The Disclosure Conundrum

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Outline

- The environment
  - Legal & social context for disclosure

- The worker with SMI
  - Disclosure as a rational choice

- The employer & co-workers
  - Workplace culture

- The evidence
  - Impact of disclosure of a schizophrenia diagnosis
Legal and social context

THE ENVIRONMENT
Don’t Ask, Don’t Tell

Scenario:

You have a client with a diagnosis of schizoaffective disorder, whose symptoms are in remission. The client is applying for a competitive job at a private firm. A question on the job application asks:

Have you ever been diagnosed with a chronic physical or mental health condition?

What is the best answer?

• Yes
• No
• It is illegal to ask me that
The legal context

- Americans with Disabilities Act of 1990 (ADA)
  - *Employers* are prohibited from asking about disabling health conditions on job applications
  - *Workers* who can perform the essential functions of a job have the right to reasonable accommodations, so long as the accommodations do not impose undue hardship on the employer
  - In order to receive job accommodations, *workers* must disclose their disability to their employer
The social context

- Mental disabilities differ from physical/sensory disabilities in important ways
  - Mental disabilities are generally *less visible* than physical/sensory disabilities → mental disabilities can be *concealed*
  - Mental disabilities are subject to *greater stigma* than physical/sensory disabilities → disclosure carries *real risks*

Hence, the disclosure conundrum ....
Disclosure as a Rational Choice

THE WORKER WITH SMI
Rational choice model of disclosure

Assumption:
Persons with SMI who are capable of working in competitive jobs are rational economic agents

Competitive job
- Open to anyone with or without a disability
- Paying at least the minimum wage
- Not associated with supported employment/job coach

Rational economic agent
- Has a set of well-ordered preferences
- Capable of making decisions in his/her own best interest
Workers’ objectives: acceptance

- What is a worker with SMI seeking in the workplace?
  - Wages, benefits, hours, workplace amenities
  - Acceptance
    - More acceptance is preferred to less
    - Up to the point of full acceptance, where the worker is treated just like any other employee

“I want to work, and I want to fit in, and I want to be normal. I don’t want people staring at me like I’m a zombie or something from the zoo. I don’t want to be stared at like I’m different just because I have bipolar.”
Acceptance continuum

- Acceptance in the workplace can be viewed as a continuum
  - No acceptance – “I don’t want this person in my work place”
  - Full acceptance – the worker with SMI is treated “just like any other worker”

<table>
<thead>
<tr>
<th>No acceptance</th>
<th>Full acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Stigma, harassment</td>
<td>Sympathy, support</td>
</tr>
<tr>
<td>Social isolation</td>
<td>Job accommodations</td>
</tr>
</tbody>
</table>

You're Fired.
Workers’ objectives: disclosure

- Disclosure can also be a valuable commodity for workers with SMI
  - To request employer-provided job accommodations
  - To relieve the stress of keeping a secret

- But, more disclosure is not always preferred to less –
  - Most workers with SMI prefer to keep some aspects of their illness private

“I feel I would be happier [to disclose] because I could really be myself and not have to work so hard to make sure nobody notices that maybe I’m a little bit stressed or tired.”

“If I feel forced to disclose] I’ll be angry that I had to reveal the most intimate part of myself to people I would not want to do that with.”
Disclosure continuum

- Because SMI is concealable, workers can control
  - *When to disclose*
  - *To whom*
  - *How much to disclose*

**Selective disclosure**

<table>
<thead>
<tr>
<th>0</th>
<th>No disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Full disclosure</td>
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</tbody>
</table>
Selective disclosure

When?
- The general consensus is that disclosing SMI before you are hired is a mistake

How much?
- Many workers say they disclose ‘laundered diagnoses’ such as metabolic disorder or exhaustion syndrome

“You wouldn’t get taken on in the first place if you told them you had a big mental history [before you were hired].”

“I mean, you can talk about well, perhaps a depression or something but if you say ‘psychosis’ – God forbid!”
Workplace culture

THE EMPLOYER AND CO-WORKERS
Tradeoff between disclosure and acceptance

- Workers with SMI can choose how much they reveal about their illness to employers and/or co-workers, because mental disorders are largely concealable.

- Once the worker chooses a level of disclosure, the degree to which they are accepted depends on the culture of the workplace.

“I don’t want to tell anybody, because people who aren’t ill, they do have a tendency sometimes to treat you different. They’ll start teasing you or they’ll shy away from you.”
Workplace culture I

The workplace culture determines the penalty, or “price” a worker pays for more disclosure.

“…if anybody at work or my professional body knew that I’d got schizoAnything. I wouldn’t be allowed to practice.”
There is no penalty for disclosure, but the worker’s preferred level of disclosure may still be \textit{less than full}.

The worker’s preferred level of disclosure yields full acceptance.

<table>
<thead>
<tr>
<th>Acceptance</th>
<th>Disclosure</th>
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</thead>
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<tr>
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</tr>
<tr>
<td>1</td>
<td>1</td>
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</table>
A worker who prefers less disclosure may be better off working at a more discriminatory firm!!!

THE EVIDENCE
Data

- Survey of 258 people over age 18
- With diagnosis of schizophrenia, schizoaffective disorder, other schizophrenia spectrum disorder

Demographics
- 38% currently employed
- 55% female, 78% Caucasian
- 37% college graduates, but 65% have incomes <$35,000/ year

Survey asked
- To whom participants had disclosed their diagnosis, and how open they had been
- Whether the response was positive, negative, or neutral, and specific consequences of disclosure
Disclosure

Participants were asked to rate how open they had been about disclosing their diagnosis of SMI within various relationships:

- 1 – not at all open
- 2 - somewhat open
- 3 – quite open
- 4 – completely open

- Participants were most open with their doctors/spouse
- Only ‘somewhat open’ with employers/co-workers
- Least open with the neighbors
Table 2: Openness scores by type of relationship

<table>
<thead>
<tr>
<th>Type of Relationship</th>
<th>Mean score</th>
<th>SD</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Parents</td>
<td>3.3</td>
<td>1.0</td>
<td>239</td>
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<tr>
<td>Extended family</td>
<td>2.6</td>
<td>1.1</td>
<td>251</td>
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<tr>
<td>Spouse/significant other</td>
<td>3.4</td>
<td>1.0</td>
<td>153</td>
</tr>
<tr>
<td>Children</td>
<td>2.3</td>
<td>1.3</td>
<td>146</td>
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<tr>
<td>Friends</td>
<td>2.7</td>
<td>1.0</td>
<td>254</td>
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<tr>
<td>Coworkers</td>
<td>2.1</td>
<td>1.1</td>
<td>178</td>
</tr>
<tr>
<td>Employer</td>
<td>2.2</td>
<td>1.2</td>
<td>177</td>
</tr>
<tr>
<td>Place of worship</td>
<td>2.0</td>
<td>1.1</td>
<td>177</td>
</tr>
<tr>
<td>Neighbors</td>
<td>1.7</td>
<td>0.9</td>
<td>248</td>
</tr>
<tr>
<td>Doctors</td>
<td>3.6</td>
<td>0.7</td>
<td>256</td>
</tr>
<tr>
<td>Law enforcement</td>
<td>2.0</td>
<td>1.1</td>
<td>183</td>
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<tr>
<td>Overall mean score</td>
<td>2.6</td>
<td>0.7</td>
<td>258</td>
</tr>
</tbody>
</table>

Source: Pandya, et.al., p. 615.
Disclosure

% At Least Somewhat Open

- Doctors / health care
  - All People Living with Schizophrenia: 97%
  - Males Living with Schizophrenia: 98%
  - Females Living with Schizophrenia: 96%

- Parents
  - All People Living with Schizophrenia: 86%
  - Males Living with Schizophrenia: 82%
  - Females Living with Schizophrenia: 91%

- Friends
  - All People Living with Schizophrenia: 86%
  - Males Living with Schizophrenia: 86%
  - Females Living with Schizophrenia: 85%

- Extended Family
  - All People Living with Schizophrenia: 78%
  - Males Living with Schizophrenia: 73%
  - Females Living with Schizophrenia: 64%

- Spouse / Significant other
  - All People Living with Schizophrenia: 48%
  - Males Living with Schizophrenia: 55%
  - Females Living with Schizophrenia: 73%

- Neighbors
  - All People Living with Schizophrenia: 40%
  - Males Living with Schizophrenia: 39%
  - Females Living with Schizophrenia: 41%

- Coworkers
  - All People Living with Schizophrenia: 40%
  - Males Living with Schizophrenia: 45%
  - Females Living with Schizophrenia: 36%

- Employer
  - All People Living with Schizophrenia: 39%
  - Males Living with Schizophrenia: 48%
  - Females Living with Schizophrenia: 32%

- People at your place of worship
  - All People Living with Schizophrenia: 39%
  - Males Living with Schizophrenia: 44%
  - Females Living with Schizophrenia: 39%

- Police officers / corrections
  - All People Living with Schizophrenia: 36%
  - Males Living with Schizophrenia: 50%
  - Females Living with Schizophrenia: 25%

- Children
  - All People Living with Schizophrenia: 33%
  - Males Living with Schizophrenia: 37%
  - Females Living with Schizophrenia: 28%

Source: Pandya, et.al., p. 616.
Responses to disclosure

- Positive
  - Encouraged my recovery (49%)
  - Confided in me about their challenges (34%)
  - Showed admiration for me (26%)
  - Took an interest in my condition (24%)

- Negative
  - Avoided the topic of my illness (43%)
  - Treated me as though I lack intelligence (34%)
  - Made negative comments about schizophrenia (23%)
  - Dropped me as a friend (22%)
  - Appeared confused/embarrassed (21%)
  - Was afraid to be left alone with me (14%)

*Note:* # in ( ) are percent of participants reporting the response ‘always’ or ‘often’
Responses to disclosure

Source: Pandya, et.al., p. 617.
What can we learn?

- Disclosure of SMI in the workplace is influenced by:
  - The need for employer-provided job accommodations
  - The worker’s preferences for privacy vs. openness
  - The workplace culture (the tradeoff between disclosure & acceptance)

- Concerns about negative responses to disclosure are justified:
  - Selective disclosure is possible
  - Workers with SMI differ as to their preferred level of disclosure
  - Some accommodations can be initiated by the worker, without the need for disclosure
Postscript

“Passing” [Erving Goffman Stigma]

- The choice not to disclose a discreditable stigma, so as to “pass” as normal
- One who “passes” creates a false identity for themselves, which can lead to both practical and psychological problems
- Individual is torn between two attachments: their real identity with the stigmatized group vs. the normal group from whom they seek acceptance

[When my co-workers were making disparaging remarks about people with mental illness] … for a split second I sort of thought well I could roll my sleeves up and say “You mean someone crazy like me?” Because that always shocks people and they say “Oh well you don’t look like one of them.” It’s like, what am I meant to look like?
The book

Each day, millions of mentally ill people face stigma, low expectations, and outdated practices that keep them in menial jobs, demoralized, and dependent on government support—although they are capable of so much more. It doesn’t have to be this way.

“I’m not sure what has protected David from stigma and kept his self esteem intact. He tells me he held on to five words that his psychiatrist said to him as he was about to be discharged from the first hospital stay: ‘You can recover from this.’”