

This study seeks to prove that

Future Sight

will enhance the development of

Visually Impaired people

throughout life's transitions



Executive Summary

The Future Sight (FS) report is a study of the needs and wants of individuals with a visual impairment. The goal of the report is to provide the reader with; an understanding of the concept of FS, an appreciation for the potential of the FS project, the potential for Future Sight to facilitate communications and relations between the primary bodies pertaining to blind and partially sighted individuals, and specific ideas for productive support of the FS project.

Through reviewing the current literature including the constitutions of the relevant national and regional bodies for blind and visually impaired (VI) people, and by means of a questionnaire survey conducted by the FS Project Group, one common theme has become apparent. There is a need for the development of an all-encompassing organisation, which would provide its clients with a holistic, or person centred approach to (VI). This organisation (with the appellation Future Sight) shall support its clients with a planned direction of services throughout life's transitions.

The Project Group recommends the following agenda: A new body shall be set up to deal with all matters concerning visual impairment at all ages. The guiding principles of the project should be life's transitions. The structure of said body shall be focused on service delivery, and shall monitor and review its work periodically, and at least annually, with

the aid of one of the known models of qualitative measurement such as PQASSO. Member organisations are reassured that they would maintain their present independent status, but would have to subscribe to FS's mission statement. Other worthy recommendations include annual reports to stake holder's donors etc concerning the progress of the project; remaining flexible and up to date in all specialist matters; and continue with annual questionnaires surveys.

A coordinated interdisciplinary effort, supported by targeted funding, will be necessary to provide blind and partially sighted individuals with a satisfactory level of support. The resultant advances in the level of assistance will enable independent living to the highest possible degree for people of all ages, enabling individual choice and control. Substantial funding and strong leadership can help to accelerate this process.

James Harris (Vice Chairman Look Essex)

ACKNOWLEDGEMENTS

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This is the point at which I wrest the pen from Hazel Mason, and personally thank her for her unstinting effort support and enthusiasm, and not least her hospitality. She has opened her home, and given countless Saturday mornings to ensure that the FS Project has been fed, watered, and transported around Essex.

There are numerous people who have supported and helped throughout the years of our development. We thank all of you, and really do appreciate your encouragement and hard work.

John Hawker (Chairman Look Essex)

ABSTRACT

The purpose of this study is to elicit whether the formulated hypothesis, regarding the need for an overarching organisation, for visually impaired people of all ages would be desirable, and necessary. It could be envisaged that the organisation would provide holistic services particularly during major transitions of life. This could enable independent living to the highest possible degree for people of all ages, enabling individual choice and control. Sighted carers, be they parents, family or friends need attention and help, often in equal measure.

The paradigm of this study is based on a structured quantitative and qualitative questionnaire survey, held across the County of Essex in accessible formats for individual respondents. It could be deemed representative of all counties within the UK.

The findings were largely encouraging, i.e. confirming the hypothesis. The recommendations spell out, how such a body called Future Sight (FS) could be implemented.

The most urgent need is for sponsors for this huge project.

Visually impaired people must be helped to fulfil their potential, which was the message that came across loud and clear during the analysis of the completed questionnaires.

Repeat studies on a biannual basis will be necessary, for which different methodologies could be used, e.g. Action research.

FS must always be current, inclusive, empowering and enabling. It must be founded upon best current knowledge based practice.

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INTRODUCTION

Look Essex is an independent voluntary organisation that provides support and voluntary services for visually impaired children, their carers and families. Look Essex represents over 1000 people throughout Essex, who consist of visually impaired people, their families and carers. Look Essex has supported people since 1995, and has independently represented them since July 2000. Increasing numbers of visually impaired adults are requesting help from Look Essex, whilst the children and their families are expressing their desire for support as the child moves from childhood to adulthood. Look Essex has responded to this demand, by developing the Future Sight™ (FS) Project. The hypothesis that drives “FS” supports its aim and the assertion that visually impaired children, young people, and adults need and want the provision of appropriate services and support systems that enable their independence, self development and freedom of choice, throughout life’s transitions.

This trend has been tested through the distribution and analysis of the FS Questionnaire Survey among the visually impaired people of Essex.

This exercise was carried out in tandem with a number of countywide FS forums, giving the visually impaired people of Essex the opportunity to express their views, and to participate in a wide ranging consultation regarding their needs and wishes. There were four forums held at different venues and events throughout Essex. The first was hosted in Basildon with the intention of encouraging visually impaired people to volunteer for FS. This resulted in the recruitment of several volunteers and the formation of the Project Development Group. The second forum set the theme for the Look Essex AGM, attracting over 40 people from other organisations and a distinguished visually impaired guest speaker. The profile of FS was raised significantly, and resulted in many

other organisations wishing to stay informed of developments. The third forum was included within the AGM of another regional organisation, held in Braintree, which provided an opportunity to raise awareness among a wide range of people acting independently, and as members of other organisations and agencies. As a direct result of this forum Look Essex immediately gained numerous new clients, and the affiliation of other groups within the Future Sight family. The fourth forum was hosted as an educational event in Chelmsford, aimed specifically at raising awareness of drug abuse and the specific risks for visually impaired young people. This event was organised and hosted by Look Essex visually impaired volunteers. The result being that people were made aware of the risks and realities of drug misuse, and took advantage of the opportunity for self development and the development of transferable skills.

People have been offered the opportunity to advance their own personal development, through volunteering, involvement in organisational decision-making, and the use of technology. Other examples include a young visually impaired person, who presented to the Volunteers and Officers of a national voluntary organisation concerned with health issues. More examples include Look Essex Volunteers and carers of visually impaired children supporting others, offering representation in a wide range of forums, and gaining employment, through their development of transferable skills.

The participation of people, and the detailed consultation process throughout the years has provided Look Essex with the information for meeting people's needs, and has ensured appropriate responses that allow for change. Look Essex works with other people, organisations and agencies to ensure that the needs of visually impaired people are met appropriately, and in accordance with their wishes.

Anecdotal information received from clients who have used the Look Essex Outreach Family Support Service since 2000, and direct evidence from clients of this service confirms that when children reach different key ages, the various agencies and the wide array of national legislation has a far reaching and diverse negative impact upon their lives (Look Essex 2000), in terms of the services and support that they are able to access. It is suggested that the transition to adult services at age 18 is a particularly vulnerable time. This phase of the “FS” Project will test this assertion directly, allowing the foundation to be laid for future partnerships, and strategic organisational and service developments.

The FS survey was made available to people through statutory agencies, other voluntary groups, and directly to visually impaired people and carers. It was made available in all formats. The analysis of the FS survey will play an important and vital role in determining the development of services and opportunities afforded to visually impaired people in Essex. It is envisaged that any personal, organisational or service development should be through partnership with a diverse range of people and organisations

CHAPTER ONE

LITERATURE REVIEW

Due to the nature of this study, the analysts had to review the current literature, including the mission statements and constitutional aims of the relevant national and regional organisations, for blind and visually impaired people in the United Kingdom (UK). The organisations examined included Look National, the Royal National Institute for the Blind (RNIB), Action for Blind People, The National Federation of the Blind, National Association of Local Societies for Visually Impaired People (NALSVI), Network 81, Essex Social Care, and others. This was done in order to establish the range of ages that the organisations represent, and whether they provide a holistic cross-generational approach through their activities and overall functions. A series of important questions arose from this. Examples include, “Do they take particular notice of the needs arising from pre and post transitional events and needs in the lives of visually impaired people?” “Do they mention sighted carers, guardians and friends?” “Do they provide services to those, who found or heard about them, or do they actively become an integral part of a visually impaired person’s ‘life plan’?” “Do they serve visually impaired individuals with a magnitude of actual and potential needs or problems, which would make effective interagency communication absolutely important?” “Do these organisations consider the input of other organisations as important?” “Is there a national, and a local network in existence?”

These questions have a bearing upon the whole approach of this study, inasmuch that a totally different hypothesis would be required as its basis if the organisations had similar mission statements and constitutional aims to FS. In that scenario the study should have been

limited to the County of Essex, by virtue of the fact, that some or all of the national organisations represented the whole of the UK holistically, as FS has this at the core of its mission statement, however it is clear that in common with statutory provision, the national regional and local organisations have an approach that is very much more broadly 'age specific'.

This conclusion had to be drawn, following the detailed study of those organisations and their mission statements.

Here now follows a detailed review of the above organisations' Aims / Mission Statements: -

Look National, an organisation for visually impaired children, has a coordinating function, providing support for children and their families.

The Royal National Institute for the Blind (RNIB) supports people with sight problems of all ages to a degree, their families and professionals. It is a large organisation, providing services for a whole range of matters relating to sight loss, aiding independent living, providing schooling in some special schools, which it owns, and colleges, providing literature on such topics as eye conditions, benefits, magazines, and aids to make daily living tasks easier, and lots more. Furthermore, the RNIB also fulfils a campaigning and lobbying role.

The RNIB has also produced a report entitled "*Shaping the Future*", which studied five to sixteen year olds, recommending greater recognition of the potential and abilities of blind and partially sighted children and young people; A greater voice for children, young people and their parents; Increased support and resources for inclusive education; increased access to main facilities and activities; and more opportunities to take part in specialised activities for those with similar abilities and experiences; Appropriate timely support for families and parents; Greater collaboration between agencies; Young people and their advocates organising themselves. These are important themes for young people, but adult visually impaired people also need similar help and support. Although this is an important part of a holistic approach to

the visually impaired community and highly valued as such, it seems to provide these services in a 'disjointed' fashion, i.e. different sections of the organisation provide important parts without actually providing everything. Interestingly, the report starts at the age of five and finishes at the age of sixteen, which leads one to ask 'what about the ages between 0 and five, and from sixteen onwards, considering that statutory providers take variable ages between sixteen and nineteen years, as the transitional ages from adolescence to adulthood, and hence the change over to adult sensory services. This does not diminish the importance of this report, which will need a follow-up study to see whether any of the recommendations have been implemented and to what degree, but it just demonstrates the fact that an age group has been taken somewhat arbitrarily and written about. Has Look National for example internalised this report and taken it into part of its service provision?

For the RNIB to provide education in its special schools for blind and visually impaired children, is laudable and was very important, especially when blindness and visual impairment were not taken very seriously by society in the 19th and early 20th century, which compares with today, where education is provided in main stream schools and colleges, where appropriate. When it comes to supporting families of visually impaired children, counselling, and advocacy in individual cases, other more local agencies have to provide this. This example demonstrates, that this important big organisation does provide services, but not in a holistic way, especially for children, and to some degree for adults. This very revered and large organisation still carries out very important work and research, but is too centralised. Its services are not reaching out into local towns and villages through a network of small branches of the central RNIB. This is another example, where teaming up with FS, these deficiencies could be overcome.

Action for Blind People is a national organisation, very strong on information on benefits, eye conditions, providing information on aids

for independent daily living, and providing a mobile information service across the UK in a specially adapted medium sized bus. Interested local organisations and others can book this. They are well known and respected for their work and willingness to collaborate with other organisations, thus being an important part in providing a holistic approach to visual impairment. They could be, if they so wish, important partners in FS.

The National Federation of the Blind of the UK is largely a campaigning organisation, seeking improvements in services and facilities for blind and partially sighted people. Whilst this is always an important aspect in providing care for visually impaired people of all ages, it is only part of a truly holistic approach. Again, FS could welcome the Federation as a partner organisation in its overall work.

National Association of Local Societies for Visually Impaired People (NALSVI) has 12 regions, which cover the whole of the UK, including Northern Ireland. Its main purpose is to aid local, i.e. county organisations for blind and visually impaired people, to fulfil their role in helping local member organisations in a variety of ways. These include such issues as social inclusion, I.T. training, information giving and other services regarding more local issues, i.e. Essex or other Counties. Again, this is an important function, but in the greater scheme of holistic provision for visually impaired people, it is only one part of the whole.

Network 81 is a national network of parents, working towards properly resourced inclusive education for children with special needs (all disabilities). They provide a helpline service Mondays to Fridays. They advance the education of children with special needs. They educate parents about all matters relating to the education of their children, link support groups and individual parents with Special Educational Needs (SEN), raise awareness and good practice in inclusive education, encourage parents to take their rightful place in educational policy

making, and other areas. Yet again, this organisation is fulfilling an important aspect in the lives of visually impaired children, who are going through their education process, however following the transition from childhood to adulthood, this organisation's input ceases to exist. Despite this it is a very important organisation as part of the holistic view of services provided for visually impaired people, and as such FS could welcome its membership.

Essex Social Care has a Children's Sensory Team. The transition to adult services takes place at age eighteen, yet in education transition takes place at different ages, i.e. fourteen and nineteen years, depending on the educational route chosen by the student.

It is obvious from this review that all the mentioned organisations are providing much needed services and support systems for visually impaired people and their sighted carers, whether they are family or otherwise. There are many local organisations that provide important social care functions on a regular basis, particularly for more mature visually impaired people.

The project group is aware of all the good work that is being done year in, year out, but has by virtue of this study found, that too many aspects of daily life are a matter of chance more often than not. It is here, that FS sees its role as enabling and providing joined up thinking and action. All the great and good institutions remain intact and should continue their remarkable work for the good of all visually impaired people of all ages. This approach for all people of all ages is left too much to chance at present. It is here, that FS could provide the necessary linkage in the holistic service provision for all visually impaired people. One important factor however, will be whether the diverse range of organisations will be willing to agree and to participate in this new approach of truly holistic service provision.

CHAPTER TWO

SCOPE, AIM AND PURPOSE OF THE STUDY

The scope of this study has grown from a relatively simple idea, first muted by the Chair of Look Essex, and after some considerable thought had found the agreement of the committee's leadership. For this purpose, a project group (PG) was set up to work on an initial programme of consultation, information about the idea, and how to set about getting this implemented. Should it be what clients of Look Essex and beyond wanted?

It was most memorable, when at one of the forums a gentleman by the name of Charles King (2002) declared, that he found it most satisfying and reassuring, that young adolescents and adults, who no longer fell into the remit of Look Essex, an organisation for visually impaired children and their sighted siblings and parents, would have a continuation of care and attention by something called Future Sight. He was able to verbalise the start of an idea, which has since grown and grown, and seeks to look at the whole person throughout all ages. The writers were presented with the scope of the study.

The aim of this study, therefore, is to test the PG hypothesis regarding the need for a regional/national, overarching organisation for visually impaired people of all ages, which is dealing with all matters, concerning visual impairment, in a holistic manner.

The hypothesis to be tested is the following: -

“This study seeks to prove that Future Sight will enhance the development of visually impaired people throughout life's transitions”

This hypothesis has its origin in the stated main aim of FS, the organisation, which would act as a coordinating body for all services, voluntary, discretionary and statutory, providing services and support of varying degrees, to and for visually impaired people. The PG has, therefore, formulated the following aim: -

“To offer to visually impaired people, their families and carers the provision of appropriate services and support systems that enable their independence, self development and freedom of choice, throughout life’s transitions”

The rationale for this is the fact that at present there is fragmentation, in voluntary and statutory provision for visually impaired people. This contravenes the espoused principles of ‘Choice and Control’ in the Social Model of Disability (Morris 1993). Services are geared to seemingly fulfil the needs of the providing organisations rather than the needs of those, who actually need services. Furthermore, as stated previously, various national groups in particular are often looking at and dealing with a particular aspect, such as Network 81 who cover education, or Action for Blind People concerned with equipment and appropriate benefits. Others like RNIB are more geared to lobbying e.g. Parliament.

Individually the organisations work in a coordinated way, but in isolation from each other. People often hear about them by chance rather than by design. Provision of help and support is provided in much the same way. This is not an ideal state for those concerned. Morris argued in her book on the Social Model of Disability (1993) that, “Often well meaning,

non impaired people seem to think that they knew best, what people with an impairment needed. By doing so, they would get an honour bestowed upon them of some description, but the help may not always be the appropriate one.”

Future Sight are a group of people, who realise that there is a great gap in provision, particularly during the transitions of life that any human being has to undergo, but particularly in the lives of visually impaired people.

Visually impaired members of Look Essex, who by virtue of their own transition from adolescence to adulthood, theoretically should no longer be members of an organisation, which exists for visually impaired children and their families, often come back to Look Essex, maintaining their membership in some shape or form. They often help as volunteers, and do not want to move on to other local social organisations for visually impaired people. One of the major reasons for this phenomenon is the fact, that most visually impaired people in adult life have an acquired visual loss problem, usually but not always, as a result of degenerative processes. These other organisations, therefore, are heavily slanted towards elderly members, and fulfilling their needs. Whilst this is laudable, the generation gap, different interests, and particularly differing needs, are not conducive to ‘bridging the gap’ between the needs of the very young and those, who are at the other end of the scale of the age range, who nevertheless have their own particular needs to be met.

Age returns

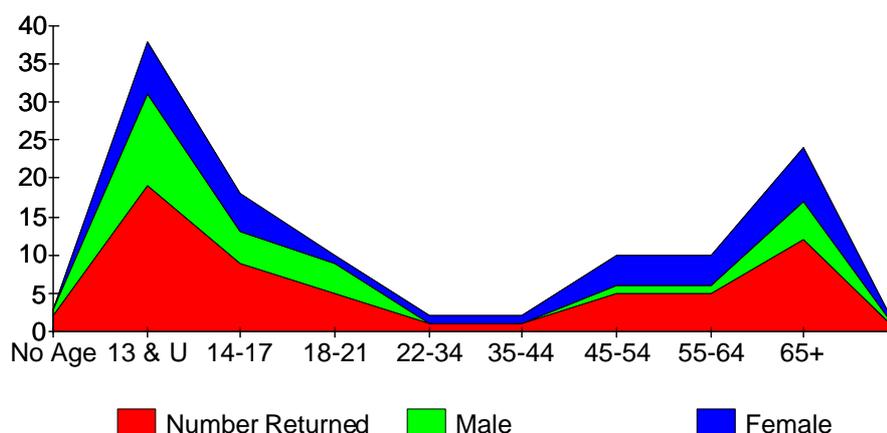


Fig 1

The survey questionnaire confirmed this national trend, i.e. the return rate of questionnaires between the ages of 22 to 44 was two (out of 60) in those intervening years between the stated ages. In that period the national trend of acquired sight loss without incidence is very low. The writers are aware, that the number is possibly somewhat higher, but not by a great number, see Department of Health statistics (DOH 2003) and Royal National Institute for the Blind (2004). It became obvious that there clearly existed a need to be addressed in a holistic manner. Rather than sitting back and waiting for someone else to investigate the present state, the writers identify an actual need through an extensive survey and consultation, followed by the formulation of appropriate recommendations, relating to a structure that could make a real difference in provision for visually impaired people. They were courageous enough to decide that well reasoned, and thought out action was needed.

How did they start on their 'journey'?

A small seminal group of like-minded people within Look Essex formed to discuss the concept of an overarching organisation, which would not take over and run just about every service imaginable, and necessary to

help visually impaired people of all ages. It was decided to create something, such as Future Sight, which would generate ideas, and be open to useful suggestions. It could have a membership of specialists in different disciplines, ranging from ophthalmology to psychological, social, spiritual, educational, employment and other support providers. Future Sight would not provide all this itself throughout the country, but would suggest that other organisations could become member organisations. They would maintain their own specialist and organisational structures, however, they would have to subscribe to the mission statement of Future Sight, the Social Model of Disability, and the principles of Independent Living, as identified by the Social Services Inspectorate (Fielder 1997). Future Sight would be a service provider in its own right, a coordinating body and referral agency, depending on an individual's needs. To become a member of Future Sight, an organisation would have to be reviewed, audited and monitored, to ensure that the ethos of Future Sight would be their guiding principle, i.e. they would subscribe to the same mission statement as Future Sight, encourage independent living and enable visually impaired people to reach their full potential as members of society. Small, or large local, regional or national organisations, representing all ages would be equally welcome.

The unique structure of that organisation would truly ensure that the espoused principle of the World Health Organisation (WHO) definition of total health (Ata 1980) would be achievable for all visually impaired people of all ages. Future Sight would truly work towards ensuring the complete physical, mental, spiritual, social and economic well being of all visually impaired people.

The actual 'business structure' required to achieve this, could be minimalist, and many specialists could be engaged in its work on a

consultancy basis. Please find a more detailed description of such an organisation in Chapter 5, entitled Recommendations.

The purpose, therefore, is the creation of an overarching body, such as Future Sight, should the survey clearly state that such an organisation would be helpful to the majority of the respondents, having participated in this survey.

CHAPTER THREE

RESEARCH METHODOLOGY

This chapter describes in detail the methodology chosen, and will give a rationale for the choice.

The methodology chosen is a mixture of quantitative and qualitative data, which had been obtained with the aid of a specially designed questionnaire (Cohen *et al* 2000). They describe in detail the use of postal surveys and questionnaire surveys, which can either be quantitative or qualitative or both.

To explain the meaning of research, the writers chose the definition, given in the Little Oxford Dictionary (1995), which states

“...research is the careful search or enquiry into subjects to discover facts by study or investigation”.

This investigation, in the form of the aforementioned quantitative and qualitative questionnaire survey, has been backed up by a quite extensive literature search, and the investigation has been carried out by an extensive questionnaire survey.

Methodology has been defined in the Little Oxford Dictionary (1995) as

“...way of doing something: orderliness”.

The Project Group (PG) chose the combined methodologies of quantitative and qualitative data gathering. The reason for this combined approach becomes clear, when one looks at the definitions of both quantitative and qualitative. The Little Oxford Dictionary (1995) describes quantitative as

“...of or measured or measurable by quantity”.

The same dictionary describes qualitative as

“...concerned with, or depending on quality”.

This means that the questionnaire devised, had for each section a quantifiable part, such as ages, and other common facts of a positive or negative nature that when counted together, showed clear numerical data, however what they did not demonstrate was what respondents felt about the issues, they had been questioned on.

For this purpose, the numerical data sections were followed by comments sections, in which respondents could clearly give their own views and express their own feelings about the qualitative nature of their experiences provided for them, or attitudes expressed towards them and others. It has to be said, that not all numerical data was backed up in part or completely by the qualitative comments provided. This 'discrepancy' was expected to occur in some parts, and the PG found it useful, as it made numbers come to life.

The questionnaire method, as described by *Cohen et al* (2000) had been chosen, as it seemed to be the most practicable approach to a county wide data gathering exercise, with a finite budget. Furthermore, as the target group was the visually impaired community spanning all ages, the questionnaires had to be made available in different formats, i.e. normal print, (Appendix 1a,b) large print, on tape, and in Braille. Burgess (1989) states the importance of 'accessibility' of questionnaires for the target group. This had been achieved by providing the different formats. Anonymity had to be maintained throughout, and even where names had been given, these were not stated in the analysis of the findings. Another helpful guide to this project was Bell (1993) a book on conducting research projects.

It was impossible to involve the entire county's visually impaired people in this survey. The PG decided that participants should be selected randomly. Geographical spread had to be achieved to be representative of the whole county. 205 questionnaires were distributed, i.e. either

mailed out or handed out during a jointly organised seminar between Look Essex and the Children's Sensory Team. Local welfare and social groups for visually impaired persons were also given the number of requested questionnaires, in order to distribute to their members locally.

Attached to each questionnaire was a covering letter, detailing the date, by which the completed questionnaires had to be back with the PG, and thanking the would be respondents for their kind help and time in filling in the questionnaire (Appendix 1a) The original return date had to be extended, because some visually impaired people had to wait for help with filling in their questionnaire. In one case, an organisation had misplaced the questionnaires to be handed out, and could only deliver them to the target group after the actual return date. Nevertheless, it was a rather important part of the geographical area, and the late distribution was still most helpful to the PG. The term 'random' applies in so far, as the PG had selected no participant in this survey. The Little Oxford Dictionary (1995) defines random as

"...made or done, etc. without method or conscious choice".

60 completed questionnaires were received back, one of which was a spoken reply on a tape (appropriate format), which was then transferred on to a paper questionnaire by a member of the analysis team.

It became clear during the analysis that follow up interviews with a number of the respondents would have been helpful in providing additional and clarifying data. To aid the validity of this additional approach, a pre-designed questionnaire with open-ended questions, would have been ideal. Burgess (1989) suggests that research is conducted within a theoretical framework. While there may be a small number of questions to orientate a study, further questions may arise during the course of the investigation. Different methods of investigation may be used to complement qualitative methods.

The researcher has to consider for whom he is producing the report and the main concerns to be included. The original anonymity of this survey, and the geographical spread made this almost impossible. With hindsight, the writers found, that the inclusion of a question on the questionnaire regarding the sight loss either having been congenital or acquired, would have been helpful, particularly as the questionnaire aimed to address the whole life span.

It is the intention that the findings of the survey are distributed to those who participated if they expressed this interest. A registration form was included with the survey (Appendix 1b). Upon analysis of the questionnaires, it became apparent that a Glossary of Terms should have been provided, as key words, such as, “Inclusion, support, attitudes” and others, mean different things to different respondents. Please see analytical critique of the questionnaire itself in (Appendix 1c)

CHAPTER FOUR

QUANTITATIVE and QUALITATIVE Data Analysis

60 Questionnaires returned out of 205 sent

13 & under	19 returned	12 male	5 female
14-17	9 returned	4 male	4 female
18-21	5 returned	4 male	1 female
22-34	1 returned	0 male	1 female
35-44	1 returned	0 male	1 female
45-54	5 returned	1 male	4 female
55-64	5 returned	1 male	4 female
65+	13 returned	5 male	8 female
No age given	2 returned	1 male	
Male =	28		
Female =	28		
Un specified -	4		

Geographical Spread

Thurrock	6
Southend	19
Chelmsford	8
Basildon	9
Brentwood	4
Colchester	8
<i>Harlow</i>	1
Epping Forest	1
Clacton	3

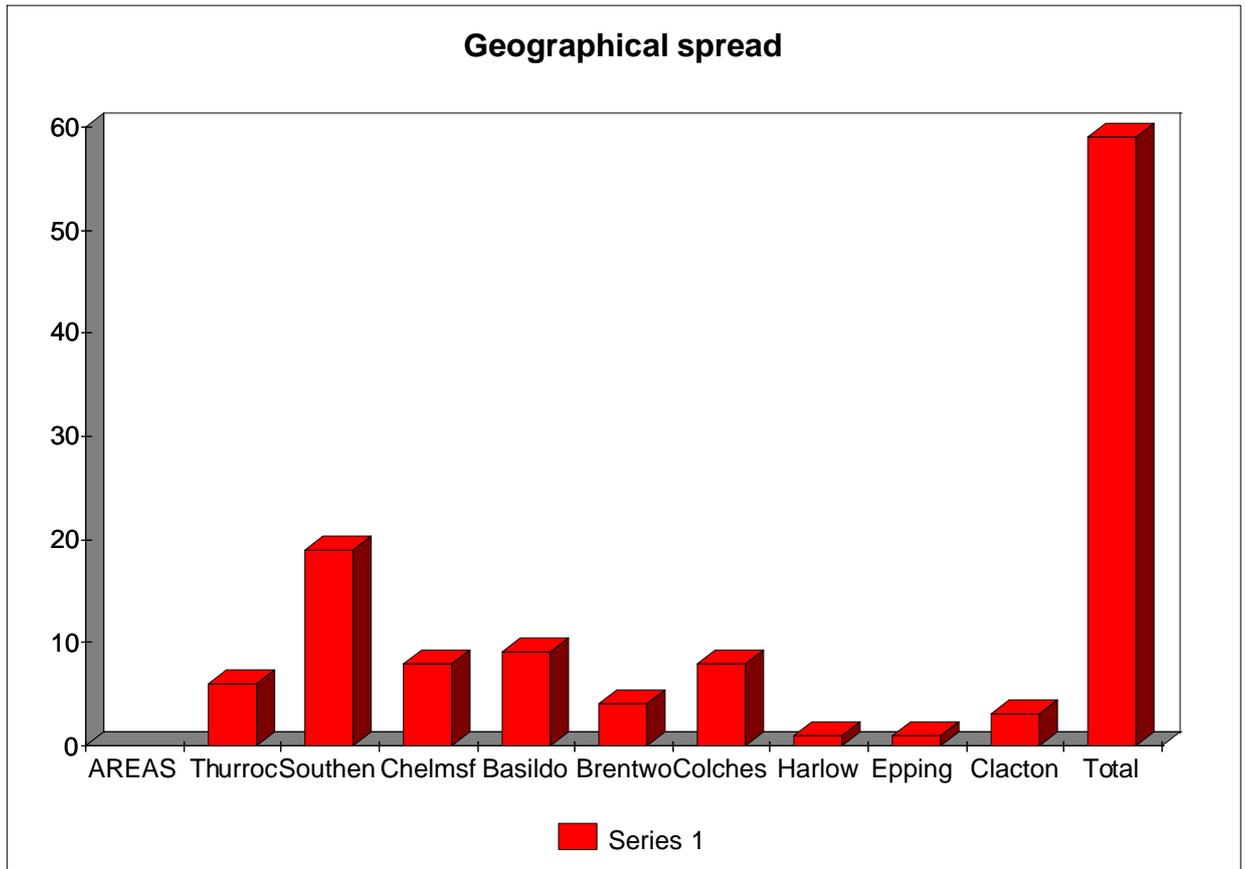


Fig 2

2 did not state their age and 4 didn't give their gender. However comments made would suggest the inclusion into certain groups

1) EDUCATION

Please select which of the following you are currently studying at: -

Mainstream Education (23) Specialist Education

(13)

School (23)

College (4)

University (1)

Other (0)

Please State Which

If you are no longer in Education please tell us were you in: -

Mainstream Education (8)

Specialist Education i.e. Special School/College (2)

School (6)
College (1)
University (0)
Other (0)

Please State Which

Have you experienced or experiencing difficulties with

Inclusion (9)
Access (4)
Equipment (14)
Attitudes (pupils) (11)
Attitudes (staff) (9)
Support (8)

If there were an Organisation that provided support, advice and information throughout your time in Education, would it be of use?

Yes = 39

No = 6

Do you anticipate difficulties with: -

Inclusion (7)
Access (3)
Equipment (8)
Attitudes (pupils) (9)
Attitudes (staff) (6)
Support (7)

Do you feel you have or had the opportunity to reach your full potential

Yes = 33

No = 11

13 and under

Equipment seems to be a problem in mainstream schools.

One comment was

“Wheelchair user-always access problems. Inclusion with transport-wheelchair bus necessary. Making sure appropriate equipment is used including speech machines.”

Other examples mentioned were: -

“School provides some items but could do with more e.g. large print rulers, science equipment, books etc.” See individual choice and control

(Morris 1993)

This respondent is attending specialist education for multi disabled, and has lots of problems with wheelchair access to various venues at that specialist school. Whether this also includes problems with accessible formats of reading materials or not, cannot be ascertained from this comment. Another respondent commented *“Finds even when items of work are in enlarged they insist that he still uses the magnifiers even though he doesn’t always need them.”*

However, the Disability Discrimination Act 1995 (DDA), which was added to the statute on 1st October 2004, states very clearly, ‘giving disabled people important rights of access to everyday services that others take for granted’ This is certainly a reason for revisiting this particular venue in order to ascertain whether the DDA has been implemented fully for the benefit of this and all the students. However, there were also problems with transport, as the school bus was not fitted with wheelchair lifting equipment. Another commented

“No because school for the blind”

This comment was positive i.e. no special problems encountered, as it was a specialist school for blind pupils and students. This comment was positive, i.e. no special problems encountered, as it was a specialist school for blind pupils and students.

Although the questionnaire did not particularly ask about Statementing and its help, or otherwise, there were some comments made of note, which should not be overlooked.

Whilst one comment was on the whole positive about the help and support given, one comment made it very clear that the spirit of the Statementing process had not been adhered to at all by writing the following comment: -

“... our son is statemented, and it is a battle to fight for his needs even

when on his statement”.

Another comment, equally disturbing, was the following

“... recently taken off statement”.

Why and by whom, particularly as problems in future are anticipated.

The writers are concerned that even in this modern day and age, support/inclusion/attitudes are still very mixed, particularly when it comes to practice.

Some disturbing comments have been received in the questionnaire survey, such as

“... children at my son’s school are brilliant. X often left out when the other kids go to their friends, when home from school”.

“Lack of communication from school and lack of understanding from staff on what a special needs child and its family needs”.

“...Pupils and staff do not, or struggle, to see X as an equal”.

Do you feel you have or had the opportunity to reach your full potential?

The writers were encouraged to find, that a majority of respondents felt positive about reaching their potential.

Here are some of the comments received.

“... not given an equal opportunity to show what she can do”.

“... if support was there sooner to learn touch typing, etc., it would make life a lot easier for our son”.

“... but only through constant monitoring by me, his mother”.

“... working well above age level. Support is there, albeit sometimes a bit overbearing! He sometimes feels, because his teachers / support do not understand his disability, they can think they know what is better for him. They don’t like him taking responsibility for which visual aid he may need in class”

Although 2 of the questionnaires do not reveal an age, from the

comments there is evidence to suggest that they both are of the same age group as the others above. Their comments, however, seem to be important enough to be included in this section.

“... solitary due to autism”. And

“... understanding of condition”.

The writers would argue that such ‘children’ are not helped at all by the attitudes of teaching staff and / or pupils as seem to exist in their education institutions. Understanding of such conditions is paramount to help these children to reach ‘their potential’.

14 - 17

Amongst this age group we found 2 comments of note, namely

“... this happened in Infant Junior School – Senior seems to have accepted me more”.

The interpretations of this statement can be manifold, i.e. understanding of staff and pupils was wanting and needed far greater attention, when preparing to receive students / pupils with a sensory impairment, or it could be that the pupil, because of the impairment felt intimidated and had not yet learned enough social defence mechanisms, or both.

Whatever the reason, it should not happen, and teachers should feel more responsible for the well being of their pupils at all times.

“ ... full understanding of the limitations, vision and co-ordination, difficulties, are not understood by Education or individual teachers”.

It clearly demonstrates the fact, that schools and their staff have a responsibility to deal with pupils as individuals with all their strengths and weaknesses, including any impairment that may make it far more difficult for them to follow the rest of the class at the same speed. This has nothing to do with natural intelligence, but everything with nurturing such pupils on a more individual basis. The writers would suggest that staff need more visual awareness training in order to understand what difficulties such pupils can have simply by the fact that their sight is

impaired. As is often the case with questionnaires, simple YES/NO answers do not give the same answer as any accompanying comments. The writers found the same phenomenon in this survey.

1 respondent replied that... *'had achieved'* .. potential. Yet, it seems as if the comment had been written by a parent. The comment clearly states, that *"... we feel that X had to adapt and tends to hang back to avoid others noticing his difficulties"*. This again demonstrates clearly that the local educationalists are blissfully unaware of the difficulties that x experiences. Instead of making special efforts to bring x up to speed, i.e. to improve performance, this is allowed to go unnoticed. Educationalists seemingly are not aware of the difficulties or seem to ignore them. This needs urgent action to help x.

18 – 21

5 responses 2 comments

"... X has behavioural difficulties. He is on 'puberty' hormone injections, and experiencing a difficult time". Without any further indication, it is difficult to interpret this statement. However, X's endocrinological deficit may well be the cause for being excluded or feeling excluded. We have no further data to analyse it in more depth qualitatively.

Again, another respondent in this age group bemoaned the fact that *"... it would have been 'nice' to have another year at specialist college, which Social Services would not fund as they thought needs could be met in 'borough' "*

Although the writers cannot deduce from this statement the reason, why this was the case, but clearly it was felt by the person concerned, that their needs were not, or not as adequately, met in the ordinary school. This may have nothing to do with the teaching staff per se or even the equipment, but the change to another peer group for the final year at that age, making new friends, getting to know new buildings and various other problems, was certainly a change at the wrong time. Money saving

may not have been the right reason at this point in the educational process for the above reasons. Education and particularly Social Care, viewed in a holistic manner, should have taken above mentioned issues and others into consideration, before making such a drastic decision. Did Social Care know best? Was this client allowed to practice choice and control as outlined in the Social Model of Disability? (Morris 1993) Or was the person deemed too young to have a mind of his or her own?

22 – 34

Only 1 respondent in this age bracket, stating that they had been to school and university, but did not make any comments or statements about any difficulties.

35 – 44

Again, only 1 respondent from this age bracket, who had gone to college. Again, there were no comments.

The writers, however, wonder whether the term ‘mainstream’ or ‘specialist’ school had been understood as to its meaning by respondents in these age groups.

45 – 54

5 responses. Although the questionnaire had not specifically asked, whether respondents had a congenital or acquired sight loss, the responses received from this group seem to suggest that most had acquired their sight loss at a later stage in life.

2 of the respondents supplied comments, such as

“... currently in specialist adult education”.

Has not indicated to have any difficulties, but commented, that

“... was due to being adult education. People were very helpful and helped me reach my full potential”.

Another reply stated

“... many college resources are unavailable to visually impaired people, because enabling technology is unavailable”

This respondent also commented

“ ... he had not been able to reach his full potential, because at school he was not able to see the blackboard or read text books. He was left to his own devices”

55 – 64

5 responses and 1 of these respondents had stated that they had congenital sight loss.

2 have made comments, which are inconclusive, i.e. they do not state whether they had not reached their full potential in school due to a visual impairment, or whether they generally were dissatisfied, because they did not quite reach what they had set out to achieve during their lives.

64 +

13 responses 3 comments, received in the Education Section. Yet, on trying to analyse them, it becomes clear, that the comments appear nothing to have to do with education in the sense the questionnaire wanted to elicit.

Please find more on this subject in the section on the critique of the questionnaire

2) EMPLOYMENT

Are you employed?

Yes = 5

No = 45

If Yes part time (2)

Full time (2)

If No are you currently looking for Employment?

Yes = 4

No = 30

Have you experienced or experiencing difficulties with: -

Inclusion	(0)
Access	(1)
Equipment	(2)
Attitudes from colleagues	(0)
Attitudes from Management	(4)
Attitudes from client	(1)
Support	(4)
Discrimination	(2)

Has your visual impairment ever been an issue regarding career development and opportunities within the workplace?

Yes = 9

No = 17

Do you feel you have or had the opportunity to reach your full potential?

Yes = 9

No = 10

If there were an organisation that provided support, advice and information throughout your transition from education into employment and beyond would it be of use

Yes = 17

No = 5

14 – 17

No comments

18 – 21

5 responses 2 of the respondents gave some thought provoking comments, such as

“ ... have learning and physical disability as well as being totally blind”.

This respondent is not looking for employment at present; the writers do not know the reason why. Apart from this comment, no other

information has been given.

Another respondent stated the following:

“... found it very hard to get a job because of my eye sight”.

This respondent stated further, that support and discrimination had been an issue. The writers would argue that the ‘Essex’ Social Care Policy ‘*Equal Lives*’ and legislation, such as the DDA have been totally ignored. It also seems that advocacy services would have been necessary and most useful for this respondent.

Has VI been an issue regarding career development and opportunities within the workplace?

Another respondent gave the following comment: -

“... certain employment is an impossibility whilst being visually impaired”.

The writers understand the feeling expressed, but also have to emphasize that visual impairment is usually permanent. It would be important to ascertain that the respondent at this age is not hoping to regain full sight, which is highly unlikely.

22 – 34

1 response no comment

35 – 44

1 response no comment

45 – 54

5 responses 5 comments

2 respondents are not working, and gave the following comments: -

“... no part time jobs available locally for people like me with limited sight”.

The other respondent commented that
“ ... *on long-term income support and DLA*”.

3 of the respondents commented on factors, such as Inclusion, Access, Equipment, Attitudes from colleagues, attitudes from management, attitudes from client, Support, and Discrimination with the following statements: -

“ *Employers assume they know what you can or cannot do. You are rarely given the chance to prove yourself*”.

Another one stated that

“ ... *discrimination against me, because I had a Guide Dog*”.

The third respondent commented that “ ...*didn't apply when I worked*”.

This last comment is difficult to analyse as one can mean it to be different things, such as the respondent had no difficulties with things, such as support, access and others, or has become visually impaired after having given up work, e.g. retired.

2 other respondents in this age group commented; 1 stating,

“ ... *the funding has never been available to provide the equipment necessary for me to continue working*”.

The other respondent said that

“ ... *employers seem reluctant to provide visual aids to help in the workplace, they rarely give you the chance to prove that you can do the job* ”.

Respondents would have needed guidance on equipment available for the workplace through Job Seekers, RNIB or other providers. It is a sad reflection on lack of communication regarding the availability of such help that does not allow people to achieve their full potential.

Do you feel you have or had the opportunity to reach your full potential?

2 of the respondents commented on achieving their potential in the

following way: -

“ ... I didn't develop sight problems until later in life”.

This comment does not make it clear, whether this refers to the question of having reached one's potential.

The other respondent stated,

“ ... I feel I have a great deal to offer an employer, but I have never had the opportunity to prove myself”

This respondent's answer raises as many questions as it tries to give answers. The writers can only assume that this respondent has been working at some point in their life. Yet, the questionnaire states that the respondent is not working – at least at present. Furthermore, the comment provided, sounds very much like that this person would have liked to prove itself, but had never had the chance, hence perhaps has never worked. Again, it is clearly a human right and as such enshrined in the Equal Lives Policy of Essex Social Care (2001).

55 – 64

5 responses, of which 1 had definitely been employed.

1 of the above commented,

“... because no one wants to give me a job, and it's not for trying, 'cause' I have tried, ok”

This comment is inconclusive, as the writers have no indication whether this respondent has ever worked or not. It also raises the point that the questionnaire in this aspect did not help a clearer analysis.

Another respondent gave the following comment: -

“... it is always going to be difficult raising awareness of needs as each individual visually impaired person presents differently”.

This comment may be viewed as very true, and had indicated on the questionnaire difficulties from management. As outlined earlier, lack of knowledge about help available for visually impaired people in the workplace is relatively easily available. It appears that an organisation, in addition to Social Care, ought to be acting as agents for people who need help with equipment to enable them to work. 'access to employment' is one of the chapters in the *Equal Lives Policy*, Essex County Council Social Care, which clearly states the individual's right to employment, and through that to fulfil their potential.

" ... 1963 – 1986 – lack of equipment, poor attitudes, lack of training".

This answer clearly raises the question whether anything has changed now. Legislation has, but whether attitudes have, remains to be tested.

64 +

13 responses most respondents stated that they had retired.

4 respondents provided the following responses: -

"... had worked as a Senior Physiotherapist, and is now working part-time in a museum".

"... age related condition". This, however, does not tell the writers whether this person has ever worked before or not.

"... do work at a pub sometimes". This response begs the question whether this is a post-retirement job, more as a hobby than as real employment. As above, it does not indicate whether this respondent has ever been in full time employment.

"... surprise from clients, but overcome with explanation". This response demonstrates that sometimes VI persons have to explain how they still can do a job efficiently without sight or diminished sight. This is certainly a pointer for people of much younger age. However, the older age that blind people are only suitable for being either physiotherapists or piano tuners has to be challenged.

Also in this section two comments were received, such as

" ... no, I was ok then".

“ ...bar cleaning?, because management only need you for menial tasks”

The first part of that comment was somewhat illegible, hence the question mark behind the ‘cleaning’. Yet, it would be rather discriminatory, certainly within the parameters of the DDA. If anything, it indicates that ignorance of employers can often lead to people with impairments not to get / have the same career opportunities.

3) VOLUNTARY WORK

Have you ever done any Voluntary Work?

Yes = 22

No = 20

Have you experienced or experiencing difficulties with

Inclusion	(1)
Access	(2)
Equipment	(1)
Attitudes from colleagues	(1)
Attitudes from management	(1)
Attitudes from client	(2)
Support	(1)
Discrimination	(2)

Has your visual impairment ever been an issue regarding opportunities within the volunteering?

Yes = 7

No = 20

Do you feel you have or had the opportunity to reach your full potential

Yes = 16

No = 4

The 2 received with no age indicated did not comment, writers to believe, that both respondents are actually still going to school

13 and under

19 responses 3 comments

These comments, however, seem to have been largely provided by the parents of VI children. A VI respondent, however, had provided one comment. To give an example of either, the writers are including two of the three very similar sounding comments, such as

“... Yes, as a parent”.

“...helped in (charity known) meetings, and someone has always helped me”.

14 – 17

9 responses no comments

18 – 21

5 responses 2 comments

“... played records on a radio station for an Old Peoples Complex”.

“... St. John’s Ambulance”.

It was encouraging to find, that there were young VI people, doing voluntary work. Even more encouraging was the fact that neither of the above had to experience any kind of discrimination on the grounds of their VI disability.

However, two other comments in this section were received, one of which appears to have been made by a parent of a VI young adult, who commented, that

“...needs constant support”

It has become clear that with constant support volunteering had been made possible. It was very encouraging to see that a visual impairment had been no barrier to volunteering work.

The second comment made it clear, that

“... certain things cannot be done”

Whilst this has to be taken into consideration and accepted, the writers would argue that – with appropriate understanding and help – this should be no barrier to volunteering work, giving the satisfaction of being useful.

Do you feel you have or had the opportunity to reach your full potential?

A comment was made by the same person, where the writers assumed that the parent/s had completed the questionnaire, which was rather negative by stating, that

“... when the VI person ceased to do this (volunteering) activity, there was no other alternative”

The writers are not sure, whether this was the parent’s view, or whether this was fact. The writers would hope that this person will yet get a chance to fulfil her / his potential.

22 – 34

1 response no comment

35 – 44

1 response no comment

45 – 54

5 responses 4 comments

2 commented that they were volunteering for blind welfare groups, enjoyed this, and felt in turn well supported through their activities.

Has your visual impairment ever been an issue regarding opportunities within volunteering?

“... my vi has prevented me taking on more of a role in the voluntary sector”.

“... I have no choices – my VI prevents me from being flexible/quick/accurate enough for most jobs in voluntary sector”. This statement is rather sad and implies that this person has very little self-confidence. Even with a VI and with an appropriate volunteering task, this person should find some satisfaction, i.e. maybe even fulfil her / his potential.

One person had ticked YES, but then stated, that they wanted to avoid doing a Risk Assessment. The first part seems to negate the second part of the answer.

55 – 64

5 responses 1 comment

“... I think wherever VI’s are we struggle with all the above (inclusion, access, equipment, attitudes from colleagues and management and clients, support and discrimination) at various times”.

This comment is a valid one, but not only for VI’s, but also for anyone else at times throughout life. The same person as above stated, ***“... environments are not geared to the VI”.*** The same respondent, however, realised and stated, that all those ‘negative’ comments ***‘create blockages to reach one’s potential’.***

This insight into the matter should be part of developing a coping process and establishing answers of how VI persons still can achieve satisfaction / fulfil at least part of their potential. This certainly clearly demonstrates that an organisation like FS would have a tremendously positive and enabling role to play.

65+

13 responses most of who provided comments

“...only fear gave clients attitudes”

“... surprised at blind persons capabilities. Praise for doing everyday things”.

These two comments demonstrate clearly that the VI person's own attitude to their condition / impairment and how they deal with it, plays an important part in coping with, and enjoying, everyday life.

This question elicited two responses, one of which was very positive, and the second one was inconclusive as far as its analysis is concerned.

The writers would like to ask you to come to your own conclusion, when reading particularly the latter comment.

"... reservations from sighted people , but overcome".

"... had full vision". One must assume, that this person had done some volunteering whilst fully sighted, but had since acquired a VI.

"...No I am only chatting to patients"

"... only since registered Partially Sighted".

Both comments are most difficult to interpret correctly, as the context in which they were made, is not clear at all. The second comment seems to imply that only after registration, this person fulfilled her / his potential somehow. It does, however, not state in what way.

4) SOCIAL ACTIVITIES

What types of Social Activities are of interest to you?

Park	(1)	Wine circles	(1)
Radio	(1)	Theatre	(1)
Running	(1)	Flower arranging	(1)
Tumble tots	(1)	Meeting friends	(1)
Outings	(1)	Reading	(1)
Rainbows	(1)	Choral singing	(1)
Martial arts	(1)	Ten pin bowling	(1)
Arts	(1)	Concerts	(1)
Night Clubs	(2)	Beach	(1)
Social club for the blind	(2)	Drama	(1)
Singing	(2)	Indoor soft play areas	(1)
Church	(2)	Tap dancing	(1)
Trampoline	(2)	Folk club	(1)
Dancing	(2)	Brownies	(1)
Eating out	(2)	Girls brigade	(1)
Drawing	(2)	Bike riding	(1)
Cricket	(2)	Climbing	(1)
Socialising	(2)	Bridge	(1)
Youth club	(3)	Chess	(1)
Sports	(3)	Basket Ball	(1)
Music	(3)	Judo	(1)
Shopping	(3)	Rugby	(1)
Football	(4)	Scouts	(1)
Cinema	(4)	Play station	(1)
Horse riding	(6)	Shooting	(1)
Walking	(7)	Athletics	(1)
Swimming	(13)	Ballet dancing	(1)
		DJ	(1)

Have you experienced or are you experiencing difficulties with integration into social activities

Inclusion	(8)
Access	(8)
Equipment	(5)
Attitudes	(11)
Support	(7)
Discrimination	(5)

Do you anticipate problems in the future?

Yes = 17

No = 20

Inclusion	(10)
Access	(6)
Equipment	(3)
Attitudes	(12)
Support	(8)
Discrimination	(4)

In the quantitative section of this survey respondents had listed the type of activities, and the numerical result can be studied. However, the qualitative nature of those activities will be examined in more detail now.

1 of the respondents commented,

“... mum had to stay at trampoline sessions”.

1 of the respondents ticked the entire list of difficulties (please refer to numerical data.) and stated that he/she was experiencing difficulties with all of them from the general public. The writers would challenge this statement, as it is sweeping in nature without making reference to any particular incident or occurrence. The writers are fully aware, that impairment places certain restrictions on people, but are no bar against any kind of enjoyment in daily life.

13 and under

19 responses 3 comments

“...the need for more clubs”

“...have a lot of help”

“...may not always be thought of as able to compete”

These demonstrate that these young persons have experienced some difficulties with the previous list of activities. At this stage of their development, they will have to learn that some activities will either always be out of their reach or that they can only do those with some help or special enabling equipment.

The writers are aware that organisations, such as Look Essex and FS have an important role to play in helping these individual people to develop their capabilities as best as possible on an individual basis – tailor made.

Do you anticipate problems in the future?

“...there is not enough support for disabled children in clubs”

“... as I get older, there will probably be more competitive sports”

“...hopefully not. I want to use the gym, when I am older and hope this will not be a problem”

“...possibly, because of delicate appearance”

“...we do anticipate problems, but we will find a way to cross each bridge as we come to it. Having said that, some difficulties can be prevented, e.g. we have been able to get a statement, before our some starts school”

It seems clear that parents have made most of the comments. It is understandable, that they show some concern about the future of their growing children with sight problems. The questionnaire had not asked, what sight problem or its severity existed. The comments, however, are surprisingly ‘positive’ on the whole, and with proper support and enabling empowerment, most of the children concerned should be able to live independently as adults, and fulfil their potential.

14 –17

“...difficult to find activities to suit”

“...mainly due to the learning disability more than the vision, although poor lighting at some venues causes problems. Also uneven pavements and not well defined steps (without edge marking)”

“...have been accepted in both sports (horse riding and swimming)”

“...scouts and social activities. Very accepting of individuals needs”.

On the whole all these comments were encouraging. The additional condition of learning disabilities in one of the comments, obviously necessitates additional help and support, but does not preclude the young person concerned from having / enjoying appropriate social activities.

18 – 21

“...x has a few behavioural problems due to puberty hormones”

This person seems to experience problems rather due to puberty / adolescence than due to the sight problem. Social activities should not be impeded, however, but well supervised.

22 – 34

1 response no comments

35 – 44

1 response no comments

45 –54

“...I do not enjoy social activities with sighted people”.

The writer’s feel that this comment obviously must be due to some experience or other, but none of which seemingly enjoyable. The comment could be almost deemed discriminatory vis à vis the sighted community. It would be helpful to know, what brought this negative feeling about. Furthermore, some help ought to be available to this

person to live a happier life despite the VI.

“... have to be taken to the loo, etc.” Activities stated were rambling, going out to pubs and clubs.

The writers accept that it is difficult to be dependent on help from others, but the authors feel that acceptance of help, where needed, do not reduce the ability of some independent living.

“... Keep fit. I am unable to follow instructor. Tried several classes. Shopping – need a one-to-one guide”.

The writers would agree, that keep fit classes are a good way of preventing disease. However, the respondent seems to choose the wrong kind of classes. The instructors should make allowances for someone with a VI. There are some ‘over fifties’ clubs and independent instructors, who can arrange so called ‘chair aerobics’, especially as VI persons often have problems with maintaining balance.

55-64

5 responses 1 commented throughout.

“...lack of understanding, supports all the above”.

It appears that this respondent had a thoroughly miserable experience in their life thus far. The writers would not wish to interpret this one way or the other as, without follow up interview, the writers cannot second guess whether this is the person’s feeling, or whether the person is of a rather melancholic nature, i.e. cannot be cheered up by anything.

Do you anticipate problems in the future?

“...as long as society has its fixed ideas on VI I will have problems”.

The writers are rather concerned to note, that this respondent seemingly does not have any joyful moments in life. The question really is, what could be done to make this person realise that sometimes one has to work towards one’s own happiness.

65 +

13 responses 2 comments

“...I have to get lifts and avoid steps” (had ticked access as being a difficulty)

This is an obvious problem to nearly all VI people.

“... a visually impaired person puts people at ease”.

The respondent understandably feels that VI people put other VI people at ease. Yet, one should not generalise as it depends very much on the general character and nature of a person, be they VI or not.

One person had ticked ‘support’ as an anticipated problem, and given this somewhat enigmatic comment that

“...old age”.

This could be interpreted in many ways, and the writers are not at all clear whether this is meant in matters physical, psychological, or spiritual. Only a follow-up interview may provide some more clarity.

5) SOCIAL INCLUSION

To refresh readers of this report’s memory 2 respondents had not stated their age as requested hence the above heading.

Have you or are you experiencing difficulties claiming benefits?

(Please refer to list in numerical data)

1 comment received namely

“...no, mum deals with this”

The writers would agree that there could be difficulties, but if there are, the respondent was not aware of those. It appears that the questionnaire was completed not by the VI person, but her/his mother was dealing with such things as claiming benefits, presumably such as Disability Living Allowance (DLA)

13 and under

19 responses 2 comments

“...I do not fit the criteria for higher rate mobility component”.

The writers would have found it helpful, if the comment had given also some indication why?

“... we need to renew our claim for disability and mobility, but the forms are so difficult to fill in”.

The writers would agree that the uniform DLA form, trying to cover all forms of physical and sensory disabilities is totally inadequate in view of the sensory perspective. Needs may differ greatly, but the headings are mainly physical disability orientated. This is certainly something that would require urgent action. The writers are aware that institutions, such as the RNIB, are running courses in how to interpret those forms for VI people. The writers would argue that interpretation is not good enough as it is easily open to misinterpretation. Clarity can only really be guaranteed by having a clear and appropriate form for sensory disabled/impaired people.

14 – 17

9 responses 2 comments

“...because I am a border I don't get my full carer allowance”.

“...was turned down for DLA years ago – have not bothered to apply again – felt like we were applying for something we shouldn't have been”.

The writers feel that certain agencies, dealing with benefits, are speaking 'forked' tongues. On one hand there are TV adverts, advising of benefits available in general and that people should apply if entitled to, yet the writers are often told as well as involved in appeals, where people have justifiably applied for a certain benefit, such as DLA, and have been turned down. Could it be the above described ambiguity of the form? Could it be the subjective assessment of a completed form by

the benefits agency? This raises many questions and warrants closer scrutiny. As it is such an important countrywide issue, pressure groups of the size of the RNIB and Action for the Blind People would have to be involved in this.

18 – 21

5 responses no comments

22 – 34

1 response no comment

35 – 44

1 response no comment

45 – 54

5 responses 2 comments

“...want to get the high rate of mobility of the DLA”.

“...I was not notified, when the rules for claiming my benefit changed”.

The writers found it almost impossible to put any kind of interpretation to those two comments. Suffice to say or repeat the interpretation earlier on in a lower age group. However, once again it cannot be overstated enough that the whole question of benefits and the entitlement to them, needs to be dealt with properly and unambiguously e.g. We do not use or prescribe wheelchairs because someone has lost their sense of sight or hearing. Equally, not one form fits all impairments, and yet all of them are entitled to benefits in their own right. Someone in a wheelchair regrettably cannot walk, but usually can see. Conversely, someone with impaired sight may find it difficult to walk without a Sighted Guide, because they cannot see kerbs, steps, slopes, lamp posts, and other such things. When will benefit agencies, i.e. The State realise that, and act accordingly. It seems that having a blind Home Secretary, who relies on the services of a guide dog, but obviously doesn't need to rely on

any benefits, seemingly is not concerned about bringing about a long overdue review of the whole disability benefit system. One can only hope that maybe someone else will see sense and finally act accordingly.

55 - 64

5 responses no comments

65 +

13 responses 1 comment

“...help from Sighted Person. ‘One Form Fits All’, not appropriate for VI person. Couldn’t claim any Carer’s Allowance, because in receipt of DLA”.

The writers’ opinion is that some people lack understanding of what they are entitled to or not. However, ‘the one form fits all’ comment was dealt with in the previous age group. The writers would wish to reiterate that action on this ambiguous state is urgently required.

6) MOBILITY AND INDEPENDENCE

Have you experienced or are you experiencing difficulties with independence in education/employment due to mobility difficulties?

2 responses 1 comment no age stated

“...going up to Junior School was hard, even though it is the same building, just a different side. The playground is much larger, and going for lunch was hard”

It appears that this respondent – although having stated that he/she had attended a special school – the school in question had not catered for pupils with a VI at the later stages of schooling. Although the writers have no way of knowing whether the school was a special school for VI

pupils or a special school for another major disability group, it has to be said that it does not deserve to be called special in view of the amenities available. Whilst the writers agree that school ought to prepare pupils for later life in the outside world, which often does not cater for any special needs, schools should not call themselves 'special', if they do not cater for an individual's needs completely. They certainly will not refuse any extra funding for their status, so they should provide accordingly.

The writers would suggest, that it would take an outside agency, such as F S, who have no vested interest in any establishment, to do a thorough audit of such establishments and provide a quality mark, much in the way it is now provided to individual hospitals.

Have any sighted carers received any form of training in relation to any of the above issues?

"...school has, but not mum and / or family members"

This comment highlights the importance of all the other respondents, however, answered the following question in that section: - carers, including parents, other relatives, siblings, and so on, have to be trained, if possible together with the VI person. There is still a long way to go in achieving this goal.

13 and under

19 responses 3 comments

"...his school is a very busy place, which I difficult on the mobility side, when left unaccompanied"

"...there is lack of a mobility teacher in the County of Essex"

"... not yet but anticipate when I get to secondary schools that are larger and very confusing".

The writers, reading these comments, understand the concerns expressed in them, and feel frustrated in their inability to change attitudes sufficiently and quickly enough to bring about real changes,

not only in one school, but throughout the whole country. The writers are fully aware that this is utterly idealistic, but the DDA was passed in Parliament for exactly this purpose. Although implemented in October 2004, in reality there is still a very long way to go until a somewhat ideal state will exist. The passing of laws alone is not sufficient. Auditing, monitoring and reviewing on a regular basis are the only way to ensure that standards improve, and once improved, stay at the same level in future.

14 – 17

9 responses 1 comment

“...dark presents a problem. Speed of traffic. General confidence in getting around”.

The writers can agree with the above mentioned difficulties, and are forever trying to educate anyone, who wants to listen, that these problems are real problems, which could often quite easily be overcome with common sense. Again, it is a message that needs to be repeated constantly forever.

18 – 21

5 responses 1 comment

“...now have a Sighted Guide as College is too busy and large to get around independently”.

This comment is an example of good practice, which should be emulated more often.

22 – 34

1 response no comment

35 –44

1 response no comment

45 – 54

5 responses no comments

55 – 64

5 responses no comments

65 +

13 responses 1 comments

“...I have an Attendance Allowance only for my general bad health and lack of sight”.

Whilst this comment is regrettable, it is not really ‘explicit’ enough to analyse.

TRANSPORT RELATED TO EDUCATION

Has Transport ever been an issue during your education?

Yes = 13

No = 11

2 responses no comments from those who didn’t indicate an age

13 and under

19 responses 6 comments

Some of the comments are very non-specific. The writers, therefore, will concentrate on those, which give more information as to difficulties experienced or otherwise

“...some, but easily resolved with the help of our specialist teacher”.

“...the taxi was always late, and the journey took an hour each way. This was due to the amount of children collected. Thankfully these problems have been resolved”.

“...we now get full mobility for our son, so we have a car, so it is not a problem. Due to expire in June. Need to claim again”.

The last comment demonstrates clearly the discriminatory way in which the DLA system works. The authors would argue, that it is petty bureaucracy, which does not understand, that certain conditions and all true congenital disabilities do not improve with advancing age, such as puberty. Understanding of this point, not only for those who need wheelchairs, would reduce the work of the benefit agency concerned with DLA, but even more importantly, it would help reduce an otherwise already very stressful parental life. Re applying is not easy, and the claims are often interpreted differently, depending on which bureaucrat is dealing with the claim. This is clear proof that FS’s advocacy work is clearly an urgent requirement.

Although transport is an important issue for this age group, the writers are aware that in a lot of cases the parents are car owners, and that helps to alleviate transport problems a lot. Children of that age, who are dependent on other forms of transport, seem to have a variety of problems as some of the examples above show. It is really not good enough to talk about ‘education’, but then not to provide the appropriate form of transport for all those, who need it. The Social Services Inspectorate published by the Department of Health (2001) has identified ‘*access to goods and services*’ as one of the important corner stones for disabled people of whatever age. It is clear that there is still a lot of work to be done to achieve this for individuals in this age group.

14 –17

9 responses, 4 comments

“...the taxi driver was abusive and smoked”.

“...the Council expected me to travel alone with a male driver”.

Some comments were a reflection of the above overall comment. It is however, most disturbing to read the above comments, which clearly

demonstrate that adolescents do need the appropriate protection in the transport system provided. This may now be less of an issue with the Criminal Records Bureau (CRB) clearance required for working with vulnerable people, but nevertheless, vigilance is continued to be required, and vulnerable young people need to be taken seriously, when they report or talk about such incidents.

18 – 21

5 responses 3 comments

“...had to fight for transport, when left school, and went to a specialist college outside area”.

“...financial”.

It appears that the opinions of local authority and of parents did not come to the same conclusions as far as the students further studies were concerned in view of which college this student should attend. The local authority may well be of the opinion, that it could provide such schooling adequately within their locality. The student, or parents, was of the opinion that the college outside the local boundaries was the better one for whatever reasons. One of the reasons may have been that the student had got used to the college and developed good relationships with teachers and peers, which is terribly important in the learning process. It may have been for this reason that they wished to maintain continuity.

Local authorities regrettably have to think in budget terms, but also at times do not have the necessary understanding to appreciate the importance of seamless education and its benefits for the person's future.

Again, an independent assessment of need by an agency, such as FS could be most valuable in such a situation in future.

22 – 34

1 response no comment

35 – 44

1 response no comment

45 – 54

5 responses 1 comments

“...I had to have somebody with me”.

The writers assume that this was for the period of this respondent’s time at school only, but not in later life

55 - 64

5 responses no comments

65 +

13 responses no comments

Most VI people at this age are those who have an acquired sight loss, i.e. may have, therefore, not experienced any problems with transport during their education period.

The questionnaire did not ask whether the respondents had an acquired or congenital sight loss. This can only really be assumed of those, who fall into the 0 – 13 category. In future surveys this may be an important aspect to ascertain as part of the questions.

TRANSPORT RELATED TO EMPLOYMENT

Has Transport ever been an issue throughout this time?

Yes = 5

No = 18

No age indicated

2 responses no comments

13 and under

19 responses no comments

14 – 17

9 responses no comments

18 - 21

5 responses 1 comment

“...transport seems to be an ongoing problem”.

See comments and final general comment about transport at the end of this section.

22 – 34

1 response no comment

35 – 44

1 response no comment

45 – 54

5 responses 3 comments

“...it’s everyone’s responsibility to get themselves to work / I did so, using a guide dog and bus or by taxi. Just as I finished working, I learnt, that I could have got assistance with fares under ‘access to work’

This comment is clearly showing determination and the will to be as independent as possible, despite the VI. To be able to use taxis (the comment did not make clear how often) needs a certain amount of income in order to do so. The writers agree, however, that transport is

an issue, which seems to be one of the most important underlying difficulties as far as independent living and particularly employment is concerned.

“...seeing bus numbers, train times, etc, is a problems”

This comment is self explanatory but under the DDA (1995), as from October 1st 2004, Access to Information is one of the demands, expressed by this act.

55 – 64

5 responses 1 comment

“...until I had a driver through ‘access to work’, life was difficult using public transport”.

It appears that employers need more information about acts / parts of employment laws, which deal with disabilities and needs arising through them. It is laudable that this person’s employment was continued, but it is at the same time lamentable that human resource departments / personnel departments are so ignorant about the help that is available to aid V.I. persons to continue their employment.

The writers would emphasise most strongly that only continuous education / information of such departments will keep knowledge at levels, which are useful for their VI employees in future, another role for FS?

65 +

13 responses 1 comment

“...time spent using public transport led to a longer working day, and through that to more fatigue and stress”.

This is a very important comment in view of a person’s right to sufficient rest and leisure time. The journey to and from work should not be made unreasonably longer and more stressful, than it already is during peak

times of the public travelling to work. The writers would suggest the same measures to be taken as mentioned above, i.e. in previous age groups.

TRANSPORT RELATED TO VOLUNTEERING

Has transport ever been an issue throughout this time?

Yes = 4

No = 22

No age indicated

2 responses no comments

13 and under

19 responses 1 comment

"...someone has helped me".

The writers find it very commendable that people / parents help developing young VI people to help others through volunteering. This really should be encouraged wherever possible, because it gives a sense of achievement and enhances their conviction that they still are valuable and valued young member of society.

Volunteering is always, but especially at this age, an insightful learning process and helps to deal with one's own needs from a more positive perspective. Maslow's Hierarchy of Needs (1954) becomes a guiding principle in such a young person's life. Furthermore, volunteering can become part of Bruner's Spiral Learning (1915) in the sense that it teaches 'life skills', which are not only invaluable, but also aid the understanding / cognitive processes of such a young person. Having a V.I. can only help making such young persons more sensitive to the needs of others.

14 - 17

9 responses no comments

18 – 21

5 responses one comment

“...was taken there”.

22 – 34

1 response no comment

35 – 44

1 response no comment

45 – 54

5 responses 2 comments

“...my voluntary work is within walking distance from home”.

“...would have been, but friend took me”.

55 – 64

5 responses 1 comment

“...unable to drive, creates all kinds of mobility problems”.

65+

13 responses 4 comments

“...late evening meeting equals difficulties”

The writers are aware that VI people have great problems in travelling at night as many people are totally night blind, hence do not see obstacles that they might be able to see during the day.

“...only because I am very arthritic, too, I hate steps”.

The writers are aware that other physical conditions can exacerbate the V.I. and inhibit activities of daily independent living, and through that any volunteering activities.

TRANSPORT RELATED TO SOCIAL ACTIVITIES

Has transport ever been an issue when it comes to Social Activities?

Yes = 9

No = 32

No age indicated

2 responses 2 comments

Both comments state that transport is not an issue as parents take both respondents to social venues.

13 and under

19 responses 4 comments

“...someone helps”.

“...transport will always be an issue, unless I take him in my car”.

“...parents take me”

“...but we are trying for a badge for the car to make things easier”.

It is most unhelpful, that local welfare transport systems do not cater for young disabled people. It is usually only people of a certain age, particularly retired people. Furthermore, social activities often take place in the evening, and then local welfare transport schemes are not operating. The writers need to investigate the whole issue of transport and how it could be improved, to be worthy of the 21st Century. Young people do need to socialise and become members of society by socialising with their peers. This issue is one of many that an organisation like FS has to tackle.

14 – 17

9 responses 3 comments

None of the comments talk about difficulties with transport as the parents take them to social events.

18 – 21

5 responses 4 comments

“...I don’t drive, lack of finances”.

The writers are not at all certain, whether this questionnaire has been completed by the VI person her/himself or the parent/s. The response would lead the writers to believe that a parent has completed it.

Conversely, if the VI person had completed the questionnaire, the writers would be most concerned that this person would drive despite being registered VI.

“...I would take x to a social activity as long as I knew how to get there. He wouldn’t be capable of going on his own”.

The writers find this comment understandable as this VI person has some behavioural problems due to puberty. It seems that the statement of knowledge of the way to such activities may rather have its roots in the behavioural problems than in the actual transport itself.

The other two comments stated that the parents provided the transport to such activities.

22 – 34

1 response no comment

35- 44

1 response no comment

45 - 54

5 responses 3 comments

“...have to get taxis everywhere which cost a fortune”.

“...travelling by bus or train can be a problem”.

“...buses not always available and taxis too expensive, if used regularly”.

The authors are fully aware that no disability transport system is operating during evening times and at weekends are literally non-existent. Solutions to this particular problem have as yet to be found.

55 – 64

5 responses 2 comments

“...have to rely on friends or taxi service for evening activities”.

“...some places I just can't get to”.

65 +

13 responses 2 comments

“...if lifts are not available”.

“...always in all areas as said before”.

The question about transport has, as usual, opened a ‘can of worms’.

The right of any person to some kind of social life and the opportunity to do so are a human right which VI people are often denied, because of transport. The same is true for other disability groups.

The most important question, therefore, must be how access to such activities can be ensured for all VI people at all times. The writers are convinced that only the relentless work of a specific pressure group under the auspices of an organisation, such as Future Sight, may bring about the change necessary.

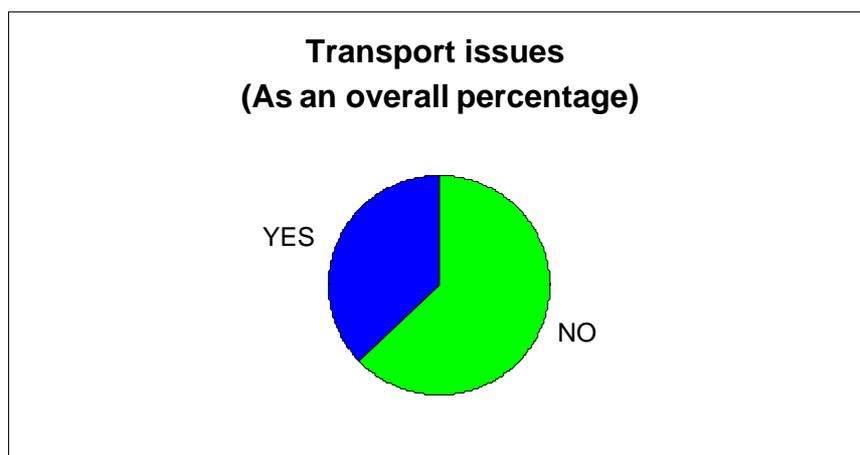


Fig 3

If there were an organisation that provided advice throughout Education/Employment would it be of use?

No age indicated

2 responses 2 comments

“...yes, LOOK Essex has been supportive and informative to the school”.

“...yes, if available to x, if he needs help and support through school and social services”.

The writers take note of the fact that Look Essex is a helpful and supportive organisation during the time of the formative years. However, the question is, who would be there for actual help and advice after VI persons have reached adulthood and need ongoing help and advice to live independently through further education / employment? The writers would argue that it would take an organisation, which covers the whole life span, not only bits of it.

13 and under

19 responses 8 comments

“...visual support team”.

“...it would help children to reach their full potential in main stream schooling”.

“...we are not sure what’s available in mainstream school for our child”.

“...if it covered the areas of expertise we need , have used RNIB, SNAP, Network 81”.

“...I have spoken to your group, which was very helpful, and I will contact you again, if the need arises. I have also gained help and advice from ACE (based in Highbury for SEN)”.

The writers understand that many different groups can lead to confusion

rather than help. Not every parent has the necessary help or knowledge about which organisation to seek advice from at the various developmental stages. The writers would, therefore, argue that an umbrella organisation, such as FS, could be of immense help in reducing confusion in a period of shock and helplessness, when having to deal with the fact that their child has a visual impairment.

“no special visual impairment teacher in his mainstream to learn him on a day to day basis. I do felt. Assistants are no where qualified in visual fields and haven’t a true understanding of their requirements”.

“...to speak to someone who is uninvolved and who could give an unbiased opinion, would be very helpful”.

“...to give me advice when needed, would be good”

The writers would argue that these comments reflect the special need for such an organisation, when dealing with educational matters. Again, an umbrella organisation, such as FS, organised in a professional and business like manner, i.e. departmentalised or with various organisational sections, dealing with different aspects, would be the ultimate in achieving unity of advice and help rather than all the important splinter groups that are in existence now. Most of them have started somewhere locally to deal with need, and have then spread regionally or nationally. Ideally, these groups would continue to exist, but would in themselves become part of FS.

14 – 17

9 responses 7 comments

“...an independent service i.e. RNIB, that could make recommendations”.

As the writers have already argued, such an organisation could be ‘FS National’.

“...my school (– Thomas Lord Audley (TLA), Colchester), is very helpful (VI unit)”.

“...Look Essex and Look National helped me get the right education (which was not TLA School)”

This respondent did not feel that to be the appropriate educational establishment as outlined in the education section of this questionnaire. These last two statements/comments demonstrate clearly that Individual Education Plans (IEP's) would cater for individuals' needs more appropriately.

It is highly commendable to have such specialised units to provide a more conducive educational environment for VI children. Yet, there still clearly is a need for meeting individual needs on an individual basis.

“...sometimes things can be hit or miss with education, and it would have been of help to be able to contact someone who is in the know”

“...we found we have needed to ask other parents, voluntary organisations, support groups, to really gather and know what's actually out there to help”.

The writers find this last statement a sad, but true, reflection of the situation as a whole. The need for a national organisation, perhaps even providing a 24-hour helpline, must surely be the answer. Otherwise, in 10 or 20 years time, comments will still reflect this rather dangerous fragmentation.

18 - 24

5 responses 2 comments

“...it would be helpful for support, so that you did not feel alone, fighting so many battles”.

The same respondent has also provided a general comment at the end of the questionnaire, which reads as follows: -

“...I think there is a definite need for this type of organisation, because my son is now 21 years old, and it would have been very helpful to have

had support through transition from school to college / adult provision (adult education), and to know there is someone to turn to if you need answers”.

These two comments, provided by the mother of this respondent, clearly demonstrate the need for an organisation, which is not only able to provide information and guidance, but is equally able to act in an advocacy role, i.e. signposting VI people or their sighted significant others to the individually appropriate school / college / or other agency they need, and be with them, if they so wish and need.

The writers are aware that the questionnaire did not particularly ask any direct questions regarding life’s transitions, but do not underestimate the importance / special needs in the periods of life’s transitions, be that from childhood to adolescence to adulthood, or from middle age to more

advanced years. Both those major transitional periods have their own characteristics and need understanding and appropriate help to make those transitions easier and more acceptable to all concerned. Future Sight could have to have an experienced team of counsellors, who could provide expert counselling and advice.

“...it would mean one less worry”.

The writers feel unable to interpret this rather enigmatic comment, as the word ‘worry’ does not give any indication what area the worry is in. However, the writers would argue that the overall comment above would include and deal with the last comment.

22 – 34

1 response no comment

35 – 44

1 response no comments

45 – 54

5 responses 2 comments

“...I was in full-time employment, before I became severely visually impaired”.

“...any support would have helped, but my low vision was never discussed”.

The writers take note of the comments, but neither of them makes a strong case for the need of a special organisation. The writers agree that any support is better than none, and were concerned that a VI person had never received any in-depth information on her / his sight problems, but even more on their ability to lead fulfilling independent lives, or available aids that would make their lives easier. The writers themselves would argue that it is one of the major roles of such an organisation, to help VI people to articulate their feelings and problems and get the appropriate help.

55 - 64

5 responses 2 comments

“...yes, it would have been” (in the Education section of the questionnaire – had gone to a special school)”.

“...VI needs contact and support all their lives”.

This person appears to have been VI all their life, and makes the case for an organisation, like FS, that would do away with compartmentalisation of people into different age groups, according to their chronological age. The writers agree, that enabling and empowering help may be needed throughout VI peoples' lives, in order to reach their full potential and live as independently as possible.

It has to be said that even the NHS and Social Care are lacking this holistic view. The writers are aware that different age groups have different needs, but compartmentalisation loses far too often sight of the fact that it is still the same person, but having just gone through a transitional stage in their lives.

“...it would have provided a way of challenging lack of awareness. In my experience, I was on my own, feeling in a weak position, stating my difficulties to teachers”

uncertain of which school attended as main stream school, and then specialist school and college had been ticked.

See comment above. It appears that both respondents were either VI from birth or soon thereafter. This would explain the way they commented. However, it emphasises the need for an organisation, which caters for all needs of VI people of all ages.

65 +

13 responses 3 comments

“...sight loss was not diagnosed until after retirement age”

It appears that this respondent was ‘misled’ by the fact that the questionnaire had been issued by Look Essex and its fledgling FS organisation. Look Essex being generally known as organisation for VI children and their sighted families, may have led to this ‘confusion’.

“...housebound book service”.

The anonymity of this survey regrettably does not enable the writers to inform this respondent that such a service has been on offer for a long time in all counties of the United Kingdom. However, a FS National would be the answer for people like the above respondent.

“...advice and support in education and career advice”.

The writers agree with this succinct statement, and its holistic nature. It encourages the writers to seriously think about how such a FS National could be set up.

CHAPTER FIVE

INTERPRETATION OF FINDINGS AND RECOMMENDATIONS

The writers, upon completing the quantitative and qualitative analysis of the returned questionnaires, found their previously formulated hypothesis confirmed in most of the respondents' answers, particularly in view of an overarching organisation for visually impaired people.

Whilst the survey did not specifically ask what type of organisation respondents would find most helpful, it did ask whether people would find an organisation of that nature useful. Most of the returned questionnaires answered this section positively. The majority of returned questionnaires clearly showed the need for some kind of an all-encompassing organisation. They made it very clear that having to approach different organisations for different aspects of need was not the most ideal way of dealing with such a situation. It could be at best be confusing, and at worst haphazard in supplying evidence of its existence, i.e. visually impaired people did not often hear about the existence of a specialised organisation, e.g. Network 81. In this time of ever increasing specialisation, there is a resultant fragmentation of the overall help and support available, within the whole range of needs of the visually impaired community. A holistic approach, or person centred approach is needed.

The findings had indeed confirmed the original hypothesis, which had been informed by a report named 'Progress In Sight' (RNIB 2002), and the Social Services Inspectorate's 'A sharper Focus' report (1997), also the report on Dual-Sensory Impairments (O'Hagan 1998) and in particular, 'Look Essex' evidence obtained from its Family Support outreach work throughout the county of Essex.

Life's transitions for visually impaired people were often not as well planned by way of all the different services, which are involved. A certain 'classification', made at birth or soon thereafter, may not be exactly correct at the time of the first major transition of a person's life at the age of eighteen, and when the visually impaired person leaves the children's services and is ideally handed over to the adult sensory services. It has been known that in some instances this transfer across does not always happen satisfactorily.

The transition from a life of work to that of imposed rest, and possible loss of many abilities, such as independent living, are special challenges for rehabilitation and habilitation services.

The question really was how that could be achieved?

The qualitative findings clearly demonstrated that services and support were far from ideal. Respondents knew that they wanted something different and more 'holistic', but in the majority of answers did not know how to verbalise this in that precise form.

Without putting all respondents through a kind of follow up interview, this can only be deduced from their answers provided in the original questionnaire. Such follow-up interviews will take place, but will take more time and effort, to allow this really to reflect the views of the majority of visually impaired people in the County of Essex beyond any doubt. To do this, the PG decided, that further Forums and Focus Groups would be needed. This will be of real value, once the planning of the overarching FS structure has been completed and can be rolled out to the whole visually impaired community.

It can however, be safely assumed that the answers provided in this survey, demonstrate beyond any doubt, that the present status quo is not satisfactory at all. The most important question of all is therefore, how these shortcomings could be addressed.

The PG, therefore, reached the following conclusions and recommendations.

- That a new body shall be set up to deal with all matters concerning visual impairment at all ages.
- That the structure of such a body, with the name of Future Sight, shall be focussed upon service delivery and will have a small leadership, and be accountable to all members.
- Shall have life's transitions as its guiding principle.
- Shall monitor and review its work periodically, at least annually, with the aid of one of the known models of qualitative measurement, e.g. *PQASSO, EFQM/Business Excellence Model & Investors in People (BVSC 2004)*.
- Produce an annual report for all its stakeholders, budget providers, and donors.
- Avoid becoming rigid in its approach and remain flexible, up to date in all specialist matters, and actively encourage further training of consultants. This training should be provided following supervision and appraisal, and must be tailored to the needs of individual consultants.
- Annual questionnaire surveys shall be continued, always in the dual approach of quantitative and qualitative.
- Member organisations are reassured that they would maintain their present independent status, but would have to subscribe to FS's mission statement, the Social Model of Disability, and the principles of Independent Living.

The writers are aware, that the recommendations are very ambitious, but believe, that in a period of approximately five years, all the above should be in place.

If we all want to serve the visually impaired community in the best possible way, then there is no other choice, but to continue the journey that the PG begun some two years ago, and to build upon that momentum. The need for such a venture has been clearly identified by the respondents in the questionnaire survey.

The question of ongoing funding for such an enormous project has to be tackled in new imaginative ways. Only then can a new sustained era for visually impaired people of all ages throughout life's transitions be guaranteed.

CONCLUSION

The project group will shortly publish this study widely, and seek views and reactions from voluntary, discretionary and statutory 'providers', as well as from visually impaired people and carers alike, regarding this proposed structure called Future Sight.

Reactions received will be studied with great care and interest, but it has to be emphasised that the completed and analysed questionnaires will always be the main basis for any FS developments. The study has proven how important it is to be 'consumer' based. We can no longer justify to be well meaning benevolent organisations, largely run by sighted people, who supposedly know best what visually impaired people really need. The PG will need to carry on with forums, but this time on a larger scale, maybe organised through county organisations for visually impaired people.

The present project group, consisting of a mixture of sighted and visually impaired people, will have to act as catalysts, spreading this important message, and be able to advise on how to set up many initial FS organisations across the country. Many visually impaired people themselves will have to be introduced to this 'revolutionary' new concept, embracing and understanding the Social Model of Disability with its emphasis on personal choice and control (Morris 1993), the Independent Living principles (DOH 2003), and the concept of FS project must stay true to its founding principles and mission statement, but also be adaptable enough to suit eventually every corner of the United Kingdom. The Social Services Inspectorate's 'Fair Access to Care' (DOH 2001) may be of considerable help especially in the field of Sensory Disabilities.

Five years implementation period may seem a long time, but one must not forget, that the concept of FS has not as yet spread across the borders of Essex. The project group will need a lot of patience, stamina, and be able to patiently explain the virtues of this project to all existing local, regional and national organisations, and to the Country's visually impaired population. Florence Nightingale (1870) referred to Nightingale Missionaries in spreading her message about 'modern nursing' in Britain. We need something similar for FS, which will be one of the main tasks of the present Future Sight project group.

Its compelling reasoning and eventual tremendous improvement in the lives of visually impaired people of all ages make this hard work worthwhile for all those, who were in it from the beginning.

In five to ten years' time people may well ask, why it took so long for someone to think in a joined up way or holistically.

Let the work commence.

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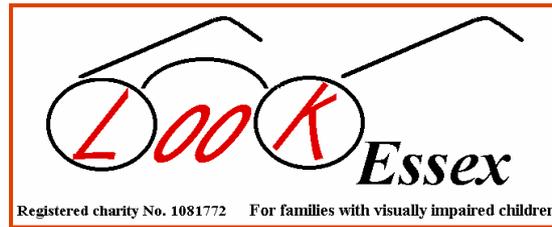
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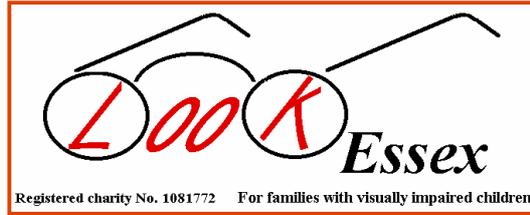
Please find attached a copy of our Looks Future Sight information survey. We are asking you to complete this because we believe you are someone who has had experiences that will provide us with useable information.

Looks Future Sight is a project team investigating the need for an organisation to provide support advice and practical help to young people throughout life's transitions e.g. school to college and employment

Our statement of intent is to offer visually impaired children, young people, adults, there families and carers the provision of integrated services and support, enabling their independence, self development and freedom of choice.

We would be grateful if you could complete this survey and return it to us in the envelope provided by 31 January 2004

All information will be used to verify our belief that the services of Look Essex should be extended to include young people, adults and older people and all information will be treated as confidential throughout the process.



Look Essex
Future Sight Information Survey

AGE: [13 & under] [14 - 17] [18-21] [22-34] [35-44] [45-54] [55-64] [65+]

GENDER: M/F

Please tick the Area you live closest to: Thurrock [] Southend []
Chelmsford [] Basildon [] Brentwood [] Colchester [] Harlow []
Epping Forrest [] Clacton []

Please tick the appropriate boxes and circle Yes or No throughout this questionnaire

1) Education

Please select which of the following you are currently studying at: -

- Mainstream education []
- or Specialist education i.e. Special school/college []
 - School []
 - College []
 - University []
 - Other []

Please State which.....

If you are no longer in education please tell us were you in: -

Mainstream education []

or Specialist education i.e. Special school/college []

School []

College []

University []

Other []

Please State which.....

Have you experienced or experiencing difficulties with

Inclusion []

Access []

Equipment []

Attitudes (pupils) []

Attitudes (staff) []

Support

Please comment.....

Do you anticipate difficulties with

Inclusion []

Access []

Equipment []

Attitudes (pupils) []

Attitudes (staff) []

Support

Please comment.....

Do you feel you have or had the opportunity to reach your full potential

Y / N

If NO please comment.....

Has transport ever been an issue during you education Y / N

Please comment.....

If there were an organisation that provided support, advice and information throughout your time in education, would it be of use. Y / N

Please comment.....

2) Employment

Are you employed Y / N

If YES part time [] Full time []

If NO are you currently looking for employment Y / N

If NO please comment.....

Have you experienced or experiencing difficulties with

Inclusion []

Access []

Equipment []

Attitudes (pupils) []

Attitudes (staff) []

Support

Please comment.....

Has transport ever been an issue throughout this time Y / N

Please comment.....

Has your visual impairment ever been an issue regarding career development and opportunities within the work place Y / N

If YES please comment.....

Do you feel you have or had the opportunity to reach your full potential Y / N

If NO please comment.....

If there was an organisation that provided support, advice and information throughout your transition from education into employment and beyond would it be of use. Y / N

Please comment.....

3) Voluntary work

Have you ever done any voluntary work Y / N

Please comment.....

Have you experienced or experiencing difficulties with

Inclusion []

Access []

Equipment []

Attitudes (pupils) []

Attitudes (staff) []

Support

Please comment.....

Has transport ever been an issue throughout this time Y / N

Please comment.....

Has your visual impairment ever been an issue regarding opportunities within volunteering Y / N

If YES please comment.....

Do you feel you have or had the opportunity to reach your full potential Y /N

If NO please comment.....

4) Social Activities

What type of social activities are of interest to you

Please specify.....

Have you experienced or are you experiencing difficulties with integration into social activities

Inclusion []

Access []

Equipment []

Attitudes []

Support []

Discrimination []

Please comment.....

Do you anticipate problems in the future Y / N

Inclusion []

Access []

Equipment []

Attitudes []

Support []

Discrimination []

Please comment.....

Has transport ever been an issue when it comes to social activities Y / N

Please comment.....

5) Social Inclusion

Are you in receipt of financial benefits Y / N

If YES are your benefits in relation to your disability Y / N

Are you receiving any other benefits Y / N

Have you or are you experiencing difficulties claiming benefits Y / N

If YES is it due to

Fitting the criteria []

Physical Access []

Access re format []

Attitudes [.]

Support []

Discrimination []

Please comment.....

6) Mobility & Independence

Have you received any mobility training Y /.N

Assessment Y /N If YES by whom

.....

Training Y / N If YES by whom

.....

Symbol Cane []

Long cane []

General mobility & orientation skills []

Guide dog []

Independent living skills []

Have you experienced or are you experiencing difficulties with independence in education/ employment due to mobility difficulties Y / N/

Please comment.....

Have any sighted carers received any form of training in relation to any of the above issues Y / N

We would like to thank you very much for taking the time to complete this questionnaire.

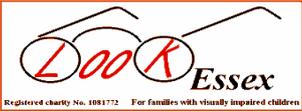
If you would like to receive future information in relation to this project please ensure that you complete the details form enclosed and return it with this questionnaire to: -

Look Essex (Future Sight)

PO Box 2092

Wickford Essex

SS11 7WE



**I would like to be kept up to date with the progress of the
Look Essex 'Future Sight' project.**

Name Sex **M / F**

Year of birth.....

Contact Name & Address

.....

.....Postcode.....

Telephone numberEx Dir' **YES / NO**

Email address.....

Preferred reading format: Braille [] Large Print []

Font.....

Please Return to: -

**Look Essex
PO BOX 2092
Wickford Essex
SS11 7WE**

Positive Critique of the Questionnaire

Whilst this structured questionnaire served its purpose of quantitative and qualitative data gathering well, on analysing returned questionnaires it had become clear, that some minor changes/additions might have been helpful to respondents, and some to the analysis team.

Respondents, particularly those of a more mature age, might have found a Glossary of Terms useful. Terminology, such as INCLUSION, ATTITUDES, SUPPORT, and many others can mean different things to different people. Members of LOOK Essex are used to those terms, but one cannot assume that everyone else knew.

Please find a Glossary of Terms in Appendix 2.

Another fact, which would have been helpful on analysis, was the fact whether respondents had a congenital or an acquired sight loss problem. The authors found in a small number of returned questionnaires, that this was not entirely clear. To avoid, having to make assumptions, this will be included in any future questionnaire survey.

Glossary Of Terms

ACCESS:

- **Dictionary:** Approach- Means of admission)
- **Look Essex Context:** (Opportunity to receive a service or goods or to enter a facility)

ASSESSMENT:

- **Dictionary:** (Estimate magnitude or value, or quality of)
- **Look Essex Context:** (Judging and offering advice regarding the needs of a disabled person)

ATTITUDES:

- **Dictionary:** (Posture of body-Way of regarding things-Disposition or reaction)
- **Look Essex Context:** (To assume, and stereotype, whether positive or negative)

DISCRIMINATION:

- **Dictionary:** (Make or see a distinction especially as a basis for unfair treatment)
- **Look Essex Context:** (To treat in a negative way, or less favourably because of person's disability)

EQUIPMENT:

- **Dictionary:** (Tools or apparatus)
- **Look Essex Context:** (Aids, and items that enable disabled people)

GUIDE (Dog):

- **Dictionary:** (Dog trained to lead blind person)
- **Look Essex Context:** (A trained dog that enables the mobility and independence of visually impaired people)

INCLUSION: (Social)

- **Dictionary:** Comprise, regard or treat as part of a whole)
- **Look Essex Context** (Opportunity to participate on ones own terms)

INDEPENDENT LIVING SKILLS:

- **Dictionary** (Self governing-Not depending on something else for validity or efficiency or on another person for one's livelihood or opinions)
- **Look Essex Context** (Opportunity to live without carers or to make one's own decisions)

INTEGRATION:

- **Dictionary** (Complete, combine, into a whole-Bring or come into equal membership of society)
- **Look Essex Context** (Opportunity to join the mainstream-Lost within the mainstream)

LONG CANE:

- **Dictionary** (A walking stick [Long])
- **Look Essex Context** (An aid to mobility and for guidance)

MAINSTREAM EDUCATION:

- **Dictionary** (Prevailing trend of opinion [Education])
- **Look Essex Context** (Inclusion within state or private education with ones peers)

MOBILITY:

- **Dictionary** (Moveable, readily or freely)
- **Look Essex Context** (The ability to travel and move independently and freely)

ORIENTATION SKILLS:

- **Dictionary** (Of the East [Skills])
- **Look Essex Context** (The ability to recognise ones whereabouts and the context in which one finds oneself there)

SOCIAL ACTIVITY:

- **Dictionary** (Concerned with energetic mutual relations between human beings)
- **Look Essex Context** (Opportunity to meet other people and reduce isolation)

SPECIALIST EDUCATION:

- **Dictionary** (Not general-Exceptional)
- **Look Essex Context** (Opportunity to receive a bespoke and individual education)

SYMBOL CANE:

- **Dictionary** (A walking stick that typifies or represents)
- **Look Essex Context** (Indicator to others that the user is visually impaired)

SUPPORT:

- **Dictionary** (carry all or keep from failing- encourage-help)
- **Look Essex Context** (To offer assistance that does not detract from a person's independence)

TRANSITION:

- **Dictionary** (Passage or change from one set of circumstances to another)
- **Look Essex Context** (Key life change stage of a person's development)

VISUAL IMPAIRMENT:

- **Dictionary** (Sight that is damaged or weakened)
- **Look Essex Context** (Our client base consisting of people with a wide variety of sight and eye conditions that reduce their ability to see effectively)

VOLUNTARY WORK:

- **Dictionary** (To work of one's own free will)
- **Look Essex Context** (Opportunity to give one's time freely for the good of others, and to enable individual development)