

**The Institute on Public Policy for People with Developmental Disabilities
Crisis Innovations Pilot
Overview and Outcomes through May, 2007
Report prepared by Rod Patterson, Exec. Director Mosaic in Pontiac, 6/7/07**

The following is a summary of important activities and outcomes since the inception of the Pilot in June, 2005:

- June, 2005 – Concept and proposed outcomes originated during the Institute's Board retreat and strategic planning sessions.
- August, 2005 – Proposal shared with DHS, Division of Developmental Disabilities Director and staff. During this joint meeting between DHS/DDD and representatives of The Institute, the following three focus areas were identified and approved:
 - Developing effective services and supports in the community for people in community settings who are, or may soon be, requesting admission to a State Operated Developmental Center (SODC).
 - Developing effective services and supports in the community for people currently residing in an SODC who have been having difficulty in locating or being accepted by community providers.
 - Meeting with parents, families and guardians of people currently residing in an SODC to gain support for seeking and developing community based services and supports for people with goals to transition into the community.
- September, 2005 – The Institute's Board of Directors approved a set of Values and Principles for the Pilot (see attachment A). The board also directed that the outcomes of the Pilot be used to develop recommendations for definitions and guidelines for establishing Individual Support Options (ISO) in Illinois.
- September, 2005 – Invitations sent to SODC Parents Groups
- October, 2005 -- “Organizational” meeting held by Institute Board Members, clinical/program staff from member agencies and staff from DHS/DDD SODC and Community Operations. Derrick Durfresne of the Institute and Rod Patterson, Executive Director of Mosaic in Pontiac and member of the Institute's Board of Directors agree to be co-chairs of the Pilot. A preliminary outline for procedures developed:
 - Referrals made to either Derrick Durfresne or Rod Patterson
 - General information about the person and the presenting issues shared with task force members at a general meeting.
 - Team of two to three task force participants identified to focus on each person referred.
 - The identified team travels to the location where the person is receiving services to meet with the person and people providing supports.
 - Team develops a general plan for Individual Support Options necessary to assist the person to maintain community supports or to locate community supports if he or she is already residing in an SODC.
 - The community agency wishing to provide the ISO develops a proposal, based upon the task force recommendations, to be presented to DHS/DDD.
 - Review and approval of proposal (funding request).
 - Progress and outcomes followed by the Co-Chair persons of the Pilot.
- November 2005 – First meeting of the Pilot Task Force
- December, 2005 – The Values and Principles were approved by DHS/DDD Director Jeri Johnson.
- March 2006 – Status/assessment meeting held to include members of the task force, members of the the Institute Board of Directors and DHS/DDD staff.
- June 2006 – Presentations made to the parents groups at the Mabley and Jacksonville Developmental Centers.

Outcomes:

- Since November 2005, the Task Force has met 13 times.
- Task Force members have represented at least 29 community agencies, some that are members of the Institute and others that are not.
- 19 people living in the community have been referred to the Task Force.
 - 17 of these people continue to receive supports and services in the community
 - The 2 people who have been admitted to an SODC were admitted in November 2005 having already been in a crisis situation prior to the referral.
- 9 people living in SODCs have been referred to the Task Force. Unfortunately, as of 6/6/07 all 9 remain in an SODC or have been transferred to a Mental Health setting.
- One 2 person ISO home has been established for a person referred to the Pilot.
- As of 6/6/07, several additional proposals for ISO in a variety of settings are in the process of being finalized or reviewed.
- An SODC resident has transitioned to a community agency in Rockford after his guardian attended the presentation about community supports at the Mabley Center Parents Group meeting.
- An open and cooperative dialog between members of the Pilot and staff at DHS/DDD continues to result in identifying system changes that support the concept of Individual Support Options.
- Participants in the task force have been provided with opportunities to engage in training and educational activities sponsored by the Institute.
- As can be seen in the summary below, people referred to the CIP are very similar to the people that have been admitted to State Operated Developmental Centers over about the same time span (18 months).

Characteristics of people referred to the Pilot:

- Referrals from community by diagnosis
 - 58% -- dual diagnosis, generally “mild” MR
 - 32% -- autism
 - 10% -- DD, Mild
 - In addition, one person with dual diagnosis also had an addiction diagnosis
 - One person with DD also was diagnosed as deaf/blind
- Referrals from SODC by diagnosis
 - 89% -- dual diagnosis
 - 11% -- Profound MR
- All referrals by diagnosis
 - 68% -- dual diagnosis
 - 21% -- autism
 - 11% -- DD
- Referrals from community by network
 - 11% -- Northwest
 - 16% -- Central
 - 21% -- South Suburban
 - 16% -- Metro (Chicago)
 - 21% -- North Central
 - 05% -- North Suburban
 - 11% -- out of state

Comparison of CIP referrals to SODC admission data¹

- Referrals and admissions by diagnosis
 - Dual – CIP Referrals = 58% SODC Admissions = 71%

¹ Data taken from most recent report distributed at the Statewide Advisory Council meeting for past 18 months

- Autism – CIP Referrals = 32%, SODC data not available at this time
- DD – CIP Referrals = 10%, SODC Admissions = 37%
- Referrals and admissions by Network
 - Northwest – CIP referrals = 10%, SODC Admissions = 13%
 - Central – CIP Referrals = 16%, SODC Admissions = 18%
 - South Suburban -- CIP Referrals = 21%, SODC Admissions = 13%
 - Metro (Chicago) -- CIP Referrals = 16%, SODC Admissions = 30%
 - North Central -- CIP Referrals = 21%, SODC Admissions = 5%
 - North Suburban -- CIP Referrals = 5%, SODC Admissions = 12%
 - Southern -- CIP Referrals = 0%, SODC Admissions = 33%
 - Out of state -- CIP Referrals = 11%, SODC Admissions = 1%

Recommendations:

- Identify the barriers to community based supports for the people referred to the CIP from the SODCs.
- Once again attempt to schedule presentations at SODC parent group meetings²
- The outcomes of the Pilot should be incorporated into recommendations for community based crisis teams.

2 Presentation scheduled for the Board of the Fox Center Families and Friends for its August meeting. (6/7/07)

Appendix A

Values and Principles

- People deserve a life. We will do everything possible to help them achieve that goal.
- We will look at people and supports, not facilities and slots.
- We believe that behavior is communication and we need to listen to what people are telling us.
- An intensive individual support plan must be developed that is person-centered and community-based. There must be a provision for ongoing crisis supports, medical, health care and other needed supports for the plan to succeed.
- We acknowledge best practices trends to separate housing and services. The first option to be explored should be the individual or family directly renting or owning the housing. As settings are small, they are more available than larger settings. The support provider should work on support. A separate housing provider is preferable and desired.
- We believe that people deserve to be healthy and safe. We acknowledge that people with significant and complex behaviors create issues both for the individual with difficult behavior and the group with which he/she lives.
- We will commit to develop supports for one person at a time. Settings are likely to be 1 – 2 persons. If there is a roommate, it will be a person who is compatible, not based on diagnosis. All individuals will have his/her own room if he/she has a house mate.
- We understand the urgency of the situation. We know we must act quickly and yet deliberately and effectively.
- We believe we must challenge the traditional shift staffing pattern as the only one used. In many cases, people with significant and complex behaviors need and want the stability of relationship that comes with live-in staff, or a family setting. This option needs to be offered utilizing creative approaches that are fiscally affordable. This will require acceptance of the host family rate methodology. We must be good stewards of public resources to offer this option to as many people as possible.
- We will first see if it is possible for the person to remain with his/her existing provider with alternate or additionally needed supports in place. If not, we will look to find a provider who subscribes to these principles and values. Institute members will not be given preference in this process.
- There must be an individual budget developed that is based on individual need. Because the individual is at immediate risk of institutionalization, it is possible that a budget based on the current CILA rate model equal to that of an SODC may be needed based on each individual's needs. Such budgets will be authorized in 90 day increments. In all cases this budget will be individualized, and flexible to respond to the situation.

Summary of Referrals to CIP

<i>People referred from the community</i>						
Agency	Location	Network	Diagnosis	Reason	Month	June 07 Status
Milestone	Rockford	NW	Dual	Behavior	Nov 05	SODC
Mosaic	Rockford	NW	Dual	Behavior	Nov 05	SODC
HRC	Paris	Central	DD	Behavior/Medical	Nov 05	HRC
Sertoma	Alsip	South Sub.	Dual	Behavior	Dec 05	Sertoma
We Live too	suburban	South Sub.	Dual	Behavior	Dec 05	Community?
Anixter	Chicago	Metro	Dual	Behavior	Apr 06	Anixter
Futures Unlimited	Pontiac	NC	Autism	Behavior	May 06	Futures ISO
Seguin	Cicero	South Suburban	Dual & addiction	Behavior	May 06	Seguin
Anixter	Chicago	Metro	DD / Deaf/Blind	Behavior	Jun 06	Anixter
Home (Anixter)	Chicago	Metro	Autism	Behavior	Jul 06	Packet review
Mosaic	Peoria	NC	Dual	Behavior	Oct 06	Mosaic Peoria
Autism Center	Kansas	n/a	Autism	Can't find supports	Nov 06	CTF offered to provide supports
Autism Center	Alabama	n/a	Autism	Can't find supports	Nov 06	6/18/07 Update Neumann has submitted packet.
AID	Aurora	North Suburban	Dual	Behavior	Nov 06	In MI setting, AID plans to submit packet for ISO
CTF	Charleston	Central	Dual	Behavior	Dec 06	CTF to submit packet for ISO
CCAR	Charleston	Central	Autism	Behavior	Feb 07	CCAR to submit packet for ISO
Futures	Pontiac	NC	Autism	Behavior	Apr 07	FUI to

<i>People referred from the community</i>						
Unlimited						submit packet for ISO
Horizon House	LaSalle/Peru	NC	Dual	Behavior	Apr 07	Team to visit
Agency	Location	Network	Diagnosis	Reason	Month	June 07 Status
Sertoma	Alsip	South Suburban	Dual	Behavior	May 07	Team to visit
<i>People Referred from SODC</i>						
Agency	Location	Network	Diagnosis	Reason	Month	June 07 Status
Howe	Tinley Park	N/A	Dual	Could not find community supports	May 06	Transferred to MI facility
Ludeman	Park Forest	N/A	Dual	Not able to find community supports.	Jun 06	Remains at Ludeman
Fox	Dwight	N/A	DD – Profound	Not able to find community supports.	Jun 06	State guardian refused to let team visit
Ludeman	Park Forest	N/A	Dual	Not able to find community supports.	Jul 06	Remains at Ludeman
Howe	Tinley Park	N/A	Dual	Not able to find community supports.	Dec 06	Team visited. Going to visit possible provider
Jacksonville	Jacksonville	N/A	Dual	Not able to find community supports.	Jan 07	Community agency in process of submitting packet for ISO
Jacksonville	Jacksonville	N/A	Dual	Not able to find community supports.	May 07	Team to visit
Jacksonville	Jacksonville	N/A	Dual	Not able to	May 07	Team to visit

<i>People referred from the community</i>						
				find community supports.		
Jacksonville	Jacksonville	N/A	Dual	Not able to find community supports.	May 07	Team to visit
<i>Presentations to SODC Parent Groups</i>						
Center	Month	Outcome	Center	Month	Outcome	
Mabley	Jun 06	One person moved from SODC and now receives community based supports in Rockford	Jacksonville	Jun 06		