

helping the mother of an autistic kid

INFORMAL LEARNING PROJECT - TAPE 20

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INTERVIEWER: Okay. Just say your name and where you are from.

SPEAKER: Okay. I'm Gerry Robinson from the Boston Children's Museum. I should tell you my story about (inaudible).

One of the most important things that have happened to me in the children's museum is being able to work with lots of families and very young children. And we have been able to really build strong relationships with a number of families. And one little boy came to our attention because he came often and was visiting, but obviously there was something different about his development. And he really came to our attention because he used to spend a lot of time -- when the place would get very crowded -- screaming a lot. Which would sort of push other parents and kids away. And we noticed that his mother particularly was, you know, very sort of uncomfortable in the museum and uncomfortable about her child's behavior.

So our staff really went about befriending her and really spending some time with her and this young child. They became good friends of mine, because part of what we were trying to do was to try to get her away from him so that he could be encouraged to explore and do things. And we realized how really smart he was. And by the same time we knew that he was probably autistic. And one thing she really didn't like him to do was to walk on the stairs, for whatever reasons. And she just could never explain why.

one of the most imp. things that has happened to him is getting to know families + young kids

one little boy used to scream a lot, in other words uncomfortable

staff befriended her tried to get mother to let son explore realized he was very smart -- but probably autistic

of
F/EX/CM

walking through the museum w/ block to
stand on to see higher exhibits

But one of the things that he and I would do probably twice a week would be to go and take a walk through the museum, ^{he would} go with me to get the mail. And in the process of doing that he would need to climb a flight of stairs. And so we did this for several weeks. And then one day we went to do this and he stopped, and he went back and he picked up a cardboard block, to take the block with him. And I couldn't figure out why. And what he was going to then as we walked through the building was to take the block and place it in places where he couldn't reach. So he could stop and do lots of things that he would point and look at, but really had no real language for.

son in end w/ him to get he used

In the process of really getting to know her we also got to pair her up with some other families, and were able finally to begin to broach the issue of him and his language. That he really didn't have a lot of language. And got her comfortable with the idea through another ^{family} (inaudible) families whose husband actually was a language therapist. To encourage her to go to try to get some testing done at Children's Hospital. We got the appointment all set up, they went to the hospital and the kid totally freaked out and they couldn't do anything about him. But we got involved and talked with her husband, and got the team from Children's Hospital to actually come to the museum and watch him there and see him in a natural setting. And was really able to get him some help and her some help actually as a result of it.

paired her up w/ another family
(he was a speech therapist)
they encouraged her to get him tested

(didn't have much
language)

→ were able to get them
some help

by pairing mother w/ other families
& using museum as site to get
him diagnosed by staff of children's hospital

the power of a place that is not really
set up for interventions - still having an impact
on people's lives

And for me, it was just sort of the power of a place that really isn't set up to do anything about intervention, or build those kinds of coalitions or supports with families that we could ^{both} befriend a family and get them connected up with really just another set of visitors. ^{That's} They were really in the end going to be able to make a significant impact on her life and on that child's life as well. And he was able to get some support, was able, with a lot of support, to enter into a regular kindergarten and is now talking. Really bright little boy, but behaviourally kept pushing everybody away because of this bizarre behavior. But our staff really stuck by her and him, and there has just been an amazing turnaround. He is now nine years old and doing fine.

INTERVIEWER: Is he in a regular --

SPEAKER: He's in a regular school now.

INTERVIEWER: Was he diagnosed as autistic?

SPEAKER: He was. He'd also had a pretty severe head injury when he was pretty young. The reason why she didn't like him on stairs, we found out that she had dropped him down a flight. And with that information they were able to do some other neurological testing. And through a pretty structured program were able to begin to bring him around, to get him to talk. And we did a lot working with the Head Start program and encouraging them to both support her and him. Because you could see just so much that he had great intelligence. You could talk about something -- we were talking about Mr. Rogers one day in

had had severe head injury from
being dropped down stairs by mother

Museum not set up for intervention but may have been able to have impact on boy's/mother's life

he was able to start a regular kindergarten (was autistic, and early handling w/ got him talking)

still hear from them occasionally -
kid doing fine

the office. He went out and he found a Mr. Rogers book out in the space and brought it back in. You know, so we knew that he was picking up a lot of things, but just that they both needed support to be able to see the good things that he was able to do.

INTERVIEWER: Does he still come in a lot, or just occasionally?

SPEAKER: Not anymore. We hear from them -- again, as kids get older and the families that we really had a lot of strong contact with, we see them often on holidays. So the last time I saw was about a year ago. She called up during one of the school vacation weeks to say that they were coming in. And you know, often they call back to say what a difference just having people support her in terms of trying to continue to advocate for him when she really didn't feel that he was going to be able to amount to much. But he's just a great kid.

See families less as he's getting older
she calls to say what a difference the
Museum made

INTERVIEWER: Have you got any other wonderful stories like that?

SPEAKER: I said most of mine are about families and their issues. I don't know. I can just say, you know, just the pieces about how important having a space like Play Space has been in terms of being able to watch families grow, and to sort

of get to that other side of the visitor. I remember once sitting out in the space with another mother who was watching her toddler go up and down the slide. You know, time and time again. And watched her body language and watched her getting more and more sort of puzzled by what was going on. And sat down with her

staying in play space
w/ mother who watched
toddler go up & down the
slide

+ Flex/cn
ref

Realizing mother that child's
repetitive behavior was normal learning

and began to understand that what she thought was the child had
some retarded behavior, because she was doing something over and
over again.

realized that mother
thought the child's
behaviors were retarded

And we sat there and watched together, and I
was able to help her to watch the child's body language change,
to realize that this child was really about mastering going up
and doing the slide fifty different times. And that each time
the child went up and came down she would watch other children,
she would try it a little differently. Her whole body language
was changing. You know, you could just see the power coming into
this little, tiny being. And by the end of that sort of twenty
minute interlude, the mother had gone from beginning to under-
stand that repetitive behavior really as a strength of learning,
and not a sign that there is something wrong.

They watched together she pointed
out that she was mastering the slide
- watching kids & trying new techniques

And just realizing again how little parents
often understand about normal development. And if we hadn't
taken the moment and she hadn't been willing to say what was on
her mind, she would have probably stopped her child any time her
child tried to do something, you know, more than twice for fear
that the child was getting into a rut versus being able to
understand that there was real learning going on.

Realize parents don't und.
much about child development
she began to understand
(otherwise she would have always interrupted repetitive behavior)

I've got hundreds. I'm just trying to think
of which ones would make -- they are all just little tid-bitty
things about, you know, kids making connections later on about
stuff. I think the power for me about the museum -- I told this
one once before about just sort of my own history of having --

always interrupted repetitive behavior

Children's Museum as a part of her life
starting as a child & then a teen babysitter

* you know, that I never thought I'd ever end up working at a museum. But the children's museum has always been part of my own life from the time I came to the museum as a child in Jamaica, and played all those little paper and pencil games, you know, in the really old museum. And then came back probably as a seventh or eighth grader as a babysitter. The first time I met Marian (Carey) during Thanksgiving time, and they were doing the old colonial kitchen and dipping candles. And we thought we were so sophisticated because we were like twelve and thirteen bringing these little kids to the museum.

Children's Museum has always been a part of life, from when he was a child in Jamaica, dipping candles

The next time I saw the museum it was probably as a young teacher, and met up with Bernie and Dotty when they used to go to do the community workshops. And that's how I got all excited about bubbles and doing stuff with them. And then they invited me to come and do some work with them, and then got hired on. And my first day at the museum I met up with Marian (Carey) in September while the building was closed. And we were over cleaning, you know, getting ready. And she said, "Here, hold this for a minute." And turned around and handed me a boa constrictor, which is the first time in my life I had ever touched one. And I kept thinking, is this the orientation to the museum? And I'm going to find out today whether or not I'm going to be able to work here or not. And you know, I just thought okay, we can do this.

handling a boa constrictor

Prof MS/CM

But I think the most excitement for me was being able to go back and take the museum back to the community,

later joined as a young teacher & work on community program and had first encounter w/ a boa

Most exciting thing was bringing the museum back to the community

and to see the museum and the community be something that could really come together. And that I could get to do as a teacher-educator things I couldn't do as a teacher, which was to really have lots of time to work and deal with resources and see the museum really become something that, you know, teachers could really come to. And then for me to be able to really work through and do the things with families, and to build the relationships that we have been able to build. And now twenty years later I'm still there and still as excited about it as the first day that I entered there. And realized that, you know, for each new generation the museum really has wonderful things to offer. And that it really is a part of that community, and really a strong part of my life both personally and professionally as well.

seeing the museum
community come
together

building relationships w/
families

his own son has
in the museum
and important moments

MS+F/EX/CM Pers So it's a place I like a lot, a kid likes a lot. My kid likes a lot. Has done wonderful things and many things from having grown up there. There will be little things that will come back into his life. You know, things that you never think were important to kids. And I remember very young his excitement about the scrubbing board. And we found one at a flea market and he just went wild, because it was just like the one that he had used at the museum. You know, all the sort of important steps of independence that kids could take there or learn. You know, his working through lots of issues around this "What If You Couldn't" exhibit. I remember him accosting Janet. You know, years later after the exhibit we would go back and

Son's interest in scrub board
and handicapped exhibit
as a neuroplastic

David is a cripple

every time he'd see her, "When are those wheelchairs coming back? It's really important that kids could learn about those wheelchairs." And I realized he was really working through real issues for himself, that he might really end up in a wheelchair. And whether this could be something that could be fun learning, but he really felt that that was something he would bring a lot of his friends to see at the museum. And then as other exhibits would come and go, still always going back to that as being the really most important exhibit for him.

San was working through an issue of the wheelchair exhibit.

INTERVIEWER: Tell a little bit about David and (inaudible).

SPEAKER: David is now eighteen years old. I adopted him when he was five. And he has hemophilia. And so living has been a big issue for him. And you know, playing and being and future has come and gone. And in the last couple of years he's had some pretty severe instances, and we wonder whether he wants to live or not. But now he seems to want to. And I think the museum has -- you know, the museum and all the people that he's met there have been a very important extended family for him. And a place that has really supported his learning style too, since he's not a real wonderful school person. But he has learned a lot, more than I would even ever imagine, through having lived in the exhibits at the museum. So it's a wonderful place.

adopted son is hemophiliac, has had diff. here has learned a lot in IM + having extended family in IM

TAPE INTERRUPTION

SPEAKER: . . . so yes, pretty much. He's going to ask me some questions, I'm going to answer them.