

Executive Summary

Implementation of a Diagnostic Method for Persons with Co-Occurring Mental Retardation and Mental Illness

Funded by the Ethel and James Flinn Foundation

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People with co-occurring intellectual and mental health concerns are a major challenge to our nation's network of community supports and services. It is estimated that between 30-50% of individuals with intellectual disabilities have some degree of mental health concern that leads to a dual diagnosis (DD). Often these individuals fall through the cracks, with mental health professionals being unwilling to treat individuals with intellectual disabilities, and developmental disability services not having the experience and skill to diagnose and treat mental health concerns. Confounding the diagnosis and treatment issues is the Michigan Department of Mental Health policy mandate that all program recipients have the opportunity to exercise choice and self determination in accessing their desired services and supports. The long term aim of this research project was to improve diagnosis and management of mental health concerns in people with intellectual disabilities in Michigan. This project provided the first step toward that long term aim by examining the diagnostic process and opportunities for self determination among a sample of individuals in Macomb and Oakland counties in southeast Michigan.

The two specific aims of this project were:

1. To evaluate the effectiveness of a new specialized diagnostic instrument for identifying co-occurring intellectual and mental health concerns (dual diagnosis)
2. To evaluate the impact of a dual diagnosis on an individual's ability to self advocate.

Significant Findings

Aim #1

- The Mini PAS-ADD is a quick, cost effective and easily administered screen for mental health concerns in individuals with intellectual disabilities
- The Mini PAS-ADD is most effective in identifying dual diagnosis in individuals who are not currently taking psychotropic medications
- The Mini PAS-ADD is recommended for use as a general screening tool at intake and referral for all individuals with intellectual disabilities

Aim #2

- Overall individuals with intellectual disabilities in the sample were not very self determined.
- Individuals with dual diagnoses were less likely to see family members regularly.
- There was some indication that individuals with dual diagnoses had less choice with regard to voting, joining social organizations or clubs, and having their own phones.

Dissemination Venues

More than 2,500 persons attended dissemination activities of this project

1. Southeast Michigan, through Wayne State University Press Release and Crain's Business Report
2. American Association on Mental Retardation, Michigan chapter, Annual Conference 2007
3. Come to Your Senses Conference, Toronto, Ontario
4. International Association for the Scientific Study of Intellectual Disabilities, European Regional Meeting of the Special Interest Research Group on Chronic Disease Management in People with Intellectual Disability , Prato, Italy
5. National Association for the Dually Diagnosed, Annual National Conference 2007, Atlanta, Georgia
6. Association of University Centers on Disabilities, Annual Conference, Washington, D.C.
7. American Association on Intellectual and Developmental Disabilities, Michigan chapter, Annual Conference 2008 (formerly AAMR)
8. Ethel and James Flinn Foundation Board, Detroit, Michigan
9. Michigan Department of Community Health, Developmental Disabilities Performance Improvement Team, Lansing, Michigan
10. National Association for the Dually Diagnosed, Annual National Conference 2008, Niagara on the Lake, Ontario
11. National Association on Dual Diagnosis Bulletin (juried publication of findings)
12. Training Module on Dual Diagnosis developed for Michigan Direct Support Professionals Empowerment Education Project

13. *Assessing Mental Health Concerns Individuals with Intellectual Disabilities: a Guide to Existing Measures*. Disseminated to all Michigan Community Mental Health Boards

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Project Management

The project was staffed by personnel from the Developmental Disabilities Institute at Wayne State University and the Macomb-Oakland Regional Center, Inc. Specific staff and their roles are described below.

Principal Investigator: **Barbara LeRoy, Ph.D.** served as the project principal investigator. Dr. LeRoy is the director of the Developmental Disabilities Institute at Wayne State University. Her responsibilities included liaison with the Flinn Foundation Board, oversight of the project budget, convening of the project management team, oversight of the research activities and dissemination of findings.

Project Director (1): **Dr. Kirsti Reeve** served as the project director during the first quarter of the project. She was a Research Associate with the Developmental Disabilities Institute. She was responsible for obtaining Human Investigation Committee approval for the study, for liaison with the clinical director and staff at Macomb-Oakland Regional Center. Dr. Reeve was forced to terminate her employment at Wayne State University shortly after this project began due to a medical condition.

Project Director (2): **Dr. Karen Hobden** served as the project director for quarters 2-10 of the project upon the termination of Dr. Reeve. Dr. Hobden is a Research Associate with the Developmental Disabilities Institute. She was responsible for the daily operation of the project, including oversight of screening and assessment of participants, self determination protocol design and implementation, data entry and analysis, report development, manuscript development, and dissemination activities.

Clinical Liaison: **Diane Lindsay** served as the clinical liaison to the project. Ms. Lindsay is the Director of Clinical Operations at the Macomb-Oakland Regional Center, Inc., which is located in Clinton Township in Macomb County, Michigan. She was responsible for identification and support to the psychology interns who served as assessment specialists for the project and for clinical expertise on data analysis and reporting.

Project Support Staff: **Elizabeth Elder** served as the administrator on the budget. Ms. Elder is the business manager at the Developmental Disabilities Institute. She was responsible for budget oversight and reporting. **Latosha Marshall** provided secretarial support to the project. She is the program secretary at the Developmental Disabilities Institute. She was responsible for correspondence, copying of materials, and production of power point presentations.

Project Consultant: **Dr. Steven Moss** served as the project consultant. He is the developer of the clinical assessment instrument (PAS-ADD). Dr. Moss is a clinical psychologist at the Estia Centre, Munro-Guy's Hospital at the University of London, United Kingdom. He provided clinical training to the project team and assessment interns. He also provided off-site consultation and review on the project findings.

To ensure successful implementation of the project, the project management team (Principal Investigator, Project Director, and Clinical Liaison) met on a monthly basis throughout the data gathering phase of the project. During data analysis, interpretation and report production the Clinical Liaison provided insight and feedback on the findings and reports to the other members of the Team.

Research Aim One

To evaluate the effectiveness of a new specialized diagnostic instrument for identifying co-occurring intellectual and mental health concerns (dual diagnosis).

Based on a preliminary review of the assessment literature and tools on dual diagnosis, this project selected and evaluated the effectiveness of the Psychiatric Assessment Schedule for Adults with a Developmental Disability (The PAS-ADD) instrument (Moss, Ibbotson & Prosser, 1994). The PAS-ADD is composed of three instruments: a checklist; a Mini PAS-ADD; and the PAS-ADD Psychiatric Interview. The Mini PAS-ADD has seven subscales: Depression; Anxiety; Expansive Mood Disorder (Bipolar); Obsessive-Compulsive Disorder; Psychosis; Unspecified Disorder (including Dementia); and Autism. Upon receipt of study approval by the Human Investigation Committee at Wayne State University, the following activities were implemented in support of research Aim One.

Activities:

1. Staff Training: On May 22 and 23, 2006, Dr. Steven Moss provided training to 15 individuals (project staff, MORC project staff and interns, and five graduate students from WSU). He trained the participants to implement the three components of the PAS-ADD system: the PAS-ADD checklist; the Mini PAS-ADD Interview, and the PAS-ADD Psychiatric Interview (extended form). Following the training, the participants received certificates from Dr. Moss indicating that they were qualified to use the PAS-ADD instrument in assessing potential dual diagnosis among people with a primary intellectual disability.
2. Participant Recruitment: In the initial six months of the project, 1,987 recruitment letters were sent out to potential participants through three sources: guardians, families, and persons with disabilities themselves. All potential recruits had a primary diagnosis of intellectual disability, according to a review of MORC client records. Three hundred (n=300) interested participants returned signed consents. A second group of 40 participants was recruited in quarter six of the project in order to assess the effectiveness of the PAS-ADD among new referrals to MORC.
3. Participant Screening: MORC staff and psychology interns under the supervision of Ms. Lindsay conducted the participant screenings. In total 261 individuals were screened using the PAS-ADD. An additional 19 people returned signed consent forms and expressed interest in the study. However, they were not able to complete the screening. Two people died prior to screening.
4. Database Development: A database and codebook were developed to contain participant demographic information, participant diagnostic and serve data, PAS-ADD screen and interview (if appropriate) scores, and participant indicators of self determination.

5. Focus Group: On October 4, 2007 a focus group was held with the clinical staff and psychology interns who conducted the PAS-ADD screenings and interviews. The purpose of the focus group was to present the initial findings to the participants and to obtain their impressions and recommendations with regard to the use of the PAS-ADD as an assessment tool for dual diagnosis within the target population.
6. Population Record Review: A secondary analysis of the entire MORC population database (n = 4314) was conducted to examine psychopathology among persons with Down syndrome. This analysis was conducted based on preliminary findings from our sample (n=23 with Down Syndrome) as well emerging research which suggests that persons with Down Syndrome have higher rates of psychopathology than persons with intellectual disabilities due to other causes.
7. Polypharmacy and Dual Diagnosis: A post hoc analysis of the sample was conducted to examine the types and frequency of psychotropic medication use. This analysis was conducted based on emerging findings from European studies that indicate that individuals with intellectual disabilities and suspected mental health concerns are passive recipients of diverse, powerful medications. Moreover, they seem to be prescribed these medications over long periods of time. The analysis was conducted to compare this sample's findings to other reported findings.

Findings:

Assessment Tool

- The Mini PAS-ADD is a quick, cost effective and easily administered screen for mental health concerns in individuals with intellectual disabilities
- The Mini PAS-ADD appears to be most effective in identifying dual diagnosis in individuals who are not currently taking psychotropic medications
- The Mini PAS-ADD is recommended for use as a general screening tool at intake and referral for all individuals with intellectual disabilities

Clinical

- 29% of individuals with an intellectual disability in our sample were found to have a co-occurring mental health concern
- Nearly 20% of the sample had multiple mental health concerns
- 58.9% of the sample were receiving psychotropic medications; the vast majority of whom were receiving >2 types of medications

Down Syndrome

- Individuals with Down syndrome were more likely to have a mild or moderate intellectual disability than those without Down syndrome
- 53.6% of individuals with Down syndrome had a co-occurring mental health condition with compared to 27.5% of individuals with other intellectual disabilities.
- Individuals with Down syndrome were eight times more likely to have dementia than individuals without (3.2% versus 0.4%).

Outputs:

- Hobden, K.L. & LeRoy, B. (2008). *Assessing Mental Health Concerns in Adults with Intellectual Disabilities: A Guide to Existing Measures*. Developmental Disabilities Institute, Wayne State University.
- Hobden, K. L. & LeRoy, B. W. (2008). *Mental Health Conditions in Individuals with and without Down Syndrome*. Developmental Disabilities Institute, Wayne State University.
- Juried article: Hobden, K.L. & LeRoy, B.W. (May/June 2008). Assessing mental health concerns in individuals with intellectual disabilities. The NADD Bulletin, 11(3), 45-48.
- Article: Hobden, K.L., LeRoy, B.W. & Lindsay, D. (2008). Assessing dual diagnoses: A test of the PAS-ADD Checklist and the Mini PAS-ADD. (Submitted for review to Journal of Mental Health Research in Intellectual Disabilities).
- Power point: *Assessing Mental Health Concerns in Individuals with Intellectual Disabilities*
- Power point: *Dual Diagnosis and Self-Determination: Any Relationship?*
- Power point: *Dual Diagnosis: Finding a Reliable and Easy Assessment Instrument*.
- Power point: *Assessing Mental Health Concerns in Individuals with Intellectual Disabilities: Preliminary Results*
- Power point: *Assessment of Dual Diagnosis: An Evaluation of the Mini PAS-ADD*
- Poster: *Dual Diagnosis and Self-Determination: Any Relationship?*

- Poster: *Assessing Mental Health Concerns in Individuals with Intellectual Disabilities*
- Poster: *Predictors of Self-Determination in Consumers with and without Dual Diagnoses*
- Poster: *Dual Diagnosis and Polypharmacy*

Recommended Future Directions:

Future research should examine the benefits of screening for dual diagnoses at intake. We recommend a longitudinal study comparing individuals with intellectual disabilities who are and are not screened for mental illness at intake and an examination of outcomes over a two or three year period.

Research Aim Two

To evaluate the impact of a dual diagnosis on an individual's ability to self advocate.

The current best practice model in the field of intellectual disability, and the one mandated by Michigan Department of Community Health public policy, is one of self advocacy and self determination. People with intellectual disabilities and their families are encouraged to be involved with planning service needs and delivery, express their wishes and make choices about how they want to live their lives, and be given the opportunity live and work in the community. In contrast, traditional mental health practice operates on a very different premise: the doctor is seen as the 'expert' with the answers, and the person with mental health concerns is a passive 'patient', encouraged to comply with the treatment options. Treatment and service delivery often take place at the hospital, in an environment with other individuals with mental health concerns. There is a fundamental discrepancy between these two models – one that may not be beneficial to people with dual diagnoses and may have a detrimental effect on their ability to self advocate. Therefore, the second research aim of this study is to examine the impact of a dual diagnosis on an individual's ability to self advocate.

Activities:

1. Self Determination Checklist Development: The initial project design indicated that 5 markers of independence would be used to assess self determination among participants. However, based on the initial analysis of these markers, it was found that the markers were not effective in discriminating the respondents' self determination opportunities and skills. Therefore, a 22-item checklist was developed and field tested on a small sample of community mental health program participants who had intellectual disabilities but who were not involved in this study. The checklist assesses choice making related to living arrangements, community involvement, and employment/finances. It was designed to be completed by an informant who knew the participant well in collaboration with the individual with a disability.
2. Self Determination Checklist Implementation: 195 Self Determination Checklists were completed by participants with their support coordinators, as needed. Data was analyzed according to the three indices: Living Arrangements; Community Involvement; and Employment/finances.

Findings:

- Overall individuals with intellectual disabilities in the sample were not very self determined (61.1% reported having choice in their living arrangements; 49.8% reported having choice in community involvement activities; and 37.7% reported having choice in their employment and finances).

- The existence of a dual diagnosis did not significantly impact the overall index percentages.
- There was a statistically significant difference in opportunities to see family members on a regular basis for individuals with dual diagnosis. These individuals were much less likely to see their family members.
- There was some indication (trends) that individuals with a dual diagnosis had less choice than individuals with only an intellectual disability with regard to voting, joining social organizations or clubs, and having their own phones.

Rankings of Self-Determination Items

Rank	Indicator	%
1	Has unstructured Time	98.2
2	Shops in Community	95.9
3	Chooses TV Program	94.2
4	Has access to private space	91.8
5	Has a Bank Account	87.6
6	Chooses when to bathe	71.9
7	Lives in typical residence in the community	71.5
8	Chooses what to eat	63.9
9	Plans/takes vacations	60.8
10	Chooses where to live	60.2
11	Attends Worship Service	43.3
12	Chooses personal doctor	37.6
13	Goes on spontaneous outings	37.5
14	Sees family members when chooses	33.5
15	Joins community organizations	29.4
16	Chooses roommate	29.4
17	Has personal budget	28.4
18	Has access to telephone for personal use	21.1
19	Has employment	15.2
20	Makes minimum wage or more	14.7
21	Votes in community elections	14.3
22	Uses ATM for discretionary funds	5.9

Outputs:

- Self Determination Checklist
- Power point: *Dual Diagnosis and Self Determination: Any Relationship?*
- Poster: *Dual Diagnosis and Self-Determination: Any Relationship?*
- Poster: *Predictors of Self-Determination in Consumers with and without Dual Diagnoses*

Recommended Future Directions:

Further research is needed on the reliability and validity of the Self Determination Checklist.

We recommend examination of the relationship between dual diagnosis and self-determination in a broader sample of individuals with intellectual disabilities. In the current sample, 86% of individuals lived in group homes restricting the range of self-determination these individuals could experience and, possibly, undermining our ability to detect a relationship between dual diagnosis and self-determination.

Project Dissemination Activities and Products

Presentations

Date: March, 2007

Title: Dual diagnosis: Finding a reliable and easy assessment instrument.

Venue: Paper presented at the American Association for Intellectual and Developmental Disabilities Conference, Midland, MI.

Audience: Professionals, paraprofessionals, consumers, family members (30 participants)

Date: May, 2007

Title: Assessing mental health concerns in individuals with developmental disabilities: Preliminary findings.

Venue: Poster presented at the 2nd International Come to Your Senses Conference, Toronto, ON Canada.

Audience: Professionals, paraprofessionals, consumers, family members (400 participants)

Date: May, 2007

Title: Dual Diagnosis and Self-Determination: Any Relationship?

Venue: International Association for the Scientific Study of Intellectual Disabilities, European Regional Meeting of the Special Interest Research Group on Chronic Disease Management in People with Intellectual Disability, Prato, Italy.

Audience: Professionals, paraprofessionals, consumers, family members (350 participants)

Date: October, 2007

Title: Assessing mental health concerns in individuals with intellectual disabilities.

Venue: Poster presented at the 24th annual conference of the National Association for the Dually Diagnosed, Atlanta, Georgia.

Audience: Professionals, paraprofessionals, consumers, family members (450 participants)

Date: November, 2007

Title: Dual diagnosis and self-determination: Any relationship?

Venue: Poster presented at the annual meeting of the American University Centers on Disabilities, Washington, DC.

Audience: Professionals, paraprofessionals, consumers, family members (550 participants)

Date: March 4, 2008

Title: Presentation to Flinn Foundation Board

Venue: Ethel and James Flinn Foundation Board, Detroit, Michigan

Audience: Members of the Flinn Foundation Board (10 participants)

Date: March 2008

Title: Assessment of Dual Diagnosis

Venue: Michigan Department of Community Health, Developmental Disabilities Performance Improvement Team, Lansing, Michigan

Audience: Professionals, CMH Directors (25 participants)

Date: April, 2008

Title: Assessment of Dual Diagnosis: An Evaluation of the Mini PAS-ADD.

Venue: Paper presented at the American Association for Intellectual and Developmental Disabilities Conference, Midland, MI

Audience: Professionals, paraprofessionals, consumers, family members (20 participants)

Date: September 2008

Title: An Introduction to Dual Diagnosis (Participant and Trainer's Manuals)

Venue: Developed for use as part of the Empowerment Education Project: Consumer Driven Training for Michigan Direct Support Professionals

Audience: Direct Support Professionals (estimated 20 participants per year)

Date: October 2008

Title: Assessing Mental Health Concerns Individuals with Intellectual Disabilities: a Guide to Existing Measures.

Venue: Disseminated to all Michigan Community Mental Health Boards

Audience: Professionals, paraprofessionals, consumers, family members (200 participants)

Date: November 2008

Title: Dual Diagnosis and Polypharmacy

Venue: National Association for the Dually Diagnosed, Annual National Conference 2008, Niagara on the Lake, Ontario

Audience: Professionals, paraprofessionals, consumers, family members (250 participants)

Date: November 2008

Title: Predictors of Self-Determination in Consumers with and without Dual Diagnoses.

Venue: National Association for the Dually Diagnosed, Annual National Conference 2008, Niagara on the Lake, Ontario

Audience: Professionals, paraprofessionals, consumers, family members (250 participants)

Publications

- Hobden, K. L. & LeRoy, B. W. (2008). *Mental Health Conditions in Individuals with and without Down Syndrome*. Developmental Disabilities Institute, Wayne State University.
- Hobden, K. L. & LeRoy, B. W. (2008). Assessing mental health concerns in individuals with intellectual disabilities. *NADD bulletin*, 11(3), 45-48.
- Hobden, K. L. & LeRoy, B. W. (2008). *Assessing Mental Health Concerns in Adults with Intellectual Disabilities: A Guide to Existing Measures*. Developmental Disabilities Institute, Wayne State University.
- Hobden, K. L. & LeRoy, B. W. (under editorial review). Assessing Dual Diagnoses: A Test of the PAS-ADD Checklist and the Mini PAS ADD. *Journal of Mental Health Research in Intellectual Disabilities*.
- Hobden, K. L. (2008). *Assessing Mental Health Concerns Individuals with Intellectual Disabilities: a Guide to Existing Measures*. Developmental Disabilities Institute, Wayne State University.

For further information on the PAS-ADD family of assessment products contact:

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