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Abstract

This brief article describes how a family held true to their values of home and family, and brought their son and daughter home from institutions. Support was provided by family, friends, the community and professional agencies. Challenges were seized, and a vision based on the value of "home" and "community" was developed. **Keyword: Families**

Every Moment Counts For Something

by Joe Wykowski

Joe Wykowski is the director of Community Vision, a Portland metro area agency that supports people with developmental disabilities in their own home. This is the first in a series of articles that will be submitted by the TASH Committee on Community Living.

In the fall of 1989, I became acquainted with the Bos family, whose belief - that regardless of illness or disability children belong at home with their families - was their focused strength. Feelings of both elation and panic surfaced as we prepared for Donald to move home after many years at a state institution. Donald was the second oldest of four children all of whom were living at home. Both Donald and Tammy, his older sister, had a rare neurological disease called "Battens Disease". Their parents had successfully fought an unsupportive system to bring their daughter Tammy home from a nursing home as her disease progressed to where she needed, and was given, intense medical care by the family. Tim, Donald's younger brother, also happened to be labelled developmentally disabled.

Early on, Donald focused on his move home by stating "If you move me to a group home I'll bust everything to pieces" - and no one doubted him. All of our support to the Bos family centred around a small team of people the family could trust that became extended family. As we supported the Bos family, they have supported and directed our vision as Donald's move home represented the beginning of our agency "Community Vision". Upon Donald's moving, what the Bos family needed the most, aside from staff time to take Donald out for activities, doctor appointments, etc., was support - in this case, support meant being there 24 hours a day, seven days a week when they have needed us - not every minute of the day, but when it was important to them. Sometimes support meant having a back-up person available to other staff when Donald would have a difficult day. Although this seemed to happen less and less as Donald became used to his home and us used to Donald.

On Christmas Day 1990, Donald's sister Tammy passed away. The realisation that Batten's Disease would someday also claim Donald's life was almost too much. From this point on I began to realise the struggle the Bos family had endured for so many years, yet they had still held true to their values of home and family. Helping plan for Tammy's funeral, I discovered that the Bos family, through their church and neighbourhood, had a lot more community built around them than I realised. The church community and neighbours pitched in and supported the family in ways that agencies alone will never be able to match in terms of friendship and community.

All of us have enjoyed our times at the YMCA, Mike's Drive Inn, fishing and listening to **Kenny Rogers** tapes! We have learned to listen more to what people tell us. Sometimes we learned after a few things got broken - it tends to get your attention and helps you to focus and communicate a little better - Donald has been good at that. We have learned that support means fixing toilets and

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seeing the humour in the situation, caused by mom's glasses getting stuck in the bowl accidentally. Or fixing the heater when it's broken, or that everyone needs a shoulder to cry on and a hug for support.

And we've learned about vision. Donald had felt that God would give him his eyesight back at some point, and I don't doubt that he's looking down on us today trying to reassure us to go forward, that he's doing just fine. I thank the Bos family for such wonderful lessons in hope and love, I thank Donald for providing the vision it takes to support people on a day-to-day basis, and for providing the impetus to create Community Vision.

On November 9, 1992, Batten's Disease finally claimed his body and Donald passed away. Through all the pain we have had to tell ourselves that although it has been a struggle, Donald died at home peacefully with his family the way he wanted to. In retrospect, Donald and his family have taught us much about love and support and nurturing relationships.

The vision that Donald brought us was to seize those challenges and cling to our values, even if we have to "bust things to pieces" sometimes to get people to focus on what home represents and how that it is different in all of our hearts. Donald and his family have taught us how precious life is and how every moment counts for something and should never be taken for granted. These days when I think about Donald and his wonderful family and their time together home, I hear the words of **John Lennon**: "Life is what's happening while we are busy making other plans."