Who Holds Your Story?

David Pitonyak

I hope, wherever you come from, there is someone who holds your story. Someone who remembers you when you were knee-high to a grasshopper. Where I come from — Montpelier, Vermont — there are people who hold my story. Maria Blakely, one of my mother's best friends, still calls me "Two Tot," a nickname I acquired when I was two and a tot.

At my mother's funeral, Maria came to me and held my face in her hands. "Your mother was a warm mother, Two Tot, and a warm mother will always go to the river first."

And then she told me this story:

One August morning, when I was less than two, still in diapers, my mother put me in the back yard with my older sisters so that she could have uninterrupted time to clean. Closing the gate firmly, she told them to "Watch the baby."

"Pick up, pick up, pick up" Maria said, still holding my face. "All a mother does is pick up, pick up, pick up."

In 10 minute intervals, my mother would return to the yard to make sure I was alright. If I understood Maria correctly, "alright" basically meant <u>no blood</u>. A mouth full of dirt, tears, a missing diaper — things so minor did not warrant my mother's intervention. Only blood in substantial quantities constituted a reason to stop this business of "picking up."

During one of these "checks," my mother discovered the "gate open" and her "baby gone." She shouted at my sisters who were oblivious to my disappearance, and neither one of them accepted responsibility. "It was Jani's turn to watch the baby!" Marsha screamed. "It was not!" Jani screamed back. My mother immediately turned from the yard and ran down our driveway

toward the street. From there, she ran immediately to the river, worried that I would get caught in the fast water. But I was not on my way to the river, I was heading in almost the opposite direction towards the Montpelier swimming pool where my two older brothers, Michael and Steven, were taking swimming lessons. With the family dog Brownie (a long-haired yellow dog), I wandered almost a mile up Elm Street before Betty Cody, outside watering her flowers, came to my rescue. She knew right away that I was a Pitonyak and called my mother. But my mother was not home, she was at the river, so Betty called the police who promised to send a squad car.

Maria held my face a little tighter and stared at me, her voice chocked with some funny mix of sadness and joy. "Two Tot" she said, "Your diaper was full of shit." She sent out a laugh that bounced off the ceilings of the church, her hands went into the sky like an evangelist praising Jesus at a revival. "You smelled horrible, Two Tot!" she cackled. "The policeman put you in the back seat of the car with the dog and the dog — the *dog*, Two Tot! — he jumped to the front seat! When the police car came to your house, the policeman had his head out the window and the dog — the *dog*, Two Tot! — he had his head out the window! You smelled horrible!"

I was laughing (and crying too) as Maria held my face. "The policeman picked you up from the front seat and handed you to your mother, Two Tot" she said. "She kissed you and cried. She was a warm mother, Two Tot. And a warm mother will <u>always</u> go to the river first." Gently, she slapped my face as if to warn, "Do not forget."

I hope, wherever you come from, there is someone who holds your story. Someone who remembers you when you were knee-high to a grasshopper. Being *known* is critical to our well-being. Having our stories held and told by others gives us a sense of place in the world, a sense of belonging, what Pema Chodron has called, "the good ground."

Reclaiming the Person's Story

A sad and all too common truth for people who experience developmental disabilities is that little, if anything, is known of their stories. Reams and reams of paperwork are generated each year, but only a fraction of what is generated describes the person's connection to the world. The file is instead a collection of things that the service system wants — a chronicling of interventions, evaluations, signatures, data points. There is no unfolding of things in these files, no character development, no plot. It all reads like the fine print on a cough medicine bottle. You won't find sisters arguing about a baby gone, or a family dog named Brownie. There is no river, no shit, no police, no police car. It is, after all, only <u>paperwork</u>.

When there are details about the person's story (e.g., in the social history section of the psychological evaluation) professionals do everything they can to make sure it is textbook sterile: "Delivery normal. Child failed to reach developmental

milestones. Problem behaviors began to emerge in special education classroom at the age of 7. Mother and father no longer able to care for child. Child institutionalized at age of 14. Mother visited every Sunday afternoon until she passed away in 1977." If lucky, there may be a photograph of the child holding someone's hand. We can see in the child's chin and eyes the adult's chin and eyes. We wonder whose hand he was holding. He stares blankly. No way to tell if he was happy or sad. We can only guess.

A person who has lost his/her story is at risk of being misunderstood and disrespected. Sandra Landis and Jack Pealer (1990), in their paper, *Personal Histories: Suggestions for Studying and Recording Them,* describe four important reasons for developing a person's story (p.5-6):

1. Spending some time on developing a personal history with a person will help us to make plans that will take advantage of the strengths and capacities the person has demonstrated in the past. There are bright spots in everyone's life (more in some lives than in others, of course), and part of our aim in planning is to figure out how to increase the number of such bright spots.

2. Working on a personal history will help us try to avoid the occurrence or repetition of experiences that would be damaging to the person. A good place to begin thinking about this is to study the kinds of experience patterns that are typical of people who have been rejected or otherwise systematically hurt by others… serious study and extensive reflection about the pattern of those hurts will help us to understand about things that have happened to someone that, if possible, we don't want to allow to happen again.

3. Many people with disabilities go through life "carrying" with them, as it were, a history that they had little hand in shaping or writing. The story of a person's experience that is often told in "case records" may be neither enhancing to the person nor accurate. Developing a personal history with the person whom we're trying to assist will help to assure that the person's own version of her/his story is heard. This can also mean that the person's own story can, then, be carried with him/her instead of or in addition to "case records", if the person moves to a new place or new program or when the "faces" (i.e., helpers) change, as they inevitably do.

4. Development of a personal history of someone whom we're helping will be a valuable learning experience for the writer and also for potential readers. Seldom would we volunteer to trade past situations with a person who has been labeled. As we learn more about these situations we recognize even more clearly the anguish that many people endure throughout a lifetime. We may recognize our own participation in the kind of anguish that some people experience. It is important to learn the story about "how things have been" with people so that our understanding about what really matters and our conviction about "how things could be" can be strengthened.

Strategy: Construct a timeline.

One of the most helpful things you can do is to construct a timeline of major events that have occurred throughout a person's life. Draw a straight line across a large piece of paper. On the far left hand side of the line, write the person's birth date. On the right hand side of the line, write today's date. Working backwards, indicate any major events — good and bad — for each year of

the person's life for which information is available. What professionals often find out when they construct a timeline is that a great deal is known about the person since he/she began to receive their service, but before that, there are huge gaps — periods of time in which little or nothing is known.

Imagine what it would be like if huge gaps existed in your story. Imagine if there were significant periods of time in your life in which no one had any recollection of you.

Strategy: Learn to tell the person's story in a way you would want your own story told

- A timeline can be a helpful way to begin organizing what you know and don't know about a person. Landis and Pealer (1990) offer a variety of ways for gathering and recording information, as well as for evaluating whether the story is well told (see pages 5-6).

Remember:

Ask the person for permission to construct a timeline first.
If the person is unable to grant you permission because he or she does not have a formal means of communication, ask anyway. It has been my experience that people often understand far more than people assume they understand.

Remember too that it can be extremely painful to discuss certain aspects of our story. If the person is uncomfortable talking about traumatic events, ask permission to glean the information from reports/files/interviews, etc.

Some Ways of Gathering and Recording Information

- Sandra Landis and Jack Pealer

- Encourage and help someone think about their own story. Then try to think of ways to "publish" the autobiography — on tape, in pictures, in words or stories. Add this to the other information you collect.

- Have conversations, interviews, or correspondence with people who are close to the person now or who have been in the past. Think like a journalist, and do some digging.

    - What ties these people together? How active or intimate a part of each other's lives are these people? What experiences have these people shared?
    - What does the informant know (and how well) about the life of the person? Especially, what experiences can the informant relate that are unknown to others (e.g., human services workers)?

- Read and otherwise review material compiled about the person by that person or by other people (e.g., official "case records"). You'll want to pay special attention to issues such as:

    - Where, and in what kind of places, have people lived?
    - Have people been separated or set apart from natural relationships and settings?
    - For how long or during which periods of their lives have people been set apart?
    - What did the person miss out on (or get more than his share of)?
    - What kind of image of the person is created by these materials?
    - What things about the person get the most attention?
    - What kinds of interests or capacities is the person portrayed as having?
    - How relevant (or irrelevant) is all this material to the person whom you know?
    - How current is the information?
    - How continuous is the information — are there gaps or periods of time with little or no information?
    - How and with whom have people spent their time? Have they been educated or undereducated? Have they been taught useful skills in helpful ways?
    - Has the person been helped to be a good decision-maker? Is she/he experienced in choosing, risking, succeeding, failing?

- There are other things to keep in mind as well as you review "official" records on a person.

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For example, as you review someone's file, try to find answers to these questions:

- How and why did this person come to be where she/he is?
- What, in particular, is happening to the person at this place?
- Are there major problems or issues that need to be addressed?
- What is the meaning/implication of any "diagnostic" labels? What past responses have there been to the various labels attached to the person? (This is especially important if the labels are ones that often have led to the exclusion of people).
- What have been the "solutions" proposed for the person in the past? How well have these solutions worked?

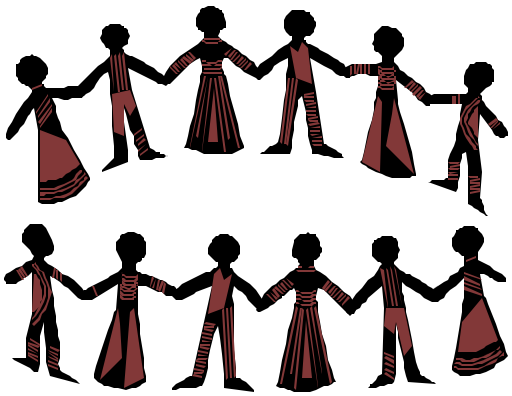
- Get involved in activities that assist you in making inferences and judgements about a person's pattern of life experiences. For example, you might consider:

  - If possible, come to know about the things a person saves, treasures, or regards as very important. Perhaps these are pictures, clippings, personal possessions, memories, places, people, songs.
  - Make a diagram of the important events of the person's life. Note the ups and downs, as they think about it, and, as others share their experience, add things you discover and regard as influential.
  - Help make a "picture" of people's relationship patterns. Graphically display who's close now and who has been close before. Where do people stand with the person? How many people are in the picture?
  - Reflect about events or situations in the past and their possible relationship to current attitudes, behaviors, and aspirations. Are there some situations that should be avoided at all cost? Are there some positive experiences and qualities about the person that should be safeguarded and strengthened at any cost?
  - Write down stories and images that simplify yet convey in ways that others might understand moments and events that portray the person or his experience. What are favorite holidays, pastimes, trips, foods, hopes, etc.?

- Histories can be recorded in many ways: in narrative summaries, either written or recorded on tape; through the use of charts or other graphics; in pictures with captions; in scrapbooks; or as journals, poems, or stories. The form the history takes is less important than the learning that comes to the "subject" and to the "historian" (and probably to others as well) from the process of assembling the history.

- The test for a good history is to ask whether it accomplishes these things:

  - Does it seem to portray a person's life experiences respectfully and honestly?
  - Does it provide an interesting introduction to the person?
  - Does it offer insight into the person's current interests, relationships, aspirations, and burdens?
  - Does it meet the standard the person who writes it would probably require for his/her own personal history?



Additional Ideas and Resources

- Sit down with the person, family and friends and look through old photographs. Photographs can dislodge forgotten memories and help people to remember important parts of the person's story.
- Help the person to tell his/her own story with words, photos, art, and or technology (consider using a Power Point presentation with photos, audio, music, etc.)
- Develop a scrap book with the person that includes photos and art and a narration that can be shared with others.
- If the person is shy or would prefer to have someone else tell the story, find someone who the person trusts — someone who will make a commitment to telling the story in a way that is respectful to the person and interesting.
- Find a local storytellers group and attend meetings with the person. Learn from and practice with people who know! For information about story-telling groups across the United States, check out Story Net at www.storynet.org.
- Check out books about storytelling, such as Moore's (1991) *Awakening the Hidden Storyteller from Within*, or (1999) *Creating a Family Storytelling Tradition;* Allison Cox and David Albert's ( ) *The Healing Heart: Storytelling to Encourage Caring and Healthy Families*; and Margaret Read MacDonald's (1993) *The Storyteller's Start-Up Book*.

References

Cox, A. & Albert, D. ( ). *The healing heart: Storytelling to encourage caring and healthy families.*

Landis, S. & Pealer, J. (1990) *Personal histories: Suggestions for studying and recording them.* Chillicothe, OH: Ohio Safeguards.

Moore, R. (1999). *Creating a family storytelling tradition*. Boston: Shambhala.

Moore, R. (1991). *Awakening the hidden storyteller within.* Boston: Shambhala.

Read-McDonald, M. (1993). *The storyteller's start-up book*.

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For contact information and additional resources, visit David's website: www.dimagine.com