

ALBINISM AND EDUCATION

A FAMILY PERSPECTIVE

Outline

- What's the same; what's different ?
- Academic issues arising in
 - Preschool
 - Primary School
 - Secondary School
 - Social-emotional Implications of Albinism
 - Leaving School

What's the same?

What do parents want for their children?

- Child to 'do well'
- Be safe
- Be healthy
- Be happy
- Make friends
- Hold to family values
- Learn how to make and keep satisfying relationships

What do parents want for their children?

- Learn
- Pass exams
- Perhaps achieve in sport or arts
- Learn to be independent
- Find a satisfying vocation in life
- Learn how to make a living

What do parents fear for their children?

- Child will be bullied
- Child will not be safe
- Child will make wrong or unwise choices
- Child will not make friends
- Child will not establish satisfying relationships

What do parents fear for their children?

- Child will not learn
- Child will not achieve
- Will not achieve independence;
- Will not find a satisfactory way of making a living.

What does the child want?

- Play and have fun
- Try new things
- Learn new things
- Achieve
- Make friends
- Feel loved
- Feel safe
- Feel valued

What does the child fear?

- Hopefully nothing
- Perhaps 'I might get hurt'
- Being left out
- Some children fear disappointing the people they love
- Some children fear not being able to match up to an admired sibling or even parent

What does having Albinism add?

- Parents may alter priorities
- Fears may be greater
- Expectations may be lowered, or parents may be unsure of what their expectations should be
Parents may make *fewer* demands on the child in certain areas, such as independence skills
- May make *greater* demands in terms of extra work on learning skills like handwriting or computers
- Parents may find it hard to balance the needs of their different children

What do we expect from Preschool?

Child will learn some **independence** skills:

- Take off and hang up coat
- Fetch toys and other objects from their place and put them back when finished
- Go to the toilet independently
- Wash hands
- Eat and drink simple foods independently
- Take care of own possessions.

What do we expect from Preschool?

Child will learn some **social** skills.

- Child will learn to separate from family for a short while each day.
- Greet others appropriately
- Take turns and share
- Communicate wants and needs
- Learn to play alongside and then with other children

What do we expect from Preschool?

Child will learn some **early language** skills

- Express needs, wants, thoughts intelligibly in words.
- Understand most of what is said to him/her by adults and children.
- Able to give name and age.
- Know simple rhymes and songs.

What do we expect from Preschool?

Child will learn some **early academic** skills.

- Know *big, small* and *more*
- Know primary colours
- Simple manipulative skills: jigsaws, block building
- Matching, sorting
- Early pencil/crayon skills: holding pencil correctly; early drawing
- Recognise some letters and numerals
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What are the challenges in Preschool?

Unless there is another disability present, the child who has Albinism can be expected to achieve all of these skills.

One may expect some delay in independence skills, in fine motor skills and in pre-writing and drawing, but not usually in cognitive, oral language or social skills (though exceptions do arise).

What do we expect at Primary School?

- Learn to read
- Learn to write
- Learn number and maths
- Participate in music, art
- Participate in sport, P.E.

Reading and Albinism

- Identifying distinguishing features of letters
- Tracking left to right
- Tracking top to bottom
- Scanning rows of text
- Seeing whole word if enlarged too much
- Glare from page or board
- Fatigue, poor posture

Additional difficulties that can arise

- Reluctance to read aloud
- Reluctance to write
- Difficulty reading own writing
- Considered to be inattentive or dreamy
- Expectations too high: child gets discouraged
- Expectations too low: child does not reach potential

Some Research Finding on Reading

- Use of Low Vision Aids, Large Print and technology is very much an individual thing.
- Slower readers tended to have better comprehension.
- Children with visual impairments read 'running text' better than single words (They probably use contextual and other cues to meaning).
- Not all reading difficulties are due to low vision.
- Teachers' attitudes and knowledge of the child are crucial.

Possible Solutions to Reading Difficulties

- Appropriate Low Vision Aids/ Large Print when needed
- Early introduction of computer technology
- Appropriate writing materials
- Appropriate teaching materials
- Correct positioning in class
- Sufficient time
- Sufficient breaks
- Teachers well informed about child's needs
- (Sometimes) assessment of child

Spelling and Albinism

The child with Albinism....

- May have less exposure to incidental learning from the environment
- May not perceive the word as a whole, and so have difficulty with recognising the visual outline of the word
- May rely on phonetic spelling
 - May find reading laborious and be less inclined to read for pleasure

Possible Spelling Strategies

- Focus on most common words and on words that occur frequently in student's own writing
- Break down words into components
- Spend extra time 'visualising' word
- Use of auditory mnemonics (fri- the -end of your friend; always a bab in probably etc.)

Handwriting and Albinism

- Slow speed
- Effort
- Fatigue
- Glare from page
- Difficulty reading back work
- Difficulty with cursive script

Possible Solutions to Handwriting Difficulties

- Practise on an easel
- Scribble on a white board
- Tilted desk
- Use strong black markers, pens
- Use yellow rather than white paper
- Use strong lines and wider spaces
- Practise motor movements for cursive writing
- Use finger space between words for cursive writing
- Stick mostly to printing
- Learn typing at an early stage

Specific Learning Disabilities

- Child with Albinism can have Specific Learning Disability, e.g. Dyslexia, Dyscalculia, handwriting difficulties arising from Dyspraxia.
- Specific Learning Disabilities usually identified by comparing intellectual ability with academic attainment: not necessarily appropriate for students with visual impairments.
- Need to conduct diagnostic testing to identify the types of errors and difficulties experienced by the student.

Examples of Intrinsic Difficulties with Literacy

- Poor Phonological awareness (i.e. awareness of sounds in reading process)
- Poor visual or auditory recall
- Poor sequencing, both visual and auditory
- Confusion about orientation and direction
- Poor language skills (often early history of language delay)
- Poor tracking and scanning (can be aggravated by visual impairment)

Testimony of a 16-year-old

My writing is still mostly unlegible but i can type faster than anyone my age

Okay spelling is not a strong point and i can make my writing readable but it takes so much time i usually only do for maths

i am now ahead of the average 16 year old when it comes to reading age

Once i find something i enjoyed i decided reading was not that bad and am now a certified book worm

Recommendation for computer fonts:

One recommendation was
Tahoma

Another recommendation was
Verdana

Number

Difficulties may arise because of:

- Limited experience in dealing with quantity, mass, and numerical relationships.
- Difficulties with written output for maths, either visually or in tactile form.
- Difficulties with shapes and spatial concepts.

Transition to Secondary School

- Larger environment, both physical and social
- Lot of moving around
- New subjects
- Lot of teachers to deal with, not all of whom have experience of visual impairment
- Practical subjects may have safety implications
- Longer day, more reading, study, greater fatigue
- Travel to and from school usually longer

What should parents do?

- Make use of Visiting teacher
- Try to meet as many of the teachers as possible
- Provide information about Albinism
- Listen to your young person
- Try to keep open communication with the school at all times
- Discuss exam provision at an early stage
- Make sure appropriate LVAs and other equipment are in working order
- Seek an assessment if your young person seems to be floundering

The Social-Emotional Aspects of Growing Up
with Albinism

Social-Emotional Aspects of Growing Up with Albinism

Albinism has some specific characteristics:

- Usually permanent and stable
- More visible than most disabilities
- Implications for skin care
- Additional socio-cultural implications for non-white races

Thoughts for Parents

- Your child is probably more resilient than you think
- Don't assume that other children are being malicious
- Provide your child with a quick and easy explanation for Albinism
- Listen to your child
- Keep in touch with your child's teachers
- If you think serious bullying is happening, take action

Dealing with Stares, Smirks and Shout-Outs (NOAH 2011)

(Taken from Webinar presentation April 2011 by Kelsey Thompson, NOAH counsellor and person with Albinism)

- The Silent Stares (people who stare and say nothing)
- The Rudely Curious (people who ask questions and make comments not intended to be offensive, but which may be so)
- The Curiously Rude (Shouts and comments made with the intention of humiliating)

Dealing with Stares, Smirks and Shout-Outs

- A. (Affect) How does this episode make me feel? (embarrassment, fear, withdrawal?)
- B. (Behaviour) How do I respond physically to this situation? (Avoid? Fight back? Bite nails? Slink down? Respond with humour?)
- C. (Cognition) What am I thinking during and after these situations? (I should never have come here? Why does this always happen to me? Now he/she won't want to come out with me any more?)

Maintaining Positive Self-Image

- Posture: Stand up tall and straight; walk with confidence
- Make appropriate eye contact
- Dress in clothing that is flattering and fashionable
- Don't fidget
- Use appropriate facial expressions
- Speak clearly; think about the tone, timing and pace of what you say

Maintaining Positive Self Image (cont.)

- Keep a diary of significant events, good and bad

- Affirm yourself from time to time in writing

I'm a good person because.....

I'm proud of myself because.....

People like me because.....

Albinism is beautiful because.....

Additional strategies

- Have a simple, short explanation of Albinism (Elevator story) available when you need it.

- Have a few handy 'comebacks':

They say *Where did you get hair that colour?*

You say

They say *Why do you wear sunglasses all the time?*

You say.....

Summary of strategies from KelseyThompson

- Talk to a friend
- Choose your battles
- Always look your best when out in public
- Convey confidence with your nonverbal communication
- Let the bad stuff go
- Look out for your personal safety
- Find a healthy outlet (music, sport etc)
- Seek professional help if feelings of anxiety or depression are interfering with your life

Some tips for parents from Kelsey Thompson

- Model positive self-advocacy
- Don't lose your cool yourself
- Use the experiences to teach empathy and sensitivity
- Know when to educate the public and when to walk away (you don't have to entertain everything)
- Realise that your child may not always want to talk to you
- Allow your child to confide in another trusted adult if that is their choice

LEAVING SCHOOL

Reasonable Accommodation for Certificate Examinations

- Intended to minimize the impact of the person's disability without giving an unfair advantage.
- May involve an explanatory note on the candidate's certificate
- Application for RACE should be made in good time through the school to the State Examinations Commission
- Students should practise taking school examinations using the 'accommodations' they are requesting

Examples of Accommodations Possible

- Exemption from an examination component e.g. Map reading
- Modified question papers substituting alternative questions for those involving visual material such as pictures, diagrams etc
- Papers in Braille or large print
- Use of tape recorder, word processor or typewriter
- Use of a reader or a scribe
- 10 minutes extra time per hour of examination
- Use of Low Vision Aids
- Special seating arrangements or separate room
- Taking of breaks

Disability Access Route to Education

- Scheme for school leavers under 23 with disabilities offering college places on a reduced points basis
- Intended for students who have the ability to benefit from and succeed in higher education but may not be able to meet the points for their preferred courses due to the impact of their disability

What colleges participate in DARE?

- Athlone Institute of Technology
- Cork Institute of Technology
- Dublin City University
- Dublin Institute of Technology
- Mater Dei Institute of Education
- National College of Ireland
- Pontifical University, Maynooth
- NUI Galway
- NUI Maynooth
- Trinity College Dublin
- University College Dublin
- University College Cork
- University College Limerick

What College Places are Available?

- Each participating college has a quota of places reserved for students applying through DARE. Quotas vary depending on the college
- Applicant must supply evidence that disability has had a significant impact on academic performance
- Applicants must meet minimum entry requirement (matriculation) for their chosen course
- Applicants must compete for one of the quota places allocated by their chosen college.

How does a student apply for DARE?

- Apply to the CAO in the normal way (For next year, by 1st Feb 2013)
- Disclose disability and complete Supplementary Information Form by 1st March
- Return completed Second Level Academic Reference and Evidence of Disability by 1st April

Supplementary Information for DARE

- Personal Statement by student outlining the academic impact of the disability
- Second Level Academic reference completed by school, outlining student's academic history to date. Helps to inform college regarding supports that might be needed in the future
- Evidence of Disability form completed by medical consultant (e.g. Ophthalmologist or Ophthalmic Surgeon)