

June 10<sup>th</sup> 2015

# Strategies for the Implementation of Disability-Competent Care

## Stimulating and Supporting Participant Engagement



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## Strategies for the Implementation of Disability-Competent Care

### Disability-Competent Care; What Is It and Why Is It Important



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## Overview of Webinar Series

### Strategies for the Implementation of Disability-Competent Care

- This series takes a fresh look at topics that were presented in the previous two webinar series, which are available for viewing at <https://www.resourcesforintegratedcare.com/>
- We aim to provide participants with updated information and the opportunity to discuss topical questions with leading healthcare professionals and subject matter experts. We hope you come prepared with questions and comments for this discussion.
- The Lewin Group, under contract with the CMS Medicare-Medicaid Coordination Office, partnered with Christopher Duff and other disability practice experts to create the eight-part weekly webinar series, **Strategies for the Implementation of Disability-Competent Care**.

# Introductions

## Presenters

Christopher Duff, Moderator  
Disability Practice and Policy Consultant



Patricia Yeager, Ph.D.  
Chief Executive Officer  
The Independence Center  
Colorado Springs, CO



Gavin Kerr, President & CEO  
Inglis Life Communities  
Philadelphia, PA



## Webinar Agenda

- Understand the connection between health, health care and quality of life
- Learn about Centers for Independent Living (CILs) and their role achieving and supporting community participation
- Explore approaches to facilitate and enable community participation
- Audience questions

## Foundation of a Quality of Life

Quality of life depends on good health and an engaged, productive life for every human, including those who have functional limitations. The question before us is how people with a wide variety of disabilities and functional needs achieve a high quality of life.

# Persons Living with Disabilities have Experienced Barriers to Community Participation

Common barriers:

- Access
  - The inability to:
    - Physically access facilities and equipment
    - Communicate with providers
- Attitudinal
  - The assumption that persons living with disabilities are incapable and unhealthy

**Together these lead to distrust, avoidance and isolation**

## Centers for Independent Living (CILs)

- CILs are community-based non-profit organizations designed and operated by people with disabilities
- CILs are unique in that they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization
- 400+ across the US
- Centers for Independent Living provide:
  - Peer support
  - Information and referral
  - Individual and systems advocacy
  - Independent living skills training
  - Transitional services



## What does Community Involvement mean to Persons with Disabilities (PWD)?

Community involvement means asking, listening and acting on suggestions from PWD

- PWD are often seen but hardly ever heard - their views are not sought out or are discounted
- Who knows better than PWD to determine what they need - when, where, and how
- Able bodied people are well meaning but generally over-react, over-protect, over-treat, and possibly over-medicate leading to avoidable costs
- Paternalism leads to non-participation or non-compliance. Paternalism also leads to dependency – not helpful and expensive

# Self-Awareness and Acceptance is the First Step to Health

CILs focus on working with participants to integrate a disability into their self-image. A person that does not integrate their disability into their self-image, in a positive way, will fail to become independent and productive.

Peer support is a gateway to impacting health

- Recreation
- Support groups
- Seeing role models who live successfully with a disability
- Encouragement to try new things, get services to assist
- Education on how to be a “person with a disability”
- Reducing isolation and depression through active engagement

## The Independence Center

- Serves 600+ people annually throughout the Colorado Springs, CO area
- Besides the core services provided by all CILs, we also provide:
  - Home health program serves 230 persons ages six to 103 in their homes
  - Benefits counseling
  - Assistive technology
  - Assistance finding housing in the community
  - Employment services
- Specialized services to individuals who are blind, deaf, hard-of-hearing, and head injured

## The Independence Center: Engaging Participants

- Engages people with various disabilities through a modern, comfortable, upbeat center with a majority of staff, management and board members having a disability
- The “waiting area” is setup much like a Starbucks where people can sit at café tables and talk while waiting for staff or to join an activity. Informal peer support often starts here
  - Peer support program
  - Peer support groups
  - Peer mentoring

# The Independence Center: Independent Living Skills Training

1. Transit skills for the local community
2. Cooking skills (menu, adaptive cooking, grocery shopping, gaining confidence in the Kitchen through peer support and practice)
3. Money management
4. Self- advocacy
5. Positive thinking classes
6. Coming soon: Fitness for everyone (group and individual fitness programs)

# The Independence Center: Accessing Services in the Community

1. Home and Community Based Services (personal attendant care in the home)
2. Assistive technology: what works for them?
3. Benefits counseling and troubleshooting
4. Employment services: PWD can work!
5. Getting involved in changing our community for the better (transit advocacy, ADA compliance, speakers bureau and volunteering)

# The Independence Center: Improving Access in the Future

Several key opportunities have been identified

- Participant access to needed health care
- Caregivers support and training - to address health conditions when they arise
- Removal of barriers that delay participants from obtaining care which results in an alliance on 911 and emergency rooms
- Improving the participant experiences with health care will improve health outcomes and quality of life

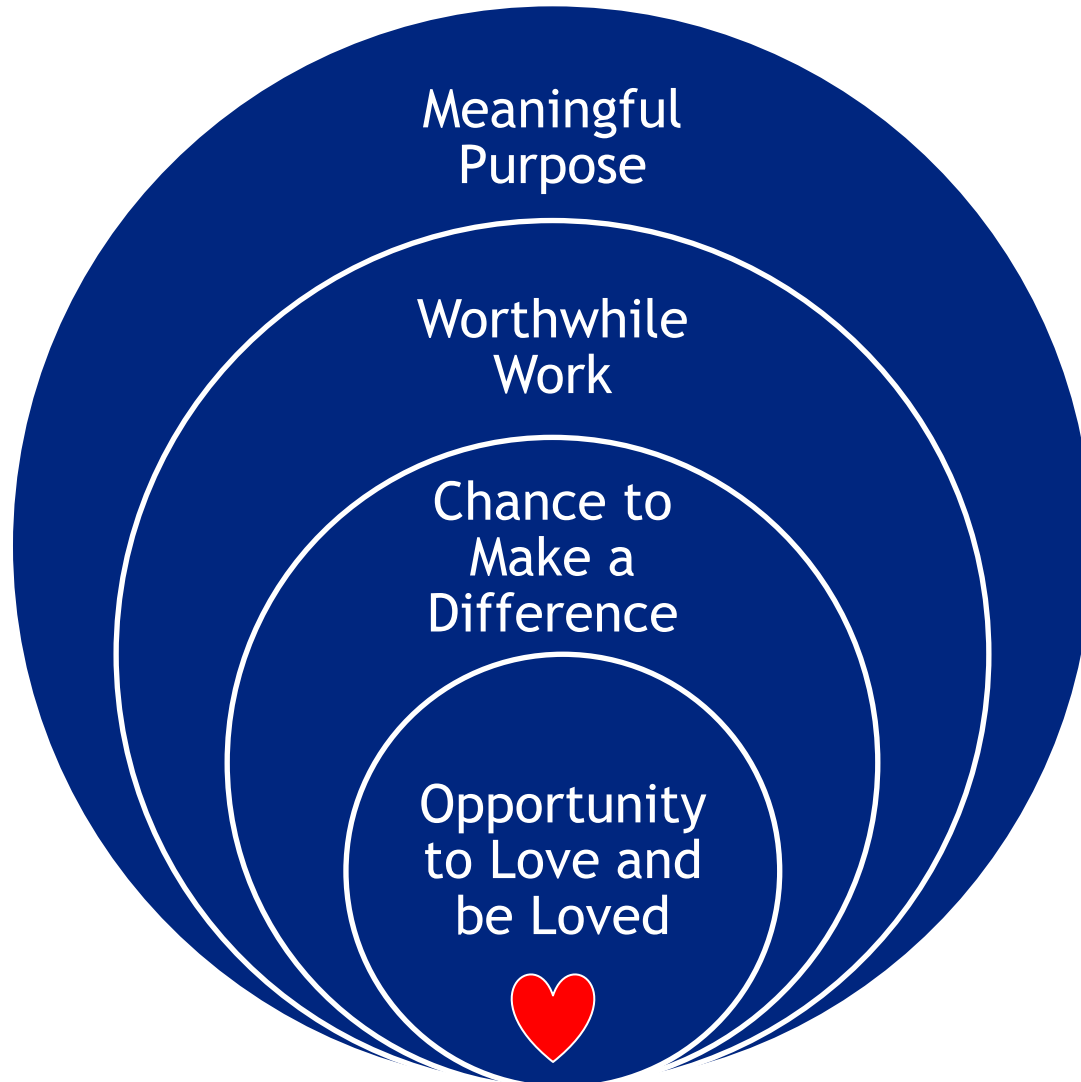
**Addressing these opportunities will help the health care system and participants achieve the *Triple Aim***

# Inglis Life Communities

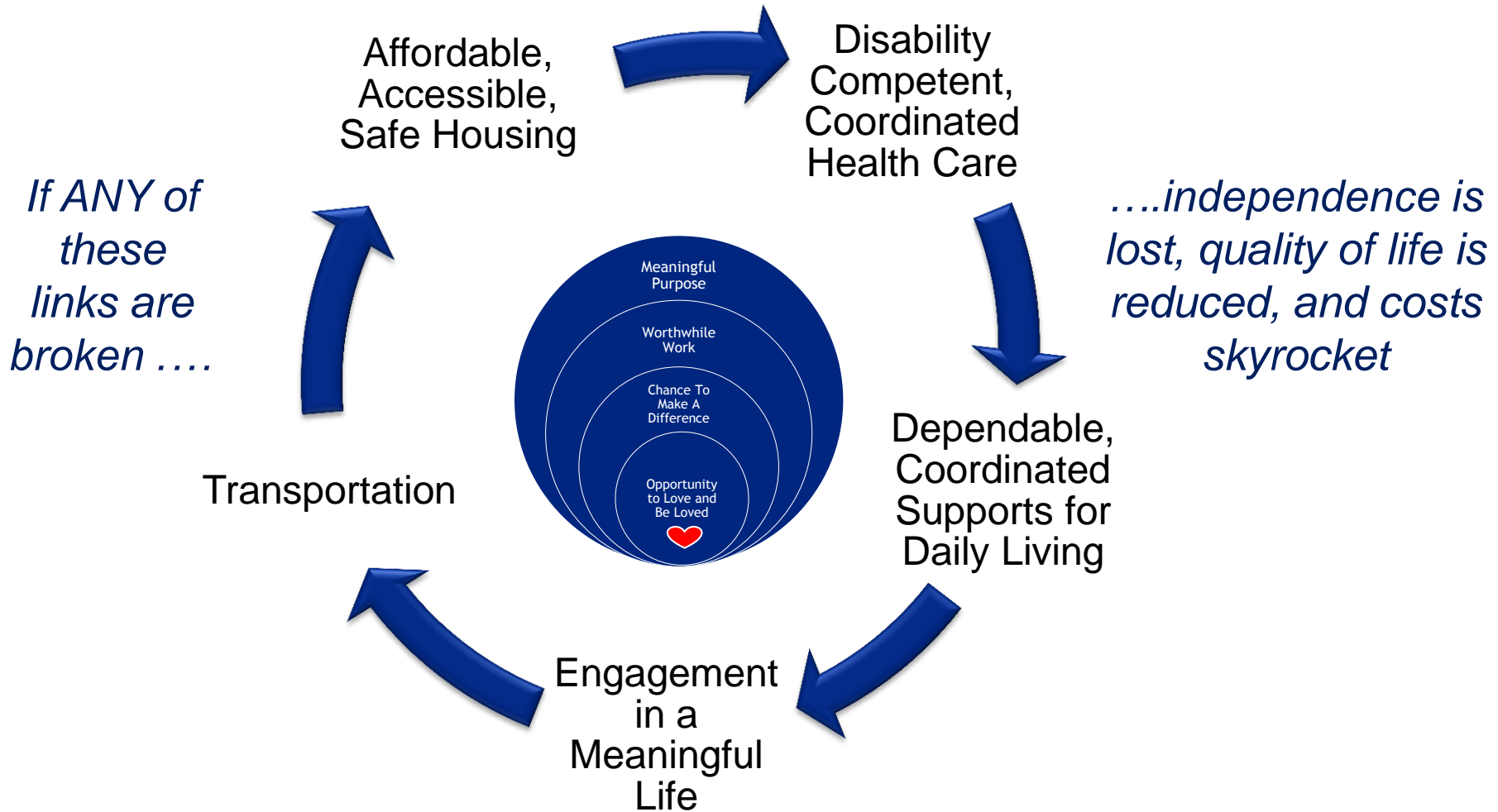
- Inglis' mission is to enable people with disabilities to achieve their goals and live life to the fullest
- Serve nearly 1,000 people who have healthy minds but - due to bad genes, bad luck or a bad accident - have functionally impaired bodies
- Primary focus is on those with the most significant disabilities and complex health care needs
- Provides a full spectrum of services designed to enable consumers to live as independently as they choose including
  - Accessible, safe and affordable homes
  - Complex care management and supports coordination services
  - Employment services
  - Innovative day program targeted at younger people with disabilities
  - Adapted technology services including computing, home environmental controls, tele-health, mobility and 3D printing technologies
  - Person centered long term care facility



# Inglis: Vision of a Full Life



# Inglis: The Virtuous Cycle For Independence



## Inglis: Top 10 Participant Defined Needs

Top 10	Participant Needs
1,2,3,4	Housing
5	Supports coordination and attendant care
6	Employment and financial health
7	Transportation
8	Physical and emotional health
9	Adapted computing and technologies
10	Education and social engagement

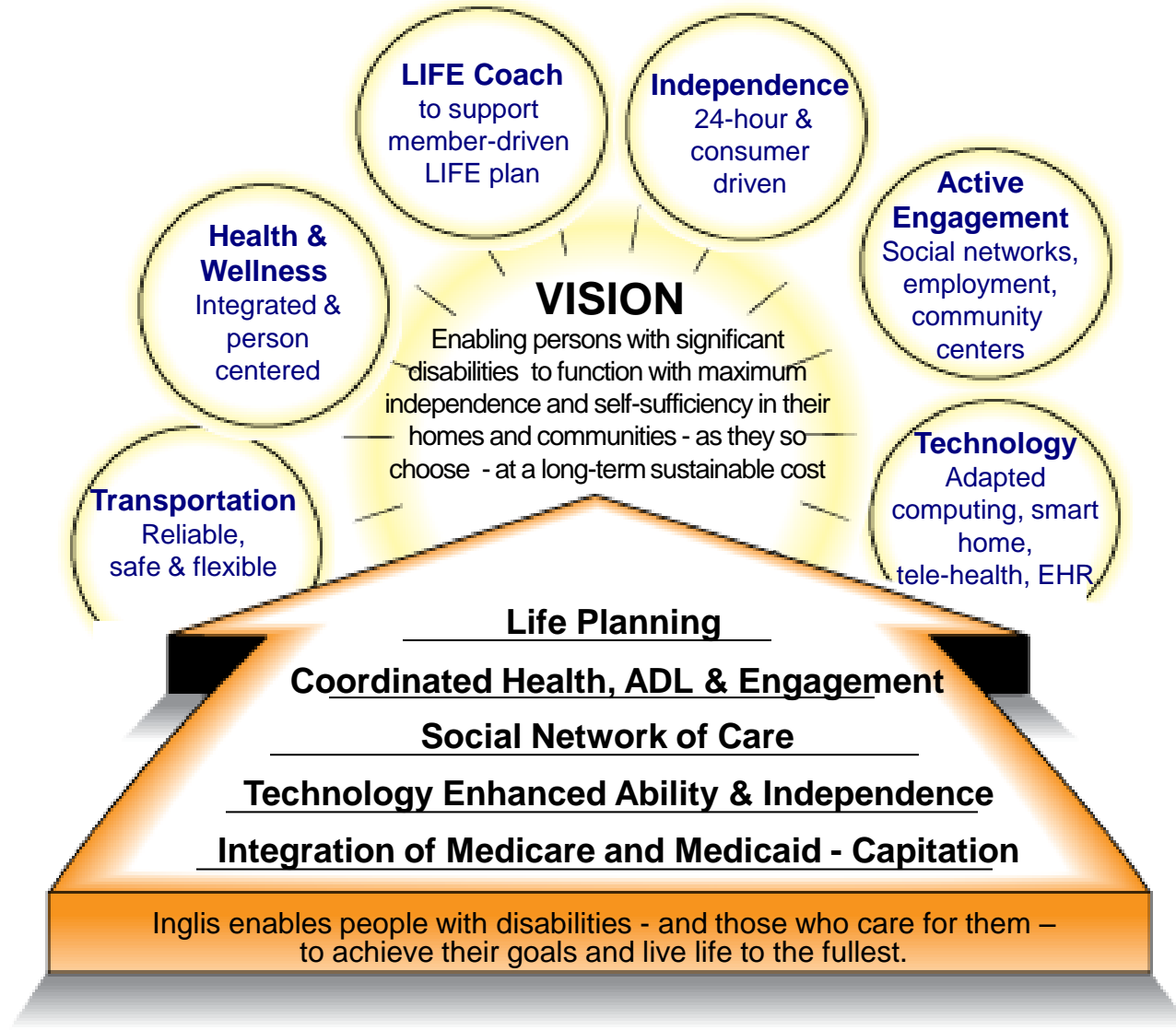
## Inglis: Consumer Research – Key Learnings

1. In its many forms, **housing** dominates the list of consumer needs as ever greater numbers of people with disabilities seeking to live in the community must wait for accessible, safe and affordable housing
2. The stress, frustration and barriers faced on a daily basis by **caregivers** trying to provide supportive care at home is itself disabling. These issues will become an even greater concern as the population ages.
3. The provision of **attendant care** that is reliable, well trained, caring and affordable is key to preserving the dignity, well being and independence of those living with a disability in the community and at Inglis House

## Inglis: Consumer Research – Key Learnings

4. When applied intelligently to maximize mobility, independence and engagement, **technology** can remove limitations and barriers to achieving goals and living life more fully
5. People living with a disability, and their caregivers, need equal opportunities for **social engagement, education, employment and transportation**

# Inglis: Consumer Vision Ability and Independence Redefined



## Summary

- We need to stop treating person's with disabilities as diagnoses – instead as individuals with the same hopes and aspirations as the rest of us
- As those working with persons with disabilities, our responsibility is to help them achieve their goals
- Achieving goals entails accepting and respecting the inherent risks
- Engage the local community as partners – CIL's, health plans, providers, fitness centers, public transit and others to facilitate inclusion, participation and acceptance

# Audience Questions and Discussion



## Next Webinar

### “Flexible Long-Term Services & Support”

Wednesday, June 17th, 2015

2:00-3:00PM EST

Session VII will:

- Explore the existing disconnect between medical care and long-term services and supports
- Explore care delivery in terms of thinking outside the box – focusing on creative approaches to participant goals
- Examine different participant choices for community-based living and the importance of supporting these choices.

Please respond to our survey!

# Thank You for Attending



- For more information contact:
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  - Gavin Kerr at [gavin.kerr@inglis.org](mailto:gavin.kerr@inglis.org)
- Disability-Competent Care Self-Assessment Tool available online at:  
<https://www.resourcesforintegratedcare.com/>

## Resources and References

- Best Practices for Meaningful Consumer Input in Health Care Delivery Models
  - [http://www.communitycatalyst.org/doc-store/publications/meaningfulconsumerinput\\_healthcaredeliverymodels.pdf](http://www.communitycatalyst.org/doc-store/publications/meaningfulconsumerinput_healthcaredeliverymodels.pdf)
  
- Kailes, J.I. Effectively Including People with Disabilities in Policy and Advisory Groups, Edition 2, 2012, published and distributed by the *Harris Family Center for Disability and Health Policy*
  - <http://www.hfcdhp.org>
  - <http://www.jik.com/Effectively-Including-People.pdf>

# Disability-Competent Care Self-Assessment Tool

## 1. Relational-Based Care Management

[Introduction](#)

[1. Relational-Based Care Management](#)

[2. Highly Responsive Primary Care](#)

[3. Comprehensive Long-Term Care](#)

[Appendix A](#)

Participant-centered care is based on the recognition that the participant is not merely a passive recipient of medical care but rather the primary source for defining care goals and needs. This type of care requires cultivating a relationship with the participant, seeing him or her as a whole person with hopes and preferences, and recognizing that the participant is oftentimes the best steward of resources. Inherent in participant-centered planning is also the concept of the dignity of risk [1] which honors and respects the participant's choices even if they are inconsistent with the recommendation of the IDT.

[1] Dignity of risk means the right of individuals to choose to take some risk in engaging in life experiences, even if that choice would not be one that a health professional would choose (e.g. choosing to smoke).

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- ▶ [1.1 Participant-Centered Practice](#)
  - ▶ [1.2 Eliminating Medical and Institutional Bias](#)
  - ▶ [1.3. Interdisciplinary Care Team \(ICT\)](#)
  - ▶ [1.4. Assessment](#)
  - ▶ [1.5. Individualized Plan of Care](#)
  - ▶ [1.6. Individualized Plan of Care Oversight and Coordination](#)
  - ▶ [1.7 Transitions](#)
  - ▶ [1.8 Tailoring Services and Supports](#)
  - ▶ [1.9 Advance Directives](#)
  - ▶ [1.10 Allocation of Care Management and Services](#)
  - ▶ [1.11 Care Partners](#)
  - ▶ [1.12 Electronic Health Record](#)

**Available at <https://www.resourcesforintegratedcare.com/>**

## Send Us Your Feedback

Help us diversify our series content and address current Disability-Competent Care training needs – your input is essential!

Please contact us with your suggestions at

[RIC@Lewin.com](mailto:RIC@Lewin.com)

### **What We'd Like from You:**

- How best to target future Disability-Competent Care webinars to health care providers and plans involved in all levels of the health care delivery process
- Feedback on these topics as well as ideas for other topics to explore in webinars and additional resources related to Disability-Competent Care