

Standing with Jon

Excerpted from an article

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(Jon has given his permission for reprinting this article.)

We have supported Jon in living in his own apartment for almost three years. During that time Jon has taught us a lot about what support means. Our agency has a commitment to support people in the lives that they want and to stand with them over time.

When we met Jon he had not had anyone other than his family stand with him for a long time. He had been kicked asked to leave several group homes and employment agencies. His service coordinator said six or seven months with one agency was about the average. He would usually get mad about the way he was treated and he would *shout* with his behavior. He would scream, kick, bite, and break things to express his anger.

Jon tells a story about when he lived in a group home. One Sunday after church, Jon came home and insisted that he had to change out of his church clothes, before having lunch (he did not want to get them dirty). When he came down for lunch after having changed, they told him he was too late to eat. Jon got mad. Two things critically important to Jon were being violated, his need to change into comfortable clothes, and his need to have a meal as he had planned.

In Jon's own home, he always changes his clothes when he comes home. He likes to put on his sweats and his power ranger tennis shoes. Jon eats his meals that he has planned when he has planned to eat them. He knows he can count on having people help to unlock his cupboards and refrigerator and to help him prepare his meals. These are all non-negotiables for Jon. These are all part of his essential lifestyle plan. Doing an essential lifestyle plan with Jon has let us get to know him and understand what is important to him. It has provided us with a framework for our relationship with him.

Standing with Jon means that we lock his cupboards and refrigerator, so he won't eat himself to death (this is a critical aspect of Prader Willi Syndrome). We help him keep his money in a locked box and we hide the key so he cannot get into it and spend all of his money on food. Providing this degree of control or supervision was not something we were comfortable with when we first met Jon. Standing with Jon requires that we provide this kind of support. Jon feels that we need to keep the cupboards locked because, as he puts it: "I don't have enough control."

Supporting Jon is also about trust. Jon knows that when he comes home, he can always change his clothes. He will be able to put on his sweats and power ranger tennis shoes and then have the support that he needs to eat the meal that he has planned. He will have someone there to unlock his cupboards and refrigerator and help him prepare meals.

I asked Jon to help me think about this idea of standing by him, the idea of trust. I told him I was struggling with how to explain it. He said he knows we won't "kick him out," and he said:

"You will never leave me or take my apartment away from me. You always come back the next day when I am in a bad mood. You never threaten to stop helping me or make me move. You don't think I am bad or a crazy person. When I am in a bad mood or having a bad day you don't threaten to stop helping me and make me move. You don't send people away to the state hospital. You think I can live on my own. You think I can do it."

Jon has a strong drive to help other people with PraderWilli syndrome get out of the state hospital. He says "it's not good for them there." He wants to let them know about how he is living in his own home so they will know it could happen for them. Jon tells others about this by sharing his plan. He is such a good speaker that after presenting at two conferences he has been asked to be a speaker at training sessions for other agencies and gets paid for doing it. Jon has said that this is what he wants to do. It is not clear that Jon will continue to make enough money to meet his financial needs but for now Jon's occupation is consultant.

Standing by Jon also means that we continue to listen and continue to figure out with Jon how to support him. When Jon speaks at a conference where lunch is served, dessert will arrive and dessert can have 50% of Jon's calories for the day. What Dawn (one of the people who supported Jon) learned is that once dessert is there it is too late. Jon will eat it and telling him no just makes matters worse. Dawn learned that if she talks with Jon before the meal is served, she can help him decide what to do. When presented with options such as: eat dessert and skip two snacks every day for a week; tell the banquet people not to serve it and eat nothing; or ask the server to bring you a cup of fruit instead Jon will pick the option that makes the most sense to him. Jon will arrange to be served a cup of chopped fruit. We have learned that Jon must have choices, he cannot be told no. However, when he has reasonable choices, he will make a choice that everyone agrees with as a wise choice.

Jon has taught us a lot about supporting people. Jon taught us that what he wants is no different from what the rest of us want. He wants:

- his own routines and control over them;
- to have the people who are important to him present in his life;
- to earn money doing things that he likes;
- to make his own contribution to society; and,
- to have the support he needs to stay healthy while he gets these things.

Jon taught us to listen to each person and how they want control to be shared. Standing with Jon is like dancing. Sometimes we step on each other's toes, but most of the time we hold hands and laugh together. We have to know when to lead and when to follow, and together we take new steps never taken before.