East Sussex
Health Action Plan Framework

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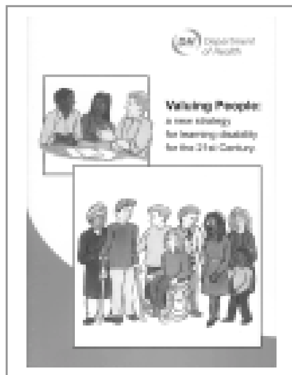
Introduction

People with a learning disability are often not as healthy as the rest of the population. They tend to have more health problems and sometimes do not get the right treatment. If people are to achieve what they want from life then they need to be healthy. So helping people with learning disabilities to have good health is important.

The government has said in Valuing People that:



"all people with a learning disability should have the chance to have a Health Action Plan by June 2005"

"all people with a learning disability should be registered with a GP by June 2004"

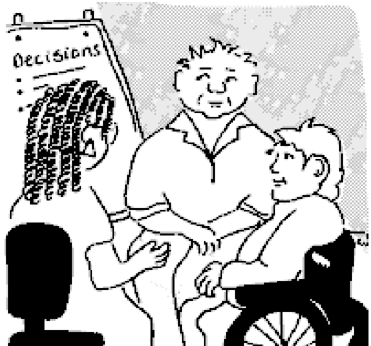
and

"Health facilitators should be identified for people with a Learning Disability by 2003".

Valuing People also says that Primary Care Trusts when they are buying services, should ensure that general healthcare for people with a learning disability is built into their planning and is seen as important.

What is Health Action Planning?

A Health Action Plan shows the actions needed to keep a person healthy. It is a way of linking the person to a range of services and supports which will help them to have better health. Health Action Plans are part of a person's Person Centred Planning so that they are able to enjoy life. The plan is for the person who has a learning disability and where possible they should help to develop it.



What is Health Facilitation?

Health Facilitation is about working with people to help them use ordinary health services. It also includes helping ordinary health services to better support and understand the needs of people with learning disabilities.

This is important because good healthcare, needs to be given by ordinary health services like GPs and hospitals, as well as by specialist Learning Disability services.

Health facilitation is also about working with services to help them plan better to meet people's health needs as well as supporting people to take charge of their health and lead healthier lives.

Health Action Planning Implementation Group

The Government expects all Learning Disability Partnership Boards to have a framework for the introduction of Health Action Plans and to have ensured that there are identified Health Facilitators for all people with a Learning Disability by June 2003.

East Sussex Learning Disability Partnership Board has set up an Implementation Group to deliver this.

Membership

Simone Button	Chair of Group
Chris Pain	Service User/Mencap
Darryl Patterson	Parent Carer
Maxine McDonough	Head Physiotherapist CLDS

Simone Button

Chris Pain

Bob Nisbet	Mencap
Iain Adenis	Lead Community Nurse CLDS
Dr Kate Stokes	GP
Sue Walter	West Kent NHS & Social Care Trust
Frances Martin	Eastbourne Downs PCT

Bob Nisbet

Sue Walter

Frances Martin

The chair of this group sits on the Partnership Board as the Health Action Planning Group representative.

The group has carried out a mapping process of how well people's health needs are being met in East Sussex. It has also developed an implementation plan for the introduction of Health Action Planning and Health Facilitation in East Sussex.

Users and carers have been involved in this work by:

- Membership of Implementation Group
- Part of Group developing Compact Health Passport which will become My Health Action Plan.
- Part of group working with hospital services to improve service provided to people with a learning disability.
- Partnership for Change Conference and Project.

Where are we in East Sussex?

What is Going Well

- All people with a learning disability using services are registered with a GP.
- Good links between the specialist Community Learning Disability Teams and GPs exist through work with individuals. The nurses in the Community Learning Disability Teams have also requested meetings with every GP practice in East Sussex to talk about how the Community Learning Disability Team can support them and about Health Action Plans and Health Facilitators.
- Evidence of good joint working between the Community Learning Disability Teams, practice nurses and district nurses.
- Evidence that GP practices provide a better service in areas where there are more people with a learning disability registered with them.
- Areas where more support is needed are being identified.
- Registers of people with a learning disability in each GP practice are being set up through the Community Learning Disability Teams. We aim to develop the use of appropriate read codes in GP practices.
- A modular training programme is being developed for service providers and carers, aimed at addressing the healthcare needs of people with profound multiple disabilities.
- There are a number of health promotion initiatives in East Sussex with people with learning disabilities, their families and carers.

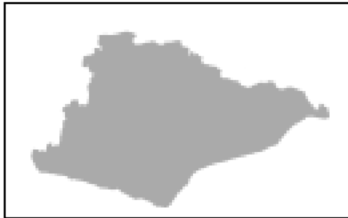
- Training sessions such as healthy eating, sex education, smear tests, breast awareness, testicular self-examinations and diabetes management occur. Also epilepsy training and management is commonplace.
- Protocols are in place to alert and involve the local CLDT when people with learning disabilities are routinely admitted to hospital.
- Joint working protocols between CLDS and Mental Health Services (including older people's and CAMHS services) are being developed.
- A working group has been running for some years at the local Eastbourne Hospital. Membership includes someone with a learning disability, as well as representatives from the CLDS, departments within the hospital including outpatients and pre admission clinics. The group works to improve the quality of the service provided to people with a learning disability in the hospital. The group has recently developed a resource pack for each ward of the hospital. It is planned to roll this resource pack out to other hospitals.

What is not Going Well

- Not every person with a learning disability has annual physical health checks with their GP.
- Few people with learning disabilities receive appropriate health screening .
- Some people still do not have a good experience when they go into hospital as an emergency.
- It is still difficult for people with learning disabilities to use some mainstream NHS services, such as audiology.

- Local Primary Care Trusts and hospitals have not thought about the needs of people with learning disabilities when writing their local health plans

What we want to do in East Sussex

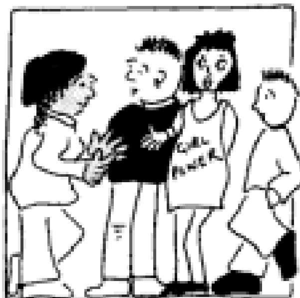


- We want to make sure that everyone in East Sussex can have a Health Action Plan by June 2005 and that they have the right support in getting one
- Luckily everyone we know in East Sussex is already registered with a GP but we want to make sure that GPs, Primary Care Service Staff and Hospital Staff understand about Health Action Plans and the health needs of people with a learning disability so that they can help them to be and stay healthy.
- We want to make sure that the Primary Care Trusts and Local Hospitals and Trusts think about people with a learning disability when writing their local plans.
  These should include areas of priority such as:
  √ Cancer including palliative care
  √ Mental Health
  √ Older People
  √ Coronary Heart Disease

- √ Children
- √ Diabetes
- √ Sensory disabilities
- √ Complex physical healthcare needs (e.g. people requiring PEG feeds, catheterisation, tracheostomy care and dysphagia)

- We want to make sure that services that people with a learning disability need to stay healthy are set up and available to them.
- We want to make sure people are aware of what Health Staff work in the local Community Learning Disability Teams and what they do. We also need to make sure that people are able to access those services within acceptable timescales.
- There will be standards set about examinations and tests that people with a learning disability will be encouraged to have.

Who will be prioritised?



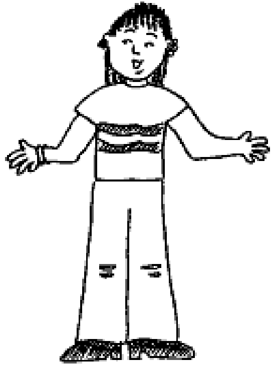
The Implementation Group realise that Health Action Planning is very important for young people going through transition. Parents say that in Child Services, Health input is well coordinated usually by the paediatrician. The absence of this person in Adult Services means that it is very important to use Health Action Planning to coordinate all healthcare especially when this will mean new adult services being used.

- We also want to prioritise people with complex healthcare needs

- and those going through life changes.

What will people do to make sure Health Action Planning happens?

The Person



Leading a healthy lifestyle and having your health needs well met is very important if people are able to realise their hopes and ambitions. It is, therefore, very important for there to be close links between Person Centred Planning and Health Action Planning.

The person needs to be supported to take responsibility for their Health and staying and being healthy.

All Health Action Planning that takes place must centrally involve the person and be done with them.

Health Facilitation

This is carried out by Health Supporters and Health Action Planning Coordinators.

The Health Supporter

They will know the person well and help support them with their day to day health. They will help the person with a learning disability to develop their Health Action Plan. This could be a parent, a staff carer, advocate, keyworker in day service, worker from the Community Learning Disability Team or Practice Nurse or worker from Primary (or GP) services.

They will receive training and support in this role from the local Community Learning Disability Team. The Health Supporter will help the individual fill in the Health Action Plan Book, which is the record of their health information. They will also be involved in the Health Action Plan meeting which will then be arranged to develop the Health Action Plan. Everyone wanting a Health Action Plan will have an identified supporter.

Health Action Plan Coordinator

This is someone from each of the locality Community Learning Disability Teams. They will be responsible for

1. Coordinating all Health Action Planning Meetings
2. Gathering information for service development purposes.

GPs and other Health Professionals

The person and their health supporter will meet with the GP, and where appropriate, other health professionals to form the Health Action Plan.

Locality Health Action Plan Group

There will be a Locality Health Action Group in each local area.
The group will include:

- PCT champion
- GP
- Locality HAP Coordinator
- Locality CLD Team Manager

They will make sure that Health Action Planning happens in each area and works well
Information collated from all Health Action Plans that have been developed in this locality will go to this group. That way we can identify services that have not been provided and decide how to change this.
The PCT champion will have responsibility of taking this information back to the local PCT.
The group will also ensure that information collected and progress with Health Action Planning is fed back to the Partnership Board.
It will be important for the group to work closely and liaise with people with learning disabilities, carers and advocacy services.

East Sussex Partnership Board

The Partnership Board is responsible for making sure Health Action Planning happens. It will do this by:

- Making sure that people with learning disabilities, regardless of their background or level of disability are represented and asked what they think.
- A member of the Partnership Board has been identified as leading on Health action Planning
- Make sure training and support is provided :
    - People with learning disabilities
    - Family carers
    - Primary care staff
    - Specialist health staff
    - Other health workers
    - Social care staff
    - Staff carers and keyworkers
    - Advocacy workers
    - PALs advisors

East Sussex Learning Disability Partnership Board

- People with learning disabilities and carers are involved
- People with learning disabilities have equal access and outcomes regarding healthcare
- Any discrimination is identified

- Breaking down barriers between services to ensure that people receive the best possible care

- Make sure that a person's lack of money does not stop good health

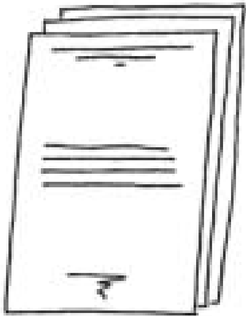
- Provide accessible information

- Provide information about local Health services

- Ensure Budgets are in place for
    1. Healthcare Equipment for individuals including communication aids
    2. Improving environments accessibility
- Making sure that local services include learning disability issues within their development plans.

- Receiving regular information from each of the 3 Locality Health Action Groups about progress on the development of Health Action Plans for people living in each locality area. Also information about service deficiencies within each locality area.

How will Health Action Planning happen?



How will people get a Health Action Plan?

People who are using Learning Disability Services will be asked if they would like to have a Health Action Plan and told why that may be a good idea.

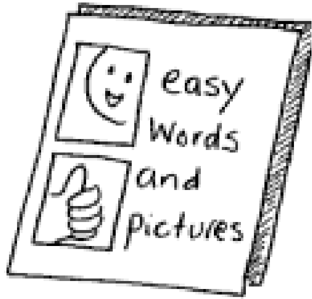
The person, their parent carer, staff carer, advocate or key worker, etc can contact the local Community Learning Disability Team for help and advice on how to get a Health Action Plan.

Where people are not using Learning Disability Services but are registered with a GP, the GP practice can talk to the person about having a Health Action Plan. The GP service will have a contact name of the local Community Learning Disability Team and can ask them for advice on how to get a Health Action Plan.

Giving consent

It is very important that we make sure that the person gives consent to having a Health Action Plan and that this is recorded on the plan. Where it is difficult for the person to give consent, we must use the procedures we would use when gaining consent for anything else. (These are based on Department of Health Guidance).

Health Action Plan Paperwork



My Health Action Plan Book

This is based on the COMPACT that has been used in East Sussex for a number of years. It is a book that the person can use to record their health information with help from their Health Supporter. This information will be shared and discussed with the individual's GP and other health professionals as appropriate. This book is kept by the individual.

Health Information Sheet

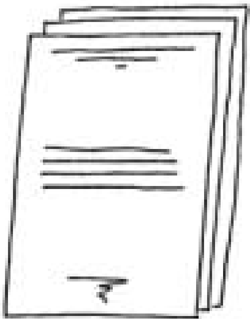
This is a form that summarises the relevant Health Information of the Individual. It will be completed by the individual's GP and a copy kept on their patient records as well as with any case notes kept by the Community Learning Disability Team.

Health Action Plan Meeting

Once the My Health Action Plan book is completed, a meeting is arranged to decide what actions need to be recorded to help the person stay healthy or become healthier. These are recorded on the Health Action Plan.

People invited to the meeting:

The person with a learning disability
Their Health supporter
Relevant Health Workers
The GP



Health Action Plan

This will be attached to both the My Health Book and Health Information Sheet when it is completed.

The Health Information collected is used to decide what are the health issues for the individual and how should these best be addressed. These are written on the Health Action Plan. There will also be a date when these will be monitored and reviewed and who will be doing this.

How will we know that Health Action Planning is making a difference?

1. An annual report will be written for the Partnership Board.
   - It will be based on information collected by the 3 Locality Health Action Plan Groups
   - It will tell us how many people now have Health Action Plans
   - If people are doing Health Action Planning right. We will find out about this through sampling some Health Action Plans and from getting feedback from Health Action Plan Coordinators in each Locality CLDT.
   - If there is evidence of people getting better access to general healthcare services.
   - If there is evidence that service deficiencies are being addressed.

2. Through a customer satisfaction survey asking people how they are experiencing using health services and the Health Action Planning process.

3. From studying the local results of the Mencap Consultation survey on Health access which is being carried out soon and will be repeated in a years time.

4. There is clear evidence of training being carried out for people with learning disabilities, health supporters and GPs/ Primary care and hospital staff in particular. That this training has been seen as very helpful.

5. That there is evidence that the needs of people with learning disabilities are mentioned in local health plans that the Primary Care and other Trusts develop.

IMPLEMENTATION PLAN

What needs to be done?	How we are going to do it?	When and who is going to do it?
1. General Health Action Plan awareness	Talk to: • User Groups • Carer Groups • Staff Groups • Advocacy Services • ESPB About our plan about Health Action Plans and Health Supporters/Facilitators	Members of HAP Implementation Group Lead: Simone Button July 2004
2. .Health Action Plan awareness for GPs .	Visit all GP practices and tell them about Health Action Plans	Community Nurses within three CLDTs August 2004.
3.. Information sharing	Develop information leaflet about Health Action Planning	May Lee August 2004

4. Develop "compact" into "My Health Action Plan Book" with service users.	Develop book Consult with user groups and others Pilot with some individuals	Maxine McDonough September 2004
5. <u>Training</u> 5.1 For People with a Learning Disability. •	further develop training courses about Health Action Plans and healthy lifestyles with local colleges and day services. Identify a group of people with a learning disability • set up a programme for them to be supported to develop own Health Action Plans. • Enable these individuals to move on to provide training for other people with a learning disability about developing Health Action Plans.	February 2004 Iain Adenis – Community Nurse Sussex Cowns College Hastings College Nancy Stembridge – Day Services Sussex Downs College – September 2004 Chris Pain Iain Adenis Simone Button – March 2005

What needs to be done?	How we are going to do it?	When and who is going to do it?
5.2 Training for Health Supporters Provide training and support package	For Health Supporters – develop training and support package for every Health Supporter.	Lead: Simone Button Implementation Group December 2005
5.3 Training for GPs and Other Health Staff	develop a range of training events at GP practices, PCT venues, hospitals for staff re: Health Action Plans and health issues for people with a learning disability.	Lead: Iain Adenis Community LD Nurses From February 2005
6. Ensure that all Local Health Plans of PCTs and Trusts have mention of people with a learning disability. Make sure areas of priority have specific plans.		ESPB Lead Simone Button Each E.S PCT ESCH

What needs to be done?	How we are going to do it?	When and who is going to do it?
7. Identify a Learning Disability champion from the local PCT and also champion GP for each Locality Health Action Group		DPB Lead: Keith Hinkley July 2004
8. Set up locality Health Action Plan Group in each area.		Community Learning Disability Team Managers July 2004
9. Identify who is Health Action Planning Coordinator in each Community Learning Disability Team.		Community Learning Disability Team Managers April 2004
10. Identify priority individuals for Health Action Plans • Individuals coming through transition • Individuals with complex needs.	Each CLDT to identify those individuals	Community Learning Disability Team Manager

What needs to be done?	How are we going to do it?	When and who is going to do it?
11. Pilot – Health Action Planning – with priority groups – broaden out to wider community with individuals	Over a six month period.	Report back in December to the Partnership Board • Feedback from pilot • Broaden out – what feedback to services.