



**Together We Stand Initiative**  
for the  
**Administration on Developmental Disabilities**

**Kentucky**

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**A DD NETWORK THAT WORKS, AND  
HOW!**



# **Collaboration Between Us As Partners Must Show.....**

**“ Meaningful examples of how the councils, protection and advocacy systems, centers, and entities funded... have taken coordinated activities” that have brought about “advocacy, capacity building, and systemic change activities” (Section 105, *Developmental Disabilities Assistance and Bill of Rights Act of 2000*)**

# Challenges We Face in Kentucky

## Building a community-based infrastructure:

- **Transportation**
- **Employment**
- **Housing**
- **Education and Transition**
- **Personal Care Attendant (PCA)  
Support**



# Overcoming Our Obstacles...

- **Assuring funding and services are individualized and flexible to allow for creative and personalized choice**
- **Increasing knowledge of legislators, policy makers, and community leaders on the need for individualized choice and supports**
- **Increasing effective use of current resources**

# Collaboration in KY's DD Network – PCMR and KY HB 144

- ⌚ **Our state DD partners collaborated as members of the KY Delegation to the *President's Committee on Mental Retardation* National Academy.**
- ⌚ **The result has been the development of KY Legislation (HB 144) to expand critically needed services in KY and a Ten-Year Plan to address the long-range needs of KY citizens with developmental disabilities.**

# **Collaboration Continued - *Olmstead* Public Forums**

- Ω We recently collaborated on a series of *Olmstead Public Forums* throughout KY, including a PowerPoint presentation at each forum by a consumer and family member.**
- Ω This has resulted in heightened awareness of *Olmstead* across disabilities groups and ages.**
- Ω We are currently surveying participants to see how they have used this information .**

# **Collaboration Continued - *KY Assistive Technology Loan Fund***

## **Ω Our Respective Contributions:**

- DD Council – initial funding for the Loan Fund**
- UCDD – training, technical assistance, AT evaluations, and management of the Loan Fund**
- P and A – legal advice and representation of individual clients to insure services.**

**Ω Results: Greater access to assistive technology for persons with disabilities.**

# **Collaboration Continued – Family Support in KY**

- Ω We collaborated in the development and implementation of the Family Support Grant awarded to KY SPIN through the US Administration on Developmental Disabilities. This grant's objectives are to :**
- expand statewide parent to parent support**
  - provide education to families and agencies about the concepts of family support.**



# **A Closer Look at KY's DD Partners**

- Ω KY Council on Developmental Disabilities**
- Ω KY University Center on Developmental Disabilities**
- Ω KY Protection and Advocacy**
- Ω KY Family Support Project**



# **The Kentucky Council on Developmental Disabilities has a history of focusing on:**

- **Assistive Technology**
- **Inclusive education**
- **Transition from school to adult living, including employment**
- **Quality Assurance- Community based services and supports**
- **Public awareness**
- **Self-advocacy**



# The Council's Vision

***To assure all Kentuckians have equal opportunity for choice and control in their lives.***



# **Council Five-Year Priorities**

**We will work towards our vision in our five -year plan (2001-2006) through our focus on:**

- Assistive technology**
- Education**
- Quality assurance**
- Formal and informal community supports**
- Health care**
- Employment**



# **A Look at One of Our Projects: KY Assistive Technology Loan Fund (KATLF)**

- **KATLF Mission: *to provide low interest loans to individuals with disabilities for the purpose of assistive technology that will promote independence and life.***
- **Over the course of 2 years, the Council has invested \$225,043 of its budget in the ATLF.**

# **Our KATLF Partners...**

- **Fifth-Third Bank of Kentucky**
- **Kentucky Housing Corporation**
- **KATS Network (Kentucky Assistive Technology Services)**
- **Five Independent Living Centers**
- **Six Assistive Technology Resource Centers**
- **Interdisciplinary Human Development Institute - UCDD**

# Information about KATLF

- **As of 10/1/01 KATLF has loaned \$343,713 to 33 individuals through Fifth-Third Bank on loans that range from \$500-\$25,000.**
  - **For adaptive computers, adapted transportation, and mobility devices.**
  - **The interest rate is 6% with an option to buy the rate down on specific loans depending on need.**
- **\$19,105 to 2 persons through KY Housing Corp.**
  - **Loans have been for home modifications**
  - **Interest rate is 4%**

# A Story....

**Alicia and her family were able to purchase a van with a lift through the KATLF. She lives in Florence, located in Northern Kentucky.**



# Alicia's Story Cont....

**This vehicle has afforded both Alicia and her family the opportunity to become more involved in and enjoy their community.**



# Expanding the Impact of KATLF...

- **KY received a grant in October 2001 from the US Department of Education, National Institute on Disability and Rehabilitation Research.**
- **\$1.05 million-for the 6% fixed rate assistive technology loans.**
- **This grant will offer assurance that the loan program will be self-sustaining.**
- **Awarded to KY Dept. of Vocational Rehabilitation and co-authored by IHD-UCDD.**



# **Council Disseminated Products**

- 1. Legislative handbook**
- 2. Disability Etiquette handbook**
- 3. KCDD Brochure**
- 4. ADD information**
- 5. Self-Determination Video and Inclusive Education Videos**
- 6. Assistive Technology Loan Fund Brochures**
- 7. Folic Acid information**
- 8. KCDD Newsletter**
- 9. KCDD Annual Report**
- 10. KCDD Web site**



# **Interdisciplinary Human Development Institute – KY's UCDD**

- Ω At the national level, we are known for our outreach to states in developing alternate assessments and in implementing IDEA 97.**
- Ω We are known for our work in KY especially in education, transition to adult life, supported employment, community living, and assistive technology.**

# IHDI Training – One Example

- We focus on *enhancing the capacity* of service systems to address the needs of persons with disabilities and their families.
- Recently we trained over 400 educators and administrators to more effectively include transition planning into the IEP to improve post-school outcomes for students with disabilities.
- We plan to assess the impact of this training on individuals with disabilities by changes in state follow-up data on successful transitions.

# IHDI Outreach- An Example – Assistive Technology

- ∞ ***To whom:*** Persons with significant disabilities in school, work, and home settings.
- ∞ ***About:*** Using assistive technology to achieve life goals and independence.
- ∞ ***Because:*** Transition-age students and adults with significant disabilities often have unmet technology needs in the basic areas of their lives.
- ∞ ***Through:*** On-site assistive technology evaluations and on-going consultations.



# IHDI Research

- ❧ **Research questions we are tackling right now include the impact of alternate assessments, the role of families in early intervention decision-making, and the extent to which preschool children should be included in state educational accountability systems.**
- ❧ **We have learned that classroom practices are changing for the better as a result of the inclusive assessment requirements of IDEA 97.**



# **IHDI Popular Products**

- Ω We have developed books and book chapters, journal articles, and training materials on alternate assessment.**
- Ω They are popular with teachers and administrators because they show practitioners how alternate assessments can have a positive impact upon student outcomes, and how to integrate assessment into ongoing instruction.**

# Other IHDI Products

- Ω **IHDI Newsletter**
- Ω **Topical or project newsletters (e.g. supported living, community-based work transition)**
- Ω **Practitioner and consumer manuals**
- Ω **Much of what we publish is accessible via our web-site: *[www.ihdi.uky.edu](http://www.ihdi.uky.edu)***

# IHDI Long Range Plans

**We hope to have a more direct impact upon:**

- ⌚ **The *quality and intensity* of supports and services to adults with developmental and other disabilities in Kentucky.**
- ⌚ **Measurable improvements in *life outcomes*.**

**(KY currently ranks 50<sup>th</sup> in fiscal support for community services for persons with developmental disabilities).**

# UCDD Person Profile

- ⌚ **What we do through the eyes (voice) of Shelley Lane.**
- ⌚ **“I went so long without a voice, and now I am communicating with more people than I ever imagined. That is an awesome feeling to have.”**



# UCDD Person Profile

- ⌚ **What we do through the eyes (voice) of Kevin Burberry.**
- ⌚ **"The Liberator has removed the barriers of communication and allowed me to be known to people."**



# **KY Protection and Advocacy - Current Major Cases**

**Ω We are now devoting a great deal of our resources to *Olmstead* and waiting list issues. This represents a continuation of activity from last year.**



# **P&A**

## **Choices We Make**

- Ω Every year, P&A sets priorities based on consumer and staff input, trends gathered from information and referral data, and advisory board approval.**
- Ω Our priorities determine case acceptance criteria. P&A strives to accept clients that represent underserved populations, such as people living in institutional settings.**



# **P&A Strategies**

**P&A uses different strategies in its advocacy activities, including:**

- **Negotiation**
- **Investigation**
- **Individual client representation**
- **Technical assistance**
- **Self-advocacy materials and assistance**
- **Litigation (used rarely)**



# **P&A: Challenges and Planned Responses**

- Ω Our major challenge is a greater need and demand for our services than available resources.**
- Ω We plan to focus on systemic change to maximize the impact of these limited resources.**

# P&A Products

- Ω **P&A publishes self-advocacy materials.**  
**P&A also publishes reports of abuse/neglect investigations that it conducts.**
- Ω **All of these products may be accessed by calling 1/800/372-2988 or downloaded from our website: [www.kypa.net](http://www.kypa.net)**

# **P&A: A Student's Success Story**

- Ω Tim, a 17-year-old student, sustained a severe closed head injury about three years ago. Tim's father contacted P&A to express his concerns regarding his son's education, including the lack of sufficient homebound services, assistive technology and a transition plan.**

# **Tim's Story – cont.**

**P&A successfully negotiated for Tim for:**

- **Consistent homebound instruction**
- **A new AT assessment**
- **A new computer with appropriate software and computer training**
- **A transition plan with measurable goals**
- **One transition service provided Tim (much to his delight) was driver's education with his typical peers.**

# **P&A: An Adult's Success Story**

Ω **Ralph, a 41-year-old African American man diagnosed with mental illness and mental retardation, had been institutionalized in state psychiatric hospitals for the past 13 years. P&A filed an OCR complaint on his behalf.**



# **Ralph's Story – cont.**

**Transition and placement in a community program were developed. Ralph now:**

- lives in a staffed apartment**
- attends a sheltered work program**
- eats at community restaurants and**
- shops for his own clothing, an activity he enjoys very much!**

# **P&A: An Older Adult's Success Story**

**Ω Bennie, age 61, had resided in facility placements since 1954, with the exception of a few months when he was placed in a community program. P&A educated Bennie's treatment team, facility staff, and guardian about community alternatives. With intervention by P&A, Bennie was discharged to a community program.**

# **Bernie's Story – cont.**

♫ **Bennie loves his new home and his new job at the Humane Society. Staff from the state ICF-MR has visited him and is impressed with his transition into the community.**






# **Family Support**

## **Our Contribution**

- Ω The Family Support Project of Kentucky focuses on a holistic approach to family support that is family directed .**
- Ω We address both instrumental and interpersonal support in a statewide initiative for families across the life span.**



# **Family Support – Our Contributions cont.**

- Ω With continuing support, we will expand statewide advocacy and public policy components.**
- Ω Our long range plans include the development of a comprehensive plan to substantially increase funding for family and community supports in Kentucky.**



# **Family Support**

## **The Challenges We Face**

- Ω We need a strong commitment to family support through a legislative mandate for a statewide system of individually determined supports for families with persons with significant disabilities of any age who are living at home.**

# Family Support

## The Challenges We Face – cont.

- ⌚ **If this mandate occurs, we can enable families of people with disabilities to live as much like other families as possible, and assist them to move them beyond the lives of isolation they face due to disability in the family.**
- ⌚ **The effect would be improved life experiences affording choice, dignity, and meaning.**



# Family Support

## Highlighted Activity or Product

- Ω **We are especially proud of the willingness of parents, state agencies, and others interested in family support issues to collaborate despite limited financial resources.**
- Ω **This collaboration shows the broad-based commitment of Kentuckians to improve the lives of people with disabilities.**

# **Family Support**

## **The Face of a Family**

- ❧ Bonnie is a member of an Eastern Kentucky family. She is a young person with multiple, significant disabilities.**
- ❧ Her family has sought support for aligning educational and medical services so that Bonnie could continue to live at home with her family.**
- ❧ Right now they have received support to coordinate and expand services, so Bonnie's ailing parents can care for her.**
- ❧ The result is she is remaining in the family home with the supports she and her parents need.**



# **We Will Only Reach Our Final Goal....**

**We realize that we cannot achieve our mutual goal to bring about “advocacy, capacity building, and systemic change activities on behalf of individuals with developmental (and other) disabilities and their families”**

***unless...***



# **Realizing our Mutual Goal**

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**.... we truly work together to integrate our respective agencies' roles and functions within our state, as well as the effective and thoughtful use of our combined resources.**



# **Our Contact Information - Council**

**KY Council on Developmental  
Disabilities**

**100 Fair Oaks Lane, 4ET  
Frankfort, KY 40601**

**502-564-7841**

**877-368-5332**

**Pat.Seybold@mail.state.ky.us**

**Web: [www.kddc.org](http://www.kddc.org)**



# **Our Contact Information - UCDD**

**Interdisciplinary Human Development Institute**

**126 Mineral Ind. Bldg.**

**University of Kentucky**

**Lexington, 40506-0051**

**859-257-1714**

**E-Mail: [webmaster@ihdi.uky.edu](mailto:webmaster@ihdi.uky.edu)**

**Web: [www.ihdi.uky.edu](http://www.ihdi.uky.edu)**



# **Our Contact Information – P and A**

**KY Protection and Advocacy**

**100 Fair Oaks Lane, Third Floor**

**Frankfort, KY 40601**

**502/564-2967**

**1/800/372-2988 (voice and TTY)**

**E-mail: [i\\_r@mail.pa.state.ky.us](mailto:i_r@mail.pa.state.ky.us)**

**Web: [www.kypa.net](http://www.kypa.net)**



# **Our Contact Information – Family Support**

**Family Support Project of Kentucky**

**10301-B Deering Road**

**Louisville, KY 40272**

**1-800-525-7746**

**Fax (502) 937-6464**

**E-mail: [spininc@aol.com](mailto:spininc@aol.com)**

**Website: [www.kyspin.com](http://www.kyspin.com)**



# **Our Stats - Council**

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**ADD Funds: \$1,218,271**

**Staff Members: 6**

**No# of Projects: 10**

**People Being Helped: 437**

**People Being Trained: 911**

**Persons Who Have Received  
Information: 12,000**



# **Our Stats - UCDD**

**ADD Funds: \$1,218,271**

**Staff Members: 6**


**No# of Projects: 10**

**People Being Helped: 437**

**People Being Trained: 911**

**Persons Who Have Received**

**Information: 12,000**



# **Our Stats – P and A**

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**\$511,656 FY 01**

**27 staff**

**Clients served FY 01: 239**

**Clients provided**

**Technical Assistance: 627**



# **Our Stats – Family Support Project**

**ADD funds: \$100,000**

**# of staff: 2**

**# of projects: 2**

**People being helped: 1,000+**

**People being trained: 1,000+**

**# of partners: 7**