

Documentation- Meaningful Writing in Rehabilitation and Disability Supports

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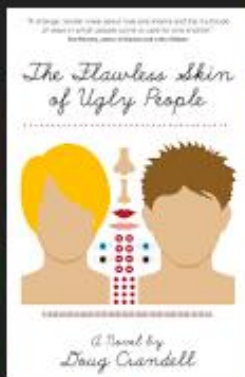
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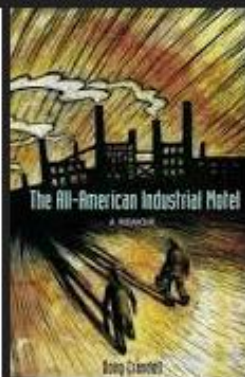
Doug Crandell / Books



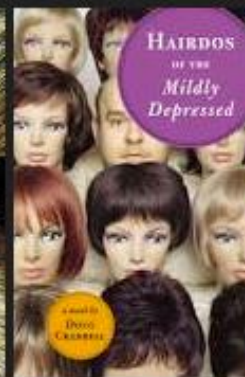
Pig Boy's Wicked Bird: A Memoir
2004



The Flawless Skin Of Ugly Pe...
2007



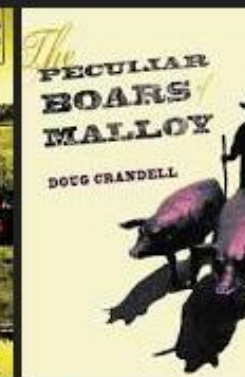
The All-American Industrial Motel: ...
2007



Hairdos of the Mildly Depressed
2008



Fear Came to Town: The Santa...
2009



The Peculiar Boars of Malloy
2010



They're Calling You Home
2012

In addition to my work in employment supports, I write books (memoirs, novels and true crime) focused on disability, mental health, and human services. You may win some of these if you participate today!

How to participate today:

- Chat pane
- Question pane
- Raise your hand
- Text me at: 770-896-5812
- Email at: crande@uga.edu
- Participate by doing the writing exercises!

Frameworks...

- I come to this work first as a sibling,
- Then a professional,
- Then as a writer.

I blend these points of view to arrive at a certain approach to documentation in our field, to writing, and as a method of “knowing” a specific person.

Knowing someone well requires understanding their personal narrative, not just their clinical documentation.

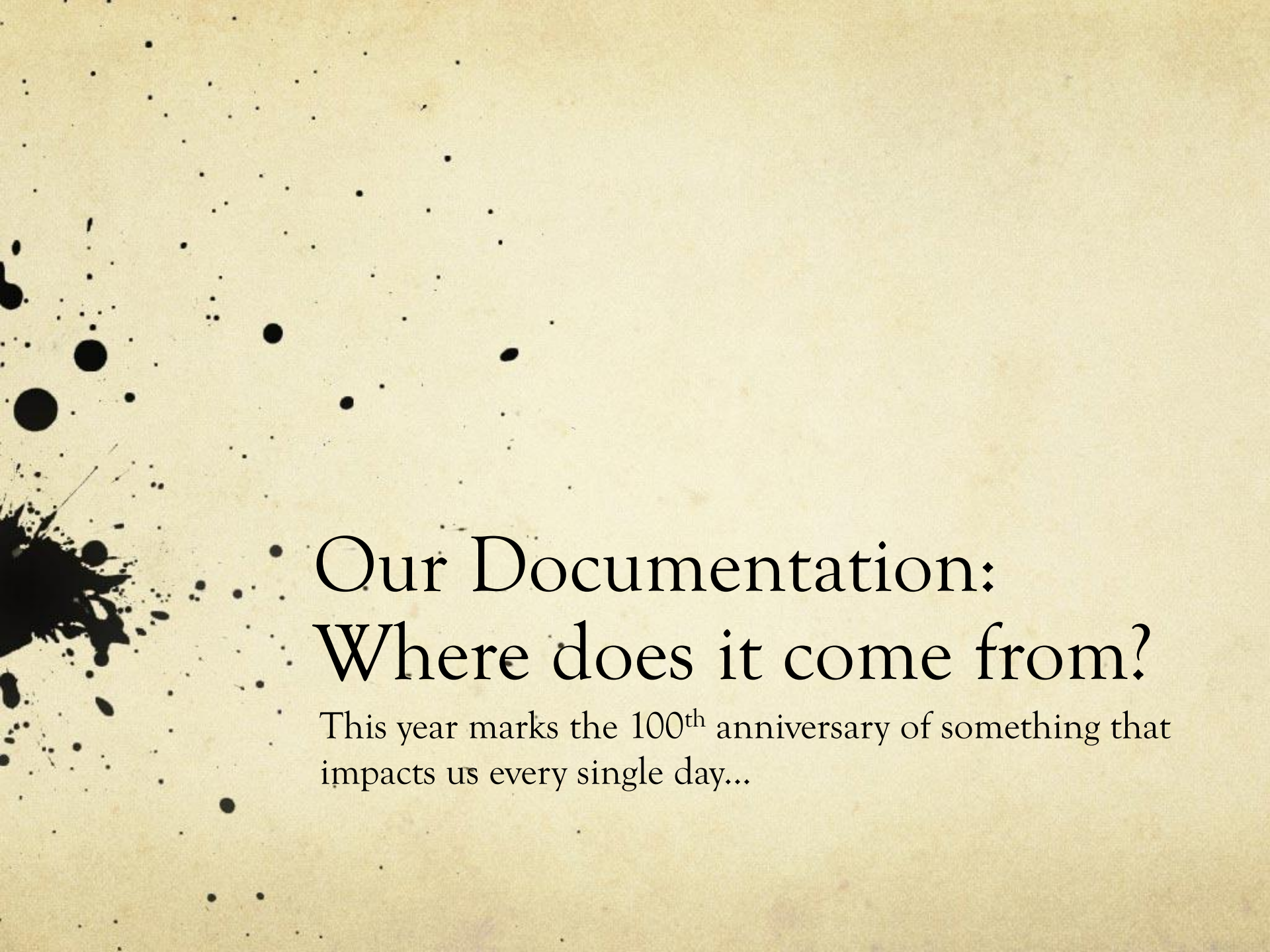
Narrative in our work:

- “The effective practice of human services requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others.”

Adapted from Narrative Medicine framework, Columbia University School of Professional Studies.

Why think about writing and words in general?

- The average person spends 11 hours per week responding to/writing emails. McKinsey Global Institute 2014
- Words and people are the two primary elements of most human activity.
- Most of us tend to write in one way, without thinking about our audience and/or purpose.
- We are reading less every year, and that makes us less able to write. (A Snapshot of Reading in America in 2015, Pew Research Center)
- Our social service systems are embedded in ameliorating problems, deficits, and weaknesses. Documentation becomes rote, and an exercise in repetition with little connection to outcomes.
- The transportation example: ride the non-existing bus through goals and objectives, included in the ISP for four years.



Our Documentation: Where does it come from?

This year marks the 100th anniversary of something that impacts us every single day...



Look familiar?

Nurses' Notes

NANDA Dx	Date & Time	Documentation
<u>2</u>	<u>3/21/11</u> <u>0800</u>	<p><u>(2) Mrs. GH alert, awake, and oriented to person and situation but is confused as to time and place. She is able to state her name and that she is in the hospital but states that it is afternoon and that she is in the long-term care facility. Was reoriented to time and place. (3) Skin, warm, dry, pale but without pallor or cyanosis. Bilateral arms have purpura but skin remains intact and without skin tears. No noted decubitus ulcers on coccyx, hips, or heels. Respirations regular and non-labored. (1) Lung sounds clear except for crackles noted in left lower lobe but improved when compared to earlier assessment. Encouraged to cough and deep breathe; crackles lessened after use of incentive spirometer, coughing, and deep breathing. Pulse ox on right index finger showing saturation of 96% on 2 liters O₂ by nasal cannula. Ears and nares checked and are clear of irritation from cannula. Heart rate regular. S₁ and S₂ apical heart sounds clearly heard. Peripheral pulses are +2 at radius and +1 at dorsalis pedis pulses. Equal hand grips; left pedal push is weaker but unchanged since admission. Per graphic flow sheet, voided clear amber urine at 0715. C/O abdominal pain of 7 on 0-10 pain scale. Abdomen firm, distended, and tender to slight touch. Bowel sounds hyperactive in RUQ and absent in remaining quadrants. States she does not know when she last had a bowel movement. No indication of BM on graphic flow sheet since admission. Refuses breakfast stating that she is nauseous. VS 148/92, 100.6° F, 114, 24. Charge RN notified of nausea, abdominal pain, and distention. -----E. Darwin, LVN</u></p>
<u>3</u>		
<u>1</u>		
<p><i>Note to student: For instructional purposes, the abnormal findings are put in bold here. Notice that any abnormal finding must include nursing intervention(s) that indicate what nursing actions address that problem/concern.</i></p> <p>NANDA Diagnoses are listed in the NANDA column and, for our example, within the nurses' notes.</p>		

The Medical Model in Disability Services and Supports

- It creates a system that views all supports and services through amelioration.
- Non-medical supports (employment, community access and inclusion, developing relationships, etc.) and their associated goals, must be delivered using medical documentation.
- This documentation mirrors medical charts.
- Everything should be documented! (How we train people impacts their work values.)

Training people entering our systems:

(From a state's orientation manual)

Documentation: General Rules (from a state's orientation manual)

- Make sure that the record is safe from loss or damage.
- Make sure that the individual's privacy is assured.
- Keep separate records for each person. Never mention the name of one person receiving services in the file of another
- The originals of all documents should be in the file.
- Photocopies and fax copies may be placed in the file if the original is not available.
- Use only black or dark blue ink (some programs use green and red ink to denote evening and night shifts) – no pencil, markers, colored pens, crayons, etc. Do not use liquid paper, erasable ink or correction tape. If you make an error, cross it out with a single line and initial over the line.

More documentation rules:

- Never make an entry for someone else or sign an entry for something that you did not perform or witness.
- If initials are used for any purpose, there must be a key or code in the record identifying those initials.
- Use only abbreviations approved by your agency. The instructor will give you a copy of them.
- Write the complete date (month, day and year) for all entries.
- Include the time (including AM or PM) that the entry is made.
- Make entries only after the fact – i.e., after the treatment, task, or activity has been completed or after an observation has been made.
- Make sure entries are legible.
- Sign using your full name and title.

Going Narratively!

Specific Requirements for Narrative Notes

- The following guidelines apply specifically to narrative entries you make in daily charting such as progress notes, health notes, etc.
- A complete chronological history of any situation is documented. You should always write so that someone who does not know the person and who was not present will easily understand. Your information will be complete if you answer the following questions:
 - Who?
 - What?
 - When?
 - Where?
 - How?
 - Why?

Going Narratively Some More!

- Do not leave blank lines or spaces when writing progress note entries. Use the full line in progress notes – draw a line from the end of your entry to the right margin if you need less than the full line for writing.
- Keep entries in chronological order.
- Sign all entries with your first name or initial, your full last name, and your title.
- Make entries comprehensive and complete. Include all important information so that someone with no knowledge of you or the person can understand the situation without having to ask for clarification.

Some quick information!

- For every hour spent with patients, physicians spend 2 hours on electronic health records (EHR) and desk work, according to an *Annals of Internal Medicine* study.
- A new survey (*ITHealthNews*) of hospital nurses found that they estimate spending one quarter of their 12-hour shift on indirect patient care, with paperwork taking up much of the rest of their time.
- Our services and supports have ALWAYS tried to mirror medicine!
- Direct Support Professionals during exit interviews often list “paperwork requirements” as a part of their job that is overwhelming. (Provider surveys, 2015)
- Some studies show that even with the advent of mobile devices, the human service field is spending more time rather than less on documentation. (NYTimes, 2014)

Documentation is here to stay:

- We shouldn't think we can somehow sidestep this important function.
- Funding is tied to outcomes, which is a good thing, and proof is required.
- We can always improve what we write in terms of goals and objectives.
- Where and how does documentation become narrative writing?
- Where and how can true narrative support outcomes?

Quick and Fun Exercise:

(There are prizes for your participation!)

- Think of a person you are supporting in some way...
- Change their first name, don't use a last one.
- Take a few minutes to write something about them that is absurdly in "human-service-speak." Don't forget acronyms!
- Let's hear some!

Quick and Fun Exercise #2

- Think of the same person...
- Now, write several sentences focused on the person's most endearing traits.
- Notice how you are reacting to this (difficult? Or is it easier to write about good things, without our human service language?)
- How often do you get to do this in your daily work?
- Why?
- Let's hear some!
- Returning to Narrative Medicine and the Parallel Chart.

Writing that is deficit-based is at odds with inclusion:

- Functional Limitations.
- Gaps in accomplishing activities of daily living.
- Labels and diagnoses are clinically described to qualify for services.
- Funding is rooted in fixing something (behavior, traits, learning, coping, working, functioning etc.).
- While this type of writing is necessary for funding and services, it doesn't translate well to "person-centeredness" or "strengths-based" supports and services.

The Writing Audit:

- Where do I spend most of my writing time during a typical week?
- What is the purpose of this writing?
- Why am I doing this writing?
- What are the rules that apply? Formal or informal? Are these rules useful in the writing I'm doing?
- Is there an editor on my shoulder? What is its name?
- What outcome (intermediate and long-term) does this writing serve to support?

The #1 Question:

What is the purpose of the writing?

- To qualify for services, maintain funding, treatment? (VR, waiver supports, treatment).
- To create a work plan, ISP, IEP, or other formal human services plan.

After the services determination is made, what type of writing is necessary to arrive at an outcome?

Am I purposefully switching from “deficit-based” to person-centered narratives, or am I dragging the negative into what is to be positive and strengths-based?

Understanding the “Deficits System” and the impacts on:

- Person-centeredness.
- Focusing on strengths.
- Moving from problems to contributions.
- In other words, we are asked to view a person in the most negative way to qualify for services, then switch to a holistic, contributive role for that person, building on gifts, positive traits, possibilities and situations/factors that will help the person thrive. However, we don't consciously make the switch.
- We are not the only field that is attempting to challenge narratives and services...

Person-Centered Planning in other Disciplines

- Patient-Centered Healthcare
- Recovery-Oriented Mental Health Treatment
- Narrative Medicine (Dr. Rita Charon)
- Narrative Mental Health
- Person-Centered Secondary Education and Transition

Writing, “Knowing” the Job Seeker, and Creating a Discovery Narrative



The insidious power of calling things by the wrong name!

Words matter...

1. Creating a Discovery Profile requires **action** not just talk and conversation.
2. **Different environments** produce varied information, and opportunities to explore preferences.
3. Other people know a person **differently than we do**.
4. Being person-centered in Discovery planning requires an understanding of **the power of roles**.

Awareness of Traditional Roles in Career Planning

- Buildings and offices are not neutral places; they signify the professional fortress and can extinguish obtaining good information.
- A desk, and which side you sit on, immediately creates a dominant role. We believe in these situations there are right answers.
- Holding a form, making notes, and flipping pages reminds us of school, the doctor's office, and other spaces where we are not in control.
- Asking “yes” and “no” questions can seem procedural, legal and further establishes power differentials.

Remedies

- When possible, spend time with the job seeker in their home. Visit the neighborhood, go where they go. Accompany the person to faith-based activities, join in during regular chores, family routines, and daily schedules.
- Strive to first initiate and then sustain an on-going conversation. Repeated contact develops social capital, as does the absence of pressure.
- When possible, talk with others close to the job seeker. Friends, siblings, neighbors, educational personnel and others. (Of course, get permission first. The person chooses who is involved). This may be the only information you can obtain with a job seeker who doesn't communicate well or at all.
- Photo albums, cards, videos, and other assorted documents can act as ways to jumpstart the employment discussion. Big surprise: These things are usually in the person's living space, not in our offices!

More about how not to use the Discovery Profile

- It isn't a good idea to use the Discovery profile form as a **questionnaire**. In other words, we don't recommend sitting with a client and asking question after question while you fill in the answers. You could ask if it is all right to take a few notes while the person is talking, but try to spend most of the **conversation** making eye contact and allowing the conversation to flow in a natural way. Remember, one of the goals of working on the profile is to **develop a relationship**. Also remember that you don't have to fill out the entire profile in one meeting. In most cases, you will want to spend two or three meetings getting to know the person and gathering information that can be added to the profile.
Excerpted from Supported Employment: Applying the Individual Placement and Support (IPS) Model to Help Clients Compete in the Workforce. Hazelden, 2011.

Ideal Conditions of Employment (ICsE)

- Knowing the ICsE is directly connected to time spent with the person and writing about the experiences.
- Writing about these conditions actually helps us know the person better (Charon reading).



Using a person-centered narrative to determine Ideal Conditions of Employment

- What must be present? (Or not?) **Write it out.**
- What should the work culture be? (Consider it all!) **Write it out.**
- What are the top three most important elements that need to be present for success? **Write it out.**
- Consider natural supports first, not as an after-placement issue. **Write it out.**
- For the focus person to celebrate one year on the job, who will need to be the strongest supporter? (Think past the immediate supporter, and make it specific to the person!) **Write it out!**

Turning experience into a narrative...

- Most people struggle with taking what they've observed and listened to and forming the information into a narrative document.
- Think of sentences and paragraphs, not one word answers.
- Use description, anecdotes, and narrative threads to create a living, breathing document that captures a job seeker's ideal conditions of employment.
- Honor life experiences, preferences, and other people's insights to generate a Discovery Profile that captures a life rather than a form that gets filled in.

QUICK REFERENCE GUIDE FOR EFFECTIVE WRITING

- Write notes immediately after the contact. Don't edit.
- Read the notes aloud shortly after the contact.
- State information but also use description.
- Edit out any unnecessary words, but make the document “alive.”
- Consider a *parallel chart* (more on this in a bit) to bolster what has been learned in Discovery
- Share with the focus person/family, other team members (I do this during CE Team meetings and with permission)

Record observations, do not make judgments, and avoid use of labels.

EXAMPLES:

Sara separated the whites from the colored clothes, put the white clothes in the washer, measured a quarter cup of detergent and poured the soap into the machine, set the washer dial for whites, closed the lid and pressed the start button. (observation or judgment?)

Sara is competent in washing clothes. (observation or judgment?)

Fred does not want to work. (observation or judgment?)

Fred was not home when I arrived to pick him up for the scheduled meeting with the owner of Auto Zone. (observation or judgment)

Use Respectful, People First Language that is neutral or positive and strengths-based.

- National Center on Disability and Journalism is publishing a list in conjunction with an [updated style guide](#) intended for journalists and members of the general public who are seeking the appropriate and accurate language to use when writing or talking about people living with disabilities.
- What is considered acceptable language regarding disabilities has changed dramatically over time, and standards continue to adapt as understanding and perceptions evolve. Many of the terms below were once widely used and were not always considered offensive, but now are widely considered to imply inferiority or have other negative connotations. Others are outdated medical or colloquial term.
- This is a great resource for local reporters, agency newsletters, staff responsible for writing progress notes, vocational profiles and other human service writing.

Creating a Discovery Profile

- The job seeker and team should have an opportunity to review the draft Discovery profile.
- Sensitive portions (interpersonal skills, substance use, family problems, incarcerations) of the Discovery profile should only be shared per the job seeker's approval.
- The bulk of the Discovery Profile should reflect **ideal conditions of employment, strengths, interests, support needs and preferences**. There's already a plethora of negative information.

Descriptive writing

- In the most essential aspect, you are capturing a portion of a person's life, so the writing must be personal and individualized. Each profile should read as a distinctly different, individualized document. Sadly, most sound very similar.
- Language and words direct actions. Does what you've written propel the person toward employment or put up more barriers?
- After creating the Discovery Profile, do you know the person better? Can you clearly link the information to specific job development activities?
- Does the information read well? Or is it in human service speak, and lack concrete details, settings, experiences, and real-life nuances?

Our own Discovery Profile

- How would you like to be engaged in this process if you were the person of focus?
- What parts of yourself would you rather not include?
- We get jobs based on strengths and skills, not the things we aren't good at, yet our traditional vocational systems tend to emphasize the negative. This is a chance to do the opposite.
- A Discovery Profile is a **document**, a **process** and a **map** that will create an employment outcome. If it doesn't, why do it?
- Does it avoid stereotypes? (An example...)

Part II: Tuning it up: Editing, and re-writing for clarity.

- Who is the audience?
- Is it written in that specific audience's vernacular?
- Are the desired outcomes related to the writing?
- What to leave in, what to leave out? (Yes, Bob Seger!)
- Reading aloud for clarity.
- Transporting text to traditional and/or visual resumes.

Audience and How to Write

Assessments for Eligibility

(limitations, impact of disability, diagnosis, metrics related to mental health)

Examples: “IQ, problem behaviors, daily living tasks, developmental narration”

Person-Centered Plans for Employment and Inclusion

(contributions, endearing traits, preferences, dreams and plans for the future, friends, home, love)

Examples: “language is based in strengths, and focuses on environment, and relationships”

Waiver Charts:

Diagnosis, portable, symptoms/issues, daily notes, goals, repetitive

On-going Disability Reviews

(purpose is to keep services, healthcare, SSI/SSDI)

Examples: “What is the long-term impact of disability, how are supports needed to ameliorate the condition?”

Behavioral Support Plans

(what is being communicated? what are the needs and wants being expressed)

Examples: “Functional behavior, what is the person trying to say?”

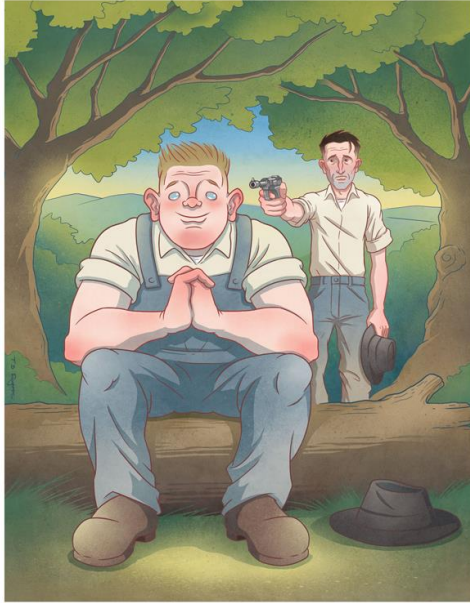
Reading Aloud for Editing

- Make sure the room is quiet and confidential.
- If possible, record the reading.
- Read as if reading prose.
- Listen for parts that are clunky, repetitive and aren't smooth.
- Don't stop to edit. (you can do that later)
- If recorded, listen to the playback, make notes on the document.
- Repeat!

Fine Tuning

- How often does the person's first name appear?
- Choose a random paragraph and determine if it's 90/10 regarding strengths to deficits.
- What parts of the text can be used in job development?
(Endearing traits)
- Do I have at least some quoted comments?
- Note if the writing reflects multiple environments
- How much of what is written is taken from other sources?
- How much is new writing based on new experiences?
- Does the writing create stereotypes or lessen them?

Templates of Deficit, Stereotypes and the *Other*



Being Aware of How we are impacted by stereotypes!

“...crystallized into plots that act as a readily available, pre-formed narrative skeleton easily brought to bear on stories, master plots **bestow legitimacy** upon beliefs, practices, institutions, and identities.” Andreea Ritivoi

A Repeated Template of Deficit: From *Of Mice and Men* to Inanity in Portrayal



Acting on a template of deficit...

The problem with replicating templates of deficit, is that the portrayal often becomes more and more exaggerated.



The ripple effect...

More exaggeration and less and less individualized character traits ripple inside and outside the original creation, insinuating themselves into other characters presumed to be similar.



Looney Tunes and The Abominable Snow Rabbit



"I will name him George, and I will hug him, and pet him, and squeeze him"

Golden Globe and Emmy for Mickey Rooney, 1981, reportedly talked about Lennie as an inspiration for Bill's character.



Teaching *Of Mice and Men*...

“I've **chosen** this picture because throughout the book Lennie has been the moronic one . So I wouldn't say this is offensive to the character but this is how I see him.” Tyanni S.: student (business major) and blogger



The point is, a template of deficit is cemented:

- A character with an intellectual disability that is suspected of a wrongdoing will be better off dead. Stephen King's *The Green Mile* is nearly identical. Similar to Lennie, John Coffey is portrayed as large, unintelligent, and innocent at heart. In both stories, mice fall into their care and Lennie and John Coffey are executed in what is considered the most compassionate manner.
- Not a month goes by where I don't hear someone described as "Rain Man," "Lennie," or some other visible character in books, TV, or movies. "People with Down Syndrome are very loving and like to hug." "He doesn't know his own strength."

Awareness Avoids Templates of Deficit

- **Heroically Courageous** (Physical Disabilities)
- **Death is Dignity** (“Brain-dead” and Physical Disabilities)
- **Crazy and Violent** (Mental Illnesses)
- **Sexually Deviant** (Intellectual Disability, Traumatic Brain Injuries, Autism, Dementia)
- **Eternal Child** (Intellectual Disability)
- **Extraordinary Sensory Abilities** (Deafness and Blindness)
- **Perpetually Affectionate** (Intellectual Disability)
- **Soothsayer** (Mental Illnesses, most often Native-American)
- **Admirable for Overcoming Everyday Adversities** (Physical Disabilities)
- **Pitiful Lives** (All Disabilities)
- **Parents sinned** (Intellectual Disability)
- **Holy Innocent/Affectionate** (Down Syndrome)
- **Two different personalities** (Bi-polar)

Parallel Chart

- It's basically an opportunity for the physician to tell a patient's story through the patient's eyes. It's an opportunity for the caregiver to reflect on their emotions about a particular experience that really had an impact on them. Parallel charting is becoming pretty popular across the country and now many medical schools and residency programs are incorporating it into their curriculums.
- "In the beginning it was difficult for me to write a narrative about a patient experience without delving into the medical aspect of what was occurring, but it's a great way to really get a lot off of your chest about a troubling situation that you may have never had the opportunity to talk to anyone about in a judgement-free environment. I love the direction that medicine is moving in currently, and hope that it continues to move in this more humanistic direction." Kris, medical student, 2015.

How we're using it in our human services world:

- Pilot with Employment Specialists and VR Counselors
- Sessions are six-weeks, facilitated, and confidential. No actual names are used.
- Participants are encouraged to read from their work (memoir, fiction, poetry, journals).
- The group provides feedback on the experience and the writing and how the process is impacting their professional work (clinical, vocational, job seeker engagement).
- Follow-up at 3, 6 and 9 months. Basic data is collected about the ES and VR Counselor related to practice and effectiveness.
<http://medhum.med.nyu.edu/blog/?p=535>

Some sources

<http://ncdj.org>

National Center on Disability and Journalism @ The Walter Cronkite School of Journalism and Mass Communication at Arizona State University.

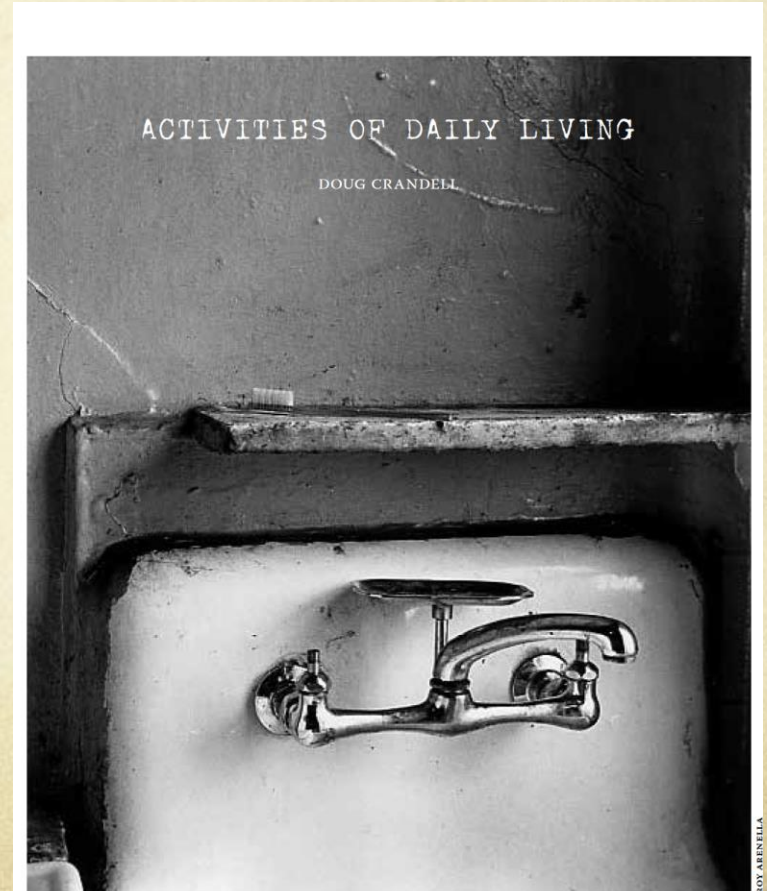
www.massgeneral.org

Mental Health and the Media at Mass General Hospital

- The mission of the Center for Mental Health and Media is to de-stigmatize mental illness, comfort and educate families about optimal development, and to change the public's outdated and inaccurate perceptions of the nature, causes and treatment of mental illness.

Creative Writing and Our Work

- http://thesunmagazine.org/issues/491/activities_of_daily_living



Resources

- <http://sites.dartmouth.edu/ips/>
- <http://www.griffinhammis.com/>
- <http://www.narrativemedicine.org/>
- <http://www.pacer.org/>
- <http://ncdj.org/>
- <http://thesunmagazine.org/>
- crande@uga.edu