Writing Our Journey: Poems and Essays by Family Caregivers

Each meeting has a suggested prompt, or idea, for people to write about. Everyone is free to interpret that prompt however they’d like. Below is one of the prompts, followed by a sampling of what was written in response.

Please remember that each piece of writing belongs to the writer and, if quoted, must be credited to that writer.

Self-identity

Write about how you think your child perceives him/herself. Does he think he has a disability, or is different in some way from his peers? Does she think other people see her as different? If so, how do those perceptions seem to affect him? Are your answers to these questions based on what your child says, what you’ve observed, or some of both?

- “Chris’s Picture” by Kathy Mullery
- “Identity” by Kathy Roberson
Chris’s Picture

“Why did you miss the bus,” I asked my son, but of course he couldn’t tell me. Just as I do after so many daily mini-episodes in our lives, I had begun the task of trying to fit the puzzle pieces together, hoping a picture of reasonable explanation would emerge.

I am an experienced puzzler - in a jigsaw, you start with the edges, the obvious. This one started with a call from the secretary at school. A teacher found Chris outside. Yes, alone. No, not where the buses gather, near the exit from the gym. Yes, we did ask Chris but he didn’t answer. No, not sure which teacher. Yes, it is cold out. Frustrated, I knew that so far I had only a vague outline. On to other possible fits, the irregular shapes. Maybe he forgot where he was going. Maybe he was following a teacher. I didn’t yet have the answers, but, undaunted, I knew these things take time. More work to do, so I go next to the source, Chris, who smiled to himself like a smug 14-year-old when I asked him where he had been going. Chris couldn’t tell me, at least not directly, but his look made me wonder if he did know but just wouldn’t say. Is he just keeping secrets from his parents as teenagers are known to do. I would look at this from different angles, remember I am dealing with a kid who is confident, cool and independent, but often in his own world. I am determined to get a glimpse. I know Chris loves basketball, and so connects with his coach from the fall cross country team that...yes, he would see the varsity team practicing in the gym after school, see his “coach” head that way, and try to join the team. But, now that he got to where he was headed, he can’t find the words one would use. He might then realize he is about to miss his bus, might even be afraid to be found out, knows he is in the wrong place, will feel embarrassed, will exit the building and lose his bearings. It’s a reasonable explanation. I stubbornly push the conversation with Chris and he smiles some more, speaks the “Yes” I was hoping to hear and his picture materializes.

Chris is a player, never mind that he is not on the school team. This does not stop him from talking of “his team,” packing a gym bag and putting on basketball shoes on some random evenings and announcing he is going to practice. A few times we found him in the car in the driveway and only Chris knew where he was going. He is a basketball player, serious about his obligations. In the fall he is on the football team and he dresses in full gear and asks what time does practice start? Many days he is a rock star. We have found him with his suitcase packed, in his room, dresser drawers emptied, he is heading to California. I knew there had been simply too much TV-watching that week, that must be it, because I recognized the characters he thought he was going to go see, knew their songs, their every move. Chris wants to be in, no, is in their band. I listen intently when Chris talks to himself. Often I invite myself into his conversation.
There is no talking Chris out of these fantasies. I treat these as dreams, and with respect. I acknowledge what he has set out to do and we connect briefly in the reality and relief that I know what he is thinking. Then we part, as I struggle to figure out a response that respects his dreams but gets him out of the cold, a response that speaks of other choices he might make that keep him in a reality in which I can be a guide for him. I want him to find his way, put his own puzzle together, use the odd shapes but stay within the edges.

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Identity

When discussing her problems, we find ourselves using euphemisms, spelled words, small gestures, lowered voices, though she always seems to know anyway. It’s hard to say for sure, of course, she never does, just pauses in the next room, focuses her eyes on us, resumes what she was doing. Hanging back from children farther along in every way was one sign early on; these days she doesn’t seem to notice teenagers in the street snickering when she passes by. Rather it’s my heart that tightens as I whisper reminders, *stop staring, stop sucking your thumb.* If she has some inkling she quickly moves beyond, asking gleefully and often, *Mom loves me? Dad, Laurel, Nathan, Diana, Sandra, Albus?* the list goes on and on, and she without the slightest doubt of what response they’ll be.

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