

# Coping with Sibling who Has Disabilities

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4<sup>th</sup> June 2014

# Family History

- Aunt has a daughter with Autism
- Cousin sister has a son with Autism
- My sister is an Autistic girl
- Cousin brother had a son with Trisomy 18 (Edwards Syndrome)– passed away 2 months ago.

# Profile

- 17 years old
- Born premature
- Attended SK Pinji Ipoh (Primary 1– 6)
- Attending ASAP (Autism Support Association for Parents) Special School & SMKJPP Ipoh (special class)
- Like: Music, drawing, outdoor activities like swimming, hiking and travelling.
- Learning piano, drum & Ukulele.





# Her Likes





# Her Problems

- Poor motor planning skill.
- Dislikes the texture of the ground, esp. cemented & carpeted floor/ ground—refused to sit during assembly etc.
- Impatient.
- Prefers playing alone.







# Her Talents

- Drawing - comics
- Balancing- stand on a swimming board in the pool.
- Music
- Creative/ Imaginative
- Brave



# Experiences in Schools

- Kindergarten (since 4 years old)
  - First kindergarten: Being ignored & often sat at the reading corner.
  - Second Kindergarten: Well accepted and being taught well
- Primary School (since 7 years old, delayed 2 years)
  - First year: A lot of behavior problems (took off shoes & socks, cried in the class, refused to copy from board, rejected by form teacher, being bullied in school)
  - Second year: attended special class
  - Third year: went back to mainstream class (standard 2)
- Secondary school (since 14 years old)
  - Loved by teachers
  - Opportunities to perform & participate in National Quiz in Melaka



# How I got Involved

- 2 years old- Speech therapist- closest sibling- eye contact activity- singing
- Part time job after SPM in New Horizons
- Became her tutor at home

# My Major Struggles

- Expectation from parents- to help her with her homework every night (even weekends)
- People around expect you to be able to handle her.



# Past Struggles

- Swimming
- Shopping
- Special outings: movie, theme park.
- Behavior in school
- At home: noise, crying (365 days, few times in a day).
- Hair cut
- Self-care: dry at night, make bed & brush teeth (revised “economy system”)
- Lack of cooperation from dad: too protective & dislikes her crying
- Church: Sunday School

# Struggles: Swimming

- Couldn't wait
- Jumped from the highest board into the pool for diving. (w/o knowledge of diving)
- Ran up and down the stairs and then jumped from above without taking other ppl into consideration.
- All the life guards and staffs knew her.
- Being Gossiped



# Shopping & Movie Outing

- Lied on the floor
- Threw a book down from 3<sup>rd</sup> floor to ground floor
- Go up and down the escalator

# Self-care Issue

- Shared room- wet her bed- smelled- kept her bed- chart with dates & day- Tick if she did, cross if she didn' t.
- Brush teeth- morning & night- chart- tick & cross- reward/ punishment



# Strategies

- Social story books
- Visual cards
- Time out– e.g. (in the toilet) during movie outing and church activities
- Pre– planned schedule
- Talk before anything else
- Distraction: comic books, arrive later/ on time, paper & pen.
- Sentence Strips (to request help)

# Current Challenges

- Helping her to understand that she is a teenager now.
- Protect herself from any inappropriate touch from teachers/ classmates.
- She still does not have her menses yet.
- Preparing for future– still a question mark.



# What had Mom done?

- School: Standard 1– 6
  - Mom begged students to borrow her school works;
  - Sat in class copying what sis didn' t complete;
  - Bribed her classmates so that they might take care of her.
  - Talked to teacher now and then to check on sister' s behaviors.
- OTHERS:
  - Exposed her to many different places and events no matter what others might think and talk about her.
  - Boldly told people about her condition and often told people how she had improved.

# Activities Out of School





# Other Activities



# Where I Get Emotional Support?

- God
- My boss
- Church members
- Spouse
- Sisters



# How Has My Life Changed?

- More patient.
- Truly learn what OWL means—
  - Observe.
  - Wait.
  - Listen
- Play to build rapport instead of reprimanding her all the time.
- Love overcomes challenges.

# Conclusion

- Cooperative family members
- Cooperative friends and people around.
- Play to gain trust & rapport instead of reprimanding all the time
- Independent skills is very important
- Be consistent





THANK YOU!