

PROJECT ECHO Knowledge Network

RUTGERS CANCER INSTITUTE OF NEW JERSEY & NORTH JERSEY HEALTH COLLABORATIVE PROJECT ECHO: *Addressing Barriers to Healthcare & Preventive Cancer Screenings in Individuals with Developmental & Intellectual Disabilities (IDD)*

Scenario Briefing Form

ECHO ID:

Key Questions for Discussion

(Note to the presenter: Please focus on the key question relating to the most significant challenge faced by your consumers/patients/providers related to barriers to healthcare and cancer screenings for individuals with IDD.)

Scenario/Examples	
	<ul style="list-style-type: none">1) Cancer screenings:<ul style="list-style-type: none">a) Colonoscopy- prep can be a challengeb) Mammogram- images can be difficult to obtainc) Pap smear- Procedure can be difficult to complete 2) Eye exams:<ul style="list-style-type: none">a) screenings for vision, glaucoma, macular degeneration, diabetic retinopathya) cataracts- surgical repair, lens measurements, can be a challenge 3) Dental:<ul style="list-style-type: none">a) Daily hygieneb) Cleaningsc) Dental proceduresd) Oral cancer screenings 4) Psychiatric care:<ul style="list-style-type: none">a) Psychiatric diagnoses vs disabilityb) Polypharmacy

Key Stakeholders	<ol style="list-style-type: none"> 1) Consumers 2) Families 3) Support agencies 4) Medical professionals 5) Diagnostic centers 6) DDD 7) Pharmacies 8) Community 9) Day programs/work environments 10) Hospital/ER 11) Emergency responders
Local-Related Issues: (Local access, processes, staffing, etc.)	<ol style="list-style-type: none"> 1) Staffing: <ol style="list-style-type: none"> a) Hiring- finding staff that pass screenings, trainings, work well with consumers b) Training- medical history, medication administration, supporting the individuals vs doing “for” the individuals c) Turnover- creates gap in knowledge of consumers, medical continuity of care 2) Vehicles/transportation- availability with multiple schedules to accommodate 3) Finding providers that take insurance, understand our consumers’ needs, complete paperwork & documentation per DDD requirements 4) Accessibility- mobility, visual, auditory, cognitive, etc

<p>National-Related Issues</p>	<p>1) Education:</p> <p>a) What are group homes vs medical facilities</p> <p>b) Understanding & caring for individuals with disabilities: May have difficulty with:</p> <ul style="list-style-type: none"> • following direction • Physical barriers • Comorbidities • Fears • Sensory • Touch sensitivity • Communication <p>c) Communicating with individuals with disabilities:</p> <ul style="list-style-type: none"> • have patience • explaining procedure prior • May use iPads/visual <p>2) Attitude:</p> <p>a) Medical care for individuals with disabilities</p> <p>b) Worth of the individual- understanding & caring</p> <p>c) Involving the individual in the process- what are their wants, needs, feelings</p> <p>3) Social:</p> <p>a) Inclusion vs integration</p>
<p>Governance Issues: (Funding, Structures, Processes, etc.)</p>	<p>1) Insurance- difficult to find MDs taking these insurances</p> <p>2) DDD Regulations- finding MDs that will cooperate with the necessary paperwork needed</p> <p>3) Guiding philosophy: care support vs care giver- supporting vs doing “for”</p>



Other Relevant Information:

Legal:

- a) Should people with IDD have their rights removed
- b) Guardians- medical decisions- being able to separate, boundaries, what's best for the individual

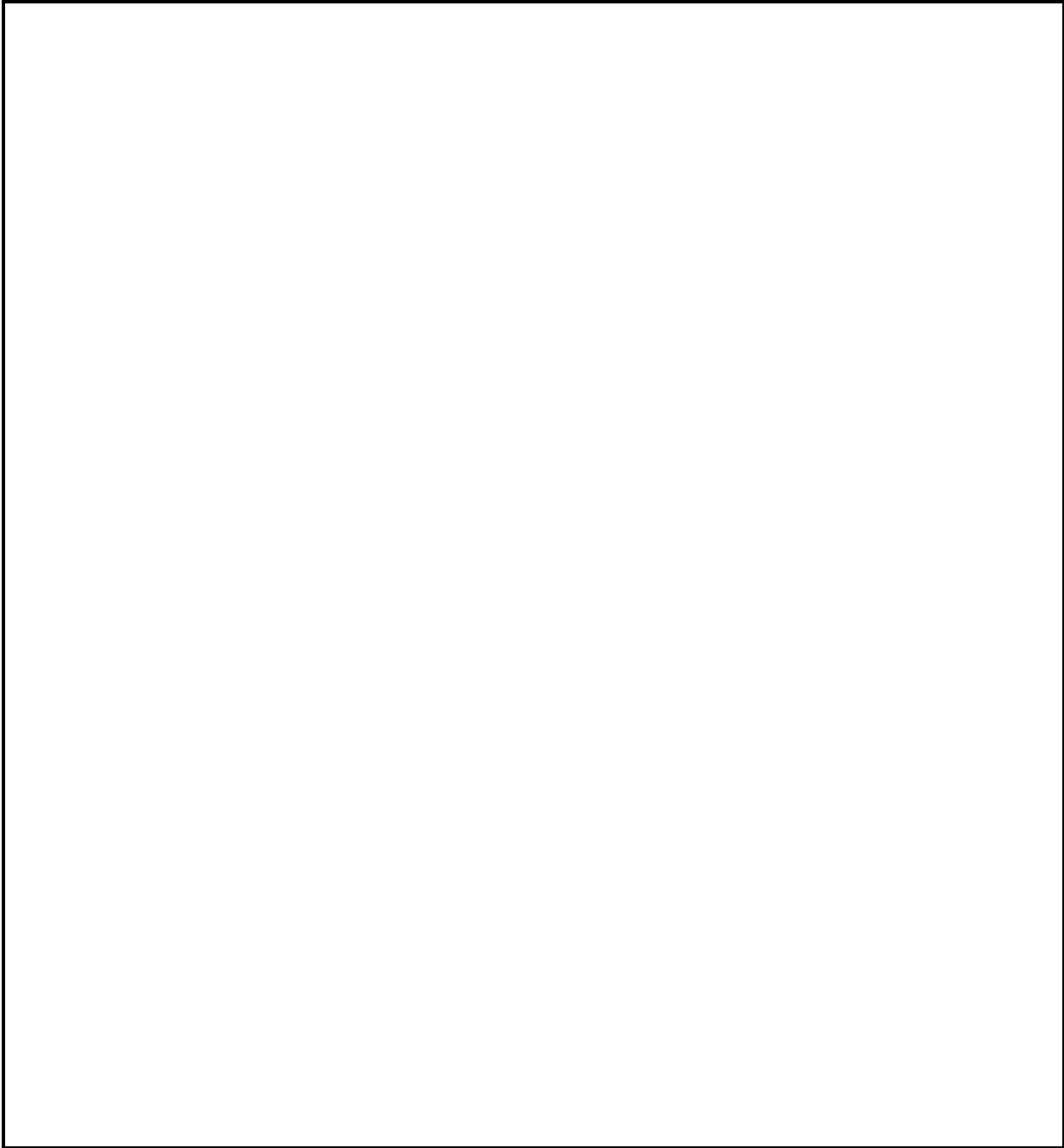
Outcomes

In this section, include the anticipated outcomes that would occur if changes are made as a result of interventions made. What might happen without this intervention?

Decreased quality of life
Decreased longevity
Wasted resources
Late detection of cancers
Lack of education
Lack of acceptance
Segregation and exclusion
Missed diagnoses

Reflections and Points for Discussion:

Ongoing process- not a linear process
American healthcare system



- **It is intended the above text will be prompts only visible to presenter when completing electronic case presentation.**

PROJECT ECHO Knowledge Network

RUTGERS CANCER INSTITUTE OF NEW JERSEY & NORTH JERSEY HEALTH COLLABORATIVE PROJECT ECHO: *Addressing Barriers to Healthcare & Preventive Cancer Screenings in Individuals with Developmental & Intellectual Disabilities (IDD)*

Scenario Briefing Form

ECHO ID:

What are the barriers to cervical, colorectal and skin cancer screening and how can it be addressed?

(Note to the presenter: Please focus on the key question relating to the most significant challenge faced by your consumers/patients/providers related to barriers to healthcare and cancer screenings for individuals with IDD.)

Scenario/Examples	
	<p>A 38 woman with I/DD enters the gynecologist's office for an annual exam. APN performs a blind cervical sweep in hopes to get cervical cells. NEGATIVE for cancerous cells.</p> <p>Woman has spoken to DSP's that she trusts about being raped in the past. Senior admin staff have verbally confirmed this.</p> <ol style="list-style-type: none">1. Incomplete documentation and medical history2. Incomplete family history due to lack of involvement.3. Incomplete sexual history due to individual's inability to convey her past.4. Staff lack of knowledge of her past.5. APN assumed no sexual activity6. Incomplete testing7. No STD tests ordered8. No abuse screening <p>A 53 Caucasian YO Male loves to sit on the porch and sunbathe. He has done so his whole life though his utilizes a wheelchair now. Staff apply sunscreen regularly. He has never been screened for skin cancer.</p> <ol style="list-style-type: none">1. He does not get a complete physical exam because he cannot be lifted onto the examination table.2. The doctor any sees the skin on his lower arms.3. Has not been asked of family history of skin cancer.4. No standards or requirements like other screenings.

	<p>A 50 YO male is had a handful of bowel incontinence episodes and starting to leave stool marks on his bedsheets both of which are unusual for him. APN states that is most likely the diuretic he is on. After a decrease in the diuretic with no change strong advocacy he is referred to the gastroenterologist. GI states since he is having less incidences therefore, a cologuard at some point is acceptable.</p>
Key Stakeholders	<p>DSP Individuals Physicians Families/guardians</p>
Local-Related Issues: (Local access, processes, staffing, etc.)	<p>Staff shortage Lack of training from nurses Accessibility issues</p>



National-Related Issues	Staff shortage Lack of training from nurses Accessibility issues
Governance Issues: (Funding, Structures, Processes, etc.)	Fee for service doesn't recognize non-billable nursing fees.



Other Relevant Information:

Possible Interventions-

1. Talk and train staff on the individual on a continuous basis.
2. Discuss each individual's status at each staff meeting.
3. Document each individual's health history-sexual, mental and physical health.
4. Allow management and staff to be a probationary period where they could learn how to complete appointments correctly.
5. Train the individual to observe his/her own body and what it means. (i.e. normal bowel movement consistencies, urine color, etc.)
6. Advocate for complete and thorough medical exams.
7. Utilize a database to document care that includes an in-depth description of their past.
8. Have lifts and larger examination rooms
9. Offer complete screening for all
10. Advocate for screening for all

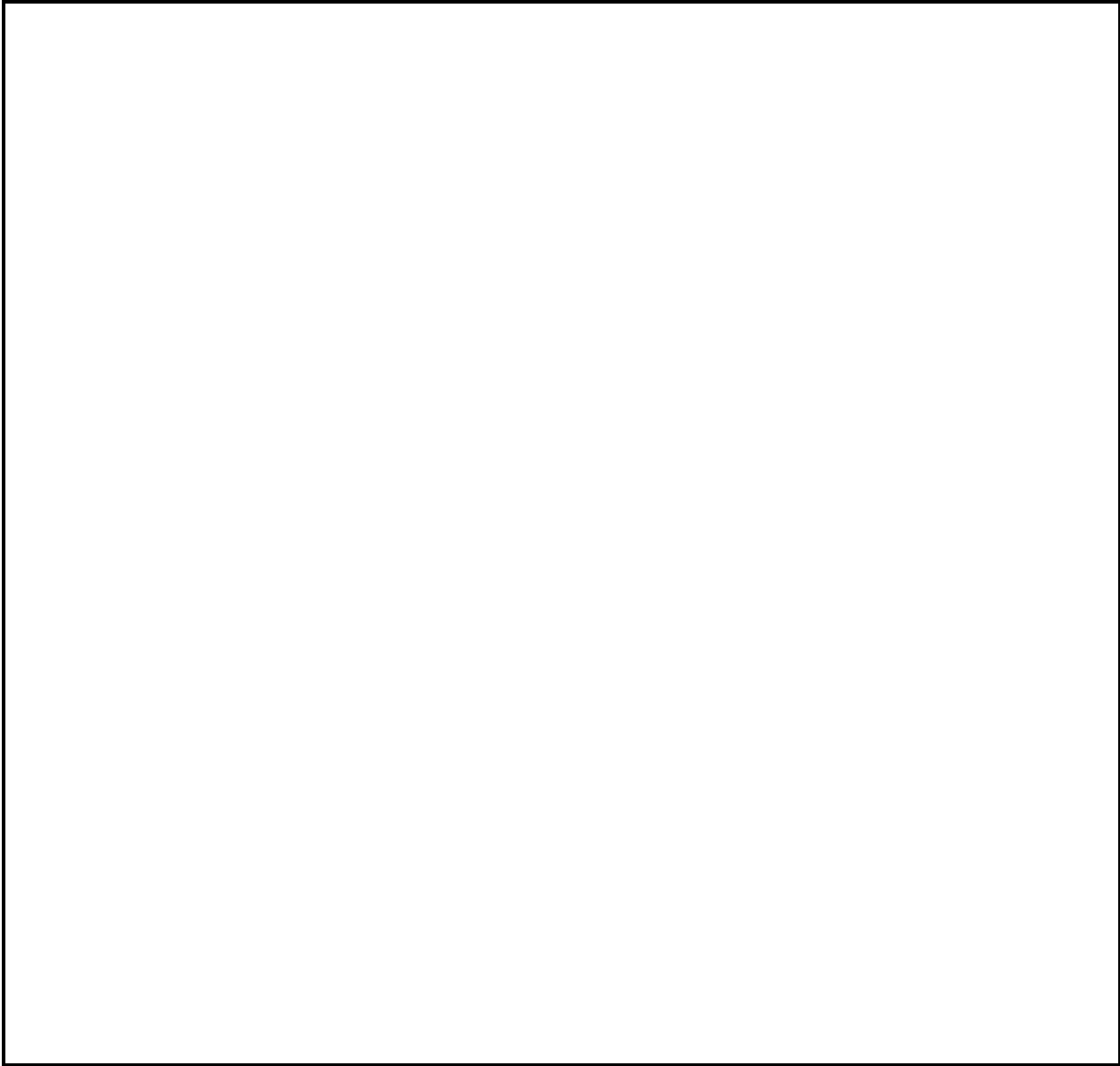
Outcomes

In this section, include the anticipated outcomes that would occur if changes are made as a result of interventions made. What might happen without this intervention?

If implemented, there would be overall improved quality of care, decreased hospitalizations, less polypharmacy and less staff turnover.

Reflections and Points for Discussion:

What can we do within our own constraints now? What can we can our goals be for the future?



- It is intended the above text will be prompts only visible to presenter when completing electronic case presentation.