

Extended Families Australia

30 Years



*O*f Magical Moments,
Milestones and Memories



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Sandy, Jean and Thelma with children in St Nicholas' garden.



Mary Simmons



Vi Cox, St Nicholas Hospital 1978.



Marjory Kelly and Michelle, Yooralla 1978



Marion Owen and Greg at Gumnut Cottage, Yooralla 1982



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Elsbeth, Vic and Juliette, Yooralla 1978

Introduction

Extended Families Australia, previously the Foster Grandparents Scheme, is 30 years old. That is a great achievement, especially when you consider the enormous social changes and barriers along the way. There are many ways to reflect on history; we have chosen a few approaches to presenting this special section reflecting on EFA's 30 years. You will find a summary of the milestones that have shaped the organisation's development as well as some of the events and stories about people that are at the heart of EFA. We have also 'given the past a voice' through interviews with volunteers and segments from annual reports, newsletters, media coverage or other reports to jog memories, reflect, inform and at times amuse.

In celebration of our 30 year milestone we also wanted to write a story about EFA. A group of us got together to do this: to write a story about what makes EFA work. We looked for the glue that binds us together; the stuff that makes us special. We realised that in a world that's focused on individuals, money and success, we're a group of people that's concerned about people and relationships. That's pretty special glue!



The EFA Story - Relationships and Connection.

This our relationship story... a story that says who we are and what continues to keep us working together. Relationships are the heart and soul of this organisation. So much of EFA is about the connections that are created. Sometimes we choose the connections and sometimes we fall into them; whichever way it is, it is how we use and value them that makes all the difference.

According to a parent, Michelle, the greatest benefit of being involved with EFA and its volunteers is being reconnected to the community. "You feel as though you are part of something bigger than your own family situation," Michelle said.

At EFA we are concerned with how we connect people – with each other, with the children and families and with their communities. Within that, we focus on the natural or organic connections, the ones that make people stronger. EFA has always actively created links between people and their communities - from the early days when volunteers brought the community into the institutions and the children out into the community, to today when we go into family homes to link up children and families in the community.



Sharing Hopes and Dreams

A lot of families and volunteers tell us about the central role of relationships and how these develop over time. There is such a wide range of relationships and each one is unique. People are growing together, and together they share hopes and dreams and achieve great things.

We hear many stories of giant steps with little feet: of the reward of a child smiling when a volunteer arrives; of a young adult with a disability getting her first job; or perhaps even a 'miracle' such as Hussein, who has cerebral palsy, walking unaided and working out at the gym. Take for instance Rebecca, a lovely young lady with Down Syndrome who wanted to work with children. With the help of her volunteers Rhonda and Graeme, her family and the Glen Allen School, Rebecca obtained a Working with Children Check and became a volunteer at the school alongside Rhonda and Graeme helping the children with outdoor activities.

It's About Being, Not Doing

Sometimes in relationships it is more about being.... rather than about doing.

For Cass, mother of eight-year-old Shannon, what is memorable in what volunteer Kate does, is not necessarily the 'doing' but the 'being'. She explains that Kate's relationship with Shannon is about them just being together. "Shannon has cerebral palsy and not many people are able to slow down and spend time with her... Seeing Kate and Shannon, there is a wonderful connection. Their communication has become so intuitive. They just enjoy being together, sometimes holding hands, sometimes watching the boys play."

To really 'be' with someone means seeing, accepting and valuing their true self. We see this in the way volunteer Evelyn communicates. Reflecting on the early days of the program, she describes nine-year-old Carl who only lived a few years after Evelyn met him. "I used to stroke his hands and tell him that he had beautiful hands. He had his hands all clenched and when I stroked them and told him that he had beautiful hands, he used to relax and put his hands out straight. And when I came of a morning he would have his hands out straight; he wanted me to look at them."

Sometimes we are struck by the very ordinariness of what makes things special. Volunteers Jan and Tom talk about how, as new volunteers, they thought they were going to take on this great role, do great things with the kids, give them new experiences. Whilst they do some of that, they have come to realise it's the ordinary things that are most important and what the kids really wanted. "We are just accepted as part of their lives on a daily basis and this brings stability and security of a sort to them... We don't do anything special or difficult, other than treat these children as our own grandchildren," they said.

So now Jan and Tom see their role as being ordinary; if only everyone could grasp how special that is.

Being Extended Family

It struck us that many EFA families have come from overseas where extended families are so important. When they come to Australia they are often cut off from that support. One of the great things about EFA is seeing those families develop ties here and how that can help heal the wound of being torn away from the support system of relationships they left behind.

Even our name **Extended Families** reminds us of a bygone era and makes us think of a sense of community and connection that we sometimes seem to lose ... it takes us back in time to when extended families offered the constant of family. Having a constant in our lives can be really important. It's someone to talk to about the ordinary things; an extended family member who takes the time to listen and care.

Michelle, mother of 5-year-old Erin, says that volunteers Jan and Tom have relieved some of her pressures through their simple acts of friendship. "With no extended family in Australia it's great to have someone with whom we can share the full extent of our feelings and problems through friendship and just being there to listen to the good and the bad."

For 9-year-old William, consistency had been lacking in his life in foster care. When his volunteer Kay died suddenly in 2007, he was sad and knew he would miss his special relationship. At Kay's funeral he was heard to say "no one's going to want me anymore". Surrounded by caring people, it didn't take long for volunteers Billie and Laurie to step up and embrace William as another match.

Extended families sometimes produce unusual relationships, bringing people together who are very different. We often see this at EFA too and wonder how the connection was made... sometimes the individuals have made that connection themselves and sometimes we have helped them.

When we think about our work and how much of it is finding the point of connection, we can reflect upon 13-year-old Storm and his relationship with volunteer Helen. Despite the family wanting a 'bloke', in the absence of a male

volunteer, Helen - a woman in her forties who also had a physical disability - was matched with Nick. Despite their different ages and gender, Helen and Nick found a special point of connection at their very first meeting when they sat down on the floor, peeled off their callipers and compared notes on their issues with mobility!

When we think about successful relationships that span cultures and time we think about the ability to cope with change and to embrace diversity. 70-year-old volunteer Mabel admits she didn't know anything about other cultures when she heard about the tragic loss suffered by a young Eritrean mum with two young children with disabilities and the grief the family was experiencing.. Realising she'd experienced her own share of grief; Mabel said "Well I guess I'll go in there and give it a go and we can just cry together if we need to".

It's about belonging - we're all human beings, with the same needs, we want to belong... and EFA can provide that sense of community.

Good extended families also manage to keep relationships despite distance and



change. We see that in many of our volunteers, those whose children were moved long distances when institutions were disbanded or where other natural life moves have occurred. Founding volunteer Marion Owen managed to keep meaningful relationships with all her 'foster grandchildren' and their families, including Julie who was moved to Wodonga. 30 years later Julie still phones and says "are you still my foster grandmother?"

What makes relationships work?

We also thought about what makes relationships work; why does EFA continue to succeed after thirty years and so many changes?

We realised that the things that are important about relationships are the things that are important at EFA, things like:

- Building understanding
- Seeing similarity and embracing difference and diversity
- Reciprocity
- Believing that relationships are better when you give more than you receive
- Having fun together
- Being able to be ourselves
- Allowing ourselves (and each other) to adapt and change over time and changing relationships
- Sharing our hopes and dreams

These are the things that matter. You will find these in the many stories of relationships that make up EFA and in the organisation's own story. Extended Families Australia works because we work on relationships. It's all those little things that add up to something bigger; relationships that work because they've found a point of connection. Imagine if we continue the next 30 years the way we have our first 30 years. We will continue to build enduring relationships and connections. Build a better place for children of all abilities to grow.

Jan and Ken Bishop and Hussein – Dreams Coming True

Jan and Ken Bishop are matched to a wonderful young man named Hussein who is 17 years of age and has cerebral palsy. The relationship began when Hussein was only three years old. Their loving friendship has spanned 15 amazing years and continues today even though Hussein's volunteers now live 120 km away in Eildon.

Jan and Ken have described Hussein as "the bright light of his family as well as ours" and their wish for Hussein when he was little was to help him achieve his dream of being able to walk. Over the years that dream has become a reality, and more.

In 2007, Hussein won a scholarship enabling him to undertake weekly personal training at a local gymnasium. Hussein's Mum works full time and his EFA volunteers advocated for community transport assistance for Hussein to attend his gym appointments. Hussein has now completed his scholarship and hopes for a career in the fitness industry. His personal trainer so enjoyed the time spent with Hussein in the gym, she has offered to provide ongoing sessions free of charge whenever she can.



Evelyn Crouch and Louise – Communication Through Touch

Every Saturday Evelyn visits Louise, who has profound disabilities and lives in a community residential unit not far from Evelyn's home. They are good friends. Evelyn has supported children in residential care for nearly 23 years.

Recently Evelyn introduced coordinator Julia Klieber to Louise. Julia describes the moment when Evelyn approached Louise who was gently rocking back and forth in her wheelchair with her head bent to the side ... "it was a special moment, Evelyn bent down on one knee alongside Louise and placed her hand on Louise's arm, gently stroking it while softly telling Louise she was a lovely girl and that she had brought Julia for a visit".

"Louise's rocking subsided; she tried to move her head closer to Evelyn's and a wonderful smile spread across her face....it was moment I will never forget – the power of touch communicating so much warmth and care, so much beautiful emotion" says Julia.

Heather Boreham and Storm – Finding the Point of Connection

Storm's parents had him down on the EFA waiting list for several years. As he had cerebral palsy and was not very mobile, and as they did not have involved extended family themselves, they wanted a male volunteer grandparent to form a relationship with him and take him on outings.

In the absence of a male volunteer in the area, EFA matched 13-year-old Storm with Heather, a woman in her forties, who also had a physical disability. Heather was initially unsure if she could fill the role the family wanted her to fill. As she said - she wasn't a bloke! What she became to Storm was a mentor.

Like Storm, Heather had been born with a physical disability. From their very first meeting – when they sat on the floor together and peeled off their calipers- Heather was able to share her journey through life with him and together they swapped notes on their experiences. They also discovered some shared interests along the way - Tolkien's 'Lord of The Rings', playing cards, ice-cream and computers.

When Heather moved interstate after a couple of years, Storm was so well settled in secondary school, he and his family did not feel the need for another volunteer to become involved in their lives.



Kate Gallagher and Shannon – It's a Complementary Relationship.....

Listening to volunteer Kate and Shannon's mother, Cass, talk about the volunteer/family relationship, what stands out is the mutual benefits.

Kate is in her sixties and a retired school teacher. She is married with adult children but has no grandchildren. The idea of volunteering with EFA was to be able to enjoy some regular contact with children again. Kate has also enjoyed being able to observe the dedication of Shannon's parents, seeing how their family works and being a part of it.

For Cass what is so important is that Kate has chosen to be involved with a child with a disability and is so supportive. It means a lot that Kate is so genuinely interested in hearing about all the different issues that constantly come up in Shannon's life. "What's important in what Kate does is not necessarily the 'doing' but the 'being'" says Cass. She explains that Kate's relationship with Shannon, who is eight, is about them just being together. "Shannon has cerebral palsy and not many people are able to slow down and spend time with her... Seeing Kate and Shannon, there is a wonderful connection. Their communication has become so intuitive. They just enjoy being together, sometimes holding hands, sometimes watching the boys play. It's become a special relationship over the past couple of years" adds Cass.

Mabel Wilkins, Asmeret and Family – Just being there

Mabel is a volunteer in her seventies, who had lived all her life in suburban Melbourne. Mabel's match to Asmeret and her three sons is a wonderful example of cultural diversity.

When they were first introduced, Asmeret was very recently widowed with three pre-school age children, two with significant disabilities. Asmeret is from Eritrea and had only been living in Australia for four years. She described being very much in need of involvement with a "grandmother" figure. Although she had support from a range of local community agencies, she acutely missed the support of her extended family overseas.

Mabel began to spend a day at the family home each week to give support to Asmeret and spend time with the children. As the match developed, Mabel described lots of new and varied experiences. At times the two women laughed over their struggle to understand each other, but through all this they forged a very significant relationship over the past four years. Mabel was touched by how appreciative Asmeret was of her involvement and how much she welcomed her into her home. For Asmeret it was just so important that Mabel cared about them.

Recently Asmeret moved some distance away and the boys are all at school so the formal volunteer/family relationship has come to an end, but they all plan to keep in touch.



Rhonda and Graeme Hamilton and Rebecca - Following Your Dreams

Rhonda and Graeme are matched with Rebecca, a lovely young lady with Down Syndrome. Earlier this year, Rebecca celebrated her 20th birthday, but when she first met Rhonda and Graeme she was only 11 years of age.

In 2006, after Rebecca finished her schooling, she commenced working for two hours a day at a local fast food restaurant. Her duties largely involved cleaning dishes and after some time, Rebecca commented that she would like to experience working with children.

Rhonda and Graeme listened to Rebecca and thought about how they could help her realise her dream. After speaking with her mother, they approached Glen Allen Special School where they both also volunteer each week.

With the help of her volunteers, her family and the school, Rebecca obtained a Working with Children Check and became a volunteer at the school alongside Rhonda and Graeme helping the children with outdoor activities.



Nicole Molnar and Nicholas and Family – A Sense of Belonging (that works both ways)

Nicole joined EFA just six months ago and at 19 is our youngest volunteer. Nicole is studying Occupational Therapy at Latrobe University. Two-year-old Nicholas, who is hearing impaired, warmed to Nicole from the first minute he laid eyes on her and the feeling was mutual.

“Every time I visit the family I am greeted with a beautiful smile from both Nicholas and his brother Matthew, and I am welcomed by the whole family. I feel uplifted and very happy after visiting with them,” Nicole said.

Nicole helps Lenke, mother of Nicholas, with medical appointments and provides support to attend a play group. Lenke was feeling isolated, having moved to a new area, and says their relationship with Nicole has given them much more than just assistance – it has given them friendship and a sense of belonging.

The Family Day at the Zoo highlighted that feeling for Lenke and her family. “I cannot remember a more relaxing and fun day,” Lenke said. “Everyone was so lovely; like their name says, an extended family”.

Jan and Tom Hughes and Erin and Family – Reconnecting to the Community

When you're the parent of a child with multiple disabilities, it can be all-consuming. Your child is the focus of your day, your week, your life. There's not much time for anything outside of the everyday demands of your situation. And when there are no other family members or relatives around for support, it can feel extremely isolating. It's a story we hear time and time again. A story like this one:

Malcolm (Billy) and Michelle are the parents of Aiyana and 5-year old Erin, who has Cerebral Atrophy, Global Development Delay and Epilepsy. With no extended family in Australia, they turned to EFA. Enter volunteers Jan and Tom Hughes, who now enjoy a relationship with the whole family – helping to meet Erin's needs, bringing a bit of normality into Aiyana's life and just being there for Billy and Michelle.

“With no extended family in Australia it's great to have someone with whom we can share the full extent of our feelings and problems,” Michelle said. And, according to Billy and Michelle, perhaps the greatest benefit of being involved with EFA and its volunteers is being reconnected to the community. “You feel as though you are part of something bigger than your own family situation. You are not on your own, not isolated.”



Chau Phan and Dylan and Family - Sharing and Supporting

What does the mother of a child with Down Syndrome do when her child becomes a teenager and she finds she has a little more free time? If you're Chau Phan, you decide to use your additional free time to help another family in your community who has a child with a disability.

Chau has recently become a volunteer with Extended Families and has been matched with six-year-old Dylan and his family. Like Chau's daughter Gina, Dylan has Down Syndrome. And like Chau, Dylan's family migrated to Australia from Vietnam and settled in the Western Suburbs of Melbourne.

While Chau is enjoying developing a special relationship with young Dylan, she is also able to share her own experiences of managing challenging behaviours and how she has coped with all the ups and downs of parenting over the years with Dylan's mum Chi. And that's exactly why she became an EFA volunteer.

Early Volunteers – Bob and Winn

Janet Doyle interviewed Margaret McGregor (April 2008) to find out more about Bob and Winn who volunteered at St Nicholas' Hospital. Here are some of Margaret's comments.

Bob Wubrick

"We ought to first describe the ward at St. Nicholas' Hospital. There were severely disabled children, who could not walk, talk, or feed themselves. They made noises, but couldn't talk, and in the daytime they sat, in beanbags, on the floor. Bob came to see me about being a foster grandparent. He was a bachelor ... about 60, he was retired ... I suspected that his sister had said to him 'go and see if you can be a foster grandparent'. So I talked about it and explained what was involved, and then I took him into the ward. He took one look and through up his hands and said 'Never, Never, Never, I could never go in there'. And so we went outside and I had a bit more of a chat to him and I said 'How about I get one of the children in there and put them in a pusher, and we go for a walk around the Exhibition Buildings?' He said alright, so I got this little boy and put him in the pusher and we went for a walk around the Exhibition Buildings and by the time we got back I could see he was looking at this little boy and feeling a bit related. And then I said, 'How about coming back tomorrow and doing the same?' He was very reluctant, but ultimately he agreed. And from that very, very small beginning he became one of the most devoted men, particularly to this one little boy. At one stage one of the papers ... came to talk about Foster Grandparents, I got Bob and this little boy and they wrote a story about him. And the heading of it was 'The love story of a boy and a man'. It really was the most remarkable relationship, to see Bob, he would come at least four days every week, for five hours and get this little boy and put him in the pusher and take him for a walk and it really was the true love story of a boy and a man".

"It was remarkable for me to see people who had never had experience with little children, how they became so involved and were such fantastic foster grandparents. It's a two-way thing, if it's not a two-way thing it doesn't work. It's so important. I don't think I ever had foster grandparents who continued to be foster grandparents for a few months or longer ... who wouldn't have said that they got more out of it than they gave".

Winn Skurrie

"Winn was certainly one of the first ... she had been a very, very professional person, an accountant and had quite a lot of people on her staff. She had retired from her position. She was tiny in stature, beautifully dressed and beautifully spoken. And she had no experience of working with children. Come hail, rail, shine she's there, twenty hours a week. She would put her two little children in the pusher and take them out for a walk. And she became one of the most devoted foster grandparents it was possible to have"

"The thing about the Foster Grandparent's Scheme, and I'm certainly thinking of Winn in this regard, is that it became their lives. That became the real interest for them in their later lives. And she was an absolutely wonderful example of somebody who became so totally involved with her two little children".

"And I think the other thing it would be fair to say too, is that, because they had their own room, and they all came about the same time and left about the same time, they became a family in themselves, and they cared about each other as well as about the foster grandchildren. And for some people, when they retire, or they get to their seventies and eighties, it's a very lonely life ... and to have that relationship with both the foster grandchildren, and with their peers, was a very important part of the Foster Grandparent's Scheme. That doesn't apply to the same degree now.

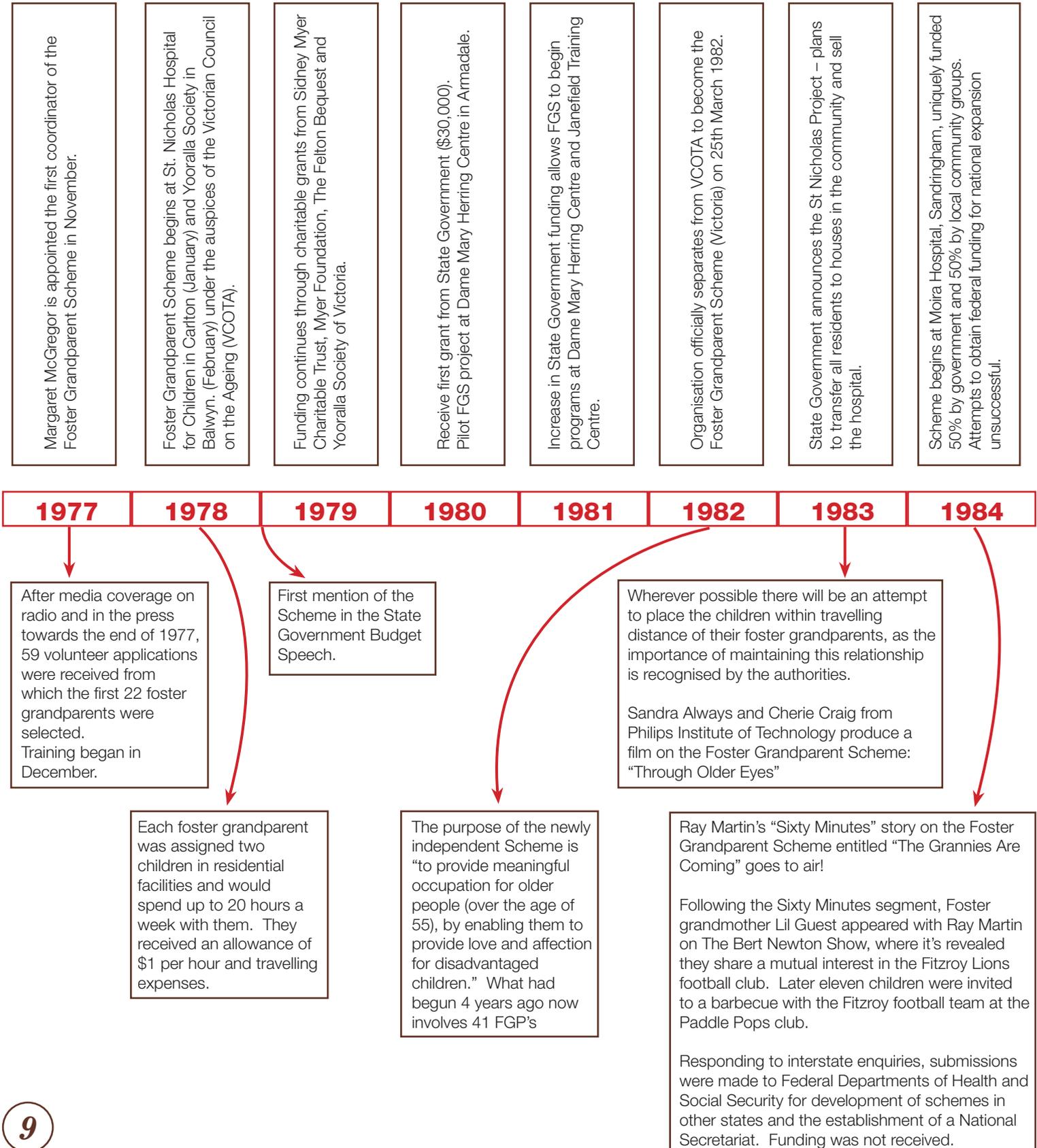
"At St. Nicholas they took their own food, but at Yooralla they were even given a meal at night. See the children at Yooralla got out of school, the foster grandparents came at 4pm and left at 8pm, and they would have a meal together. So for those that were living on their own, it was a really, really good thing".

1970s

Institutional care was the primary focus of service delivery for people with disabilities. Doctor's advised parents that children were better off in institutions. There was little direct support for families caring for children with disabilities and access to day care depended on parental knowledge and individual advocacy. When parents were unable to care for their children, an institution was the only alternative offered. Parent advocacy groups began to form to argue for a better quality of life for people with disabilities.

1980s

A radical change in the discourse about people with disabilities occurred. There was a shift from seeing people with disabilities as patients or as sick to seeing them as citizens with rights. The new thrust of Government policies was to ensure that people with disabilities had such rights and that these were safeguarded. This approach can be seen in changes to the law, in the development of advocacy services and, ultimately, in the movement from institutions to supported housing and community services for people with disabilities.



1980s continued

The first legal reform was the passing of the Intellectually Disabled Persons Services Act 1986, which identified people with intellectual disabilities as citizens with rights whose needs "are best met when the conditions of their everyday life are the same as, or as close as possible to, norms and patterns which are valued in the general community". Following the Act, an intensive review of services for people with intellectual disabilities took place, including State wide consultation with advocacy groups, parents and both government and non-government agencies. This resulted in a Ten Year Plan which was highly critical of institutional living and argued strongly for a transition from institutional life into community based services. This plan was then translated into an initial Three Year Plan, effective in 1989, which set objectives to increase community services such as employment, day programs and residential services for people with an intellectual disability.

The second major reform occurred when the government officially recognised the importance of advocacy and passed the Guardianship and Administration Board Act 1986 which established an Office of the Public Advocate and other agencies to act as safeguards for the rights of people with disabilities. The Office of the Public Advocate soon became a strong voice in the argument for systemic change in disability services and policies and an important ingredient in the movement towards deinstitutionalisation



By the time St. Nicholas Hospital closed its doors for good, 35 foster grandparents had contributed nearly 60,000 hours of volunteer work over seven years. The closing of St. Nic's led to the establishment of the first Area Coordinator (Western/North West Region), marking the beginning of the distribution of coordinators on a geographical rather than institutional basis.

SBS screened a program on the FGS that had been filmed at Yooralla and Janefield.

Vi Cox receives Senior Citizen of the year award (given by VCOTA) for her grand total of 6,595 volunteer hours to date!

Although Stawell has a large elderly population, the Scheme had great difficulty recruiting volunteers, as country residents could not seem to meet the required time commitment of 10 -20 hours per week.

10th Anniversary Celebrations include: luncheon at the Hilton Hotel with the Governor General's wife Lady Steven; 10 year certificates presented to Vi Cox, Marjorie Kelly, Marion Owen and Zara Wildenauer; and a private afternoon tea for FGP's at Government House with the Governor's wife, Mrs. Jean McCaughey.

Margaret McGregor holds her first Christmas lunch for foster grandparents at her house - which was to become a much-anticipated tradition!

Recommendations of the CSV funded review include:

- Replace hourly payment with weekly 'out of pocket expenses' reimbursement
- Implement written agreements between parties involved in a match
- Volunteer time commitment to be worked out on a match by match basis
- Accepting Special Development Schools and Day Training Centres onto the program
- Establish working party for a pilot program with ethnic communities

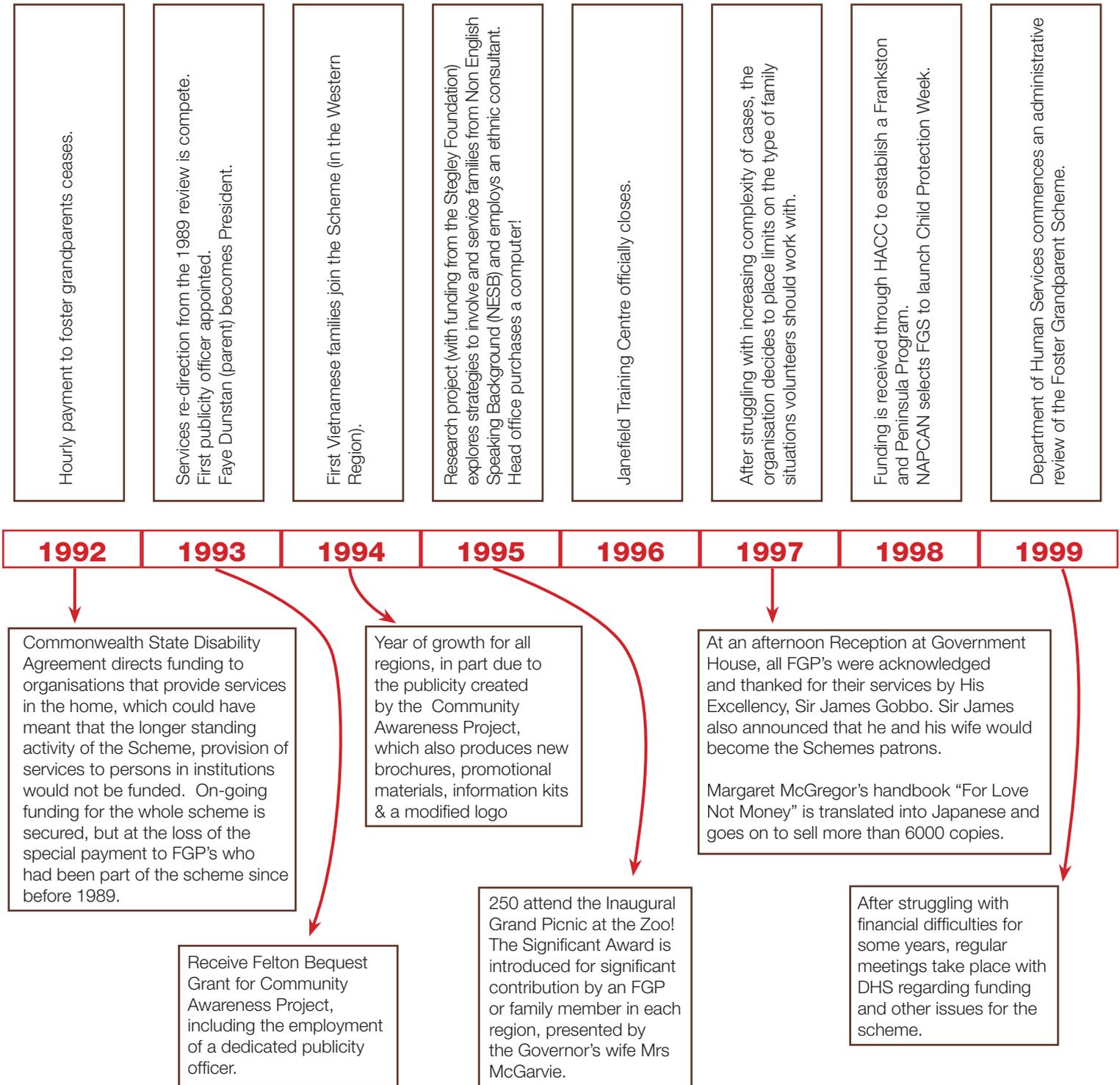
Margaret McGregor receives the Order of Australia Medal for her efforts in community work and, particularly, in establishing the FGS

New role of Executive Officer is created to work with committee to implement the recommendations of the 1989 Review; especially to look at the needs of families raising a child with a disability in the community.

1990s

The Ten Year State Plan did not meet all of its objectives. Because of increasing financial problems the State Government did not implement a second Three Year Plan but concentrated on the closure of institutions.

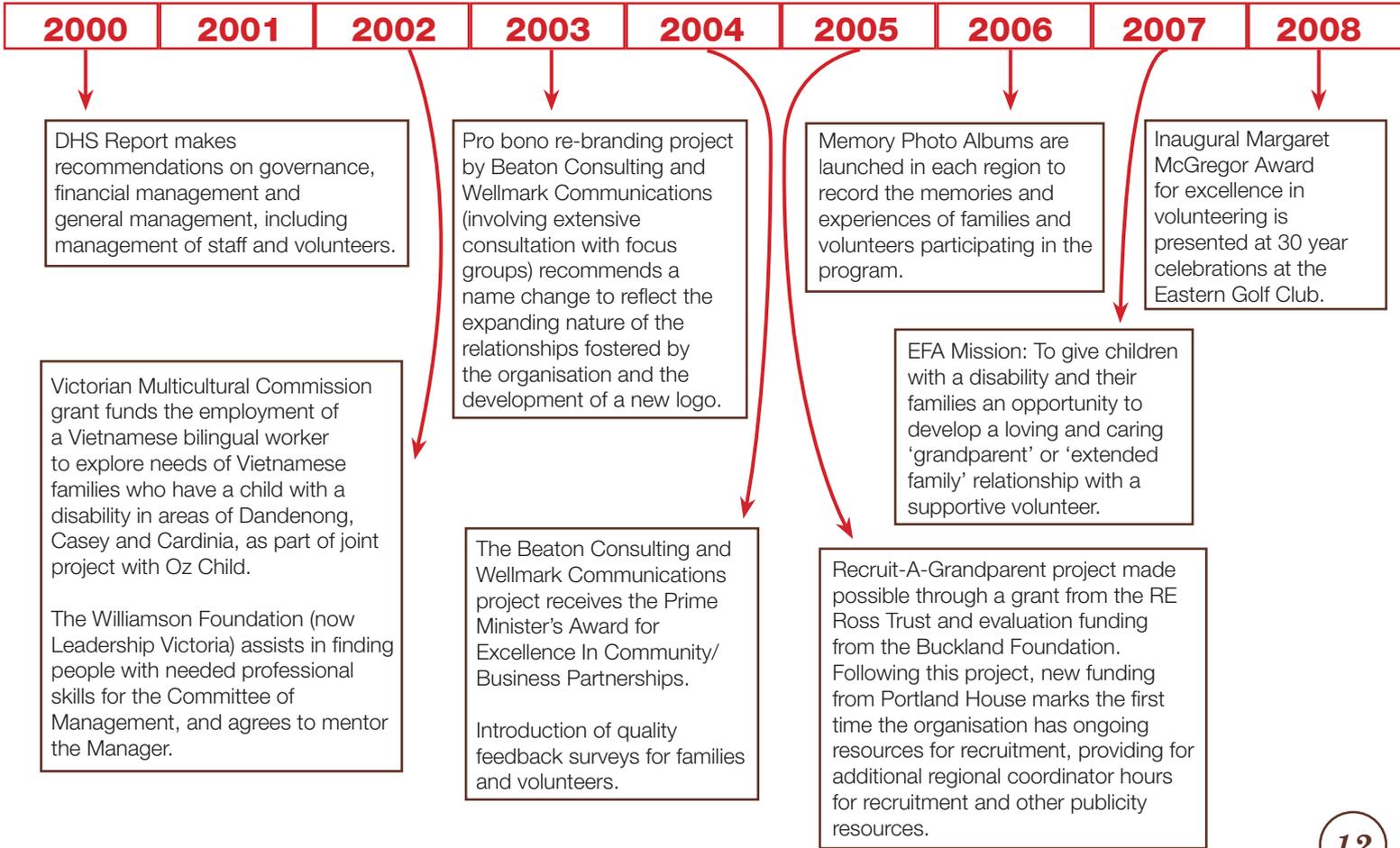
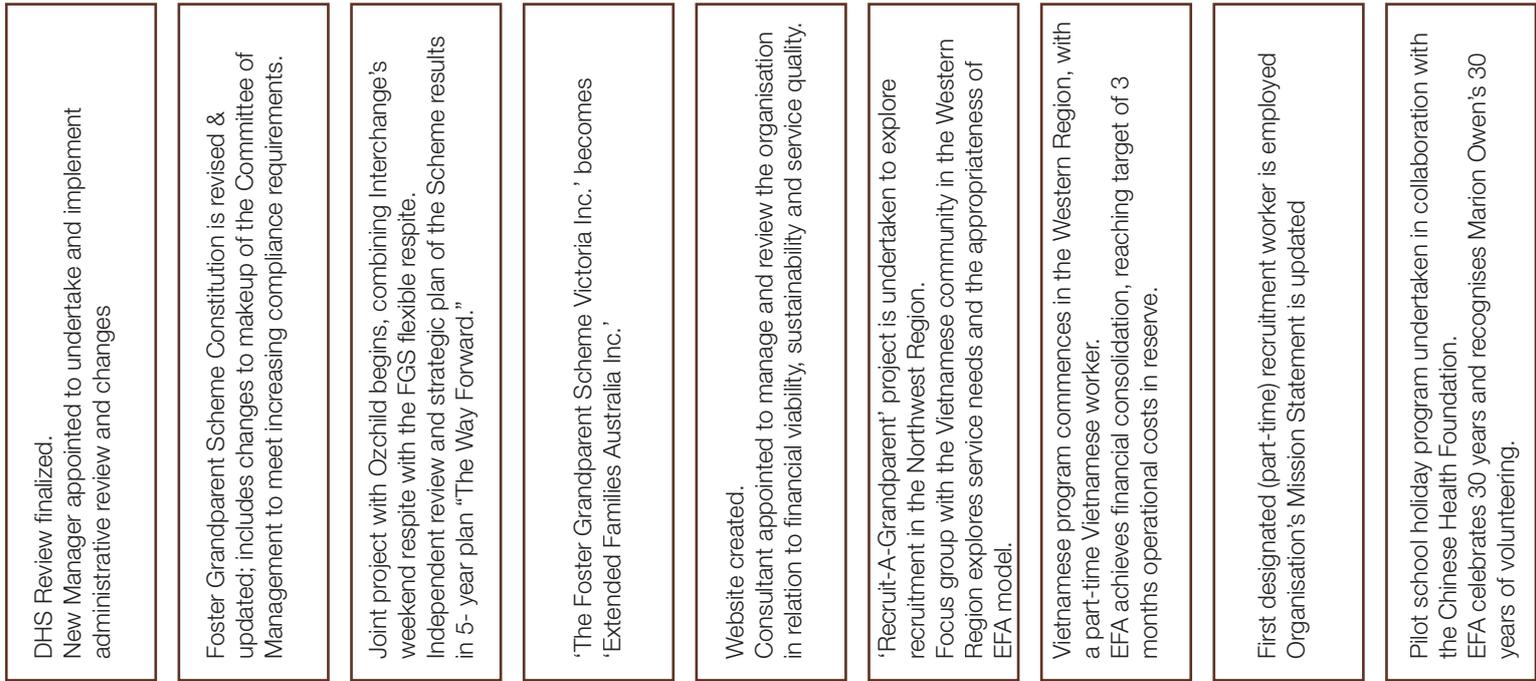
The Disability Services Act 1991 was developed in response to the first Commonwealth-State Disability Agreement in 1991, which transferred responsibility for the administration of accommodation and support services from the Commonwealth Government to the State and Territory governments. The Act provides for the funding of disability services to people with intellectual, physical, psychiatric and sensory impairments, and binds Victoria to principles and objectives for service delivery that are consistent with those in the Disability Services Act 1986 (Commonwealth).



2000s

In 2002 the Victorian Government released the Victorian State Disability Plan 2002–2012 which outlines a vision for the future and strategies to realise it. The vision is that “By 2012, Victoria will be a stronger and more inclusive community, a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria”.

As part of the release of the State Disability Plan, the Government made a commitment to review legislation for disability services - the Intellectually Disabled Persons’ Services Act 1986 and the Disability Services Act 1991. In June 2007 the Disability Act 2006 was proclaimed. The Act has two sets of principles: the first for people with a disability - that they should have the same rights and responsibilities as other members of the community; the second for disability services outlining their role in providing high quality, individualised, family centred and culturally appropriate support to assist people with a disability to participate in the community and maximise choice and independence.



Evelyn's Reflections

Evelyn Crouch has been a volunteer for nearly 23 years and has remained working in residential facilities. Zoe Sweeney interviewed her in April 2007. Here are some of Evelyn's reflections:

On her early 'Foster Grandchildren'

"(First) ... I had Carl and he only lived a few years he was 9 when he died ... I used to stroke his hands and tell him that he had beautiful hands, he had his hands all clenched and when I stroked them and told him that he had beautiful hands he used to relax and put his hands out straight and when I came of a morning he would have his hands out straight, he wanted me to look at them".

"After Carl died I had Steven, he had been at home until he was 13 ... until his parents couldn't cope with him anymore. He had a mother that doted over him and up there (Rosine) he had no-one. So I was given him as his 'fostergran' and I grew to love him very much."

"One child's father considered him a vegetable, but he was far from a vegetable I used to take him out of his wheelchair and cuddle him ... there used to be big bean bags and on a nice barmy autumn day I would lie with him in my arms under the apple tree and I'd tell him wonderful stories about the autumn ... the sun would be shining on us and the apples and the leaves would be falling down ... and he used to go 'Ahhh!'

On the Institution

"Oh there could have been 20 to 30 children in the home. About 10 in a room ... the beds were very well stacked in the room. ... We used to go up 2-3 times a week - we'd go to school with them but the government stopped us and said they only wanted us to go once a week, and that was on a Saturday. ... But on a Saturday I would be having music with my boy and somebody else would be watching football and another kid would be listening to racing and somebody else would be having a story read to them, and we all fitted in, there was no divide or anything it was just a huge big room".

On the move to new smaller houses

"They all got healthier as they got into these newer houses ... more individual attention and the staff talking to them and loving them. The staff are very wonderful they have a way of talking with the children and laughing, they talk to them ... normally". In the new houses there was only five and six ... so they would get a lot more attention ... and they have their own room ... and better sofas and can watch TV, listen to music ... the equipment they have is good".

On music and communication

"Steven was a Catholic ... his family and the priest used to visit ... and Steven was always pleased to see the priest ... I used to give Steven some Christian songs and he loved them. I had Swan Lake music and he really thought that that music was the Virgin Mary and when he discovered that it wasn't the Virgin Mary he'd weep. So I had to be careful and tell him, you know what the music was and he had the pope above his bed and whenever he wanted something about the pope or Christian music he'd look up to the pope and smile".

"Steven couldn't talk ... or move. One day my husband had been over to Korea and I gave him some Korean Christian music ... it was in a another language and it was very beautiful, many voices and parts and you know he actually spoke to me and I actually heard him say, 'thank you Evelyn' he was so elated with the music ... that was the only time I heard him (speak) ... He would communicate with his eyes ... and his lovely smile... and his tears".

"There was this huge room and ... all the children, after they were dressed, would be all in this room. And they would see my other helpers like Joan, Jill, and Joe, they'd all laugh and joke and talk to the children and they'd sing. They'd say 'come on lets sing' and ... they taught the kids to put their hands to the beat, they like the beat".

On Feeding

"We used to feed them, they were capable of being fed, but we had to be careful that a piece of food didn't go into their lungs, the physio used to watch us and he would quickly take the child and pat its back and give it back to you".

"... being a 'fostergran' has taught me to love a deformed child ... each one, needs to be loved and its love that keeps them alive. They are not fed (orally) these days; they just have a liquid into their stomach. We used to feed them and have a close contact ... it could take an hour to feed a child as you wanted to put everything in ... they wanted to eat it but they could only eat it slowly. If we had two children one of the nurses would do one ... the nurses wouldn't take the same amount of time that we would. We'd talk to them and laugh with them and we'd tell them funny jokes and we'd see that they ate their food whereas the nurses would say 'oh I've had enough', whereas we would go on feeding. That's what I miss, the feeding ... because of the closeness. They have got too big to cuddle now (laughter) ... I used to have them on my knee".

On intellect and communication tools

"My friend had a boy Travis and they got a pointer on his head and they pointed it to numbers and he pointed one day 'the light in my room shines in my eyes and I can't get to sleep' all that! And my boy Steven he pointed out 'I like Evelyn but I love Rachel' (laughter) ... Rachel was one of the helpers who came up in the holidays ... (she was) very young (laughter).

(Zoe asks - "So before they got the pointers did you think that they had that level of intellect")

"They had an intellect of their own that talked to you through smiles and tears and attitude you get to know. But they began to say all sorts of things and it was very interesting ... they knew how to spell. That was the amazing part about it; they knew what the word was to put it down, (with) the pointer to on their head".

On death

"... it leaves a sadness. There was Nicky, he was a 19 year old boy and he had a perpetual smile and he was always laughing and ... when my boys all died I had him for a while, quite a while until he died ... he was very frail"

"... others were unexpected as they were healthy ... we didn't think he could die so quickly because he was so healthy, you know, so full of fun. But it just shows you how the lung is ...".

"The thing that consoled me about all those that have gone, that have departed this world, that they would not have known, they would have been deprived of love. We have all had a part; the physio, the cook, the nurses and carers and the cheerfulness of them and the joking of them the laughing and the cuddles.

"Cameron was 17. I had him from the time he was four and I got to know his parents and his mother ... he had good intellect but he couldn't talk. He (became very unwell) ... and was becoming very distressed and ... they had to make the decision to let him go and that was very hard. That was hardest of all".

"Its just something you go through and you see the parents and the other girls that knew him in other homes they'd come down and nurse him and cuddle him and one girl even got shifted, Kerri got shifted and she came and she was his carer".

"His mother used to be very, very good to me, she'd be giving me ... books to read and she was always very nice to me and we felt very close together. She arranged that he was buried in the ground and they made him a nice garden and they've put a seat out there that you can go and sit and that's very comforting".

On attitude of others

"My husband always encouraged me to go, doesn't matter if he was sick he would always say 'oh you must go for the children'".

Marion's Reflections

Marion Owen has volunteered for 30 years – in institutions, community residential units and with families. Zoe Sweeney interviewed her in February 2007. Here are some of her reflections:

On beginning in the Scheme and meeting the children

“We had a training process of about a week ... then placement of the children with foster grandparents was the next thing to take place, which was done between Margaret and the sister in charge at the institutions. I was allotted a boy and a girl. The girl about seven and the boy I think was about nine then”.

“... the first day at Yooralla and I remember that very vividly. I was quite excited and quite nervous of course, meeting up. It was arranged that we would be at Yooralla to meet the children when they came from school ... they came tearing down in their wheelchairs, all in this group ... Margaret was there with us to greet them and introduce them. She brought Julie across to me (who was apparently aware that she was going to meet somebody) ... this little blond girl, very pretty ... had cerebral palsy in a wheelchair and very vivacious ... and smiling all over her face and she came up to me and she said ‘are you my mum?’ She had not had contact with her mum from birth ... as she was left in the Queen Vic hospital, and her mother had never come back. So I had to say, ‘No I am not your



mum but maybe I could be your grandmother’. She accepted (this) very well and we had no problem at all because she was so used to institutional life and she made friends with everybody... we became very good friends.

“... maybe I met Greg the same day or the next day ... he had only been in Yooralla a very short time. He had been living in a very lovely environment at home with his parents, and his mother was killed in an accident and of course his father could not cope, Greg was very disabled. ...When I walked into the room where he was, he was sitting in his chair in the corner facing the wall. He couldn’t look at anybody, he was very introverted, and he did not turn around when Margaret said there was someone to see him. I think to this day that he thought that it was his mother had come back and he turned around with an inquiring look on his face, and he could see that it wasn’t, and he turned back and that was it. He didn’t want to have anything at this stage to do with me. So I stayed in the room and I said to Margaret ‘... it is not a very good idea to push a child I’ll just do it gradually’ which I did. However, he was moved down to a CRU (community residential unit), only a

few doors down, the only one Yooralla had because they thought it would have a more homely atmosphere there. There were only five other children there, and as his foster grandmother I would visit him at that cottage also, which worked out very well. There was a very warm cottage mother there and he gradually fitted in there...”.

On caring

“Greg had Muscular Dystrophy... he was the first operation in the children’s hospital because he got to the stage where he ... had difficulty trying to sit up. I was able to visit him, in the daytime in the hospital, which was very good for him to have someone to come as ... his father could only visit at night-time as he was working. But he got through that operation and he was able to sit up, and he was able to have much more pleasure for the rest of the short span of life he had. It got to the stage where I did everything I possibly could when I was there for him. They would lift him onto the bed; I would undress him and shower him. They would carry him onto the bed, and I would dress him. I brought him home here yes. I had him home here sometimes for the weekend. In fact, I had all those children that I wasn’t actually their Foster Grandma, all those children in the CRU had a couple days holiday with me at various times. I unofficially ... they all called me granny and I was very much a part of the carers there.”

On the Institution

“(The children) were very insecure and it was very difficult at first to get them to come out and go for a walk, away from that building. It was a very lovely ...warm building, very well equipped. But you know, it was large and they did not have their own room and not much privacy, more of a dormitory style”.

On the move from institutions

“... whilst I was able I visited (Julie), when I could, at Wodonga, because I had my brother ... and his wife lived there and I used to go up and stay there. In fact, my brother used to go and visit her occasionally.

“It was very sad that she was moved up there, she really hasn't really got anybody close to her now. ... I suppose Julie not having any family contact; they decide to move her up there. ... It was very much an emotional thing for me because I mean, I always put them first. I would never have put my own needs first; whatever was best for the child was always my motto. It might have been the right move at the time but that staff member didn't stay very long that was there, and Julie had a lot of upsets there. ... Well she's got every photo of me because she always carried them around up there and she would wear them out by showing them to people. Then she would lose the bag she had them in. The last time I went there, I took a little bag and another photo. The last one I sent her I posted it but I haven't got anymore now ... when you have such a long relationship with someone like that you know, it takes a long time, you don't ever really get them out of your mind. ... She always says to me “are you still my grandmother” she has never forgotten you know and I always say “yes I am” and to me I will always be grandma...”.

“It was round about the same time that Greg ... passed away ... it was fairly close together that I lost the both of them. It was fitting that Danielle, who I had known in Yooralla for a long time, was asked if she would like me as her grandma and it suited me too as I knew her and so that worked out very, very well. It's been fortunate that it's been such a long relationship because ... I think she went into three different ones (CRU's) before they settled her in the one where she is now, and I was able to move with her and I mean, that was the only security she had really. I was always there rain hail or shine, ... foster grandparents always turned up, they had that continuity”.

“See they don't get it from staff, especially the days that I go on the weekend, they have casual staff, and I strike somebody new nearly every Saturday when I go. Of course Danielle is older now, she is 30 now, and she is very accepting to all this, and she tells them what to do, well in a nice way, often its helpful with a new person coming in, it's very hard for them too”.

“(It is good that they are) meeting more people and getting out into the community more and that is how they became to be accepted. They are so much more in the community and I noticed that this is gradually happening. When you took them out from Yooralla in those early days in the wheelchairs, people would put their head down and walk past - they would not stop and speak to them ... there was stigma. People didn't accept ... but now things have just changed so differently and I see it so much in Box Hill Shopping Centre. Some of the boys who can go in their wheelchairs ... and are stopping and talking to people, ... taking pride in their room, having something of their own, to call their own, their own room and telling somebody if they wanted privacy”.

On family support, attitude and the rewards of caring

“... actually they were very, very thrilled. Oh they have given me so much support over the years, so much encouragement and taken so much interest, so that has been a great help to me because, when I first joined the scheme, I had to give up quite a few activities. I lived near the golf club, I was a member down there, and I played golf. I couldn't see as much of my family and they accepted that because they



knew it was a two-way thing. It was very good for me, and I was doing something worthwhile, which I like to do so, it all worked out very well”.

“... so I have seen quite a lot in my life of happiness, and I've perhaps had heartaches I've had to contend with, but I've come through I think more positive than negative ...

“I don't know whether it was from my, coming from a large family or that my mother loved children ... I felt that when I heard Margaret speaking on the radio, well that would be exactly right for me and it was and I just enjoyed it so much and I am quite sure that I wouldn't perhaps be here today. I think that ... being able to get up each morning and know that I was going out to do something worthwhile and see the children and you know, it made my life so interesting. It was so rewarding and you know it was not something you expected. To give so much love, but you receive so much in return, it was good for both the children and the foster grandparents”.

Voices from the past...

"Before the first foster grandparents started working at St. Nicholas Hospital I was required to work a shift in each of the wards—commencing at 7 am and finishing at 7:36 pm. I was responsible for one child – a few ward assistants and the sister-in-charge had about twenty-four!

Margaret McGregor

"Basically we were looking for people who could love children without needing a lot in return; people who could accept children for being children, whatever their handicap."

Margaret McGregor, *New Idea*, March 1978

"They commenced in January and, while on duty for between ten and twenty hours per week, are each responsible for two children. They feed them, dress them, walk them, play with them, sing, read, talk to them and, most of all, love them...Staff of all disciplines have commented on all sorts of changes seen in the 'grandchildren'. There are more smiles, some appear more relaxed when being fed, there is a greater awareness of surroundings, less limb tension, increased movement and so on. One doctor even 'prescribed' a foster grandparent as part of a treatment/therapy program. "

"Foster Grannie Scheme in Action" by Robyn Pritchard, *Mental Health Authority Newsletter*, May 1978

"This is the first time in Victorian training centres for the retarded that staff have been provided purely to meet the emotional needs of the children. While other staff are very much aware of these needs, their training and responsibilities determine their objectives. For example, a physiotherapist feeds a child to improve posture, mastication and swallowing. A teacher feeds a child to introduce tastes, textures and colours. A nurse feeds a child out of a primary concern with nutrition and health. But a foster Grandparent feeds 'his/her' child because he/she loves him and has all the time he/she needs to do it."

"The Scheme In Host Centres" report on St. Nicholas Hospital for Children, Carlton



"Mr Prime Minister, would you please take note...and all you readers too:

'We want more Foster Grans please!'

"Tony, a 12-year-old at the Yooralla Centre in Balwyn holds up his poster plea, grabbing the limelight from Mr Fraser for a moment or two when Mr. Fraser visited the Centre on the eve of this year's Yooralla Appeal. "

Herald Sun, 1/3/1979

"The extent to which the grandparents could show their affections for their grandchildren was very much constrained by

the realities of a medical – and therefore very regimented – environment. One gran explained that the way in which they treated their child was dependent upon the nurse in charge at the time. Some would allow a great deal of 'petting'; others would not. 'We knew how to behave because a sister would say 'no petting today girls.' "

"Some Impressions of 15 Years of Visiting" by Social Work student Anna Wellington

"Very recently an advertisement in local papers, and a personal approach to the congregation of St. Martin's Uniting Church, Beaumaris, resulted in the recruitment of twenty volunteer drivers to provide transport home each evening for four foster grandparents who faced the winter gloom and haphazard public transport at the end of their day's work. This marvelous assistance has benefited both Foster Grandparents and children, and we are most appreciative. The volunteers are required to drive once monthly, and it is hoped that many will remain on the roster long after winter has passed."

Judy Taylor, Moira program coordinator report, 1987 Annual Report

There are often references to 'a roster of volunteer drivers'. Little more is written of these trusty volunteers upon whom many foster grandparents relied for safe transport home, often in the dark hours, after a long day caring for their children. Could the early days of the Scheme have worked so well without them?

"Foster Grandparents began at Janefield in 1981, at a time when the winds of change were beginning to blow throughout what was then known as the Mental Retardation Division. As a consequence of staff uncertainty with regard to the future, new innovations and ideas were not always welcome so the implementation of the Foster

Grandparent Scheme provided a real challenge. ... The success of the Scheme depended on the acceptance of the first Foster Grandparents (May Simmons, Margaret Visser, Mary ? & Mary ?) and it is to them that the credit must go for the requests for more and more Foster Grandparents."

Excerpted from "The Scheme In Host Centres" report on Janefield Training Centre

"Conditions were very poor at first, the children had not toys to occupy them and I used to have to sit on the floor with them as I didn't even have a chair. The staff didn't understand my role at first and some seemed to think I wanted to take over their jobs. However, these problems were solved and things improved greatly."

May Simmon, on starting at Janefield, excerpted from The Scheme in Host Centres

Fundraising, it seems, has always been part of the package for Foster Grandparent Scheme/Extended Families Australia volunteers, as indicated in the 1983 Annual Report:

"The Yooralla Fete was one of the year's highlights. Foster Grandparents

were asked to run a stall, and chose the 'Treasure Stall'. Their quite exceptional efforts... netted over \$400!"
Bobbie Holmes, 1983 Annual Report

"It was a scene so touching that it almost brought tears to my eyes. Lil guest stood in the driveway and waited until Robbie caught her eye. When he did, the reaction was instant... his face beaming, Robbie ran and leapt into Lil's arms. Not a love scene, Robbie is a nine-year-old retarded child and Lil is his foster grandmother. In less than six months, the two have established a bond equal to any among blood relatives."

"They're Special Grannies" by Helen Gillman, Diamond Valley News, 21/6/83

"The foster grandparents visiting at Yooralla and St. Nicholas' benefited from a close sense of comraderie. They shared stories of their grandchildren, swapped experiences, helped and supported each other. This emotionally satisfying contact came about during communal meals, when the high demands and pressures of becoming perhaps the most significant person in one child's life could be reduced and put into perspective, in an environment characterised by peer support."

Excerpted from "Some Impressions of Fifteen Years of Visiting" by Social Work Student Anna Wellington

"Janefield management had agreed to provide a hot meal for Foster Grandparents, but the real benefit of this was that it enabled them to have time together to discuss their respective Foster Grandchildren, their families and their football teams. It even gave time for a little romance as well, as we had not one but two weddings at Janefield!"

Excerpted from "The Scheme In Host Centres" report.

"On the paper-hanky scale, there is a 'Sixty Minutes' segment on Sunday's show which rates a box and a half. It's about foster grandparents and their contribution to the pitiful lives of handicapped children incarcerated in institutions."

"For the love of a foster grannie" newspaper article, 1984

"Perhaps the event with the most impact at Janefield this year was the recent week-long strike of most nursing, domestic and artisan staff. During a time of stress and great disruption to the residents' lives, the Foster Grandparents worked many long and at times difficult hours. Besides being familiar faces, they provided much needed practical assistance, caring and support in the three residential units in which they worked..."

Robyn Pritchard, 1985 Annual Report

"In September 1986, the first International Conference for volunteers hosted by Australia was held in Sydney, with delegates from 26 countries. I presented a workshop on the Scheme, showing our video "Through Older Eyes." Many representatives from overseas attended including French, Japanese, Tonga, New Zealand, Israel, America and England. Our video was purchased by a French woman who expressed interest in commencing a scheme there." Margaret McGregor, 1987 Annual Report



"In March 1985, Kevin Dallinger was appointed coordinator of the Foster Grandparents Scheme at Pleasant Creek, Stawell... the Scheme's first venture outside the Melbourne area... There were certainly many young people at the Centre who would have benefited greatly from the scheme, and it appeared the community of Stawell consisted of a large percentage of elderly residents. However, in this country area a commitment to the minimum 10 hours per week proved too difficult... and not one Foster Grandparent was recruited for Pleasant Creek..."
"The Scheme In Host Centres"

In my report last year I spoke about tin being a symbol for a tenth anniversary and that I hoped, like tin, our scheme would be 'resistant to corrosion and unusually malleable.' There is no doubt the last few years have been difficult. In the early years when funding for the program seemed an impossibility, we continued in faith knowing the worth of the program. I know that, like tin, the Foster Grandparent Scheme will not be eroded but it may have to change.

The only real issue is ensuring that foster grandparents and foster grandchildren can continue to enjoy that very special relationship which will be an enduring memory for those privileged to have seen it and especially for those who have been participants."

Margaret McGregor, President's Report (final) 1988 Annual Report

"Being their friend in their world was confronting to each of us. My own world before the beautiful ones had been blessed with marriage, a loving and caring daughter, grand and great-grandchildren and for these I was truly grateful. But my twilight years were becoming empty and I had become lonely and unwanted. Now, after nearly five years with these beautiful people, I feel wanted and loved and my ten hours per week has become 35 hours a week. Each day I return to my loved ones. I am truly grateful for being wanted, being loved and never lonely." Len Wagener



"Two separate groups seem to be emerging from the residue of deinstitutionalization: The established grans - many of whom are taking this time of change as an opportunity to review their involvement with the scheme - and the 'new recruits.' This latter group is reporting totally different experiences to those anecdotal tales of foster grans."

Kathy McGee, Southern Suburbs coordinator, 1991

When foster grandparent Cath Bryant met Sue Wershon and her daughter Michelle, they knew they were well suited right from the start. Their social worker used to say it was a match made in heaven. How right she was. One day while sharing a cuppa, Sue began to tell Cath about her mother, who had died seven years earlier. As Sue shared her memories, Cath discovered that the woman Sue was talking about had been her best friend at school. The two friends had lost touch during the war; now destiny had lead Cath to be a foster gran for her old friend's daughter and grandchild.

Edited excerpt from "Hand-picked grandparents," Herald Sun 1992

Ken Mast was the first fostergrandparent to hold the office of President of the Scheme. Although he only served as President for six months, one of the ways he left his mark was in the successful "Wings Of Love" fundraising raffle where he singlehandedly managed to persuade not one, not two, but three airlines - Australian Airlines, Cathay Pacific and Air Vanuatu --to each donate a holiday flight prize, and was himself the number one raffle ticket seller!

"It's been my salvation. Something to get up for."
Alice Tuttey, Moorabbin Standard , June 1995

GRAN TO THE RESCUE

Three Grans were visiting their children - all sitting in a group talking - when a sweet young person came in from the kitchen, where she was preparing the children's meal, wanting to know what she had to do with the custard powder to turn it into custard as there were no directions.

Exit one Gran, to instruct the sweet young person into the mysteries of the ancient art of making custard!
"Special People" 20th Anniversary booklet

Past Presidents and Staff

Presidents

Mr. J C Crisp: 1982 – 1984
Ms. Libby Saunders: 1984 - 1985
Mrs. Margaret McGregor: 1985 – 1988
Mrs. Anne McCulloch: 1988 - 1990
Mr. Frank Webber: 1990 - 1992
Mr. Ken Mast: 1992 - 1993
Mrs. Faye Dunstan: 1993 - 1995
Mr. Kevin Curran: 1995 - 1998
Mrs. Sylvia Giles: 1998 - 2001
Ms. Katherine Rechtman: 2001 – 2005
Ms. Norah Breekveldt: 2005 - 2008

Executive Officers / Managers

Maureen Breen
Irene Rolfe
Jane Ware
Julie Langdon

Coordinators (based in residential facilities) and Field Workers / Regional Coordinators

Margaret McGregor (founding coordinator)
(From Annual Reports 1982 onwards)
B Holmes
B O'Connor
R Whitty
M Greening
Tess Dowell
Judy Taylor
Robyn Pritchard
M. Head
Jan Ross
K Dallinger
G Glazebrook
Jane Barr
Martha Heady
Jan Coleman
Kevin Dallinger
Alison Whitby
Norma Howes
Rosemary Gibson
Jan Burns
Ailsa Denyer
Norma Howes
Kathy McGee
Elizabeth Kinrade
Libby Morrison
Debra Frey
Barbara Moran
Shirley Sinclair
Jutta Goodall
Barbara Moran
Jo Anne Hansby
Jenny Michael
Megan Erm
Sandra Littman
Robyn Murray

Sandy Martini
Claire Chatterton
Rod Clements
Helen Ridgeway
Denise Kosnar
Kathleen Oldham
Topsy Petchey
Lavinia Jenkin
Valli Mendez
Kathryn McEvoy
Rosemary Nicholls
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Zoe Sweeney
Hadassa Kessler
Karen Purtle
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Congratulations on the 30th

**extended
families** australia

supporting families
of children with a disability

Anniversary

