Background & Objectives

In 2010, an intelligent 27-year-old man with cerebral palsy and limited ability to communicate his needs was admitted to hospital for surgical removal of a baclofen pump. He was subsequently placed on an adult unit where there was limited understanding of people with disabilities. No one asked him about his competence to make personal decisions. While fully continent but unable to express this, he was placed in diapers until discharge back to his group home. To this day, he remembers this hospital stay as the "most humiliating experience of his life." With this distressing story as a "sentinel event", in 2011 a multidisciplinary group at Kennedy Krieger Institute and Johns Hopkins created IAM (Important Information About Me) - to be a "voice" for those who cannot "speak".

IAM is an innovative and comprehensive patient portability profile app under ongoing development to empower children with neurodevelopmental disabilities. We initially presented IAM as a demonstration poster featuring a paper booklet version at the Academy meeting in Toronto in 2012. We now return to the Academy with an electronic prototype (iPad app version) - both to demonstrate the development of our idea as well as to seek input from Academy members in regard to future directions for added features.

Description

We recognize that children, adolescents and adults with neurodevelopmental disabilities often have complex medical histories and long-term care needs that are difficult to share with others due to challenges in communication, cognition and/or motor function, as well as the time constraints in a fast moving society. Households often rely on their memory, loose papers or 3 ringed binders to manage family health records. Both in breadth and scope, IAM is the only iPad app equipping the disability world with the tools to communicate who they are and their individual needs. Beyond medical history, IAM has novel ways to express coping mechanisms, behavior, feeding, communication and self-perception of disability. Our app allows for video and picture embedding and medication notifications, providing readers with a better understanding of the child's baseline abilities and needs. Ultimately we see this becoming a platform compatible with electronic health record software, where patients of all ages can access and store their medical records.

Future Aims

10 families have been piloting our IAM iPad app since April 2014. Over the summer, we created a comprehensive web-based survey to test user interface and user experience. Our survey is designed to identify the use cases, price points, and areas of weakness for further development. We will be using the survey results to tailor our app for the January 1st 2015 apple store launch. Although we will not be using the feedback from our 10 families for research, we plan to submit an IRB for a future research project among our Apple store downloaders.

Currently, the medical transition of care of children with disabilities to the adult world is less than optimal. With the nation invested in telehealth and patient, we envision IAM as a standard tool in the transition of care from medical and rehabilitative centers to community providers and on into adulthood.

Acknowledgments: We thank the parents who shared their time and experience and gratefully acknowledge the efforts of Peter Dziedzic, Jim Anders, Karen Cox, Manu Khare, Kevin Kennedy, Tammie Parker, and Michael Johnson.