

- CancerLink
- Carers National Association
- ISIS (Black Mental Health Group Lewisham)
- King's Fund Centre Carers' Unit
- Lewisham Turkish Carers Project
- Man Sangathan
- North Kensington Family Centre
- Women's Alcohol Centre

QBAN (Kin)

"The lack of support from services means that some caring situations may be seriously neglected: especially where there are very young carers"

– A Study of Carers in Three Minority Ethnic communities

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Young Carers in Black and Minority Ethnic Communities WORKSHOP DAY REPORT

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Background to the workshop day

The idea for a workshop about Young Black Carers sprang from the Young Carers Project at Carers National Association and the Black Carers Initiative at the King's Fund Carers Unit. We both knew that the needs of young carers in Black and minority ethnic families formed an important part of our work. But we had come to realise that carers workers had few effective links with minority communities; whilst those active in those communities often had limited resources to deal with extensive issues such as racist violence, housing, welfare rights, refugees, and so on. As a result, young Black carers were being denied an effective voice; and there was a general lack of awareness amongst professionals of their existence.

"They would all individually tell me what problems THEY were having – nobody asked me what I felt like. You'd think they'd give me a break, but I was seen like everybody's social worker"

Our first step was to draw together a shortlist of interested colleagues from a range of voluntary sector services. We invited workers from minority ethnic organisations, and specialist staff from mainstream organisations. We agreed that there needed to be far more opportunity for agencies involved in different ways with families to work more closely together.

Two issues stood out in particular. First, that false assumptions about the family's role in minority cultures appeared to discriminate against young carers, leaving them to provide practical and emotional support. Second, it seemed normal practice for children to act as interpreters and to liaise with professionals, even on the most personal matters regarding the health of a parent.

We agreed that we needed to verify our awareness of these factors, to learn about the great many other issues which affected young carers in different situations around the country, and to plan an effective way to move forward.

So the idea of a workshop day was born.

Objectives of the day

The workshop day aimed to bring people together from a wide range of statutory and voluntary agencies in the field of health, social services, and education, with a particular emphasis on grassroots organisations working in minority ethnic communities. A list of delegates is given in the appendix to this report.

The overall objective was to create an awareness of young Black carers. We hoped to:

- pool the experience of those already supporting families in the community in a variety of settings
- share learning on how we could help young Black carers find a voice
- break down professional boundaries and establish a multi-disciplinary approach to working with young Black carers.

"People shouldn't make so many assumptions that the family will always help out. Well, that kind of talk, because that was what I used to get a lot. 'Well aren't there any aunts or uncles or anyone that can come in and help?' What would actually happen was that my Mum would shut a lot of people off who were in the extended family"

The speakers

● Joy Ann McCalman

Joy came across young carers in the course of researching her report – *The Forgotten People* – for the King's Fund and Help the Aged in 1988-9.

"Despite the greater awareness generally about carers, very little is known about children who are carers.

Three communities within the London Borough of Southwark were covered by the research – Asian, Afro-Caribbean and Vietnamese/Chinese. In all of these, I found children are playing a key role, ranging from 'helping out' another adult carer – usually their mother – after school to full personal care like bathing, washing and feeding.

Children were also observed to act as interpreters between the adults involved and the service providing agencies. Sometimes this caused problems where complex information needed to be communicated.

In one particular family, a young carer provided full care to her grandmother, and some assistance to her grandfather. She was the only person available to provide this support; and because she was a new resident, she was very unfamiliar with her way around the system. The role of the extended family is a myth. In the other families researched, I found that only immediate relatives were available to provide care.

I observed that there is an impact on children's school work – they were often tired, and unable to complete their homework requirements. They felt very lonely, and found that adults did not believe them when they described their situations. Some had been threatened that they would be taken into care; all wished they had someone to go to for practical help.

We must explore how we can best help them."

● Zubda Khan

Zubda Khan is the Inner City Development Officer of NSF – the National Schizophrenia Fellowship – an organisation for the carers and sufferers of severe mental illness. Through her work at Man Sangathan which is an NSF project in Southall, she has identified needs of young carers between the ages of 9 and 13.

“Through my own experiences as well as my outreach work in Southall, I have realised that families are under an enormous amount of pressure when one member is suffering from an illness, as services offered do not meet the families’ needs adequately.

As hardly any training is available when working with young carers, I had only my personal experience to draw on. I recognised that the support for these young carers would have to be varied to meet their needs effectively.

Young carers often have feelings of guilt, isolation, anger and confusion. They need to express these feelings as any other adult carer would.

Having recognised the problem we need to target resources. Resources which may improve the life of a carer are literature in their own language, interpreting services, counselling and advocacy. It is when there are gaps such as these that younger members of the family are expected to take on caring responsibilities which would not be tolerated within formal care services if young carers were recognised.

The young carers at Man Sangathan required support in how to cope with being a carer, the freedom to express their feelings without guilt, and to gain an understanding of the illness of the sufferer. These needs were met through counselling and art and music therapy, through which it was obvious that the emotions the young carers carried became much clearer and easier to cope with.

Young carers have been the forgotten ones in society for too long, and through carrying the feelings that I have mentioned into adult life, there is an enormous danger that they may become withdrawn or depressed as adults and

so a vicious circle is being perpetuated. Young carers must be allowed to come to terms with their emotions and encouraged to deal with the problems they face.

Something desperately needs to be done and we as professionals have the power to do something positive. It might be as little as approaching the younger members of the family and talking to them next time you make a home visit. This makes all the difference to the carer as it means their contribution as a carer has been recognised.

There are gaps in training for professionals. We need to look at this whole area and take into consideration young carers, and what form of support we can effectively offer them.

I have now moved on from Project Co-ordinator at Man Sangathan to become Inner City Development Officer at the NSF. One of my aims is to develop services for young carers from the ethnic minorities. This Conference for me is a step forward in taking action, as I hope it is for all of you."

"Black social workers – I think there should be more of them actually explaining step by step the maze of social security, what services can be offered by the council"

The consumer view

It was important that the workshop day provided an opportunity for the voice of young people to be heard. Some of the delegates who attended were able to speak from their own experience, or, whilst not feeling they were 'carers', could recognise common issues from their own childhood.

It is easy to forget, however, that for people who from an early age have learned to put other people's needs first, 'speaking out' can be a painful and frustrating process, which requires a great deal of support. We hoped that, by speaking to us, the process could also be an empowering one, and are deeply grateful to the two young people who allowed us to use their contributions.

A young Nigerian man described his situation on tape.

My Mum lives with my younger sister who has just passed her 15th birthday. My Mum has been steadily going blind for about twelve years now, and she has also got mental health problems. When my Mum had my younger sister, we found ourselves having to do even more to look after her and I used to have to child-mind my sister who was 3 at the time. When my sister was born I was about 9.

A young woman from an Irish family gave us a written interview, which we put on to tape for the workshop day.

My first perception was that there was something wrong with my father – he wasn't like other people's fathers. Then when I was three or four, I remember being sent to a foster home for a few weeks. There were some references to my mother having some kind of breakdown at that time – I remember coming home and thinking, 'I'll have to look after myself from now on.' Then with my youngest brother, again he had some kind of breakdown. Then the cycle of him being in and out of institutions began.

We have quoted from these young carers' experiences to illustrate parts of this report.

Workshop sessions

● What are the issues facing young carers from Black and minority ethnic communities?

Isolation

Young people are missing out on their childhood – they cannot participate in the activities of their peers and have to 'grow up' faster.

Young people often do not know what help may be on offer or who to turn to, and those who do not have English as a first language may have difficulty in communicating and understanding what is happening.

There is often pressure put on the young carer to care, from within their family and their own community. There may be feelings of guilt if they do not take up this role.

Young carers are often given the responsibilities to carry out adult tasks. On the other hand they are not fully informed and not involved in the decision-making.

Racism

There is the myth that within the Black community, because of extended family networks, the carer will receive support. In reality people are missing out on services to which they are entitled.

The young Black carer can be trapped between two cultures, with pressure coming from both sides to conform.

Young people are often expected to take on the responsibility for interpreting for the person they are caring for. This can be regardless of their age, their ability to comprehend the information given to them or to any cultural factors which may make it difficult.

Access to services

There is very little evidence of services which are appropriate to the needs

of young Black carers.

Those services which are available are not culturally sensitive. Service providers do not consult directly with families or tailor services to meet their particular needs.

Information about support may be inaccessible to people whose first language is not English; this results in many missing out on vital benefits, social services, and housing.

Some other issues were pinpointed:

- the particular hardship faced by single parent families
- the lack of confidence on the part of young carers to approach adults and raise concerns
- issues of loss and bereavement around entering, and leaving the caring role

● What are the barriers to working with young black carers?

Terms and perceptions

Although many Black people may be caring for someone in their family, they do not see themselves as carers, but as doing the responsible and accepted thing. Many felt that this was the most important issue to be tackled – members of the Black community should be empowered to identify with organisations and services aimed at carers.

Service providers' perceptions of need may differ from those of the family, but also from those of other agencies.

Service issues

There is an overall lack of awareness of young Black carers' needs amongst professionals. Where action is taken, it is all too often to deal with behavioural

problems, such as lateness for school, rather than the underlying causes.

Little has been done to make services appropriate to the Black community. This means that although carers may be aware of what is available, they may not use them because, for example, their dietary, language or religious needs are not catered for. During the present economic climate there may be a reluctance on the part of service providers to commit resources to addressing the needs of young Black carers.

Someone to talk to

There is a lack of trust – the fear around talking to social workers can cause problems at home, and the fear of a child being removed from the family is very apparent. There is no independent agency to advise and support young carers.

The Media

Conflicting images are seen in the media, which portrays down-trodden young carers, whilst giving awards to others. It was felt that the media did nothing for the cause of all young carers, and as they already have a negative view of Black and minority ethnic people, the situations of young carers from these communities would not be treated in a very sympathetic way.

"I don't think the sometimes heavy-handed attitude of social services or other voluntary agencies should be the same as it is because that is one really frightening thing that I had about social services in particular, this 'We're going to put you into care' thing"

The way forward

● Professional and service targets

A constantly recurring theme of the conference was the need for more joint working between professionals of different disciplines, and with members of the community. There was a great deal of discussion about the difficulty, or even reluctance, to work together where young carers are concerned. In addition:

- Workers should have up-to-date knowledge of the Children Act and Community Care Act, and how they can be used to support young Black carers.
- Good practice should be encouraged by making use of interpreting and translating services.
- More training is needed in the particular ways to help young Black carers.
- National bodies should argue to get these issues included in the centre of local authority agendas.

● Awareness

Awareness raising across the board is essential. This should include educating professionals about what services are available and how to make referrals; but also about the sensitive and vulnerable position of young Black carers.

Information should be targeted at young people themselves who may not see themselves as carers. This could be done through contact with schools and youth clubs; through roadshows, or children's books.

Agencies themselves, when producing information or developing services, should ensure that issues for young Black carers are taken into account.

Independent, confidential support should be developed for young Black carers, independent of the statutory authorities.

Care must be taken to ensure that the media does not exploit young people and that their personal experiences are not misused.

Further action

- Produce a report of the conference to be used as the basis for good practice and awareness-raising.
- Prepare a 'charter of rights' for young Black carers, focusing on children's rights, the rights of carers, and equal opportunities issues.
- Establish a 'standing committee' to continue the initiative started at the workshop day.

● The proposed Standing Committee

Provisional representation:

Carers National Association Young Carers Project
King's Fund Centre Carers' Unit
Ethnic Minorities Workers
Social Services
Health Services
Education Services
Voluntary organisations
Young Black carers, former carers or their representatives
Equal opportunities advisors
UK-wide representation

Aims

- Produce a report of the conference and follow up with awareness raising articles
- Promote awareness of young Black carers issues
- Act as an information source for and about services
- Facilitate a national network of young Black carers to raise awareness about issues
- Develop guidelines, information packs and briefing packs from the conference and through future work

Appendices

▼ Workshop guidelines

All group members are expected to share in the responsibility for creating a safe, constructive and non-oppressive environment in which everyone feels able to participate, and for drawing attention in a supportive and constructive way to any behaviour which falls outside these guidelines.

Specifically this will include:

- Group members should all be responsible for ensuring that everyone has the opportunity to contribute and to be heard.
- Everyone should respect other people's right to their own opinion – thus if challenging or commenting on another person's statements or views, criticism should be given constructively, sensitively and specifically.
- Everyone should recognise and respect differences of race, culture, class, sexuality, age, ability etc., and should not make assumptions that such differences do not exist within the group.
- This should also include recognition and respect for differences in knowledge, skills and experience and the need to learn by sharing. Members should feel free and comfortable to say if they do not understand something and other members should assist each other by explaining and sharing knowledge and ideas where they are able.
- Any member wishing any information to be treated in confidence should make this clear to the group.
- Group members should make every effort to arrive and start on time.

Any members wishing to propose any additions may raise and agree them with the group at any time.



Further reading

Atkin, K. and Rowlings, J. (1991)

Informal Care and Black Communities. HMSO

Bilsborrow, S. (forthcoming)

You grow up fast, as well... – Young Carers on Merseyside. Barnardos

Brown, E.M. (1989)

My Parent's Keeper: Adult Children of the Emotionally Disturbed.

New Harbinger Publications, Inc.

Dugmore, J. (1991)

Language Lessons. Community Care 7th February

Fallon, K.M. (1990)

An Involuntary Workforce. Community Care 4th January

Grimshaw, R. (1992)

Children of Parents with Parkinson's Disease: A Research Report for the Parkinson's Disease Society. National Children's Bureau

Honigsbaum, N. (1991)

HIV, AIDS and Children: A Cause for Concern. National Children's Bureau

McCalman, J. (1990)

The Forgotten People: A Study of Carers in Three Minority Ethnic Communities. King's Fund Centre

Meredith, H. (1991)

Young Carers – The Unacceptable Face of Community Care. Social Work and Social Sciences Review 2 (3 – supplement)

Sandwell Metropolitan Borough Council (R. Page) (1988)

Report on the Initial Survey Investigating the Number of Young Carers in Sandwell Secondary Schools.

Tameside Metropolitan Borough Council (A. O'Neil) (1988)

Young Carers – The Tameside Research.

▼ **Summary of feedback on the workshop day**

- The day met my needs and expectations much more than I thought it would.
- Positive, instructive and educative day.
- I have been to countless workshops and training sessions. This was the best! I am extremely impressed.
- I had a wonderful day; I have also made many useful contacts.
- I felt very moved by the testimony on tape of the two young carers.
- I learned a lot and feel enthusiastic about finding out where all the Black and minority ethnic young carers are in this district.
- The taped interviews with the young carers were very powerful.
- A very important subject, that was sensitively treated.
- When people think about what approach to take to young Black carers (or young carers generally) from a professional aspect, they get bogged down in administrative and departmental thinking. It's like a wall of negativity which rises to barricade action. The idea of a Children's Charter is an interesting one. The issue of young carers demands answers to "What is a child?"



Delegates

- **Beverley Harrison** Evaluation Officer
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- **Clive Yeadon** Principal Officer (Disability)
Barnardos, Ilford
- **Mrs Chandra Sanghavi** Research Worker
Medway Community Support Centre
- **Miss Judith C. Sage** Research Worker
Medway Community Support Centre
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Wandsworth Crossroads
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- **Nansubuga Kaweesa** Development Worker
Lewisham Association of People with Disabilities
- **Kishor Patel** Development Officer
Ethnic Minorities RNIB
- **Ricky Tang** Community Worker
Camden Chinese Community Centre
- **Mary Kersey** Social Worker
RB Kensington and Chelsea
- **Sandra Bilsborrow** Young Carers' Research Worker
Barnardos, Liverpool
- **Mr Vasant Shendge** Co-ordinator (Respite Care)
Asian People with Disabilities Alliance
- **Sandie Ching** Supervisor
Bishop Ho Ming Wah Association
- **Ms Pratima Solanki** District Home Care Organiser
Social Services Haringey
- **Nwadi Okereke** Training Co-ordinator
FIAC
- **Alison McFadden**
The Network
- **Mike Hatch** Disabled Persons' Act Worker
Glos County Council Soc Services

- **Iris Gelly** Specialist Social Worker
Hanley Road Neighbourhood Office
- **Patricia Worsnip** Public Affairs Team Assistant
Carers National Association
- **Judi Dumont** Service Co-ordinator
Crossroads Care
- **Madhu Patel** Asian Development Worker
Family Placement Scheme
- **Raj Gupta** Asian Social Worker
Islington Council SSD
- **Ahmed Shahab** Manager/Home School Liaison Officer
Bedford Education Service
- **Mr Ranjit Sohal** Education Welfare Officer
Bedford Education Service
- **Reginald G Coley** Carers' Liaison Officer
Newham Social Services
- **Helen Armstrong**
Carers' Centre Hove, West Sussex
- **David E R Obaze** National Development Officer
RUBV
- **Joyce Usher** Carers' Support Worker
Carers Barking & Dagenham
- **J Abimu Heal** Home/School Liaison Officer
Bedford Education Service
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London NW5
- **Helen Owen** Projects co-ordinator
Liverpool Pagoda Centre



Workshop day organisers

- **Kayhan Alsaç** is the Turkish Carers' Worker based at Carers Lewisham, working to identify and to improve support to Turkish carers in the locality. Ballantyne, Lushington Road, Bellingham, SE6 3RJ. 081-697 7185
- **Pavlina Georgiades**, from the Women's Alcohol Centre in North London, is their Childcare worker who offers support to the children of those people with alcohol related problems. 66a Drayton Park, N5 1ND. 071-224 4581
- **Zubda Khan**, based at the National Schizophrenia Fellowship, is the Inner City Development Officer. She develops and supports project work for people with mental illness and their carers. 28 Castle Street, Kingston-upon-Thames, Surrey KT1 1SF. 081-547 3937
- **Huw Meredith** is Young Carers Worker at Carers National Association. The project, funded by the Department of Health, co-ordinates research, development and support work nationally for young carers. 29 Chilworth Mews, W2 3RG. 071-724 7776
- **Joy McCalman**, at the time of the workshop day, worked with North Kensington Family Centre in London.
- **Meena Patel** is Development Co-ordinator for Black and Minority Ethnic Services in CancerLink, developing services for black people affected by cancer. 17 Britannia Street, WC1X 9JN. 071-833 2818
- **Karen Shelton** from Isis, a Black Mental Health Group based in Lewisham, provides support and advice to African Caribbean people experiencing mental health problems, as well as their carers. The Playtower, Ladywell Road, SE13 7UW. 081-314 1660
- **Lydia Yee** is a Development Officer in the King's Fund Centre Carers' Unit. She works primarily on Black Carers' issues through both service development work and the production of information for them. 126 Albert Street, NW1 7NF. 071-267 6111

You are invited to contact any of the organisers for further information.



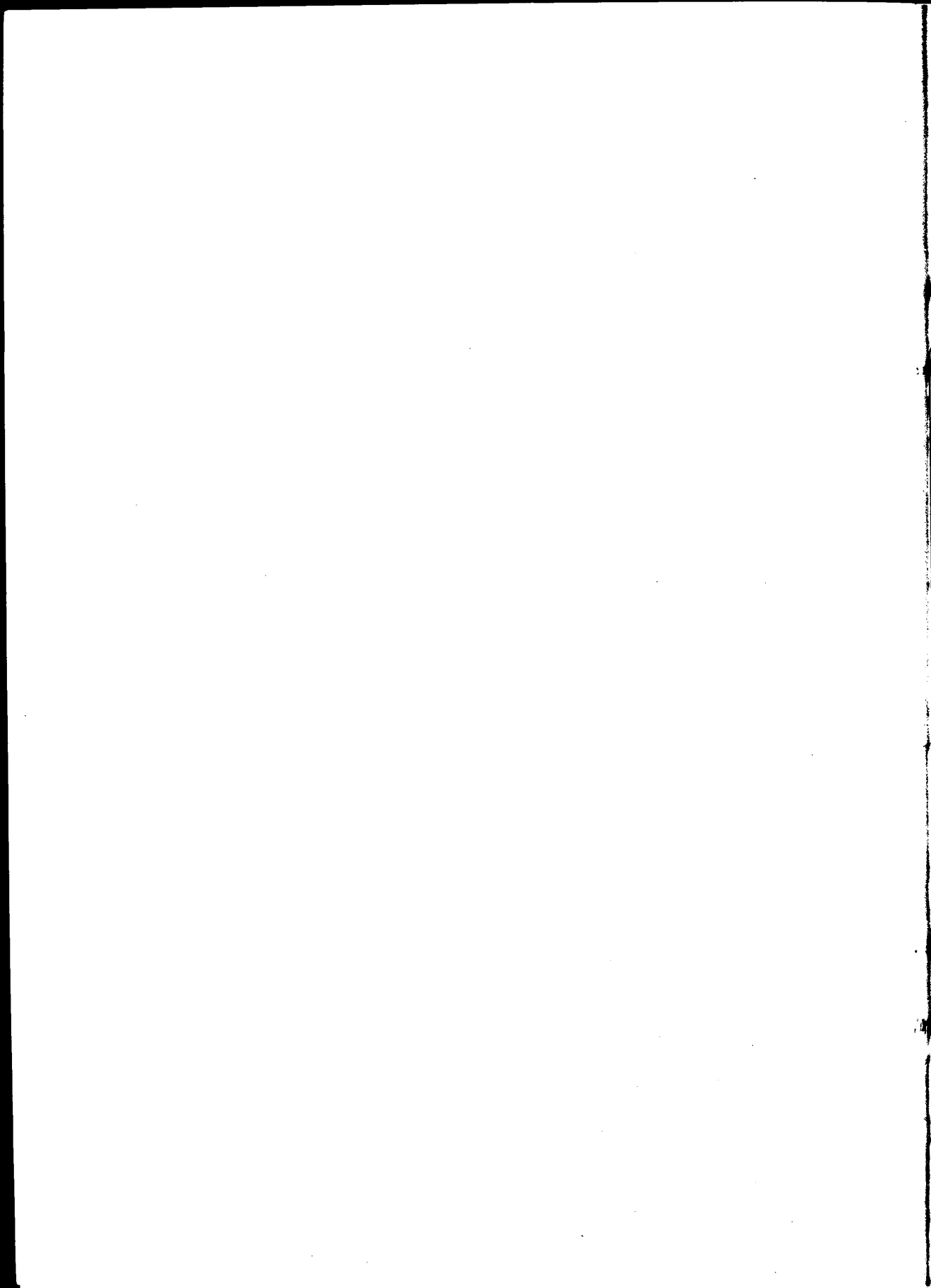
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- The two young carers who shared their testimony on cassette tape with workshop delegates. They helped us to look at the situation of young Black carers, and made us determined to find ways of supporting them.
- Diane Gaston of Carers National Association, for managing design and print production.
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- Tattersall Hammarling & Silk, designers.

"I think that one positive thing that did happen was that I managed to break quite a lot of stereotypes. I think it made me quite tough actually. I had to grow up pretty quickly. I think that could be either deemed positive or negative"



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