

FUNCTIONAL, ROUTINES-BASED OUTCOMES AND ACTIVITIES

Karen, Bill, and Matthew

Our names are Karen and Bill. We are the parents of an 18 month old boy with cerebral palsy (CP). We have a loving, happy family; and like any family, we are having some challenges raising our son, Matthew. We had both heard of CP, but are learning that we don't know much about how this diagnosis will likely affect Matthew. We have been accessing information on the internet; but we wish we knew others who have children with CP so they can give us more practical information. We really have no idea what we should be preparing ourselves for. He has delays in all of his development, and we would like for him to develop as "normally" as possible, whatever that means.

We enjoy playing in our backyard. We have a lot of push toys, but Matthew usually uses those to "ride on" while we push/pull him around the yard. We hope Matthew will start using those toys to pull himself up and push them by himself some day. He really seems interested in his toy cars and balls, but hasn't quite figured out what to do with them. We wish he could pick up his cars or roll or throw his ball. It would make us feel better about him actually interacting with us or his toys. He also likes watching birds and our dog while we're outside. He just started making a "tweet" and "woof" sound when he sees the animals, and we are really excited about that. It makes us really optimistic that he will eventually be able to talk to us, to let us know what he likes (or doesn't) or when he wants to go somewhere or do something. We recently bought some children's songs and we play/sing those a lot. Matthew kind of moves and bounces around and smiles when we play the music.

One of Matthew's favorite places to go is the neighborhood pool. He loves for us to guide him around in the water. He really likes when we splash a little in his face, and he looks like he wants to splash us back so badly. He moves his arms around a little, but can't quite make a splash. That will be really exciting when he finally gets that. We will have fun splashing each other, kind of like playing a game together. We've noticed that he seems to try to move around more when he's in the pool. Another favorite place is the playground. Matthew loves the swings and slide. Other outings are more difficult, like when we go to the grocery store or mall. Matthew seems really sensitive to loud sounds and a lot of different people. Life would definitely be a lot easier if Matthew could go with us to the grocery store and other public places without screaming and crying and getting so upset.

Matthew's favorite activity is probably eating! He really seems to like just about anything. We worry sometimes if we're feeding him enough or too much! It's hard to tell when he is satisfied. We also wonder if he really does like what we're giving him, or if he just doesn't know how to tell us he doesn't want it. We wish he could let us know somehow. He's having trouble feeding himself. We would like for him to be able to use a spoon by himself and drink from a cup by himself at lunch and snack times. We're not pushing it so much at dinner because by that time he's really tired and we tend to try to keep everything calm and as easy for him as possible to help him get settled down to go to sleep. He "fights sleep" by screaming and flailing his arms, and sometimes it is really a challenge getting him calm enough to be still and quiet so he can just go to sleep.