

# Family Advocates Case Presentation

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## ECHO **Autism**: Advocates

### Case Presentation Form

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Complete this form to the best of your ability. This survey is individualized and should only be completed and submitted by the listed presenter/s. If your presentation includes patient information all protective health information should be excluded. An ID number (ECHO ID) has been created for your presentation and must be utilized when identifying your case/patient during clinic.

Email our clinic coordinator Michael Hansen at [michaelhansen@health.missouri.edu](mailto:michaelhansen@health.missouri.edu) if you have any questions or comments.

**PLEASE NOTE: Project ECHO case consultations do not create or otherwise establish a provider-patient relationship between any UMH clinician and any patient whose case is being presented in a Project ECHO setting.**

**ECHO ID Case Number:**

\* must provide value

FA072

**Presentation Date:**

\* must provide value

04-19-2024

**Presenter Name:**

\* must provide value

April Anderson Ravert

**Presenter City:**

\* must provide value

Columbia

**System Discussion Topic**

\* must provide value

Advocacy



# Please provide example/s of what difficulties/barriers families face and what questions the group can answer to help you best support autistic people and/or families of children with autism.

## Example 1

\* must provide value

This is a case that was presented last fall; since then and thanks to this panel, the child has all that they need on board medically, who in addition to having ASD, has many other chronic health conditions, one being a major seizure disorder (April will have the details of the medical dx'es when she presents); Some history learned by April since presenting this case is: the little boy's bio mom tried to suffocate him at birth; one of his other medical conditions is CPalsy. This little boy is 3yo and along with his 6yo sister (who is neurotypical) were adopted by their grandparents 2 years ago.

Difficulties and barriers (through recent events) and situation regarding the ECSE public school where child attends are the include:

- \* Child is accompanied by a para for transport to/from school bus (home to school) each day
- \* Child had a shunt placed last fall and wears a safety helmet when out on playground (included in his IEP)
- \* Child fell on the playground (on a Wednesday), hit his head, had 3 seizures, and 2 nosebleeds that were reported to the para (only).
- \* On Friday of that week, child was kept home from school by GM because he was not feeling well and was running a low grade fever and appeared to be in pain; teacher showed up at the house along with his SLP to offer home therapy; teacher asked how child was feeling and said she was sorry about the incident that happened at school; GM was shocked that this was the first mention of event to her.
- \* GM contacted the agency contracted through the pub school and asked to speak w/manager and reported incident.
- \* By late that evening, child had 2 grand mal seizures and lost consciousness; GM (who has healthcare training) chose to transport him to ER in her own vehicle; on the way to hospital, child stopped breathing and GM pulled over and administered CPR to resuscitate him.
- \* ER attending quickly assessed that child had a concussion and asked if he had fallen and hit his head recently; when he saw that he had a shunt, he sent a message to the child's neurosurgeon who ordered tests; ER doc was very alarmed about the condition of the child and admitted him for the rest of that weekend; tests revealed that shunt had been displaced and that on of his ventricles and looked like it had colapsed which spoke to the level of pain child was in; neurosurgeon was out of town but requested child be brought to where she practices 3 days later upon her return; pain was managed through hospital stay and was sent home 3 days later; neurosurgeon was able to readjust the shunt with a magnet in the follow-up visit.
- \* GM contacted April to let her know about these events and was referred to a local IEP consultant b/c GM had arranged an emergency IEP meeting at the school the following week to learn about exactly what took place on school's end and why she was never contacted directly when incident occurred; the IEP consulting firm referred GM to MoDE who after hearing this story, recommended that GM hotline the school.
- \* DSS-DFS worker contacted GM the next morning and asked to visit 2 hours later; she arrived with a local PD officer, was interviewed.
- \* Since this time, GM has attended another IEP meeting and school is working on improving communications and including some new accommodations to be added to her GS's IEP.
- \* The para assigned to the child has been terminated and replaced.
- \* GM is concerned about moving forward with school and has trust issues/concerns

**Regarding this example, what question/s can we answer to help you best support autistic people and/or families of children with autism.**

\* must provide value

Are there additional steps the hub and family advisory team members recommend that GM considers for advocacy and/or prevention (safety) measures for her grandson?

**Do you have another example to provide?**

\* must provide value

- Yes  
 No

**Have you recommended resources in the past that have been helpful to families experiencing challenges?**

\* must provide value

- Yes  
 No

**Please tell us more about the resources you have utilized.**

\* must provide value

MPACT in addition to the ones listed in case description (IEP consultant, MoDE)

**Please rate how helpful these resources have been.**

\* must provide value

1 - Not helpful      2 - Somewhat helpful      3 - Very helpful

**Are there any additional comments you would like to share?**

\* must provide value

- Yes  
 No

**Please describe:**

\* must provide value

I have reached out to GM today so I may have some additional questions/concerns she has to add and will bring those with me on Friday.

**Form Status**

**Complete?**

Complete ▼