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DESCRIPTION

1425

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La Costa Rickford
Operator's Signature

10/16/03
Date

2003 HOUSE HUMAN SERVICES

HB 1425

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Almeta Rickford
Operator's Signature

10/16/03
Date

2003 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

House Human Services Committee

☐ Conference Committee

Hearing Date February 5, 2003

Tape Number	Side A	Side B	Meter #
1	x		0.7 -20.7
2	x		44.8 -48.0
Committee Clerk Signature <i>Sharon Rengrow</i>			

Minutes:

Rep. Galvin appeared as prime sponsor stating this bill would allow family members or relatives to be able to have access to medical records of family members who are developmentally disabled in order to do a family history. He also suggested changing heirs to descendants and handed out the South Dakota Statute.

Rep. Amerman asked about the word heirs. Answer: Heirs meant inheritance and feels descendants is a better word.

Rep. Grande appeared in support as cosponsor also stating that checking with Legislative Council they felt heirs was not appropriate and that descendants should be used instead. Descendants definition meant direct blood line.

David Boeck, Lawyer for Protection and Advocacy Project appeared in opposition with written testimony. (See attached)

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House Human Services Committee
Bill/Resolution Number HB 1425
Hearing Date February 5, 2003

Rep. Kreidt noted that referencing Rep. Galvin's testimony we are presuming that all of these people are dead and gone, there is no possibility to do what you are referencing, I feel in this situation.

Answer: Putting the word descendants in, means the law would apply to people who are alive. If I have a developmental disability and I have children, they would have access to my records right now, assuming I appear alive yet. That is one of the problems with the way this is written. The other is that it only applies to people with developmental disabilities. It doesn't apply to your great great uncle who was never diagnosed with a developmental disability but of whom you have no records. You suspect there's going to be medical records somewhere and try to find them. I think what this bill would do is give access to ALL records and if we want to serve this purpose and I don't object to somebody putting together a family history, we need to define more carefully just what information were going to make open. Generally psychiatric records don't need to be disclosed, I don't know how detailed this family history is going to be. It seems to be unusual to go into lots of the medical issues that someone had while they were alive. I do think that it might be part of a history to describe how the person was treated while alive in 1902 and having a developmental disability. How did we treat people then.

Rep. Amerman asked: if this bill was passed and descendants got the medical records from the relation, is there a law or are they bound by a law to not show it to anyone or can they show it to anyone?

Answer: Mr. Boeck's understanding was that once they have the records, HIPPA (the new medical privacy law) would not prohibit them from putting information in a book and sharing it

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House Human Services Committee
Bill/Resolution Number HB 1425
Hearing Date February 5, 2003

with anyone they want. Putting it solely in a family history, they just went to other members of the family, I believe there is no protection on that.

Rep. Wieland asked if the bill were to state that the parents of a legal guardian and the subject has deceased, so that there was no one else to ask for these records, would that have an effect on your testimony?

Answer: It would have some affect on my testimony because we wouldn't have the problem of somebody alive now who's records are being examined. But as I stated, lots of codes of professional ethics require confidentiality even after a patient or client has died. There are arguments, some things are private and you don't want them out, whether your dead or alive. I don't think you should have to forfeit that when you have that protection for contacts with a social worker or physician but suddenly this law would change that and I think this law could be amended. It sounds like descendants isn't actually the term that we want, because I believe the scenario with this person has no children, so we might want something other than simply descendants. I also think we would want to define more narrowly what records could be shared with those relatives.

Rep. Devlin asked about a situation with adoption and needed medical information, how does that work with someone that has been in the Center at Grafton or wherever, is that information available through a court order to a family member or what?

Answer: I believe that would be governed by the new provisions of the Federal Health Insurance Portability and Accountability Act and I don't know for sure how that is covered. In adoption laws we tried to open it up so that medical records can be found out, for a narrow purpose and once that purpose is satisfied, that's it.

La Costa Richard
Operator's Signature

10/16/03
Date

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House Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date February 5, 2003

Rep. Potter asked if we changed the words and verbage, wouldn't there still be a problem with keeping it just developmentally disabled persons and wouldn't we need to expand that also.

Answer: Yes, just limiting it to one category of people because of a disability, seems to me to be a significant problem and as I suggested before, maybe we want some amendments to this although its going to be some pretty significant amendment.

Rep. Kreidt asked that if it works in South Dakota (HB 1427), why wouldn't it work here?

Answer: Doesn't know how South Dakota works and is not familiar with HB 1427 ?

Closed the hearing.

Afternoon Committee:

Rep. Price noted that a parent or legal guardian is what we are having a request for change.

Rep. Amerman stated he would oppose the bill because he is uncomfortable with it.

Rep. Wieland still wonders why they need those records in order to do a family history. It seems real strange to me. But if the language could be amended and if everybody is gone or everybody is deceased and if the individual before he/she passed away or the parents or the legal guardians didn't express that someone couldn't do it. I don't understand that once they are gone, why they couldn't.

Salvatore Riccardi
Operator's Signature

10/16/03
Date

2003 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

House Human Services Committee

☐ Conference Committee

Hearing Date February 11, 2003

Tape Number	Side A	Side B	Meter #
1	x		52.0 - 61.1
Committee Clerk Signature <i>Sharon R. Crawford</i>			

Minutes: Committee Work

Rep. Price stated that she spoke to Alex Schweitzer of the State Hospital and spoke further to the bill sponsors and the issue is that they don't know where this person is buried, the cause of death and they were not able to get any sort of information. So as a recommendation, they have gone to Vital Statistics to try to get the death certificate, which would give them 5 pieces: date and place of birth, date and place of death and how the death. But the piece they still don't know is was this disability caused by a birth defect, accident or illness, which is the one thing they are concerned about because they have another family member in South Dakota with the South Dakota bill who is developmentally disabled also and they are trying to find out if it is hereditary. Now they can go to court to do that. I also asked Mr. Schweitzer to check to see if there was anyway we could deal with this without passing a law and he has not responded to me. What does the committee wish to do? Amend the bill and pass it, kill the bill or do you wish to try to

Page 2

House Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date February 11, 2003

make it work like South Dakota's Law. If you wish, we could have our intern try to amend the bill to mirror South Dakota Law.

Rep. Devlin stated he feels were opening up some privacy things for family members that we shouldn't be doing and I can't support the bill and doesn't know if we can amend the bill enough to fix it.

Rep. Porter moves an amendment on line 7 to change heirs to descendants, second by Rep.

Wieland. 12 - 0 - 1 Amendment passed

Rep. Amerman doesn't like the bill for a number of reasons, one of which as Mr. Boeck stated it is a little bit discriminatory because it only deals with disabled people and recommends DO NOT PASS as AMENDED, second by Rep. Potter. 10 - 2 - 1 Rep. Amerman will carry the bill.

38341.0101
Title.0200

Adopted by the Human Services Committee
February 11, 2003

VK
2/11/03

HOUSE AMENDMENTS TO HOUSE BILL NO. 1425 HM 2-12-03

Page 1, line 7, replace "heirs" with "descendants"

Renumber accordingly

Page No. 1

38341.0101

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Richard Costa
Operator's Signature

10/6/03
Date

Date:
Roll Call Vote #:

2003 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. HB ~~1425~~ 1425

House _____ HUMAN SERVICES _____ Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken DNP as Amended

Motion Made By Rep Amerman Seconded By Rep Potter

Representatives	Yes	No	Representatives	Yes	No
Rep. Clara Sue Price - Chair	✓		Rep. Sally Sandvig	✓	
Rep. Bill Devlin, Vice-Chair	✓		Rep. Bill Amerman	✓	
Rep. Robin Weisz	✓		Rep. Carol Niemeier	A	
Rep. Vonnie Pietsch	✓		Rep. Louise Potter	✓	
Rep. Gerald Uglem	✓				
Rep. Chet Pollert	✓				
Rep. Todd Porter	✓				
Rep. Gary Kreidt		✓			
Rep. Alon Wieland	✓	✓			

Total (Yes) 10 No 2

Absent 1

Floor Assignment Rep Amerman

If the vote is on an amendment, briefly indicate intent:

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Jo Costa Rickford
Operator's Signature

10/16/03
Date

REPORT OF STANDING COMMITTEE (410)
February 12, 2003 8:12 a.m.

Module No: HR-27-2346
Carrier: Amerman
Insert LC: 38341.0101 Title: .0200

REPORT OF STANDING COMMITTEE
HB 1425: Human Services Committee (Rep. Price, Chairman) recommends
AMENDMENTS AS FOLLOWS and when so amended, recommends **DO NOT PASS**
(10 YEAS, 2 NAYS, 0 ABSENT AND NOT VOTING). HB 1425 was placed on the
Sixth order on the calendar.

Page 1, line 7, replace "heirs" with "descendants"

Renumber accordingly

(2) DESK, (3) COMM

Page No. 1

HR-27-2346

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Yolanda Rickford
Operator's Signature

10/16/03
Date

2003 SENATE HUMAN SERVICES

HB 1425

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Yolanda Rickford
Operator's Signature

10/16/03
Date

2003 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

Senate Human Services Committee

☐ Conference Committee

Hearing Date March 12, 2003

Tape Number	Side A	Side B	Meter #
1		X	4279 - end
2	X		0 - 965
Committee Clerk Signature <i>Donna Kramer, Clerk</i>			

Minutes:

SENATOR JUDY LEE opened the public hearing for HB 1425 relating to treatment or care center records of developmentally disabled persons.

REPRESENTATIVE GALVIN introduced the HB 1425 on behalf of a family in his district. The proposed amendments regarding privacy were reviewed. (copy of amendments provided) ... many reasons why a family would want medical records ... asked for support for bill ... (Meter # 4487 - 5020)

SENATOR LEE: Asked for circumstances about the family that started this bill.

REPRESENTATIVE GALVIN: Family was writing family history ... wanted to include developmentally disabled person ... questions about reason of disability ... (Meter # 5057 - 5260)

SENATOR FAIRFIELD: Replacing "descendants" with "four degrees of relation" ... is that getting at what you want? What are those degrees?

REPRESENTATIVE GALVIN: Short degree (Meter # 5261 - 5464)

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Senate Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date March 12, 2003

REPRESENTATIVE GRANDE: Testified in support of Representative Galvin and the bill. ...

genetic issue ... (Meter # 5620 - 5748)

SENATOR POLOVITZ: Do we have a definition of "developmentally disabled persons"? I was

told we would call them "people with disabilities." ... Does developmentally disabled include

everything a person might have? ... word "persons". (Meter #5740 - 5947)

SENATOR LEE: One thing about individuals ... in looking at the amendments, it says

individuals instead of persons ... The definition for a developmentally disabled person is spelled

out in Sec. 25-16-14 ... several different criteria ... (Meter # 5950 - 6065)

MRS. GARY ZENZ: Testified in opposition. ... Genealogy is important in LDS Church ...

largest genealogy society in the world ... disabled persons in Grafton getting personal records

... court order ... maintain privacy ... (Tape 1, Side B, Meter # 6110 - end and Tape 2, Side A,

Meter 0 - 380)

DAVID BOECK, Lawyer for the Protection & Advocacy Project, testified in opposition to the

engrossed bill. ... current law ... bill deals with confidentiality inspired by HIPAA ... (Written

testimony) (Meter # 404 - 940)

SENATOR LEE closed the public hearing for HB 1425. (Meter # 965)

2003 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

Senate Human Services Committee

☐ Conference Committee

Hearing Date March 19, 2003

Tape Number	Side A	Side B	Meter #
1		X	1450-2405
Committee Clerk Signature <i>[Signature]</i>			

Minutes:

Senator J. Lee (mtr #1450) - Opened the hearing on HB1425. All committee members are present. This bill relates to the confidentiality of treatment or care center records of developmentally disabled persons. Asked a question about the bill and the availability of open records to families. Discussed judicial procedure and the availability of information for families. There is a proposed amendment at the bottom of the e-mail to Talisa. Copy of e-mail is attached. Requested Talisa to look up the meaning of the federal regulations cited in the proposed amendment in relationship to privacy. Conversation between Senator J. Lee and Talisa the committee room intern regarding privacy, court systems, and family rights of disabled.

Bruce Murray (mtr #2170) - Discussed privacy issue with disabled people.

Senator Fischer (mtr #2269) - Question regarding a family wanting children, and a person in a development center that is a close relative. How do we balance the rights?

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Senate Human Services Committee

Bill/Resolution Number HB1425

Hearing Date March 19, 2003

Mr. Murry (mtr #2311) - Is a matter of balancing and not a matter of information. Is there a way to lessen the burden without completely opening it up.

Senator J. Lee (mtr #2405) - We are not going to act on this today.

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Operator's Signature

Salvatore Riccardi

Date

10/6/03

2003 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

Senate Human Services Committee

☐ Conference Committee

Hearing Date March 24, 2003

Tape Number	Side A	Side B	Meter #
1		X	2393 - 4097
Committee Clerk Signature <i>Donna Kramer, Clerk</i>			

Minutes:

SENATOR JUDY LEE reopened the committee discussion on HB relating to confidentiality of treatment or care center records of developmentally disabled persons. TaLisa had printed an amendment possibility. ... Talks about authorizing disclosure of genetic information underneath various conditions ... let's look this over.

SENATOR FISCHER: So, this is a "hog houser". ... Does make sense ... medical records for genetic counseling ...

SENATOR LEE and committee continued discussion on requesting records for genetic reasons or medical reasons.

TALISA NEMEC, the Intern, gave an opinion on the amendments ... whether HIPAA violations ... (Meter # 2650 - 2805)

SENATOR FAIRFIELD: Does this amendment actually get to what this family was after? ...

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Senate Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date March 24, 2003

Continued committee discussion regarding genetic information ... HIPAA problem with genetic information ... Caution - more detailed look at HIPPA ... Section 23-12 which allows physicians to authorize disclosure of genetic information ... (Meter # 2810 - 3300)

SENATOR POLOVITZ: How much information is there on my genetic background now?

SENATOR LEE: ... If you had a disease that was genetically caused - that would be in your records. ... (Meter # 3304 - 3380)

SENATOR FAIRFIELD: Referred to statute 23-12 ... a physician may authorize the disclosure of genetic information of a former patient ... pretty limiting - when you have to go to the actual physician who had that patient ... would have to be somebody who died recently ... referred to grandfather who died ... limiting ... (Meter # 3388 - 3530)

Continued discussion on getting genetic information ... getting any medical information ... (Meter # 3540 - 3814)

SENATOR LEE asked TaLisa to talk to Mike Mullen about whether or not there is a legitimate barrier to getting genetic information? and if there is a way that we can amend it so that somebody who would genuinely benefit from that information could have access to it without violating the privacy of the individual whose information is being sought.

SENATOR LEE explained generic information i.e. Downs Syndrome ... Muscular Dystrophy ... predisposition for any number of different conditions ... (Meter # 3914 -3980)

SENATOR FAIRFIELD: Wondered if there is a current definition of genetic information. There are those who argue that everything from obesity to alcoholism, everything has a genetic trait associated with it. So, I would be curious as to how broadly this covers.

SENATOR LEE: Asked TaLisa do a little homework on this issue ... (Meter # 4097)

2003 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

Senate Human Services Committee

☐ Conference Committee

Hearing Date March 25, 2003

Tape Number	Side A	Side B	Meter #
1	X		297 - 4870
Committee Clerk Signature <i>Donna Kramer, Clerk</i>			

Minutes:

SENATOR JUDY LEE opened the committee discussion for HB 1425 regarding to the confidentiality of treatment or care center records of developmentally disabled persons.

MIKE MULLEN, of the Attorney General's office, stated that the committee had an opportunity earlier to review the amendments proposed by the Protection & Advocacy. ... HIPAA provides confidentiality of individually identifiable health information ... personal rep can get access ... under HIPAA family members may obtain information ... Two things (1) HIPAA permits the disclosure if it's necessary to find out genetic information to treat an individual and (2) HIPAA also permits a personal representative of a deceased person to get access to the deceased person's health information. (Meter # 275 - 675)

SENATOR LEE: So, if my physician requests the information, that doesn't necessarily mean that my physician can tell me about it.

MIKE MULLEN: As part of treatment or counseling, I believe they could.

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Operator's Signature

10/16/03
Date

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Senate Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date March 25, 2003

SENATOR LEE: So that would apply when an estate is all settled and there is no longer a personal representative. (Meter # 700 - 728)

TOM MAYER, Attorney General's office, stated that it could be. Unless you were discharged by the probate court, but that doesn't always happen. ... (Meter # 735)

SENATOR LEE: This would say that a person would not have to go to court.

MIKE MULLEN: Under this language, an heir could act as a personal representative ... Referred to both proposed amendments ... (Meter #966 - 976)

SENATOR LEE: Because HIPAA covers it, we don't need it?

MIKE MULLEN: HIPAA permits this unless state law is more restrictive. ... Someone might say, well if this section of the Century Code 25-1607 doesn't permit the disclosure in this situation, then arguably someone could go to court and say that even though it is permitted under HIPAA, ND law is more restrictive. You can't see this and so in that regard you may wish to make some amendment here to commit this under ND Law (Meter # 993 - 1050)

SENATOR LEE: And if we did the one Mr. Murry suggested, that is acceptable? (Meter # 1061)

MIKE MULLEN: That is acceptable. Don't need to do both. ...

SENATOR LEE: ... Tell me again what I can get out of this one from the Attorney General's office ... is it that I don't have to go to court on this one?

MIKE MULLEN: You don't have to go to court. ... And you can also could get health information in addition to genetic information. ... (Meter # 1111 - 1180)

TALISA NEMEC: With access to a broader base of medical insurance with your proposed amendment ... more expensive?

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Operator's Signature

Date

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Senate Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date March 25, 2003

MIKE MULLEN: HIPAA refers back to state law. A person who is a personal rep under state law has access to the deceased person's health information. ... (Meter # 1227 - 1280)

SENATOR POLOVITZ: What is the definition of a personal representative?

MIKE MULLEN: Under HIPAA, look to state law as to the meaning of personal representative. ... a personal representative is an executor, an administrator of an estate, but it is also any one who is authorized by law under state law to act on behalf of an individual with respect to their health care ... except with respect to deceased persons, then you can go farther. ... (Meter # 1227 - 1500)

SENATOR POLOVITZ: Open door?

Continued committee discussion regarding getting information on deceased persons ... consanguinity chart ... (Meter # 1528 - 1800)

SENATOR LEE: Discussion not opened just for genealogy, I think we are interested in doing it for genetic information. Continued discussion about getting genetic information ... (Meter # 1801 - 1977)

MIKE MULLEN: If you're not addressing a situation of a person who is a resident of the developmental center, just any citizen or resident of North Dakota, then I believe you would have access to that information through a clinic or hospital who could disclose information to a relative ... that can be disclosed without the authorization from the individual to whom the record pertains ... the only reason that the concern came up here is that there is this specific statute that limits the disclosure of information about residents of the developmental center in Grafton ... (Meter 2001 - 2100)

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Senate Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date March 25, 2003

SENATOR LEE: Moving in a new direction now ... that would be significantly different because in many cases people would have been life-time residents there. Whereas if somebody who is at the State Hospital - the records would be available because of it being hospital ... unique facility? ... whole chapter devoted to that condition ... (Meter # 2105 - 2160)

TALISA NEMEC: Questioned expanding the access - going to the 4th degree - discriminatory?

SENATOR LEE: Whether or not it is appropriate that it be treated a bit differently? ... It is different for people who are long-term residents of a developmental center ... (Meter # 2179 - 2310)

SENATOR FAIRFIELD: Unique situation - chapter speaks specifically to the developmental center - there is still a process by which records could be obtained through judicial process.

Maybe, it is appropriate that the "bar" is set a little higher ...

SENATOR LEE: Read North Dakota Century Code 25-1607 relating to information released ... (Meter #2360 - 2450)

TA LISA NEMEC: Pointed out "licensee" or "their agent" - definition of that is more extensive than Grafton Developmental Center. ... (Meter # 2451 - 2512)

SENATOR LEE requested "encouragement" from either Thomas Mayer or Mike Mullen as to which direction to go.

TOM MAYER: My thought is with regards to designating an heir as a personal representative ... Continued discussion regarding language of descendants or heirs ... relatives ... person who has authority ... an heir by being an heir doesn't have authority on behalf of the deceased, but if you designate a personal representative - they would have the authority and could get the records without having to go to court ... definition of an heir: reference to consanguinity code - a relative

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Senate Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date March 25, 2003

... the law designates someone who is a relative as a personal representative ... personal representative only has the right to get records ... restrictive portions of the law ... court orders authority ... which amendment? ... (Meter # 2527 - 3950)

MIKE MULLEN: Made a point on one thing about amendment from P & A. It says the former resident is dead. ... There may be relatives and the resident is not deceased and yet there's a concern about the genetic information. ... Cases where someone may want obtain information about a resident who is still living. (Meter # 3951 - 4085)

SENATOR LEE: Would like some amendment that might throw this into conference committee ... figure out a way to appropriate disclosure without violating privacy ... (Meter # 4090 - 4540)

SENATOR FISCHER made a motion to the Move the Amendment (Mayer amendment)

SENATOR ERBELE seconded the motion.

Roll call was read. 6 yeas 0 nays.

SENATOR BROWN moved DO PASS AS AMENDED

SENATOR FISCHER seconded call was read.

Roll call was read. 5 yeas 1 nay

SENATOR FISCHER to be the carrier. (Meter # 4860)

38341.0204
Title.0400

Adopted by the Human Services Committee
March 25, 2003

[Signature]
3-25-03

PROPOSED AMENDMENTS TO ENGROSSED HOUSE BILL NO. 1425

Page 1, line 1, remove "subsection 3 of"

Page 1, line 5, replace "Subsection 3 of section" with "Section"

Page 1, replace line 7 with:

"25-16-07. Records of treatment or care center confidential.

1. No agent of the department of human services or the superintendent of the developmental center at westwood park, Grafton or the licensee or their agents or employees may disclose the contents of the individual records of a treatment or care center for developmentally disabled persons, nor of the reports received therefrom, except:
 - ~~1-~~ a. In a judicial proceeding when ordered by the presiding judge;
 - ~~2-~~ b. To officers of the law or any other legally constituted boards or agencies serving the interests of the residents; or
 - ~~3-~~ c. To the parents, heirs, or legal guardians of the resident.
2. For the purposes of this section, an "heir" must be within four degrees of consanguinity. Under this section, an heir is authorized to act as the personal representative of a deceased resident regarding the deceased resident's health records."

Renumber accordingly

Date: 03-25-03
Roll Call Vote #: 1

2003 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 1425

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Move Amendments as proposed

Motion Made By Sen. Fischer Seconded By Sen. Erbele

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee - Chairman	✓				
Senator Richard Brown - V. Chair.	✓				
Senator Robert S. Erbele	✓				
Senator Tom Fischer	✓				
Senator April Fairfield	✓				
Senator Michael Polovitz	✓				

Total (Yes) 6 No 0

Absent

Floor Assignment

If the vote is on an amendment, briefly indicate intent:

Date: 03-25-03
Roll Call Vote #: 2

2003 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 1425

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 38341.0204

Action Taken Do Pass as amended.

Motion Made By Sen. Brown Seconded By Sen. Fischer

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee - Chairman	✓				
Senator Richard Brown - V. Chair.	✓				
Senator Robert S. Erbele	✓				
Senator Tom Fischer	✓				
Senator April Fairfield		✓			
Senator Michael Polovitz	✓				

Total (Yes) 5 No 1

Absent

Floor Assignment Sen. Fischer

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
March 26, 2003 8:24 a.m.

Module No: SR-54-5761
Carrier: Fischer
Insert LC: 38341.0204 Title: .0400

REPORT OF STANDING COMMITTEE

HB 1425, as engrossed: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (5 YEAS, 1 NAY, 0 ABSENT AND NOT VOTING). Engrossed HB 1425 was placed on the Sixth order on the calendar.

Page 1, line 1, remove "subsection 3 of"

Page 1, line 5, replace "Subsection 3 of section" with "Section"

Page 1, replace line 7 with:

"25-16-07. Records of treatment or care center confidential.

1. No agent of the department of human services or the superintendent of the developmental center at westwood park, Grafton or the licensee or their agents or employees may disclose the contents of the individual records of a treatment or care center for developmentally disabled persons, nor of the reports received therefrom, except:
 - 1- a. In a judicial proceeding when ordered by the presiding judge;
 - 2- b. To officers of the law or any other legally constituted boards or agencies serving the interests of the residents; or
 - 3- c. To the parents, heirs, or legal guardians of the resident.
2. For the purposes of this section, an "heir" must be within four degrees of consanguinity. Under this section, an heir is authorized to act as the personal representative of a deceased resident regarding the deceased resident's health records."

Renumber accordingly

2003 HOUSE HUMAN SERVICES

CONFERENCE COMMITTEE

HB 1425

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Salvatore Riccardi
Operator's Signature

10/16/03
Date

2003 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. HB 1425

House Human Services Committee

☒ Conference Committee

Hearing Date 4-8-03

Tape Number	Side A	Side B	Meter #
1	x		14.2-27.2
Committee Clerk Signature <i>Sharon Longfellow</i>			

Minutes: Chairman Price called the conference committee to order on HB 1425.

Representative Grande, Representative Price, Representative Nelmeier, Senator Brown, Senator Erberle, Senator Fairfield were present.

Representative Price: handed out amendments from Senator Lee.

Representative Grande: I had the opportunity to sit down with Mike Mullen from the AG's office, who specializes in the HIPPA, he has read through these and is quite satisfied with these new set of amendments and approved of them and thinks it would be a good part to do.

Representative Price: I guess I would ask Senator Brown to first maybe your action that you took on the bill.

Senator Brown: we have been through this over and over, and what started out as a simple little request to a simple little bill, has turned out that it is not so simple, that we can encroach on someone's privacy and maybe unfairly, and yet there is a need for some information, do heirs have a need to know, and we felt there are some heirs that do have a need to know, but we tried

Page 2

House Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date 4-8-03

to limit how far out that goes. And at the same time that were dealing with HIPPA, so that is why we get an attorney involved, and this is the amendment that has come through to satisfy all those requests and still stay with in the legality of privacy without over reacting. Yet there is a need for some information and that is where we came from, first of all the information that this person requested, just looking at their family, is a reasonable request and the other side is the health side. And I have used the word of consanguinity.

Representative Price: We don't have to make a distinction between lineal and collateral. Because consanguinity was your Rep. Grande, do we need to specify collateral or lineal. I think its just because we use the word it should exist, it should mean both, shouldn't it? Answer: I should mean both.

Rep. Fairfield: Is it really necessary at this point with these amendments then for you to have that 4th degree of consanguinity in it, is that really a, really pertinent, before we were trying to control the number of people who might have access to this information because its for these 2 reasons only, its genealogy and genetic information. Is it really necessary to limit it to the 4th degree of consanguinity.

Rep. Grande: I wouldn't mind having that left in here just because I wouldn't want, I guess my thought is that we wouldn't want just anyone to be able to request that information, I realize its going through a physician and stuff but keeping it within a boundary of why somebody is or needs to have that information, I think its important.

Rep. Fairfield: From a genealogy perspective those 4 degrees of consanguinity don't give you much room. I mean genealogy may go back much further than that so that wouldn't have you anyway.

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Salvatore Riccio
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10/16/03
Date

Page 3

House Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date 4-8-03

Rep. Grande: In 5 I see where your at, in 4 I think it needs to stay.

Rep. Fairfield: In # 4 then, its going to be for genetic information and its going to be through a physician, isn't then assumed that there must be relation, I mean if its genetic information why would you still need to define the 4 degrees of consanguinity there? Because its genetic, there has to be a genetic relation there. I understand what your saying about trying to limit it, so that would be your limitation.

Mr. Mullen: I understand the point that Sen. Fairfield has raised but on the other hand, I mean genetically we're all related genetically to some extent, it can go on to a very wide extent. To be very honest we just incorporated the 4th degree as stated in prior amendments thinking that would be broad enough. And even if you might be more distance than the 4th degree there might be another relative that you could contact who would fit within this definition, they could ask for the disclosure of genealogical information and respect to the genetic information, again there might be other relatives that you could ask, this just tries to limit, I'm not an expert in that area I looked at the chart you had and it seemed to include a fairly wide number of relatives, I thought. So its a judgment call for you as a conference committee. But I thought it included enough husbands, aunts & uncles.

Rep. Price: I would assume, its probably not going to be in the lineal anyway in most cases, so 4th degree should be fine for the genetic information if its collateral only, because very few of these have descendants. So for # 5 I guess very limited exposure to genealogy from what my family has done but I would doubt that if they were any further out that they need to be aware of this of the person. It's hard to know, because you'd have to go and make a specific request for a specific person. I'd like to have some sort of degree in there just from the fact that if your not, if

Page 4
House Human Services Committee
Bill/Resolution Number HB 1425
Hearing Date 4-8-03

you don't have something that you can prove, how is the care center going to be able to say yes or no your entitled to the information? Because they are going to have to prove some sort of, I don't know if they are going to be able to prove enough genealogy to get the information based on this language. Whether 4 is right or not, I don't know.

Sen. Fairfield: I don't have my chart, does that include, it is assumed then that that includes spouse, so if your a nephew that would include the nephew's wife?

Rep. Price: read the definition of consanguinity (see attached) So the spouse is out, that's what I would assume. So it may, their limits may be there for any sort of relationship by marriage to do that type of research. I think it probably comes up so seldom that they should, if their a spouse they've got to know someone within a closer degree as you said to contact to find the information.

Mike Mullen: If it was the child, the individual that's fits within the definition, then the spouse, the mother lets say, who is not a blood relative, she could make the request on behalf of the child.

Sen. Brown: Made a motion that the Senate recede from their amendments and the Conference Committee further amend, second by Sen. Erbele.

Rep. Price: Any other discussion?

Rep. Fairfield: I think the amendments help. I still have some real concerns, again I understand the sponsors and what they are trying to do and I think its a valiant effort, I just have some concerns about the chapter that has been __ developmentally disabled and I think we are just asking for trouble here and I still have some real concerns with it. I do like the amendments and will vote for them.

Salvatore Riccardi
Operator's Signature

10/16/03
Date

Page 5

House Human Services Committee

Bill/Resolution Number HB 1425

Hearing Date 4-8-03

Mike Mullen: I understand and I looked at this bill hard too because I want to balance privacy vs. what the sponsors wanted to accomplish, but with respect to a person who is not a resident of the developmental section, under HIPPA and I believe under ND Law a physician treating one of my children could request genetic information about me to determine if they were predisposed to have some genetic issues. Because there is no statute that says you can't have access to my genetic information to treat one of my children, the physician can't see that. The reason this amendment becomes necessary is because we have this law providing special privacy protection to a resident of the Developmental Center. So that's the reason for putting that, justifying putting in this genetic provision in this section.

Rep. Price: This bill was killed in my committee and was overturned on the floor, so we have major concerns about it.

The clerk will call the roll on the motion.

Sharon Renfrow, Clerk:	Chairman Price - yes	Sen. Brown - yes
	Rep. Grande - yes	Sen. Erbele - yes
	Rep. Niemeier - yes	Sen. Fairfield - yes

VOTE: 6 - 0 - 0 PASSED Rep. Price to carry the bill

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LoCosta Richard
Operator's signature

10/16/03
Date

38341.0205
Title.0500

Adopted by Conference Committee
April 8, 2003

Conference Committee Amendments to Engrossed HB 1425 - 04/08/2003

That the Senate recede from its amendments as printed on page 1171 of the House Journal and page 938 of the Senate Journal and that Engrossed House Bill No. 1425 be amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to amend and reenact section 25-16-07 of the North Dakota Century Code, relating to the disclosure of individual records of a treatment or care center for developmentally disabled individuals.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Section 25-16-07 of the North Dakota Century Code is amended and reenacted as follows:

25-16-07. Records of treatment or care center confidential. ~~No~~ An agent of the department of human services or the superintendent of the developmental center at westwood park, Grafton or the licensee or their agents or employees may not disclose the contents of the individual records of a treatment or care center for developmentally disabled ~~persons~~ individuals, nor of the reports received ~~therefrom~~ from those records, except:

1. In a judicial proceeding when ordered by the presiding judge;
2. To officers of the law or any other legally constituted boards or agencies serving the interests of the residents; ~~or~~
3. To the parents or legal guardians of the resident;
4. To a physician to aid in the treatment of an individual within the fourth degree of consanguinity of a deceased resident, if the disclosure is limited to genetic health information that has a direct bearing on the health of the relative, the relative's child, or the relative's decision to have a child; or
5. To an individual who is within the fourth degree of consanguinity of a deceased resident, if the disclosure is limited to information about a resident needed to establish a family's genealogy."

Renumber accordingly

**REPORT OF CONFERENCE COMMITTEE
(ACCEDE/RECEDE)**

Bill Number HB 1425 (, as (re)engrossed):

Your Conference Committee House Human Services

For the Senate:

For the House:

Sen. Brown	<i>yes</i>	Rep. Price	<i>yes</i>
Sen. Erbele	<i>yes</i>	Rep. Grande	<i>yes</i>
Sen. Fairfield	<i>yes</i>	Rep. Niemeier	<i>yes</i>

recommends that the (SENATE/HOUSE) (ACCEDE to) (RECEDE from)

the (Senate/House) amendments on (SJ/HJ) page(s) _____ --

_____ and place _____ on the Seventh order.

☒ , adopt (further) amendments as follows, and place _____ on the
Seventh order:

having been unable to agree, recommends that the committee be discharged and a
new committee be appointed.

((Re)Engrossed) _____ was placed on the Seventh order of business on the calendar.

DATE: 4/8/03

CARRIER: Rep. Price

LC NO. of amendment
LC NO. of engrossment
Emergency clause added or deleted
Statement of purpose of amendment

REPORT OF CONFERENCE COMMITTEE (420)
April 9, 2003 8:43 a.m.

Module No: HR-64-7141

Insert LC: 38341.0205

REPORT OF CONFERENCE COMMITTEE

HB 1425, as engrossed: Your conference committee (Sens. Brown, Erbele, Fairfield and Reps. Price, Grande, Niemeler) recommends that the **SENATE RECEDE** from the Senate amendments on HJ page 1171, adopt further amendments as follows, and place HB 1425 on the Seventh order:

That the Senate recede from its amendments as printed on page 1171 of the House Journal and page 938 of the Senate Journal and that Engrossed House Bill No. 1425 be amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to amend and reenact section 25-16-07 of the North Dakota Century Code, relating to the disclosure of individual records of a treatment or care center for developmentally disabled individuals.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Section 25-16-07 of the North Dakota Century Code is amended and reenacted as follows:

25-16-07. Records of treatment or care center confidential. ~~No~~ An agent of the department of human services or the superintendent of the developmental center at westwood park, Grafton or the licensee or their agents or employees may not disclose the contents of the individual records of a treatment or care center for developmentally disabled ~~persons~~ individuals, nor of the reports received ~~therefrom~~ from those records, except:

1. In a judicial proceeding when ordered by the presiding judge;
2. To officers of the law or any other legally constituted boards or agencies serving the interests of the residents; ~~or~~
3. To the parents or legal guardians of the resident-;
4. To a physician to aid in the treatment of an individual within the fourth degree of consanguinity of a deceased resident, if the disclosure is limited to genetic health information that has a direct bearing on the health of the relative, the relative's child, or the relative's decision to have a child; or
5. To an individual who is within the fourth degree of consanguinity of a deceased resident, if the disclosure is limited to information about a resident needed to establish a family's genealogy."

Renumber accordingly

Engrossed HB 1425 was placed on the Seventh order of business on the calendar.

2003 TESTIMONY

HB 1425

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Yolanda Richardson
Operator's Signature

10/10/03
Date

SD - Care, Treatment & Rights of Residents in Facilities

27B-8-47. Disclosure of information to certain persons. If the community service provider or facility and the person with a developmental disability and the person's parent, if a minor, or the person's guardian consent, information may be disclosed to providers of supports and services to the person with a developmental disability, or to the person with a developmental disability, or to any other person or agency, if, in the judgment of the community service provider or facility, the disclosure would not be detrimental to the person with a developmental disability.

27B-8-48. Identity of person to be protected. If information is disclosed, the identity of the person to whom it pertains shall be protected and may not be disclosed unless it is germane to the authorized purpose for which disclosure was sought. If practicable, no other information may be disclosed unless it is germane to the authorized purpose for which disclosure was made.

27B-8-49. Further disclosure of information. Any person receiving information made confidential by § 27B-8-47 shall disclose the information to others only to the extent consistent with the authorized purpose for which the information was released.

Submitted by: Pat Galvin

UA 1425

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Operator's Signature

10/16/03
Date

House Human Services Committee
Fifty-eighth Legislative Assembly of North Dakota
House Bill No. 1425
February 5, 2003

Good morning, Chairman Price and Members of the House Human Services Committee. I am David Boeck, a State employee and lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project serves people with disabilities, some of whom have developmental disabilities.

HB 1425 amends a law to change the confidentiality of treatment or care center records only for persons with developmentally disabilities. The law would make a person's medical records available to the person's heirs. This would not improve current law.

The bill addresses only the records of a person with a developmental disability, not any other category of persons. The developmental disability appears to be the sole reason for this disparate treatment and, if so, it may be unlawfully discriminatory in violation of the Americans with Disabilities Act and the North Dakota Human Rights Act. There is no justification for treating persons with developmental disabilities differently from other people in this regard.

Substantively, the bill would make a person's medical records available to all heirs if the person had a developmental disability. This would not be good policy.

According to the Administrative Code, North Dakota social workers must protect the confidentiality of a dead client's records as though the client were still alive. See N.D.A.C. § 75.5-02-06.1-01 (7)(r). Other professionals have similar requirements. See Swidler & Berlin v. United States, 118 S.Ct. 2081 (1998) (the attorney-client privilege continues after the client's death).

A patient can authorize a medical provider to disclose medical records to anyone. It may be especially important to a patient to keep medical

records confidential from prospective heirs, a spouse, children, brothers, sisters, parents, in-laws. The patient's right to confidentiality survives the patient's death and deserves respect. If an heir had been interested during the patient's life, the heir could have asked the patient for permission to see the patient's records. If the patient denied a request, it should stand.

If the patient had a guardian, the heir could have asked the guardian, while the patient was still alive, for permission to see the patient's records. If the guardian denied a request, that decision should stand.

Many times, a patient would not participate in psychiatric care or would not be open with a psychiatrist if a particular relative (heir) might have access to the patient's records after the patient's death. Sometimes a patient most wants confidentiality to apply to an inquiring relative.

If it were desirable to change the law for everyone, this bill would have been much different.

Thank you. I am happy to answer any questions you may have.

Page 2 of 2

Al Costa Rickford
Operator's Signature

10/16/03
Date

38341.0303
Title.

Prepared by the Legislative Council staff for
Representative Galvin
March 11, 2003

PROPOSED AMENDMENTS TO ENGROSSED HOUSE BILL NO. 1425

Page 1, line 1, remove "subsection 3 of"

Page 1, line 5, replace "Subsection 3 of section" with "Section"

Page 1, after line 6, insert:

"25-16-07. Records of treatment or care center confidential.

1. ~~No~~ An agent of the department of human services or the superintendent of the developmental center at westwood park, Grafton or the licensee or their agents or employees may not disclose the contents of the individual records of a treatment or care center for developmentally disabled ~~persons~~ individuals, nor of the reports received therefrom, except:
 - ~~+~~ a. In a judicial proceeding when ordered by the presiding judge;
 - ~~2.~~ b. To officers of the law or any other legally constituted boards or agencies serving the interests of the residents; or"

Page 1, line 7, overstrike "3." and insert immediately thereafter "c." and replace "descendants" with "or other relative within four degrees of consanguinity"

Page 1, after line 7, insert:

- ~~"2.~~ The identity of the individual to whom the information pertains may not be disclosed unless germane to the purpose for which disclosure was sought. If practicable, other information may not be disclosed unless that information is germane to the purpose for which the disclosure was made. Any person receiving information may disclose the information to others only to the extent consistent with the purpose for which the information was released.
3. A disclosure may not be made under subdivision c of subsection 1 if in the judgment of the treatment or care center the disclosure would be detrimental to the individual with a developmental disability."

Renumber accordingly

Senate Human Services Committee
Fifty-eighth Legislative Assembly of North Dakota
House Bill No. 1425
March 12, 2003

Good morning, Chairman Lee and Members of the Senate Human Services Committee. I am David Boeck, a State employee and lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project serves people with disabilities, some of whom have developmental disabilities.

HB 1425 would compromise the confidentiality of records and reports from treatment or care centers for persons with developmentally disabilities. These records and reports would become automatically available to the person's descendants. This would include records and reports from the Developmental Center at Westwood Park, Grafton.

As this Committee is aware, this Legislature has seen many bills designed to improve the protection of confidential records. Several bills referred to this Committee have arisen from the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA). Other bills improve the confidentiality of financial information.

In HIPAA terms, the "records and reports from treatment or care centers for persons with developmentally disabilities" constitute "individually identifiable health information." These records and reports would also include confidential financial information.

The bill addresses only the records of people with developmental disabilities, not any other categories of people. The developmental disability is the sole reason for this disparate treatment and, if so, it may be unlawfully discriminatory in violation of the North Dakota Human Rights Act and the Americans with Disabilities Act. There is no legally adequate justification for treating persons with developmental disabilities differently from other people in this regard.

Enactment of the bill would be a bad policy outcome. A son, daughter, grandchild, great grandchild could look at Mom's records against her will. Mom may be competent but she could not prevent disclosure of these confidential records and reports to her descendants. Once Mom's descendants had the records and reports, they could disclose them to the world.

In other words, son Bobby could get the records and reports against Mom's wishes. Son Bobby could then disclose them selectively (or entirely) to Mom's roommate, Mom's neighbors, everyone who knows Mom, and total strangers. This formula invites problems.

Mom might legitimately insist that her records and reports remain confidential after her death. These records and reports contain private information. For example, Mom might not want son Bobby to know something she considered scandalous. Mom might not want son Bobby to know private thoughts that she had disclosed to her psychologist or caseworker.

Several laws protect confidentiality after death. According to the Administrative Code, North Dakota social workers must protect the confidentiality of a dead client's records as though the client were still alive. See N.D.A.C. § 75.5-02-06.1-01 (7)(r). Other professionals have similar requirements. See Swidler & Berlin v. United States, 118 S.Ct. 2081 (1998) (the attorney-client privilege continues after the client's death).

Current law provides adequate opportunity for descendants to see records and reports when they have a legitimate purpose. First, a competent person with a developmental disability could authorize disclosure of records and reports to any descendant. Second, a parent or guardian could authorize the disclosure of records and reports to any descendant. Third, a court can order disclosure, permitting disclosure only of material that would serve a legitimate purpose.

Page 2 of 3

Yolanda Richardson
Operator's Signature

10/6/03
Date

It might be especially important to Mom to keep medical records confidential from prospective heirs, a spouse, children, brothers, sisters, parents, in-laws. Mom's right to confidentiality survives her death and deserves respect. If son Bobby had been interested while Mom was alive, son Bobby could have asked Mom for permission to see her records. If Mom denied the request, her decision should stand.

If a guardian denied a request, that decision should stand.

Many times, a person would not voluntarily participate in treatment and care regimens if a particular relative might have access to the person's records after the person had died. Sometimes a person most wants confidentiality to apply to an inquiring relative.

Thank you. I am happy to answer any questions you may have.

Page 3 of 3

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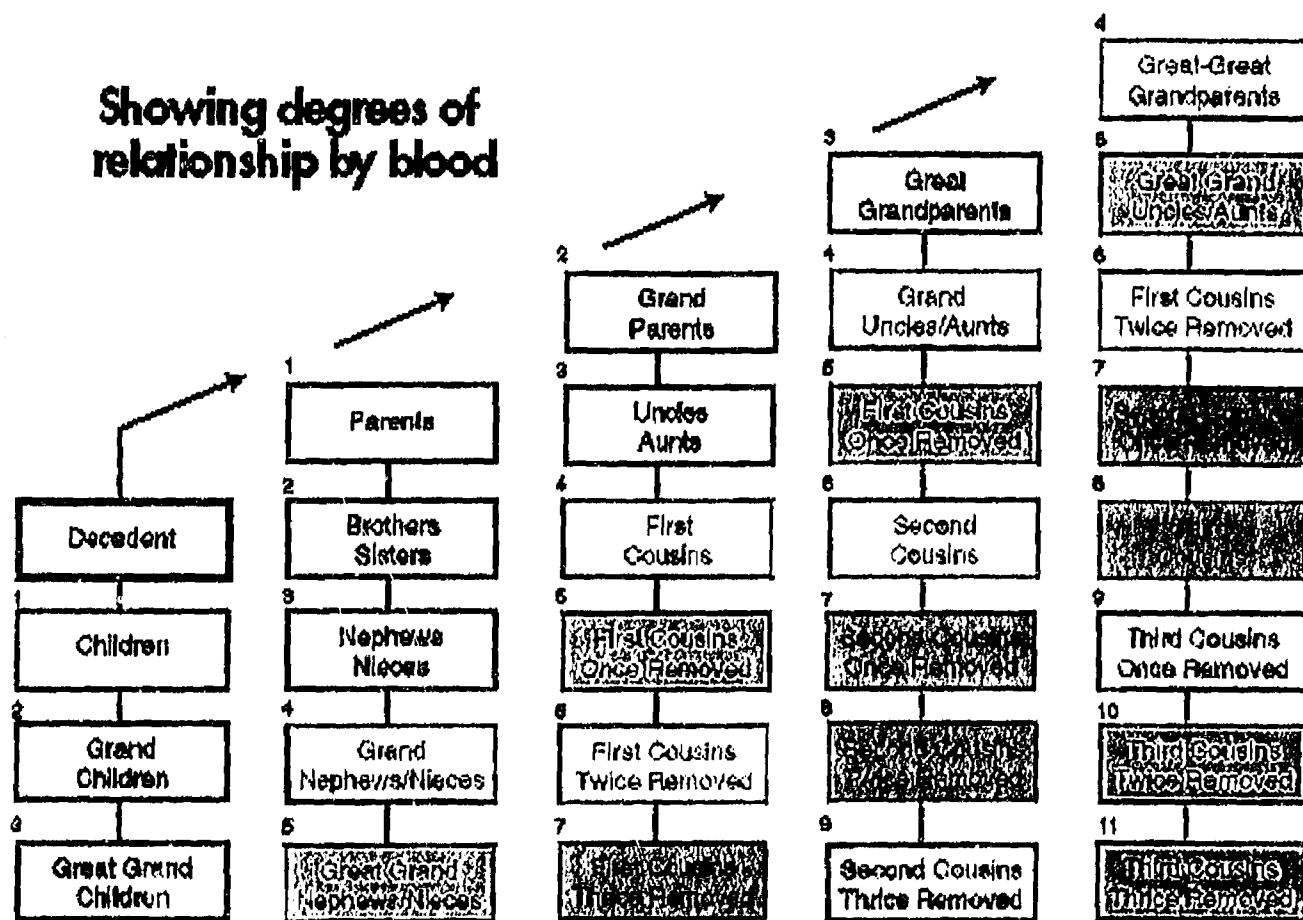
Sal Costa Richardson
Operator's Signature

10/16/03
Date



Consanguinity Chart

Showing degrees of relationship by blood



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La Costa Rickford
Operator's Signature

10/6/63
Date

Mayer, Tom A.

From: Mayer, Tom A.
Sent: Monday, March 17, 2003 8:29 AM
To: Tabor, Sandi L.
Subject: FW: HB 1425

-----Original Message-----

From: Mayer, Tom A.
Sent: Monday, March 17, 2003 8:26 AM
To: Grande, Bette B.; Tollefson, Ben C.
Subject: HB 1425

Rep. Grande and Sen. Tollefson,

I had another thought about this bill. As I mentioned I still think reference to "heirs" is best because it limits access to records of a decedent; but it would be acceptable to say "heirs within four degrees of consanguinity" to also limit access to closer relatives.

Another subsection could be added to avoid having to go to court to get these records as is required under the HIPAA regulations. The subsection could read:

"For purposes of this section an heir [within four degrees of consanguinity] has authority to act on behalf of a deceased resident regarding the deceased resident's health information records." ^(as)

The phrase in brackets is to indicate the optional nature of that provision.

Thomas A. Mayer

the personal representative

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talisa@justice.com

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From: "Mullen, Mike J." <mmullen@state.nd.us>

Date: Wed Mar 12 11:16:50 2003 (PST)

To: "'talisa@justice.com'" <talisa@justice.com>

Subject: HOB 1425

Content-Type: multipart/alternative;

boundary="----=_NextPart_001_01C2E8CA.E506121A"

Message-Id:

<EDCDEBD30204D411B28300508B5E071514505E18@email1.state.nd.us>

X-Received: 12 Mar 2003 19:16:53 GMT

X-Mailer: Internet Mail Service (5.5.2653.19)

Return-Path: <mmullen@state.nd.us>

Received: (cpmta 18891 invoked from network); 12 Mar 2003 11:16:53 -0800

Received: from 165.234.95.15 (HELO email1.state.nd.us)

by smtp.c014.snv.cp.net (209.228.35.69) with SMTP; 12 Mar 2003 11:16:53 -0800

Received: by email1.state.nd.us with Internet Mail Service (5.5.2653.19)

id <GJRKFC28>; Wed, 12 Mar 2003 13:16:52 -0600

MIME-Version: 1.0

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Talisa,

You asked if there might be a HIPAA issue. In my view there may be one and this is a possible way to address it.

I have not had time to polish the language; so there may be better verbs or intro words, etc.

THE AG HAS TAKEN NO POSITION ON THE ULTIMATE WISDOM OF THE BILL, BUT YOU MIGHT Wish TO KNOW IF THE DESCENDANTS OF A NON-DISABLED PERSON COULD SEE THEIR relatives HEALTH RECORDS AFTER THEY DIE.

PROPOSED AMENDMENT ENGROSSED TO HOUSE BILL NO. 1425

On page 1, line 7, after "resident" insert a comma and "except that with respect to protected health information, the disclosure is subject to the requirements of title 45, Code of Federal Regulations, part 164, section 502, subsection g"

HIPAA

Renumber accordingly

<http://mail.justice.com/mail/msg?fld=Inbox&id=5278>

3/17/2003

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Operator's Signature

Talisa Richardson

Date

10/16/03



"Bruce D. Murry"
<bmmurry@pioneer.state.nd.us>

03/21/2003 04:47 PM
Please respond to
bmmurry

To: <jlee@STATE.ND.US>, <rlbrown@STATE.ND.US>, <rerbele@STATE.ND.US>, <afairfle@STATE.ND.US>, <tflischer@STATE.ND.US>, <mpolovlt@STATE.ND.US>, <intern1@STATE.ND.US>
cc: <llarsen@STATE.ND.US>, <dboeck@STATE.ND.US>, <bmmurry@STATE.ND.US>, "Bruce Murry" <bmmurry@mac.com>
Subject: P&A language HB 1425

MEMORANDUM

TO: Honorable Judy Lee, Chairman
Senate Human Services Committee

FROM: Bruce Murry, Attorney at Law
North Dakota Protection and Advocacy Project

DATE: March 21, 2003

SUBJECT: House Bill 1425

Thank you for inviting me to suggest changes to HB 1425.

It is my understanding that the committee was especially concerned with issues facing prospective parents who may have congenital conditions in their family histories. It is also my understanding that the committee was especially considering disclosures concerning deceased residents.

I believe the goal of the committee was to balance the legitimate privacy interests of the person whose records are in question with the health interests of the person making the request.

I believe the committee would wish to avoid constitutional and statutory challenges to the proposed procedure. Focusing the legislation on persons with developmental disabilities raises constitutional issues and may violate the ADA and North Dakota Human Rights Act. The legislation could avoid these difficulties

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by addressing the records of all people, and not those with a specific disability.

The law amended by the current bill uses the term "treatment or care center." This term is defined for chapter 25-16 as:

"... any hospital, home, or other premises operated to provide relief, care, custody, treatment, day activity, work activity, or extended employment services to developmentally disabled persons."

The scope of the legislation would extend beyond the records of the State Developmental Center. The proposed legislation would include the records of numerous private providers, apartments, homes, and workplaces. It does not appear the goals of the legislation require access to the records of these entities.

The records these entities would include those created by others. Examples would include psychologists, psychiatrists, gynecologists, emergency rooms, and surgeons.

To avoid these concerns, it may be best to enact a separate law allowing limited access to medical records for genetic counseling:

A new section to chapter 23-12 of the North Dakota Century Code:

A physician may authorize the disclosure of genetic information of a former patient when requested if

1. The former patient is dead;
2. The genetic information is not available to the requesting individual from another source;
3. The genetic information includes only a list of diseases and conditions that could have been or could be passed genetically from one person to a biological descendant;
4. The individual requesting the information must be a relative of the deceased, former patient; and

5. A physician with appropriate specialty training or person with a doctorate and professional experience with genetics, states that the information would have a direct bearing on the health of the individual, the health of the individual's child, or the individual's decision to have a child.

If the Human Services Committee determines it is best to amend N.D.C.C. 25-16-07, P&A recommends the following changes to current law:

25-16-07. Records of treatment or care center confidential.

1. No agent of the department of human services or the superintendent of the developmental center at westwood park, Grafton or the licensee or their agents or employees may disclose the contents of the individual records of a treatment or care center for developmentally disabled persons, nor of the reports received therefrom, except:

1a. In a judicial proceeding when ordered by the presiding judge;

2b. To officers of the law or any other legally constituted boards or agencies serving the interests of the residents; or

3c. To the parents, or legal guardians of the resident.

2. The superintendent of the developmental center at westwood park, Grafton, has discretion to disclose genetic information of a former resident when requested if

a. The former resident is dead;

b. The genetic information is not available to the requesting individual from another source;

c. The genetic information includes only a list of diseases and conditions that could have been or could be passed genetically from one person to a biological descendant;

d. The individual requesting the information must be a relative of the deceased, former resident; and

e. A physician with appropriate specialty training or person with

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a doctorate and professional experience with genetics, states that the information would have a direct bearing on the health of the individual, the health of the individual's child, or the individual's decision to have a child.

Again, thank you for this opportunity. I would be happy to answer any questions the committee may have or offer any assistance.

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EXPLANATION OF THE HOGHOUSE AMENDMENT TO HB 1425

The original purpose of this legislation as explained by the bill sponsors was to permit a family to complete a genealogy of their family, which included a family member who resided at the developmental center in Grafton. But, the original bill provided for the unrestricted disclosure of any information regarding an individual with a developmental disability upon the request of an heir (or descendant) within the fourth degree of consanguinity.

In contrast, the conference amendment is limited to information that is needed to permit the family to complete a family's genealogy. So the disclosure is targeted and limited to the purpose of the legislation.

Similarly, the Senate Human Services Committee in examining this legislation identified a concern regarding the disclosure of genetic information if the relative of a resident of the developmental center requested that information to determine if they might be the carrier of a gene creating a risk to themselves or to one of their children, etc.

Therefore, the conference amendment permits a physician to request disclosure of genetic information regarding a blood relative within the fourth degree of consanguinity of a deceased resident, if the disclosure is limited to genetic health information that has a direct bearing on the health of the relative, the relative's child, or the relative's decision to have a child.

Finally, the conference amendment is limited to disclosure of information regarding a deceased individual who was a resident of the developmental center. If the resident is living, their parents or legal guardian are available to make decisions regarding a disclosure of the resident's health information or other personal information.

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Connivance /kənáyvənt(s)/. The secret or indirect consent or permission of one person to the commission of an unlawful or criminal act by another. A winking at; voluntary blindness; an intentional failure to discover or prevent the wrong; forbearance or passive consent. *Pierce v. Crisp*, 260 Ky. 519, 86 S.W.2d 293, 296.

As constituting defense in divorce action, is plaintiff's corrupt consent, express or implied, to offense charged against defendant. *Muir v. Muir*, Del.Super., 7 Terry 578, 86 A.2d 857, 858. This defense has been abolished by many states with the enactment of no-fault divorce laws.

Connive /kənáyv/. To co-operate secretly with, or to have a secret or clandestine understanding with. To take part or co-operate privily with another, to aid or abet. To look upon with secret favor; it implies both knowledge and assent, either active or passive. See *Connivance*.

Connoissement /kónéysmón/. In French law, an instrument, signed by the master of a ship or his agent, containing a description of the goods loaded on a ship, the persons who have sent them, the persons to whom they were sent, and the undertaking to transport them; similar to the English and American bill of lading.

Connubium /kən(y)úwbíyám/. In the civil law, marriage. Among the Romans, a lawful marriage as distinguished from "concubinage" (*q.v.*), an inferior marriage.

Conocimiento /konóslým(t)yéntow/. In Spanish law, a bill of lading. In the Mediterranean ports it is called "póliza de cargamento."

In Spanish law, a recognizance.

Conpossession /kómpszésh(y)ow/. In civil law, a joint possession.

Conqueror /kónkərər/. In Norman and old English law, the same as "conqueror" (*q.v.*).

Conqueror. In old English and Scotch law, the first purchaser of an estate; he who first brought an estate into his family, or into the family owning it. 2 Bl. Comm. 242, 243.

Conquest /kónkwést/. In feudal law, acquisition by purchase; any method of acquiring the ownership of an estate other than by descent. Also an estate acquired otherwise than by inheritance.

In international law, the acquisition of the sovereignty of a country by force of arms, exercised by an independent power which reduces the vanquished to the submission of its empire. To conquer a territory or nation by means of force.

Conquestor /kónkwéstər/konkwéstər/. Conqueror. The title given to William of Normandy.

Conquète /kónkwéstə/kónkétə/. In French law, the name given to every acquisition which the husband and wife, jointly or severally, make during the conjugal

community. Thus, whatever is acquired by the husband and wife, either by his or her industry or good fortune, inures to the extent of one-half for the benefit of the other. In Louisiana, these gains are called *acquète*.

Conquisitio /kónkwəzish(y)ow/. In feudal and old English law, acquisition. 2 Bl.Comm. 242.

Conquisitor /kónkwəzáytor/. In feudal law, a purchaser, acquirer, or conqueror. 2 Bl.Comm. 242, 243.

Consanguineus /kónsəngwíniyəs/. Lat. A person related by blood; a person descended from the same common stock.

Consanguineus est quasi eodem sanguine natus /kónsəngwíniyəs est kwéysay iyówdəm səngwəni néytəs/. A person related by consanguinity is, as it were, sprung from the same blood.

Consanguineus frater /kónsəngwíniyəs fréytər/. In civil and feudal law, a half-brother by the father's side, as distinguished from *frater uterinus*, a brother by the mother's side. 2 Bl.Comm. 231.

Consanguinity /kónsəngwíniyədí/. Kinship; blood relationship; the connection or relation of persons descended from the same stock or common ancestor. Consanguinity is distinguished from "affinity," which is the connection existing in consequence of a marriage, between each of the married persons and the kindred of the other.

Lineal and collateral consanguinity. Lineal consanguinity is that which subsists between persons of whom one is descended in a direct line from the other, as between son, father, grandfather, great-grandfather, and so upwards in the direct ascending line; or between son, grandson, great-grandson, and so downwards in the direct descending line. Collateral consanguinity is that which subsists between persons who have the same ancestors, but who do not descend (or ascend) one from the other. Thus, father and son are related by lineal consanguinity, uncle and nephew by collateral consanguinity.

Conscience. The moral sense; the faculty of judging the moral qualities of actions, or of discriminating between right and wrong; particularly applied to one's perception and judgment of the moral qualities of his own conduct, but in a wider sense, denoting a similar application of the standards of morality to the acts of others. The sense of right and wrong inherent in every person by virtue of his existence as a social entity; good conscience being a synonym of equity. In law, especially the moral rule which requires probity, justice, and honest dealing between man and man, as when we say that a bargain is "against conscience" or "unconscionable," or that the price paid for property at a forced sale was so inadequate as to "shock the conscience." This is also the meaning of the term as applied to the jurisdiction and principles of decision of courts of chancery, as in saying that such a court is a "court of conscience," that it proceeds "according to conscience," or that it has cognizance of "matters of conscience."