Application of the Concept of "Dignity of Risk" – John's Story

A genuine person-centered approach is a key priority for effective disability competent care coordination. Care Coordinators help people with disabilities and chronic health conditions manage risk, within the context of what is important to them and what is important for them.

John's Story

John[1] is a 56 y/o man with severe osteoarthritis, which particularly affects his knees and shoulders. His mobility has been limited for many years. He currently weighs almost 500 pounds and is no longer able to walk or bear weight long enough to transfer from his bed to a chair. As a result, he has not left his bed for the past six months. He also has significant longstanding mental health issues related to depression and anxiety.

John has lived in his own apartment for many years. He is dependent in most Activities of Daily Living (ADLs) and Independent Activities of Daily Living (IADLs) due to mobility limitations and his weight. He receives nine hours per day of personal care and homemaking services through county waiver long-term care services. John has many interests and made his living as a professional artist for many years. He has emotional support from family and friends, but they all live outside the state. If there is a gap in personal care or provider coverage, no one else is around to help. His emergency backup plan is to have a cell phone within reach at all times and to call 911 if necessary. John feels it is important to remain in his home and stay out of the hospital.

Prior to his referral to care coordination, John had problems with cellulitis and skin breakdown on the back of his legs and abdomen. John also experienced recurrent urinary tract infections (UTI) resulting in multiple hospital admissions. In addition, with each admission his cellulitis was aggravated and he developed skin breakdown, which extended his recovery time. John is highly sensitive about his weight and does not want to discuss this with any health care provider. He does not want to lose weight and has a history of changing medical providers if he is told he must lose weight. As a result, John has significant anxiety about attending medical appointments and often did not keep them.

Below is a summary of what the assessment team took away from their first meeting with John, and how they approached developing a plan for their work with him.

Understanding the Story

- 56 year old male with severe osteoarthritis and weighs just under 500 pounds
- Limited Mobility, and is no longer able to bear weight or transfer out of bed to chair
- Significant, long -standing mental health issues related to depression & anxiety
- Dependent with most ADLs; some IADL dependencies

[1] *John's story was written by Kathy Thurston, MS, PHN, Director of Health Coordination at AXIS Healthcare, a disability-competent care coordination organization in Minnesota. Some facts have been modified to protect the participant's privacy.*

- Highly sensitive about his weight, and does not want to discuss losing weight
- Good emotional support system, but lives alone and has no one close by
- Health History includes:
  - ❖ Recurrent cellulitis and skin breakdown
  - ❖ Recurrent UTIs & Hospital Admissions

Understanding What is Important to Him

- It is very important to him to remain in his own home
- It is important to him to stay out of the hospital
- He does not want to discuss his weight or the need for weight loss, and is therefore anxious about going to medical appointments
- He is satisfied with staying in his bed, and is able to call for help if needed

Developing a Plan

1. Framing his key risks
2. Identifying ideal short and long-term goals
3. Developing a strategy for approaching John to discuss his plan of care
4. Ideas for supporting John to achieve his goals

Care Coordination Intervention & Outcome:

When the care coordinator first met with John, she learned it was important to him to have someone "in his court" at appointments and help ensure that his needs, symptoms and concerns were communicated. They worked together and made a plan to support him. His care coordinator arranged for a wound nurse to work with him in his home, who established a wound management program. In addition, the coordinator worked with John and his primary care provider and urologist to establish a home-based UTI fast response plan in partnership with an in-home lab service. John currently has no skin breakdown and has not been in the hospital for over a year.

The care coordinator now attends all initial medical consult visits, his annual physical and helps him prepare written questions via phone prior to other appointments. John understands that he lives with risk by continuing to live on his own and not losing weight. Through the support of care coordination, John has improved access to appropriate care and greater respect of his choice to live with risk.