Alzheimer's Family Care Center
Chicago, IL

Theme
Do not disturb.

What this case study shows:

· The advantages and disadvantages of a highly-segmented approach to dementia day care.
· The implications for the physical setting of a program that emphasizes modulating environmental stimuli to match the needs of different participant groups.

Place Profile

Director
Jane Stansell

Site/context
The remodeled commercial building is situated on the east side of a busy thoroughfare in Chicago, which is lined primarily with commercial shops and offices. To the north and east of the Alzheimer's Family Care Center (AFCC) is a residential neighborhood consisting of two-story frame houses, a large Catholic church and a school.

Facility type
Adaptive reuse of a commercial building

Building size
Day care alone: 9,000
Building total: 11,500 square feet

Estimated cost of renovation
$600,000

Architect/designer
Eckenhoff Saunders, Chicago, IL

Program

Mission and goals

According to Director Stansell, the mission of the AFCC is "managing many of the complications of dementia, improving the quality of life of the person with the illness and lightening the families' burdens. The Alzheimer's Family Care Center assists its participants and their families throughout the course of the disease in dealing with the intellectual decline and increasing dependency that characterizes the disease."
General description

AFCC is a not-for-profit organization under the direction of a general sponsoring authority, Rush Presbyterian-St. Luke's Medical Center. The organization provides day care services to a daily average of 55 older adults experiencing varying types and levels of cognitive impairment. Key to the day care programming at AFCC is the concept of participant groups: participants are segregated by interest and abilities and assigned to specialized units, i.e. the music room group, the hobby shop group, the parlor group, and the recreation group. This ability and interest-based approach toward adult day center was developed over time by AFCC.

Established in 1987, AFCC originally provided adult day care services in a large single room located within the Irish American Center in Chicago. Soon after, staff perceived that this single undifferentiated area seemed to exacerbate difficulties in caring for the cognitively impaired, a consequence of the diversity and heterogeneity of dementia sufferers.

Two years later, AFCC moved to a residential home where they initiated the policy of dividing the population into three participant groups on the basis of a subjective assessment of attention span, and then caring for these groups in different areas within the home. Eventually, these groups would come to be recast in terms of exhibited strengths and weaknesses. After two years in this residential location, the organization determined that the environment was restricting their ability to establish the intended therapeutic setting. Three primary shortcomings were identified: accessibility problems resulting from serving one participant group in the basement of the house; having only one toilet; and an administrative sense that participants could well be divided into more than three ability groups. Given their unique programming approach and experience with adult day care, AFCC initiated planning and development for the new facility.

Today in their newest facility, AFCC's program has settled on seven spaces used by four explicit participant groups. The music room group--made up of the most functionally able participants--typically consists of 20 participants attended by one staff member. Their activities take place in four different rooms: the dining room, the living room, the den and the music room. Three other groups of lower and varied functional abilities--the hobby shop group, the parlor group, and the recreation room group--stay throughout the day in the room for which they are named.

The participants of AFCC's largest participant subset, the music room group, can communicate effectively, perform activities of daily living (ADLs) with minimal verbal and visual cues, and engage in "hands on" activities. Hobby shop group participants can communicate verbally and/or non-verbally and perform a variety of "hands on" tasks, but require some cueing for ADLs as well as structure and reassurance to cope with their high levels of anxiety. Parlor participants have the same skill level as those in the hobby shop, but are more sensitive to overstimulation and require greater assistance with ADLs. The parlor is intended to provide a calm, quiet, slow-paced environment with modulated sensory stimulation and activities that highlight gross motor movements. Recreation room participants typically communicate non-verbally, are physically active and interested in exploring and interacting with the environment, and require assistance with all ADLs.

AFCC provides services to its participants and their families from 7:00 a.m. to 5:30 p.m. Monday through Friday. Services at AFCC are provided based on participant needs and in accordance with
financial and staffing constraints. No counseling, clinical services or physical/speech/occupational therapies are provided. Services offered include:

- A light breakfast (i.e. toaster pancakes or pastries)
- A hot noontime meal
- Afternoon snack
- Activities (i.e. bingo, crafts, music);
- Personal care (i.e. toileting, medication);
- Care planning, and
- A family support group

These daily activities are carried out independently within each participant group, with each group following different care and activity plans depending upon participant abilities. This approach to programming results in several activities being simultaneously conducted throughout the day; however, given that participants are assigned to particular groups and settings, there is little sampling by participants of the different activities that are taking place. AFCC’s day rate is $45.

Staffing

AFCC has 17 employees, all whom have some degree of direct contact with participants and provision of services. Three people make up the organization’s administration: the program director, clinical coordinator and financial coordinator. Providing guidance to AFCC administration is a 10-member advisory committee comprised of professionals in aging and clinical practice. The staff takes turns developing the activity programming and giving staff assignments on a round-robin basis. In effect, this allows for planning and administrating responsibilities to be shared among all staff members. Weekly staff meetings are scheduled to review care plans, scheduling issues and the like. AFCC has been successful in supplementing staff with volunteer support, typically receiving an average of 10 total volunteer hours per week.

Participant Profile

AFCC has an enrollment of 94 participants and an average daily census of 55. Its service area stretches from the southside of Chicago into Southern Wisconsin. Geo-economic profiles range from Northwest Chicago blue-collar to Northern suburban professionals. Participants range from 38 to 97 years old, with an average age of 80. Approximately 75 percent of the participants are white, 14 percent are African American. One-third of participants are Medicaid-eligible. All participants of AFCC are cognitively impaired, with an average MMSE score of eight (maximum = 30). Eight percent of participants use wheelchairs, and 60 percent are incontinent.

Institute Have families mentioned a willingness to be involved in activities?

ADC Yes, but we discourage it because families need a break. I know there are places and there are programs where families are involved almost on a daily basis, and that’s a good thing in some ways depending on how it’s done. I’ve also seen (places) where families are used almost as staff. What we prefer to see people do is volunteer somewhere else, to have a change in focus. You don’t need to be living Alzheimer caregiving 24 hours a day.
AFCC's building is a square, single story structure with masonry bearing walls and a steel truss roof. The exterior is primarily brick and concrete block and features a continuous mullion window system with painted metal frames. The facility's entrance consists of a single door with glazed sidelights. In addition to this door, there are two others through which one must pass to reach the main corridor of the facility. The third door utilizes one of the City of Chicago's approved exit alarms--the door does not open for 19 seconds.

The interior layout of AFCC is organized around a convoluted "figure-eight" type corridor scheme that connects the program spaces. Once inside, one sees two long, undifferentiated corridors. To the right is the receptionist's office where staff on "door duty" await visitors and arriving/departing participants. The intersection of these two corridors is often congested, with participants waiting in the nearby chairs, staff waiting to assist participants, and others checking their mailboxes or retrieving office supplies.

Ceilings throughout the facility are dropped acoustical tile with fluorescent light fixtures. Interior partitions consist of either painted concrete block bearing walls or painted gypsum board. Floors throughout the participant spaces are glossy vinyl tile. Each participant space has a single entry door with a window-like vision panel, although the window is typically shuttered by a corridor-side blind.
There are a total of eight participant areas in the facility; the four participant groups regularly use seven. These areas comprise the living room, dining room, music room, recreation room, parlor, hobby shop, den and sun room.

The living room and den are essentially duplicates of each other, and furnished with approximately 20 chairs lining the perimeter of each space. These rooms are typically used for discussion groups, exercise and word games.

The music room and dining room are mirror images, both furnished with round tables and chairs arranged around them. The music room is used for breakfast and lunch as well as for bingo in the late afternoon, while the dining room is primarily used for crafts.

The recreation room is an internal room with no visual access to the outside. The door into the room remains closed at all times. This room is the largest space in the facility (approximately 800 square feet) but serves the fewest participants, with an average daily census of six. There are various pieces of furniture in the room (i.e., tables, piano, and desk) as well as a custom cabinet that serves as a staff workstation. The walls have little decoration.

The parlor is designed as the "low stimulation room." There is a small window that looks out into the courtyard of the facility, but the window blind remains closed. Many items are displayed in the parlor: games and magazines on shelves by the window; purses and scarves on the pegboard; and laundry baskets of craft materials piled against a wall.

The hobby shop is the one room that provides setting options for participants. Available for participant use are office-type cubicles, three round tables and a five-chair discussion area set up in a corner. Many items are out for participants to touch and use: craft material along shelves; old cameras and electronics; and books and magazines. This room has east-facing windows fitted with blinds. This is the one room in the facility that requires daily intervention to maintain thermal comfort, i.e. window ventilation and blinds to regulate sunlight.
Coming and going

Arrivals begin around 7:00 a.m. with most occurring between 8:30 and 10:00. Upon arriving, participant coats and hats are removed by staff in the corridor; the arrival of several participants creates a bottleneck in the hall space directly in front of the entry as participants wait for others to be assisted. This bottleneck is exacerbated as other vehicles pull up to unload participants. In an effort to alleviate the crowding, participants may wait up to 20 minutes in the van while others are taken into the facility one by one. This sort of delay happens even more frequently during departures.

Many participants were observed as unable to find their way from the entrance to their assigned rooms, so staff lead them through the internal corridors to the appropriate area.

Institute

Do you think the lack of outside visual access from the corridor impedes participants' abilities to find their way around?

ADC

No, certainly not. Why? If you don't know where you are and you don't know how to get home and you know that you've got to get there, what is your prime concern? Getting home. Now if every room had visual access to the outside, that would just increase that anxiety.

Depending upon the length of their van trip, participants may also request a bathroom stop en route to their assigned room. Once in their assigned room, participants are greeted and offered coffee. From van to cup of coffee, the arrival sequence can take a half-hour or more to complete.

Departures begin around 3:00 p.m. and continue until 5:30, with most participants gone by 4:30. Those that wait until 5:30 usually are engaged in bingo, but seem to be preoccupied with leaving. The front-entry bottlenecking experienced in the morning is repeated, often exacerbated by wanderers who congregate by the front door.

The sequence of departure is initiated by a van driver or family member coming to the front door and requesting their riders. Front staff intercoms appropriate room staff to call for the participant(s). Each time this call comes into a room, nearly all participants were heard wondering aloud whether the call related to them. Participants were often observed trying to follow those departing, prompting staff intervention.
Because van arrival is somewhat informal, it is difficult for staff to assemble van-mates ahead of time. Collecting and dressing other participants for departure often entails long waits for those who are readied first. Coincidentally, departure marks an occasion for toileting most participants. Often this delays the departure process as well.

**Primary program spaces**

In their facility development process, the staff of AFCC devoted a great deal of effort to space planning and room names. The notion that places have meaning was recognized and they endeavored to capitalize on that idea for the therapeutic enrichment of the new facility. Current literature in the field of architectural design for dementia advocates residential flavor, thus the room names at AFCC are associated with "home." There is a living room, dining room, music room and den. These spaces are used by the most able. The hobby shop is for those who need an outlet for their energy. The parlor is reserved for those who require a quieter place, and the recreation room is for the most physically active. While the link between place names and the environmental qualities AFCC desired to instill in these spaces is creative, the "follow-through" in terms of architectural and interior design is less effective. Few of the spaces look, or more importantly, "feel" like their place names and therefore don't achieve the desired qualities.

As mentioned in the general description of the program, AFCC's program strategy dictates different activities for each space and participant group. For all participant groups, the first formal activity of the day begins around 10:00 a.m., and there is a general mix of cognitive and physical activities through the day. The final activity of the day, bingo, is scheduled for those "late-staying" participants from all four groups who are gathered together in the music room.

The group with the most intact level of skills, the music room group, uses four rooms throughout the day—the music room, the dining room, the living room and den. Typically, the music room is the most-utilized space for this participant group, with the living room used somewhat less and the other two rooms rather sporadically. The music room is the place for meals and snacks, bingo at the end of the day, and the occasional discussion group. The living room is used for cognitive activities and social groups. The den hosts some discussions and is also the site for evening family group sessions. Inconsistent with its name, the dining room is used primarily for craft activities.

As a rule, the three less functionally able participant groups spend their entire days in the rooms for which they are named. In the hobby shop, there are three distinct sub-settings: three round tables for focused activity (puzzles, eating); a sitting corner for socializing and exercise; and two carrels and a desk for individual activities. Notably, this participant group exhibits the most initiation, although they are characterized as having the highest level of anxiety.
Interestingly, the center's clinical coordinator considers the hobby shop room as having the greatest correspondence between space and participant group ability.

The parlor is the designated space for individuals deemed sensitive to overstimulation and who require greater assistance with ADLs. This census is kept quite low (typically six to eight) and not much activity occurs in this room. Sometimes a card game or a board game will be played, but the pace of life in this room is quite slow. Due to the low level of stimulation, any entry to or exit from the space attracts the attention of participants.

The recreation room houses the non-verbal, physically-active participants. Despite it being the facility's largest room, the census is kept to a handful of participants in an effort to provide adequate room for physical activity. This room provides no outside visual access. "Stations," for example, a piano, desk, washing machine, bookcase, line the perimeter of the wall to engage participants. Researcher observations suggest this participant group exhibited the greatest amount of agitation and physically abusive behavior.

**Kitchen and kitchen work**

The kitchen at AFCC is used almost exclusively by staff for the purpose of preparing lunch for 50-75 people. There is little of the ambience of a home kitchen and staff usually discourage participants from entering the kitchen.

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**Institute**

You mentioned that activities generally need to be initiated, but among the more competent group, are there people who express their willingness to do something in the kitchen or use the kitchen?

**ADC**

Sometimes. Do we have cooking activities? Yes. Do we do all of those in the kitchen? No. Why not? 'Cause there "ain't" room. You can't have a group of 15
people or 10 people in the kitchen that's not big enough, so we have cooking activities that don't occur in the kitchen. There are folks who would like to help in the kitchen that we discourage from doing that because they are diabetics and they would eat everything in sight that is not tacked down...their families don't let them help fix dinner at home either.

Dining

With the exception of the music room group, participants eat lunch in their respective program rooms. For music room participants, the routine is natural: they proceed from their activity in the den to find tables set and their salads awaiting them. Participants are seated and beverage orders are taken.

The lunchtime experience in the other rooms is quite different. Often a program activity will be interrupted by the arrival of the food cart, at which point participants are asked to relocate as tables are cleared and set for dining. At other times, participants sit and wait at the tables for extended periods of time as food arrival times can be variable.

Bathing

At AFCC, each participant's personal care is attended to individually depending on abilities. Some individuals are toileted every two hours with prompting and assistance by staff; others are completely independent. Personal care activities like hand-lotioning and nail care are here conceptualized as therapeutic activities. Care planning occurs in weekly staff meetings where individualized care plans are reviewed.

Although AFCC's facility has two showers (no bathing tubs), officially, the organization does not provide bathing services. A shower original to the building is located adjacent to the sun room, a space that is not utilized by the program. During remodeling, a second shower was installed in the handicapped-accessible toilet room. However, because of the frequency of the use of the handicapped toilet, use of this shower is negligible.

**ADC**

We have two showers in the building, but the one is very difficult to use because of the arrangement of it. It was there when we moved in and we left it. We've used it a couple of times, but it's very difficult to use. The one that we built is very easy to use, but it ties up the bathroom too much. I wish we had another of those...

**Institute**

Have families expressed a desire to have bathing service?
I think for a number of people that would be a helpful service. That's a real mistake we made when we renovated this building. We put the shower and the handicapped bathroom in one room, and we probably should have done two rooms, because it takes us a half-hour or forty-five minutes to an hour to give someone a shower. We thought when we were putting in this shower that we were going to start offering that service. We were too dumb to realize that it would tie the bathroom up too much and we need that bathroom on this side of the building. So we don't offer it because it would tie the bathroom up too much. We shower people when there's a need, but it's not an ongoing service. If I had been smarter and brighter when we renovated I would have put in a shower in a room separate from the handicapped toilet.

Toileting

AFCC has four toilet rooms and a total of nine fixtures. Two toilet rooms contain one fixture, one of which is handicapped-accessible. Two additional rooms have ganged stalls. These toilet rooms remain in their original state (pre-AFCR remodel). As they are of standard size, the toilet stalls allow little room for movement, and the ganged toilets have become awkward as the population has increased its need over time for assistance with toileting. In addition, the location of the toilets in relation to the program rooms has proven problematic: Many participants require assistance in being lead to the toilet rooms.

(If I could) I would have at least two handicap accessible bathrooms instead of one. One that's large enough for two person assists. Lately we've had a lot of two person assists. In fact in January we had three participants needed three people to toilet, two people to assist in the transfer and one to clean their bottom because you couldn't do that while you're holding them during the transfer. So I would have two bathrooms. If I could have done this anyway I wanted, I think that in some rooms I would have the bathroom in the activity room, particularly for the parlor and the rec room....

Are there difficulties for participants in finding the restrooms?

Oh sure, absolutely, no question about it. Even if we had signs everywhere, there would still be problems. People have difficulty finding the bathroom at home when it's next to the bedroom and they've lived there for 30 years. I firmly believe that wayfinding is a real issue in terms of the bathroom, and I think that not being able to find the bathroom is a real cause of incontinence in some people. Short of having bathrooms open so that everybody can see in there at all times, I really don't know what the answers are. When we have the sun room open (there is a bathroom in the sun room), you can leave the door open and people can see it. That doesn't mean that they can connect that it's a bathroom though.
Wandering and Elopement

At AFCC, wandering takes place in the facility's main corridor. The layout of the corridor is confusing and difficult to discern for even competent individuals. There are no memorable orienting devices or landmarks along this corridor. The only marker on the wandering loop is the front door, which is, unfortunately, a feature that typically increases agitation and cues elopement desires. Together, the general lack of stimulation along the corridor and the attraction of the front door confound pacing behavior.

A long view of the corridor.

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