Research and Best Practices in Family Support and Engagement

Jay Yudof, MS
Certified Psychiatric Rehabilitation Practitioner
NAMI NEW JERSEY Statewide Consumer Outreach Liaison
732-677-3842
jyudof@hotmail.com

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I WANT YOU
TO TURN OFF
YOUR CELL PHONE

Please Tolerate My Imperfections

- Keep me on track

- Ask me questions if I start losing folks

- Save complex questions and insights for the end

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My Profession and Personal Context

- Living with Mental Health Issues, as does my wife

- Psychiatric Rehabilitation – Assisting adults with psychiatric disabilities to live, learn, work, socialize, parent, worship, etc. in the community

- Wellness and Recovery Educator at the Collaborative Support Programs of NJ Institute for Wellness and Recovery Initiatives. www.welltacc.org.

- Research Adjunct Instructor with UMDNJ Department of Psychiatric Rehabilitation and Counseling Professions http://*shrp.umdnj.edu/**dept**/psyr/index.html*

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Disclaimers

- No financial interests

- 90 minutes $\neq$ 6-12 semester hours

- YMMV

Audience Expectations & Background

Overview of the Presentation

- Why Research
  - Why is it important to us?
  - How can we access and understand it?
- What are Best Practices and EBPs
  - How do they get there?
- Research and Best Practices in Family Support and Engagement
  - Families can and do play a role in maximizing recovery
  - Families experience trauma and burden, and several best & emerging practices help with that
- Questions/Action Steps

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What we Will Not be Addressing

- Kids

- Prevention and Causality

- Nosology

- Basic biology or psychology

- Government, policy, or local post-implementation research

- Pharamcology/biological interventions

Why Research?

- Adds to our knowledge
  - Of the world in general
  - Of the conditions we and our loved ones and clients lived with
  - Of the interventions (services and supports) which help with prevention, treatment, amelioration, and rehabilitation

- Supports the evolution of knowledge base and interventions

- Stand on the Shoulders of Giants

- Research is neither necessary nor sufficient to change public policy, agency practice, communal option – but it can't hurt
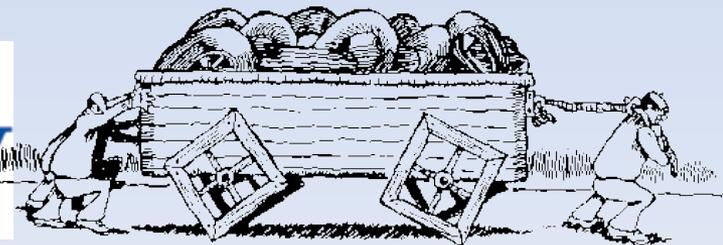
Research in our Fields

- Theories are based on basic psychology, but evolve differently

- No rodent models

- Very few opportunities for DBRCTs
  - Difficulty with placebo interventions is part of the problem

- Naturalistic Studies

- Objectiified and Subjective Measures

- Tougher to Measure Distal Outcomes

Some Threats to Applicability

...Generlizability

• "Town vs. Gown"

• Observer Effects

• Small sample sizes – Problems found in scale

• Exclusionary Criteria

• Applicability to any individual

Accessing Research (1/3)

- Attend sessions like we have
  - Welcome researchers, and try to get opportunities in your own groups and communities
  - If needed, read up in advance
- Do not shy away from research – delve where it interests you
  - Ask the good questions of "implied" research or casual research references
  - Consider journal clubs in professional settings

Accessing Research (2/3)

- Avoid narrowing interest by diagnosis

- Research evolves, so should our knowledge

- Subscribe to journal abstracts

- Consider the academic journey for knowledge and credibility

- The web is full of resources – even Wiki articles, online courses, course handouts

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Accessing Research (3/3)

- Access research databases online
- Abstracts often meet your needs. Access at
  - www.scholar.google.com
  - www.pubmed.gov
- Fulltext Resources
  - EBSCO Academic Search Premier – most local NJ library patrons
  - Colleges can help with articles in Ovid, PsycInfo, etc.

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Best Practices and EBPs

- Research basis needed to set standards

- Quality and quantity of research adds to the level of research - eventual EBP adoption

- The SAMHSA NREPP (www.samhsa.nrepp.gov) lists 260 EBPs & PPs in mental health, addiction services for kids, adults, families

- Implementation Toolkit, including manualization & fidelity measures

Best Practices and EBPs - Benefits

- Protect us by reducing risks of iatrogenic harm
- Give us (including the public payor) best value for our time ane money
  - Including reducing risks of malpractice claim
  - Make training, data collection, and assessment practical
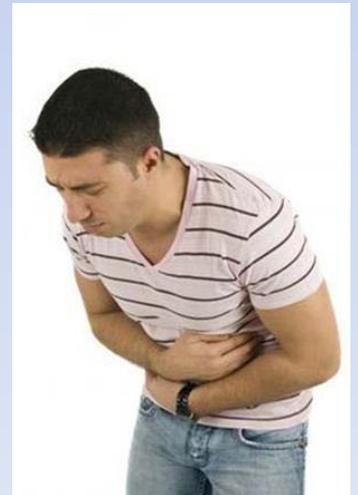
Families Can and Do Play a Role in Maximizing Recovery

- SMI raises risks of parenting custodial loss... "Recommendations to mothers are to (a) ensure family health (b) prevent psychotic relapse, (c) prepare in advance for crisis, (d) document daily parenting activities, (e) take advantage of available parenting resources, and f) become knowledgeable about legal issues that pertain to mental health and custody. " **(Seeman, 2012).** Grandparents often play a key role.

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- Interventions targeting mothers with schizophrenia spectrum illnesses and their children are lacking. Women with schizophrenia are at risk for not engaging in treatment due to fears of barriers and losing their children. Although scarce, inpatient MBUs offer focused treatment, but services are limited to the baby's first year. Minimal outpatient psychosocial treatments are available to this population. Flexible treatment approaches that incorporate environmental supports, childcare resources, child welfare systems, and family involvement are highly recommended. **(Gearing, Alonzo & Marinelli, 2012).**

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- These findings demonstrate the effectiveness of a program of routine care integrated with motivational interviewing, cognitive behavior therapy, and family intervention over routine psychiatric care alone for patients with comorbid schizophrenia and alcohol or drug abuse or dependence **(Barrowclough, et. al., 2001).**

- The results suggest that systematic family involvement enhances the rehabilitation and family-related outcomes of assertive community treatment. Patients in multifamily group treatment had better employment outcomes**. (McFarlane, Dushay, Stasny, Deakins & Link, 1996)**

- "In schizophrenia, high levels of critical comments by significant others are associated with early relapse, especially if medication adherence is sub-optimal. Levels of criticism may be influenced by family knowledge about both the disorder and its treatment. In the patient-family member dyads …the odds ratio ..for admission was 3.3 (..in individuals with low levels of medication adherence, high perceived criticism, and a family member with poor knowledge and understanding **(Scott, Colom, et. a., 2012)."** Re-raises the old issue of Expressed emotion.

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Recommendation from the 2009 PORT study

- Persons with schizophrenia who have ongoing contact with their families, including relatives and significant others, should be offered a family intervention that lasts at least 6–9 months. Interventions that last 6–9 months have been found to significantly reduce rates of relapse and rehospitalization. Though not as consistently observed, research has found other benefits for patients and families, such as increased medication adherence, reduced psychiatric symptoms, and reduced levels of perceived stress for patients. Family members have also been found to have lower levels of burden and distress and improved family relationships.

- IPS principles can be successfully extended to integrate supported education and supported employment within one treatment program. The distribution of return to school, work or their combination in this group of individuals with recent-onset schizophrenia supports the view that an integrated program of supported education and supported employment fits this initial period of illness. Work with family members also characterized this application of IPS. **Nuechterlein, Subotnik, Turner, Ventura J, Becker & Drake (2008).** .
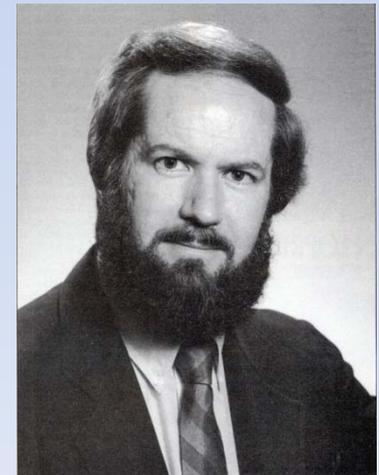
- The current study provides naturalistic data documenting the pathways-to-care to vocational services for ..veterans who were receiving some form of mental health care ..but were not currently enrolled in vocational services. ...Filtering factors associated with quicker recognition, seeking help, and receiving services included diagnosis, level of disability, type of vocational need, and support from primary providers, family, and friends. The results provide information for designing interventions to improve service entry by adults with mental health problems and vocational needs.

  (Drebing, Mueller, et. al. (2012).

~ Dr. Charles Drebing ~

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Families Experience Trauma and Burden

- Psychotherapeutic intervention may be needed for within-family stigma and conflicts over genetic test results **(Gershon, 2012).**

- Results demonstrated a high burden on caregivers because of many factors such as other commitments, lack of resources, insufficient financial support, education level and ageing. This study found that long-term caregivers suffer more than short-term ones..Burden increases further for those having to cope with both work and care giving at the same time. **(Tan, Yeo, et. al., 2012)**

- The mean scores of the Zarit caregiver burden decreased significantly for the group that participated in the psycho-educational program, while scores in the control group did not change significantly. **(Navidian, Kermansaravi & Rigi, 2012).**

- Crisis intervention reduces the number of people leaving the study early, reduces family burden, is a more satisfactory form of care for both patients and families and at three months after crisis, mental state is superior to standard care. **(Murphy, Irving, et. al., 2012). Cocharane reviews.**

- **A life tiptoeing: being a significant other to persons with borderline personality disorder.** The results revealed four categories: a life tiptoeing; powerlessness, guilt, and lifelong grief; feeling left out and abandoned; and lost trust. The first two categories describe the experience of living close to a person with BPD, and the last two categories describe encounter with psychiatric care. **(Ekdahl, et. al., 2011).**

- **It's Us That Have to Deal with it Seven Days a Week": Carers and Borderline Personality Disorder.** It seems carers of those with a diagnosis of BPD are continuing to be overlooked by mental health services, and subsequently require more support to ensure their own well-being **(Dunne & Rogers, 2012)**.

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- People with schizophrenia have a high prevalence of co-occurring substance use disorders, which is related to a worse course of psychiatric illness, more frequent relapses, and increased depression and suicide, compared with those with schizophrenia alone. The Family Intervention for Dual Diagnosis (FIDD) program, which includes psychoeducation and goal setting and focuses on building communication and problem-solving skills within the family, can aid in decreasing the stress related to having a close relationship with someone with a dual disorder. **(Gottlieb, Mueser & Glynn, 2012).**

- The stress of living with unpredictable, disturbing schizophrenic symptoms can erode interpersonal relationships. Stressful family interactions are associated with poorer prognosis. Several investigators have developed educational or more intensive skills-based family programs to increase illness knowledge and improve prognosis in schizophrenia. An extensive body of research supports the benefits of participating in family-based treatments for schizophrenia, especially those of longer duration and emphasizing skill development, in reducing relapse rates. In spite of the data, these programs are underimplemented and underutilized. ....

…Barriers to their use likely arise from patients, relatives, and mental health professionals. Newer programs, which include novel engagement strategies, target subpopulations with poor prognoses, or use innovative technologies, may make these programs more accessible to a wider range of families. Engaging individuals with schizophrenia and their loved ones in a collaborative effort to design new, more consumer-driven family interventions is warranted.

Glynn, S. M. (2012). Family interventions in Schizophrenia: promise and pitfalls over 30 years.

- Severe interpersonal problems are common in veterans with combat-related posttraumatic stress disorder (PTSD) and their families. The authors first detail the rationale and use of behaviorally based family therapy to help reduce avoidance and withdrawal symptoms of PTSD and improve the active coping capacities of both veterans and their loved ones. **(Glynn, et. al, 1995).**

- Participation in exposure therapy reduced PTSD positive symptoms (e.g., reexperiencing and hyperarousal) but not PTSD negative symptoms. Positive symptom gains were maintained at 6-month follow-up. However, participation in Behavioral Family Therapy had no additional impact on PTSD symptoms. **(Glynn, et. al, 1995).**

- Family involvement in the care of persons with psychiatric illness is important for recovery-oriented comprehensive mental health services; however, family involvement infrequently occurs. The Department of Veterans Affairs Office of Mental Health Services has sponsored Family Forum II to provide a broad intervention framework for family involvement in the care of persons with psychiatric illness. This article presents guidance provided by Family Forum II. Services highlighted include family consultation, family education, and family psychoeducation; and an intervention framework is presented **(Dausch, et. al, 2012).**

- Administrators of publicly funded mental health services are increasingly interested in evidence-based practices that can be reasonably implemented to help people in recovery. This article offers an example of a service that meets these requirements. It describes the successful development and implementation of Intensive Family Support Services, a New Jersey–based program available to families caring for a loved one with a mental illness. Contributors to the article share their direct experiences over the past 25 years, which have led to the program's current operation…

… These experiences include the essential steps taken to develop policy, implement standards, and provide ongoing funding for an emerging best-practice model in family support. Also detailed are the many ways New Jersey has embraced a family-driven approach to develop and deliver support services **(Schmidt & Monaghan, 2012)**

•Partnering with families while also ensuring that the consumer is at the center of all decisions is a profound challenge for practitioners who work with adults with severe and persistent mental illnesses. Consumer centered family consultation (CCFC) is a brief, education-based engagement and consultation service designed to promote collaboration among adult consumers of mental health services…

members of their family or social network, and service providers to support each consumer's recovery. In the present article, we describe the CCFC model and its development, with an emphasis on strategies to engage and include both consumers and family members as equal partners. We also provide a brief overview of the Family Institute for Education, Practice and Research's CCFC training and implementation activities to date in New York State. We highlight findings from preliminary program evaluations as well as lessons learned from helping clinicians conduct CCFCs at more than 50 agencies **(Jewell, et. al., 2012)**. (PDF online at www.ccsi.org/pdf/CCFC%20-%20AJPR.pdf)

- Efforts have been made to remove systemic barriers to community psychiatrists proactively collaborating with family members of the people they treat once consent is granted, but progress has been slow. This article summarizes approaches used to accelerate this progress by the Pennsylvania Psychiatric Leadership Council (PPLC), an initiative funded by the Pennsylvania Office of Mental Health and Substance Abuse Services to encourage excellence in public psychiatry. The barriers to family-psychiatrist collaboration targeted by this council include lack of uniformity in family collaboration competencies required for community psychiatrists and lack of incentives in community behavioral health centers…

Family inclusion competencies for community psychiatrists endorsed by the state are provided. Steps taken to overcome systemic barriers to family-psychiatrist collaboration by the PPLC's fellowship programs as well as other Pennsylvania coalitions are described and discussed. **(Mannion, et. al, 2012)**

- Despite the evidence that including families, relatives, friends, and other "significant people" (SP) of mental health clients in treatment and recovery services enhances client outcomes…

...confidentiality concerns and misconceptions by agency staff remain a major barrier to the implementation of family inclusion efforts for adult clients in behavioral health systems nationally and internationally. This article reports on a survey of providers and administrators regarding their beliefs about sharing information with these significant individuals in clients' lives in a behavioral health system that is undergoing a system transformation to become more recovery oriented. Furthermore, it describes an agency pilot program that involved clarifying agency confidentiality policies and state regulations or laws, training staff about this information, and assessing the effects of the training. Evaluation results of staff training about these policies are also reported **(Solomon, et. al., 2012).**

- Among potential resources for people with SMI and their families, professionally delivered FPE)is designed to engage, inform, and educate family members, so that they can assist the person with SMI in managing their illness. In this article, we review research regarding FPE outcomes and implementation since 2001…Research on a range of FPE variations continues to return mostly positive effects for adults with schizophrenia and increasingly, bipolar disorder. More recent studies include functional outcomes as well as the more common relapse and hospitalization. FPE research involving adults with other diagnoses is increasing, as is FPE research outside the US. In both cases…

uneven methodologies and multiple FPE variations make drawing conclusions difficult, although the core utility of access to information, skill building, problem solving, and social support often shines though. Since the previous review, several FPE programs for parents of children or youth with mood disorders have also been developed, with limited research showing more positive than null results. Similarly, we review the developing inquiry into early intervention and FPE, short-form FPE, and cost studies involving FPE. The second half of the article updates the paradox of FPE's evidence base versus its persistently low use, via recent implementation efforts...

Multiple challenges and facilitating factors across healthcare systems and financing, individual programs and providers, family members, and consumers shape this issue, and we conclude with discussion of the need for empirical evaluation of implementation strategies and models. **(Lucksted, McFarlane, Downing & Dixon, 2012)**

- Older parents of adults with long-term mental illness need professional help with planning for their offspring's future. This assistance should focus on mechanisms such as estate planning to enable case management and other services after parents' death. The involvement of nondisabled siblings in planning should also be encouraged **(Smith, Hatfield & Miller, 2000).**

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- This study provides evidence that FTF is effective for enhancing coping and empowerment of families of persons with mental illness, although not for reducing subjective burden. Other benefits for problem solving and reducing distress are suggested but require replication **(Dixon, et. al, 2011)**.
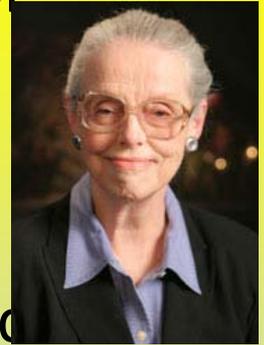
- The needs and preferences of family members of adults with mental illness are diverse and varied. Consequently, these families may benefit from ongoing provision of information and support tailored to meet the families' individual needs. Continued efforts should be made to understand and address consumer and family needs, potential barriers to participation in family services, and the relationship between stigma and family need. **(Drapalski, et. al. 2008)**.

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- "... More than half of consumers and almost a third of family members felt directly punished or stigmatized by staff." in a post-suicide attempt ED visit. "Consumers and family members also reported negative experiences involving a perception of unprofessional staff behavior, feeling the suicide attempt was not taken seriously, and long wait times...Individuals who visited the NAMI website reported a range of negative experiences in EDs following visits for suicide attempts" **(Cerel, Currier & Conwell, 2006)**.

- Mental health professionals do not often collaborate with families when providing treatment to the mentally ill, even though research shows better patient outcomes with family involvement. NAMI developed a course, Professional Provider Family Education Course (PP FEC), to educate mental health providers in outreach to families. This article reports the findings of a study which evaluated the PP FEC and identified barriers to collaboration between families and mental health professional providers. **(Kaas, Lee & Peitzman, 2003).**

- The belief that poor parenting and dysfunctional families give rise to mental illness has been perpetuated by psychodynamic and family systems theories that lack supporting scientific evidence, and interventions based on these theories have failed to produce clinical improvements. Nevertheless NAMI found that many clinical training programs continue to teach these outdated theories and interventions and that the mental health system is often destructive to family systems. This article describes a new 10-week program [Provider Education] that is designed to educate service providers that will include families in the care of their chronically ill loved one. The program is based on a competence and adaptation rather than a pathology foundation and it shifts the discourse from causes to effects of illness **(Mohr, LaFuze & Mohr, 2000).**

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- Services directed toward supporting the family caregivers of persons with SPMIs are virtually nonexistent despite the fact that such interventions may have the potential to improve outcomes for both the caregivers and the clients. This qualitative study expands our understanding of the caregivers' perspective of nonsupportive and supportive aspects of the current mental health care system as well as desired services. The written narrative responses of 76 family caregivers from NAMI chapters across the United States were analyzed using content analysis. The caregivers focused on relationship issues, service issues, and broader social system issues (Doombos, 2002).

- The views of 487 members of NAMI concerning stigma were surveyed in 20 different States. Almost all identified stigma as a problem for their mentally ill relatives and for families in general. The most frequently cited effects of stigma on ill relatives were damage to self-esteem, difficulty making and keeping friends, difficulty finding a job, and reluctance to admit mental illness. The most frequently cited effects on families were lowered self-esteem and damaged family relationships. NAMI respondents identified popular movies about mentally ill killers, news coverage of tragedies caused by mentally ill people, casual use of terms like "crazy" and "psycho," and jokes about mental illness as prominent sources of stigma...

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…The things families reportedly found most helpful in dealing with stigma were factual information about mental illness, interaction with other families with mentally ill relatives, support within the family, and research findings that establish a biological basis for mental illness. Mental health professionals received mixed reviews from family members. While not generally viewed as contributing to stigma, mental health professionals were seen as least helpful in dealing with stigma. Overall, survey results indicate that considerable concern about stigma exists among families with mentally ill relatives and that substantial numbers of family members experience the stigma of mental illness in one form or an-other and perceive that their ill relatives experience it as well

(Wahl & Harman, 1999).

1989).