Health Symposium: Health Care for Adults with Intellectual and Developmental Disabilities

Monday, November 18, 2013

RUTGERS
Robert Wood Johnson Medical School

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES
New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service

New Jersey Developmental Disabilities Transition to Adult Health Care Forum

Presentation for AUCD Health Symposium:

Health Care for Adults with Intellectual and Developmental Disabilities

November 18, 2013

Made possible by funding from Special Hope Foundation

The Special Hope Foundation

Project Personnel

Principal Investigator
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Project Manager
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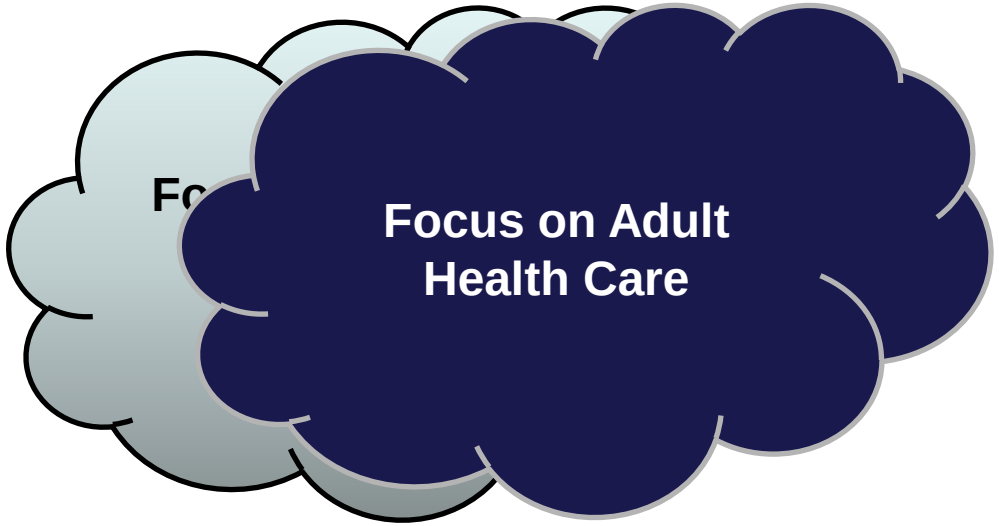
Project Coordinator
Susan R. Ellien, MSW

Project Goal

To build the capacity of the adult health care system in New Jersey to support the transition of emerging adults with developmental disabilities to transition to appropriate health care.

Paradigm Shift



Objectives

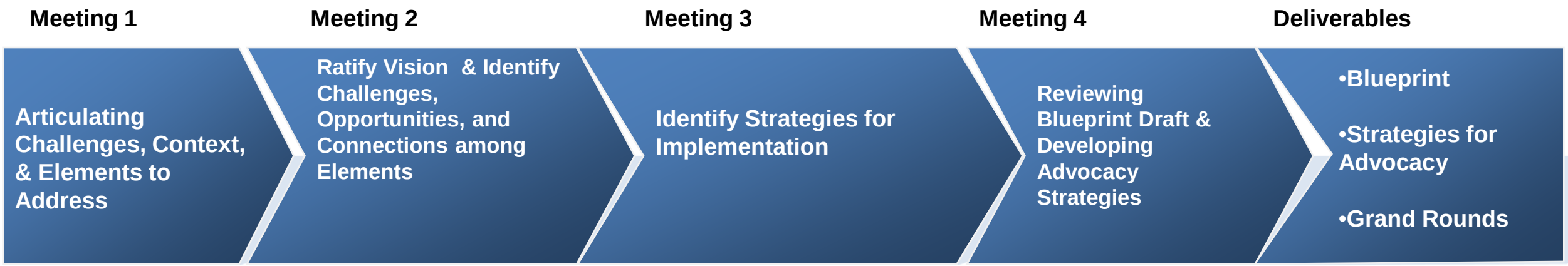
- Convene a year-long **Adult Health Care Forum** with a **broad array of stakeholders**
- Support the planning processes of the Forum
- Develop and Disseminate "**An Action Blueprint for Transition to Adult Health Care**"
- Develop and promote **advocacy strategies for implementation** of the Action Blueprint
- Provide a **Family Medicine Network Grand Rounds** on transition to Adult Health Care

Stakeholders

- **Medical School**
  - Chair, Family Medicine and Community Health
  - Chair, Internal Medicine
  - Chief, Division of Adolescent Medicine
  - Division of General Pediatrics
  - Family Medicine/Boggs Center Primary Health Care for Adults
- **New Jersey State Departments and Agencies**
  - Department of Children and Families
  - Department of Health
  - Department of Human Services
  - Division of Developmental Disabilities
  - Division of Disability Services
  - Special Child Health Services
  - Medical Assistance and Health Services (Medicaid)
- **Medicaid Managed Care Organizations (MCOs)**
  - Amerigroup
  - HealthFirst NJ
  - Horizon Health NJ
  - United Health Care
- **Health Care Providers**
  - Director, Matheny Institute for Research in Developmental Disabilities
  - Division Director, Developmental Disabilities at Atlantic Health
  - Associate Vice President Rehabilitation Services, Children's Specialized Hospital
  - Developmental Disabilities Health Center at Atlantic Health System
- **Family Members**
- **Self-Advocates**
- **Community Provider and Advocacy Organizations**
  - Arc of Mercer County
  - Arc of Monmouth County
  - Arc of New Jersey
  - Catholic Charities
  - Disability Rights New Jersey
  - Family Resource Network
  - New Jersey Council on Developmental Disabilities
  - Statewide Parent Advocacy Network of New Jersey (SPAN)/PTI

Increasing the Capacity of the Adult Health Care System to Support the Transition of Young Adults with Developmental Disabilities

PLANNING PROCESS



Vision Statement

(*still in draft*)

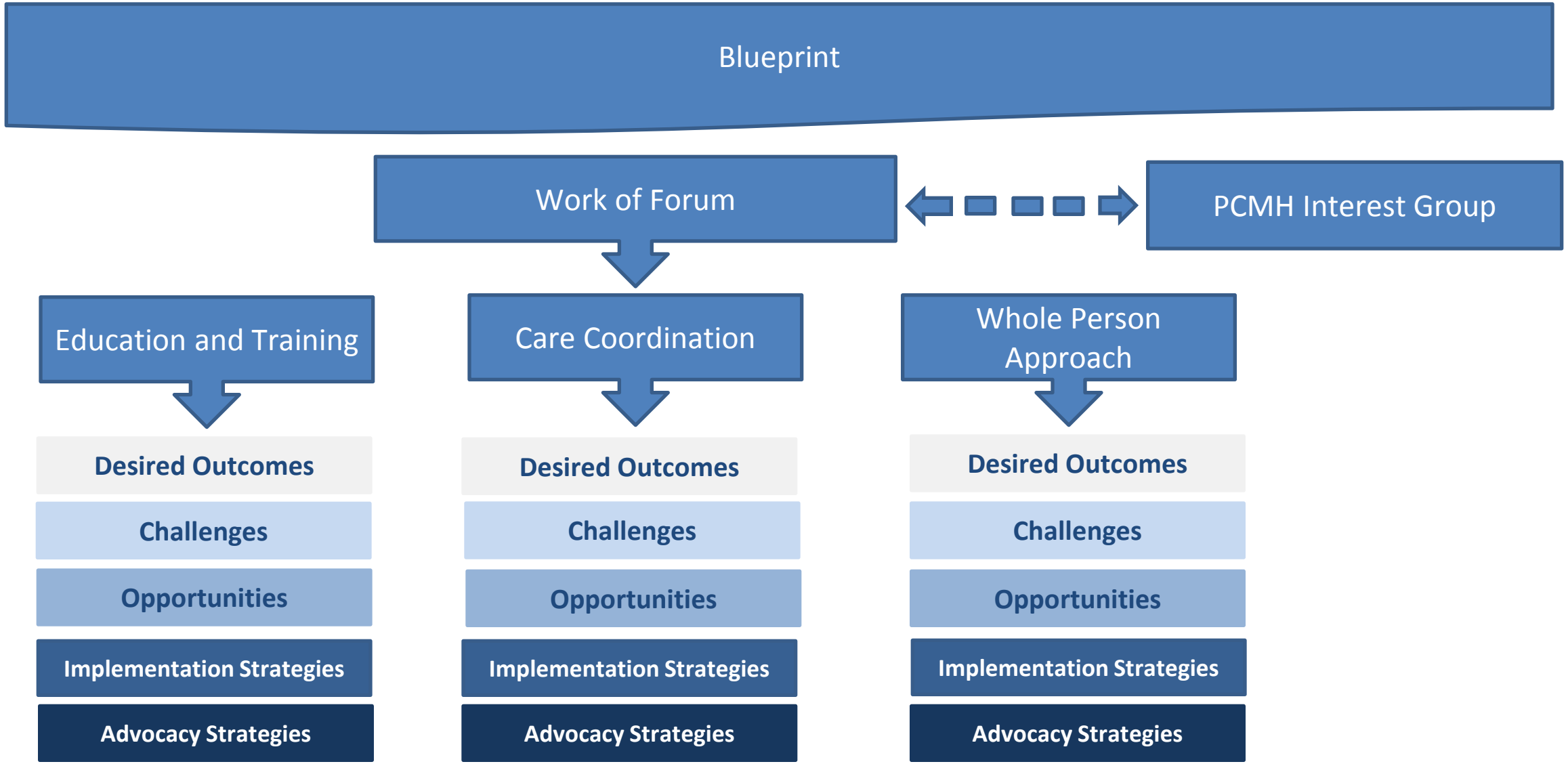
Emerging adults have access to comprehensive, personalized, quality health care which emphasizes wellbeing and prevention. Health care is provided in a manner that is respectful, age and developmentally appropriate, patient and family centered, and culturally competent.

&

A Series of Important Considerations


Action Blueprint for Transition to Adult Health Care
Work of Forum
PCMH Interest Group

New Jersey Developmental Disabilities Transition to Adult Health Care Forum



Education and Training

Desired Outcome

Providers across the spectrum of health care will have the knowledge, skills, attitudes, and judgment to provide comprehensive, multidisciplinary, responsive, and personalized health care for patients and families with developmental disabilities.

Challenges

- Limited undergraduate curricular time and already crowded curriculum.
- Too much time spent in in-patient settings during residency

Opportunities

- Patient-Centered Medicine course- finding ways to integrate disability into current curriculum
- Fellowships based around this population to fulfill research, scholarship, and community service requirements

Care Coordination

Desired Outcome

Comprehensive care coordination that is responsive to the health and developmental needs of the individual and family, and facilitates access to primary, preventative, and specialty health care and other supports.

Challenges

- Location and auspice of care coordination
- Multiple and complex service systems
- Payment for comprehensive coordination

Opportunities

- Promising models/pockets of excellence
- Medicaid contract as driver of service
- Patient Centered Medical Home Demonstrations

Whole Person Approach to Health

Desired Outcome

- Achievement of balance of health within the other domains of quality of life as defined by the individual and the family.
- Cross-sector engagement and involvement

Challenges

- Decreasing level of systems involvement once individual has left childhood system
- Silos dictated by professional practice

Opportunities

- Law for transition in education is perfect segue to health transition
- Consortium of Care Model

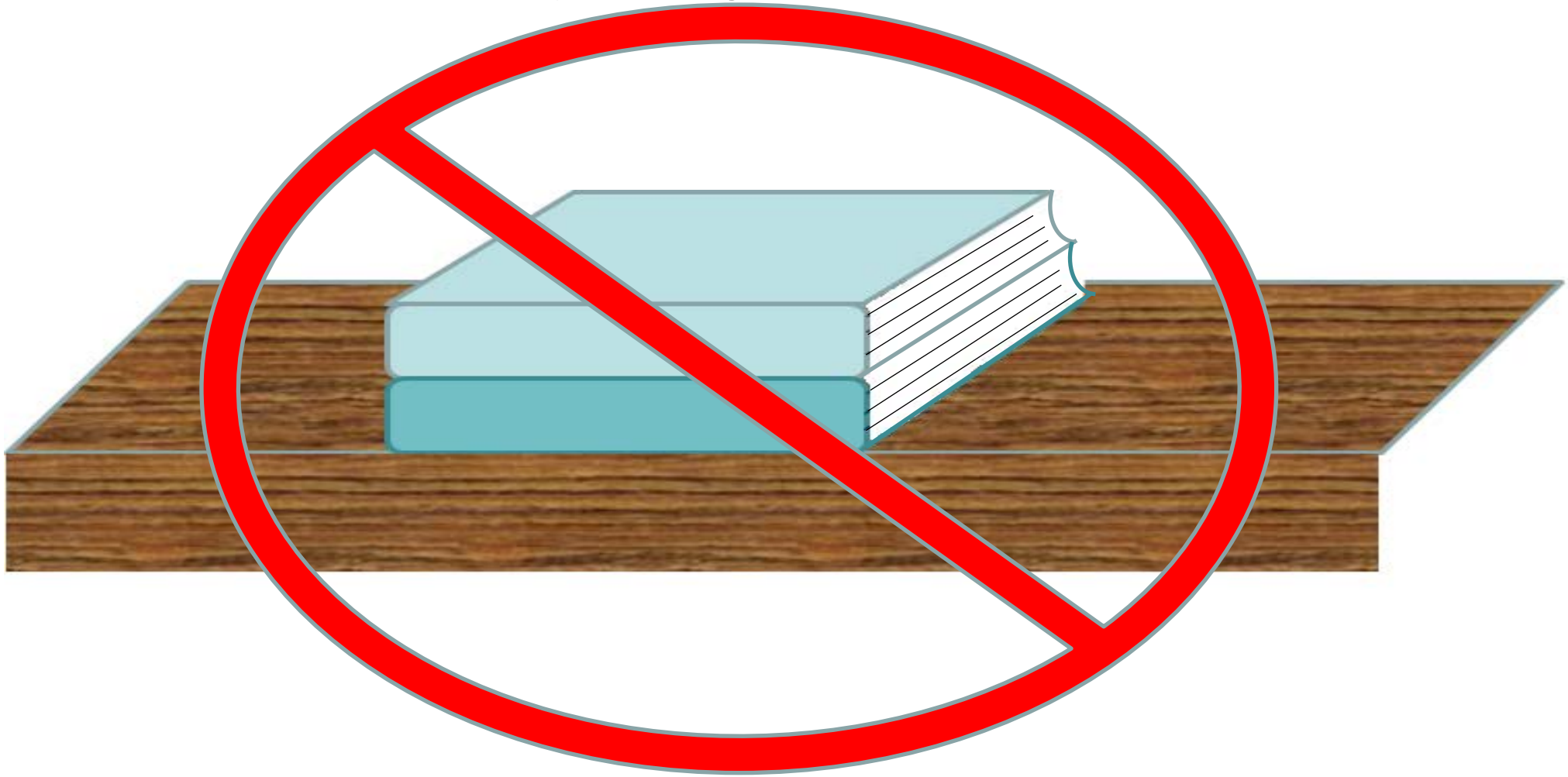
Crosscutting Issues	Education	Care Coordination	Whole Person Approach
Cultural Competence	X	X	X
Financing	X	X	X
Aligning resources with purpose and need	X	X	X
Medicaid			
Health Across the Lifespan	X	X	X
"Buy-in" by adult practitioners	X	X	X
Transition and discontinuities	X	X	X
Complexity Across Systems	X	X	X
Collaboration/breaking down silos	X	X	X
Advocacy	X	X	X
Ensuring important information reaches families	X	X	X
People and families want someone to go to, not just information (coordinated health care team)		X	X
Connections with Community	X	X	X
Understanding Options			
		X	X
		X	X

Action Blueprint for Transition to Adult Health Care

1. Introduction
    - *Population Characteristics*
        - Emerging Adults
        - Families/Caregivers
2. Vision for Transition for Adults with Developmental Disabilities
3. Elements, Challenges, Opportunities, and Actions
4. Patient Centered Medical Home
    - *An Exemplar of the Vision*
5. Larger System Issues
    - *Need for Data*
    - *Specialty Care*
    - *Coordination of Systems*
6. Health Care within the Context of a Full Adult Life
7. Taking Action in New Jersey
    - *Next Steps*
    - *Larger Challenges*
    - *Strategies for Advocacy*

Making it Happen

Implementation and Advocacy Strategies



For more information on The New Jersey Developmental Disabilities Transition to Adult Health Care Forum, please contact:

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VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Developmental Disabilities Health Care E-Toolkit

Elise McMillan, JD, Co-Director, Vanderbilt Kennedy Center University Center for Excellence in Developmental Disabilities

Tom Cheetham, MD, FAAIDD

Director, Office of Health Services, TN Department of Intellectual and Developmental Disabilities

Deputy Commissioner, Office of Child Health, TN Department of Children's Services

Project Overview

The Vanderbilt Kennedy Center UCEDD and LEND, University of Tennessee Boling Center UCEDD and LEND, and the Tennessee Department of Intellectual and Developmental Disabilities were awarded a one-year Special Hope Foundation Grant in 2012, to develop an electronic Health Care Toolkit, an adaptation of Canadian Primary Care tools.

Goals & Objectives

- Our electronic toolkit, an adaptation of the Canadian tools, will give providers in the U.S. easy access to best practice tools, and equip providers to better serve adults with intellectual/developmental disabilities.
- Improvements in the health and wellness of adults with IDD across the nation as well as increased access to appropriate health care are the primary goals.

Goals & Objectives

The IDD Toolkit website will serve as a resource for health care providers, individuals with disabilities, their families and support staff.

Background

- The planned closure of all Ontario, Canada, developmental centers by 2009 caused concerns about the adequacy of primary care in the community.
- Canada's Consensus Conference in 2005 developed guidelines that became Developmental Disabilities Primary Care Initiative.
- To apply the guidelines to problem-based learning cases it became necessary to develop tools.
- Updated guidelines were published May 2011.

Background

- *Tools for the Primary Care of People with Developmental Disabilities* was published 2011 and freely distributed to all primary care providers in Ontario.
- Guidelines and tools are divided into General Issues, Physical Health, Behavioral and Mental Health.

The Rationale

- Canada already had created a consensus-based set of tools for primary care physicians, which have been well-received, to begin to address these disparities.
- The need to adapt these tools for use in Tennessee and nationwide was apparent.
- Making the tools accessible electronically across platforms would increase the likelihood that providers would use them.
- Families will be able to bring this website information to the attention of their providers to enhance care.

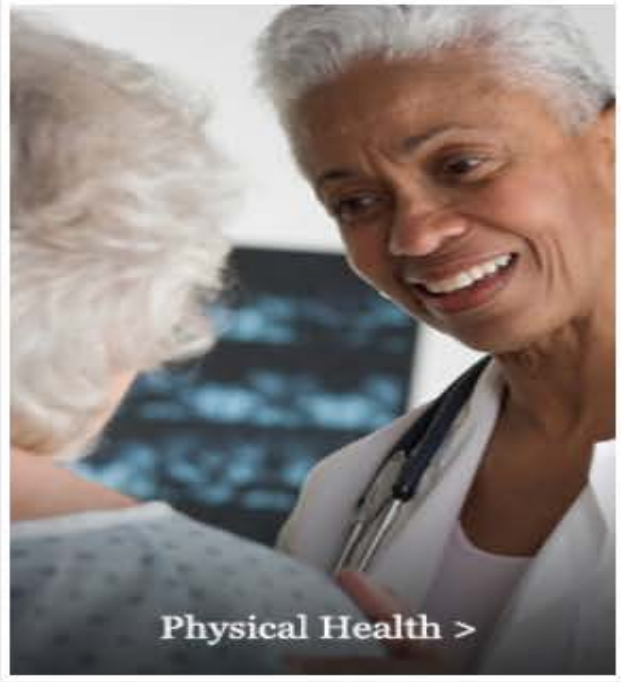
Impact

- By making these tools accessible electronically, health care providers may begin to better understand the physical and mental health needs of adults with intellectual and developmental disabilities.
- This greater understanding may allow health care providers to feel more comfortable in serving adults with IDD.

HEALTH CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Toolkit for Primary Care Providers

HOME



Current Efforts

1) Review and revise selected tools, make available electronically on website, and disseminate state- and nationwide; tools shared at end of this presentation will be revised for the new website
2) Produce at least three electronic tools in each of three categories and 3 “Tip sheets”
3) Promote to all UCEDDs, LENDs, IDDRCs, and 100–130 TN and national organizations

Next Steps

- Test the functionality of the website and the usefulness of the tools with health care providers including the Tennessee Academy of Family Physicians
- Seek feedback on the website from health care providers, families, and caregivers.
- Make adjustments and revisions as needed based on the feedback.

Hopes and Expectations

- We hope to develop a second phase of the project to provide trainings to providers about the tools and treating adults with IDD.
- We expect that this website will give providers in the U.S. the necessary information to better serve adults with IDD.
- We want individuals with IDD and families to share this information with providers.

Acknowledgements

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Fred Palmer, MD
Tyler Reimschisel, MD
Sherry Robbins, MD
Jan Rosemergy, PhD
Jessica Solomon, 4th year VU Medical Student

Selected Tools

1. Communicating effectively
2. Office organizational tips
3. Informed consent
4. Cumulative patient profile
5. Preventive care checklist for adult females
6. Preventive care checklist for adult males
7. Health Watch tables
8. Initial management of behavioral crisis
9. Risk assessment
10. Guide to understanding behavioral problems and emotional concerns
11. Crisis prevention and management plan
12. Psychotropic medication issues

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- Down Syndrome
- Fragile X
- Prader-Willi
- 22q11.2 deletion syndrome

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Following is an example of one of the tools that will be revised for the new website.

DIAGNOSTIC FORMULATION OF BEHAVIOURAL PROBLEMS

Patient brought to family physician with escalating behavioural concerns

Individual communicating concerns verbally? — YES

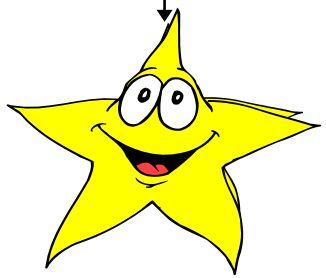
NO

Carers expressing concerns? — YES

NO

Should there be concerns? (Is anyone at risk?) — YES

NO



Medical condition? — YES: *Treat condition*

NO

Problem with supports/ expectations? — YES: *Adjust supports or expectations*

NO

Emotional issues? — YES: *Address issues*

NO

Psychiatric disorder? — YES: *Treat disorder*

NO

Bradley & Summers 1999; modification 2009

PART A: PRIMARY CARE PROVIDER SECTION	Name: DOB:

1. REVIEW OF POSSIBLE MEDICAL CONDITIONS [See also Preventive Care Checklist]

Many medical conditions present atypically in people with developmental disabilities. In some cases the only indicator of a medical problem may be a change in behaviour or daily functioning. Consider a complete review of systems, a physical exam, and necessary investigations until the cause of the behaviour change is identified.

Would you know if this patient was in pain? ☐ No ☐ Yes: If yes, how does this patient communicate pain?

☐ Expresses verbally ☐ Points to place on body ☐ Expresses through non-specific behaviour disturbance (describe):

☐ Other (specify): _____

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behaviour change?

☐ No ☐ Yes ☐ Possibly: _____

Assess/Rule out: _____

- ☐ Medical condition giving rise to physical discomfort (e.g., rash or itch)
- ☐ Medication side effect
- ☐ Change in medication
- ☐ Allergies
- ☐ Vision problem (e.g., cataracts)
- ☐ Hearing problem
- ☐ Dental problem
- ☐ Cardiovascular
- ☐ Respiratory
- ☐ Pneumonia
- ☐ GERD/Peptic ulcer disease/H.pylori infection
- ☐ Constipation, or other lower GI problems
- ☐ UTI
- ☐ Dysmenorrhea/Premenstrual syndrome
- ☐ Peri-menopausal/menopausal (may start earlier)
- ☐ Musculoskeletal (arthritis, joints)
- ☐ Osteoporosis
- ☐ Degenerative disc disease (DDD)
- ☐ Spasticity
- ☐ Neurological (e.g., seizures, dementia)
- ☐ Dermatological
- ☐ Sensory discomfort (e.g., new clothes, shoes)
- ☐ Hypothyroidism
- ☐ Diabetes (I or II)
- ☐ Sleep problems/sleep apnea
- ☐ Other: _____

Comments:

2. PROBLEMS WITH ENVIRONMENTAL SUPPORTS OR EXPECTATIONS

Review Caregiver Information Identify possible problems with supports or expectations

- ☐ **Stress or change in the patient's environment?** (e.g., living situation, day program, family situation)
- ☐ **Insufficient behavioural supports?**
- ☐ **Patient's disabilities not adequately assessed or supported?** (e.g., sensory and communication supports for patients with autism)
- ☐ **Insufficient staff resources?** (e.g., to implement treatment, recreational, vocational or leisure programs)
- ☐ **Inconsistencies in supports and staff approaches?**
- ☐ **Insufficient training/education of direct care staff?**
- ☐ **Signs of possible caregiver burnout?** (e.g., negative attitudes towards person, impersonal care, difficult to engage with staff, no or poor follow through in treatment recommendations)

Do caregivers seem to have inappropriate expectations associated with:

Recognizing or adjusting to identified patient needs	☐ Yes	☐ No	☐ Unsure
Over- or under-estimating patient's abilities (boredom or under-stimulation)	☐ Yes	☐ No	☐ Unsure

Comments:

PART A: PRIMARY CARE PROVIDER SECTION

Name:

DOB:

1. REVIEW OF POSSIBLE MEDICAL CONDITIONS [See also Preventive Care Checklist]

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Do caregivers seem to have inappropriate expectations associated with:

Recognizing or adjusting to identified patient needs ☐ Yes ☐ No ☐ Unsure

Over- or under-estimating patient's abilities (boredom or under-stimulation) ☐ Yes ☐ No ☐ Unsure

Comments:

PART A: PRIMARY CARE PROVIDER SECTION	Name: DOB:

3. REVIEW OF EMOTIONAL ISSUES

Review Caregiver Information Identify possible emotional issues

Summary and comments re emotional issues (e.g., related to change, stress, loss):

4. REVIEW OF POSSIBLE PSYCHIATRIC DISORDERS

History of diagnosed psychiatric disorder: ☐ No ☐ Yes – Diagnosis: _____

History of admission(s) to psychiatric facility: ☐ No ☐ Yes (specify): _____

(See Appendix: Psychiatric Symptoms and Behaviours Screen)

Summary and comments re symptoms and behaviours indicating possible psychiatric disorder:

SUMMARY OF FACTORS THAT MAY CONTRIBUTE TO BEHAVIOURAL ISSUES

PART A: PRIMARY CARE PROVIDER SECTION	Name: DOB:

MANAGEMENT PLAN: Use the "Diagnostic Formulation of Behavioural Concerns" to assess and treat causative and contributing factors

1. **Physical exam, medical investigations indicated**
2. **Risk assessment**
3. **Medication review**
4. **Referrals for functional assessments and specialized medical assessments as indicated**
   - e.g., to psychologist, speech and language pathologist, occupational therapist for assessments and recommendations re adaptive functioning, communication, sensory needs or sensory diet
   - e.g., genetic assessment/reassessment, psychiatric consult
5. **Assessment and treatment and referral as indicated for**
   - Supports and expectations
   - Emotional issues
   - Psychiatric disorder
6. **Review behavioural strategies currently being used, revise as needed**
   - De-escalation strategies
     – Use of a quiet, safe place
     – Safety response plan
   - Supports
   - Use of "as needed" (PRN) medications
7. **Identify and access local and regional interdisciplinary resources for care of patient**
   - Case management resources
   - Behaviour therapist
   - Other
8. **Focus on behaviours**
   - Identify target symptoms and behaviours to monitor
   - Institute use of Antecedent-Behaviour-Consequence (ABC) Chart
9. **Develop a proactive and written Crisis Prevention and Management Plan with caregivers and an interdisciplinary team**
   - Applicable for all environments in which the behaviour could occur, e.g., home, day program or community
   - Caregivers to monitor for triggers of behaviour problems and use early intervention and de-escalation strategies
   - Periodic team collaboration to review issues, plan and revise, as needed
   - If hospital and/or Emergency Department (ED) involved, consider including ED staff in developing the Crisis Prevention and Management Plan
10. **Regular and periodic medication review**
    - Use Auditing Psychotropic Medication Therapy tool for review of psychotropic medications

PART B: CAREGIVER SECTION
(Caregiver to fill out or provide information)

Name:

DOB:

What type of Developmental Disability does the patient have (i.e., what caused it?)

(e.g., Down syndrome, fragile X syndrome)_____ ☐ Unsure/don't know

What is the patient's level of functioning?

☐ BORDERLINE ☐ MILD ☐ MODERATE ☐ SEVERE ☐ PROFOUND ☐ UNKNOWN

BEHAVIOURAL PROBLEM

When did the behavioural problem start?

(dd/mm/yyyy) _____

When was patient last "at his/her best"? (i.e., before these behaviour problems)

(dd/mm/yyyy) _____

Description of current difficult behaviour(s):

Has this sort of behaviour happened before?

What, in the past, helped or did not help to manage the behaviour?
(include medications or trials of medications to manage behaviour[s])

What is being done now to try to help the patient and manage his/her behaviours? How is it working?

Risk?
- ☐ To self
- ☐ To others
- ☐ To environment

- ☐ Aggression to others
- ☐ Self-injurious behaviour

Severity of Damage or Injury
- ☐ mild (no damage)
- ☐ moderate (some)
- ☐ severe (extensive)

Frequency of Distressing (Challenging) Behaviour
- ☐ more than once daily
- ☐ daily
- ☐ weekly
- ☐ monthly

Please check (√) if there has been any recent deterioration or change in:

- ☐ mood
- ☐ bowel/bladder continence
- ☐ appetite
- ☐ sleep
- ☐ social involvement
- ☐ communication
- ☐ interest (in leisure activities or work)
- ☐ seizure frequency
- ☐ self care (e.g., eating, toileting, dressing, hygiene)
- ☐ independence
- ☐ initiative
- ☐ cognition (e.g., thinking, memory)
- ☐ movement (standing, walking, coordination)
- ☐ need for change in supervision and/or placement

When did this change/deterioration start?

Caregiver comments:

PART B: CAREGIVER SECTION
(Caregiver to fill out or provide information)

Name:

DOB:

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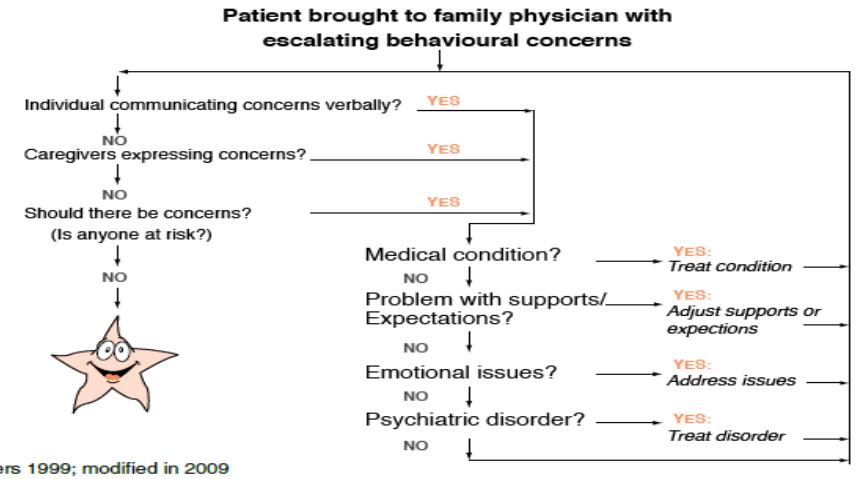
(Caregiver to fill out or provide information)

Name:

DOB:

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS



1. POSSIBLE PHYSICAL HEALTH PROBLEMS OR PAIN

Are you or other caregivers aware of any **physical health or medical problems** that might be contributing to the patient's behaviour problems? ☐ No ☐ Yes: If yes, please specify or describe:

Could pain, injury or discomfort be contributing to the behaviour change? ☐ No ☐ Yes ☐ Possibly

Specify: _____

Would you know if this patient was in pain? ☐ No ☐ Yes: How does this patient communicate pain?

☐ Expresses verbally ☐ Points to place on body

☐ Expresses through non-specific behaviour disturbance (describe): _____

☐ Other (specify): _____

Are there any concerns about medications or possible medication side effects?

2.1: CHANGES IN ENVIRONMENT before problem behaviour(s) began

Have there been any recent changes or stressful circumstances in:

☐ **Caregivers?** (family members, paid staff, volunteers)

☐ **Care provision?** (e.g., new program or delivered differently, fewer staff to support)

☐ **Living environment?** (e.g., co-residents)

☐ **School or day program?**

PART B: CAREGIVER SECTION

Name:

DOB:

2.2: SUPPORT ISSUES

Are there any problems in this patient's support system that may contribute to his/her basic needs not being met?

Does this patient have a ☐ **hearing** or ☐ **vision problem?** ☐ No ☐ Yes: If yes, what is in place to help him/her?

Does this patient have a **communication problem?** ☐ No ☐ Yes: If yes, what is in place to help him/her?

Does this patient have a problem with **sensory triggers?** ☐ No ☐ Yes: If yes, what is in place to help him/her?

☒ If yes, do you think this patient's environment is ☐ over-stimulating? ☐ under-stimulating? or ☐ just right for this patient?

Does environment seem **too physically demanding** for this patient? ☐ No ☐ Yes

Does this patient have enough opportunities for **appropriate physical activities?** ☐ No ☐ Yes

Does this patient have **mobility problems** or **physical restrictions?** ☐ No ☐ Yes: If yes, what is in place to help him/her? If yes, does he/she receive physiotherapy?

Are there **any supports or programs that might help this patient** and which are not presently in place?

☐ No ☐ Yes: If yes, please describe:

Caregiver comments:

3: EMOTIONAL ISSUES

Please check (√) if any of these factors may be affecting this patient:

Any recent change in relationships with significant others (e.g., staff, family, friends, romantic partner)

- ☐ **Additions** (e.g., new roommate, birth of sibling)
- ☐ **Losses** (e.g., staff change, housemate change)
- ☐ **Separations** (e.g., decreased visits by volunteers, sibling moved out)
- ☐ **Deaths** (e.g., parent, housemate, caregiver)

Issues of assault or abuse

	Past	Ongoing	Date(s)
☐ Physical	☐	☐	_____
☐ Sexual	☐	☐	_____
☐ Emotional	☐	☐	_____
☐ Exploitation	☐	☐	_____

Comments:

- ☐ **Teasing or bullying**
- ☐ **Anxiety about completing tasks**
- ☐ **Issues regarding sexuality and relationships**
- ☐ **Being left out of an activity or group**
- ☐ **Stress or upsetting event, at school or work**
- ☐ **Inability to verbalize feelings**
- ☐ **Disappointment(s)** (e.g., being surpassed by siblings; not being able to meet goals, such as driving or having a romantic relationship)
- ☐ **Growing insight into disabilities and impact on own life** (e.g., that he/she will never have children, sibling has boy/girlfriend)
- ☐ **Life transitions** (e.g., moving out of family home, leaving school, puberty)
- ☐ **Other triggers** (e.g., anniversaries, holidays, environmental, associated with past trauma)

Specify:

Caregiver Comments:

PART B: CAREGIVER SECTION

Name:
DOB:

Has this patient ever been diagnosed with a psychiatric disorder? ☐ No ☐ Unsure

☐ Yes: _____

Has this patient ever been hospitalized for a psychiatric reason? ☐ No ☐ Unsure

☐ Yes: _____

CAREGIVER CONCERNS AND INFORMATION NEEDS

Do you, and other caregivers, have the information you need to help this patient, in terms of:

- The type of developmental disability the patient has and possible causes of it? ☐ Yes ☐ No ☐ Unsure
- What the patient's abilities, support needs, and potential are? ☐ Yes ☐ No ☐ Unsure
- Possible physical health problems with this kind of disability? ☐ Yes ☐ No ☐ Unsure
- Possible mental health problems and support needs with this kind of disability (e.g., anxiety more common with fragile X syndrome)? ☐ Yes ☐ No ☐ Unsure
- How to help if the patient has behaviour problems/emotional issues? ☐ Yes ☐ No ☐ Unsure
- Recent changes or deterioration in the patient's abilities? ☐ Yes ☐ No ☐ Unsure

Are there any issues of **caregiver stress** or potential burnout? ☐ Yes ☐ No ☐ Unsure

Caregiver comments:

Caregiver's additional general comments or concerns:

Thank you *for the information you have provided. It will be helpful in understanding this patient better and planning and providing health care for him or her.*

PRIMARY CARE PROVIDERS AND CAREGIVERS:
Psychiatric Symptoms and Behaviours Screen

Name:
DOB:

Can be filled out by **primary care provider**, or by **caregiver, and reviewed** by primary care provider.

Symptoms and behaviours	BASELINE [1] Check if usually present	NEW Check if recent onset	COMMENTS If new onset or increased
Anxiety-related			
Anxiety			
Panic			
Phobias			
Obsessive thoughts			
Compulsive behaviours			
Rituals/routines			
Other			
Mood-related			
Agitation			
Irritability			
Aggression			
Self-harm behaviour			
Depressed mood			
Loss of interest Unhappy/miserable Under-activity			
Sleep			
Eating pattern			
Appetite			
Weight (provide details)			
Elevated mood			
Intrusiveness			
Hypersexuality			
Other			
Psychotic-related [2]			
Psychotic and psychotic-like symptoms (e.g., self talk, delusions, hallucinations)			
Movement-related			
Catatonia ('stuck')			
Tics			
Stereotypies (repetitive movements or utterances)			
ADHD-related or Mood Disorder			
Inattention			
Hyperactivity			
Impulsivity			
Dementia-related			
Concentration			
Memory			
Other			
Other			
Alcohol misuse			
Drug abuse			
Sexual issues/problems			
Psychosomatic complaints			

[1] Establish usual baseline i.e., behaviours and daily functioning before onset of concerns.
[2] **Use caution when interpreting psychotic-like symptoms and behaviours** in patients with DD. These may be associated with anxiety (or other circumstances) rather than a psychotic disorder.

Patient brought to family physician with escalating behavioural concerns

Individual communicating concerns verbally? — YES

NO

Carers expressing concerns? — YES

NO

Should there be concerns? — YES

(Is anyone at risk?)

NO

Medical condition? — YES: *Treat condition*

NO

Problem with supports/ expectations? — YES: *Adjust supports or expectations*

NO

Emotional issues? — YES: *Address issues*

NO

Psychiatric disorder? — YES: *Treat disorder*

NO

PART A: PRIMARY CARE PROVIDER SECTION

Name:

DOB:

1. REVIEW OF POSSIBLE MEDICAL CONDITIONS [See also Preventive Care Checklist]

Many medical conditions present atypically in people with developmental disabilities. In some cases the only indicator of a medical problem may be a change in behaviour or daily functioning. Consider a complete review of systems, a physical exam, and necessary investigations until the cause of the behaviour change is identified.

Would you know if this patient was in pain? ☐ No ☐ Yes: If yes, how does this patient communicate pain?

☐ Expresses verbally ☐ Points to place on body ☐ Expresses through non-specific behaviour disturbance (describe):

☐ Other (specify): _____

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behaviour change?

☐ No ☐ Yes ☐ Possibly: _____

Assess/Rule out: _____

- ☐ Medical condition giving rise to physical discomfort (e.g., rash or itch)
- ☐ Medication side effect
- ☐ Change in medication
- ☐ Allergies
- ☐ Vision problem (e.g., cataracts)
- ☐ Hearing problem
- ☐ Dental problem
- ☐ Cardiovascular
- ☐ Respiratory
- ☐ Pneumonia
- ☐ GERD/Peptic ulcer disease/H.pylori infection
- ☐ Constipation, or other lower GI problems
- ☐ UTI
- ☐ Dysmenorrhea/Premenstrual syndrome
- ☐ Peri-menopausal/menopausal (may start earlier)
- ☐ Musculoskeletal (arthritis, joints)
- ☐ Osteoporosis
- ☐ Degenerative disc disease (DDD)
- ☐ Spasticity
- ☐ Neurological (e.g., seizures, dementia)
- ☐ Dermatological
- ☐ Sensory discomfort (e.g., new clothes, shoes)
- ☐ Hypothyroidism
- ☐ Diabetes (I or II)
- ☐ Sleep problems/sleep apnea
- ☐ Other: _____

Patient brought to family physician with escalating behavioural concerns

Individual communicating concerns verbally?

YES

NO

Carers expressing concerns?

YES

NO

Should there be concerns?

(Is anyone at risk?)

YES

NO

Medical condition?

YES: *Treat condition*

NO

Problem with supports/ expectations?

YES: *Adjust supports or expectations*

NO

Emotional issues?

YES: *Address issues*

NO

Psychiatric disorder?

YES: *Treat disorder*

NO

PART B: CAREGIVER SECTION

Name:

DOB:

2.2: SUPPORT ISSUES

Are there any problems in this patient's support system that may contribute to his/her basic needs not being met?

Does this patient have a ☐ **hearing** or ☐ **vision problem?** ☐ No ☐ Yes: If yes, what is in place to help him/her?

Does this patient have a **communication problem?** ☐ No ☐ Yes: If yes, what is in place to help him/her?

Does this patient have a problem with **sensory triggers?** ☐ No ☐ Yes: If yes, what is in place to help him/her?

☒ If yes, do you think this patient's environment is ☐ over-stimulating? ☐ under-stimulating? or ☐ just right for this patient?

Does environment seem **too physically demanding** for this patient? ☐ No ☐ Yes

Does this patient have enough opportunities for **appropriate physical activities?** ☐ No ☐ Yes

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Are there **any supports or programs that might help this patient** and which are not presently in place?

☐ No ☐ Yes: If yes, please describe:

Caregiver comments:

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NO

3: EMOTIONAL ISSUES Please check (√) if any of these factors may be affecting this patient:

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Comments:

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- ☐ **Life transitions** (e.g., moving out of family home, leaving school, puberty)
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Specify:

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Obsessive thoughts			
Compulsive behaviours			
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Agitation			
Irritability			
Aggression			
Self-harm behaviour			
Depressed mood			
Loss of interest Unhappy/miserable Under-activity			
Sleep			
Eating pattern			
Appetite			
Weight (provide details)			
Elevated mood			
Intrusiveness			
Hypersexuality			
Other			
Psychotic-related [2]			
Psychotic and psychotic-like symptoms (e.g., self talk, delusions, hallucinations)			
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Tics			
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Hyperactivity			
Impulsivity			
Dementia-related			
Concentration			
Memory			
Other			
Other			
Alcohol misuse			
Drug abuse			
Sexual issues/problems			
Psychosomatic complaints			

[1] Establish usual baseline i.e., behaviours and daily functioning before onset of concerns.
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Eating pattern			
Appetite			
Weight (provide details)			

Transition from Pediatric to Adult Health Care for Youth with Intellectual and Developmental Disabilities

Health Symposium: Health Care for Adults with Intellectual and Developmental Disabilities

AUCD Annual Meeting

November 18, 2013

Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities

The Project: Development and Evaluation of Self-Paced Learning Modules Designed to Support and Evaluate the Use of Evidence-Based Health Transition Practices

Phase 1: Develop and evaluate curricula designed to respond to critical issues and questions raised by young adults with IDD and their families about the problems they face in making a transition from Pediatric to Adult Health Services and assist them in making an effective transition plan

Outcome: three curricula

- Young Adults with IDD
- Peer Mentors
- Family Members

Evidence-Based Health Transition Practices

Phase 2: Develop and evaluate a smart device application to support

- self-paced learning
- individualized transition plan development
- provision of direct feedback on the effectiveness of the transition-planning process
- self-advocacy

Health Care Transition for Youth with Special Health Care Needs: A Review

- 3,370 articles considered – all had recommendations on what to do
- 15 had data on post-transition outcomes
- Implications and Contribution:

  "Although many youth with mild special health care needs transition successfully to adulthood, those with more complex medical conditions experience less educational and employment success. Youth with cognitive or mental health impairments have poorer transition experiences. Few programs demonstrated evidence of success in improving youth's transition outcomes.... We recommend additional studies with strong research designs to guide best practice in preparing YSHCN for adulthood."

  Bloom, et al. (2012). *Health care transition for youth with special health care needs.* Journal of Adolescent Health 51, 213-219.

Health Literacy

- Institute of Medicine workshop reports:
  - o Promoting health literacy to encourage prevention and wellness (November 1, 2011)
    Research to find better pathways to improved health literacy and better health
  - o Innovations in health literacy (March 10, 2011)
    Health literacy and health disparities, better use of IT improve health literacy
  - o Overall nearly nine out of 10 adults have difficulty using health information to make proper health decisions

Premature Deaths of People with Learning Disabilities

- **Data from a study between 2010 and 2012 in the UK**
  - o Looked at the causes of death among all known deaths among people with learning disabilities in the Bristol area of south-west England
  - o Men with learning disabilities died, on average, 13 years sooner than the general population
  - o Women with learning disabilities died, on average 20 years sooner than the general population
  - o Overall, 22% of the people with learning disabilities were under 50 at the time of death compared with just 9% of the general population
  - o “The cause of their premature deaths appears to be because the NHS is not being provided equitably to everyone based on need. People with learning disabilities are struggling to have their illnesses investigated, diagnosed and treated to the same extent as other people.”

Heslop, et al, (March 19, 2013). Confidential inquiry into the premature deaths of people with learning disabilities. Norah Fry Research Center, Bristol University, England. http://www.bris.ac.uk/cipold/fullfinalreport.pdf

Transition Project Process

- Literature/ materials review
- Young adult and family member focus groups
- Curricula design
- Curricula evaluation

Transition Project Process – Literature & Materials Review & Selection

- Identified existing health transition website funded by the NYS DDPC
- Identified several existing video training resources
- Identified two evidence-based health planning resources appropriate for transition planning use
- Identified “peer mentoring” as key strategy for achieving effective self-advocacy among transition age youth

Evidence Based Curriculum Resources

- *ask for it: a health advocacy intervention for adults with intellectual disability and their general practitioners.* Lennox, et al, 2004. Health Promotion International
  - a communication tool package, the *ask* (advocacy skills kit) 5-year health diary and educational session
  - the *ask* diary topics:
    - All about me
    - Health Advocacy Tips
    - For the Doctor
    - Medical Records

- CHAP: Comprehensive health assessment program
  - Lennox, N., Bain, C., Rey-Conde T., Purdie D., Bush, R., & Pandeya, N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a randomized controlled trial. Int. J. Epidemiol. 2007 Feb; 36(1): 139-146.

Young Adult and Family Member Focus Groups

•Young adults – peer led focus groups
  • a key theme: parents will continue to take care of my health needs, get me to appointments, remind me to take my medicines, etc.,
  • curriculum emphasis – providing tools to promote health self-advocacy

• Parents – WIHD staff let focus groups
  • key themes: future of health insurance - parents continuing to work to keep child eligible for parent's insurance, low expectations for health care self-management
  • curriculum emphasis – a strong plan and letting go

Current and Next Steps

- Phase 1: curriculum topics and training resource development and evaluation
- Phase 2: creation of apps for smart devices to promote self-directed learning and health self-advocacy

Cognitively Accessible Telehealth Portal – Desktop/Touchsmart

Westchester Institute for Human Development

University Center for Excellence in Developmental Disabilities

My Health,
My Choice,
My Responsibility

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Session 1
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Session 8
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AbleLink Technologies

Session 7: Feel Good about Yourself and Others

Listen and Learn

Test What You Learned

Things to Remember

Feelings

Beating the Blues

Cognitively Accessible
Windows or Macintosh Computing Environment

ENDEAVOR CONNECT

Brian Brown

Works at AbleLink Technologies, Inc.
Lives in Colorado Springs, CO
Married to Beth Berland Brown

Mike Linz
Check out the cool new pictures from our trip to Epcot Center!

2 people like this.

Tom Tindell - Looks like a blast! Wish we were there with you!
1 hour ago

Larry King - The world's largest golf ball! Here's the world's largest golf course...

3 hours ago

Brian Brown
Check out what my daughter bought for me this morning!

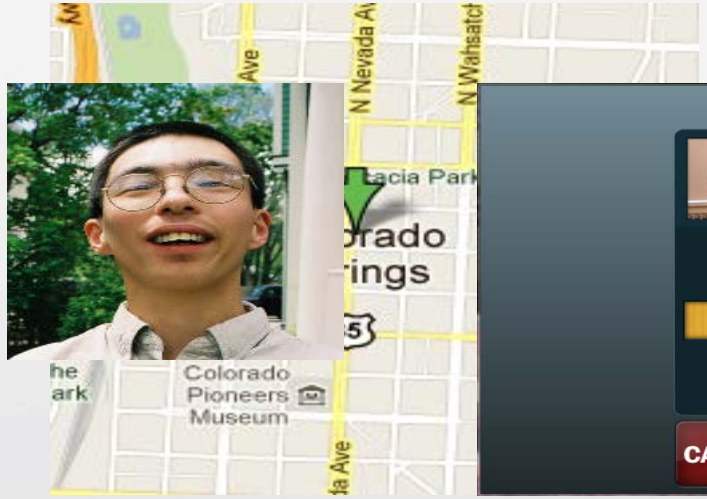
EXIT

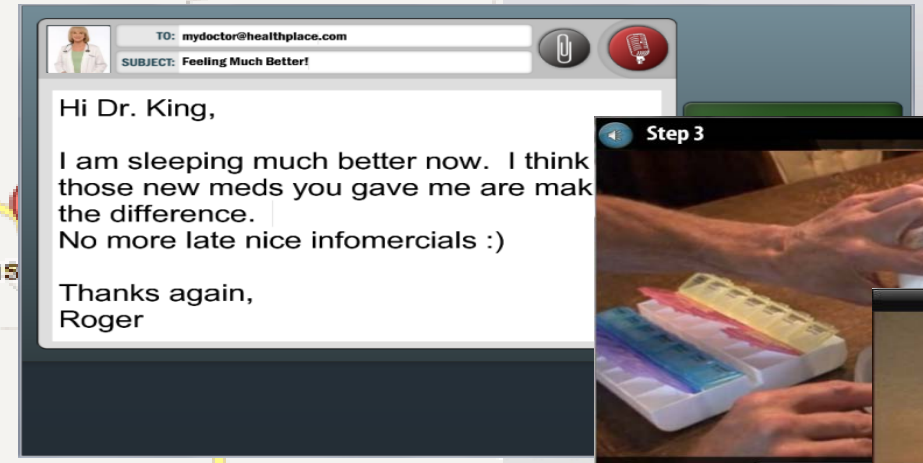
Endeavor Connect: Cognitive Access to Facebook

Tele-Health: Existing and Emerging Technology Platforms

The User Interface is the Key (Software)

Accessibility Settings Applied to Each User via the Cloud





HealthCare Manager – Personalized Health Plan on iPad

Health Symposium: Health Care for Adults with Intellectual and Developmental Disabilities

Video

Adult Health Case-Based Modules for LEND and UCEDD Trainees

Karen Edwards MD MPH

Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities

"The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care"

National Council on Disabilities 2009 http://www.ncd.gov/publications/2009/Sept302009 (*The Current State Of Health Care For People With Disabilities*

The HealthMeet Project of The Arc
Provided support to develop the modules

"**HealthMeet®** will … provide training and education …and will raise public awareness of health issues that impact people with intellectual disabilities across the country."

Adult Health Case-based Modules

Developed with support from the HealthMeet Project of The Arc

Module 1: "Understanding Health and Health Promotion for People with ID"

http://www.IDDHealthTraining.org

Developed by:
Karen Edwards MD MPH, Susan Havercamp PhD,
Leslie J Cohen JD, and David O'Hara, PhD

With Review and Input by:
Jamie Perry MD MPH, Adriane K Griffen MPH MCHES, and George S Jesien PhD
Association of University Centers on Disabilities

Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities

Modules designed for use by LEND and UCEDD trainees with these goals:

- LEND and UCEDD trainees learn about the adult phase of the health and health care continuum for people with I/DD.
- Trainees gain knowledge and perspective concerning:
  - common health issues for adults with I/DD;
  - socio-cultural influences on health of adults with I/DD;
  - self-determination and person-centered care as essential elements of health promotion and healthcare for adults with I/DD;
  - the important influence of competitive employment and place of residence on health status;
  - central importance of optimal health status on quality of life and on the ability of adults with I/DD to live the lives they desire in inclusive communities.

http://www.iddhealthtraining.org/

Adult Health Case-based Modules

Search

Developed with support from the HealthMeet Project of the Arc

AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH. EDUCATION. SERVICE

The Arc. HealthMeet

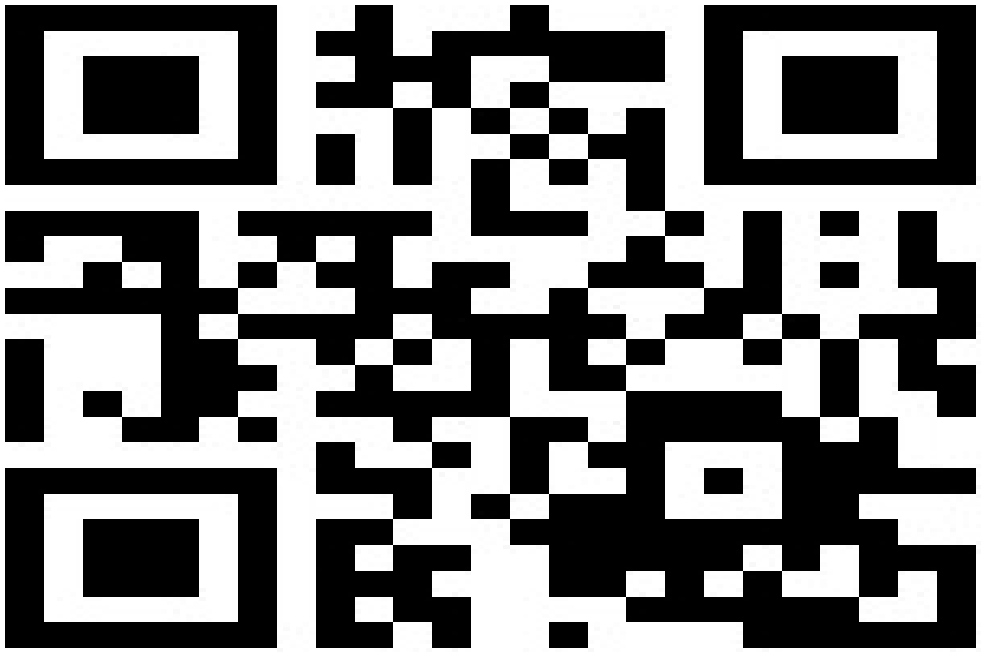
Westchester Institute for Human Development
Creating Better Futures

Case-based Modules on Health of People with Intellectual Disabilities

These cases are designed for LEND and UCEDD trainees to learn more about the adult phase of the life course continuum of health and health care for people with developmental and intellectual disabilities. By participating in this case-based curriculum, LEND and UCEDD trainees will gain knowledge and perspective concerning: common health issues for adults with ID; socio-cultural influences on health of adults with ID; self-determination and person-centered care as essential elements of health promotion and healthcare for adults with ID; the importance of competitive employment and place of residence on health status; and the central importance of optimal health status on quality of life and on the

Module 1: "Understanding Health and Health Promotion for People with ID"

http://www.IDDHealthTraining.org



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University Center for Excellence in Developmental Disabilities

Case content and learning goals

- See flip side of handout for details
- This table also included in faculty materials on AUCD ITAC Training Toolbox

Resources for faculty and staff to use in training

- LEND and UCEDD Faculty will find case materials (with and without answers/resources) and suggestions for using the cases in training at http://www.aucd.org/itac/template/strategy_list.cfm?id=14 OR (AUCD.org ► http://www.aucd.org/itac/ ► Training Toolbox ► Adult Health)

Suggestions on using the cases for instruction

LEND trainees may be assigned to work individually or in pairs of teams on the cases at http://www.IDDHealthTraining.org in preparation for in-class discussion of:

- Results of search for additional resources
- Additional questions they would ask about the case
- Pre-class written assignment related to a case:
  - What is the role of my discipline in optimizing health and health promotion in this situation?
  - Describe several local resources that would be helpful to the person described in this case.
  - Identify other issues that may be important for the health of the person described in the case.
  - Use the case as a template to write a case of their own with questions to present to other trainees in class

Module 2 is under development

Module 2 will address barriers to health care noted by the HealthMeet Project:

- Lack of accessible information about healthy habits, or not enough help in navigating of health care systems and insurance plans
- Lack of communication training for health professionals, making interactions with people with ID difficult
- Discrimination and stigma associated with disability

Goals of Module 2…..

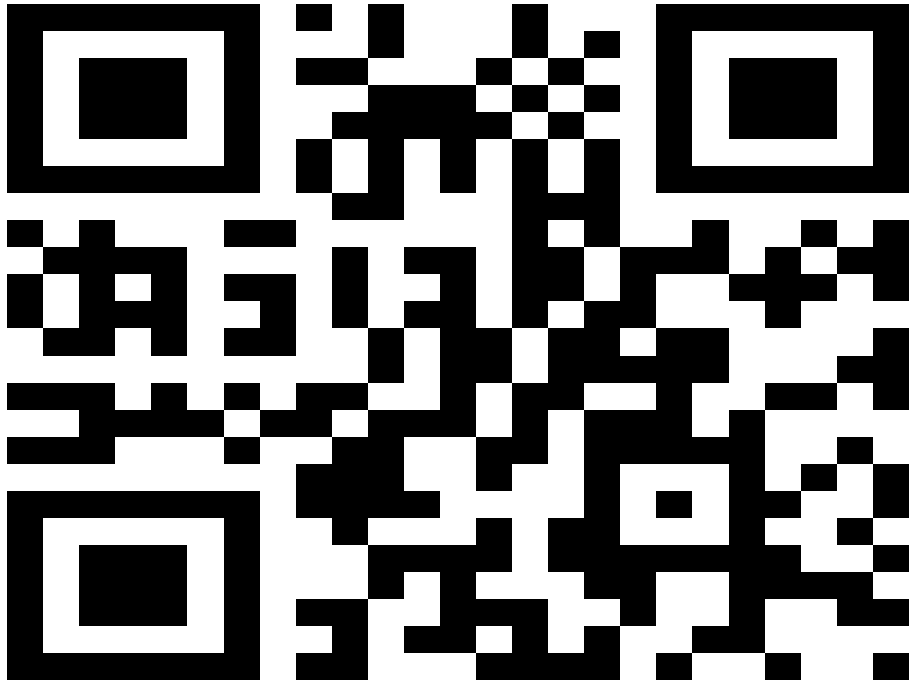
…will relate to:

- **Communication skills for working with people with I/DD in the context of health care and wellness encounters**
- **Universal design in written and electronic communication with people with I/DD concerning health and wellness**
- **Use of person-first, non-victimization language**
- **Communication to support self-determination in health**
- **Use of technology to enable effective communication by and with people with I/DD**
- **Communication with people with sensory challenges**
- **Communication using a translator**

Suggestions for Module 2

- If you have recommended resources, links, training modules OR have suggestions about what you would like to see included in this module, please tell us at: https://www.surveymonkey.com/s/Module2Input

Scan to provide input for Module 2



Westchester Institute for Human Development
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Summary

- Module 1 of the Adult Health Case-based modules available now
- Module 2 under development
- Please tell us:
  - Feedback on Module 1
  - Suggestions for Module 2

Health Symposium: Health Care for Adults with Intellectual and Developmental Disabilities

Q&A