

An International Perspective: The Geel Story

Jackie Goldstein, Ph.D.  
Samford University Psychology Department

Presented at Eighth Annual Conference of  
National Association of County Behavioral Health Directors  
Milwaukee, WI - Hyatt Regency Milwaukee

July 11, 2003 General Session  
9:00 - 10:30 am

Jackie Goldstein, Ph.D.  
Professor, Psychology  
Samford University  
SU #292308  
Birmingham, AL 35229-2308  
Phone: (205) 726-2118  
Fax: (205) 726-2895  
e-mail: [jlgoldst@samford.edu](mailto:jlgoldst@samford.edu)

## An International Perspective: The Geel Story

Thank you for this opportunity to share my interest, and even passion, for Geel. As many of you know, Geel is a city in Belgium with a legendary and unique system of foster family care for the mentally ill. I first visited Geel in 1997 and have been back three times since then. But, I still I do NOT consider myself an expert on Geel. I am, however, a student of Geel, and I am constantly gaining new knowledge – AND identifying old misunderstandings. Because, when one reads about Geel – especially historic accounts – it’s not unusual to find diverse, even conflicting, reports or anecdotes. But, there’s one thing about which there is no doubt or conflict. For at least 700 years, the people of Geel have accepted the mentally ill into their community and even today hundreds of Geel families have taken them into their homes.

Because of Geel’s attitude I want to present the city’s story in a context that I hope will give it meaning for today because I think the city has more to offer than just a unique story. And, at the end of this session, I hope to explore together ways that we can use Geel’s experience and success to motivate improvements in our own communities.

It’s common today to talk about a “recovery model” of mental illness. And, I’ve come to believe that recovery of individuals happens most effectively when there is also “community recovery.” Let me explain what that means to me and then, I invite you to hold this idea as we look at Geel’s past and present.

Mark Ragin, a psychiatrist at The Village, a pioneering agency in Long Beach, California, recently wrote of the “recovery model” in a book entitled “Road to Recovery.” (SLIDE 2) Here he discusses the difference between recovery and cure and gives examples of how recovery allows one to live with the realities of mental illness.

I believe that communities must also “recover” in that they must learn to live WITH the realities of mental illness. Mark identifies the four stages of recovery as: hope, empowerment, self-responsibility, and a meaningful role in life.

I believe that, for communities to recover, they too must be given HOPE that they CAN live WITH mental illness. I think that Geel can help to inspire that hope.

I understand that many of you have visited Geel and later I hope to hear of your experiences. (SLIDE 3) I first

learned of Geel in 1982 when I was in my final semester as an adult undergraduate student and I read about Geel in an abnormal psychology text book. The legend and tradition and persistence of the system fascinated me.

The article that was cited in that text was published in 1974 but it was a report, by a Cincinnati neurologist, on his 1936 visit to Geel. Since that information was pretty old, from time to time I tried to find more current information, and then, as time went on, my interest became more personal.

In 1986, my best friend's 16 year old son began a tortuous journey with mental illness and I became acutely aware of the social side effects of severe mental illness. During those years, I naturally thought a lot about Geel, where those with mental illness are accepted, visible members of the community.

In 1993 these concerns about social isolation led us to start-up a Compeer agency in Birmingham. I'll talk more about this organization a little later, but many of you probably know about Compeer.

By that time, I wanted to learn about Geel first hand and I made contacts that led to my first visit in January 1997. I remember sitting on the train from Brussels to Geel, wondering what I would find. All I could envision was the old picture that I'd seen in my text book and an image created from the report of a doctor's 1936 visit. I was met at the train station by psychologist Marc Godemont, and during that one day visit I learned that this was a city with more than a history. First of all I didn't find a relic from the middle ages. I found a busy little city of 30,000 with clear signs of 21<sup>st</sup> century awareness (SLIDE 4) But, most importantly, I found a remarkably modern and realistic approach to mental health care

But, before we look at today's system, let me take you back 1500 years to events that would motivate the evolution of the system that I first visited in 1997.

Many of you are probably familiar with Geel's story. It begins with the sixth century legend of Dimphna, the daughter of the pagan Irish king, Damon. There are variations on the legend but it goes something like this.

Damon was married to Odilla, a beautiful woman who had become a Christian. When their daughter, Dimphna, was born, the mother arranged for the child to be raised by a priest, Gereberne, and Damon had little to do with her. But then, when Dimphna was in her teens her mother died. King Damon was overcome with grief and insisted that his aids find him another wife, as beautiful as Odilla. After an unsuccessful search, they

reminded Damon that he did, in fact, have a beautiful daughter who might be a good replacement for her mother. Damon liked the idea. But, Dimphna and the priest were less enthusiastic and they fled by escaping across the North Sea into Belgium. There they hid in the forests outside of Geel, taking refuge in St. Maarten's chapel. But, Damon didn't give up easily and within months he and his soldiers found Dimphna and the priest. (SLIDE 6) Even then, faced with a choice of incest or death, Dimphna did not submit to her father's mad demands and, near the chapel, she allowed herself to be beheaded

(SLIDE 7) Over the years, the site of her martyrdom, near St. Maarten's chapel came to be associated with miraculous cures and in 1247, with a history of reported miracles and the legend of her determination not to yield to her father's madness, Dimphna was canonized as the patron saint of the mentally ill.

The miracles surely led to Dimphna's canonization, and, in turn, her sainthood assured a continued influx of pilgrims seeking religious treatment (SLIDE 8) In 1286, a guest house hospital was built near the site of the chapel in an effort to accommodate the pilgrims. Though this was a "hospital," during the middle ages mental illness was attributed to devil possession and, even here, priests were the primary practitioners. (SLIDE 9) As pilgrims continued to come to Geel, a new church building was begun in 1349. Though the church suffered fire and storm over the years, the present Church of St. Dimphna was completed in 1749 and still stands today. A sickroom was first added to the church in 1480. But, even with a hospital and a sick room, there were still more pilgrims than could be accommodated. And so, in about the 15<sup>th</sup> century, a practical solution was found.

You've probably all sat in on meetings where a decision was made that, over time, had consequences, good or bad, that went beyond the immediate intentions. That's evidently what happened in Geel when the church canons instructed local villagers to house overflow pilgrims. And, many pilgrims, even after their treatment, stayed on as long-term boarders in Geel

(SLIDE 10) In the beginning, the families of pilgrims simply made informal arrangements with villagers for room and board of the pilgrims. Though arrangements were informal, there was oversight of the system by a chapter of local canons. But, the presence and type of administration changed over the years. As the system persisted, authority and supervision were transferred. There was even a time when supervision ceased to exist but

the tradition did not. In the early years, just as in other places, patients in Geel were not always treated in a kindly fashion. From the late 15<sup>th</sup> century to the mid-18th century various regulatory efforts tried to address this issue but, in 1795, during the French revolution, Belgium was annexed to France and, in 1797, religious family care was officially ended; the churches were closed and the priests were dismissed. But, the tradition wouldn't die. Mentally ill from across Belgium were still brought to Geel by their family members and, once again, private arrangements were simply made between Geel families and patient families. But, conditions were still disturbing to the government and, in 1811 the French Minister of Justice decided to put an end to Geel's family care system. "Decisions" rarely eradicate traditions, however, and the local government was able to use delaying tactics to roadblock the decision until ultimately, in 1838, the family care system came under the jurisdiction of the Geel Municipal council

In 1850, Belgium's national mental illness law was passed to address poor treatment of the mentally ill nationwide. At this time, Geel was designated as a special region and the national government assumed responsibilities. The program now became known as the Rijkskolonie, or State Colony, and, though it still functioned as a normal community, the whole Geel area was considered to be a psychiatric institute, a sort of hospital without walls. Subsequently, in 1862, a central hospital was built in the community. In 1948, a Ministry of Public Health was formed in Belgium and mental health care, including the Geel State Colony, was transferred from the Ministry of Justice to the new ministry. The most recent change took place on January 1, 1991. Geel's Public Psychiatric Hospital, the OPZ, supervises the family care system, and, in 1991 the OPZ gained autonomous status as a Flemish Public Institution subject to Belgian Hospital laws.

(SLIDE 11) The OPZ is governed by the same hospital statutes and receives the same state income as all other psychiatric hospitals. The only difference is that, since 1991, the Board consists of members assigned by the Flemish government. Having an independent Board of Directors at the OPZ was an extremely important change. Now decisions about the future of the hospital are made in Geel, rather than in Brussels.

So, Geel's system has persisted AND evolved over 700 years and, since attaining autonomous status, there is justified optimism that Geel's traditional care will continue. But, though it is healthy today, the future of the

system has often seemed shaky – even in modern times.

In a moment I'll describe it's current status. But, before I talk more about Geel of today, I'd like to describe a chapter in Geel's modern history that may have helped to ensure the future of this unique system. And, this chapter is of particular interest to us, since it was motivated in large part by the concerns and actions of American professionals.

In the case in the most cited Geel article of modern times, the 1974 *JAMA* article that was cited in my text book, Charles Aring expressed admiration for Geel and contrasted the city's success to deinstitutionalization problems in the United States.

**(SLIDE 12)** Though this article was published in 1974, it was based on Aring's 1936 visit when there were about 3,400 boarders living in a town of approximately 20,000 residents. This was not the case in 1974. In fact, the boarder population had begun to dwindle long before the publication of Aring's article.

In 1960 two University of Chicago psychiatrists, Dumont and Aldrich, had heard of Geel's diminishing patient population and their concern led them to spend two months in the town talking to hospital authorities and interviewing foster families. After their visit, they were convinced that the tradition itself was not dying among families and that it could continue – with proper support. But, it appeared that that support was not guaranteed. They reported on their visit at a 1961 American Psychiatric Association meeting and, intent that the Geel system should not be allowed to simply fade into non-existence, they conferred with Columbia University psychiatrist Viola Bernard who in turn met with Belgian authorities and Geel personnel in 1962 and 1963. Other Americans were also expressing interest in Geel at this time and renowned anthropologist, Harry Shapiro, also visited the area in 1963. These visits and meetings produced a convergence of concern about the future of Geel and an urgency to investigate the history and development of both the system and the town. It was agreed that a major study should be undertaken and the Geel Research Project was born.

It was hoped that the project would lead to rescue of the system through recommendations to the Belgian Health Ministry. Also, the successes and shortcomings of Geel had never been thoroughly or systematically examined and this study would be especially important if rescue attempts failed.

Local leadership for the project was found in the person of Jan Schrijvers, a young psychiatric resident at Belgium's University of Leuven and a native Geelian . Dr. Schrijvers agreed to begin training at Columbia's School of Public Health and, when he earned his Master's Degree in 1965, he took a joint appointment at Geel and the Leuven School of Public Health.

Dr. Schrijvers would as serve as Administrative Associate Director at the study site. But experienced leadership was also needed, and Columbia sociologist Leo Srole, who had gained fame for his participation in the Midtown Manhattan study in 1962, was enlisted to serve as Project Director. In 1966 Dr. Srole assumed that position and, over the next 10 years, he regularly visited Geel while he also retained his position as a full-time faculty member at Columbia.

(SLIDE 14) The original project plan was thorough with 40 study units in six main clusters:

1) Geel's history, 2) patient composition and changes in Geel, 3) foster family structure and process ("typology"), 4) foster family policies and practices of the Rijkskolonie as an institution, 5) Geel's role as "embracing extramural surround" of families and their boarders, and 6) ambivalent images of Geel among non-Geel residents and mental health professionals.

It was a thorough design and well-qualified researchers were involved, but, there was never adequate funding or staff and the study struggled during its entire 10-year life. There was, however, enthusiasm and perseverance on the part of the existing staff and, over the years, preliminary results from the study *were* communicated in several formats. (SLIDE 15)

For example, traditionally every five years there had been a local St. Dimphna Folk Festival. That tradition had been abandoned in the '60s but, as the study neared its end, an International Symposium was held in Geel in conjunction with a 1975 St. Dimphna celebration. Here reports on preliminary analysis from 8 of the 40 study units was presented

Even after the project terminated, Dr. Srole continued to present GRP information at scientific meetings, such as the 1976 International Symposium of the Kittay Scientific Foundation. In 1979, Belgian Eugene Roosens, head of the anthropological team, published a book, in English, entitled *Mental Patients in Town Life* .And, at least

seven European doctoral dissertations were written using Geel Project data.

Also, as intended, Dr. Srole submitted lengthy reports, with recommendations, to each new Belgian Minister of Public Health. In his final report to Josef De Saeger in 1974 he wrote that GRP data indicated that the Geel system may not survive beyond 1980.

**(SLIDE 16)** In this report Srole identified three converging trends that he believed were responsible for Geel's diminishing patient population: 1) established families were leaving the program, 2) fewer new families were applying, and 3) perhaps most significantly, there was a decrease in the number of new patient referrals by non-Geel mental health professionals.

On first learning of Geel, many, such as I, are impressed by the evidence of compassion and tolerance. However, historically others – particularly in Belgium – have viewed Geel differently. For most of Geel's history, once a patient was established as a boarder, they remained in the home of their foster family for the rest of their lives. Outside the city, the mentally ill in Geel were viewed in somewhat the same way as we might view those who spent their lives in the “back wards of state hospitals.” In Belgian communities, Geel was often referred to as “the city of fools,” where “half of Geel is crazy and all of Geel is half crazy.” This attitude might have been a major factor in the decreased referrals that Srole had noted in the 1970s. An administrative attitude in the Rijkskolonie itself might also have contributed, for GRP data found evidence that Colony administrators were discouraging new admissions.

Why would the Rijkskolonie itself adopt policies that appeared to be self-destructive? It could have been due to a problem that often exists in the field of mental health care: conflict between those who are experts based on their education and those who are experts based on their experience.

After generations of sharing their homes, foster families have always found practical solutions to problems associated with the illness of their boarders. As modern mental health treatments developed, educated professionals didn't always like the authority granted to these families. In his presentation at the 1975 Geel Symposium, Dr. Srole noted that, when the foster family takes in a patient, in most cases, the boarder becomes a functioning member of the family structure. Srole particularly noted that the medical model of treatment is not a



part of Geel's foster family system. Rather, the family serves as caretaker, teacher, natural supportive parent, and behavioral model. Srole surmised that it was this influence that allowed the boarder to function in the "normal" social world in spite of their illness.

For hundreds of years Geel's foster families have served as mental health providers with no *formal* training or education and no awareness of, or concern with, the diagnosis of their boarders. And, today the educated experts are making a more conscious effort to honor family expertise and experience.

Srole had envisioned a GRP publication that might have an impact similar to that of *The Midtown Manhattan Study*. But, in spite of his efforts and even though he had a publishing contract, Leo Srole died in 1993 without realizing his vision. Though the volume was never published, however, it is quite possible that the GRP did, in fact, influence Geel's future.

The Geel system is alive and well today. Though many things have changed in Geel across the centuries, and even decades, the foster family tradition has persisted. The population of the city itself has increased over the years: an 1885 article described a population of 5,000. Dr. Aring reported 20,000 when he visited in 1936 and the latest census reports a population of about 33,000.

Today the City limits encompass 22,000 acres and, while part of the town is still primarily agrarian, as in early times, the southern part of the town is highly industrialized. (SLIDE 18) That link between tradition and modern industry is evidenced by this sculpture that sits in the town square and was donated to the town by Amoco Chemical, one of the area industries.

It's possible that the change from a primarily agricultural community to a more industrialized area has had some influence on community motivation. In the early days, boarders were primarily taken in for practical reasons as they could provide labor and income for the family. In fact, in 19<sup>th</sup> century Geel even the "madness" of the boarders was often seen as a bonus. Patients were sometimes brought to Geel in shackles or chains and there was a belief that once they were freed they would have more energy that would then be channeled into their work.

As one can see from reading segments of 19<sup>th</sup> century reports, the system has not always been characterized by treatment that we would admire today. That has certainly changed.

More than 25 years after the GRP ended, GRP team member, Eugene Roosens, revisited 108 foster families to see what changes, if any, THEY perceived. Several changes were noted by these families.

Of course, improved medication has softened or eliminated cases of unusual behavior.

Compared to past times, whatever exploitation for hard labor might have existed has been eliminated, if for no other reason, due to the fact that a less agrarian society demands less hard labor. However, patients are still offered the opportunity for meaningful labor.

Opportunities to do paid piece work and increased social security support have offered boarders greater economic power and freedom. This has led to other significant changes. For example, at one time, boarders were quite obvious, if not due to their behavior, often according to their dress. Today, they are able to shop in local stores and, in terms of dress, they are indistinguishable from other Geel citizens.

Even though pubs and cafes are quite modern, boarders have the financial means to frequent these and often go out to dinner with their foster family, by themselves, or with other boarders or friends.

There was also some indication that a more “normal” life may have created some degree of stigma within the boarder population. It appears that some, who feel “more normal” than others, might avoid patient social clubs and activities.

In addition to changes for the boarders, families also commented on changes for themselves. Most noticeably, today they feel more respect from OPZ personnel. This respect is evidenced by respite care that is offered so that families can take a break and periodic meetings for families, held at the hospital, where they can offer input and observations.

When one reads of Geel, it’s natural to be most keenly aware of the tradition and the living history. But, if Geel has any value as a model, it’s important to understand the current status of this system – to look at the product of the tradition as well as the history itself.

**(SLIDE 19)** At the beginning of 2003, there were 516 boarders living with 423 care-taking families. **(SLIDE 20)** Sixty to 70% of boarders were men and the age range is from 15 to over 85. **(SLIDE 21)** Close to half boarders are diagnosed as mentally retarded and over 20% are diagnosed with schizophrenia or psychotic disorders .

Most patients are referred to Geel by other Belgian psychiatric hospitals, and today they primarily come from a radius of about 32 miles (50 km) around Geel.

(SLIDE 22) Patients who are considered good candidates for relocation to Geel fit the following criteria: 1) a diagnosis of severe mental illness according to DSM-IV criteria, 2) normally, aggressive patients are not considered, 3) candidate patients are not able to integrate into normal daily life on their own, 4) show a need for dependence and attachment.

Though violent behavior, such as that associated with paranoid schizophrenia, normally eliminates someone as a candidate for admission into the program, exceptions have been allowed. Even today decision making at Geel is governed by common sense and individual evaluation as much as by rules. Several patients who had exhibited violent behavior in other settings have been able to accomplish successful socialization at Geel. (SLIDE 23) On my first visit, Dr. Godemont shared such a story with me when we visited one of the day centers. We were met at the door by a friendly, out-going woman who was eager to see Marc, eager to meet me, the visitor, and very eager that we share some of the soup that they'd made that morning. When we left, Marc told me that he had first seen this woman when she was much younger and was restrained in a state hospital bed, due to her aggressive behavior. Convinced that it was the restraints that were causing her behavior rather than the other way around, he was able to have her reassigned to Geel and this picture and my experience tell the rest of the story. In a minute I'll show you a video clip with another example of a formerly aggressive patient who adjusted in Geel.

(SLIDE 24) The intake procedure from referral to placement takes from a few weeks to several months and includes the following steps:

- 1) There is a written request from the referring institution
- 2) Then the patient record is studied by an intake team consisting of psychiatrist, psychologist, and social worker.
- 3) If the team feels that the referral is a good candidate, they visit the patient at the institution where they are currently housed.
- 4) If that visit goes well, the patient is moved to a Geel observation home, a normal home environment where it can be determined if the patient is able to live in a family environment and, if necessary, where skills can be

learned that will help them to live successfully in a foster family home.

5) A foster family is identified from those that are currently available. There is normally a waiting list of families, and there is no actual screening of foster families. They are primarily investigated regarding social behavior, infectious disease, family stability, and housing conditions. Part of the housing criteria demands that every boarder have their own room in the foster family home.

6) After a prospective family is identified, there are several meetings with the family in the family's home – that is, not at the hospital.

7) If both patient and family feel there's a compatible match, the patient moves in with the family.

While the final decision is made by the reviewing panel, there is only a very rough matching procedure and this is based primarily on the wishes and needs of both family and patient. But, the match is monitored and the referring institution receives a report at four months and one year after the placement.

Many boarders stay in the system for years. In June 1999, the range of years in family care for current boarders was from less than a year to 72 years with an average stay of 36 years. And many host families simply take in a boarder from their parents' home. Though most boarders become long-term residents, today some younger patients (18-40) are placed for 2-5 years. For these boarders there is the hope that being a part of a family network will improve their social skills and allow a more independent life style outside a foster home.

Though there is some financial benefit to maintaining a boarder, it is clear from the pattern of long-term matches that the boarders are more than just a source of income. They actually become members of the family and in many cases offer companionship for an aging host.

(SLIDE 25) Including payment to the family, it costs approximately \$58 (50 Euro) a day for each boarder, with families receiving about \$20 (17 Euro) for each boarder. Social insurance pays about \$44 and the remainder is paid for by the boarder from their personal social security income. But, even with this payment the boarder still has ample cash for clothing, pocket money, leisure, etc

(SLIDE 26) With 500 patients, the annual OPZ budget is approximately \$9 -1/4 million. Staff wages, excluding medical staff account for a little over \$2 million of the budget and medical staff wages account for a little over \$1,000,000 of the budget.

(SLIDE 27) A key staffing element of the family care system is the district nurse who is part of the Family Service Team. There are twelve district nurses and each is responsible for 40 to 60 patients who live with 30 to 50 families. These nurses are the link between the family and the system itself. Family / boarder relationships are normally long term and the same can be said of the nurse / family relationship. So, their visit every two weeks becomes somewhat like the visit of another family member. (Nurse video, re Guido: 2:45 min)

During their visits, nurses deliver prescribed medication and make sure everything is going well. Of course, sometimes things are not “going well.” In situations where a boarder becomes agitated or aggressive, the immediate concern is to stabilize the situation, and it’s normal for the family to attempt, on their own, to calm the patient. Since many families have had boarders for multiple generations, their efforts are usually successful. But, if the problem persists, they can call their district nurse or the hospital.

The hospital is a modern facility with a staff of psychologists, psychiatrists, and other medical professionals. About 75% of the 120 bed central hospital is occupied by chronic psychiatric patients who need care beyond what a host family can give. It can also be used for boarders with temporary physical problems or acute psychiatric problems. Sometimes a problem does require hospitalization of a boarder for a short period. This type of temporary hospitalization is not INTENDED as a “punishment.” But, it is such a drastic change from what they experience in their foster family home, that it does sometimes appear to successfully serve the purpose of “time out” for unacceptable behavior and patients are eager to return to the freedom of their foster home.

Though patients with known alcohol problems are screened from becoming boarders, pub life is an

important part of community social life and boarders are not, as a rule, kept out of pubs. This doesn't cause any unusual problems and, in part, it has to do with the fact that, to a large degree the entire town of Geel serves as a "foster community." But, if an incident does occur in a pub and it's believed that alcohol contributed to the problem, the boarder may be banned from frequenting the pub where the incident occurred. Also, any pub that encourages, or allows, boarders to drink too much can be declared off-limits for boarders and this would present a financial loss to the pub.

In addition to offering social life for the boarders, Geel still offers opportunities for meaningful work. Many boarders live with families who have farms or small family businesses and these boarders are able to work with or for the family .(SLIDE 28) A family that I visited on my first trip to Geel operated a farm supply store and there were two male boarders in this home. One of these men had lived in the childhood home of the woman of the house. He had moved in with her and her husband when they married. The woman now had grown male children who helped run the business but her husband had passed away and these two men were an important part of the business.

(SLIDE 29) Even if the boarders don't have jobs, they're all busy during the day. About half of them regularly use OPZ activity centers. They can ride their bikes to the centers or there's a bus that will pick up and deliver boarders. Here they can do paid piece work or engage in activities such as gardening, printing, woodworking, or even sports. The OPZ also arranges day trips and even group vacation travel.

Clearly the Geel system did not become extinct in 1980 as Leo Srole had feared and it's quite probable that the Geel Research Project indirectly influenced 1991 acquisition of autonomous status.

(SLIDE 30) Also, the spirit of the project itself revisited the town in 1997 when Jan Schrijvers, who left the Colony in the mid-70s, returned as the new OPZ Director, 20 years after the GRP ended.

As a native Geelian his primary hope was that the foster family system should not end. Dr. Schrijvers knew all too well that Geel copes with the problem of mental illness in the context of old and new:

(SLIDE 31) old and new buildings, and a mingling of old and new services, attitudes, and approaches. His goal was to bring the old and the new into harmony and improved communication was his theme.

To encourage communication between Geel and the rest of the world, Dr. Schrijvers planned another international conference in conjunction with Geel's year 2000 St. Dymphna celebration. This meeting was held in a modern Geel conference center and was attended by 279 participants. (SLIDE 32) The 18 speakers included researchers, practitioners, consumers, and family members, and four of the speakers, including myself, were from the United States.

In the OPZ itself Dr. Schrijvers initiated techniques to encourage better communication between foster families and the hospital.(SLIDE 33) Though Schrijvers retired in September 2000, the current Director, Jan van Rensbergen, has continued with the same progressive spirit and goals. (SLIDE 34)

For example, general community involvement is encouraged by announcing OPZ sport and cultural activities and celebrations in the local press. Some of these activities even appear on local TV from time to time.

Initiatives within the OPZ that have been implemented or are in planning stages include:

- 1) an observation house to welcome new boarders,
- 2) restructuring of the hospital into separate units: *rehabilitation, gerontology, adult and youth psychiatric, a somatic unit,*
- 3) more intensive family care and a therapeutic family care unit for children,
- 4) a mental health network in the region to provide needed care for anyone with mental illness (i.e., not just boarders), and
- 5) approximately 20 respite families who will keep a boarder for a limited period of time, a service that was formerly available only by placing a boarder in the hospital.

Though much has changed in Geel over the centuries, what has changed very little, if at all, is the

town attitude about mental illness. There has apparently never been a “fear” of mental illness. Our own Surgeon General’s 1999 report on mental health pointed out that the stigma of mental illness, which most likely includes or leads to fear, stands in the way of proper diagnosis and treatment. But today, in Geel, if a stigma exists at all, it is a “positive stigma.” Since the mentally ill have been a part of town life for so many centuries, they’re welcomed and even nurtured by the ENTIRE community. Social interactions between patients and other community members are casual and common. (BBC store video: 2:16 min)

I recently read speculation that deinstitutionalization may have INcreased social fear of mental illness because of “closer proximity” between those with mental illness and the general public. I’d speculate that the opposite might be true. When large state hospitals were built, the mentally ill were removed from our sight. If we didn’t have personal experience with mental illness, we might only encounter it in the news when someone with mental illness is involved in a violent act. Even in books and movies and TV shows we too often meet a stereotype of mental illness that exaggerates symptoms or strays too far from an accurate picture.

For 700 years Geel has had an entirely different social experience. The citizens of Geel have known, and lived with PEOPLE with mental illness. They have lived with them in their homes and on their streets. And, in Geel there is evidence that adjustment to mental illness – RECOVERY of the individual AND the community – is as important as any other treatment.

(SLIDE 35) We can’t create for ourselves a new history but we CAN encourage new attitudes. If the first step to recovery is HOPE, that’s true for the individual and that is true for communities. When communities hear little but the horror stories of mental illness, they have little hope. With little hope, the community is not motivated to share a meaningful role in ending social isolation for the mentally ill.

I’ve now visited Geel four times and have plans for future visits. But I’ve also started to look for hopeful sites to visit in our own country. I won’t ignore the horror stories BUT I also want to identify



HOPEful stories. (SLIDE 36) Last fall I visited the Way Station in Frederick, Virginia. The building that you see in this picture houses facilities and services that began in a much more modest structure in 1978. The programs that operate in and from this building today clearly generate individual and community hope.

(SLIDE 37) I'm constantly hearing more and more stories of HOPE and I want to visit some of those hopeful communities in the months and years to come. Yesterday I almost visited Dane County services, in Madison, where the PACT model originated. Weather in Cincinnati got in the way of that trip, but I will go in the coming months. I'd like to visit Mark Ragin's Village in California

Thresholds, in Chicago, was begun in 1957 when the National Council of Jewish Women sponsored a social program to help former mental patients transition into the community. Today Thresholds has twenty-two service locations and more than forty housing developments in the Chicagoland area.

(SLIDE 38) I mentioned Compeer earlier. This non-profit agency coordinates friendship matches between community volunteers and individuals who are recovering from mental illness. It began in Rochester, New York, in 1976, and today there are over 100 Compeer agencies in the United States. I'm sorry to say that lack of funding forced us to close our Birmingham agency about a year ago. But, we had some success stories. (SLIDE 39) And, in 2001, we did chip away at the problem of stigma when we initiated a cooperative effort with the local Habitat for Humanity. We were able to obtain full funding of \$45,000 from Forest Laboratories, and workers who built the house were primarily those whose lives were affected by mental illness. This was the first such project of its kind and we were proud to name the project "Habitat Hope House."

The most gratifying aspect of working at the site was to see people working side by side, not caring, and usually not even knowing, who was a consumer and who was a professional. And, though the term "consumer" has become a politically correct term, these consumers expressed joy at being able to also

play a role as workers and providers in their community. (Conpeer video: 2:55 min)

(SLIDE 40) Marc Godemont has described what he believes to be the “secret” of Geel’s success. These factors are certainly present today and, to some degree, they have probably always been present:

- 1) Geel acknowledges and accepts the human needs of boarders
- 2) In ways that I’ve already mentioned, the city responds to those needs rather than acting on unfounded or exaggerated fears (*social clubs, free to frequent downtown pubs, opportunity to do meaningful work*)
- 3) Most importantly, the mentally ill in Geel are members of not just a foster family, but a foster community as well

As I identify hopeful programs, it seems to me that perhaps all of them include some of these same elements. In just a minute I’m going to ask you to examine your own programs – to identify hope-filled elements that you can highlight and share and expand.

(SLIDE 41) Before we do that, however, I want to acknowledge some very important resources. It would be impossible for me to do a presentation such as this without the continued help that I receive from Marc Godemont. He is a compassionate, generous man – to Geel’s mentally ill and to curious students like me.

I’d also like to acknowledge Hobart-William Smith’s library where Leo Srole’s papers are archived. This has been my primary source regarding the Geel Research Project. In addition, I’m also most grateful to Jan Schrijvers who has shared personal anecdotes and has helped me to piece together much of the written GRP material that I’ve examined.

Before we end I want to show you one more video clip, two lovely segments from a recent CBS *60 minutes* piece. (police chief & young girl video: 1:40 min)

We can’t rewrite our past, but we can shape our future. I think that the innocence and natural tolerance of this young girl is a perfect representation of WHY we dare to hope.

Once again, thank you for the opportunity to share with you my passion regarding Geel. You have my contact information as well as a description of some research I hope to do. I need collaborators and I hope that we can continue to dialogue in the months and years to come. I do have hope that community care can CREATE caring communities, and I thank all of you who have dedicated your lives to that purpose.