

BARRIERS TO UNLOCKING BIG DATA TO EXPLORE LGBTQ+ POPULATIONS IN SOUTH CAROLINA

Jennifer T. May, PhD, RN, ANP-BC

Swann Arp Adams, PhD



BACKGROUND & SIGNIFICANCE



Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ+)

- Currently, 13.9 million adults identify as LGBT¹
- More LGBT adults live in the South than any other region¹
- >80% experienced discrimination or victimization²



Health Disparities

- Elevated risk for social isolation and loneliness
- Poorer physical & mental health
- Increased risk for developing cognitive impairment or dementia



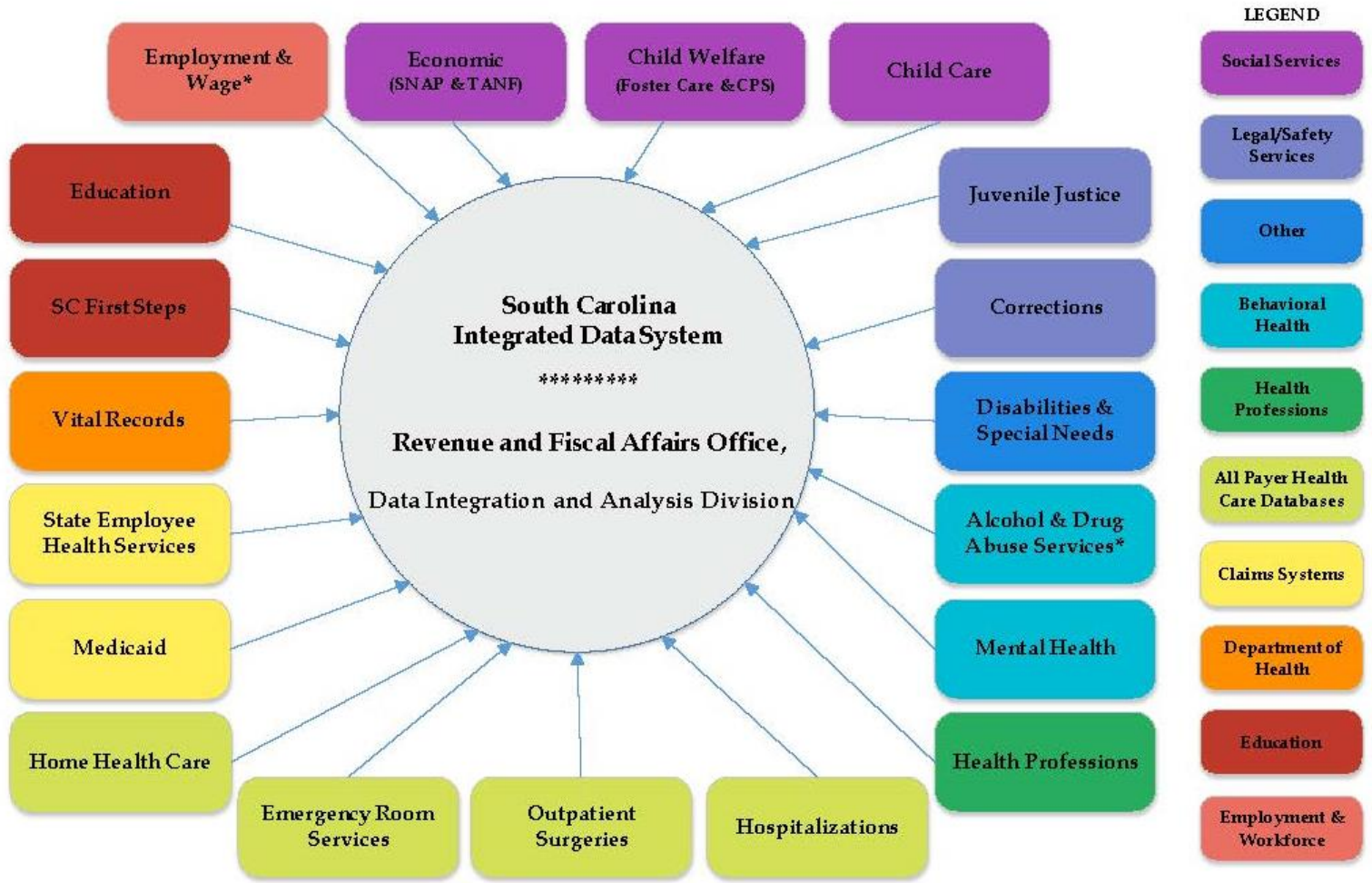
LGBTQ+ Data Collection

- 2015- CMS promoting interoperability program
- Lack of data limits the ability to provide LGBTQ+ adults the care they need³

AIM



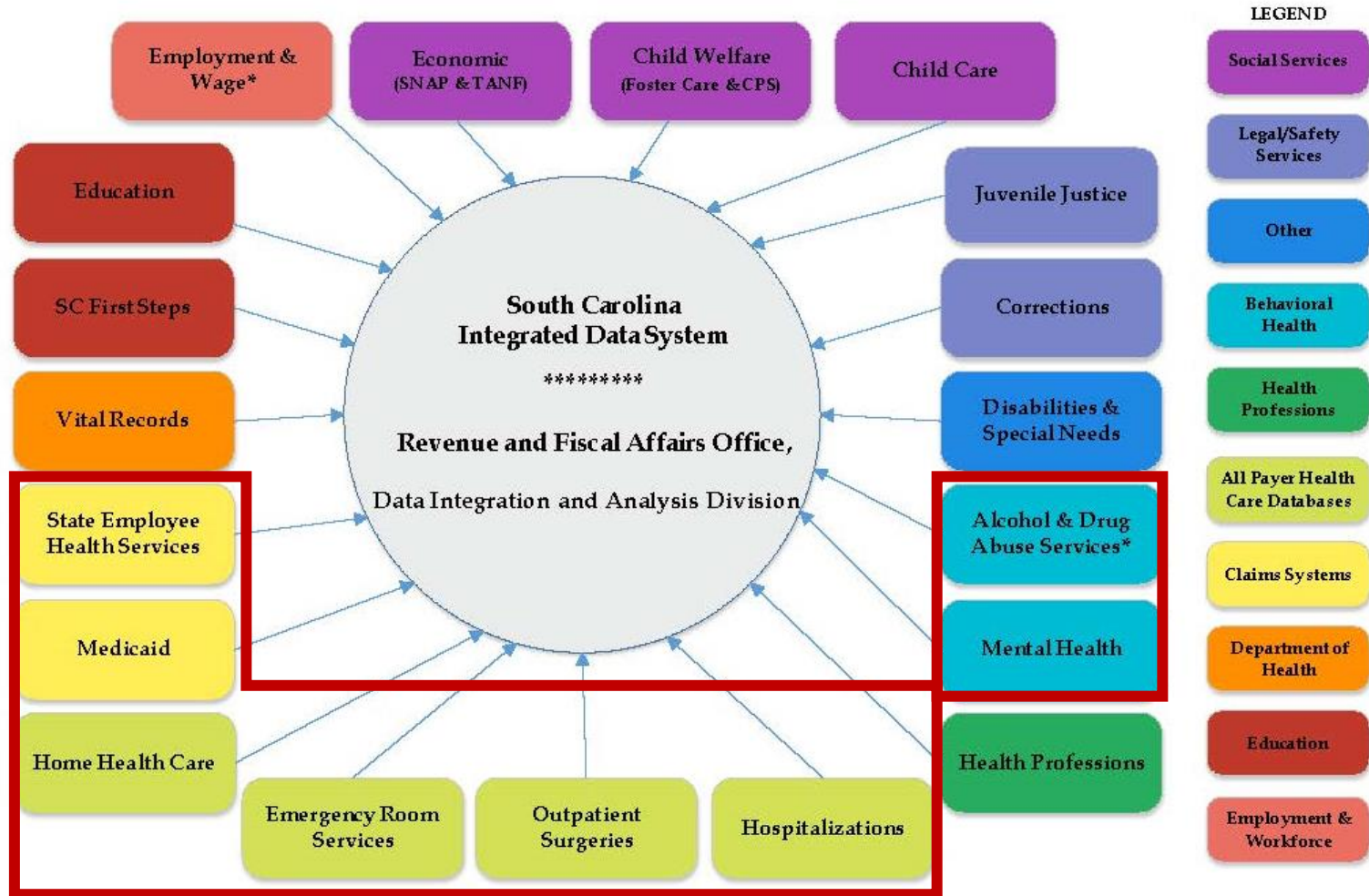
To assess the availability of data on LGBTQ+ adults (≥ 18 years) in South Carolina using the South Carolina Integrated Data System (SCIDS)



METHODS

- Sequential mixed methods
- Key informant interviews with Data Integration and Analysis Division at SC Revenue and Fiscal Affairs Office
- Descriptive data analysis 2000 to 2022 data for adults (≥ 18 years) with specific transgender ICD-9, ICD-10 codes, and DSM-5 codes

SCIDS SOURCES EXPLORED



RESULTS

- SCIDS Informant Interviews
- SOGI data not available from state agencies and organizations in the SCIDS
- Transgender adults explored with specific codes:
 - ICD-9, ICD-10, DSM-5

Key Takeaway:
SOGI data is not available from state agencies in the SCIDW

TRANSGENDER CODES EXPLORED

ICD-9	ICD-10	DSM-5
302.50 (Transsexualism with unspecified sexual history)	F64.0 Transsexualism/ Transgender in adolescence and adulthood	302.85 Gender dysphoria in adolescents and adults
302.51 (Transsexualism with asexual history)	F64.9 Dysphoria, gender (gender incongruence)	
302.52 (Transsexualism with homosexual history)	F64.2 Gender identity disorder of childhood	
302.53 (Transsexualism with heterosexual history)	Z87.890 Personal history of sex reassignment	
302.85 (GID in adolescents or adults)		

RESULTS

SCIDS Agencies Explored	Transgender Patients*
Alcohol and Drug Abuse Services	*0
SC Dept of Mental Health	Not received at the time of presentation
Medicaid	Not received at the time of presentation
State Employee Health Plan (PEBA)	Not approved
Home Health Care	33
Emergency Room Services	1045
Outpatient Surgeries	799
Hospitalizations	821

*Counts are from January 2016-2022

DISCUSSION

- SCIDS is robust and integral in understanding disparities and resource needs throughout South Carolina
- State agencies and organizations may be individually collecting SOGI
- Access to limited data from specific sources
- Lack of access to SOGI data (if collected) can lead to biased findings in disparity studies and resource needs of LGBTQ+ citizens of South Carolina
- The potential for using data for harm

CALL TO ACTION: REQUEST FOR DATA COLLECTION AND ACCESS

- Lack of fully understanding the unique needs of LGBTQ+ citizens of South Carolina.
- Recommend developing safe, protective methods of providing the option to request SOGI data if collected.

Key Recommendation: Mandating the collection of SOGI data throughout state organizations and agencies in South Carolina to ensure appropriate care and resources are being allocated.

REFERENCES

1. Williams Institute (2023). Adult LGBT Population in the United States. Retrieved from <https://williamsinstitute.law.ucla.edu/publications/adult-lgbt-pop-us/>
2. Fredriksen-Goldsen, K., et al. (2017). Chronic health conditions and key health indicators among lesbian, gay, and bisexual older US adults, 2013-2014. *American Journal of Public Health*. 107(8): 1332-8.
3. May, J.T., Myers, J., Noonan, D., McConnell, E., Cary, Jr., M.P. (2023). A Call to action to improve the completeness of older adult sexual and gender minority data in electronic health records. *Journal of the American Medical Informatics Association*. <https://doi.org/10.1093/jamia/ocad130>
4. Dragon CN, Guerino P, Ewald E, Laffan AM. Transgender Medicare Beneficiaries and Chronic Conditions: Exploring Fee-for-Service Claims Data. *LGBT Health*. 2017 Dec;4(6):404-411. doi: 10.1089/lgbt.2016.0208. Epub 2017 Nov 10. PMID: 29125908; PMCID: PMC5731542.

THANK YOU!

Jennifer May, PhD, RN, ANP-BC
University of South Carolina, College of Nursing
jm293@mailbox.sc.edu

Swann Arp Adams, PhD, MS, FACE
University of South Carolina, College of Nursing
swann.adams@sc.edu