

### A shared experience

**Fifty years of peer support for parents of children with intellectual disability.**



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Kew Cottages Parents' Association

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### Peer Support

Family-centred approach

Cost-effective(?)

Parents share experiences

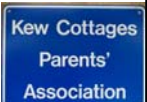
Normalises feelings

Share solutions



Kew Cottages Parents' Association  
THE FIRST FIFTY YEARS  
1957 TO 2007

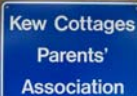
### Kew Cottages



### A shared experience

*"... no plan of work or activity ... asked me to find areas of the greatest need and design my work accordingly. ... The parents of the children were isolated, often ashamed and lonely in their problem. There was no attempt to meet or organise."*

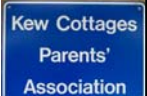
-Irena Higgins  
(December 1997 KCPA newsletter)



### Aims of the KCPA

*Peer support: "...parents needed the sympathy of other parents who had already been through this experience themselves...needed to meet with other parents who had similar problems to their own and who understood them fully..."*


*Educate wider community: "...to promote the interests and acquaint the general public with the problems of the intellectually handicapped and their families and to disseminate factual information."*



### Aims of the KCPA

Advocacy and lobbying: "...because [parents] could not express their needs themselves; they needed parents to come out openly in defence of their rights, just as they would for the child without a handicap."


Liaison with staff: "...feel that the parents cared and appreciated what was being done for their children ..."



### A shared experience

"... nearly all strangers to each other, the relief ... was indescribable. ... all we wanted was to talk ... the worries of parents with newly-admitted children; the need for facilities for diagnosis and research; the necessity for an association of parents to understand the general problems of retarded children, present them to the community and form a continuous pressure group for necessary reforms."


-June Guest,  
(‘The Image of the King’, 1970)



### A shared experience

"...frightened to attend. ... The pain of grief and isolation was overwhelming. ... we all realised how important it was .... We yacked and blew our tops about the conditions ... immense outburst of relief, of pent-up emotion, of finding out that others felt as we did." - Anonymous (cited in Lloyd, 1987)

"We didn't know what we were volunteering to do, ... we knew the reassurance of talking to someone with a shared experience. A way to counter the terrible isolation. The terrible loneliness." - Anonymous (cited in Godwin & Wade, 2007)




### 1. Government and management support

"...unwilling for a parents' association to start ... a group of aggressive busybodies who would criticise the staff ... a vicious circle – the frustration of the parents reacting in their behaviour towards the staff, and the staff reacting against their behaviour ..."

"... viewed with suspicion by the staff and administration, its nuisance value exaggerated, and the positive aspects overlooked... Gradually the attitude of the groups changed."


-Irena Higgins (1960)

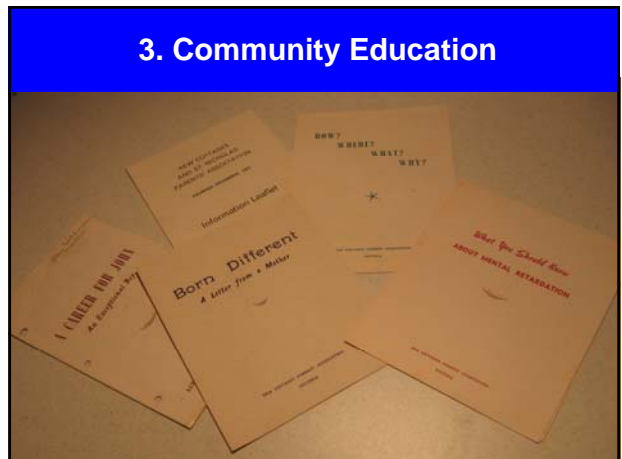


### 2. Fundraising vs lobbying

"Some were already concerned with educating the public - and ourselves - on the facts of mental retardation. Others thought we should immediately begin raising money for the benefit of the children. At times there was heated argument, but one point on which were unanimous was the necessity to improve conditions at the Cottages, either by direct action or by pressure at government level."

-June Epstein (Guest)  
(‘Image of the King’, 1970)





**4. Residents vs waiting list**

*"... we had drawn up a roster of parents willing to visit others in distress - on request, of course - and I had made many such visits. ... We were well aware that one of the most urgent needs of distressed mothers was to talk, and it must be to someone who understood ."*

-June Epstein (Guest)  
(‘Image of the King’, 1970)

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**4. Residents vs waiting list**

*"Parents were just surviving. They were simply not in a position to make representation to government. Their first priority was putting food on the table and caring for their family. This was a very dark time."*

- Parent member of KCPA

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**4. Residents vs waiting list**

*"The Association began in a time when conditions at Kew were deplorable... As conditions began to improve the Association’s horizons began to widen. Concern was felt for all retarded children and due to the notable efforts of a few dedicated parents two new organisations were formed. STAR ... and the Australian Association for the Mentally Retarded."*

- Rob Coutts  
(KCPA Newsletter, October 1974)

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**5. Membership participation**

*"We were up against adversity all the time... ....It has always been a battle to get people involved ."*

- John Cosmas (KCPA President)  
(personal communication, 2007)

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**5. Membership participation**

*"... handful of dedicated people unselfishly giving of their talents and time."*

- Peter Aubin (KCPA Vice-President)  
(KCPA Newsletter, March 1974 )

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**Aims of the KCPA**

Peer support

*"... nearly all strangers ... relief of being able to talk with people who understood ... all we wanted was to talk realistically about our handicapped children and their problems..."*

*"...a place where they could meet and talk and feel comfortable ... misunderstood by most people... At the KCPA, they found very special friends they formed life-long bonds ..."*

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**Aims of the KCPA**

Advocacy, lobbying & Education:

- Formation of advocacy groups
- Contributed to the development of legislation and policy
- Special Olympics
- Network Q (later VATMI)
- Day Programs
- Participation in Coronial Inquest into Kew Cottages Fire
- Information pamphlets and public speaking
- Annual fete

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**Aims of the KCPA**

Liaison with staff

*“From a large, aggressive, and, at first, negativistic group, the Kew Cottages Parents’ Association transformed into a coherent, positive, inspiring body that takes an active part in promoting the welfare of its own children, and in fighting for appropriate services and rights for the intellectually handicapped person in the community. Consequently the group helps the staff and the parents, and this is what it set itself out to do.”*

- Irena Higgins (1960)

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**Challenges for today**

Respond to unmet need

Partnership with families

Community education

Participation of families

Participation of individual in community

and...

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**Challenges for today**

*“... act as a coherent, positive, inspiring body that takes an active part in both promoting the welfare of its own relatives, and fighting for appropriate services and rights for the intellectually disabled people in the community.”*

-Irena Higgins  
(1960)

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**A shared experience**

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

Margaret Mead (1901-1978)

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Association

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