



A DIFFERENT KIND OF NORMAL: PART 2 OF A SERIES

In So Many Words

Jimmy Foard's parents, therapists, aide, teachers—everyone in his young life—try to get him to do one thing: speak. **BY CHARLOTTE MERYMAN**

The series so far: In Part I, we met the Foard family: mom Michelle, dad Jim, son Jimmy, 4, and daughter Maddie, 2. Jimmy was born with Alfi's syndrome, a rare chromosomal disorder in which part of the ninth chromosome is missing, and shows about half the signs for autism. As a result, this gentle, bright boy must grapple with many profound challenges. They are physical: Low muscle tone frustrates his ability to walk, move, and speak. And they are social:

Bonding with other kids doesn't come easily. Part I followed Jimmy through the minefields of an average birthday party and also offered glimpses of the roller coaster of his birth and first years. All parents, of course, brave their children's trials and savor their triumphs. But to be Jimmy's parents is something else again. You learn to embrace "a different kind of perfect," as Michelle puts it, and "a different kind of normal."



THE DRIVE TO COMMUNICATE

Jimmy Foard, at 4, can form sounds but no words; Amy Farmer, Jimmy's aide, helps him roll Play-Doh snakes to strengthen his fingers and, in the bargain, his sign language skills; Iris, one of Jimmy's classmates, is rapt as he uses his "talker" (a voice-enhanced handheld computer); Jimmy shows what he wants (a cracker, in this case) with an image from his book of icons.

"Speech is civilization itself," as the novelist Thomas Mann once said, grandly. And right now in one tiny corner of civilization—the Blueberry Hill preschool in Longmeadow, MA—a dozen fidgety children are chattering away. It's snack time. Ten boys and girls slip into blue plastic chairs around two low tables. Munching apple spirals and sipping juice, they get silly, issue various news flashes, and compare their plans for recess. The afternoon sun lights up their faces, spilling over a riot of brightly colored toys, games, blocks, easels, and books.

At one table, 4-year-old Jimmy Foard climbs wordlessly into his special chair. It's a sleek Scandinavian number with an adjustable seat and footrest to boost his braced ankles and keep him from slumping. He chews his apple pieces silently, poker-faced. To his right a little live wire named Ashley, with blond pigtails and chipped pink nail polish, watches him with interest. She turns to his ever-present aide, Amy Farmer ("Miss Farmer" to the kids) and considers

the pair for a moment. Then, with vintage preschooler bluntness, she blurts: "Why can't Jimmy talk?"

Farmer doesn't miss a beat. "He can say 'mama,'" she counters breezily. "He can say 'daddy.'"

"But that's the only thing he can say," Ashley persists.

"He can use his signs to tell us things," Farmer says. She means his very rough American Sign Language, understood only by a close few. "He can say 'more.'" She pointedly offers Jimmy the platter of apples and asks if he'd like another serving. This is the sort of dance they perform countless times a day, all in the name of engaging, demonstrating, practicing.

Dressed today in jeans and a black sweater, her short dark hair blown neatly away from her face, Farmer has worked with children with special needs for 16 years and with Jimmy since he started at Blueberry Hill almost two years ago. Her manner is strict but kind. That kindness can be a burden. She got too attached to the first child she worked with, ^{xxx}



Clockwise from top left: Though Jimmy can't manage lyrics, he loves to vocalize during music time at his preschool; speech therapist Hillary Jellison has Jimmy act out what picture is on the card—here, a bout of shouting to build up his breath strength; Jimmy takes a much-deserved game break with mom Michelle; Jimmy's talker shows icons for Eat, Play, Read, Sleep.



for four intense years, and vowed never to remain with a student that long again. It hurt too much (and, she feels, kids grow from working with new aides). So she tries to stay professional: caring but detached. It works for her and for Jimmy too. "Amy has had a huge impact on Jimmy," says Michelle. "She doesn't baby him. She makes him do everything by himself."

And so, characteristically keeping the bar high, and with Ashley and Jimmy in her sights, Amy holds the apple platter to one side and scootches Jimmy's "talker" (a voice-enhanced, handheld computer) in front of him. He quickly takes the hint, peers intently at the small screen, and repeatedly presses it to flip to the icons he wants. Found it. "Yes. Please," says a fractured, monotone male voice. "Ap-ple."

Ashley nods her approval, but she's not sold yet.

How could she know that to "talk" through a machine is a marvel for Jimmy? It ranks so much higher on the communications food chain than his binder of card-stock icons or his scant sign language. But the talker is still just another rung on the ladder. The ultimate goal is to get Jimmy to talk—on his own, discernibly, from the heart. "Say 'more apple,'" Farmer coaxes Jimmy. "Tell me. Say 'mmmore apple.'" His brow furrows as he struggles to make his mouth comply. "Mmmm," he manages at last.

It's enough. "Jim-Jim-vree!" Ashley squeals, and breaks into a delighted grin. Jimmy looks eagerly to the apples, which now land in front of him.

The Olympian

To raise a child with special needs in our interventionist era is to sign up for a schedule as packed as that of an Olympic athlete in training—with just as many handlers. Every single day Jimmy is working long and hard with someone: Amy Farmer; his preschool teachers; his physical, occupational, and speech therapists; his gymnastics instructor; and, of course, his parents.

The overarching challenge in this never-ending story of therapy sessions is to doggedly, fixedly strengthen Jimmy's low muscle tone and ease his troubles with what's known as motor planning. That's the process by which the brain takes in information and tells the body what to do: put on clothes, wash hands, climb,

“You’ve got a little genius!” says the computer rep. Michelle feels a flush of happiness.

“People discount Jimmy’s abilities until they see it for themselves,” she explains.

catch. Jimmy must train for months, for years, to master such tasks, breaking them down into their smallest steps and practicing them over and over until his muscles memorize the movement.

So he gamely bounces, balances, and tumbles at gymnastics. He reaches, throws, draws, and builds at physical and occupational therapy. His dad throws in plenty of roughhousing. All of this activity is crucial for his coordination, but the Foards have another glittering prize in mind too. Michelle read somewhere that “movement creates speech.” And, like many parents of children with special needs, she’ll try anything from the “can’t hurt, might help” category.

Jimmy’s speech therapist, Hillary Jellison, believes there may be something to the idea. “The whole thing with speaking is you need that breath support,” Jellison says. “So to build those muscles and to get moving, that’s really going to help Jimmy.” Not to mention, she adds, that when he’s doing what’s inherently fun—jumping on a trampoline, knocking down bowling pins—he’s more motivated to try to talk, and thereby share the fun he’s having. “It’s like a puzzle,” says Jellison of working with Jimmy. “We’re all trying to find out what that missing piece is so he can express all of his thoughts.” And so they keep looking.

The Bookworm

The aging cinderblock walls are painted white, and a large mirror looms by the table where Jimmy now sits at Holyoke Medical Center’s Speech and Hearing Center, not far from Longmeadow. Jellison sits catty-corner to Jimmy in the tiny room. “A says *aaah*,” she begins, picking up a small hand mirror and gazing into it as she opens her mouth wide. The silver surface reflects her friendly young face—she’s just a few years out of graduate school—her hair pulled back with a headband, and her wire-rimmed glasses.

She tilts the mirror toward Jimmy and places her

finger on his chin, gently pulling it down as they say *aaah* together. Then she lays the mirror down. “H for *huh*,” says Jellison, holding her palm in front of her mouth to feel the puff of breath and eagerly inviting Jimmy to do the same. They soldier on through E (*eh* as in “egg”) and F (*fff* as in “fish”), Jellison exaggerating her mouth movements as she pronounces.


But Jimmy isn’t really there. He keeps trying to peer past her toward a book she hustled off the table a few minutes ago when it proved a distraction. It’s something about a jaunty bear. Jellison switches gears and thinks: teachable moment. She slides a large index card in front of Jimmy and writes across it “I want book” in careful print. “Let’s read!” she suggests merrily, dropping her finger below each word as she speaks it out loud: “I-want-book.” Then she asks, “We want to get the bear book; what do we have to do?” She answers her rhetorical question with a new card, on which she writes and then says “Open book.” And Jimmy does exactly that.

James Frederick Foard III is a bona fide bookworm. He adores being read to and will happily spend hours lost in the pages of children’s books, grown-up magazines, even the phone book (he’s infatuated with the orderly lines of type on the white pages). He has a thing for signs too, especially Stop and Exit, and insists on having all read to him. At age 4, Jimmy already recognizes “tons” of words, Michelle says.

But while Jellison finesses some reading into most sessions, to play off his passion and help him learn his letters, she knows that a mere love of words can’t push Jimmy’s mouth to actually say them.

It’s been such a long haul.

When Jimmy was 2, he’d work at home with his mom, sucking a special straw and blowing on a whistle to help bolster his oral muscles. Michelle, Jim, and Jimmy will often make goofy faces in the mirror, sticking out their tongues to the left and right, and trying to lick their noses like a lizard. Jimmy is especially taken by that last game, but it

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can't hold a candle to the exercise
Jellison has saved as the fireworks
finale to today's session.

With a sly smile she unwraps a
bright green lollipop. Jimmy's blue
eyes brighten. What 4-year-old
wouldn't perform for candy? Especially
knowing it'll go home with him—
along with a bonus pop for Maddie.
"Can you stick your tongue out?"
Jellison asks. Jimmy opens his mouth
and she rolls the lollipop inside. "Let
me hear," she insists, clicking her
tongue against the roof of her mouth
until Jimmy does the same. Then she
tips the lollipop against the left side of
his mouth. "Can you put your tongue
over here?" she asks. He does. They
repeat the exercise on the right side
and on his upper lip. "Nice job!" she
exclaims. Thinking he's kept his end
of the bargain, Jimmy reaches for the
lollipop. "Oh," says Jellison in mock
surprise, "mmore pppop? Let me hear."
She pushes until Jimmy manages *mmm*
and *ppp*. Then the lollipop is truly his.

The Littlest Hacker

Michelle is torn. Here she is on the
phone with a tech support rep from
DynaVox, the company that makes
Jimmy's talker, and she's not sure
which feeling ought to dominate:
pride or exasperation. It seems this
4-year-old of hers is a hacker.

Somehow, Jimmy has figured out
how to exit the speech software, get
into the underlying handheld device
software, and record snippets of his
own voice using the personal memo
feature. "He just pushes a lot of but-
tons and then he knows how to do it
again," Michelle says into the phone.

"Wow!" the guy responds in amaze-
ment. "There are only two ways to get

out of the speech function, and your
son just figured out a way I didn't
know about. You've got a little genius!"

Michelle feels a flush of happiness.
People "discount his abilities until they
see it for themselves," she explains.
"His physical therapist says, 'He is so
smart, Michelle. You need to make
sure people know that.' I'm constantly
quizzing him in front of people so
they understand, 'Oh, my gosh, he *does*
know what's going on.'"

These days, that's a lot more obvious
to everyone. If speech is civilization
itself, Jimmy has yet to fully join in.
But his growing tool kit—sign
language, gestures, icons, sounds, and
now the talker—is finally giving him a
way to share what's happening inside
his head. Come to find out, the boy
has a sense of humor. He gets a big
kick from hitting the talker's sentence
bar without clearing it first, so it spits
out a poetry slam of all that's been said
lately. And instead of saying good-bye
via the "good-bye" icon, he punches
"see you later, alligator" instead.
Michelle has even caught him teasing
Maddie, just like any other sibling.

It's all cracked open a new window of
hope. In the early years, Michelle cried
every time she thought about Jimmy's
future. Not anymore. Now, she says,
"I see more potential than heartache."

Next in the series: Jimmy's life at
home. To read an earlier installment,
visit wondertime.com

Charlotte Meryman has written widely
about those with special
needs. She's at work on a
memoir about life with
her brother, who is
developmentally delayed.



Keepsakes



Memory Box pg. 82

Make It Yourself: To decorate a box like
the one above, try this method.

MATERIALS

- A ruler
- A large shoe box with a lid
- Decorative paper or kid's artwork
- Scissors and a glue stick
- Clear Con-Tact paper

1. Measure all the sides of the box and
the lid. Measure the decorative paper
or artwork to fit each panel of the
box, ¼ inch smaller than the margin
on all sides. Cut the paper to size.
2. Cover the back of one paper panel
with glue. Glue the paper panel on the
box, smoothing from the center out.
Repeat with the remaining panels.
3. Using the grid on the back of the
Con-Tact paper, measure and cut
Con-Tact paper panels the same size
as the box panels.
4. Peel off the backing, and one at a
time, place Con-Tact paper panels over
the decorative paper or artwork,
smoothing from the center out. Do
the same for the lid. Cut a slit in the
lid's center if desired.

—A.P.L.

Buy it (from bottom):

Photo and Video Box,
\$6, organize.com;
Pandan Box, set of three
for \$50, organize.com;
standard shoe box;
Kolo Box, \$32 to \$37
depending on size,
katespaperie.com;
Fair Field of Flowers
Photo Box, \$18,
paper-source.com.

