

We create opportunities for independence for people with disabilities through research, education, and consultation







#### Get to the Core of It: Integrating CIL Core Services for a Holistic Consumer Experience

### Day 1 Review

May 2, 2018 Tempe, AZ



### **Post-It Feedback: Day 1**

IL-NET, a project of ILRU – Independent Living Research Utilization



CIL-NET SILC-NET

### Get to the Core of It: Integrating CIL Core Services for a Holistic Consumer Experience

#### Implementing Effective I&R Services

Presenters: Darrel Christenson Kimberly Tissot

> May 2, 2018 Tempe, AZ





### Implementing Effective I&R Services at Ability360

### **Darrel Christenson**



## What is a Core Service?



 Centers for Independent Living (CILs) provide services to individuals with a range of significant disabilities from cross-disability multicultural populations.

### From § 1329.4

Independent living core services mean...

- A. Information and referral services;
- B. Independent Living skills training;
- C. Peer counseling, including cross-disability peer counseling;
- D. Individual and systems advocacy;





### What is a Core Service?, cont'd.

- E. Services that:
  - i. Facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences....
  - ii. Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community....
  - iii. Facilitate the transition of youth who are individuals with significant disabilities, who were eligible for IEPs..., and who have completed their secondary education or otherwise left school, to postsecondary life....



## Why is I&R a Core Service?

- A primary means to promoting consumer empowerment.
- Supports an individual's capacity for self-reliance and self determination.
- "Education, affirmation, collaborative planning, and problem solving."—AIRS (Alliance of Information and Referral Systems)
- Provides a road map for navigating complex and confusing systems.



# I&R Core Service: The Human Approach – The First Point of Entry



Consumers contact I&R Specialist for:

- Programs and services offered by their CIL.
  - Independent Living Skills
  - Advocacy
  - Peer Support
  - Other services





## The First Point of Entry, cont'd

- Resources offered within the community.
  - Housing
  - Employment
  - Financial Assistance
  - Healthcare
  - Transportation





### **Customer Service**

- For an I&R Specialist to succeed at providing relevant information, they must possess knowledge AND customer services skills.
- Know what you can and cannot do for the consumer.
- Know your boundaries/parameters—it's ok.
- Let them down easy.





### **Listening Skills**

- Listen and understand the consumer's issues.
- Let the consumer speak without interruptions.
- Be nonbiased with your suggestions.





### **Communication Skills**

- Relay information clearly and concisely to consumers over the phone.
- Have good written skills for consumers who choose to communicate by email or TTY.
- When face-to-face with consumer, show proper body language that is consistent with the matter at hand.



### **De-escalation / Crisis Management**



- Do not take matters personally.
- Let consumer vent without interruptions.
- Make sure consumer knows that you are there to help.
- Utilize other resources around you.
- Offer to follow-up at a later date.



## **Time Management & Prioritizing Responses**



- Establish routines and stick to them as much as possible.
- Get in the habit of setting time limits.
- Utilize a day planner or Outlook Calendar to schedule events and follow-up calls.
- Keep resources close at hand so you don't waste time searching.





### **Recordkeeping and Data Management**

- Helps assure accountability.
- Facilitates long-term planning and resource allocation.
- Identifies possible systems advocacy issues.
  - 23 referrals to Energy Assistance but only 6 received assistance (accountability).
  - Increased contacts for transportation resources after the only accessible taxi in town is gone (planning & resource allocation).
  - 10 calls regarding lack of effective communication for medical appointments (systems advocacy!).

# Recordkeeping and Data Management, ilru

• Helps decide when an I&R becomes something more than an I&R.

AND

• Can provide verifiable data for funding requests, grant proposals, and policy initiatives.



## **Prioritizing Responses**



- Consider consumer's needs.
- Look at their deadlines.
- What resources are available at that moment?
- Is there another team member who can assist?
- Keep your day planner/calendar close by to avoid overlapping of tasks.
- Don't forget your other consumers.



# Follow Up and Consumer Relationships <sup>ilru</sup>

- Timely follow-up and call backs are simple ways to show you care and value them as a consumer.
- Follow-up can earn you additional open consumers, which means additional agency revenue.

How do you feel when a business you solicited from follows-up with you?





### Creating a Welcoming I&R Process at Able SC

**Kimberly Tissot** 



# IL Philosophy Starts at the Beginning of Contact





### Able SC's I&R Process



### I&R Staff

- Front end staff
- First point of contact for introduction to IL
- Provides I&R services to callers
- Eliminates frustration
- Starts consumer driven services
- Conducts intakes/enters data
- Identifies needs
- Researches resources
- Collects separate satisfaction survey
- Provides follow-up
- Refers to IL staff if one-on-one services are needed



### All Able SC Staff

 Provides I&R if callers become consumers--natural part of IL process

### Resources



- System for community resources
  - All staff should have access.
  - Resources should be updated often.
  - Network/collaborate/research.
- Referral sources should be appropriate.
  - Provide resources that promote independence.
  - Least restrictive and community based.
  - Accessible programs
  - No wrong door approach.

### Good I&R can significantly improve someone's life!





## Follow-Up is a Must!

Following up provides—

- Support and empowerment
  - Assists with navigating resources.
  - Provides encouragement from I&R staff.
- Accountability
  - By empowering consumers to take the lead and celebrating this with them
- Excellent customer service!





### **I&R Resources**

- Information and Referral for CILs (RapidCourse tutorial) - <u>www.ilru.org/training/core-services-for-</u> <u>centers-for-independent-living-series</u>
- Recorded webinars -<u>http://www.ilru.org/topics/information-referral</u>
- Standards for I&R www.airs.org





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### Get to the Core of It: Integrating CIL Core Services for a Holistic Consumer Experience

Applying Effective Interviewing and Goal-Setting Practices that Support Consumer Control and Direction

> **Presenters: Michelle Crain Charlie Walters**

> > May 2, 2018 Tempe, AZ





### **Able South Carolina**

- Frontline staff provide I&R.
- For prospective consumers, I&R is the precursor to intake (Meeting to establish ILP, etc.).
- These conversations set the stage for peer-to-peer relationships, consumer control, and empowerment.



## Able South Carolina, cont'd. 2

- Federally required info and info specific to each case is collected.
- This is done by staff that intimately understand IL and the trajectory of consumer goals.
  - We do not field calls from "them."
  - We field calls from "us."
- Questions on employment, marital status, disability, educational status, and income bring about very common answers.
  - "I'm disabled; I can't work."
  - The way these responses are handled sets the stage for the process.



### Able South Carolina, cont'd. 3

- Peer mentoring and self-identifying as a person with a disability.
  - Empowerment
  - "I'm also a person with a disability, and I am employed."
- Empathy, Not Sympathy
  - Intimate understanding of the barriers consumers and prospective consumers are facing.
  - Practical, solution-oriented guidance provided.



### Able South Carolina, cont'd. 4



- This tone is set at the frontline & kept throughout the process.
- Goal planning with consumers ahead of signing an ILP takes this tone to the next level.
- Backwards planning based on people's vision for the life they want is simple. For many, it is a radical concept. (Backwards planning is beginning with a long-term vision for oneself and setting goals that one thinks will lead to that vision. In other words, goal planning with the end in mind.) For example, you may not set a goal of finishing a master's degree, but knowing that is your long-term aim may point you in the direction of taking a GED preparation class.
- Goals are worked out with consumers based on this vision and the effort they are willing to exert to get there.



## **Consumer Intake/ Initial Interview**

- The primary purpose of the consumer intake/initial interview is to help determine eligibility for IL services and to assist the consumer in identifying their strengths, resources, and potential barriers that may impact his or her ability to function independently in the community. Ultimately, this information is used to assist in the development of the consumer's ILP.
- Empower and encourage the consumer from the outset by informing him or her about the importance of this process being consumer-driven and directed.
- A good intake entails establishing trust, active listening and note-taking skills and effective documentation.



## **The Intake Setting**

- Consumer intakes may be conducted in different settings. Many CILs will accommodate a consumer's choice to meet at the center or in the home or respective community.
- The setting should be:
  - mutually <u>comfortable</u> for the consumer and CIL staff;
  - mutually *accessible* for consumer and CIL staff;
  - maximizes the consumer's *confidentiality; and,*
  - conducive to *a focused and productive experience*.



# **Gathering Essential Information**

- ilra
- It is essential that CIL staff be prepared and organized for the intake process, as it is respectful of the consumer's time. CIL staff should have access to the CIL's data collection program, referral information, note-taking materials and any hard-copy or electronic forms.
- Explain the process, collect demographics and inform the consumer that some of the questions asked during the assessment may be intrusive, but necessary when trying to identify IL services and other community resources instrumental to meeting his or her established goals.



# ilra

# **Determining Eligibility**

- Encourage the consumer to speak freely about the functional limitations of the disability and the impact the disability has on his or her ability to function independently.
- Discuss and document how IL services will improve the consumer's ability to function more independently in the home, family and community.
- Notify the consumer in writing if he or she is determined to be ineligible, provide Client Assistance Program (CAP) information and assist with I&R, where appropriate.



# **Assessing and Planning**



- After determining eligibility, the next major step in the IL process is following a logical sequence to develop the ILP or waived plan. Further assess:
  - the nature and extent of the consumer's disability;
  - the functional assets of the consumer; and
  - the needs of the consumer to become or remain independent
- Engage in a Strength-Based approach, whereby the focus is on the consumer's abilities and not necessarily his or her limitations.





# **Identifying IL Goals and Services**

- In the process of supporting consumers in identifying goals and action steps, it is important to use a Solution-Focused Approach—Taking a positive perspective, as opposed to a negative perspective.
- Goals should be specific and focus on what the consumer needs to do.
- Once goals for independent living (IL) are established, assist the consumer in determining what services are required to achieve those goals. Each service should clearly support the achievement of consumer's goals and objectives; and be time-limited.



## Identifying IL Goals and Services, cont'd. <sup>ilra</sup>

- Examine the assessment information with the consumer. Discuss whether options are consistent with the consumer's needs and attributes. Ensure that the IL goal(s) meet identified consumer needs and expectations. This approach supports the consumer's ability to make informed choices about:
  - suitable goals;
  - services needed to achieve his or her goals;
  - preferred methods and settings for service delivery; and,
  - potential providers



#### **Self-Assessment**

- What are the top three strengths you see in your intake/goal setting processes?
- What are three areas of improvement you see in those processes?





## **Scratching the Surface**

- This session likely scratches the surface of a much larger conversation.
- To take things further, check out:
  - An Introduction to Consumer Service Records, Independent Living Plans, and Service Coordination for CILs at <u>http://www.ilru.org/introduction-</u> <u>consumer-service-records-independent-living-plans-</u> <u>and-service-coordination-for-cils</u>





#### **More IL Resources**

- Interviewing and Assessing Needs (RapidCourse tutorial) - <u>http://www.ilru.org/training/consumer-</u> <u>service-records-series</u>
- Goal Setting with Consumers (RapidCourse tutorial) -<u>www.ilru.org/training/consumer-service-records-series</u>
- Effective Service Coordination: Engaging Consumers with a Holistic Approach to Independent Living (recorded video modules) -

http://www.ilru.org/effective-service-coordination



#### **Small Group Activity**

IL-NET, a project of ILRU – Independent Living Research Utilization



#### Get to the Core of It: Integrating CIL Core Services for a Holistic Consumer Experience

#### Lunch Presentation: Great Fight for Disability Rights, Part I

May 1, 2018 Tempe, AZ





CIL-NET SILC-NET

#### Get to the Core of It: Integrating CIL Core Services for a Holistic Consumer Experience

Implementing or Strengthening Effective Individual and Systems Advocacy Activities

> Presenters: Bruce Darling Kimberly Tissot

> > May 2, 2018 Tempe, AZ



#### The Rehabilitation Act, as amended, Content



- •Title I Vocational Rehabilitation Services
- •Title II Research & Training
- •Title III Professional Development & Special Projects
- •Title IV Nat'l Council on Disability
- •Title V Rights & Advocacy
- •Title VI Employment Opportunities
- •Title VII Independent Living Services and Centers for Independent Living

Only Title VII emphasizes consumer control as part of the foundation and philosophy of the funding.

# Notice that IL Philosophy is first in the **ira** law!

- Consumer control
- Peer support
- Self-help and self-determination
- Equal access
- Individual and system advocacy
- Maximizing leadership, empowerment, independence, and productivity of individuals with disabilities
- Promoting integration & full inclusion of individuals with disabilities into the mainstream of American society...by funding the statewide IL network & centers.





#### What is Consumer Control?

- More than 50% of the board of a CIL must be people with significant disabilities.
- More than 50% of the management of a center must be people with disabilities.
- More than 50% of the staff of a center (not including attendants if you hire them) must be people with disabilities.
- More than 50% of the members of the SILC must be people with disabilities who do not work for either the State (in any agency or capacity) or a CIL.



#### § 1329.4 Definitions.— Individual with a disability



Individual with a disability means an individual who-

- 1. Has a physical or mental "impairment" that substantially limits one or more major life activities of such individual;
- 2. Has a record of such an impairment; or
- Is regarded as having such an impairment, as described in the Americans with Disabilities Act of 1990 (42 U.S.C. 12102).



#### § 1329.4 Definitions.— Individual with a significant disability

"Individual with a significant disability means an individual with a severe physical or mental "impairment" whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited and for whom the delivery of independent living services will improve the ability to function, continue functioning, or move toward functioning independently in the family or community or to continue in employment, respectively."







#### **Philosophy of Equal Access**

The expectation is that all operations of the IL Network are accessible. Your policy might include:

- Communication interpreters, readers, video, CART, captions, Braille and other alternative formats as needed for reasonable accommodations.
- Physical access to all sites used by the Council for meetings or for input.





## Philosophy of Equal Access, cont'd.

- Notice regarding fragrance & smoke-free meetings to accommodate people with environmental illness/multiple chemical sensitivity and adherence by Council members.
- Signage for public areas meets ADA requirements for height, raised letter and Braille.
- Advocacy to achieve public access.



#### **Advocacy**



- Advocacy is a planned action to support an issue, interest, cause, or idea.
- Advocacy addresses a power inequality.
- Advocates must be aware of the constitutional rights of people with disabilities and assert them.



#### **Individual Advocacy**



- Addresses issues and needs identified by the consumer.
  - Listen to the consumer.
  - Hear what is being said and not said.
  - Be willing to listen more than once.
  - Don't be surprised if different information is given each time you listen.
- Individual Advocacy issues and barriers inform Systems Advocacy efforts. Connect the dots.



#### **Role of the IL Advocate**



- Gather all the facts from all parties involved be non-judgmental.
- Identify approaches to address the problem and assist the consumer with sorting through the options.
- Provide information and support the consumer towards personal empowerment.



#### Role of the IL Advocate, cont'd.



- Provide referrals and linkages to other options and expertise.
- Teach self-advocacy skills as you work with the individual.
- Follow the consumers lead as to how much assistance is needed.



#### Role of the IL Advocate, cont'd. 2



- Provide an objective insight to the situation.
- Provide mediation resources and negotiate on consumer's behalf if requested.
- Create a partnership so the consumer never feels alone in the process.



#### **Breaking through Bureaucratic Barriers**



- Never take "no" as the answer.
- Document everything! (It protects you, the Center, and the consumer.)



#### Why do Systems Advocacy?



Aside from it being a required core function of Centers...

If we do not fight for our own rights, no one else will.

We have the obligation to make this world better for others. (At least we think so.)

We have the privilege to be the voice of many who cannot, yet, be their own.



## **Framing is Everything**



#### When I started in Independent Living...

Our IL Advocate would talk about the conflict between service delivery and systems advocacy, questioning which he should do.

# When I began working for a children's advocacy organization...

Our Executive Director explained that we did individual advocacy (a form of service delivery) to inform our systems advocacy.





### **Effective Systems Advocacy and Direct Services are Interdependent**

Direct services identify the barriers and systems; advocacy removes them.

Service delivery can...

- Help identify people who can make the case for change.
- Frame individual issues in terms of systems bias which underscores that the problem is in the environment – not the person.
- Support individuals in joining systems advocacy efforts to empower them.

#### **The Pitchfork of Advocacy**



- Public Education / Media
- Legislative Advocacy
- Judicial Process
- Executive / Administrative
- Direct Action
- from Bob Kafka

All of these prongs are necessary at one time or another to bring about change.



## **Putting the Pitchfork into Action**



- Identify the issue.
- Set goals.
- Develop strategies (which prong(s) of the pitchfork is/are most appropriate for the situation?)
- Celebrate (even the small) victories.



## Lobbying

- CILs <u>can NOT</u> lobby with Subchapter B & C or any other federal funding.
- CILs (non-profits) <u>CAN</u> lobby with unrestricted, nonfederal funding.



# Your Certification Regarding Lobbying / ilra form promises you are not. . .

- Improperly influencing activities re: obtaining grants, contracts, cooperative agreements or loans.
- Attempting to improperly influence employee or officer of Government.
- Attempting to influence outcomes of federal, state, or local elections, referendums, or initiatives through inkind or cash contributions, endorsements, or publicity.





#### You are not. . ., cont'd.

- Contributing to expenses of a political party, campaign, or political action committee.
- Attempting to influence votes for or against specific legislation with certain exceptions.
- Keep the form on file.



# More about Lobbying – What IS Allowed with Federal Funding



- Technical and factual presentations on topics directly related to the performance of a grant, contract, or other agreement in response to a documented request.
- Information must be readily obtainable and readily put in deliverable form.
- Costs of travel, lodging, or meals are allowed when incurred to offer testimony at a regularly scheduled hearing pursuant to a written request.
- Lobbying within limits set by the IRS related to your non-profit status, as long as you don't use federal funds.





## Able SC's Lobbying Activities\*

- Contracts with a Legislative Liaison/Registered Lobbyist
- ED and Lobbyist meet together with representatives
- Writes and advocates for bill to pass
- Testifies in support/opposition of a bill
- Provides guidance to state agencies regarding passed legislation
- Reports to the Ethics Commission every six months
- Spreads IL and disability rights throughout the SC general assembly
- Funding requests

\*Not using federal funds.



## Careful Considerations when Lobbying <sup>/ ilra</sup>

- Check with your state laws regarding lobbying.
- You may need to register at your State's Ethics Commission and report often about lobbying activities.
- Register as a lobbyist.
- Document lobbying activities in your database system, timesheet, mileage, receipts, etc.



## Careful Considerations when Lobbying, cont'd.



- Plan & prepare to show documentation of lobbying activities. You will need to show that you are using funding other than federal.
- Lobbying should not constitute a "substantial" percentage of an organization's activities (IRS rule).
  - IRS restricts organizations from using a "substantial" percentage of time, staff, and resources on lobbying.
  - More information about what constitutes "substantial" is available here: https://www.irs. gov/charities-non-profits/measuringlobbyingsubstantial-part-test.





#### **Advocate to Remove Barriers!**



## **advocacy day** for Access & Independence



## **Community Organizing/Direct Action:** It's all about POWER!

"Power concedes nothing without a demand." ~ Frederick Douglass

"Power never takes a step back, except in the face of more power." ~ Malcolm X

There are many different types of power, but for us... People = Power!



# Community Organizing as an Element of Independent Living

Community Organizing – as contrasted with the Social Work/Helper model – is consistent with Independent Living Philosophy.

- The locus of the problem is the environment/society.
- The solution is changing the external not the disabled individual.
- The solution is not secured by professionals, but through self advocacy.

When addressing an issue as a Community Organizer, we work with groups of people, instead of individuals.



### Direct Action— More than Civil Disobedience



Although people always think about civil disobedience, there are many different forms of Direct Action:

- Delivering declarations by organizations or petitions
- Distributing leaflets
- Picketing
- Bird-dogging, "haunting" or taunting officials
- Holding vigils, mock funerals and marches
- Doing street theatre
- Holding teach-ins, walk-outs, or sit-ins
- Overloading of facilities or administrative systems



#### **Centers CAN Support Direct Action**



- Systems advocacy is a core service.
- Free speech is protected by the Constitution. It was the FIRST Amendment for a reason.
- Centers can provide in-kind support (like space to meet) to other groups within the disability community who engage in direct action, including civil disobedience.
- Centers should establish policies that promote our movement and protect the Center.



## Centers SHOULD Support Direct Action *ilra*

- Direct Action is transformative; it shows people who may not have seen themselves as having power that they are – in fact – powerful.
- Everyone has something they can contribute to doing Direct Action.
- It bolsters the other forms of advocacy within the pitchfork model.
- It WORKS, and it's FUN!





#### A Good Systems Advocacy Issue Meets Most of These Criteria

- Result in real improvement.
- Give people a sense of their own power.
- Alter the relations of power.
- Be winnable.
- Be worthwhile.





### A Good Systems Advocacy Issue Meets Most of These Criteria, cont'd.

- Be widely felt.
- Be deeply felt.
- Be easy to understand.
- Have a clear target.
- Have a clear time frame that works.



## A Good Systems Advocacy Issue Meets Most of These Criteria, cont'd. 2

- Be non-divisive.
- Build leadership.
- Lay groundwork for next campaign.
- Be consistent with your values.
  - from Organizing for Social Change



#### **Some Other Tips to Remember**



- Anyone can be a leader.
- Invest people by using their strengths.
- The most important victory is the group itself.
- Leverage our perceived weaknesses as strengths.

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." ~ Margaret Meade



#### **Advocacy Resources**



- Updating Your Policies to Match Current Financial Regulations, Module 15: Lobbying or Advocacy? (recorded video module) - <u>http://www.ilru.org/training/updating-</u> your-policies-match-new-regulations
- Systems Advocacy in CILs and Individual Advocacy in CILs (RapidCourse tutorials) -<u>http://www.ilru.org/training/core-services-for-centers-for-independent-living-series</u>
- Get to the Core of It: Best Practices in CIL Core Services— Systems Advocacy (recorded webinar) -<u>http://www.ilru.org/training/get-core-it-best-practices-cil-</u> <u>core-services-systems-advocacy</u>



#### **Breakout Activity & Discussions**





Get to the Core of It: Integrating CIL Core Services for a Holistic Consumer Experience

#### Wrap Up and Review of Day 2

May 2, 2018 Tempe, AZ



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