

Aware

Newsletter of the East Sussex Disability Association



Actively empowering and supporting disabled people

Issue 32 September 2008

ESDA Platinum Party Celebrations



Group picture at ESDA's 70th birthday party with Lord Morris of Manchester second left

One of our local groups, DELTA, organised a party to celebrate our 70th birthday. The event was an afternoon tea at Deans Place, Alfriston on 19th June.

They invited representatives from all the local groups, the ESDA Board and office together with dignitaries and special guests from around the County to join with them in celebrating this great achievement.

We were also very fortunate to have Lord Alf Morris of Manchester as our guest of honour.

Lord Morris gave an inspiring speech outlining how he became involved in disability issues and how he pushed for improvements for disabled people during his time in the House of Commons.

For those of you who don't know of Lord Morris, he is renowned for his work on behalf of all disabled people. He effected a change to a great many lives with his Chronically Sick and Disabled Persons Bill in 1970.

He was appointed the world's first Minister for Disabled People in 1974 under then Prime Minister Harold Wilson. He went on to be chairman of the World Committee on Disabled People's Rights.

He had also brought a number of signed copies of his book which became an instant bestseller on the day.

DELTA members really know how to throw a party and the event was an enormous success. Everyone who attended had a great time.

Our thanks go to Robert Benfield, DELTA's Chair for all the efforts his small team put into making the day a fantastic celebration of ESDA's 70 years.

Special thanks must go to Coralie Clement and Edwina Morris for all their hard work in ensuring the event was a success.

Thanks also to Ann Payne for the birthday cake.

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Obituary: Joan Pearce



It is with sadness that I have to inform members that Joan Pearce has passed away.

Joan has been an ESDA board member and Chairman of the

Seaford Committee since before I took up the job of Chief Executive. She has also been on several governing bodies giving of her time freely in order to help others.

There is nothing one can say at this time except she will be sadly missed.

Our thoughts and prayers are with you, Dave and family at this sad time.

Reg McLaughlin

New Age Kurling: Seaford Kurlers

Seaford Kurlers was formed about a year ago with Lottery Funding and is part of ESDA's Seaford Committee. What is New Age Kurling you may ask?

Based on the ice version, it uses a 'stone' made with resin and underneath there are three large ball bearings. The stone is sent down the side of a badminton court to a target at the far end. It can be played solo, in pairs or three up. I first saw an article in Aware showing the Lewes DELTA Group and it seemed a way to bring disabled people into a sport on equal terms with non-disabled people.

Our club is roughly divided between disabled and non-disabled people. It's great to see everyone mixing on the lanes and the noise and banter are terrific.

We recently went to The World Championships on Hayling Island. Although a two day event we only went on Sunday when the pairs played. We have about 50 members and sent six pairs, along with a gaggle of supporters.

We had moderate success. Two pairs, (Joyce Lane, Barbara Bradley, Sheila Matthews and Harry Bucklew) got through to the last 16. Three games were lost on a 'measure'. There were some 52 pairs playing. Two of the best players came from Scotland and despite being limbless they delivered the stones from their chairs with devastating accuracy.

We meet every Tuesday between 2pm and 4pm at the Downs Leisure Centre. We do not have a membership fee. You just turn up and pay £2.50 for the two hour meeting. Why not join us? Bob Matthews, Organiser, Seaford Kurlers, 01323 892647, matbobshe@aol.com



Reg McLaughlin, CEO

Editorial

As you will notice this edition of *Aware* has a new look with lots of new features. We

welcome your comments.

What we are also looking for are people who will be willing to write book and television reviews. So, all you budding writers get your thoughts onto paper. As well as reviewers we want your letters to the editor. We want to make this your magazine so with your help we can make it represent your views and interests.

As you know this is ESDA's 70th year Celebrations. We want to use this opportunity to get ESDA better known, but also to raise funds for ESDA to continue for another 70 years.

The main article is about independent living. We want to ensure that the services that you receive are the ones you want. Until February 2007 we were the organisation that was supporting people on direct payments but we lost the contract to a profit making organisation. We want to know if the service you are now receiving is good, bad or indifferent. Let us know.

I do hope you enjoy reading this issue, please email us your stories, reviews and letters to info@esda.org.uk or write to the Editor at ESDA, 1 Faraday Close, Eastbourne BN22 9BH.



Tony Powell, Chairman

View from the Chairman

Many people enjoy the experience of going out and about to visit places of interest and leisure. None more so than a large

number of our members. Yet what may be a simple activity for many in the community frequently turns out to be a major planning exercise for many disabled people and their families. That is why I pay tribute to all those people in ESDA's local groups who have the hard task of organising all the arrangements for such trips.

It is very important we continue to organise these trips because many local ESDA members live on their own with little opportunity to meet people and socialise outside of these regular gatherings and trips. While, from time to time, changes are forced upon us, we continue to work very hard to cope with these changes to enable our members to be able to keep on visiting these places of interest.

On the subject of outdoor activities, I recently attended with my wife Pat, a sponsored walk around the Arlington Reservoir. Our enjoyment with actually being on this walk was only bettered, I think, by that of watching the way two of our wheelchair users refused to let two locked gates hinder their progress in completing this activity. The way they dealt with this challenge reminded me, very much, of the way the members of the Royal Artillery carried their field guns over an obstacle course at the Royal Tournament. The serious side of this is, of course, that the wheelchair users should have had freedom of access. The same freedom of access enjoyed by us walkers.

Challenging times for ESDA continue from day to day as we all strive to ensure that the very valuable services we offer to disabled people are secured and developed, in a climate of ever increasing and rapid change. There is however, one important factor that all these valuable services depend on. That is the involvement of people. Please do get involved and participate in ESDA's local groups. We most certainly continue to need you to do so.

Closing the gap: a five-year strategy

(Article adapted from RADAR article of the same name)

On 3 May, the Government published its Independent Living Strategy, the product of an 18-month review led by the Office for Disability Issues (ODI). The strategy sets out a strong vision for services that support disabled people to participate fully in society. However, ESDA believes it must be backed up by legislation if all disabled people in the UK are to realise independent living.

The Independent Living Strategy sets out a five-year cross-government plan for closing the gap. The aims are that by 2013 disabled people have more choice and control over how our needs for support and equipment are met and to make significant progress in tackling barriers to health, housing, transport, and employment opportunities.

The detail is largely a summary of existing initiatives: moves to self-directed support and the commitment to ensure all publicly funded housing meets the Lifetime Homes criteria by 2011. ESDA welcomes the pledges to:

- Review charging policies against the Disability Equality Duty;
- Remove disincentives in the benefits system to disabled people taking up public appointments; and
- 'Initiatives' to promote better understanding of Independent Living, boost disabled people's leadership and involvement and develop user-led advocacy and brokerage.

However, notable by its absence is the radical reform programme disabled people want.

There is no mention of reform of eligibility criteria for social care, protection against involuntary institutionalisation or the lack of portable support packages.

The Government continues to state that change can be brought about through the existing framework. This goes against advice from the Review's Expert Panel that, without a new legislative framework rooted in Independent Living principles, guaranteeing a minimum standard of support and providing for individual redress, the strategy risks having but a 'limited impact' and failing to meet the aspirations of disabled people.

Another weakness is that the Strategy does not pitch Independent Living as a human rights issue. Nor does it explain how it is crucial for gender equality, ending state exploitation of carers or safeguarding the rights of children.

ESDA does not believe the Strategy represents a watershed moment, but it could be an important milestone. It needs legislative underpinning, but may hold the seeds of real progress, if we actively engage with it and hold the Government to account.

Once the Government publishes its Green Paper on Social Care, due out later this year, we will have full details of how the Government aims to fulfil its vision, laid out in the Life Chances report, that by 2025 disabled people have full opportunities and choices to improve our quality of life and will be

respected and included as equal members of society.

The 'Independent Living Review' was set up by the Office for Disability Issues in July 2006 to come up with practical proposals to deliver Independent Living, develop the business case for investment and consider the need for changes to the law. The Review Team was advised by an Expert Panel chaired by Baroness Jane Campbell DBE. The Strategy includes Government commitments in the following areas:

➤ **Promoting Independent Living**

To promote a shared understanding of the principles and practice of Independent Living

➤ **Young disabled people in transition to adulthood**

Government will seek to achieve a 'seamless transition into adulthood for young disabled people, including those with complex health needs, in all aspects of their life' by means of:

➤ **Health**

Government will enhance the understanding of health services' contribution to Independent

Living and enable disabled people to have choice and control over their non-acute healthcare needs, and manage their own long-term conditions

➤ **Transport and Mobility**

Government will enhance personal mobility and transport choices for disabled people including those whose needs can't be met by public transport and improve the service disabled



people receive from transport providers

➤ **Housing**

The Strategy pledges action to maximise disabled people's housing opportunities and choices by:

➤ **Disabled Parents**

Government will promote more joined up working locally to provide timely and flexible support to disabled parents, including by encouraging inter-agency protocols to support disabled parents and their children

➤ **Employment and Economic Wellbeing**

There will be a cross-Government national strategy on job retention. Government will try to increase access to volunteering opportunities for disabled people

➤ **Personalisation, choice and control**

The transformation of social care to deliver choice, control and high quality preventative services is to be achieved

➤ **Support, information, advocacy and brokerage**

The goal is a universal information, advice and advocacy service for people who need support to exercise real choice and control.

➤ **Older People**

The Office for Disability Issues, in partnership with other Government departments, will develop and publish a cross-Government toolkit that provides a 'one stop' information resource on Independent Living for older people at a national, regional and local level.

➤ **Measuring Progress**

Progress on the Strategy will be

measured using the new performance framework, in particular the Equalities Public Services Agreement (PSA) and ODI 'Life Chances' indicators.

➤ **Independent Living Strategy, as part of its annual report**

Life Chances departments will review delivery in time for the next Spending Review 2011-2014)

The Government will review the need for Legislation if sufficient progress has not been made against the outcomes by 2013. An Independent Living Scrutiny Group is proposed to monitor progress annually and report to ODI Board of Management and Ministerial Group. Membership would include members of Equality 2025 and members drawn from the Expert Panel.



ESDA says: Waving a Strategy at a Care Manager who wants to cut your package is not going to work. Involvement in monitoring is vital.

The crucial point is that at some point Government needs to go beyond listening and then rejecting key points to a more genuine form of co-production where listening is followed by real action and changes to policy.

Alongside an insider scrutiny group of disabled people, independent external scrutiny will be vital with engagement of disabled people at local as well as national level. ESDA plans to be very involved in this.

One of the main arguments against a legislative commitment to Independent Living is the prohibitive cost. However, ESDA argues that investment now will bring returns to the Government significantly exceeding anything that it might cost. To take three examples:

1. On unemployment, the Government is aiming to get '1 million disabled people off Incapacity Benefits and back to work in the next 10 years'. The Incapacity Benefits claimant figures remain stubbornly high, despite the Labour Government having consistently worked to reduce them. At the moment, if a disabled person is receiving a support package in a specific Local Authority, it can be very difficult to move. If there were portable support available, people would find it easier to relocate to take up work. And if we were able to purchase our own care through Individual Budgets, we could buy the support and equipment that we know we need, rather than that we are deemed to be eligible for.

2. On adaptations, the "Better outcomes, lower costs" report from the Office of Disability Issues finds that:

Falls leading to hip fracture cost the UK £726 million in 2000. Housing adaptations including grab rails and better lighting, reduce the number of falls for a fraction of the cost. Providing adaptations can speed up hospital discharge or prevent hospital admission by preventing accident and illness. The

Welsh Care and Repair Agencies' Rapid Response programme estimates savings of up to £40 million for a £2.3 million expenditure. Good housing adaptations can enable seriously disabled people to move out of residential care, with estimated potential savings of £10 million a year on residential care costs in England. Home modifications can prevent or delay residential care for disabled older people. One year's delay will save £26,000 per person, less the cost of adaptation which averages at £6,000.

3. On informal carers, there are an estimated 6 million in the UK, with 1.25 million providing at least 50 hours of care a week without pay. Many carers are unable to work because of their caring responsibilities. Reducing the burden on informal carers is not only just, but would enable people to work and provide a financial return to the economy as well.

But, it's not just about costs and return to the economy. Providing coherent and effective Independent Living support enables disabled people to live the lives we want to live, in homes that are accessible to us, participating in leisure activities, social activities, our communities, or our family life without our family having to be our carers.

The final verdict

While the Strategy may not represent a watershed in the fight for Independent Living, it could yet become an important milestone. Its impact will be diminished by the lack of legislative underpinning but insiders are convinced it holds the seeds of real progress - if we engage actively with it and hold Government to account.

For a full copy of RADAR "Closing the Gap a five-year Strategy contact the ESDA office or see the new ESDA website: www.ESDA.org.uk

Full of Life

By 2020, half the population of the UK will be aged 50 and over. This brings fundamental changes to the nature of society and we want to ensure we adapt successfully to these changes.

This is a long-term challenge which we will need the support of everyone. Under the Full of Life banner, the Government and other supporting groups are undertaking a wide programme of activity to raise the profile of the issues around older people and our ageing society.

UK Older People's Day will be a key focus for 2008 - it will take place on the 1st October 2008. The main aims for the day are to:

- Celebrate the huge contribution older people make to our society and economy
- Create a positive view of later life and tackle outdated stereotypes
- Raise awareness of the opportunities and entitlements for older people across society
- Ensure older people don't feel excluded or isolated from the rest of society.

Get involved - there will be events across the country and we encourage you to get involved. This year the focus of the day is bringing generations together to promote greater understanding and respect. For example:

A grandchild spending time with their grandparents or a partnership between an older people's group and a school or youth group, enabling different generations to learn from each other.

Taking advantage of the huge amount of knowledge held by older workers, and inviting employees to learn from each other. Further information:

<http://campaigns.direct.gov.uk/fulloflife/>

Local Involvement Network (LINK)



The County LINK team - Val, Elizabeth, Jane and Jan

East Sussex LINK - The County's Local Involvement Network in Health and Social Care.

An update on the work of the LINK

We are pleased to announce that the full staff team are now in place and working hard to support the emerging LINK. Managing the team is Elizabeth Mackie, while Val Shoebridge and Jan Cutting are undertaking development work across East Sussex and Jane Hay is our administrator.

In the past month we have been establishing information to take out to the public and have started attending meetings and events to engage with the community. If you are involved in a group or organisation who would like a presentation on the LINK please contact the office and we will be happy to make some arrangements with you.

The website is under construction at the moment and should be live in the next couple of weeks. The address will be: www.thecountylink.net.

We now have information packs, leaflets and forms to register your interest in participating in the LINK. The level of

your participation can be from receiving a newsletter, attending short or longer term series of meetings on specific issues or being involved in the core group.

Forthcoming meetings in public

We have arranged the following meetings at which all will have an opportunity to participate:

Thursday 4 September
2.00pm-4.30pm

United Reformed Church, Croft Road, Crowborough, TN6 1HA. The theme for this meeting will be Adult Social Care and Cross Border Working.

Tuesday 30 September
10.00am-2.30pm

Uckfield Civic Centre, Uckfield, TN22 1AE. The main topic will be the election process for the Core Group. As lunch will be provided for this meeting we would be grateful if you could let us know if you will be attending.

We are always happy to answer any questions or queries you may have or to send information to you and don't forget to register your interest in the LINK. Our telephone number is 01323 514510, text 07968 119806, email:

info@thecountylink.net or write to; 1 Faraday Close, Eastbourne, BN22 9BH.



The County LINK Road show

Newhaven Strategic Network

Newhaven is a strategic town with a vision. The town partnership is called Newhaven Strategic Network (NSN). Tracey Evans works as the Development Manager and is Chair of Lewes District Local Strategic Partnership. She has contributed to ensure issues of equality and diversity are of primary concern and positively promotes anti-bias.



The vision for Newhaven is based around three key outcomes - successful people, successful business and a sustainable environment. In order to realise this vision there is the need to tackle Newhaven's deprivation, build better facilities and develop a stronger community.

Lewes District Local Strategic Partnership (Local Voices, Local Choices) comprises representatives from the business, community, voluntary and statutory sectors, as well as representatives from five Area Partnerships covering the towns of Newhaven, Seaford, Peacehaven and Telscombe, Lewes and the rural parts of the District.

The long term vision is of vibrant, distinctive, safe and sustainable communities where everyone who lives, works, visits or studies in the District support one another and takes care of the environment - a community to be proud of. Underpinning this vision are three principles:

Sustainability - understanding the environmental, social economic and ecological impact of current and future actions and taking account of this in policies and work programmes;

Equality and Diversity - reducing poverty and social exclusion and closing the deprivation gap in parts of the District. Particularly being concerned with understanding and meeting the needs of young people, older people and those from minority groups;

Empowerment and Participation - listening to local people and communities and encouraging involvement in local decision-making.

East Sussex Integrated Sustainable Community Strategy (Pride of Place 2008-2026) is the joint policy working towards a better future for local people and local communities. "It is a great privilege to present Pride of Place - our joint policy statement, which sets out the vision for East Sussex to 2026. It includes the ambitious plans of our partner agencies, organisations and communities. Our vision is to address the inequalities in our county, and create successful people, successful businesses and a sustainable environment.

The aim is to achieve a better quality of life for all local people and improve where we live, work and spend our leisure time. It has been developed through extensive consultation and collaboration. It will be regularly reviewed and updated. Personal accountability means that every individual has a role to play and can shape our future.

Together we can tackle challenges such as deprivation, community safety and access to local services and climate change. East Sussex is a historic and unique county, with beautiful countryside and coastline. It offers a diverse collection of towns, villages and rural communities and we need to ensure the continuing promotion of equal opportunities.

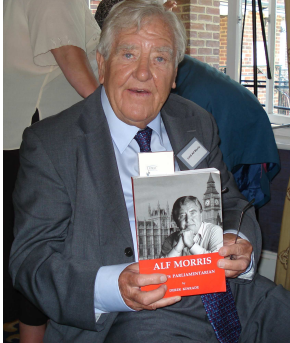
Pride of Place is about partnership working, where we unite around our common aims. We can achieve a great deal working together. This strategy provides the framework for action."

Tracey Evans - Foreword, Pride of Place 2008-2026. Tracey can be contacted at Newhaven Strategic Network on 01273 517657 or nsn@ncda.org.uk Please visit the website: www.newhaven-regeneration.org

Book Reviews

Alf Morris Peoples Parliamentarian

by Derek Kinrade



As someone who became disabled in 1983 and was busy coping with three children, I have to be honest and say I'd not heard of Alf Morris. In a way this meant when I read the book, I then

knew who it was that had made life better for all of us with disabilities.

Alf is an amazing man. He started out in life with everything stacked against him but was and still is a fighter for what he believes in, that all disabled people should have rights like anyone else in education, benefits, pensions, transport, and access to buildings. When I use my Motobility car and my Blue Badge I have Alf to thank.

I have in my lifetime seen improvements for people with disabilities. I'm sure Alf would agree we still have a way to go, but today our lives are certainly better than in 1938 when ESDA was formed. This was made possible by Alf Morris and his friends who backed him and his Bill to change the law, as it travelled the often treacherous route through the House of Commons and House of Lords. Thank you Alf, it is so good to know that people like you are prepared to fight for us all. If more people read the book they would understand what a bumpy ride it has been keeping the momentum going!

PS: ESDA's President Lady Jane Lloyd's husband Lord Lloyd gave his time for free to help the cause of one group of people, read the book to find out which ones!

Reviewer: Coralie Clement

The Uncommon Reader

by Alan Bennett

Now I love Alan Bennett's work; I think it's his bittersweet humour and wonderful way with words. The characters he writes about always seem real and I find I know people just like them. He famously had a lady living in caravan in his drive and I have a friend who has someone living in his shed!

Anyway, onto the subject of this review. This is a great little book. It starts with the Queen finding the mobile library at Buckingham Palace as she's chasing the corgis. So as not to appear rude she borrows a book and then another and becomes hooked on reading. The Queen's famous sense of duty and 'doing the right thing' begins to suffer. She finds that literature makes her question her life and the world around her.

In his portrayal of the Queen, Alan Bennett has created an eminently believable and endearingly loveable character. In a similar way to Helen Mirren on the screen, Alan Bennett has shown us a human being with real strengths and failings.

Above all this book is a delight, it's funny, thought provoking and easily devoured in a few hours. I finished it in an evening and then started it again.

I'd advise the same as the Country Life reviewer who writes, "Turn off the phone, lock the door, and devour it".

Reviewer: Nick Tapp

Letters to the Editor



I read the following article in a recent addition of the Metro. I think that it is about time that learning disabled people are fighting for their rights. As a dyslexic person I am fed up with people thinking that it is ok to test me when it is not necessary. So go for it medical student. Name withheld.

Dyslexic student in exams court battle (Metro, Tuesday, July 29, 2008)

A dyslexic medical student is taking legal action against the General Medical Council over its use of multiple choice tests. Naomi Gadian says the exams discriminate against people who have the learning disability that can hinder a person's ability to read and write. The 21-year-old student said the system was unfair. 'Patients aren't going to ask you, "Here's four answers. Which one is right?";' she added. The GMC said it had recently issued new guidance for medical schools to improve the accessibility of education for students with disabilities.

Ed: if you are experiencing discrimination we want to know about it. Please contact us by email info@esda.org.uk or post.



I would like to bring to your reader's attention the article in the metro "Disabled Killed by Discrimination". **Vin Tapp**

Disabled Killed by Discrimination

Patients with learning disabilities are being neglected or even dying at the hands of the NHS, a report claims. They are suffering because laws designed to protect them are being ignored it warns. 'Witnesses described appalling examples of discrimination and abuse across the health services,' an inquiry led by Sir

Jonathan Michael said. He praised examples of good practice but admitted they were patchy. Sir Jonathan launched his inquiry last year after the charity Mencap blamed the death of six patients on institutional discrimination. He made ten recommendations to improve the equality of care in the NHS.

Ed: you can get a copy of the full report at: www.iahpld.org.uk/ and Mencap's report 'Death by Indifference from: www.mencap.org.uk/document.asp?id=284



I am wondering how many other folk with disability problems especially those of us who use wheelchairs have experienced the utter frustration of accessing our lovely local Hampden Park. On a nice day I often decide to make a visit to the park using my electric wheelchair especially if I have a hospital appointment. With broken and uneven paving slabs all along Roseberry Avenue, patched and broken tarmac paths throughout the park and dropped kerbs at the end of Park Avenue into Kings Avenue which are too high and do not meet the appropriate criteria, hence a once enjoyable trip is now a nightmare. I have high-lighted the aforementioned to the Park Ranger but due to lack of funding there seems that there is little hope of improvement in the near future. I would welcome comments. **Shirley McCall**

Ed: We'll be happy to receive and pass on your comments to Shirley. If there's a problem with maintenance of footpaths it's important to let the appropriate authority know. We think not having the funding to keep a public footpath safe is completely unacceptable, and dropped kerbs which cannot be used safely are

equally unacceptable. It's time to act on these matters!

Events

ESDA EGM to discuss and agree the new Memorandum & Articles

Monday 22 September 2008 at 11am.

Meeting Room, ESDA, 1 Faraday Close, Eastbourne, East Sussex BN22 9BH

Conference - Capacity Building the Disability Sector in East Sussex

Keynote speaker; Bruce Calderwood, Director of the Office for Disability Issues

27 October 2008 from 10:30am to 4:00pm

Cost: voluntary sector £40, statutory sector £65, individual disabled people £7 (this covers refreshments and lunch)

Venue: Uckfield Civic Centre, Uckfield, East Sussex TN22 1AE

Places are available on a first come first served and places are going fast - to book your place please contact Sara Willis on 01323 514505 or email:

sara.willis@esda.org.uk

ESDA AGM

27 October 2008 from 1pm to 2pm

Venue: Uckfield Civic Centre, Uckfield, East Sussex TN22 1AE

East Sussex Disability Association

1 Faraday Close, Eastbourne BN22 9BH

Tel: 01323 514500

Fax: 01323 514501

Text: 07768 187916

Minicom: via TypeTalk

Email: info@esda.org.uk

Website: www.esda.org.uk

Welfare Rights

welfarerights@esda.org.uk

Disabled Living Centre

dlc@esda.org.uk

Information Service

information@esda.org.uk

Meeting Room Hire

info@esda.org.uk

Local Services

Localservices@esda.org.uk

The views or articles in the Aware newsletter are not necessarily the views of ESDA.