Developing a Health Surveillance System for People with Intellectual Disabilities in the United States

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Adults with Intellectual Disability

- Complex Health Conditions
- Lower Screening Rates
- Mental Health Problems
- Psychotropic Drugs Overuse
- Poor Chronic Conditions Management
- Undetected Vision & Hearing Problems
- Limited Access to Health Promotion and Services
Selected Data Challenges

Intellectual Disabilities

- Definition
- Communication
- Stigmatization
- Confidentiality
- Proxy reporting
Opportunity to Improve Surveillance for People with Disabilities

Affordable Care Act of 2010
Section 4302
Section 4302

Data Collection, Analysis, and Quality

- Develop standards of measurement of sex, primary language, disability status
- Follow OMB standards at a minimum for race/ethnicity measures
- Develop standards for the collection of data
Current Status
Data Collection, Analysis, and Quality

1. Evidence-based, worked well in practice for national survey data collection.
3. Standards already mandated by the OMB - basis for any minimum standard.
4. Standards recommended are intended for person-level data collection.
Survey providers to assess access to care and treatment

Locations where people with disabilities access primary, acute, long-term care

Providers with accessible facilities

Number of employees trained in disability awareness and patient care
Current Status
Survey Questions

- Ongoing development and analysis of questions against existent surveys
- Discussion on recommendations for the Secretary
Conclusion

- Improved data collection will allow us the opportunity to better identify gaps.
- Data gaps will support the development of quality improvement interventions to meet the needs of this population.
- Data on health outcomes, social participation and quality of life are critical to monitor progress.
Conclusion (cont’d)

- Data may also serve to determine best practices, pending careful interpretation of findings.
- We must overcome some of the current methodological challenges.
- We must expand surveillance on an ongoing basis around the country.
- We must take advantage of existent surveys to expand and improve them.
THANK YOU!

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