

Andrew's Story: Love, faith, family and MESD

EDITOR'S NOTE: For the last issue of Interaction this year, we wanted to write something allegorical of MESD's work with children, families and the community. Coincidentally, Health and Social Services Supervisor **Ann Vrabel** recently sent an email with a suggestion. It was just what we were looking for. Here's her message:

I have an idea for an Interaction story. Andrew Epperly is a student with complex needs, now in 6th grade at Reynolds Middle School. Andrew has been receiving services from MESD since preschool days, when he worked with our Early Intervention staff. He has a 1:1 RN (Debbie Seymour), an MESD teacher (FLS) Jessica, and receives speech from Greg (don't know their last names).

His mom (Connie Epperly) works for our HSS dept. as a SHA at HB Lee. She applied to work for us some years back as she was so impressed with what we have done for Andrew. Reynolds Middle also has an MESD

By Janelle Emery and Mark Skolnick

nurse and SHA. Wouldn't it be wonderful to get a photo of this whole team that supports Andrew? His mom (Connie) is very willing and interested. In fact she asked me why we never show his picture at MESD events, when he has been with us "forever."

Connie works part time and could get to RMS for a photo with Andrew and his team by 1:30 on a Tuesday, if that helps. I could ask the school RN and school SHA to be there as well, if you are interested.

We are proud to present the story of young Andrew Epperly who is thriving today because of his family's commitment and the work of MESD's team of therapists, teachers, nurses and assistants. We hope it serves as an inspiration for those who work with students like Andrew, and as confirmation that the dedication of MESD's staff is truly appreciated by families like the Epperlys.

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Andrew at four and a half years of age (center) and part of his "Band of Angels" (clockwise from lower left) Greg Lily, Jessica Sterling, Becky Wolf, Lori Skyles, Roni Sautter, Debbie Seymour, and Patty Boyd.

Part one: A fighter from the very beginning

Twelve-year old Andrew Epperly is a student in MESD's Functional Living Skills class at Reynolds Middle School. Andrew's journey has been a roller coaster of highs and lows, challenges and opportunities, and proof that love, faith and the bravery of a young boy can conquer even the most overwhelming circumstances.

When Andrew was just two days old, the medical staff at Emanuel Children's Hospital discovered he had a heart murmur and a condition known as arteriovenous malformation (AVM). AVM are defects of the circulatory system generally believed to arise during embryonic or fetal development or soon after birth.

At only a week old, Andrew underwent an MRI to measure the depth and severity AVM had on his skull and brain. His heart rate was over 200 beats per minute. He was battling his way through jaundice, high fevers, multiple tests and CAT scans.


Back at home that week, his parents, Connie and Eric, set their alarm throughout the night and took turns checking on Andrew. Luckily, they knew the signs of heart failure. When Connie recognized one of the major symptoms, they immediately rushed Andrew back to Emanuel.

During his first angiogram it was discovered he would need complicated brain surgery requiring surgeons to temporarily stop Andrew's heart. The doctor told the Epperlys Andrew would not survive surgery, so this approach was not an option. Since there was nothing further they could do for him, he was sent to Doernbecher Children's Hospital at the tender age of 8 ½ days old.

Things at Doernbecher, however, didn't go well. While in intensive care, Andrew suffered several setbacks including infections and brain hemorrhages requiring neurosurgery. No one expected him to make it through those long nights. After watching their son almost pass away, the Epperlys prayed that he would survive. Yet, Andrew surprised them all, and with the strength of a fighter, pulled through.

More complications came in such intense waves that the doctors gave up hope for Andrew. He was sent home, to be in hospice care.

After nine months of hospice, Andrew proved everyone wrong...except for his parents who never lost hope. Andrew battled his way like a warrior through each day. Instead of getting worse, he was progressing, becoming more alert all the time.

Later that year, at a meeting of the "Mom's Club of Troutdale" Connie Epperly received a brochure on MESD's Early Childhood Special Education/Early Intervention Program. Although Connie was a little familiar with MESD, she wanted to learn more about her options. She decided to call and set-up an evaluation of Andrew. 

Andrew with his dad, Eric, his mom, Connie (far right), and his siblings.



Fast forward to the present and Connie recalls how Andrew has been touched by so many MESD staff members. Here's her recollections.

Part Two: We Never Gave Up on Him

By Connie Epperly

After Andrew came off of hospice, one of my first calls was to MESD because I knew they specialized in caring for children like Andrew and I had already talked to them months before (before the surgery that went badly). I had learned of MESD through the MOMS Club of Troutdale that I belonged to. I am not sure how it all happened, but someone from MESD had given us a lot of flyers, the ones that said "is your baby a little ahead or a little behind?" And I don't know if you remember, but he was behind on his major motor skills before surgery.

I scheduled an appointment for someone to come out and evaluate him. Naturally, he qualified and I was introduced to the world of IFSPs, physical therapy, occupational therapy, speech and tons of equipment. Because Andrew's health was so fragile all his services were done in the home. My door might as well have been a revolving door. So many people had Andrew's best interest at heart. He was quite a challenge at first because he did not have his bone flaps back in his head yet. Essentially, he had a giant "soft spot" that we had to be careful of. We did get them replaced as

he got sick, it usually meant a fight for his life every time. So, I braced myself for a fight with the school because I already knew how I wanted to approach school for Andrew.

I really wanted him to be able to go because it was very evident he enjoyed everything as long as it didn't hurt him. But I knew he would have to have a gradual entry into school. He needed to acclimate one small step at a time. He was, and still is, very social. I knew he would never be mainstreamed, but I wanted him in a classroom where some of his classmates could come up and greet him. I also knew that I wanted him to have a 1:1 because he required hand over hand for everything he participated in. I can't remember the person's name who was in charge of Andrew when we did his IEP for kindergarten but all I can say is she was amazing.

She wrote up an IEP for Andrew that was very unusual and I believe never done before. She let me visit classrooms and choose the one I thought would work best for him. He started kindergarten going only half days just a couple of days a week with a 1:1 school nurse (that would be when MESD's **Debbie Seymore** came in).

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soon as we could. Andrew had a few physical therapists who came through, but MESD's **Lori Skyles**, in my opinion, was the best. She really worked hard with Andrew and he responded to her very well.

I remember she brought out a scooter board and put him on it and helped him try to scoot around the kitchen floor. Naturally, it didn't always go well but she never gave up hope on him. I can't remember which order the others came in because I didn't see everyone behind the scenes on a regular basis. There were lots of things tried, lots of things that didn't work and some that did. I can't remember the specifics. What I do remember were the great attitudes and the desire to help Andrew achieve.

The real test came when he turned 5 and "graduated" from Early Intervention. I had heard various horror stories of difficulties with schools and getting stuff done for special ed kids. Andrew was still pretty fragile and really had a hard time just coping with life.

He was very prone to seizures when he became overwhelmed, his asthma was not controlled and he needed oxygen and his Crohn's Disease was really bad. He was often sick and when


There were some days that his teacher would come to the house to introduce herself so Andrew could become familiar with her voice so he would not be scared and overwhelmed when he went to class. They all really listened to me when I told them that it was very important to tell Andrew who they were every time they approached him and to tell him what they would be doing. I already had figured out that he could "learn" people as long as he had a voice to go with the name.

Kindergarten went well even though he missed a lot that year due to illness. I have always had the approach to Andrew of never giving up on him. I do not look at his level of disability and assume he will never be able to do anything. I always conveyed that to his team at MESD and they took the same approach. Always trying new things, staying with things that worked etc.

It was a huge blessing to have him in the classroom at Woodland. I think MESD's **Greg Lily** came on board in kindergarten as well as most of the others. Andrew really loves Greg too. Greg has worked very hard and has tried so many different things to help Andrew have a "voice."

Teaching him cause and effect has been one of the things they have been working on and I love that Greg knows that Andrew's guttural sounds are him "talking" sometimes. I have some photos on a DVD with Andrew and Greg. There is one so sweet it brings tears to my eyes. He came so far in his years there.

I am sure Debbie filled you in on all that he has accomplished. I am so glad that you got to see him with her today. I can guarantee that he was very, very excited to have her back (she was on vacation last week). He looks at Debbie with love in his eyes. His face was so lit up when he heard her voice this morning. I firmly believe that his schooling is as successful as it is because of her care of him when she has him at school. Honestly, I doubt I would have ever become comfortable sending him to school as much as I have, if it weren't for her.

I have always been very impressed with Andrew's team at MESD and how they all really have a heart for the children. Our kids are special, not hopeless and they treat them that way. They all fed off of my belief that it would never be fair to Andrew to just give up on him. I never knew how much he could/would do, all I knew is that we had to give him a chance to prove to us what he can accomplish and MESD staff has worked diligently to help him, pulling all kinds of tricks out of their hats to find ways to teach Andrew how to communicate with his world. And they took time to learn his body language which is very easy to read once you get to know him. It is their hard, diligent work that made me want to somehow become a part of what they do. To help children in a capacity that can be life impacting, for myself and hopefully, for some of them. 

Part Three: Andrew's Band of Angels...

Greg Lily, Becky Wolf, Jeanne Kelly-Brown, Roni Sautter, Pam Benson, Lori Skyles, Marilyn Redwine, Patty Boyd, Jessica Sterling, Debbie Seymour (and many more)

MESD Speech & Language Pathologist **Greg Lilly** first met Andrew Epperly when he was in FLS Teacher **Becky Wolf's** class at Woodland Elementary School in the Reynolds School District. Since Andrew received early childhood education services in his home, Greg relied heavily upon Connie Epperly for help in identifying Andrew's subtle communication styles. It was clear to Greg that Connie knew Andrew best.

Greg began the process of testing Andrew with cause & effect techniques (known as tactile stimulation) to see how Andrew responded to his environment. Greg started with noise-makers, vibrating toys and different smells such as coffee, lotions and fruity scents to stimulate Andrew's senses.

By watching for subtle clues and physical signs, Greg discovered Andrew loved the smell of lemon because his eyes widened as the scent was put up to his nose. Andrew would turn his head towards the scent to take in more of the smell he enjoyed.

"It's important to experiment with different types of stimulation in order to pick-up on what a child with disabilities responds to," said Greg.

According to Greg, Columbia Regional Program has played a large part in the tactile stimulation testing component of Andrew's education. Greg and Speech Language Pathology Assistant **Jeanne Kelly-Brown** get many of their resources, such as the Bumble Ball and BIGmack switch-toys, from Columbia Regional.

Jeanne and Greg teamed up to incorporate switch toys as part of the tactile stimulation testing.

"Switch-toys have played an important role in watching Andrew's behavior emerge," said Greg.

Although the Bumble Ball was first introduced to Andrew in Becky's classroom, **Assistive Technology Consultant Roni Sautter** has joined Greg and his team to try and help Andrew progress by using different types of technology. She noticed that Andrew responded to the Bumble Ball and then incorporated it into his tactile stimulation testing.

They let Andrew see and feel the toy and decided to connect it to the voice activation device called the BIGmack, another of Andrew's favorite toys. After playing with the toy and getting Andrew more and more involved, Greg and Jeanne discovered that Andrew was activating the toy on his own, by turning his head to activate the switch.

The speech team was growing larger as staff learned of new techniques and discoveries Greg and Jeanne were implementing. Assistive Technology Consultant **Pam Bensen** teamed up with them to collaborate and introduce new voice output devices involving Andrew as well.

Computer software was then adapted to the switch-toys and in time, Greg was learning that Andrew was showing more mobility with his chin.

Greg said that Andrew is more aware now. He looks at his gains and marvels at how much more potential is yet to unfold and how far Andrew has come.

MECP Licensed Physical Therapist Assistant **Lori Skyles** met Andrew when he was just two years old and worked with him until he was age five. During those years, Lori spent a lot of time in the Epperly home working with Andrew on stretching as well as having him work with a standing frame.

When Lori would enter the Epperly's home she noticed that Andrew would often be laying on his back on his scooter-board (much like a skate-board) and would be pushing and kicking his legs to maneuver his way around the kitchen.

Lori remembers thinking: "This is a very smart boy who's very resourceful and very determined." She was amazed at how creative Andrew was to come up with such an inventive way to be mobile and get around.

Along with stretching therapy, Lori used activating toys (switch-toys) to communicate with Andrew. Lori would incorporate rolling exercises in Andrew's physical therapy routine as well. By lifting Andrew's legs up he would finish by rolling himself over.

She would play music which Andrew loved. Once the music started, he knew through repetition just what to do in their physical therapy sessions. Andrew was always excited to see Lori. She could tell he enjoyed physical therapy.

Lori then began inviting Physical Therapist (now retired) **Marilyn Redwine** to the Epperly's home when Andrew was turning five so she could show Marilyn the physical therapy routine he had come to be familiar with. In addition, home visits to the Epperlys allowed Andrew to get to know Marilyn so that the transition would be comfortable for him.

"I miss Andrew," said Lori. "It was always a joy to come to the Epperly's home. They were so welcoming. They just knew Andrew so well and they really supported one another. Anything that I needed, they came through with for me."

Jessica Sterling is Andrew's special education teacher at Reynolds Middle School. Jessica and her assistants usually have Andrew involved with a large group in the mornings. According to Jessica, Andrew likes music time the best.

Andrew loves taking field trips and being involved in the school's coffee cart. The coffee cart is a school activity where he and other students who assist Andrew, make the rounds and sell coffee to school staff and students. Andrew clearly loves the social aspect of being involved with the coffee cart activity.

"Andrew is very sociable, inquisitive and very charismatic. I just think he's adorable," said Jessica.

Debbie Seymour, RN, of MESD's Health and Social Services, is Andrew's one-to-one nurse. She has been working with Andrew since he was in kindergarten. As his constant companion, she spends a lot of time with Andrew throughout the school year.


Debbie has seen Andrew make significant improvement in his ability to interact with his environment. The largest change she has noticed in Andrew is the increased time that he is alert and engaged. Now, she says, he's excited about what every new day is going to bring.

"When I think of what I've learned working with Andrew, I'm amazed," Debbie said. "If I'm gone a week, I start to really miss him."

Debbie is thankful that she has a great team of professionals with whom she works.

"I've worked closely with members of Andrew's support team for years now. **Linda Plaza** with Columbia Regional Program has been so good in handling Andrew's vision for over four years now. Greg Lilly has been wonderful to work with, as Andrew's speech language pathologist."

"I've also worked closely with **Patty Boyd** (Physical Therapist) who has also been a strong member of Andrew's team since he was in kindergarten, all the way to his current age now, age 12 years old. Patty has been great to work with because she really thinks outside the box."

"I've been fortunate to work with Lori Skyles, who provided physical therapy for Andrew when he was in Early Childhood. It's just amazing what a team-effort can do in shaping lives and bringing out Andrew's highest potential," said Debbie. 

Debbie Seymour working with Andrew



Interaction in review:

The stories, the people, the programs...
what we covered for you in 2009-10



Thanks to: MESD Printing and Graphic Services and all the staff who graciously allowed us to interview them, snap photos and learn more about their work with children, families, schools and the community.



September

- MESD's Child Health Insurance Access Program
- Agency Goals: New initiatives take shape for 2009-11
- Meet new Functional Living Skills Coordinator Jeanne Zuniga

October

- Helensview students communicate with Officer George Weatheroy
- Legal advocate Ollie Cantos meets with Arata Creek students
- Pet care at Pathways Community School
- MESD Coop adapts to changing business model
- Pam Benson Memorial Fund established

November

- ECSE Teacher Kathy Shannon engages former students as mentors
- School Nurses Michelle MacLachlan and LueAnn Beck receive honors
- Mary McGinn and her team create fun for students at Pathways
- Outdoor School students monitor water quality

December

- Reconnecting Youth efforts explained
- Arata Creek staff bring families together for a fun night
- MESD's custodial staff keep buildings in ship shape
- Fall, 2009 E2 Foundation Terra Nova grants announced

February

- School psychologist Joni Tolon works wonders
- Mary Cox: Speech pathologist is an expert in her field
- Pam Hellesto and Roni Sautter lead MESD's Assistive Technology team
- Ron Hitchcock interviewed on legislation, district superintendents

March

- LPN Steffannie Gonzalez: She's always there for Ryan
- Arata Creek: Cory Gibson, Ethan Akre and Susan Hoelzer go the extra mile for students
- Hillary Hyde and Julie Schweigert nurture Early Intervention/Early Childhood Special Education partnerships

April

- A Taste of the View: Chaz Mortimer and the musical crew at Helensview
- Alternative Pathways: Futures Fair opens options for students
- Board Approves 2010-11 Budget

May

- Wraparound Oregon: Early Childhood - A Story of Success
- Facility Review recommendations being implemented

INTERACTION

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