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Abstract

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Figures
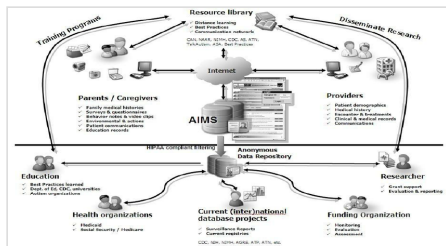
Health Informatics: A Roadmap for Autism Knowledge Sharing

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Abstract: With the prevalence of diagnosed autism on the rise, increased efforts are needed to support surveillance, research, and case management. Challenges to collect, analyze, and share typical and unique patient information and observations are magnified by expanding provider caseloads, delays in treatment and patient office visits, and lack of sharable data. This paper outlines recommended principles and approaches for utilizing state-of-the-art information systems technology and population-based registries to facilitate collection, analysis, and reporting of autism patient data. Such a platform will increase treatment options and registry information to facilitate diagnosis, treatment and research of this disorder.

I. BACKGROUND

Autism spectrum disorder (autism) is characterized by a range of neurological anomalies that typically include varying degrees of communication deficits and repetitive negative social behaviors. A tenfold increase in the incidence of autism over the past 15 years has been documented and is regarded as a significant public

maintain, and interoperability with other database projects.

In the National Institute of Mental Health's April 2004 *Congressional Appropriations Committee Report on the State of Autism Research*, the authors list the following obstacles, among others, to understanding the causes of and treatments for autism:

- Lack of a national autism twin registry that would allow researchers to access a large sample of well-defined twins where at least one twin is affected by autism.
- Lack of multi-site, high-risk population studies (i.e. pregnancies and infant siblings of individuals with autism) that would allow for increased knowledge about risk factors, early development of autism, and enhanced characterization of the disorder.
- Need for enhanced mechanisms to involve voluntary organizations, industries and potential donors in all stages of research design and implementation.

The shortcomings related to a lack of information resources can be overcome by the design and implementation of a longitudinal, person-based autism

health concern. Despite the documented increase in the incidence of autism, the cause(s) of this disorder and appropriate treatment remain mysterious. The NIH road map emphasizes the need for developing phenotypic signatures based on available evidence including documentation of behavioral, clinical and genetic traits, as well as contributions by the basic sciences and applied bioengineering such as medical imaging outcomes, auditory phenomenology, neuroscience, and brain modeling studies.

Current population-based databases include a number of cross sectional studies sponsored by the CDC (Autism and Developmental Disabilities Monitoring Network [ADDM Net] and NIMH). These involve partnerships between a variety of governmental agencies, universities, and leading nonprofit organizations. Database initiatives that have been spearheaded include the Autism Genetic Resource Exchange, Autism Treatment Network, and Autism Tissue Program. Each of these offer contributions to the understanding of autism, but have significant limitations in terms of ease of use, costs to build and

registry that would leverage the benefits provided by telehealth and the benefits offered by an interoperability infrastructure which integrates and builds on information already generated by the above referenced initiatives. This paper outlines a vision for such a registry.

II. ROADMAP: INTERGRATING DATA RESPOSITORIES, TELEHEALTH, AND HEALTH INFORMATICS

Complementary to necessary in-person examinations, the value of telemedicine and information technology to support the evaluation, diagnosis, and treatment of autism by the community of parents, health care providers, educators, and researchers has been outlined. (Oberleitner 2004). To date, the ability to create a sharable information resource to support the diverse community of stakeholders is limited. The following illustration provides the concept for a new Autism Information Management System (AIMS). This system is designed, in part, to create a complementing patient registry that will be interoperable in relation to the current database initiatives, while providing a platform

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