

Fokus Housing in Holland

The Fokus housing programme in Holland represents a massive and long-term commitment on the part of the Dutch government to the provision of serviced housing for severely disabled people. Based directly on the Swedish model, there are ten schemes already in operation, and 25 more under construction, or being planned. The programme envisages the development of 35 schemes, with at least one in each of the major towns in Holland. In this article, Selwyn Goldsmith reports on a visit he made to Holland in June 1982, when he visited two of the completed schemes and talked with people engaged on the implementation of the programme.

I am—as is everyone whose work is concerned with housing provision for severely disabled people—an admirer of Sven-Olof Brattgard. It was his vision and determination which brought to realisation in Sweden in the early 1970s the remarkable programme of serviced housing schemes for disabled people, which has been the model which advocates for disabled people in other countries have in recent years been striving to emulate. While I am an admirer, I have never been an ardent follower, and in an article *Fokus Revisited* in DSN 27 I expressed the view that in Sweden the reality has not matched the expectations. I suggested that, on the evidence of Swedish practice, there was a latent tendency for tenants in Fokus housing to become institutionalised, and to be more dependent on care services than they might be if they were living more autonomously in serviced housing scattered in the community.

An English observer who comments on the Fokus programme is vulnerable to the charge that his criticisms are a rationalisation of excuses, in that, on account of administrative obstacles, the implementation in Britain of the Fokus ideal has never happened. The most ambitious venture—the Spastics Society scheme at Neath Hill—was compromised because bureaucratic controls meant that the disabled clients must have their housing and care services managed as Part III provision (as for residential institutions) rather than being tenants with an entitlement to manage their own affairs. The essential Fokus precept, that handicapped people should be able, as consumers, to coordinate their own care and service provision, was not realisable.

Thus it has happened that the advocates of Fokus in England have seen their aspirations blighted and, interestingly, their difficulties have been paralleled in Sweden, where Fokus effectively died in 1974 when local authorities took over the management

of schemes from the founding charitable organisation. For the proponents of Fokus in Holland, there could reasonably have been the expectation, given an equally inhibiting administrative structure, that there would also be failure. But in Holland there was Mr Evert van der Horst, a staunch disciple of Professor Brattgard, who was determined that there would be success: that there has been, and that the actuality is so entirely in accord with the Brattgard ideals, is his personal and great achievement.

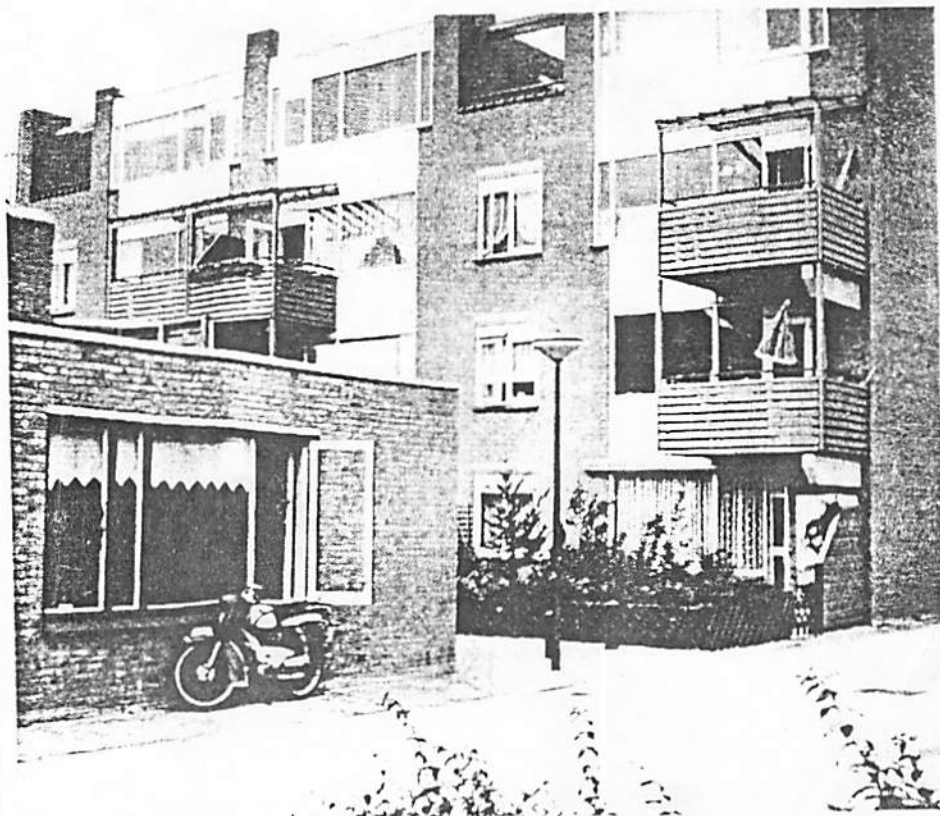
At a meeting in Luxembourg in June 1981 I spoke about the shift of orientation there has been in England in recent years, whereby the emphasis is now on support for severely disabled people living in ordinary housing in the community, rather than on the promotion of special complexes on the Fokus pattern. I noted, in the context of the difficulties that have been experienced finding tenants for special wheelchair hous-

ing schemes, the understandable inclination of many disabled people not to move from their existing homes or localities, and the desirability of developing programmes of house adaptations alongside flexible care services. Mr van der Horst expressed surprise that the English disabled should be reluctant to move to purpose-designed environments, and invited me to visit his Fokus schemes in Holland. My visit 12 months later was arranged with Mr Wiersma, his successor as director of Dutch Fokus. Mr van der Horst himself having moved across the world to take Fokus to Canada. At the time of my visit the six schemes already in operation were at Almere, Alkmaar, Emmeloord, Nijmegen, Oss and Groningen; of these I arranged meetings at Emmeloord and Nijmegen, and called briefly at Almere to take photographs. Before describing these visits, a brief account is called for of the structure of services in Holland and the evolution of Fokus.

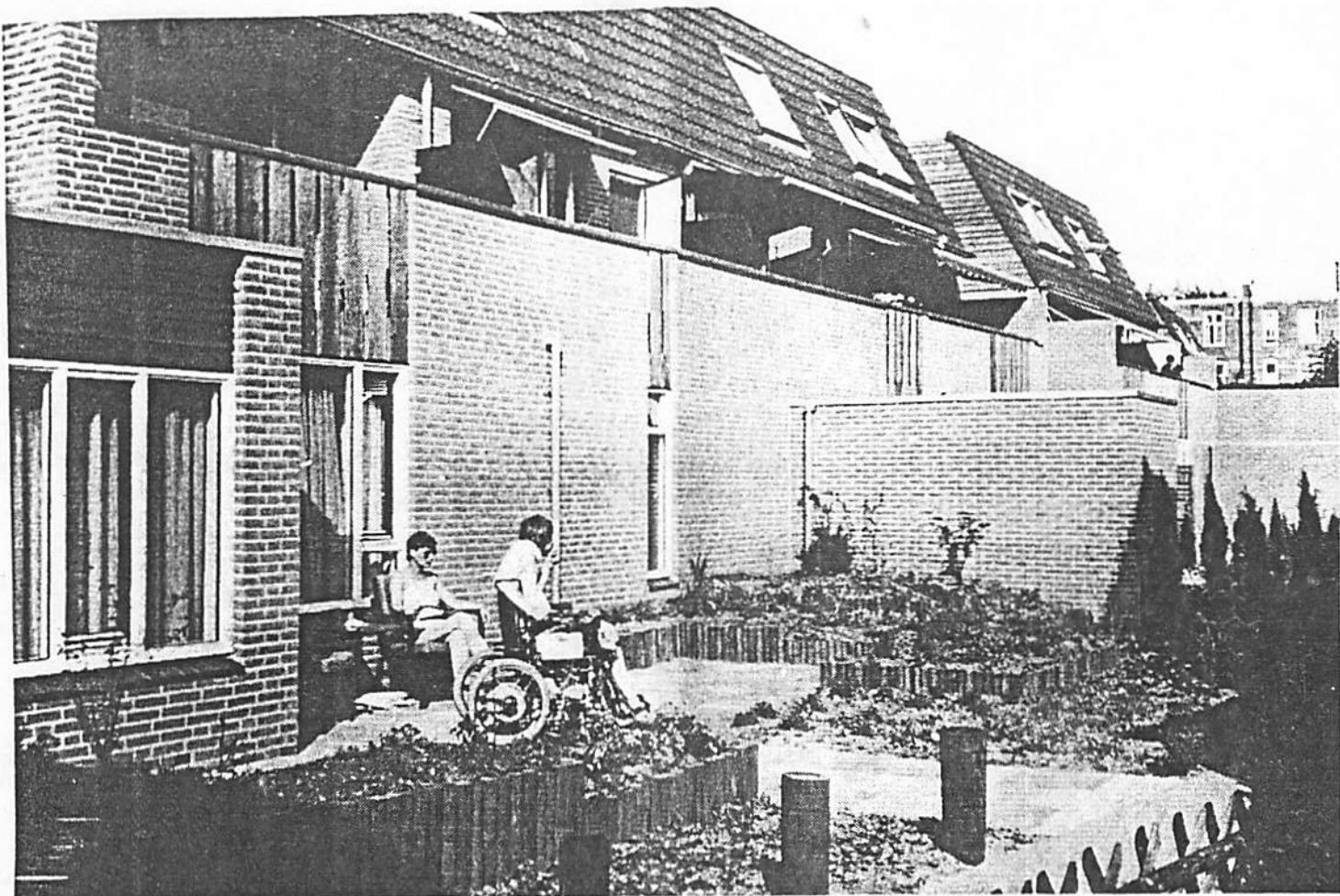
The Structure of Housing Services

Public sector housing is, under Dutch legislation, the responsibility of local authorities (municipalities), with funding from the Ministry of Housing, the implementation of housing programmes being effected by "recognised housing associations" on behalf of the municipalities and the ministry. The ministry maintains strict space and amenity standards, with additional cost allowances for special housing for disabled people. Rents are determined primarily on a criterion of floor space; there is, however, little incentive to housing associations to incorporate special housing in their schemes, since dwellings may be difficult to let if there are no prospective disabled tenants.

House building in Holland is thus geared to serve common needs, and does not have the flexibility to cater for special



Right: Almere – Fokus units are at ground floor level. Detached common room in the foreground



individual needs. In this respect, the Ministry of Housing deals with its consumer clients in a quite opposite fashion from the Ministry for Social Affairs, which is concerned exclusively with the delivery of services to individuals. It is in large part on account of the differing administrative style that effective coordination between the two ministries is hindered.

The Joint Medical Services

The liaison point, under the direction of the Ministry for Social Affairs, is the Joint Medical Services, an organisation which is responsible for arranging the provision of services (including house adaptations) for individual disabled people on the basis of medical need. The JMS is financed by a Social Fund, on whose board there is consumer representation. On individual housing needs, the JMS is formally adviser to the Ministry of Housing, who deal with cases through their regional office organisation, and cover approved costs. The service is necessarily administered in a pragmatic fashion; there is, in effect, an open-ended commitment on the part of the government, and in recent years the expenditure on house adaptations has escalated.

Aside from the public expenditure control problem, a historical shortcoming of the system has been that it was not—owing to the individual-client service of the Ministry of Social Affairs—practicable to set up grouped housing schemes for disabled people with care services shared among clients. It was against this background that in 1974 Mr van der Horst opened discussions with government officials about the

establishment of a Fokus housing programme in Holland. On their side the government officials appreciated that the system was not as flexible as desirably it might be, and were sympathetic to the Fokus cause. The plan was for there to be clusters of Fokus units in integrated new-build housing schemes in principal towns throughout Holland. Housing associations would fund the construction of these schemes in the normal fashion, covering the cost of the Fokus units and the related communal provision. The understanding was that the Joint Medical Services would vet applications from disabled people for tenancies, and would regulate the care services; at this early planning stage it was not determined how the 24-hour care (known in Fokus as Activities for Daily Living care) would relate to orthodox home help and domiciliary living care.

The Evolution of Fokus

During the early years Fokus had no organisational apparatus; it was simply Mr van der Horst working on his own account from Groningen, assisted by volunteers. The breakthrough came only in 1979, when a television fund-raising programme raised 3m guilders (about £700,000), which meant that staff could be employed on the housing programme, and could also, on the American model of Centres for Independent Living, become engaged on employment, transport and recreation issues. With its secure establishment the Fokus organisation was able to influence the development and administration of the housing programme. The original plan had been that some means

Above: The Fokus scheme at Nijmegen – common room at left

could be found for the JMS to administer the ADL service; their machinery was however geared to provide individual servicing only, and it emerged that the choice would be between having a Fokus-managed service or none at all. The Ministry of Social Affairs was understandably reluctant to abdicate control of the service it had agreed to fund, and negotiations were protracted. The first Fokus scheme at Almere opened in December 1979, and for the first two years Fokus paid the ADL workers in the initial schemes from its television fund.

There had been discussions between the Fokus organisation and government officials from 1974, but it was not until October 1979, in response to a parliamentary motion put forward by the "special committee on the handicapped" that the government formally confirmed that it would cooperate with the development of the Fokus programme. In February 1981 the coordinating minister proposed to the special committee that there should be five experimental Fokus clusters, and that the go-ahead for further schemes would depend on the evaluation of the prototype five. The Fokus organisation felt this to be unrealistic and in May 1981 the Assistant-Minister for Housing committed the government to the possible development of 35 schemes. On the care side the Ministry of Social Affairs also conceded and since April 1982 has

been indirectly funding Fokus for the cost of their ADL service.

It had been part of the original plan that tenancy allocations would somehow be the responsibility of the JMS, but they did not have the administrative organisation or resources to perform this role, and the convenient solution was for Fokus to take over. The next issue was the relationship between the ADL service and the statutory agency care services. The Fokus organisation understandably argued that the tenants should have the same entitlement as handicapped people elsewhere to the routine domiciliary services; it was not, they said, the business or role of ADL workers to provide a nursing service or perform as home helps. So parallel servicing was agreed, with the not unexpected consequence that demarcation lines are blurred.

The outcome of these extended negotiations between the Fokus organisation and the Dutch government is that the organisation has a commitment from the Ministry of Housing to fund a continuing and substantial programme of new Fokus housing, it controls the allocation of tenancies, and it controls the administration of the ADL care service, with its clients maintaining their entitlement to statutory domiciliary services. The Dutch government, on the other hand, finds itself with an obligation to finance the programme indefinitely on terms set by the organisation, without it seems any effective safeguards on how the public funds which it dispenses are used, and without any means of checking that the Fokus organisation is managed professionally or serves the best interests of its clients.

Emmeloord

It was only in the course of the various meetings that I had during the four days that I spent in Holland that this background chronicle emerged. When on the Tuesday morning I arrived at the housing scheme at Emmeloord to talk with people from the Fokus organisation, it was without the preconceptions there would have been had I already been acquainted with the history.

The Emmeloord scheme is an attractive four-storey deck-access block of flats, incorporating 15 Fokus units. On the ground floor is a common room for the disabled tenants, with alongside a laundry and a special bathroom. The 15 disabled tenants

are supported by ten care attendants, two of whom do the managing, one for the housekeeping and the other the personnel.

I was met by Geurt Heykamp and Machteld Blom. Mr Heykamp is a tetraplegic who lives in the Fokus scheme at Groningen, and works for the Fokus organisation, from its office outside Groningen, on the promotion of new schemes, the selection of disabled tenants and the training of ADL attendants. Ms Blom is the editor of the Fokus magazine *Brandpunt*, which in English means focus. Mr Wiersma had hoped to join us but was not able to do so; he arranged instead to meet me at Nijmegen two days later.

The conversation was lively, provocative and informative, but from the start it was apparent that there was a discrepancy between their ethical stance and mine. Their philosophy, and the role they perceived for Fokus in the furtherance of it, was straightforward: able-bodied people could do whatever they wanted for themselves, and disabled people as consumers should have the same right. To enable them to exercise this right, ADL attendants were paid to do whatever the disabled clients wanted of them. There should not be any occasion for tenants to feel grateful for what was done for them by their attendants, and tenants should not be expected to say "thank you". This basic principle of "rights" was, they agreed, drawn from the American CIL position rather than Swedish Fokus. It was not, in the circumstances, profitable for me to put forward the view that the "rights" of the able-bodied are constrained by social relationships, economic conditions and the formal and informal laws by which societies govern themselves; that for social relationship to flourish in the able-bodied world there needs to be mutual understandings, compromises and accommodations; that for everyone in the able-bodied world there are duties and responsibilities as well as entitlements, and that the concept of "rights" embodied in the American constitution is foreign to western Europe.

Their philosophical position was epitomised by their unwillingness to arrange visits by outsiders to disabled people living in Fokus units. Their view was that for disabled people to submit themselves to questions about disability living would be to endorse the conventional assumption that disabled people are peculiar on account of their disablement, rather than being (as Fokus asserts) consumers like everyone

else. They also emphasised that Fokus flats were private territory, and tenants were not to be imposed upon or treated as a zoo.

I did not argue the issue. Certainly, tenants ought not to be imposed upon against their wishes, but any tenant in his own home has the right not to invite a visitor in. The Fokus organisation, it seemed to me at the time, did not wish their tenants to have this right, and nor did they think it might happen that some of their tenants would actually be very pleased to talk to visitors about how they managed in their homes. They were not inclined to offer tenants the choice, for example by telling them in advance that there was a visitor from England coming to see the housing scheme on Tuesday, and would they be interested to talk with him. (This issue was subsequently commented on by Mr Wiersma, in a helpful letter which he wrote when I sent him the draft of this article; he said "You had the opportunity to visit 15 people in Emmeloord, 12 at Nijmegen, 15 at Almere by going to the front door of the house, to ring and say: 'Hello, I am . . . I am interested . . . etc etc.' In these situations we cannot mediate for an appointment; people (handicapped or not-handicapped) live on their own in the neighbourhood.")

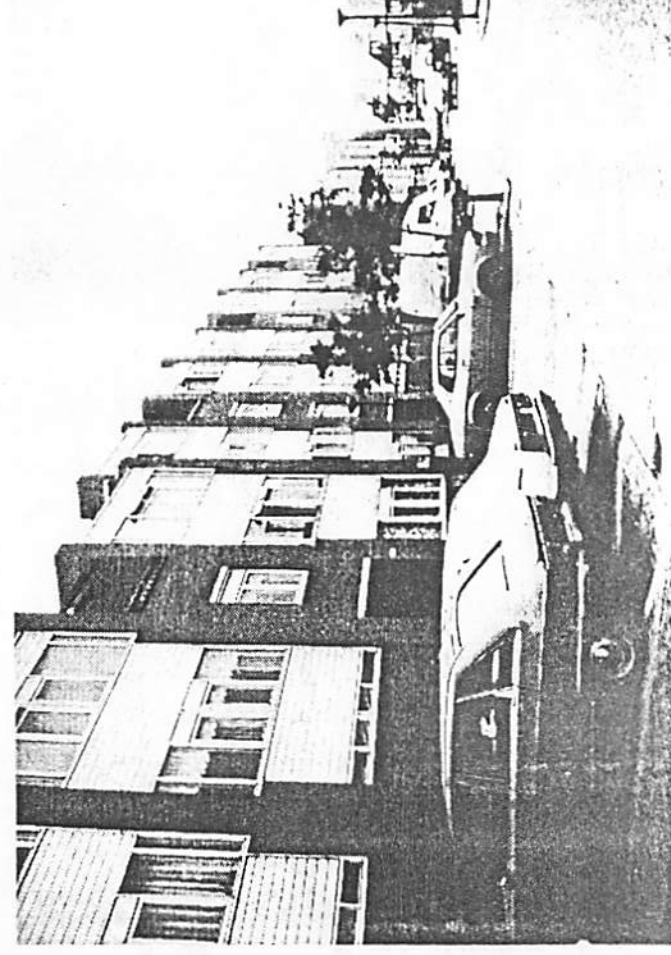
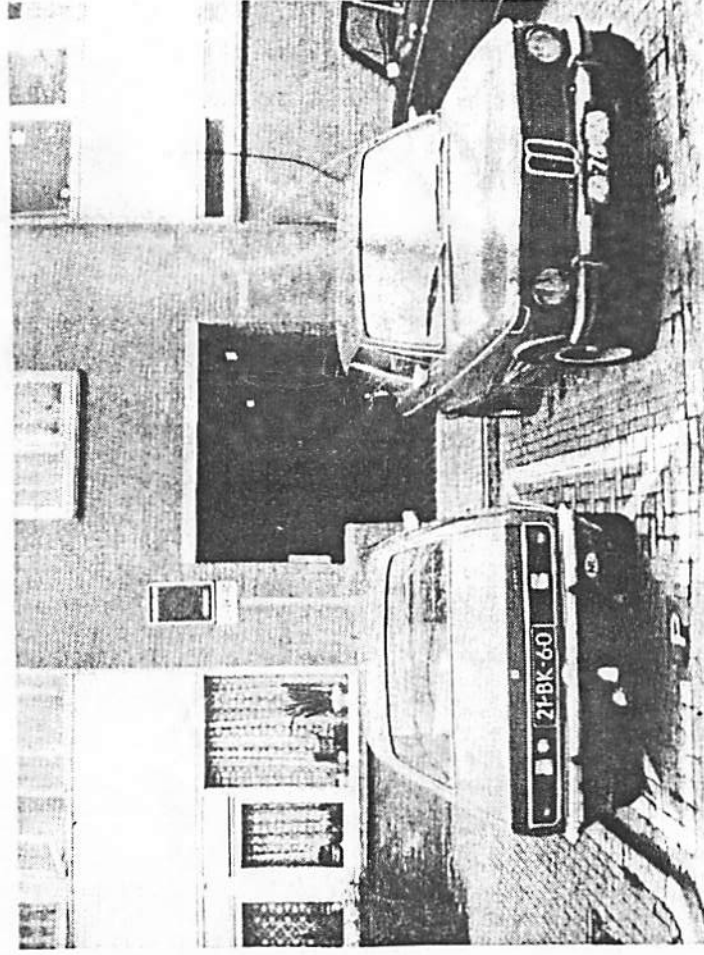
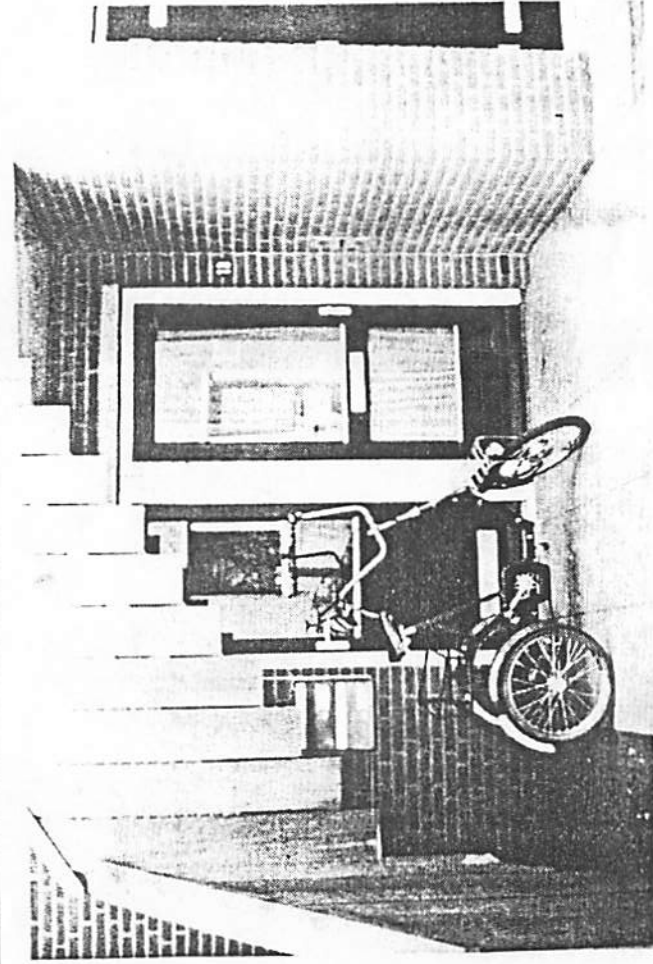
Mr Heykamp and Ms Blom were predictably harsh about institutional living and the lack of choice it entailed; independent living of the Fokus kind afforded a choice. With a colleague, Mr Keykamp made the tenancy allocations for Fokus units; they preferred that prospective tenants should have a firm commitment to independent living, and the motivation to go with it. If there were tenants who had psychological problems or who found independent living emotionally stressful, it was for them to resolve their difficulties. The ADL attendants were there strictly to provide a practical ADL service; it was not their job to provide social support, and social workers—along with home helps, nurses, priests and other experts and professionals who give a general service to the community—were outside the scope of the Fokus organisation.

I queried whether there might be disabled people who, rather than being expected to move to a Fokus housing scheme which could be some distance away, might prefer to continue living in their own local community. For the sake of example, I postulated a disabled person living in the town of Kampen which I had passed through on my way to Emmeloord. The response was that disabled people would be motivated to go to Emmeloord in order to live in Fokus housing; they would not be motivated to live in Kampen. (On this, Mr Wiersma commented "It is possible to start a Fokus project in Kampen! Fokus housing is not an experiment, but normal housing.")

Two days later I visited the Fokus housing scheme at Nijmegen, to be met by Mr Wiersma, who had very kindly driven



Left: Nijmegen – unlike Emmeloord, no carports



over from Groningen to talk with me. Not a disabled person himself, he had studied pharmacy at Groningen, and began working voluntarily with the Fokus organisation. This was in the days before the television programme; like Mr Heykamp and Ms Blom he was now absorbed with putting the Fokus programme into full operation.

Nijmegen

Unlike Emmeloord, where all the flats in the block are accessible for disabled people to visit, the Nijmegen scheme is not "integrated housing". Only the disabled flats are at ground level—other flats on the estate are reached by stairs. The current tendency in Holland, as in Britain, is for new public sector housing to be low rise, without lift provision. Mr Wiersma noted that fire officers were becoming increasingly unwilling to permit lifts to be used as a means of escape, and required always that there must be a second lift for emergency use. (In his letter, Mr Wiersma emphasised that this was a particular problem in localities of old housing such as could be found at Nijmegen; was it realistic, he asked, to fund adaptations to make old housing accessible?)

At Nijmegen the 12 disabled tenants are supported by ten ADL attendants; four of the attendants do a full-time working week of days and evenings, four are part-time and two are night attendants. The tenants are also entitled to home help and nursing services, though in practice only three have home helps. Of the other nine, seven have partners or friends to help, and two are able to manage independently. As at Emmeloord, it was not arranged that I should meet any of the tenants.

Mr Wiersma was able to give me fuller information about the administration of Fokus housing schemes. Since the start in 1974 there has always been a considerable interest in the programme, and there are some 1,200 people on the waiting list for flats; of these, about two thirds are in institutions or expect to go to institutions, the other one third being disabled people living with their families. Mr Wiersma commented in particular on the impact that Fokus has made on Het Dorp, the village for handicapped people at Arnhem, which for 14 years has been the principal resource in Holland for disabled people who want to live independently. Of the 400 people in the village, some 120 have applied for Fokus housing; these tend to be people who have been in the village for ten or 15 years, and would now like to make a change. They are in the main younger people, those who are older preferring to stay in the village.

The Nijmegen scheme opened in December 1981, two years after the first scheme was opened at Almere. The Almere scheme, in the new town on the polder 20 miles out of Amsterdam, attracted exten-

*Top left: Nijmegen – the entrance to a Fokus flat, with open stairs to flat above
Middle left: Almere – the reserved parking space for the Fokus flat alongside
Bottom left: Almere – only the ground floor units are accessible*



sive and continuing media attention, and in the early months it was difficult for the tenants to have a normal life. There were many visitors and the scheme became, as Mr Wiersma said, "a zoo"; in consequence the Fokus organisation does not arrange for the scheme to be visited.

Among tenants coming into Fokus units, two thirds are single people. Couples who are both handicapped are rare; one instance was noted at Emmeloord. A disabled woman with a husband who goes out to work can have a tenancy, on the basis that she needs ADL when the husband is out. Regarding the size of the Fokus schemes, the judgement is that 12 is the minimum number of disabled tenants for economic management, with ten ADL helpers. The maximum should be 15, beyond which additional ADL helpers are needed and the balance becomes less efficient. The rule in respect of new applicants is that they must not need more than 30 hours help in a week. But in practice this rule is not restrictive; the appreciation is that when disabled people move into Fokus schemes they need less help with ADL than they previously did in institutions. Mr Wiersma noted that one tenant at Emmeloord initially said that he needed twenty-four hours help each week, and finds now that he manages with only 14.

For newly appointed ADL attendants there is a two-day introduction course. Affected perhaps by a climate of unemployment, the organisation has never (other than with the first scheme at Almere) had difficulty attracting ADL attendants. At Groningen there were 300 applicants for

the posts, 200 of whom already worked at institutions or had had experience of work with the handicapped. At Emmeloord there were 200, at Utrecht 160 and at Oss there were 150. The range of work done by ADL attendants is determined in part by the duties of home helps; home helps, for example, do essential shopping, and therefore ADL attendants do not. Nor as part of their duties will they take clients out to cinemas etc; such outings have to be done independently, or with friends. The disabled tenant cannot require that he is always helped by the same ADL attendant, and if he needs two people to help him get to bed, the service must be before midnight. Mr Wiersma emphasised that Fokus living was much cheaper than institutional living, where the current cost was of the order of £400 per week for each resident.

I queried whether Activities for Daily Living included sex. The response was that this was for each ADL attendant to decide for herself or himself; if the decision was positive there must be no favouritism or discrimination among clients, meaning that the service must be provided to all who wished it.

Conclusion

The day following my Nijmegen visit I made a short diversion on the way to Amsterdam, to look from the outside at the Fokus scheme in Almere. The housing is part of the new town built on the reclaimed land of the polder and it is understandable that there may not in the new community of Almere have been the same success with

Above: Emmeloord – integrated housing with lift access to upper floors, and carports

social integration that there has in other schemes. (Mr Wiersma commented in his letter that during 1979 and 1980 integration was not achieved at Almere on account of the attitude of social workers; currently Almere is one of the most successful of the Fokus schemes.)

At Almere, the disabled units in the scheme were quite indistinguishable from other housing, and were difficult to find. When they were found, it was to see that they were similar to the units at Nijmegen, with adjoining flats in the housing scheme being inaccessible on account of staircase access. It seems that, unlike the Habinteg housing association which has always insisted that its integrated housing schemes must be planned with all dwellings accessible, the Fokus organisation is not able to make it practicable for their disabled tenants to visit all their neighbours. In terms of the idea of integration which motivated Sven-Olof Brattgard, the failing is regrettable. But it is unfair to Mr van der Horst, Mr Wiersma and their colleagues for there to be a negative note in conclusion; the Dutch Fokus achievement is so colossal that for disabled people in Britain, who have no similar resource available to them, there must be envy of what the Fokus organisation offers to disabled people in Holland, and good wishes for the continuing success and complete implementation of the programme.