2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

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Deinstitutionalization and Social Inclusion in Albania

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Research Abstract

This qualitative study explores institutional and community-based mental health services in Albania today. It was carried out in central Albania and southeastern (Elbasan, Korče, and Tirana) between June 1 and September 1, 2013. Information was collected through 44 semi-structured interviews with mental health professionals, family caregivers, and advocates identified through convenience sampling and online research. 30+ additional hours of participant-observation were completed with psycho-social staff and residents at the Sadik Dinci Psychiatric Hospital in Elbasan, Albania. The comparative cases of de/institutionalization of children and Albania's elderly population were also explored. Based on data collected, Albania's low rates of psychiatric institutionalization can be said to reflect the chronic underfunding of the mental health sector and *not* extensive deinstitutionalization efforts or the successful creation of community-based alternatives to institutional care. Western models of service provision such as the Community Mental Health Center and the Supported Home are only partially implemented. Major challenges related to funding, acceptability, accessibility etc. affect Albania's vulnerable populations and a trend towards re/institutionalization looms if community-based care cannot be properly supported.

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2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Research Goals

My major research interests related to post-communist transition, deinstitutionalization, social inclusion, family care, and future prospects for individuals with severe mental illness as well as children, the elderly, and other populations vulnerable to institutionalization. My goal was to take an ethnographic approach to understanding the above issues by building on the knowledge of those professionals and community members who grapple most closely with them.

My initial research goal (later modified, see Research Activities, below) was to interview 12 mental health professionals and 12 family caregivers about their experiences and perspectives relating to deinstitutionalization and community-based mental health services. Specific research questions I hoped to answer included:

- What expectations for standards of care are held by mental health professionals and caregivers today? What are their assessments of the care they are able to deliver, and does the Albanian government invest adequate resources to make quality care possible?

- Is institutional or community care more favorable for individuals with mental illness, and what factors might cause this answer to vary by case (ie diagnosis type and severity, relationships with family members, age or gender)?

- What are the current prospects of individuals with mental illness and their caregivers in Albanian society, and how might these be improved? What should current priorities for improvement be, and who should be involved in their implementation (government, international NGOs, caregivers and client groups, ?)

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Primary Research Activities

My research plan consisted of a mixed-methods approach. In preparation for fieldwork I prepared an interview guide for use with family caregivers and an interview guide for use with mental health professionals (key informants). Once on the ground, I piloted and modified these guides. In addition to recording and taking notes during formal interviews, I documented my experience as a participant-observer through extensive note-taking as well as photography. My ethnographic process was rounded out by my completion of frequent (if not quite daily) written reflections and brainstorming of new questions and angles for exploration.

Upon arrival in Elbasan, I spent a few days familiarizing myself with formal, state-run mental health services. I first visited the Elbasan Community Mental Health Center, opened in 2008 based on a West European model from which client walk-ins, medication and mental health maintenance, family consultations, and home visits are coordinated. There, I sought contacts with family caregivers living in Elbasan and established a working relationship with the resident social worker who would serve as my guide early in my research. With her encouragement I visited the Sadik Dinci Psychiatric Hospital in Elbasan, and set up running meetings with the psycho-social staff there: the social worker, four psychologists, and caregivers responsible for client supervision at the hospital's two Day Centers. Regular contact was much more difficult with the hospital doctors and nurses as they spent most of their time locked into the wards with clients.

Sadik Dinci Psychiatric Hospital, Elbasan, Albania

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

I also made several visits to the Elbasan Supported Home, home to ten women who are former Psychiatric Hospital patients. These women are supported twenty-four hours per day by a custodian and are also assisted regularly by a nurse and the social worker at the Community Mental Health Center. I was able to speak with the women about their family situations and hopes for possible transition from the supported home to their home communities.

Through my contacts in Elbasan, I gained entry to the Tirana Psychiatric Hospital, part of the Nene Tereza Hospital complex. The Hospital in Tirana offers services not available in Elbasan, like child and adolescent psychiatry and (limited) addictions treatment. Unlike Elbasan, Tirana is no longer home to chronic patients. The Italian organization Comunita di Sant'Egidio constructed two supported homes for the remaining 15 chronic patients (formerly housed in abysmal conditions in a fifth ward in the basement of the Psychiatric Hospital building) and now the hospital handles acute cases only. As Tirana is seen as the only city in Albania where anonymity can be achieved, and individuals with mental health needs frequently prefer admission to services in Tirana over the risk of being seen using local services in or near home.

I also used contacts in Elbasan to connect me to staff at the Community Mental Health Center in Korča, a large city 2.5 hours southeast of Elbasan. I was interested in comparing the everyday functioning of two CMHCs. The Elbasan and Korča centers make for good comparison. The Elbasan CMHC is part of a system in which patients admitted to the Psychiatric Hospital for an acute episode can filter down to the CMHC for maintenance care, and regular clients at the CMHC can be easily admitted to the Hospital when the need arises. The Korča CMHC represents the sole mental health resource for that community and, indeed, the entire region of southeast Albania. Even Korča's large regional hospital lacks a psychiatrist and any psychiatric beds.

After an initial few weeks of fieldwork in Elbasan, it became apparent that my initial hope to interview as many family caregivers as mental health professionals was unfeasible. Due to the stigmatization of these families (even by mental health staff) and the logistical difficulties of arranging visits and transport for myself and Albanian colleagues, I completed a total of just 8 family caregiver interviews and then turned to broadening my net for professional or "key informant" interviews. I began to make contact with additional community-based facilities, such as the Ballashe Center (a day center for the elderly and adults with intellectual disability) in Elbasan and the Kennedy Center (a church-affiliated collection of facilities serving street children, survivors of trafficking, and the elderly) in Korče. I also expanded my inquiry into the de/institutionalization of other populations, particularly children (orphans) and the elderly, about whom many NGO and policy reports and secondary literature exists

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Handicraft activities at the Ballashe Center, Elbasan, Albania

Ultimately, I collected qualitative data through a total of 44 semi-structured interviews with mental health professionals, family caregivers, and advocates. I spent 30+ additional hours of participant-observation with psycho-social staff and residents at the Sadik Dinci Psychiatric Hospital in Elbasan, Albania, and enjoyed the opportunity to assist with activities including community excursions, an art camp, and a four-week Healthy Relationships lesson series. I worked in Elbasan, Korča and Tirana and believe that the institutions and organizations I visited are representative of the range of services available in Albania today.

Secondary Research Activities

Over the course of the summer I had the opportunity to pursue a handful of secondary research interests, 2 related directly to my focus on deinstitutionalization and community-based care, and 1 related to the current economic climate in Europe:

Roma Mental Health

In late June, I met with Elga Lula, a social worker with the National Center for Community Services (NCCS) in Tirana. The organization has worked with a range of vulnerable

populations, including the Albanian Roma community. When I inquired about the mental health needs of Albanian Roma, Ms. Lula told me that to her knowledge, no studies had been done in this area and no Roma-directed mental health promotion programs had been attempted. She relayed a common misperception held by ethnic Albanians regarding Roma people: that even if the Roma are poor to the point of begging on the streets, they are "happier than you or I."

The common belief that Roma are content and even happy to live in material deprivation and social exclusion seriously conflicts with research on the social determinants of mental and emotional health. Indeed, the minority stress theory shows that members of racial and ethnic minority communities suffer the acute and chronic stressors of racism and discrimination in addition to low socio-economic status and related stressors (poor housing, high unemployment, poor diet and unhealthy behaviors), resulting in higher vulnerability for psycho-somatic and somatic illnesses than non-minority peers. Roma mental health became a running line of inquiry for me this summer. I asked all of my key informants whether they had any personal experience working with Roma mental health or had heard of any other organizations doing so (none had). I also recorded their opinions on potential mental health issues affecting the communities they served.

Human Trafficking

I have worked for nearly two years now as a steering committee member for the Indiana University Human Trafficking study group. Our group hosts periodic guest speakers, informal lunch-hour discussions, larger awareness-raising events (day-long event in spring 2013, week-long event planned for October 2013), and research symposia. We have also created an Indiana University-hosted trafficking research and resource website. Through my work with this group I have become knowledgeable about trafficking issues and took the opportunity of my months in Albania to interview Tjeter Vizion, a trafficking shelter and community center in Elbasan.

Labor Migration and the Eurozone Debt Crisis

In spring 2013 I joined the Eurozone Debt Crisis working group at Indiana University. My interest in the crisis stems from my concerns about Albanian migrants. Almost every family has a member living abroad, mostly in Greece and Italy in two of Europe's hardest-hit economies. To this end I created a 5-minute questionnaire about work and migration history and perceptions of the debt crisis and initiated a small, IRB-approved study of returned or visiting migrant laborers. I identified half of my 20 informants through my contacts in Elbasan and the other half at the Greece-bound bus stop (which was conveniently located near my apartment).

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Language Training

As a Research and Language Training fellow, I was privileged to enjoy 7 hours of advanced Albanian language training per week (for a total of 84 hours). I worked with Mr. Ervin Bebeti, who has been trained as a Peace Corps Albanian language teacher and has five years of experience working with Americans on conversational Albanian in Elbasan. Thanks to my previous tenure with Peace Corps-Albania, I began the research period with the communication skills needed for participant-observation and oral interviews. My lesson hours (usually 1 per day, 7 days per week) were extremely useful in reinforcing my existing language skills, building a more specialized health and social service-related vocabulary, and continuing to improve my accuracy with Albanian grammar. I was immersed in professional-level Albanian language to an extent that would be impossible outside of the region. In addition to completing 80% of my interviews completely in Albanian language, I led a four-week Healthy Relationships intervention for twenty clients at the Tulipan Day Center, completely in Albanian. My ability to access Albanian-language newspapers and public library materials both bolstered my language skills and has added tremendous depth to my understanding of my research interests and of Albanian society more generally.

At the end of my research period, I quantified my language learning in two ways. I took a written and spoken exam with the Faculty of Albanian Literatures and Languages (University of Tirana) and earned a B.1 or Intermediate Proficiency certificate. I also completed a twenty-minute oral proficiency exam with Peace Corps-Albania's Language and Cross Cultural Facilitator, Ms. Mira Luca, earning an Advanced Low/Advanced Mid Proficiency rating (only two levels, Advanced-High and Superior, are higher).

Important Research Findings

Despite my multiple areas of focus I will concentrate now on the most important findings related to my primary research project, deinstitutionalization in Albania. I have only begun the initial review and digestion of my notes, photos, interview tapes, and large collection of primary reports and secondary literature related to my project, and as such I will share the overall narrative-in-progress through which I have come to frame my project and provide only generalized supporting evidence.

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Picnic excursion for twenty Hospital Resident at Labinot, Elbasan, Albania

Albania's mental health system, like its overall health infrastructure (Gjonca, 2001) is historically underdeveloped. Even at the peak of Pavlovian psychiatry—an influential Soviet paradigm that called for biomedical psychiatric treatment in sterile clinical settings—Albania's communist government maintained just four residential institutions and 2,000 beds (Nuri, 2002). In 2007, Albania maintained just 24 beds for the treatment of mental illness per 100,000 population. This is the fifth lowest rate in all of Europe (WHO, 2008) and puts Albania on par with countries like Italy and the UK that have gone through long, intensive deinstitutionalization processes since the 1970s. Albania's low rate of psychiatric beds, in contrast, is due primarily to the national government's consistent and severe underfunding of the mental health sector. This is particularly striking when one considers that a full 97% of funding for Albania's mental health sector went to residential psychiatric institutions and a mere 3% to support community-based alternatives including Community Mental Health Centers or supported homes, even after most of the alternatives that exist in 2013 were established (WHO & MOH, 2006).

The Sadik Dinci Psychiatric Hospital in Elbasan illustrates Albanian de/institutionalization at the local level. During the late communist period, the Hospital treated between 800 and 1,200 individuals with an array of diagnoses including severe mental illness (schizophrenia and bi-polar disorder) and intellectual disability (such as Down Syndrome) as well as a large number of social cases (orphans, dependents of admitted patients) and individuals

exhibiting "anti-social" behavior (ie, anti-government agitation). Then in the early 1990s, a post-communist deinstitutionalization process championed by multiple EU member parties and international NGO's (Ireland, Italy, Netherlands, WHO, Comunita di Sant'Egidio) whittled the number of beds to 340. Numbers have remained relatively stable—at capacity—since.

Hundreds of Albanian residents suffer from the isolation and persistently dehumanizing conditions common to residential institutions in post-communist Eastern Europe. According to my informants, twenty years of steady improvements have included the addition of dining tables, chairs and eating utensils; access to restrooms and re-training of their use; the (occasional) unlocking of wards; (occasional) access to excursions outside of the hospital for high-functioning residents; access to Day Centers (mostly for the purposes of coffee drinking, dominoes, and television), also for the high-functioning. Despite these changes, all residents continue to live as "patients," with almost unvarying daily routines that include meals, sleep, and laundry day once a week. Consumer rights groups are unknown, and the much-touted right of residents and families to contribute to individualized treatment plans is rarely realized. Relationships between psycho-social staff and the residents are predominantly custodial, and opportunities for therapeutic interventions such as physical rehabilitation or art classes come and go with international funding. Doctors are there to administer medication, and doses are high due to the safety and security risks of violence and the fighting amongst residents. Many wake up and leave their beds only at mealtime.

A full two-thirds of Hospital residents in Elbasan are *kronike*, or chronic residents for whom deinstitutionalization has been deemed unfeasible. Length of stay of these individuals ranges from a few years to decades and are often unrelated to their medical diagnoses. Major barriers to deinstitutionalization include total loss of contact with family members back home *or* the absence of community mental health services near to home, and the financial difficulty of life outside the hospital predicated on the virtual impossibility of employment (as, according to many, many informants, "there are no jobs for health people").

Outside of the Hospital walls, the vast majority of Albanians with mental illness and/or disability have lived and continue to live in their own communities (Tobis, 2000). Though positive and loving family-care situations exist, abuses against individuals with mental illness occur with frequency outside of institutions. The confiscation of individuals' disability payments, property, or inheritance by relatives is common, based on varying degrees of maliciousness or need. Physical and verbal mistreatment is also widespread, precipitating the determination that, in many cases, institutionalization is the best option for protecting the rights and well-being of the "cared-for" family member.

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

A Healthy Relationships lesson at the Hospital day center, Elbasan, Albania

Individuals and families struggling to survive severe mental illness in their communities face the threat of re/institutionalization. In addition to facing illness itself, they must deal with challenges like poverty (FSHDPAK, 2011), "care drain" caused by labor emigration of able-bodied men and, increasingly, women (Vullnetari & King, 2008), social stigma (WHO, 2009), and a pervasive lack of access to formal support services (WHO, 2003) due to distance, cost, and other factors. Formal caregiver supports are also non-existent.

These economic and social challenges concern other vulnerable populations as well. Individuals with physical and intellectual disability, orphaned children, the elderly, and Albanians living with chronic disease are all disproportionately affected by challenges including unemployment, lack of housing, international migration of family supports, and post-communist problems such as dysfunctional government and underdeveloped civil society. Anecdotal evidence and NGO reports reveal a rise in demand for state-run and private nursing homes for elderly Albanians as their families migrate and leave them behind. Indeed, in the logic of post-communist liberalization, my informants report that Western-style nursing homes are seen as a modern and desirable model of elder care by an increasing number of Albanians. Homes are

believed to consolidate all the care that the elder might need and free younger family members to pursue other interests; well-to-do Albanian families are increasingly willing to pay for such set-ups.

Structural challenges—namely poverty and a widespread lack of adequate supports, both formal and informal—have created the prime conditions for re/institutionalization of Albania's most vulnerable populations. The future of de/institutionalization in the Albanian context is also characterized by the inherent tension between Albanians' traditional focus on community and family sacrifice and responsibility and their increasing adoption of "Western" definitions of success, which tend to value individual progress even at the expense of the collective good. Unfortunately, the concept of individual and human rights has not been operationalized in this increasingly "Westernized" society, and as a result, resources like Albania's 2011 Mental Health Law remain untested and unused in the struggle for improved quality of life for the mentally ill, whether within institutions or outside of them.

Policy Implications and Recommendations

De-institutionalization and access to community-based mental health services are international human rights issues. Individuals suffering from mental illness and/or disability are marginalized, stigmatized, and ultimately discriminated against in societal realms such as education and employment (Kleinman, 2009). Social stigma and the kinds of culture- and context-specific structural barriers revealed in my research also affect individuals, their families, and entire communities. If the rights to personal dignity, social support, and acceptance in one's community are to be extended to all, the United States must pay attention to the issue of social exclusion in lower-income countries. The internal picture of exclusion and marginalization of minorities and vulnerable groups in collectively-marginalized societies like Albania is frequently abysmal, and progress in this area should be seen as a fundamental building block of progress and development and not a secondary concern.

From a policy standpoint, Albanian leaders must be encouraged to increase and sustain attention to population-level mental health promotion and the equitable treatment of mental illness as they seek closer relationships with Western Europe and the U.S.. Deinstitutionalization is the official policy of the European Union and was an important part of EU accession talks in countries including Romania, Bulgaria and Croatia (Phillips, 2012). Mental health can also be made a component of USAID funding cycles and Public Affairs talking points out of the American Embassy in Tirana. Albania's historic lack of mental health infrastructure may yet

prove an ironic "advantage." Family caregivers in Albania have been managing mental illness in the community with limited resources for a very long time, and it is in the financial interest of the Albanian government—not to mention the best interest of individuals with mental illness themselves—to support continued community care. It is time for the government to actively provide that support by funding more and more highly functioning Community Mental Health Centers.

Two residents on kitchen duty at the Supported Home, Elbasan, Albania

Community-based mental healthcare features an important civil society component that also deserves attention. The movement towards de-institutionalization, community services and supports has been successful in West European countries in part because groups of individuals with mental illness and disability have demanded improvements in mental healthcare. The movement has worked less well in the countries of Eastern Europe and the former Soviet states, which continue to be characterized by weak civil society and ineffective governance. Most countries in Eastern Europe, Albania included, already have enlightened disability rights laws on the books. Policy makers must press for their full implementation, and move beyond the mere prevention of abuse towards the guaranteed inclusion and meaningful participation of individuals with mental illness in their communities and societies.

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Co-Curricular Activities

In my over 40 interviews with professionals, caregivers, and advocates, I was able to build myself a rather large network of Albanians working in mental health and related fields. Many of my contacts work for local or national organizations. For example, I had continuing contact with Ms. Zela Koka, founder and director of the national advocacy and services organization MEDPAK (Foundation for the Protection of the Rights of Persons with Disability), and her staff in Elbasan, Peqin, and Librazhd, Albania. Through a MEDPAK event, I also made contact with the national Albanian Disability Rights Foundation, based in Tirana, and sought the assistance of the social worker at the National Center for Community Services, with whom I was connected by a mutual friend working in civil society in Kosovo.

A few of my informants worked for international NGOs. In Elbasan, I met with two representatives from the UNDP office in Elbasan. I also met with health practitioners working for the church-affiliated ABC Community Health Clinic and the Adventist Development and Relief Agency in Tirana, and with staff and volunteers of the Catholic NGO Comunita di Sant'Egidio, which has a long-term relationship with residents of the Psychiatric Hospitals in both Tirana and Elbasan.

Conclusions

Albanians with mental illness and/or disability experience limited quality of life across residential institutions, community-based and family care situations. Staff-client relationships are custodial and rarely therapeutic, even in expressly transition-focused facilities like the Psychiatric Hospital day centers and supported homes. Narratives of community-based and family care reveal social stigma and workplace discrimination as persistently insurmountable obstacles. Albania's new network of Community Mental Health Centers is modeled on Western European mental health infrastructure but functioning far below its intended capacity. And potential local assets, such as the traditional multigenerational family structure that have always served as a fallback for an inadequate mental health system, are threatened by wider post-communist trends like domestic and international labor migration and the adoption of a neoliberal ethos which values individualism and personal successes over family cohesion.

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

Plans for Future Research Agenda, Presentations, and Publications

Primary Research

The major use for the data I've collected will be the crafting of my master's thesis for my Russian and East European Studies program. I am continuing my exploration of secondary literature as well as primary reports to create a comparative study of the politics of deinstitutionalization and social inclusion in post-communist Albania.

While my direct contact with family caregivers was limited during my stay in Albania, I am focusing on family resilience and the successful reintegration of deinstitutionalized family members in an intervention that I am creating for a fall 2013 course on Intervention Design in my M.P.H. program. I am using the responses to several questions related to best- and worst-case family care scenarios on my key informants interview guide, and I may also attempt to publish a short article on this set of responses.

My future research agenda related to the above includes a study of the mental health system in Turkey or another Balkan country, rather than a follow-up study in Albania. I'd like to further explore West European community mental health models and the dynamics of European monetary aid and influence on the development of systems and services in Albania and other East European countries. I am also interested in the role that a human rights framework can play in efforts toward social inclusion in the Balkans region.

Secondary Research

Upon my return to Indiana University, I have continued my review of existing research on Roma (and minority) mental health and have elected to design a mental health intervention for Albanian Roma women as my Master of Public Health synthesis project, a graduation requirement similar to a thesis. I intend to write an article comparing "mixed model" trafficking and domestic violence shelters in Albania (Tjeter Vizion) and the United States (Bloomington, Indiana's Middleway House), and will soon be interviewing the latter's executive director to lay the groundwork for this comparison. I may publish this on the IU Human Trafficking resource website or possibly in a peer-reviewed journal. Finally, I am planning to present my research on Albanian migrants and the Eurozone crisis to the Indiana University working group.

2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

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2012 -2013 TITLE VIII RESEARCH SCHOLAR PROGRAM
FINAL REPORT

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