Bridging communication gaps with parents
Why don’t parents share information?!
What does the world look like?
Parents can’t tell us things they don’t know
Disability is complicated
Disability often means living with uncertainty
No roadmap

• We say “kids don’t come with a manual” but…

• There are developmental milestones charts

• And known strategies for dealing with typical developmental stages

• Parents of kids with disabilities don’t have that kind of guidance, even under ideal circumstances
Parents often feel blamed

- Parents often don’t know the answers to important questions about their kids.
- (Despite caring about their kids and trying hard to find answers.)
- When parents are asked questions with the assumption that they will know the answers, it can shut down the conversation.
- Asking with room for “I don’t know” can build trust
“What works for your child?”

• They may not know.

• There are a lot of unsolved problems in education for people with disabilities.

• Solutions that exist are often not widely known.

• Most parents get contradictory advice from people who sound authoritative.
“Does your child have a disability?”

- The answer to this is not always obvious.
- Parents may get contradictory opinions from different professionals.
- (“He’ll grow out of it.” “He needs therapy.” “She’s just odd”. “She has a learning disability”. “You’re just an anxious first time mother”. “You’re in denial”.)
- Parents may be unsure how to categorize things.
“What is your child’s disability?”

• Very few kids are born with a diagnosis.

• Many kids with disabilities are undiagnosed, or misdiagnosed.

• Parents may be unsure of a diagnosis, or unsure what a diagnosis means,

• (or unsure how to explain it to you in a way that will be useful.)
A diagnosis is not very helpful by itself

• Diagnostic categories are very broad.

• They don’t necessarily tell you much about what’s going on with a kid.

• Or what will help them.

• There’s a lot of guesswork and complex trial and error involved.
"What are your child’s strengths and weaknesses?"

- When a kid’s disabilities aren’t accommodated well, strengths can be hard to see.
- Parents might not have words for the parts that matter most.
- Parents might not have enough context to give a useful answer.
- Parents may feel uncomfortable talking about things they believe to be true without proof that experts accept.
Questions with room for complexity and doubt:
“Do you know of strategies that have helped your child in the past?”

- “Are there things that others have tried that haven’t worked well?”
- “Do you know of accommodations or modifications that your child finds helpful?”
“Do you feel like your child’s classroom teacher gets them?”
“Does your child work with specialists who you think are helping them?”
Evaluating the questions you’re asking

- What questions do you ask parents?
- How might parents feel about those questions?
- Do your questions allow for “I don’t know”, “maybe”, or other forms of uncertainty?
- How could the phrasing change?
Collaborating with parents and kids on a hard problem

- Disability can be hard.
- Inclusion can be hard.
- Often, no one has any answers.
- Often, solutions are partial.
- We can’t always fix everything, but we can be in this together.
Parents don’t know whether they can trust us.
The education system is not trustworthy yet.

- Kids with disabilities were excluded from school for centuries.
- The system was not built with them in mind.
- We have a lot of catching up to do.
- None of us can do it alone.
We don’t know as much about teaching disabled kids as we should

- Teachers learn what the previous generation of teachers knew, add to it, and pass it down to the next generation of teachers.

- When kids with disabilities were excluded from school, teachers weren’t figuring out how to teach them.

- By the time parents get to us, the system has likely already failed their child in significant ways.
Discrimination

• Parents of children with disabilities can’t count on their child being welcome in school

• Or playgroups

• Or activities

• Or in religious community

• Or in public places

• Disclosing disability is risky.
Discrimination in Jewish settings

You have to understand that this is an old building.
Everyone who cares about the Jewish future sends their kids here!

We’re just not equipped to meet her needs!
It’s difficult for parents to trust you

• Most people in their lives probably don’t know how to see their kid as a kid

• They might not have anyone at all who knows how to do that.

• They might not know how to do it themselves.

• You may need to be first.

• Parents often start with the assumption that you will see their kid in the way that most other people do.
Loss of social connectedness

- Parents of typically developing children usually have many people in their lives who can relate to them.

- As a child’s disability becomes apparent, parents often find that no one in their lives shares their experiences.

- And they are often judged by people who don’t get it.

- This is very lonely.
Assessing your context

What experiences might parents be coming in with that affect their willingness to share information?
Acknowledging disability doesn’t mean talking like a clinical report

• Clinical reports, intervention plans, and IEPs often reduce a child to their diagnosis.

• Normal language for describing children often has no room for disability.

• Parents need ways to talk about disability without dehumanizing their child.
Parents are taught that they and their child are failing
“Should”
“Should” is a lot of pressure

• “At around two years of age, a child should be able to have enough balance to jump up, with both her feet leaving the ground.”

• http://www.parents.com/toddlers-preschoolers/development/growth/developmental-milestones-age-two/

• “Three-year-olds should be able to dress themselves in basic attire, such as pull-on pants or slip-on shoes,”

• http://www.parents.com/toddlers-preschoolers/development/growth/your-growing-3-year-old/
The emotional price of getting services

• Parents have to describe their kids in negative, often emotionally devastating ways

• Parents have to make long lists of everything their kid is “failing” at

• Parents have to allow professionals to describe their children in harshly negative clinical language.

• This can make it hard to see their kid in a positive light.

• It can also make it hard to trust professionals to treat them well.
Kids with disabilities are just like other kids in some big ways

- All children learn, and all children have a lot to learn.
- All children have thoughts, feelings, and relationships
- All children have interests
- All children can explore the world
- All children have bodies
- All children care how adults in their lives feel about them
- Descriptions of these childhood experiences need to include kids with disabilities.
Disability is present all the time

- When disability is not the main topic, the things you say about disability and inclusion are most more credible.
- When you describe your classroom activities, include adaptations
- “Usually” can be a useful word.
- When you take pictures, take pictures of all the kids.
- If you’re using stock images, use pictures of kids with and without disabilities.
- Mention adaptations in contexts that aren’t primarily about disability or inclusion.
- Respect privacy.
Kids with disabilities are also different in ways that matter

• Disability matters because brains and bodies are important.

• Inclusion doesn’t make everyone the same — and it doesn’t need to.

• When we stop trying to do impossible things, a lot of things become possible.
Inclusion makes room for the fact that disability matters.

- Our education system was built with the assumption that everyone who belongs can do the same things.

- When their disabilities mattered, kids were almost always excluded.

- The fact that disability matters is not the problem.

- The problem is that we spent so many centuries choosing to exclude people.
“Unique” isn’t enough.

• Everyone is unique and different. Not everyone is disabled.

• We don’t know enough about teaching disabled kids. We need to figure it out.

• “Unique” won’t get us there.
It’s like developmentally appropriate practice…

• Every kid is unique — and that’s not all you need to know.

• Two year olds are different from ten year olds.

• There’s a particular range of difference you expect in typically developing kids the same age.

• Kids with disabilities are more different than that.
Disability-related similarities matter too.

• Similarities between disabled people mean that the same access strategy can work for a lot of different people.

• If everyone needed a 100% unique solution, accessibility would be a much harder problem.

• (Teaching methods in general exist because kids have certain things in common.)

• Braille, wheelchairs, ramps, ASL, captions, and text-to-speech software are useful because of similarities between disabled people.
Kids with disabilities stay different

- Adaptations don’t make everyone the same; adaptations make room for difference.
- Some kids may never learn to dress themselves
- Some kids may always communicate differently
- Or any other of other things.
- Sometimes inclusion means accommodating long-term difference.
Connections with other parents can be game-changing. People need support from others who are dealing with similar things.
Awareness of adults with disabilities

- When the focus is exclusively on children, it can be hard for parents to see that their child has a future.

- Stories about adults and other children can make a big difference.

- Connections to adults can make a big difference.

- Connections to adult self advocacy organizations can also help.
Some communication strategies
Make it an ongoing conversation

• If you don’t expect complete information upfront, you get better information in the long run.

• Parents learn new things over time.

• (So do kids!)

• Trust develops over time.
Parents need you to see their kid as a kid

- Relating to their child as a unique person, in the way that you relate to every child as a unique person
- Acknowledging their child’s disability without flinching
- Taking their child seriously as a person who can learn, grow, and do things
- All of this is easier said than done.
Being matter of fact
Use names and normal language

• In clinical settings, children are sometimes referred to more by diagnosis than by name.

• Calling children by their names when you talk to their parents sends a message about your values.

• Describing them in more natural terms also matters.

• “David climbed the climbing wall today, and he’s been participating in races.” vs “Your child is showing improvements in gross motor skills”.
Honesty

• Don’t pretend to have answers you don’t have.

• Don’t make promises you can’t keep.

• Listen to parents and children.

• Pay attention to what’s working and what isn’t.

• Communicate with parents about what you’re trying and how it’s going.

• Make sure you’re communicating about accomplishments as well as problems.
“I’ve seen this before”

• If you’ve taught children with similar issues, tell parents this.

• Don’t present yourself as the ultimate authority on their kid.

• Do show that you’ve been willing and able before.

• “For some other kids, we have found that this works well…”

• “In the past, we have tried…”
Communicating routinely

• Talk to parents about the program in an ongoing way.

• Don’t wait for there to be a problem, and don’t make every conversation about inclusion.

• Talk to parents about their kids’ accomplishments.

• Talk to parents about things in a matter-of-fact way.

• Create space for parents to ask questions.
Active listening and wait time

• Listen to what parents are saying.

• Try to pick out the thing that’s looming largest for them.

• Repeat it, and wait seven seconds to give them a chance to respond.
Peanut allergies and other adaptations

- Many kids have peanut allergies.
- Many kids have other medical conditions.
- Many kids have disabilities.
- Allergy policy matters whenever there is food.
- Inclusion policy matters whenever there is an activity with potential barriers.
Talking to kids as well as parents
What questions could we ask the student?

• Kids have their own perspectives.

• Kids (especially teenagers) often know things about themselves that their parents don’t know.

• Kids are often more willing to talk about their other school than parents are.
“It seems like x is hard for you”

• “It seems like writing is hard for you. Does typing work better?/“Would you like to try typing instead?”

• “It seems like it’s hard for you to read this way. Do you usually do something different?”

• “Sometimes using a fidget toy can make it easier to pay attention.”
“It’s easy” vs “You’re working hard”

• Having a disability means being unable to do things sometimes, or having a lot more trouble.

• Kids with disabilities may find things difficult in unanticipated ways.

• They need the same kind of emotional support as all children do when they’re doing something hard.

• They also need emotional support related to being different.
“Can you tell me about your school?”

- Sometimes if you ask kids, they’ll tell you.
- “Do you do this differently at school?”
Asking the questions:

How do you talk to kids about disability and differences?

Do you discuss differences that may be disability-related with your students?

• If so, how?
• How has it gone?
• What else might you want to ask?
• What other sources of information might you have?
What can we do with limited information?
Living with uncertainty
It’s often not clear what kids will and won’t be able to do.
No one is born knowing how to walk.
No one is born able to have a conversation
No three year old has good motor skills
This can be misleading

- Having a motor skills impairment is different from being three
- Not everything is outgrown.
- Sometimes working on the skill isn’t a good use of time.
- Sometimes people need to do things differently.
We don’t know how kids will grow

• Some kids with disabilities look normal in early childhood

• Some kids with delays grow out of them

• Some typically developing kids acquire disabilities

• Parents are less alone than they feel
Uncertainty is ok

• You can get a lot of information about a kid’s needs without a diagnosis

• (And the usefulness of diagnosis only goes so far).

• Assessments aren’t always very reliable anyway

• Parents can’t give us answers that they don’t have.

• But with trust, there can be collaboration.
What can we offer to students without waiting for answers?

• Fidget toys
• Other adaptive strategies.
• Flexibility and problem-solving attitude
• Empathy
• Respect
With or without answers, we can commit to community.
Managing your own feelings

• The work of inclusion can be challenging to your self-image as an educator.

• Educational methods were mostly designed around the assumption that kids the same age have the same abilities.

• Teaching kids with disabilities means that you can’t always count on your methods.

• It helps to understand that this is a problem that everyone has.

• It’s hard because it’s hard. It’s not your fault that it’s hard.
The Matan Pledge

• I acknowledge that ability, disability and humanity coexist, and I pledge to see my students as they are without downplaying either.

• I will not look past their disabilities; I will instead seek to understand how their disabilities affect their life, learning and social experiences.

• I will not overlook their abilities; I will instead actively seek out their abilities and learn to teach them effectively.

• I will not overlook the humanity of my students; I will remember that they have individual interests and a perspective of their own and that they were each created b’tzelem Elohim – in the image of God.
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