

Stigma in Relationship Contexts: Implications for Behavioral Health Research

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Goffman (1963)

- “...the *individual who is related through the social structure to a stigmatized individual* – a relationship that leads the wider society to treat both individuals in some respects as one. Thus the *loyal spouse* of the mental patient, the *daughter* of the ex-con, the *parent* of the cripple, the *friend* of the blind, the *family* of the hangman, are all obliged to *share some of the discredit* of the stigmatized person to whom they are related... The *problems faced by stigmatized persons spread out in waves*, but of diminishing intensity.” p. 30



Symposia Overview

- Stigma Constructs
 - Associative stigma
 - Relationship stigma
- Stigmas
 - Substance use disorder
 - Autism spectrum disorder
 - Gender identity
 - Sexual orientation
 - Race/ethnicity
- Relationship Types
 - Parent-child
 - Romantic
- Methods
 - Qualitative
 - Quantitative

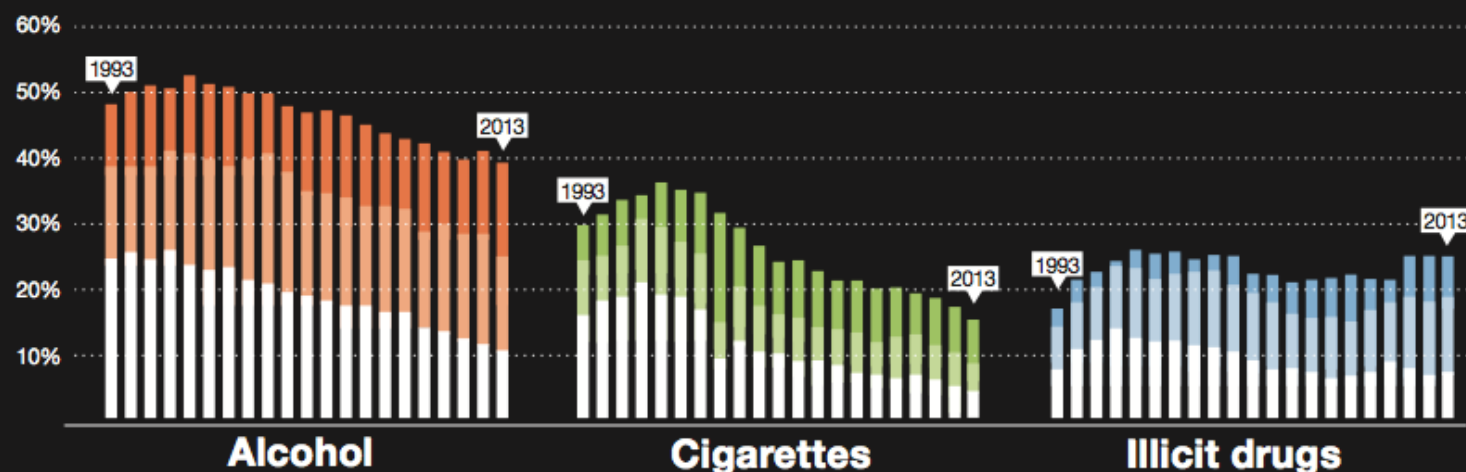
Stigma and Substance Misuse: Perspectives of Young People in Treatment and their Caregivers

Valerie A Earnshaw, PhD
Society of Behavioral Medicine
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Monitoring the Future Study¹

LAST TWO DECADES OF ALCOHOL, CIGARETTE, AND ILLICIT DRUG USE*

*Past 30 day use.



2013



39.2% OF 12TH GRADERS



25.7% OF 10TH GRADERS



10.2% OF 8TH GRADERS



16.3% OF 12TH GRADERS



9.1% OF 10TH GRADERS



4.5% OF 8TH GRADERS



25.5% OF 12TH GRADERS



19.4% OF 10TH GRADERS



8.5% OF 8TH GRADERS

¹ NIDA (2014)



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Substance Use Disorders

- Prevalence among youth¹
 - 8% alcohol use disorder
 - 2-3% illicit drug use disorder
- Recurrent use → significant impairment²
 - E.g., health problems; disability; failure to meet major responsibilities at school, home, or work
 - Defined as mild, moderate, or severe

¹ Merikangas & McClair (2012); ²American Psychiatric Association (2013)

Substance Use Disorders

- Adolescent SUD → lifetime poor health^{1,2}
 - Continued substance misuse, respiratory problems, neurobehavioral + cognitive conditions, cardiovascular symptoms, hepatitis, HIV/STIs
- Treatments demonstrate modest success rates^{3,4}
 - Younger age linked to increased drop-out risk
 - ~32% (14-47%) sustained abstinence 12 months post-treatment
 - Slightly better rates if family involved

¹ Malow et al. (2001); ²Stein (1999); ³Williams & Chang (2000), ⁴Brorson et al. (2013)

Stigma Experienced by Youth

- SUD Stigma
 - Social devaluation and discrediting due to SUD
- Stigma Mechanisms¹
 - Enacted: Experiences of discrimination in past or present
 - Anticipated: Expectations of discrimination in future
 - Internalized: Endorsement of prejudice, stereotypes
- Barrier to treatment success, recovery¹⁻³
 - ↓ Engagement, adherence, retention
 - ↑ Substance use

¹ Earnshaw et al. (2013), ²Livingston et al. (2012), ³Katz et al (2013)

Stigma Experienced by Parents

- Associative SUD Stigma
 - Social devaluation and discrediting due to *relationship* with child
- Stigma Mechanisms¹
 - Enacted: Experiences of discrimination in past or present
 - Anticipated: Expectations of discrimination in future
 - Internalized: Endorsement of prejudice, stereotypes
- Barrier to treatment success, recovery
 - ↓ Engagement, adherence, retention
 - ↓ Social support

¹ Earnshaw et al. (2013)

Qualitative Study



Participants

Characteristic	Patient (n = 19)	Caregiver (n = 15)
Age, M (SD), range	18.63 (2.95), 13-25	44.20 (8.80), 36-67
Gender, % (n)		
Female	42.10 (8)	86.70 (13)
Male	57.90 (11)	13.30 (2)
Race/Ethnicity, % (n)*		
White	84.21 (16)	100 (15)
Black	15.79 (3)	0
Native American	10.53 (2)	0

**Note:* several participants identified with more than one race/ethnicity

Codebook

- **Substance and Treatment Experiences**
 - Experiences of substance use
 - Goals and reasons for TX
 - Barriers to TX
 - Facilitators of TX
- **Intrapersonal Processes**
 - Benefit finding
 - Negative self-perceptions
 - Positive self-perceptions
- **Interpersonal Processes**
 - Disclosure of SUD or SUD TX
 - Stigmatizing treatment from others: enacted, anticipated
 - Supportive treatment from others
 - Effect of SUD on parent-child relationship
 - Attitudes toward, perceptions of others who use SUs

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Data Analysis

- Independently coded interviews
- Established inter-rater reliability
 - Substance and Treatment Experiences (Kappa = 0.84)
 - Interpersonal Processes (Kappa = 0.89)
 - Intrapersonal Processes (Kappa = 0.90)
- Continued coding

Results: Enacted Stigma

PATIENT

*People who don't understand drugs, they **really treat you differently**. Like when I go to a **family event**, like during Christmas, it's the most **awkward** thing in the world because **they don't understand** that you're still a normal person, you just have a problem.*

*I have **lost friends** that way that are like "That's like you're a heroin addict. That's disgusting."*

*Why? Because **drug addicts have a very bad rep**, because we did bad things, but because in everyday life drug addicts **are portrayed as bad people**, not like people doing bad things but as bad people...That's what they think of and that's where their brain goes to.*



Results: Enacted Stigma

*So in that elementary school group of parents... an old friend of his who **used to be very friendly** in the dog park and talkative and stuff and **now kind of walks quickly past**... maybe my dog offended them, but I don't think so.*

*She was actually **calling people and talking**, like random friends of her, and just for no other reason than to tell them that [my son] had gone to recovery. And sort of like the **town crier**.*

*I attached the discharge summary, and on it it said in capital letters... **"STOP TAKING DRUGS BECAUSE THEY WILL KILL YOU OR HURT OTHERS."** And I burst into tears and laughter when I read that... but there were **no referral** to other services, there was **no understanding** that this was not an isolated event. This was a long term serious problem that had now almost killed her, and **I was sent out with that piece of paper telling her to stop using drugs.***

Results: Anticipated Stigma

PATIENT

They would think less of me and I was weak and stuff, and that I couldn't be trusted... they think it's a moral failing... it's just like an embarrassment, I guess. Like one of the biggest things in my life is fear of embarrassment. I hate that feeling.

I didn't want to get help because I was scared of what people were going to think in high school... And so that is probably why I didn't even ask for help, because you're very scared about being judged and you know especially in high school that people are going to talk.

I find with like dating I don't really date at all, because I don't like to date other drug addicts, and any sane person wouldn't date someone who is in treatment.

Results: Anticipated Stigma

*I think there could be **some ostracism if people were aware**... I think a lot of people don't stop to think about the bigger picture when they're judging, and that goes for whatever people have a prejudice about.*

*I am **nervous that I'll be judged**, like I didn't do something, or **did something wrong** to make him that way.*

*There is definitely a concern. So, I mean he is a passionate, committed fly fisherman who wants to be a fly fishing guide, and **does not want it to be common knowledge** in his fly fishing network that he has been a drug user or in treatment, and is **concerned about that**.*

Results: Internalized Stigma

PATIENT

*I'll give you a couple of titles that I would, looking at the addict me... **Hot mess**, complete hot mess. I slept around a lot and most of the people I slept with was I would have sex with them for free drugs, **so whore, kind of a prostitute**. **Nasty, honesty nasty**... Yeah, just **nothing positive**. You know, **junkie**, that's one that should have come to my mind immediately, junkie... Just, I don't know, kind of like **a destroyer**, I guess.*

*I felt like it was, that **addiction was like a moral failing** kind of thing, that I was a **bad person** for it, not that I have a disease and that it's way out of my control... I just **wanted to fit in** and no one goes to rehab in high school, so that's not really fitting in.*

*The **guilt and shame** is probably the biggest thing with all of this... I literally **wanted to die**.*

Results: Internalized Stigma

*I just felt like **it was my fault** and I didn't know what **I had done to him** to have him do this... I was really thin for many years because **I literally couldn't eat**.*

*It is possible to think of yourself as both the **worst mother in the world** and the **best mother in the world** simultaneously. Part of my head does believe... that **if it weren't for me [my daughter] might be dead** and my other two kids wouldn't be much better. And I can believe that, part of me. And then there is part of me that says I must be the worst mother in the universe, because **look at all the problems my kids are having**. And I can feel that simultaneously. And some days one is weighing heavier than the other, but I always feel both of those things.*

Discussion



Conclusions

- Caregivers' experiences of associative stigma
 - From others: social rejection, gossip, judgment
 - Internalized: bad parents, at fault
- Concern for children's experiences of stigma
- Potential to undermine treatment
 - Concealment
 - Stress
- Future directions
 - Quantitative, longitudinal
 - Parents of youth with SUDs, not in treatment

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Thank you! Questions?



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Tips for Protecting Your Kids from **Addiction**

Get More Information

If you suspect your child is having a problem with prescription opioids or heroin, call the **MA Substance Abuse Information and Education Helpline** for free and confidential information about substance abuse, education and counseling resources for adolescents, families and adults.

We are facing an epidemic of opioid addiction and overdose deaths in Massachusetts.

STOP
Addiction
IN ITS TRACKS

Some people who are addicted may even transition to heroin, which is less expensive and widely available.

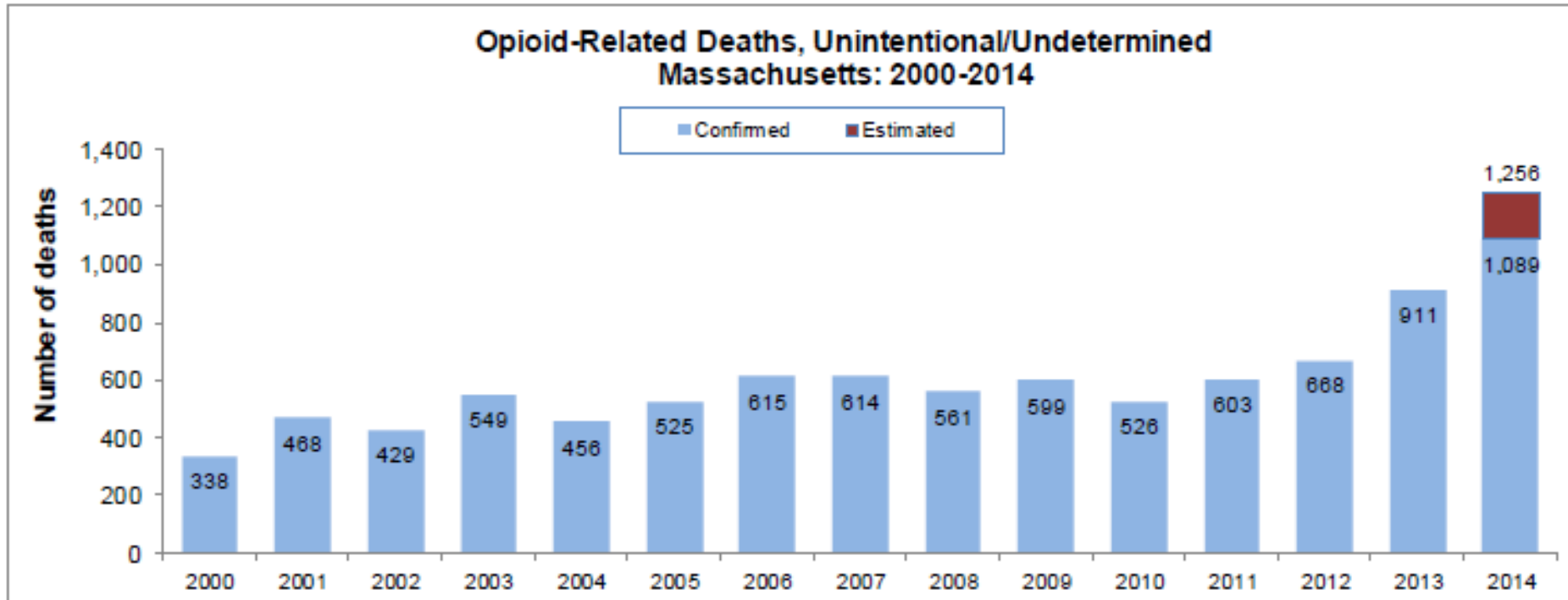


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Opioid-Related Deaths in MA



Disclosure Process Model

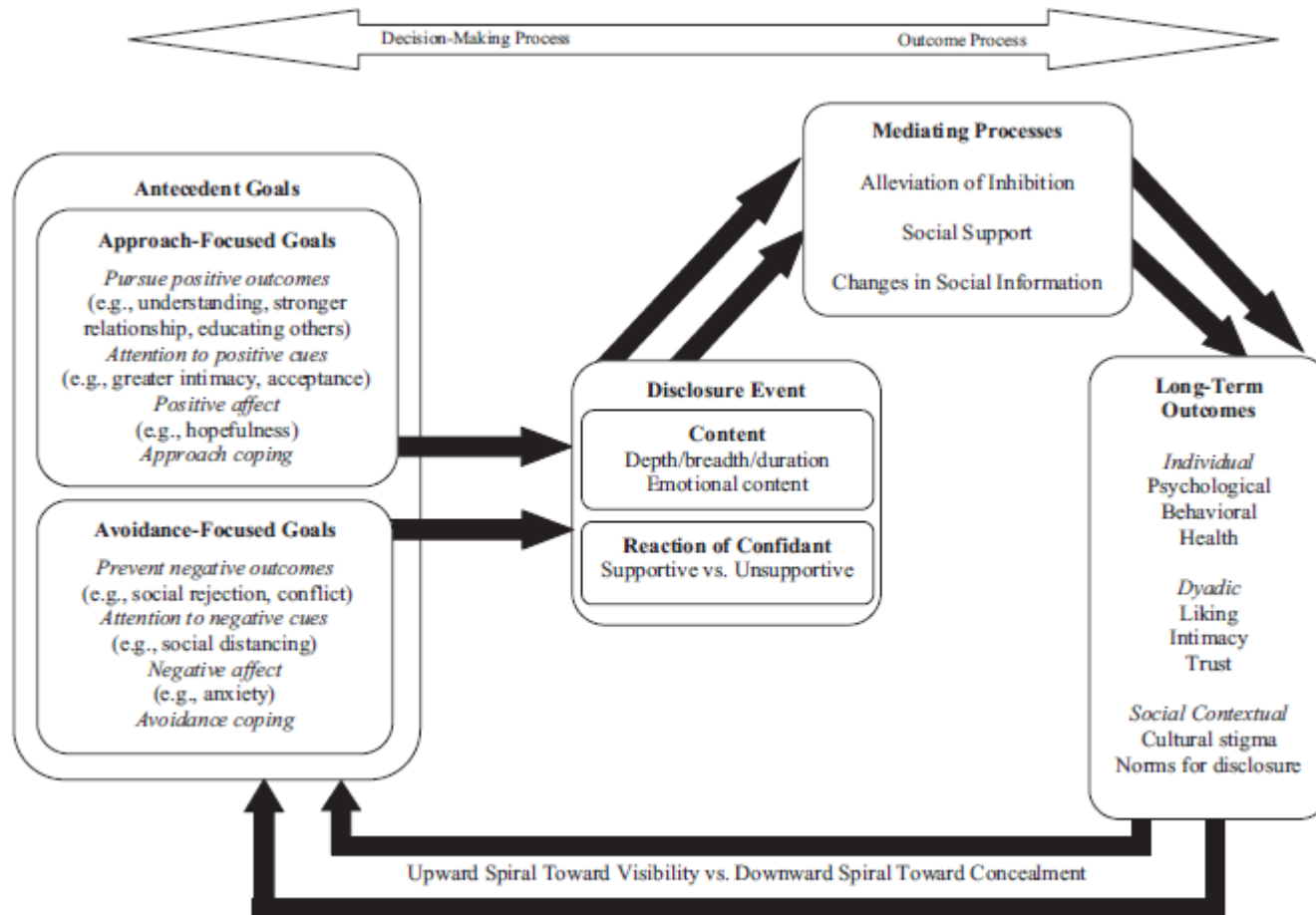


Figure 1. Diagram of the disclosure processes model.

¹ Chaudoir & Fisher (2010)

Results: Disclosure

Who knows?

PATIENT

*I can't think of **somebody who doesn't** (know).*

***Everybody** knows that is close to me.*

*My mom and dad are the **only ones** that I know for sure.*

*I have like that reputation, that image of that outgoing person, but I feel like a lot of it's hidden. The **alcohol issue is hidden**, only to certain people, but not to others.*

*The **Principal and the Vice Principal** are the only people who knew. I don't think that my teachers know.*

*I always decided to tell them, because it's the safest way to go. Honesty is always the best option.... So, I mean during **interviews** I would tell them, and they usually didn't call me back.*



CAREGIVER

Results: Disclosure Who knows?

*Pretty much everybody... . So I learned from early on mental health or substance abuse, they're **not something to be ashamed of**, they're something to get help for.*

*Yes. **Everyone except my mother**, his grandmother. We kept her completely in the dark.*

*My sister, a couple friends. But for the most part I have **not been advertising it**... There is somewhat of a stigma that goes on with it, for better or worse.*

*I did talk to **his guidance counselor** to fill her in... I needed someone to know what was going on at school. So, she knows.*

Results: Disclosure

How did they find out (or not)?

PATIENT

I told them (friends) when I got back from inpatient stuff.

I think my parents told them (aunts and uncles).

Whoever else my mom has told... Probably her friends in AA, or Al-Anon, and maybe some of her relatives.

I don't feel like my brother and sister need to know, and I think my parents are just kind of respecting that, and not telling my brother and sister.

CAREGIVER

Results: Disclosure

How did they find out (or not)?

He has told people.

*Again, **we have sort of told people** as they needed to know, because she was disappearing and she wasn't at family functions and we sort of told people.*

*Periodically, like we have a party or something or you go to a family party, and like everybody in her immediate uncles and aunts and cousins, they all know, but **she says, "I don't want to tell."** What are Jamie's parents going to think?" ... **I say, "They don't need to know anything."***

Results: Disclosure

How do you feel about them knowing?

PATIENT

*At the beginning, like the first time, I felt really **embarrassed** kind of. After it set in, like during when it was happening I **didn't care** at all, but eventually I felt kind of embarrassed, because it's not something a 17, 18 year old should be doing with their lives.*

*It **doesn't bother me**. They can think what they want.*

*I would kind of feel **happier**, because the name he called me ("addict") wouldn't be valid anymore and I could tell him that I'm getting better.*

CAREGIVER

Results: Disclosure

How do you feel about them knowing?

Fine. I think she is another resource for support.

*I feel **good** about it. I think **it was important for us** to have their support going through this... one is the former head of a psychiatric hospital and another one is a Wilderness therapist down in Hawaii, so they were very helpful talking with them, and another one had two adopted sons who have been through the whole thing too.*

*I think it would be more **my concern for how he was feeling** than for me as how I was feeling, because again I kind of feel like if you don't like it too bad feeling. I'm doing what's right. So, I try to tell him to live by that, but **he is a fragile 15 year old kid**, so obviously other people's opinions matter a lot more at that point in your life.*

Results: Social Support

*My dad worked at a heroin rehab house, so he is, I feel very confident in **enlisting them** and knowing and as a **resource** as well.*

*And so I think that that is the major message is, and that is another reason not to be hiding it a lot for people is that we're **all part of the human family** and everybody has got something. And a lot of people have this something. And so you almost **don't feel as alone** if you tell somebody and they say, "Oh yeah, this happened to my—"*

*I think I told my friends so that they could **comfort** me, and tell me I'm doing a good job, because I feel like when [Name]'s nervous, I'm nervous. I carry my own, and then I carry his, so it **feels good to talk to a friend**, and they're very good to me, like saying that I'm doing the right thing, **saying what I want to hear**.*

CAREGIVER

Results: Social Support

PATIENT

*And when I told her, she ended up bringing all my group of friends together, and was like, “Hey, [Name] has this problem, he is going through some tough shit right now, and he just needs to not be around alcohol right now.” So, **my friends completely changed their lifestyles, almost, to really benefit me, and we haven’t gone to parties** this summer; we’ve been just hanging out at different friends’ houses, going on adventures, hiking mountains, doing stuff like that.*

And it’s been for the most part an alcohol-free summer...** And they’re just really supported me in that aspect of keeping me away from it, and really making my life a lot easier, like **if I had a group of friends that was, like, “Hey, let’s go to a party,” I wouldn’t have to be like, “No, I can’t hang out with you guys tonight.”

*So, I was hoping that between here, and his other therapist that he originally started seeing for anxiety, and depression, and things, would help **give him the tools to come clean with his friends**, because at this age your friends are everything, but I want him to go to a party, and **have his friends not want to take him to a party that has alcohol.***



Disclosure Decision Aid

- Shared decision making in pediatrics
 - Engage patients, parents, + clinicians in partnerships to make medical decisions, supported by evidence and aligned with patient's values, preferences, goals¹
 - Few pediatric aids target patient-parent dyad²
- Decision aid applied to disclosure³
 - Mental health in workplace
 - Reduced decisional conflict, increased job retention

¹ Charles, Gafni, & Whelan (1997); ²Wyatt et al. (2015); ³Henderson et al. (2013)

Disclosure Decision Aid

- Complete with social worker, as pair, or independently
- Worksheet, eventually available online¹
- Content:²
 - What are the benefits and costs of disclosure?
 - What are the goals for disclosure?
 - When to tell?
 - How to tell? (Resources for building communication skills)
 - How does my child/parent feel about disclosure?

¹ AHRQ Effective Health Care Program; ²Henderson et al. (2013)

Example Decision Aid: Cholesterol

3. There are options for treating high cholesterol. Circle options you want to talk about. Your clinician may circle some too.

TREATMENT OPTIONS	Frequently Asked Questions			
	What are some reasons to choose this option?	What are some reasons <u>not</u> to choose this option?	What do I have to do?	How long do I need to make changes?
No treatments at this time	It is easy to make no changes at this time.	For many, higher chance of having a problem.	No changes to what you are doing now. Your clinician may request a follow-up visit.	No changes are being made.
Diet & Exercise	If you made changes, you could lower your chance of having a problem.	It might be hard to make these changes. Diet & exercise might not be enough to reach target cholesterol.	Change diet: limit high fat foods, reduce calories. Exercise at least 30 minutes most days.	Until target level is reached, and possibly longer.
Medicine (Statins)	Taking medicine can help lower your cholesterol and lower your chance of having a problem.	Statins can cause side effects including: muscle pain, fatigue, and liver problems.	Take medicine every day. Get regular blood tests to check cholesterol levels and liver function.	Until target level is reached, and possibly longer.
Other Options (please write in)				



Next Steps

Develop

- Focus groups with patients, caregivers
- Discussion with community stakeholders

Pilot

- Randomize 30 pairs to aid vs. control
- Evaluate feasibility, preliminary effectiveness

Evaluate

- Immediate outcomes: clear goals, perspective-taking, communication skills
- Distal outcomes: social support, treatment success