SUBSTANCE USE AND ADOLESCENT CONFIDENTIALITY:

BALANCING AUTONOMY AND WELL-BEING

JACK RUSLEY, MD, MHS

AMERICAN ACADEMY OF PEDIATRICS, RHODE ISLAND CHAPTER

ADOLESCENT SUBSTANCE USE AND CONFIDENTIALITY MEETING

MAY 30, 2019

DISCLAIMERS AND DISCLOSURES

- I have no conflicts of interests to disclose
- I am:
  - representing myself, not my employer or my affiliated institutions
  - not a lawyer, so please do not construe my statements as legal advice!

A BIT ABOUT ME

- Adolescent medicine physician
  - Hasbro Children's Hospital, Brown University
  - Primary care, specialty care (advanced contraception, menstrual disorders, etc)
- Adolescent health researcher
  - Sexual and reproductive health
  - HIV prevention, especially PrEP
  - Patient centered medical home
  - Technology, EHR

- Brown University
  - BA Education History and Policy, 2003
  - MD 2010
- Maine Medical Center/Tufts
  - Med-Peds Residency, 2014
- Johns Hopkins University
  - Master of Health Science, 2016
  - Adolescent medicine fellowship, 2017

OBJECTIVES

- Name 3 strategies for protecting confidentiality for adolescents
- Understand how explanations of benefits (EOBs) can violate privacy
- Name 3 strategies for engaging parents/guardians as partners in providing high quality health care to adolescents

CASE: GIOVANNI, 17 YEAR OLD BOY

- Well visit
- States to clinician that he's ready to get treatment for a substance use disorder
- Doesn't want to disappoint parents
- Is Giovanni allowed to get outpatient counseling for substance use without a parent's consent?

AHI, 2018

IMPORTANT DEFINITIONS

- **CONSENT**
  - Permission to act
  - Parent/guardian must give consent before their minor child can receive services (except specific confidential services)
- **CONFIDENTIALITY**
  - How providers and staff keep certain information confidential

- Consent ≠ Confidentiality

AHI, 2018

PARENTS AS PARTNERS

1. Parents/guardians can have a valuable role in their adolescent's experience as an independent health care consumer.
2. Adolescents are developing their autonomy and decision-making abilities
3. AYA often want their parents involved in health-related decisions
4. Parents/guardians are experiencing their own adjustment to their child's adolescence.
5. We have an opportunity to educate parents about the value of confidentiality in the provider-patient encounter.

Adapted from AHI, 2017

AND SOMETIMES:

- …parents do not make decisions that are in the best interests of their children
- …AYA have the capacity to make decisions without their parents
- …there is a conflict between the priorities of AYA and their parent
- …AYA may have impaired capacity to make decisions due to intrinsic (i.e. intellectual disability) or extrinsic (i.e. addiction) factors
- **These conflicts can create barriers to AYA accessing appropriate health care services**

Duffy, 2016

PUTTING IT INTO PRACTICE

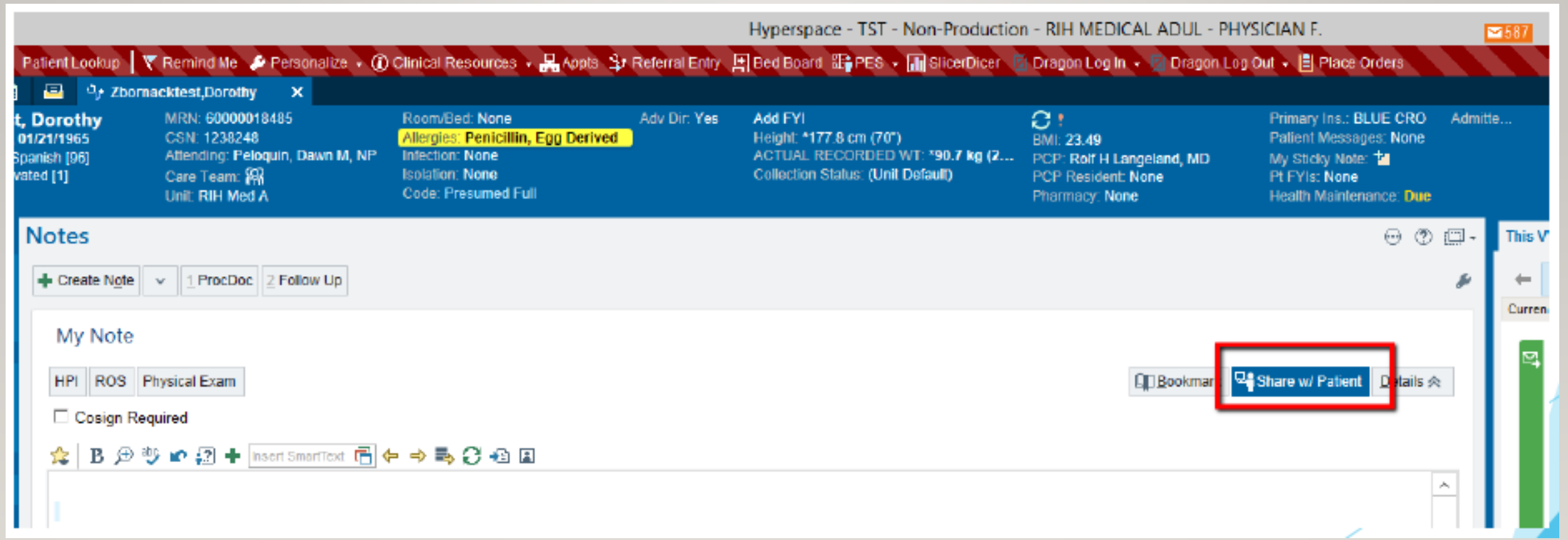
- Is your practice structured to let parents and patients know about the boundaries of confidentiality?
- How do you decide that an adolescent is capable of making good/safe decisions around substance use?
- What's your procedure for engaging parents in discussions with reluctant adolescents?
- When do you violate confidentiality?
- How do you navigate the EHR to protect confidentiality (i.e. Open Notes, requests for records, patient portals)?

STRATEGIES – PRACTICE LEVEL

1. Obtain a cell number for all teen patients and standardize systems for calling teens and young adults with test results, etc.
2. Standardize time alone for all adolescent patients with the provider
3. Use a workflow that allows for confidential completion of risk screening tools
4. Consider universal chlamydia/STI screening
5. Keep an updated list of referral resources, especially Title X funded programs
6. Train all staff and providers on practices, policies, and legal protections and limitations
7. Convey an environment of confidentiality (i.e. privacy screens at check-in, white noise machines)

STRATEGIES – PROVIDER LEVEL

1. Include parents in conversations about confidentiality, including reasons for alone time and limits of confidentiality
2. Start all visits with a brief statement about confidentiality, and include parents if possible
3. Counsel all adolescent patients on the protections and limitations of laws
4. Provide referral information for free or sliding scale clinics to adolescent patients who don't want to use their parent/guardian's insurance.
5. Consider "unsharing" notes to patient portal (i.e. OpenNotes) about sensitive topics

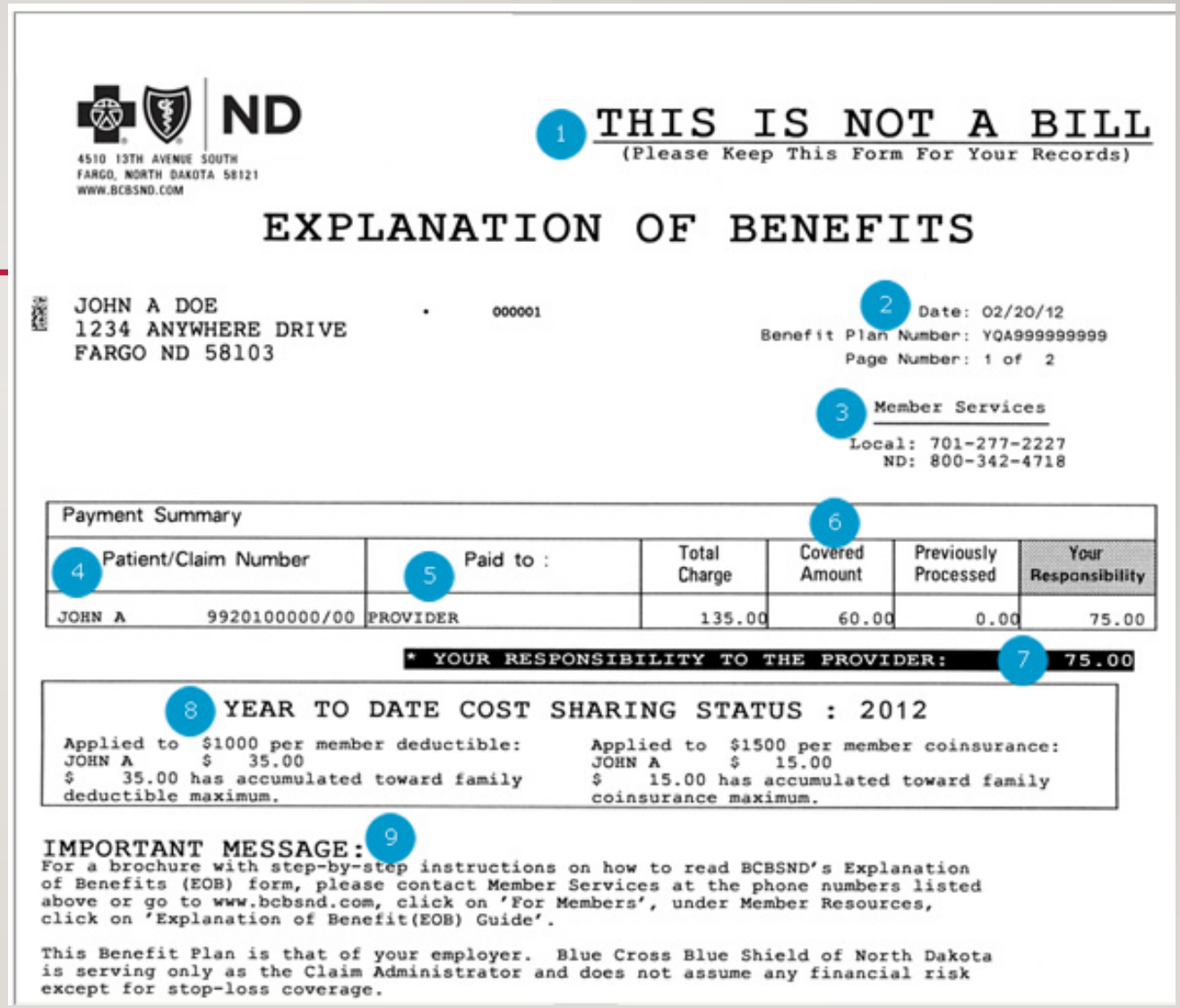

Hyperspace - TST - Non-Production - RIH MEDICAL ADUL - PHYSICIAN F.
587
Patient Lookup
Remind Me
Personalize
Clinical Resources
Appts
Referral Entry
Bed Board
PES
SlicerDicer
Dragon Log In
Dragon Log Out
Place Orders
Zbornacktest,Dorothy
t, Dorothy
01/21/1965
Spanish [96]
vated [1]
MRN: 60000018485
CSN: 1238248
Attending: Peloquin, Dawn M, NP
Care Team:
Unit: RIH Med A
Room/Bed: None
Allergies: Penicillin, Egg Derived
Infection: None
Isolation: None
Code: Presumed Full
Adv Dir: Yes
Add FYI
Height: *177.8 cm (70")
ACTUAL RECORDED WT: *90.7 kg (2...
Collection Status: (Unit Default)
BMI: 23.49
PCP: Rolf H Langeland, MD
PCP Resident: None
Pharmacy: None
Primary Ins.: BLUE CRO
Patient Messages: None
My Sticky Note:
Pt FYIs: None
Health Maintenance: Due
Admitte...
Notes
Create Note
1 ProcDoc
2 Follow Up
My Note
HPI
ROS
Physical Exam
Cosign Required
Insert SmartText
Bookmar
Share w/ Patient
Details
This V
Curren

SOME SCRIPTS

- "As teens begin to develop into adults and take responsibility for their lives, we always ask parents/guardians to wait outside for part of the visit to encourage the teen to discuss their own view of their health."
- "Everything you tell us in this office is confidential, which means I cannot tell your parents without your permission. The exceptions to that rule are if someone is hurting you, you are hurting yourself, or your health is at risk."
- "Your parent can request access to your medical record, but we will always review the request with you and your parent in person before providing them with any records."
- "If you have chosen to have your parent be a "proxy" on your patient portal, they may see the notes we write about our conversations. If you don't want them to see these notes, you can remove them as a proxy."
- "If you are on your parent's insurance plan, they may get a letter in the mail from the company about this visit called Explanation of Benefits (EOB) that may include information about the visit."

WHAT IS AN EOB?

- Explanation of benefits
- Sent by insurance companies to policyholder
- Inform about claims made, actions taken
- Any insured dependent is included (i.e. spouse, minor child, adult child)



ND

4510 13TH AVENUE SOUTH
FARGO, NORTH DAKOTA 58121
WWW.BCBSND.COM

1 THIS IS NOT A BILL
(Please Keep This Form For Your Records)

EXPLANATION OF BENEFITS

JOHN A DOE
1234 ANYWHERE DRIVE
FARGO ND 58103

000001

2 Date: 02/20/12
Benefit Plan Number: YQA999999999
Page Number: 1 of 2

3 Member Services
Local: 701-277-2227
ND: 800-342-4718

Payment Summary

4 Patient/Claim Number	5 Paid to :	Total Charge	6 Covered Amount	Previously Processed	Your Responsibility
JOHN A 9920100000/00	PROVIDER	135.00	60.00	0.00	75.00

* YOUR RESPONSIBILITY TO THE PROVIDER: 7 75.00

8 YEAR TO DATE COST SHARING STATUS : 2012

Applied to $1000 per member deductible:
JOHN A $ 35.00
$ 35.00 has accumulated toward family deductible maximum.

Applied to $1500 per member coinsurance:
JOHN A $ 15.00
$ 15.00 has accumulated toward family coinsurance maximum.

IMPORTANT MESSAGE: 9
For a brochure with step-by-step instructions on how to read BCBSND's Explanation of Benefits (EOB) form, please contact Member Services at the phone numbers listed above or go to www.bcbsnd.com, click on 'For Members', under Member Resources, click on 'Explanation of Benefit(EOB) Guide'.

This Benefit Plan is that of your employer. Blue Cross Blue Shield of North Dakota is serving only as the Claim Administrator and does not assume any financial risk except for stop-loss coverage.

EOB – THE PERILS

- Sensitive health information may be disclosed without person's knowledge or consent
- Concerned patients may seek uncompensated care, straining the safety net
- **Adolescents and young adults** may delay or defer **testing and treatment of sensitive services, such as STIs and substance use disorders**
  - Health consequences for themselves and partners
  - STI rates among youth are on the rise in RI and across the US
- **Survivors of domestic violence** may delay or defer needed medical and psychological care for fear of retaliatory violence for abuser/policyholder

Harvard Law, 2016

RHODE ISLAND HEALTH AND PRIVACY ALLIANCE

- Coalition of advocates and advisors
  - College health
  - Pediatrics/adolescent medicine
  - Family medicine
  - Domestic violence advocates
  - Substance use prevention/treatment advocates
  - Sexual/reproductive health
  - ACLU
  - Advisors: DOH, URI
- Engaged with multiple stakeholders
  - Insurance companies
  - Office of Health Insurance Commissioner
  - Department of Health
  - Legislators

RI LEGISLATION – HB 5556 AND SB 580

- Proposed during 2019 RI legislative session
- Modeled after MA PATCH Act
- Would require:
  - EOB directly to member
  - Generic descriptions of services
  - Member can suppress EOB if zero balance
  - Member and redirect EOB
  - Patient and provider education

STRATEGIES USEFUL FOR ADOLESCENTS WITH SUBSTANCE USE DISORDERS

- Encourage adolescents to talk with a trusted adult about their lives
  - Not always a parent, especially given that addiction has strong genetic component
- If you are concerned about a patient, consider meeting with parents alone, with the adolescent's consent
- Work to maintain the relationship with both the adolescent and the parent
- Use strengths-based, motivational interviewing strategies
- Be patient and have the adolescent come back to see you over time

RESOURCES

- University of Michigan, Adolescent Health Initiative
  - SPARKS on confidentiality
    - Best practice: https://www.umhs-adolescenthealth.org/improving-care/spark-trainings/confidentiality-best-practices/
    - Laws: https://www.umhs-adolescenthealth.org/improving-care/spark-trainings/confidentiality-laws/ (working on Rhode Island with them now!)
- Useful summary of issues:
  - **Berlan, 2009: Confidentiality, consent, and caring for the adolescent patient**
  - https://insights.ovid.com/crossref?an=00008480-200908000-00006
- SAHM Position Paper on Confidential Care:
  - https://www.ncbi.nlm.nih.gov/pubmed/15298005

SOURCES - 1

- Adolescent Health Initative (AHI). Colorado Minor consent and confidentiality laws. Online presentation. Available at https://www.umhs-adolescenthealth.org/improving-care/spark-trainings/confidentiality-laws/. Updated August 2018. Accessed May 22, 2019.
- Adolescent Health Initative (AHI). Confidentiality best practices. Online presentation. Available at https://www.umhs-adolescenthealth.org/improving-care/spark-trainings/confidentiality-best-practices/. Updated August 2017. Accessed May 22, 2019.
- Tebb KP, Sedlander E, Pica G, Diaz A, Peake K, Brindis CD. Protecting Adolescent Confidentiality Under Health Care Reform: The Special Case Regarding Explanation of Benefits (EOBs)(EOB Policy Brief). Philip R. Lee Institute for Health Policy Studies and Division of Adolescent and Young Adult Medicine, Department of Pediatrics, University of California, San Francisco. 2014 Jun.
- Confidentiality & Explanation of Benefits: Protecting Patient Information in Third Party Billing. Center for Health Law and Policy Innovation, Harvard Law School. Issue Brief. August 2016. Available at: http://www.chlpi.org/wp-content/uploads/2013/12/Confidentiality-and-Explanation-of-Benefits_issue-brief_August-2016.pdf.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Summing Up: Final Report on Studies of the Ethical and Legal Problems in Medicine and Biomedical and Behavioral Research. Washington DC; 1983. https://repository.library.georgetown.edu/handle/10822/559377. Accessed May 7, 2019.
- Center for Consumer Information & Insurance Oversight C for M& MS. Young Adults and the Affordable Care Act: Protecting Young Adults and Eliminating Burdens on Families and Businesses. https://www.cms.gov/CCIIO/Resources/Files/adult_child_fact_sheet.html. Published 2013. Accessed June 15, 2018.

SOURCES - 2

- Jones RK et al., Adolescents' reports of parental knowledge of adolescents' use of sexual health services and their reactions to mandated parental notification for prescription contraception, Journal of the American Medical Association, 2005, 293(3):340–348, <http://jama. ama-assn.org/content/293/3/340.abstract>, accessed Feb. 28, 2012.
- Reddy D, Fleming R and Swain C, Effect of mandatory parental notification on adolescent girls' use of sexual health care services, Journal of the American Medical Association, 2002, 288(6):710–714.
- Kaiser Family Foundation, SexSmarts: A Series of National Surveys of Teens About Sex. Sexually Transmitted Disease, 2001, <http://www.kff.org/entpartnerships/ upload/sex-smarts-survey-sexually-transmitted-disease- toplines.pdf>, accessed June 11, 2012.
- Gold RB, Unintended consequences: how insurance processes inadvertently abrogate patient confidentiality, Guttmacher Policy Review, 2009, 12(4):12–16, <http:// www.guttmacher.org/pubs/gpr/12/4/gpr120412.html>, accessed Feb. 28, 2012.

SOURCES - 3

- American Academy of Pediatrics, Achieving quality health services for adolescents, Pediatrics, 2008, 121(6):1263–1270.
- Committee on Pediatric AIDS, American Academy of Pediatrics, Adolescents and HIV infection: the pediatrician's role in promoting routine testing, Pediatrics, 2011, 128(5):1023–1029.
- American Academy of Pediatrics, Male adolescent sexual and reproductive health care, Pediatrics, 2011, 128(6):e1658–e1676.
- Protecting adolescents: Ensuring access to care and reporting sexual activity and abuse. Position paper of the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, and the Society for Adolescent Medicine, Journal of Adolescent Health, 2004, 35(5):420–423.
- American Academy of Child & Adolescent Psychiatry, Policy statements: Adolescent pregnancy prevention, Jan. 2009, <http://www.aacap.org/cs/root/policy_statements/ adolescent_pregnancy_prevention>, accessed Apr. 24, 2012.
- American Academy of Child & Adolescent Psychiatry, Policy statements: HIV and psychiatric hospitalization of children, Jan. 2009, <http://www.aacap.org/cs/root/ policy_statements/hiv_and_psy

QUESTIONS?

JACK.RUSLEY@LIFESPAN.ORG

EXTRA SLIDES

WHY IS PRIVACY AND CONFIDENTIALITY IMPORTANT?

THE PROFESSION OF MEDICINE

- Respect for patient privacy "is an important part of ethical health care practices, as well as the foundation on which a relationship of mutual trust and benefit can be built between patient and professional."
  - President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983

ADOLESCENTS AND YOUNG ADULTS WANT CONFIDENTIAL CARE AND DELAY/DEFER CARE WHEN THEY ARE CONCERNED ABOUT DISCLOSURE

- 70% **would not seek family planning services** if parent notification occurred (Jones, 2005)
- 25% would **have unsafe sex** if they were unable to obtain confidential care (Jones, 2005)
- 11% indicated that they would **delay accessing HIV or other STI services** if parental involvement were mandated for contraception (Reddy, 2002)
- Women with private insurance who used it to access contraception (Gold, 2009):
  - Adults (30+): 90%
  - Young adults (20-24): 76%
  - **Teens (<20): 68%**
- #1 barrier to STI testing: **parents will find out they are having sex** (Kaiser, 2001)

A LARGE AND VARIED GROUP OF STAKEHOLDERS HAVE ISSUED STATEMENTS SUPPORTING CONFIDENTIAL SERVICES FOR YOUTH SEEKING SENSITIVE SERVICES

- American Academy of Pediatrics
- American Academy of Family Physicians
- American Academy of Child & Adolescent Psychiatry,
- Society for Adolescent Health and Medicine
- American College of Obstetricians and Gynecologists
- American Medical Association
- National Prevention, Health Promotion, and Public Health Council

HIPAA, TITLE X, ACA, EOB…HUH?

- HIPAA = the privacy law
- Title X = clinics that can provide "true" confidential care
- ACA = extended insurance through parents up to 26
- EOB = letter in mail to policyholder (i.e. spouse, parent) about health care services

HIPAA = THE PRIVACY LAW

- Sets a "floor" for privacy protection that states can build on
- Defines protected health information (PHI)
- Allows individuals to receive PHI "by an alternative means or at alternative locations" if the disclosure "could **endanger** the individual." (42 CFR § 164.522(b)(1)(ii).
  - aka "42 CFR"

TITLE X = "TRUE" CONFIDENTIAL SERVICES

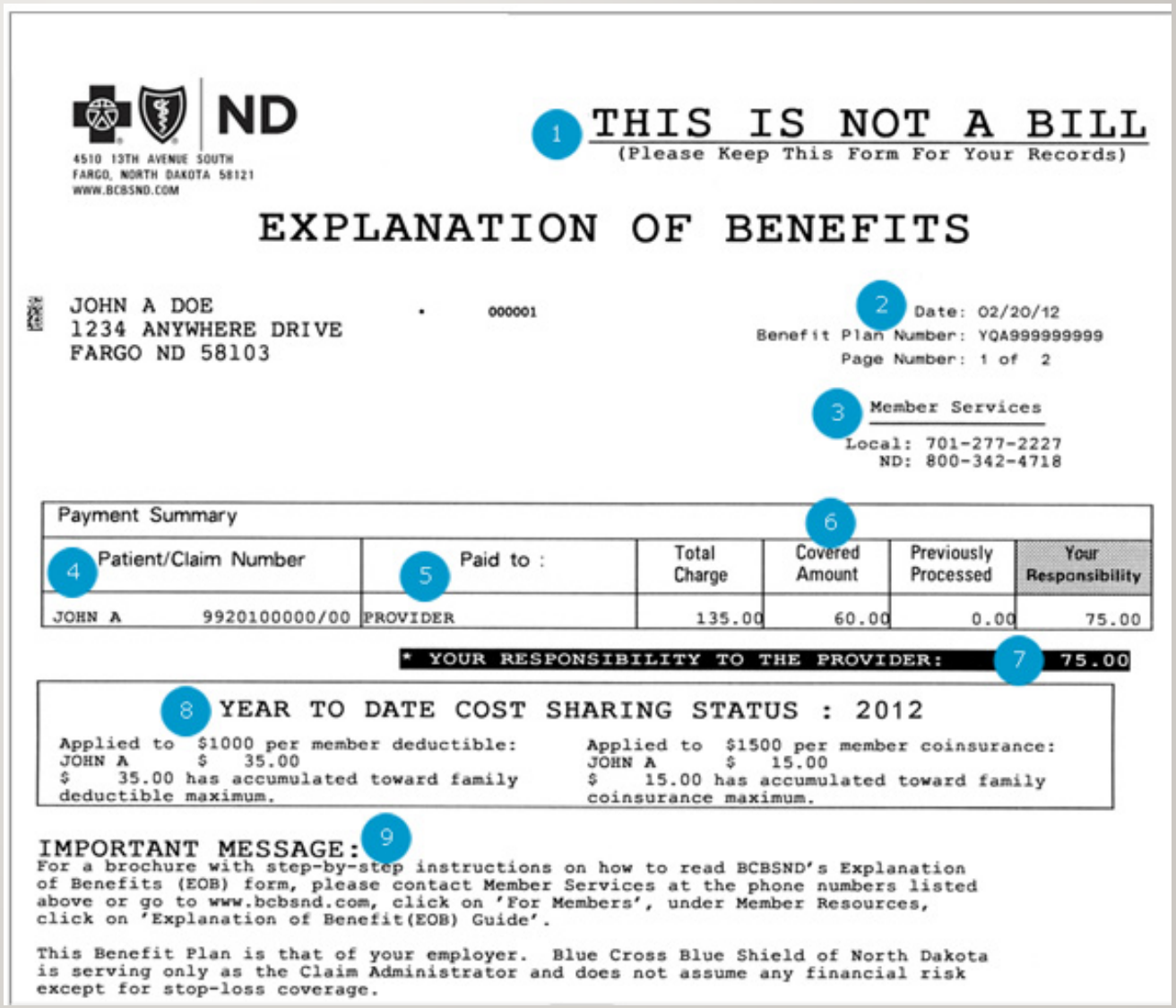
- Federally funded program started in 1970
- Provides family planning (except abortion) and preventative health services
- Allows confidential services because insurance is optional
- Grantees include Planned Parenthood, FQHCs, some academic centers

ACA = EXTENDING TO 26

- Affordable Care Act (ACA)
- Federal law, passed in 2010
- Dependent coverage provision allows youth to stay on parent's insurance until 26
- Preventative services (i.e. STI screening) must be covered without cost sharing (i.e. co-pays)

WHAT IS AN EOB?

- Explanation of benefits
- Sent by insurance companies to policyholder
- Inform about claims made, actions taken
- Any insured dependent is included (i.e. spouse, minor child, adult child)



ND

4510 13TH AVENUE SOUTH
FARGO, NORTH DAKOTA 58121
WWW.BCBSND.COM

1 THIS IS NOT A BILL
(Please Keep This Form For Your Records)

EXPLANATION OF BENEFITS

JOHN A DOE
1234 ANYWHERE DRIVE
FARGO ND 58103

000001

2 Date: 02/20/12
Benefit Plan Number: YQA999999999
Page Number: 1 of 2

3 Member Services
Local: 701-277-2227
ND: 800-342-4718

Payment Summary

4 Patient/Claim Number	5 Paid to :	Total Charge	6 Covered Amount	Previously Processed	Your Responsibility
JOHN A 9920100000/00	PROVIDER	135.00	60.00	0.00	75.00

* YOUR RESPONSIBILITY TO THE PROVIDER: 7 75.00

8 YEAR TO DATE COST SHARING STATUS : 2012

Applied to $1000 per member deductible:
JOHN A $ 35.00
$ 35.00 has accumulated toward family deductible maximum.

Applied to $1500 per member coinsurance:
JOHN A $ 15.00
$ 15.00 has accumulated toward family coinsurance maximum.

IMPORTANT MESSAGE: 9
For a brochure with step-by-step instructions on how to read BCBSND's Explanation of Benefits (EOB) form, please contact Member Services at the phone numbers listed above or go to www.bcbsnd.com, click on 'For Members', under Member Resources, click on 'Explanation of Benefit(EOB) Guide'.

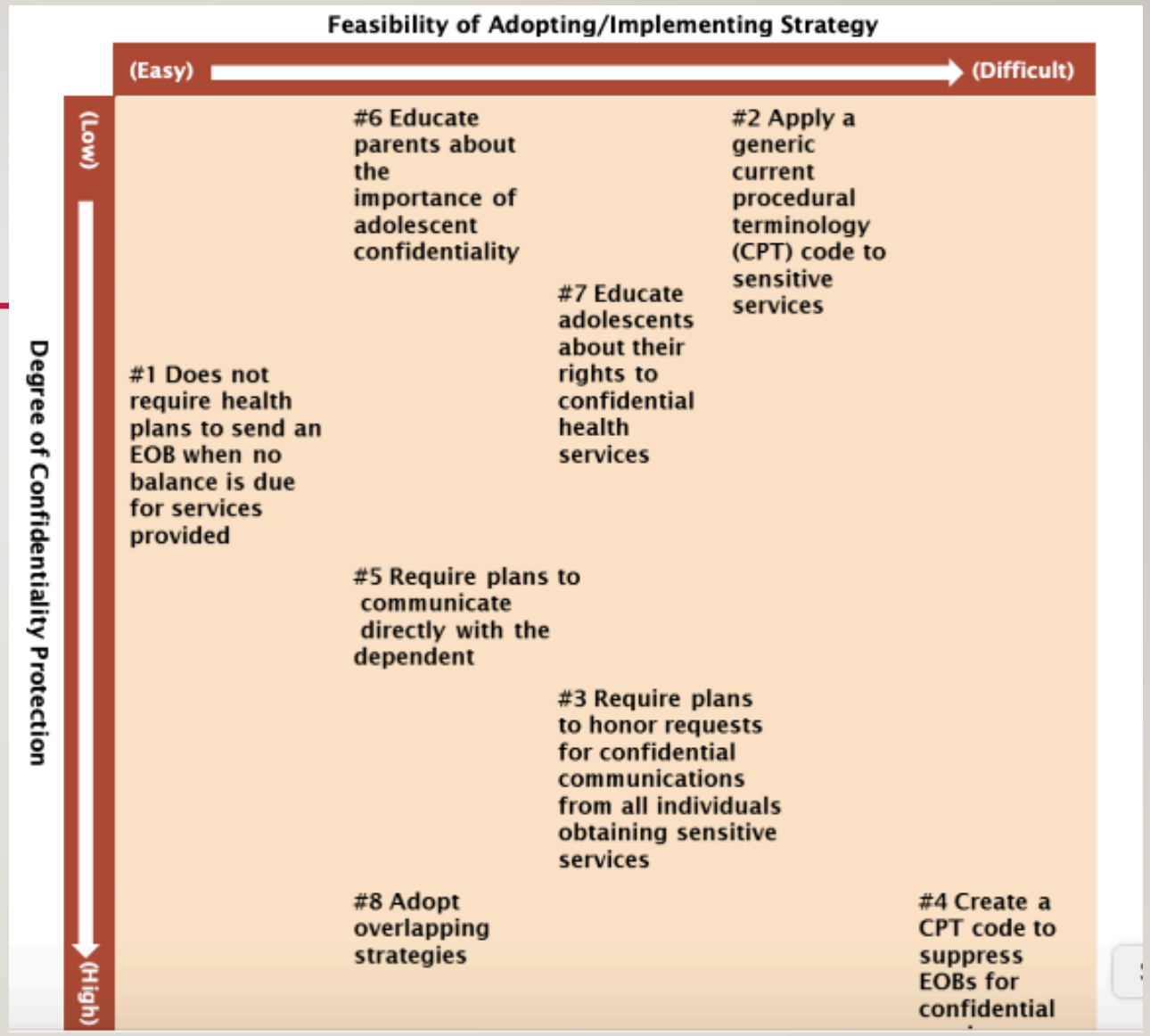
This Benefit Plan is that of your employer. Blue Cross Blue Shield of North Dakota is serving only as the Claim Administrator and does not assume any financial risk except for stop-loss coverage.

EOB – THE PROMISE

- Fraud prevention

POSSIBLE FIXES

1. Suppress if no balance
2. Use generic codes/terms
3. Patients can request "confidential" EOB
4. Sensitive services CPT code
5. Plan sends EOB to patient
6. Educate parents
7. Educate patients
8. Overlapping strategies



Tebb, 2014

CALIFORNIA'S APPROACH

- Confidential Health Information Act (SB 138)
- Created a process for patients to file "confidential communications request" (CCR)
- Goal is for CCR to suppress EOB when filed
- However, implementation has been challenging
  - Providers and patients do not always have time, knowledge to complete CCR
  - Concerns from provider that CCR process is not effective in suppressing EOBs
  - Long list of FAQs: https://myhealthmyinfo.org/faq

MASSACHUSETTS' APPROACH

- Protect Access to Confidential Healthcare (PATCH) Act of 2018
- Coalition of groups: DV, youth, substance/mental health, LGBTQ, sexual/reproductive health
- Requires insurers to:
  - Send EOB to patient only
  - Allow patient to choose method of receipt (email, address)
  - Automatically suppress descriptions of sensitive services
  - Suppress EOB when no balance is due
- Also requires patient and provider education
- Minors <18 can use this if "mature minor" (married, parent/pregnant, military, independent), or they are accessing sensitive services (family planning, STI, substance use, mental health)

CONNECTICUT'S APPROACH

- Proposed legislation: SB 977 "An Act Concerning Explanations of Benefits"
- Passed the CT Senate, likely to pass the House
- Would require insurers:
  - Redirect EOB when requested by enrolled member/patient
    - Promptly and without inquiring about basis of request
  - Cannot force enrollee/patient to waive right to these request as condition of enrollment

OPPORTUNITIES

- Join our coalition!
- Testify!
- Talk to students about getting involved!

CASE

- 19 year old female
- Recently started having sex with male partner
- Interested in IUD for birth control
- Has private insurance through parent's employer
- Your college health center does not place IUDs
- She does not want her parents to know that she is sexually active

- How would you counsel her?
- Do parents get notified somehow of any services accessed by patients in your clinic?

YOUTH IN RHODE ISLAND CAN CONSENT TO FOLLOWING:

- Any care if age 18 or over (age of majority)
- Age 16 or over in certain circumstances
  - "Routine medical, surgical, or emergency care"
- Married minors
- Minors who are parents
  - Can consent to their child's care, but not necessarily their own
- Family planning services (birth control, pregnancy-related)
  - Abortion exception: Minors (<18) must obtain consent of one parent/guardian
- STDs and reportable diseases (includes HIV testing)
  - DOH site for reportable diseases: http://health.ri.gov/diseases/infectious/resultsreportable.php
- Substance use screening, and non-residential treatment
  - Parental consent is required for residential treatment unless "not helpful or would be deleterious"

ISSUES WHERE NO RHODE ISLAND LAW EXISTS, BUT YOUTH CAN POTENTIALLY CONSENT

- Emancipated minor
- Minor "living apart"