



MICHAELANN



# An Essential Lifestyle Plan for MichaelAnn Byrne

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## Purpose of this plan:

- To assist others, who may not know MichaelAnn's communication methods, in knowing MichaelAnn's wants and needs.
- To describe what others have learned about how to assist MichaelAnn to decrease her frustration and/or increase her independence.
- To help with determining what services and supports make sense and work.

## People who contributed to this plan (give name, relationship and how long they've known each other):

Gregory & Sherry, parents

John & Dorothy, Grandparents

Richard & Elizabeth, Great Uncle & Aunt

Deb, Aide – late 2001

Peggy, Occupational Therapist – March 2000

Susan, Preschool Teacher – September 2000

## Who still needs to be asked to contribute? (give name, relationship and how long they've known each other)

Jen, Preschool Teacher

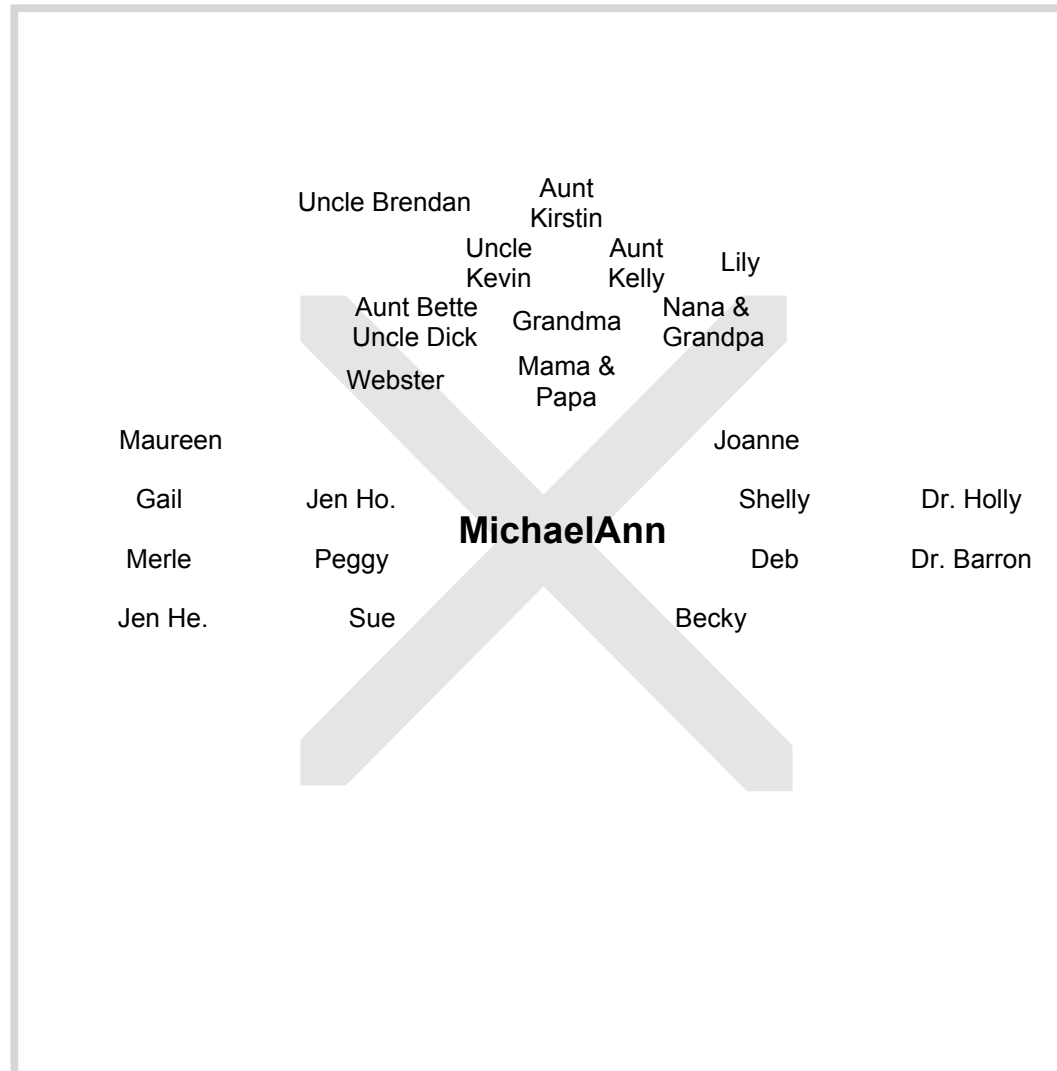
Gail, Physical Therapist – March 2000

Maureen, Speech Therapist – March 2000

Jen, Music Therapist

**People in  
MichaelAnn's  
Life**

*Family*



*Work/Day  
Services/  
School*

*Home  
and  
Other  
Paid  
Supports*

*Friends & Non-paid Relationships*

## **What people like and admire about MichaelAnn (MichaelAnn's Positive Reputation)**

## **Notes**

- ❖ Her determination
- ❖ Her independence
- ❖ Not a quitter
  
- ❖ Her joyfulness
- ❖ Her spirit
- ❖ Her magnetism
  
- ❖ Her ability to make people smile
- ❖ Her terrific attitude
- ❖ Her sense of humor
  
- ❖ Friendly
- ❖ Pleasant to be around
- ❖ Flirt
  
- ❖ Beautiful
- ❖ Great smile
- ❖ Beautiful hair
  
- ❖ Her love of music

## **What's Important to MichaelAnn: Most Important Things MichaelAnn must/must not have, the essentials.**

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### **Family**

- ∞ PAPA!
- ∞ Sitting in Papa's lap when he gets home from work and/or in the evening.

### **Food & Drink**

- ∞ MILK.
- ∞ Loves bananas!
- ∞ Meals being on time.
  
- ∞ **Bead garlands.** Has a box of different colored Christmas tree beads she loves to play with.

### **Music**

- ♯ Listening to children's music.
- ♯ Other people singing and/or playing musical instruments.
- ♯ Singing & moving to children's songs with movement. (I.E. Row, row, row your boat, If you're happy and you know it, Itsy, bitsy spider)
- ♯ Musical toys or instruments that can be activated by touch.
- ♯ Musical toys that have a lot of texture to touch.
- ♯ Music with drums. The deeper the drum the better.

## **Notes**

5/29/03

→ Is music with drums still important? *ell*

## **What's Important to MichaelAnn: Most Important Things MichaelAnn must/must not have, the essentials.**

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∞ Pacifier at bedtime.

### **Walking**

∞ Indoor Walking. Walking. Walking. Is on the go walking at home a lot of day. May look like aimless wandering.

- Walk between activities (i.e. dress, walk, hair, walk).
- Walking to process an activity and/or environment, especially if the activity or environment is new.

∞ Not being pushed from one activity/task to the next. Needs time to process between activities, especially new activities. Her walking usually does this.

∞ Not having the sun in her eyes.

∞ Blowing raspberries.

∞ Having support staff that care about her and spend quality time with her doing things she likes. (I.E. playing music, reading books)

## **Notes**

## **What's Important to MichaelAnn: Second Most Important**

**Things MichaelAnn needs to have/not have. Things important, very important.**

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- ☞ Swinging.
- ☞ Going for a walk in her stroller.
  
- ☞ Having her shoulders and back massaged.
  - Massage should be medium to deep pressure.
  - Soft rubbing, at times, can be irritating for her.
  
- ☞ Doesn't like having her hair combed.
- ☞ Doesn't like wind in her face.
  
- ☞ Taking naps through out the day.
  
- ☞ Likes to feel different types of textures (i.e. Upholstery, tables).

## **Notes**

## **What's Important to MichaelAnn: Third Most Important**

### **Things MichaelAnn does or doesn't enjoy, likes/dislikes.**

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- ☞ Favorite color – Yellow.
- ☞ Doesn't like some loud noises, may put her fingers in her ears. This doesn't always mean it's too loud or noisy.
- ☞ Prefers adults to peers.

## **Notes**

## Characteristics of People Who Support MichaelAnn Best

- ♥ Upbeat/enthusiastic
- ♥ Patient
- ♥ Calm
  
- ♥ Attentive
- ♥ Devoted (to her)
  
- ♥ Perceptive
- ♥ Intuitive

## Notes

## What People Need to Know and Do to Support MichaelAnn

## Notes

### Communication

- ☛ MichaelAnn doesn't communicate with words.
- ☛ Watch her eye gaze for what she wants to do or responses to questions.
- ☛ Kicking her leg and/or legs usually means more or yes (if she is standing, bouncing)

\_ we think it also means she's happy. *ell*

### ☛ Communication cards

- ☛ MichaelAnn uses communication cards for some activities to:

1. Know what activity is coming up or what she will be doing
2. Make a choice of what to do

- ☛ New cards are being made all the time. Let Sherry know if there is a card you would like to be made.

### ☛ Using Communication Cards

- ☛ Before an activity, show MichaelAnn the card of the activity and tell her the activity she will be doing.
- ☛ I.E. "MichaelAnn you will be brushing you teeth soon" while showing her the card for tooth brushing.)
- ☛ Let her look at the card as long as she wants.
- ☛ This gives her time to process the activity before doing it
  
- ☛ Show her the card again when it is time to do activity.

## What People Need to Know and Do to Support MichaelAnn

## Notes

- ☞ To make a choice, show MichaelAnn two different cards and ask her “Do you want to \_\_\_ or \_\_\_?” while holding the cards up and separated.
  - ☞ She will use eye gaze to make a choice.
  - ☞ Show her the card she chose and say “ok, you chose \_\_\_, so let’s go \_\_\_.”
  - ☞ If she doesn’t make a choice, change one of the cards and see if she makes a choice.
  - ☞ If no choice, chose an activity for her and show her the card and say “We are going to \_\_\_.”
- 
- 🧠 You need to be a little intuitive at reading MichaelAnn’s body language and watching her eyes to see what she wants or needs and helping her with those needs.
- 
- 🧠 Use a “sing-song” tone of voice when talking with her.
- 
- 🧠 Make communication simple.
    - ☞ One step instructions.
    - ☞ Short sentences – with one thought at a time.
    - ☞ Don’t over talk (i.e. repeating instructions without allowing process time in-between)
    - ☞ She is beginning to respond to repetitive simple statements (i.e. time to eat, time for bed).

## What People Need to Know and Do to Support MichaelAnn

- 👤 Explain everything – even if MichaelAnn doesn't seem to be listening or understanding.
  - If MichaelAnn stomps & screams when doing something with her...Did you explain what you are doing and give her time to process it?
  
- 👤 Give her choices between two (2) items throughout the day (i.e. what to wear, eat, do).
  - Wait for her response.
  - *Give her time to process what you say.*
  - It might take a few minutes.
  - If standing, she might walk away a few times before coming back.
  - Watch her eye gaze and/or kicking for answer.
  
- 👤 Does seem to understand some things that are said.
  
- 👤 Let MichaelAnn know you hear her when she “vocalizes”.
  - When you respond to her sounds, she learns that what she “says” means something and is important to you.
  
- 👤 MichaelAnn expresses some emotions through screaming-like vocalizations (i.e. happiness, madness)
  - Usually can identify the emotion by facial expressions and/or tone of voice.

## Notes

5/29/03

→ We think she understands a lot of what is being said because of different reactions she has when we are talking to her or with others. *slb*

## What People Need to Know and Do to Support MichaelAnn

- Acknowledge the feeling (i.e. “MichaelAnn, I see you’re unhappy because dinner is not ready. It will be ready in a little bit.”)

### Naps

- ∞ MichaelAnn will lay herself down on her “pillow bed” or the floor when she is tired. She is allowed to nap at home and naps anywhere from a few minutes to over an hour.

### Play

- ♪ She can play for hours with her bead garlands; taking them out of a box, flipping them, making piles with her feet.
  - Untangled the beads for her at least once a day.
    - I ask her to help and give her a pile to “untangle” while I untangle the rest. Then trade.
- ♪ MichaelAnn plays primarily with musical toys or instruments that can be activated by touch. She can usually “play” with these herself if they are available to her.
- ♪ She does not hold on to objects to play with them (i.e. mallet for xylophone or drum) with the exception of her beads.
  - Introduce different objects and toys to her.
  - Show her how to use them (she is probably walking around during this).

## Notes

## What People Need to Know and Do to Support MichaelAnn

## Notes

- Hold your hand out to her and ask her to sit down with you. (Don't force her if she doesn't want to sit down, just keep talking and playing with the item until she wants to sit.)
  - Show her again how to play with it, and then hold the toy out for her.
  - Praise her if she touches or holds it
  - If she doesn't touch or hold it, help her hold it using your hand on top of hers. She may just touch it and pull her hand away, praise her.
- ♪ Plays kids games with her. She likes ones that you sing to and also have some type of movement.
- Row, row, row your boat
  - Patty cake
  - Ring around the Rosie
- ♪ Introduce MichaelAnn to new games & toys. Show her how to play with them.
- she is showing interest in the toy phone
  - play pretend with her
    - *example:* sometimes we pretend we are going to the beauty shop to get our nails done when it's time to clip her nails. *slb*

## What People Need to Know and Do to Support MichaelAnn

## Notes

- ♪ Read books to her.
  - Show enthusiasm as you read. Read the story with expression.
  - Comment about what's happening in the story. Point to pictures and talk about what's happening in them.
  - Finish the story even if she is walking around. She is probably still listening.
  - Read books she likes over & over.

### Walking

- ☞ MichaelAnn likes to walk while inside (may look like aimless wandering).
  - Sometimes this is to process what is going on (see *Apraxia/Dyspraxia* in her plan).
  - Let her walk before changing activities, letting her know what is coming up next.
- ☞ MichaelAnn likes to walk alone and will pull her hand away if she wants to do it by herself. Let her do it by herself if it isn't on uneven surfaces or a dangerous situation.
- ☞ Doesn't like to walk much when out in community (i.e. shopping, fairs). Bring her stroller when going out where there will be lots of walking.

## What People Need to Know and Do to Support MichaelAnn

- ☞ Walk hand in hand with MichaelAnn when walking on uneven surfaces or in dangerous situations.
- ☞ MichaelAnn may fall often; wait to see if she cries before going over to her. She cries most every time if you go right to her (but know she does have a delayed cry).

### Miscellaneous

- ☞ When doing something with MichaelAnn – taking a walk, shopping, eating – talk about it.
- ☞ Introduce MichaelAnn to new experiences and new places.
- ☞ Too much external input (i.e. large number of people, too much activity happening around her) may shut her down, make her fussy and/or she may try to go to a quieter room.
  - She may go to a quieter area or you may take her.
  - Put her stroller canopy over her if she is in her stroller.
- ☞ MichaelAnn is using her legs & feet for many things
  - She takes her covers off (she can not put them back on & needs checked through out the night)
  - Take her shoes & socks off
  - Communicates displeasure by stomping
  - Plays with beads
  - Plays with you

## Notes

5/29/03

→ I think this is getting better. *ell*

5/29/03

→ Is this something we can expand on? *ell*

## What People Need to Know and Do to Support MichaelAnn

## Notes

### Apraxia/Dyspraxia

- MichaelAnn may walk to the same object/person/thing numerous times. She is interested in it but doesn't know how to interact with it.
  - Give her a few times to try and figure it out.
  - Reinforce her if she touches the object.
  - If she doesn't touch it after a few times help her in how to interact with the object.
  
- Music can help break through the apraxia.
  
- Most of the toys that she plays with are musical. The desire to play with these is so powerful that she doesn't have to think about how to play with them it just happens.
  
- Definition:
  - (Taken from The Rett Syndrome Handbook) *Motor apraxia is the body's inability to carry out what the brain signals it to do, i.e. difficulty to perform purposeful movements and actions in spite of normal mobility. Simply put, apraxia is the inability to coordinate thought and movement. It is the most fundamental handicap seen in RS, and involves all body movements, including speech and eye gaze.*

## What People Need to Know and Do to Support MichaelAnn

### Self-Help

*New people, staff or strangers are **NOT** allowed to change MichaelAnn's diaper or bathe her.*

- We are trying to build in a sense of privacy for her. With so many aides & people in her life it is extremely important she learn that people she just meets do not do private things with her.
- Sherry or Greg will let you know when you can do these things.

### Dressing

- ☆ Let her choose the outfit.

#### *Shirts/Dresses/Over-the-head items*

- ☆ Put over head first.
- ☆ Put hand in one arm hole
- ☆ Tell MichaelAnn to "push", she will push her arm through the hole. May have to tell her to push a few times, *be patient.*
- ☆ Repeat other arm.

#### *Pants/shorts*

- ☆ Usually she will lie down to put pants on.

## Notes

## What People Need to Know and Do to Support MichaelAnn

## Notes

- ☆ Start one leg in pant leg.
- ☆ Tell MichaelAnn to “push”. May have to tell her to push a few times, *be patient*.
- ☆ Repeat for other leg.
- ☆ To stand up:
  - Bend knees with feet flat on the floor.
  - MichaelAnn will hold out her hands for you to grab.
  - Let her use her arms & muscles to stand up. Do not pull her up, let her do it.
  - When she stands up she will lean into you or away from you. She will fall if you don't catch her.
- ☆ She will expect you to keep her balance when pulling her pants up. Try and have her stand on her own.

### *Dresses*

- ☆ MichaelAnn will wear underwear over her diaper when she wears a dress.

### *Undressing*

- ☆ Lift top over her head from the bottom.
- ☆ She will hold her arms up – if not, tell her to hold her arms up.
- ☆ Pants - she usually lies down so you can take them off.

## What People Need to Know and Do to Support MichaelAnn

## Notes

### Tooth Brushing

- ☺ MichaelAnn uses an electric toothbrush.
  
- ☺ Tell MichaelAnn it's time to brush her teeth.
- ☺ Show her the toothbrush and tell her to "open wide".
- ☺ Hold the toothbrush in front of her *until* she looks at it and opens wide.
  
- ☺ Let her hold the toothbrush, if she doesn't want to hold it don't make a big deal about it, just brush her teeth.
- ☺ She may want to brush her teeth by herself when you have "completed" brushing them. That's okay! You want her to be brushing her teeth independently. Praise her!
  
- ☺ When brushing her teeth she will stop a few times (close her mouth and/or turn her head), use this opportunity to rinse the toothbrush with water.
- ☺ She will, most of the time, open her mouth again. NEVER force the toothbrush into her mouth.
- ☺ MichaelAnn does tend bite the brush; just wait for her to open her mouth to move the brush.
  - We usually tell her that side of her mouth or those teeth are sparkling and we should make some others sparkle.

*slb*

## What People Need to Know and Do to Support MichaelAnn

## Notes

### Hair combing

- ☆ MichaelAnn doesn't like her hair combed but will tolerate most of it.
- ☆ If dry – spray her hair with water. Cover her face with your hand. Spraying is the worse part for her, especially if you get her face wet.
- ☆ Use the wide tooth comb to get the snarls out. Then use the brush. She likes her hair brushed.
- ☆ Then style.
- ☆ If you take a long time we will start to get upset.

### **Health and Safety**

Probably **does NOT sweat!**

- **Watch for over heating!**
- She will get fussy, her face and body will get red.
- *She needs to get cooled off.* Bring her in if she is outside. She also has a mister with cool water that you would mist her off with. (**Remember to bring the mister with you when going out.**)
- If she is unresponsive, get her cooled off as soon as possible.
- Take her to the emergency room or call an ambulance if she does not become responsive in a couple of minutes.

## What People Need to Know and Do to Support MichaelAnn

## Notes

**Allergies:** Penicillin, plastic on the outside of her diapers

### **Diapers**

- ☒ Use the diaper that parents supply.
- ☒ Occasionally she will get spots that look like boils, from the plastic. She has a prescription for this and the parents will administer if needed.
- ☒ To put the diaper on:
  - Check that the back of the diaper is flat against her bottom. Sometimes the cotton in the diaper bunches making a roll of hard cotton in the diaper.
  - Fasten both tabs.
  - Check that the plastic around the legs is not tucked under the elastic.
- ☒ To stand up:
  - Bend knees with feet flat on the floor.
  - MichaelAnn will hold out her hands for you to grab.
  - Let her use her arms & muscles to stand up. Do not pull her up, let her do it.

### **Skin Sensitivity**

- ☒ She gets a lot of rashes and/or red bumps. Her doctor usually checks these to make sure it isn't a virus. Inform parents of any new rashes.
- ☒ Needs to wear sunscreen due to fair skin and the medications she's taking.

## What People Need to Know and Do to Support MichaelAnn

## Notes

☞ Needs to wear sunglasses when going out in the sun.

### **Repetitive Hand Movements and Hand Mouthing**

- ☞ MichaelAnn hand mouths and does “handwashing” activities most of the day. This is part of Rett Syndrome. Behavior techniques will not work to decrease this activity.
- ☞ She may get calluses or sores on her hands and/or knuckles from hand mouthing. Let parents know if you see this.
- ☞ MichaelAnn gets sick a lot because of the hand mouthing that she does.
- ☞ Do frequent washing of her hands and cleaning of her toys.

### **Seizures**

Absence Seizures:

- *Typically look like:* Blank stare. Body usually still (frozen). Can still have some movement (i.e. hand wringing) during seizure. Usually takes a deep breathe after and can also be excited after the seizure. Last 5 – 20 seconds.
- *What to do:* Nothing. Can talk with her and let her know it will be okay. Document in seizure log which is in her school notebook.
- These can occur daily and many times in a day.

MichaelAnn has had other seizures in the past (Complex

## **What People Need to Know and Do to Support MichaelAnn**

Partial, Status, Myoclonic) but it has been over a year since any of these occurred.

Let the parents know as soon as possible if you think that she is having any other type of seizure other than the absence.

Notes

## Things to Figure Out

January 2003

**Is MichaelAnn having a problem with depth perception again?** *slb*

- Noticed after we moved to new house, she was very cautious or avoided moving/crossing the floor when the floor pattern or texture changed. *slb*

February 11, 2003

**Is MichaelAnn having “drop” seizures?** *slb*

May 29, 2003

**Can we expand on MichaelAnn’s use of feet &/or legs?** *slb*

## Notes

Contact Joanne, Vision Specialist, to look into.  
Possibly make appt. with Dr. Moon.

The previous month, pre-school has reported MichaelAnn has fallen straight backwards hitting the floor for no apparent reason. This has also happened at home.

ANY THOUGHTS?

## How MichaelAnn Communicates

What is happening...	MichaelAnn does this...	We think it means...	And we should...
Standing or playing in the living room.	Looks at her chair (child's chair) and/or stands in front of it rocking.	Wants to sit in the chair.	<ul style="list-style-type: none"> <li>▪ Assist her by taking her hand and turning her so her back is facing the chair.</li> <li>▪ She should be rotating in this position with just a little assistance.</li> <li>▪ Let her sit down.</li> <li>▪ May need to sit her up in the chair so she is sitting upright.</li> </ul>
Anytime	Stands in front of couch or chair.  May be kneeling on floor, laying her head on cushion.	Wants to sit there.	Assist her in sitting on the furniture.
Sitting on the floor.	Lifts her arms up.	Needs help getting up.	<ul style="list-style-type: none"> <li>▪ Put out your hands and let her use your hands to stand up.</li> <li>▪ She will stand up herself using your hands as leverage, do not lift her.</li> </ul>
Standing in front or near you when you are sitting.	Lifts her arms up or leans into you.	Wants to sit on your lap or with you.	Sit her on your lap or next to you.
Walking past toy/object.	Looks at a toy/object.	Wants to play with it or know more about it.	<ul style="list-style-type: none"> <li>▪ Allow her to walk past it a few times &amp; look at it.</li> <li>▪ Assist her in interacting with the toy/object.</li> </ul>

What is happening...	MichaelAnn does this...	We think it means...	And we should...
			<ul style="list-style-type: none"> <li>▪ When she touches the toy/object praise her.</li> <li>▪ She may only interact with it for a few seconds. This should increase with time.</li> </ul>
Standing in front of Sit & Spin.	Looks at Sit & Spin	Wants to play on it.	<ul style="list-style-type: none"> <li>♪ Sit on the floor, position the sit &amp; spin between you and MichaelAnn.</li> <li>♪ If MichaelAnn is standing hold out your hand which she will take (sometimes with assistance) and she will sit down.</li> <li>♪ Place her legs around the sit &amp; spin and slide her on.</li> <li>♪ You will have to cross her legs and spin her. Be sure to hang on to her legs or she will uncross them.*</li> <li>♪ Count each rotation. She goes anywhere from 9-20 rotations before she gets dizzy and falls over laughing.</li> <li>♪ Remind her to hang on when you are spinning her.</li> <li>♪ Be sure to catch her when she is going over so she doesn't get hurt.</li> <li>♪ She usually does this twice</li> </ul>

What is happening...	MichaelAnn does this...	We think it means...	And we should...
			and that seems to be enough for her. ♪ She may still sit on the sit & spin and play the music.
	*Continues to uncross her legs.	She wants to just sit on the Sit & Spin and play to the music.	♪ Let her sit and play the music.
A person is walking towards MichaelAnn or is near her.	Opens her mouth, usually with head tilted slightly back.	She wants a kiss or to kiss you.	Kiss her.
In bed, at bedtime	Is fussy or holding her hand out to you.	Wants her pacifier.	<ul style="list-style-type: none"> <li>▪ Give her the pacifier.</li> <li>▪ Have her grab the pacifier from you.</li> <li>▪ Do not put in her mouth.</li> </ul>
Between 7- 8 PM	MichaelAnn is fussy/cranky.	She is tired & wants to go to bed.	<ul style="list-style-type: none"> <li>▪ Get her ready for bed &amp; put her to bed.</li> </ul>
Eating	Turns her head to the side.	Doesn't want what you are giving her or she's done eating.	<ul style="list-style-type: none"> <li>▪ Give her a drink and/or</li> <li>▪ Try another food.</li> <li>▪ If she continues to turn her head to food &amp; drink, she's done eating.</li> </ul>
Mealtimes	Walks into kitchen looking around or at you.	She is hungry.	Let her know it will be ready in a little while.
Not mealtimes	Same as above	Same as above	If it is awhile before mealtime, give her something to drink &/or a small snack.
			♪

	<b>What Makes Sense</b> What works? What needs to be maintained/enhanced? (The upside right now.)	<b>What Doesn't Make Sense</b> What doesn't work? What needs to change? What must be different? (The downside right now.)
<b>from MichaelAnn's perspective:</b>	<ul style="list-style-type: none"> <li>▪ Family that adores her</li> <li>▪ Garlands of beads</li> <li>▪ Touch activated music toys &amp; instruments</li> <li>▪ Eating at regular times</li> <li>▪ Having a quiet room to go to when things are over stimulating</li> <li>▪ Deb</li> <li>▪ Getting out of bed by herself</li> <li>▪ Being able to access (walk) home &amp; bedroom</li> </ul>	<ul style="list-style-type: none"> <li>▪ Not being able to sit on furniture when she wants to</li> <li>▪ Not being able to get on her bed</li> <li>▪ Too much down time at home</li> <li>▪ Not being able to get out of bed by herself all the time.</li> </ul>
<b>from who's perspective:</b>	Parent's perspective: <ul style="list-style-type: none"> <li>▪ Teachers &amp; therapists</li> <li>▪ Supportive family</li> <li>▪ Family that loves her</li> <li>▪ Keyboard, touch activated music toys</li> <li>▪ Living in a ranch (one story) home</li> <li>▪ Deb</li> </ul>	Parent's perspective: <ul style="list-style-type: none"> <li>▪ Too much time off from school</li> <li>▪ How often she gets sick</li> <li>▪ How often she falls</li> <li>▪ Not having friends</li> <li>▪ Too many aides coming in &amp; out of her life</li> </ul>



## Action Plan

Desired Outcome:	
Discussion/Justification:	

What needs to be done	Who's responsible	By when

Date:	Comments:	Review of Desired Outcome:

