somehow Ms. Lewis was able to include both Becky and us during this transition process. She must have felt dizzy at times as she bounced back and forth between Becky and us! But she did it.

I turn onto Braskin Street. Ahead of me I see the giant piece of pizza, outlined in blinking red lights on the roof of the Pizza Palace. I spot Becky, head down, her red hair stuffed into her cap. She is pacing back and forth in the parking lot. I know what she is saying under her breath. I want to shout out the window, "I'm coming Becky. Don't worry!" but of course she can't hear me.

I once read in a parent newsletter that planning for kids with disabilities after high school is sort of like eating with chopsticks—which, of course, I can't do! With one chopstick you can pick up some foods, like meatballs, but for the other foods, like spaghetti and rice, you need two chopsticks. In a sense this is what Tom and I learned about being Becky's parents. There is a lot Becky can do on her own, all by herself... just her own chopstick will work some of the time. But there are other times when our support or ideas are needed. Sometimes she needs the second chopstick to accomplish the next adventure of her life. That's what we hope professionals understand. There is a balance.

In planning for Becky's future, we needed both—Tom and I as Becky's parents are one chopstick, and Becky is the other. As her parents, we don't want to make all the decisions for Becky but we need to actively participate and plan with her. Call us meddling, overprotective, and anything else you want, but we have to be a part

of the planning, at least for now. It's about working together. It's about coordinating both chopsticks when both are needed.

I've pulled into the Pizza Palace parking lot. Becky opens the door, with a "Sheesh, Mom!" This is accompanied by rolling eyes, a few grunts and then, "Do not be late anymore. That's it."

"I'm sorry Becky," I say, and smile at her. She seems to be developing the feistiness her Grampa used to say went with red hair.

I am aware that she has expressed her frustration with me. She has told me exactly what she thinks and feels. She is becoming a person with her own wants, needs, and dreams. She dares to take exception to what I say and do. She dares to think for herself. Difficult as it will be to get used to, this is exactly what we have worked so hard for.

There are many months ahead of us, so many pages of the calendar to pull off, propelling us forward to the next months and years. I know I need to look back at those old calendar pages and review all that Becky has accomplished with our support and the help of others. The remembering would give me strength. I'm also learning that I can't flip ahead too many months. There is a balance to moving forward, remembering the past, and living one day at a time.

As we head out of the parking lot, I say, "Hey, Becky, how about the whole family going out for Chinese food tonight?"

Becky gives a whooping, "Yay! Yay! No Pizza!"

I agree, Becky. No pizza tonight. Chinese sounds right. I settle in my seat and glance at her as she takes off her Pizza Palace cap and shakes her red curls. I think to myself, I'm going to try using chopsticks tonight. Just for fun.



## Maya Lewis, her teacher

It's Saturday, late in the afternoon, my favorite time of the weekend. Time enough for the day-in-day-out of the work week to have faded, yet far enough away from Monday morning for it not to matter. I'm in the backyard clearing out last year's tomato plants and preparing the soil for this year's crop. I take a break and stand to stretch my back. As I stroll toward the gate leading to the front yard, I remove my soil-covered gloves. Hard to believe the tulips are beginning to come up.

My mind wanders to Becky and her love of flowers and gardening. What a disappointment for everyone, most of all Becky, when her job at the greenhouse fell through. If only the manager had been a little more understanding of the limitations of "public" transportation. During her first two weeks of work she was fifteen minutes late three times because of the bus.

Since few of Becky's co-workers used the bus, there was little understanding or tolerance for her tardiness. The elms and boxwoods she watered weren't going anywhere—it's not like she had a hard-and-fast schedule to keep. I had gotten the feeling earlier in the process that the manager was not too sure how Becky would "fit in" at the greenhouse. I think he was also uncomfortable with Becky having seizures, even though we provided training for ALL of the staff on what to do if she had one. It's not like her coworkers had to remind her to take her seizure meds; she does this independently with the aid of her watch timer.

Apparently any excuse to get rid of her was excuse enough. When I inquired about the tardiness of other employees and how that was handled, the manager said, "Well, that's different. The other employees can work more quickly and get it all done." Between that and his recent unwillingness to pay her the initial wage we agreed on, I'd had enough. I'd worked so hard to get Becky a job coach I thought would work well with her, and then the manager

became the barrier. There was no getting around him. Sometimes, no matter how much I want a job placement for a student, it isn't meant to be.

Measuring myself through the success of my students is what I do. I realize this is risky, but I can't help it. People choose to teach for a variety of reasons. I chose teaching because I like having a vocation that contributes to the lives of others. Finding meaning in my work is important to me. While rewarding, at times juggling teaching responsibilities with working with employers in the community is a challenge; especially when it feels like I'm spinning my wheels.

I pull stray blades of grass that are beginning to grow in the flowerbed. I start to move the stones that border the sprouting bulbs, then I hesitate. Of the two of us, my boyfriend, Keith, is more the garden designer; best leave it to him. I recall how hard he worked last year in the rain and mud to construct the wall in time for us to host his annual family July fourth picnic.

I remember how many times I felt stuck in the mud with the Strattons over the last year. Rebuilding the relationship with them after the mess at Becky's IEP meeting was not an easy task. Much of the trust we had built up over that year was gone. And then getting Becky into community college had been more difficult than I had imagined. She was the first student that year whose parents actually came around to the idea, even if it took much deliberation and discussion.

At first I didn't believe Becky could do it, either. It was the presenters at a conference I attended who convinced me. Until I saw the session title, "All Means All: How to Make Post-Secondary Education an Option for All Students," I had no idea that students with cognitive disabilities were participating in college life and academics. But when the public school transition teachers, parents, students, and college representatives began describing how students at both community and four-year colleges were sitting in on courses, auditing courses of interest, receiving assistance from peer mentors, and riding the bus to campus, I thought: well, maybe Becky could do this, too.

To be honest, it wasn't that simple. Both the Strattons and I had what we thought were legitimate concerns: How would Becky manage a class where there were over twenty-five students? Would she understand the material? How would she complete her assigned readings when she can't read? How would she get herself to class? What about making friends? All these questions led to lots of meetings, and we all made a visit to another community college that some students with cognitive disabilities were attending.

The Strattons talked to the other parents and had some of their concerns addressed. Becky would sit in on the class with a peer mentor to whom she would be introduced before the first class started. That way she would know someone in class. Becky would get her books on tape and work with the mentor, who could help her understand the material. Her vocational rehabilitation counselor would pay for someone to teach her the bus route.

Rebuilding the relationship with the Stratton's after the mess at Becky's IEP meeting was not an easy task. Much of the trust we had built up over that year was gone.

We all learned to listen more to Becky, too. When we were discussing community college classes she might be interested in taking, she made it perfectly clear when she said, "No, I don't want to learn to teach little kids. I want to learn about plants." The Strattons wanted an education for Becky that she enjoyed, and would open the door for employment opportunities; flowers and gardening were it! Her rehab counselor was more interested in her taking courses related to restaurant work, where he believes most people with cognitive disabilities should work. Becky convinced us all that courses in plants and flowers were what she wanted.

So at least part of our plan was working: Becky was sitting in on one gardening course. Its hands-on nature was helpful to Becky, and she was even beginning to identify some new plants while she worked at the greenhouse; then that job fell through. Her professor was more welcoming than we imagined, in terms of how he talked with her, and

treated Becky like any other student. He was willing to adapt some of her assignments, and he communicated any assignment issues with Becky and then her parents and peer mentor when appropriate. He knew that we all were supporting Becky's learning.

I continue raking the new soil across what will be a thriving tomato garden by the end of the summer. Hard to believe another school year is almost at an end; each school year seems to pass more quickly. Spring always brings a sense of renewed commitment to my job. I don't know if it's the weather and being in the garden, or simply that enough time has passed that I can reflect on how the students, families and I, myself, have grown. Growth and progress are always reassuring.



### **Becky, the final word**

I can't wait for tomorrow night. I'm going to see my friend Jessica from college and we're going to work on our homework for class. We get to go to the library and look up plants. I work hard in college—just like my cousin. I want to do good work so everyone knows I'm smart too. It's funner now that I have some friends there. I was so scared at first—I didn't like it. I didn't know anyone and the classroom had steps and a big, and a big screen that came right out of the ceiling.

I was scared taking the bus the first time too. Mom told me to ask the bus driver if I got confused. The first time I asked the bus driver where the stop was for the community college, he told me to "sit down." But now he says, "Hey Becky, how's college life?" every time I get on. Yesterday I even told someone which bus they were on!

Jessica helps me find my way around campus and she helps me study. She reads the tests to me and marks down the answers I tell her. Sometimes when we get done with class early we go to 'Shivers' in the commons and get some ice cream. I love college now. I wish Ms. L. was still my teacher, though.

Tonight I have to work at the Pizza Palace but I call it Pukey Palace. Yuck! I hate working there. I have to wash dishes most of the time. My hands get all wrinkly and they hurt. When I do a good job Paul smiles at me and winks. I like Paul. I wish I could go back to my old job at the greenhouse. I wish Paul worked at the greenhouse. Then it would be the perfect job. Nobody even asked me if I wanted to work at the Pukey Palace. *Whose Life Is It Anyway?*

We thank Kyeong-Hwa Kim and Ann Turnbull for the analogy of the chopsticks as found in their article:

Kim, K-H., & Turnbull, A. (2004). Transitioning to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research & Practice for Persons with Severe Disabilities*, 29(1), 53-57.

## Talking Points

1. What is the role of the teacher/transition coordinator in supporting a student's dream? What if the student's dream is different from the parents'? How do teachers handle this conflict?
2. What is the parents' role in planning for "after high school" with their teenager? What are some of the complex emotions that parents may experience during this time?
3. What thoughts and reactions do you have about Becky "sitting in" on a class at the community college? How familiar are you with this emerging trend for youth with cognitive disabilities and special health care needs? Is this occurring in your community? If it is not, how could you help make it happen? What are the benefits and challenges of this opportunity?
4. From your perspective, how did the three characters grow over the course of the year? Describe the emotional growth you have witnessed or imagined for the characters.
5. How has reading about each character's perspective expanded or changed your expectations about transition and the relationships among students, parents, and teachers?
6. What are the current transition opportunities for youth with cognitive disabilities in your community? What kinds of work and post-secondary experiences and opportunities could there be?
7. After reading all of the scenes, what issues and concerns are you more aware of for each of the characters: Becky, her parents, her teacher? What new insights do you have about what each character is experiencing during transition?



## **A Place for Your Thoughts and Questions . . .**

# How This Book Came To Be

By Janice Fialka

In 1999, Karen Mikus and I co-authored the book, *Do You Hear What I Hear? Parents and Professionals Working Together for Children with Special Needs*. In the book, we tell the story of a mother whose four-year-old son, Sam, is going through an assessment by a school psychologist due to his developmental delays. The story, written in six scenes, gives voice to both the mother's and the psychologist's inner feelings, thoughts, and worries. In the book, we literally placed the mother's internal dialogue on the left page of the book and place the internal dialogue of the professional on right page of the book, side-by-side. Our hope in writing this story from the two voices was to offer both perspectives—to hear the similarities and differences. We believed that listening to both sides of the story had the potential to strengthen parents' and professionals' empathy and understanding for each other as they formed partnerships.

Over the past six years, our readers have graciously shared with us how helpful it was to hear “both sides of the story.” They told us how they become more cognizant of “the other” partner's worries, feelings, constraints, joys, and dreams, as well as their own. They told us that this format provided important insights often resulting in a greater capacity and desire to work on their relationship with each other.

As my son, Micah, moved into high school and we faced “what's next,” I once again became aware of the different voices and perspectives that came to the table as we discussed his future, his “transition.” Unlike his early years when he was less apt to be involved in the planning process, he now proudly sat at the table with us. He was becoming the self-advocate that we had hoped he would become. This was a good step but it added new dimensions, more voices to our planning process. We, as Micah's parents, had

our own internal feelings (lots of them!), Micah certainly had his own experiences, and I soon learned that the professionals had their unique thoughts and emotions. As is often the case, some of the inner thoughts were not discussed out loud and typically remained hidden from each other. I was struck with how little of the internal experiences were shared. Yet these very feelings and thoughts often shaped our conversations and actions.

I began a quest to find two people who would help me write a story of a high school student with cognitive disabilities facing the transition process. After the feedback we received about our approach in *Do You Hear What I Hear?* it seemed reasonable to tell the story of secondary transition using the scene format told from the experience of a parent, a student, and a teacher as they moved into the very demanding, yet potentially exciting world of secondary transition.

In 2003 at the Circles of Life conference, I had the great fortune to meet Martha Mock and Jenny Wagner Neugart, two highly motivated and talented professionals who demonstrated this capacity to understand what youth, parents, and professionals often worry about in the middle of the night. Both were experienced in the field and both expressed immediate interest in writing this story from the three perspectives of a student, a parent, and a teacher. We willingly agreed to write five scenes and naively thought we could accomplish that in several weeks. We completed the story, but hardly in the time frame that we anticipated!

Writing this book has been an adventure—not unlike the secondary transition experience faced by families and professionals. Living life or writing about it is rarely as simple as it seems. Martha, Jenny, and I never knew it would take that much time, that much paper, that many hours on the phone, that much staring at the blank computer screen, or that much contemplation.

In some ways writing this book parallels what families and professionals experience during transition. Martha, Jenny, and I had to sort through the diversity of issues for each character and writer. We had to listen to an assortment of feelings and be empathic. We had to honor the variety of constraints and wishes. We had to research topics, seek out support from others, compromise, consult, and practice compassion for ourselves and each other. We had to be patient. Nudge when needed. Listen attentively. We had to be quiet at times. Ask tough questions. Hear things we weren't so eager to hear. Be understanding and feel understood. We had to celebrate when we accomplished a next step, as tiny as it might be in comparison to the complete project. Through it all we had to dare to dream and be guided by our dream.

As the weeks turned into months, we were continually reminded by parents of youth in transition of the importance of this book. Each one of us had conversations with parents whose eyes would tear up when questions around their teen's transition arose. We knew we had hit on something meaningful, that is not typically discussed—the emotional side of transition.

When we look over this list of what we had to do to finish this book, we are struck by how much this resembles what youth, parents, and professionals do during secondary transition. It is hard work but always the work must be guided and fueled by the young person's dream.

# About The Authors

Janice Fialka, M.S.W., A.C.S.W. is a nationally recognized social worker, author, and speaker. She is also the Special Projects Trainer for CCRESA–*Early On*® Training and Technical Assistance (Part C of IDEA). She has presented to professional and parent groups throughout the country on the topic of parent–professional partnerships, inclusive education, post secondary education, and sibling issues. She speaks from her unique vantage point as a mother of a young adult with disabilities and as an experienced social worker for three decades. Janice’s training, “The Dance of Partnership: Why do my feet hurt?” has been enthusiastically received by groups who are committed to strengthening the working relationship between families and professionals. She has published numerous articles, poems, and two books: *It Matters: Lessons from my son* and *Do You Hear What I Hear? Parents and professionals working together for children with special needs* (co-authored with Karen Mikus). Many of Janice’s articles and training, including writings by her son, Micah, and daughter, Emma, can be found on her web site: [www.danceofpartnership.com](http://www.danceofpartnership.com).

Martha Mock, Ph.D., has worked with people with disabilities and their families for over fifteen years. She has worked as a special educator, teacher trainer, parent trainer, researcher, and evaluator. She has experience in the areas of adolescent transition as well as early childhood special education and inclusion. She worked at the Waisman Center on the WI Healthy and Ready to Work project as a community specialist and program evaluator, assisting the WI Children with Special Health Care Needs Regional Centers in improving community resources, parent-professional-youth partnerships, and outcomes for youth in transition. She currently resides with her family in Rochester, NY, and is a Visiting Assistant Professor at the Warner Graduate School of Education and Human Development at the University of Rochester.

Jennifer Wagner Neugart, M.S., completed her master's in Vocational Rehabilitation–Rehabilitation Counseling in May 2005. For the past six years she has worked directly with high school and college students with disabilities on the University of Wisconsin–Whitewater campus. She has become a leader in the state in improving students' leadership and self-advocacy skills by coordinating Wisconsin's Youth Leadership Forum (YLF) and the My Future My Life Transition Summer Camp. Through her work at the Waisman Center on the WI Healthy and Ready to Work project she has had the opportunity to provide parent training on transition issues and assist youth in making the transition process smoother. Jenny wrote from her own experiences as a person with a disability and from the experiences she has had with parents and youth with disabilities in transition.

We consider *Whose Life Is It Anyway?* a work in progress. Please feel free to contact us with your thoughts or comments.

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or

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# Resources

We offer these resources as a starting point for gathering information about transition-related issues. This is not a complete list. We welcome any additions.

## Assistive Technology

ABLE DATA

[www.abledata.com](http://www.abledata.com)

Assistive Technology and Transition Packet by T. Canfield & P. Reed  
[www.wati.org/Curriculum/pdf/attransitionpacket.pdf](http://www.wati.org/Curriculum/pdf/attransitionpacket.pdf)

DO-IT: Disabilities, Opportunities, Internetworking, and Technology  
[www.washington.edu/doi/](http://www.washington.edu/doi/)

Hey, Can I Try That? A Student Handbook for Choosing and Using Assistive Technology by Gail Bowser and Penny Reed  
[www.wati.org/materials/pdf/HeyCanITryThat.pdf](http://www.wati.org/materials/pdf/HeyCanITryThat.pdf) (English Version)  
[www.wati.org/materials/pdf/Oye!Puedo.pdf](http://www.wati.org/materials/pdf/Oye!Puedo.pdf) (Spanish Version)

## Transition Planning and Checklists

Checklists from the Adolescent Health Transition Project  
<http://depts.washington.edu/healthtr/Timeline/timeline.htm>

Checklists developed by the National Transition Network  
[www.ppmnd.org/factsheets/transition\\_checklist.pdf](http://www.ppmnd.org/factsheets/transition_checklist.pdf)

Full Life Ahead Foundation Workbook  
[www.fulllifeahead.org](http://www.fulllifeahead.org)

Moving On: Planning for the Future, Resources from the Institute on Community Inclusion  
[www.communityinclusion.org/publications/pdf/brief495.pdf](http://www.communityinclusion.org/publications/pdf/brief495.pdf)

Three Checklists for Parents and Students from LD Online  
[www.ldonline.org/ld\\_indepth/iep/ld\\_teenagers\\_form.html](http://www.ldonline.org/ld_indepth/iep/ld_teenagers_form.html)  
[www.ldonline.org/ld\\_indepth/iep/student\\_profile\\_parent.html](http://www.ldonline.org/ld_indepth/iep/student_profile_parent.html)  
[www.ldonline.org/ld\\_indepth/iep/student\\_profile\\_student.html](http://www.ldonline.org/ld_indepth/iep/student_profile_student.html)

## **Benefits and Financial Planning**

Social Security Administration – Youth  
[www.ssa.gov/work/Youth/youth.html](http://www.ssa.gov/work/Youth/youth.html)

## **Community Living**

Institute on Disability, University of New Hampshire – To promote the full inclusion of people with disabilities in their communities.  
[www.iod.unh.edu/](http://www.iod.unh.edu/)

National Council on Disability (NCD) – To promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.  
[www.ncd.gov](http://www.ncd.gov)

To Peak Parent Center – To ensure that individuals with disabilities lead rich, active lives and participate as full members of their schools and communities.  
[www.peakparent.org](http://www.peakparent.org)

TASH – An international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.  
[www.tash.org](http://www.tash.org)

Wisconsin Independent Living Centers  
<http://dhfs.wisconsin.gov/Disabilities/Physical/ILCs.htm>



## **Cultural Diversity**

Disabled and Proud – Information about the disability culture, history and community.

[www.disabledandproud.com](http://www.disabledandproud.com)

Transitioning Successfully: Native American Students with Disabilities

[www.msubillings.edu/transition/March%2004%20Newsflash.pdf](http://www.msubillings.edu/transition/March%2004%20Newsflash.pdf)

## **Education**

Answers to Commonly Asked Questions About Transition Services and the IEP (English)

[www.transitioncoalition.org/98commonlyaskedquestions.pdf](http://www.transitioncoalition.org/98commonlyaskedquestions.pdf)

Respuestas a las Preguntas mas Comunes sobre los Servicios de Transicion y el Programa de Educacion Especializada (IEP)

[www.transitioncoalition.org/freepub.php3](http://www.transitioncoalition.org/freepub.php3)

A Student's Guide to the IEP (NICHCY)

[www.nichcy.org/pubs/stuguide/st1.pdf](http://www.nichcy.org/pubs/stuguide/st1.pdf)

## **Student–Led IEPs**

Council for Exceptional Children - Student Led IEPs

[www.cec.sped.org](http://www.cec.sped.org)

LD Online

[www.ldonline.org/ld\\_indepth/iep/iep\\_kids.html](http://www.ldonline.org/ld_indepth/iep/iep_kids.html)

Transition Planning: A Team Effort (NICHCY)

[www.nichcy.org/pubs/transum/ts10txt.htm](http://www.nichcy.org/pubs/transum/ts10txt.htm)

[www.nichcy.org/stuguid.asp](http://www.nichcy.org/stuguid.asp)

[www.nichcy.org/pubs/stuguide/ta2book.htm](http://www.nichcy.org/pubs/stuguide/ta2book.htm)

Pacer Center

[www.pacer.org/tatra/studentIEP.htm](http://www.pacer.org/tatra/studentIEP.htm)

## **Employment**

Helping Students with Cognitive Disabilities Find and Keep a Job  
[www.nichcy.org/pubs/stuguide/ta3.pdf](http://www.nichcy.org/pubs/stuguide/ta3.pdf)

Division of Vocational Rehabilitation – A federal/state program designed to obtain, maintain, and improve employment for people with disabilities by working with VR consumers, employers, and other partners.

[www.dwd.state.wi.us/dvr](http://www.dwd.state.wi.us/dvr)

YouthRules! US Dept. of Labor Info for Teens, Parents, Educators, and Employers

[www.youthrules.dol.gov](http://www.youthrules.dol.gov)

## **Guardianship Options**

Making a Difference: Thinking About Decision-Making Support in the Transition Process

[http://wcdd.org/Publications/making\\_a\\_difference.PDF](http://wcdd.org/Publications/making_a_difference.PDF)

## **Health and Health Care**

Health Info for Kids & Teens

[www.healthinschools.org/students](http://www.healthinschools.org/students)

ICI Transition Manual

[www.communityinclusion.org/transition/familyguide.html](http://www.communityinclusion.org/transition/familyguide.html)

National Healthy and Ready to Work

[www.hrtw.org](http://www.hrtw.org)

American Academy of Pediatrics National Center of Medical Home Initiatives for Children with Special Needs

[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

## **Housing**

Going It Alone: The Housing Struggle to Expand Housing Opportunities for People with Disabilities  
[www.c-c-d.org/going\\_alone.htm](http://www.c-c-d.org/going_alone.htm)

Opening Doors  
[www.c-c-d.org/intro\\_page.htm](http://www.c-c-d.org/intro_page.htm)

Section 8 Made Easy  
[www.tacinc.org/cms/admin/cms/\\_uploads/docs/Sect8.2ndEd.pdf](http://www.tacinc.org/cms/admin/cms/_uploads/docs/Sect8.2ndEd.pdf)

## **Mental Health**

National Alliance for the Mentally Ill is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families and friends of people with severe mental illness.  
[www.nami.org](http://www.nami.org)

“FDA Issues Public Health Advisory on Cautions for Use of Antidepressants in Adults and Children  
[www.fda.gov/bbs/topics/ANSWERS/2004/ANS01283.html](http://www.fda.gov/bbs/topics/ANSWERS/2004/ANS01283.html)

Federation of Families for Children’s Mental Health  
[www.ffcmh.org](http://www.ffcmh.org)

## **Person-Centered Planning**

Building Personalized Supports that Respect the Dreams of People with Disabilities  
[www.reachoflouisville.com](http://www.reachoflouisville.com)

Resources on Person-Centered Planning – Inclusion Press  
<http://www.inclusion.com/inclusionpress.html>

## **Post-Secondary Education**

AHEAD – the premiere professional association committed to full participation of persons with disabilities in postsecondary education.  
[www.ahead.org](http://www.ahead.org)

College is Possible – A website that motivates middle– and high school students from underserved communities to seek a college education. Click here to take a quick survey about this site.  
[www.collegeispossible.org](http://www.collegeispossible.org)

College Consortium of Disability Advocates – To help students with disabilities prepare for the transition from high school to college.  
[www.ccdanet.org/](http://www.ccdanet.org/)

Dance of Partnership – Click on “Micah’s Writings” to learn more from a youth with a cognitive disability who is going to college.  
[www.danceofpartnership.com](http://www.danceofpartnership.com)

National Center on Secondary Education & Transition: Creating Opportunities for Youth with Disabilities  
[www.ncset.org](http://www.ncset.org)

National Center for the Study of Post-Secondary Educational Supports (NCSPEs)  
[www.rrtc.hawaii.edu](http://www.rrtc.hawaii.edu)

National Clearinghouse on Post-Secondary Education for Individuals with Disabilities  
[www.heath.gwu.edu](http://www.heath.gwu.edu)

On–Campus Outreach (OCO) – To provide information and support to programs and personnel that provide services to public school students ages 18–21 with significant disabilities in post–secondary settings such as colleges and universities.  
[www.education.umd.edu/oco](http://www.education.umd.edu/oco)

Think College – A website for youth, families and professionals interested in learning more about college as an option for people with cognitive disabilities.  
[www.thinkcollege.net](http://www.thinkcollege.net)

The Youthhood – Where Teens Prepare for Life After High School  
[www.youthhood.org](http://www.youthhood.org)

## **Recreation**

American Camping Association  
[www.aca-camps.org](http://www.aca-camps.org)

The National Center on Physical Activity and Disability (NCPAD)  
[www.ncpad.org](http://www.ncpad.org)

Special Olympics  
[www.specialolympics.org](http://www.specialolympics.org)

Wheelin' Sportsmen Online  
[www.nwtf.org/wheelin/?SUBSITE=wheelin](http://www.nwtf.org/wheelin/?SUBSITE=wheelin)

Winners on Wheels  
[www.wowusa.com](http://www.wowusa.com)

Very Special Arts (VSA)  
[www.vsarts.org](http://www.vsarts.org)

## **Relationships**

Bullying: PACER had developed a one-of-a-kind curriculum that offers common-sense information and encouragement to families whose children experience bullying.  
[www.pacer.org/publications/BullyingFlyer.pdf](http://www.pacer.org/publications/BullyingFlyer.pdf)

## **Sexuality**

Disability Solutions: Sexuality Education

Part 1 – [www.disabilitysolutions.org/4-5.htm](http://www.disabilitysolutions.org/4-5.htm)

Part 2 – [www.disabilitysolutions.org/4-6.htm](http://www.disabilitysolutions.org/4-6.htm)

SIECUS Annotated Bibliographies: Sexuality and Disability

[www.siecus.org/pubs/biblio/bibs0009.html](http://www.siecus.org/pubs/biblio/bibs0009.html)

## **Youth Voices**

Kids As Self-Advocates (KASA) is an organization created by youth with disabilities for youth to educate society about issues concerning youth with a wide spectrum of disabilities and special healthcare needs.

[www.fvkasa.org](http://www.fvkasa.org)

Youth Activism Project

[www.youthactivism.com](http://www.youthactivism.com)

Speaking Out: Teens with Disabilities Are Speaking Out About What Matters Most In Their Lives

[www.ncor.org/SpeakOutTeens.pdf](http://www.ncor.org/SpeakOutTeens.pdf)

# How You Might Use This Book

For professionals working in the field of transition, university faculty members, administrators, or providers of pre-service or inservice training, *Whose Life Is It Anyway?* is a useful resource to enhance the understanding of the complexities of the secondary transition process from the perspectives of a young adult, parent, and professional. The rich story telling can be used as a supplemental text to the more academic resources or can be used to creatively re-enact typical scenes found in the future planning process. The story brings the power of the “personal voice” into the learning experience. The “Talking Points” provided at the end of each scene engages the readers to delve deeper into the range of experiences (emotions and thoughts) of the student, parents, and professionals and has the potential to strengthen insight and empathy.

For parents, this book and its story may provide support, clarification, and insight into the range of emotions parents and other partners typically experience during the secondary transition experience. It is intended to offer ideas for discussing topics, and enhancing empathy and understanding of the complexity of issues faced by all the partners.

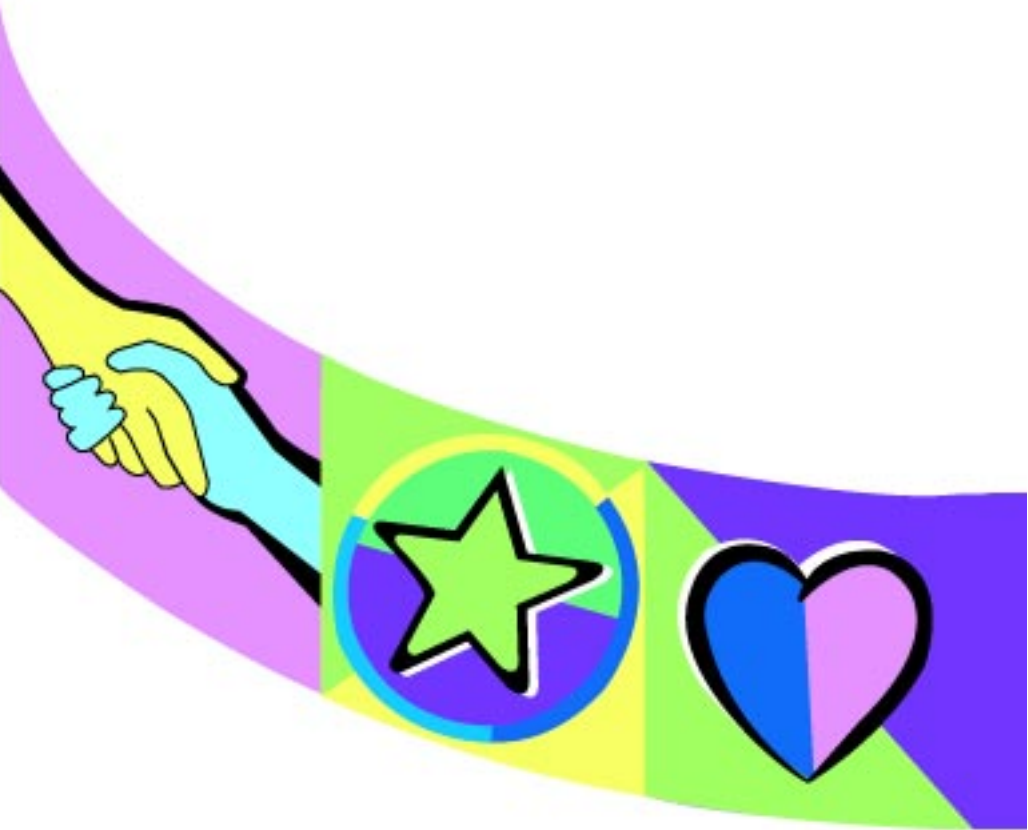
For youth, this book is an inspiration and a chance to dream big. It is an opportunity to know you are not the only one going through transition and that anything is possible.

# Ordering Information

To order a copy of *Whose Life Is It Anyway?* Contact (608) 265-9852. Cost is \$10 including shipping and handling. You can also view or download this booklet at [www.waisman.wisc.edu/wrc/pub.html](http://www.waisman.wisc.edu/wrc/pub.html)







Waisman Center  
University of Wisconsin–Madison  
University Center for Excellence in Developmental Disabilities