

BUILDING A FUTURE

Young people with Albinism

Outline

- ◉ Uniqueness of Albinism
- ◉ Early Years
- ◉ School Years
- ◉ Setting Out
- ◉ Career paths
- ◉ Personal Life

Uniqueness of Albinism

Albinism resembles other visual impairments in the following ways:

- Requires adaptations and specialised methods for education.
- Need care and possibly specialised training for mobility.
- Many everyday tasks require more care and effort.
- Young people may feel different from their peers.

Uniqueness of Albinism

- **The following features apply specifically to Albinism:**
- Usually permanent and stable.
- Almost always involves nystagmus.
- More visible than most disabilities.
- Implications for skin care.
- Additional socio-cultural implications for non-white races.

Early Years: Parents' Experience

- Anxiety
- Uncertainty
 - Dealing with wider family and friends
 - Sifting through advice
- Gaining access to services
- Attitudes of others.

Early Years: Child's Experience

- Feel no different: want to play and have fun.
- Gradually aware that others see as different.
- Gradually aware that some things more difficult than for others.
- May avoid certain tasks and have strong preference for others.
- May resist protection.

School Life: Parents' Experience

- Concerns about:
- **Safety:** inside and outside school
- **Independence:** How much help will be needed? How much to allow?
- **Learning:** What will be difficult? What help will be available? How to find right supports? How to be sure that any learning difficulties are vision-related?

School Life: Parents' Experience cont.

- **Social interaction:** friendships inside and outside of school
- **Self-esteem:** providing opportunities for achievement.
- **Pitching expectations:** High enough or too high?
- **Dealing with conflict:** Bullying or normal peer interactions?
- **Dealing with disappointment**

School Life: Child's Experience

- Trying to make own way in school. May find supports a nuisance.
- Trying to find own methods for learning. May be impatient with aids and appliances.
- Risk of sticking to things that are easy, ignoring things that are hard, avoiding games or physical activities.

School Life: Child's Experience (cont.)

- Risk of sticking with one or two friends that are comfortable.
- Difficulty explaining albinism to others.
- Asking for help when needed: knowing when and how.
- Declining help graciously.
- Learning to reciprocate.

Adolescence: Parents' Experience

- Fostering responsibility
- Negotiating independence
- Facilitating the learning of new skills
- Helping the young person discover an identity
- Evolving new relationships within the family
- Facilitating the development of new relationships outside the family.

Adolescence: Young Person's Experience

- New self awareness.
- Need to incorporate visual impairment into identity
- Need to preserve and develop self esteem
- Need to establish and grow into new relationships with family
- Need to learn new skills
- Need to make new connections with outside world.

Adolescence: Young Person's Experience cont.

- New pressures: exams, new skills. Disability has direct impact on what young person needs to achieve.
- Can affect sense of self-worth.
- Need to be clear about own identity as distinct from disability
- Need to be able to use help

Career paths:

- Developing a skill set:
 - Daily Living Skills
 - Personal and Social Skills
 - Academic skills
 - Career Preparation Skills

Daily Living Skills

- Care for one's own personal needs
- Buy, prepare and consume food
- Buy, organise, maintain and care for clothing
- Manage a living space
- Manage money, both small and large transactions
- Manage time
- Get around independently, including using public transport

Personal and Social Skills

- Know how to give and take friendship.
- Have experience of helping others as well as receiving help.
- Recognise own emotions.
- Have easy way of explaining disability.
- Distinguish honest enquiry from ignorant intrusion.
- Learn simple assertiveness.
- Find opportunities to contribute to community

Academic Skills

- Acceptable standard of literacy
- Functional competence with Maths.
- Competence with technology: word processing; internet use; smart phone.
- Study skills: budgeting time; maintaining schedule, balancing demands of study and leisure; setting study targets; using mentors appropriately.
- Acquiring specific competences leading to further study or career.

Career Preparation Skills

- Learn about what work is.
- Learn work-related skills: time-keeping, punctuality.
- How to find and use information.
- Learn about conventions in different workplaces
- Learn how to address people appropriately in different situations

Career Preparation Skills

- Learn about managers, supervisors, juniors
- Learn about work schedules, deadlines, managing pressure.
- Recognizing what are reasonable demands and how unreasonable ones might be dealt with.
- Learning how aids and supports can be incorporated into workplace.

Choosing a Career

- Learning about oneself: talents, skills, limitations.
- Finding out about careers related to one's talents and interests
- Learning what the components are for two or three of those jobs
- Learning how much of each component could be done by a person with a visual impairment
- Finding out what qualifications are necessary and how they can be achieved.

What does the research say? (Network 1000)

In population with visual impairment in general, rates of employment in the UK are low (40%).

But

- Those who have benefited from specialist educational input from an early age are more likely to achieve higher qualifications and eventual employment.
- The level of qualification is positively related to the likelihood of employment
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Dealing with uncertainty and change

- Having bank of leisure interests and activities.
- Being prepared to volunteer.
- Being prepared to consider work related to one's chosen field even if not at the level one aspires to.
- Consider internships, foreign travel, exchange programmes.
- Learn ancillary skills, e.g. in IT.