Research: Survey of members

Klinefelter's Syndrome Association UK
Research Summary

KSA SURVEY OF MEMBERS- A BRIEF SUMMARY

Aim of the Document

To outline the primary findings of a simple questionnaire research (with some interview) carried out by the KSA among members

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INTRODUCTION

In 1999 the KSA carried out a survey of it's members to gain a better understanding of their experiences, i.e. "how I got to where I am today". The aim was to give some pointers for further research.

This summary is simply the first stage in what could prove to be a long and challenging series of investigations, we have a long way to go, but with your help we could make a real difference.

METHOD

A questionnaire was sent to all member households. The replies were collected & entered into a database for analysis. More important, though, were the comments made by the members. These were grouped into common themes for each answer. Experimentation with themed replies gave interesting relationships to the more numerical data

WHO SENT IN REPLIES?

Around half of those who replied (64 respondents) were mothers of KS boys, around a quarter were filled in by both parents and most of the remainder were KS men themselves.

Who are the KS subjects represented by the survey?

The majority are of school age and above, around a quarter were over 25 years of age. There was a fairly even spread of respondents across the age classes. Around 85% of the subjects were 47XXY, the remainder being other variations of KS.

One emerging feature of the data that has been abundantly clear is that it is almost impossible to describe the "typical" male with KS, each is a unique individual; personalities, skills and character seem to span right across the spectra. All the findings are therefore little more than pointers for closer investigation, there will be some families who could rightly contradict any of these generalisations. So please treat this with due caution, we hope that you will find something that helps you to move on and that those with KS and their families will daily be able to get the very best from life.

EDUCATION.

The years we spend at school are not just a part of job preparation but also mould us into adulthood and build up our personalities and independence. The varied and often traumatic experience of many of you was a major contributor to initiating this project.

What type of schools have you attended?

The adults had generally attended mainstream schools throughout their education, with just a few attending special schools or a learning support unit whilst in their secondary school years. This contrasts markedly with those who are still in their school years: 1 in 5 attended specialist nursery and infant schools, rising to 1 in 3 at middle school and nearly half of all those at secondary school. Although many of the younger families are still fighting battles

with the authorities, they did not express the same level of despair that many of the older members had felt during their school years. Most of the adults indicated that their days at school were fairly miserable, they were written off and felt that nobody understood them:

> *"School was hard work because my teachers were not aware of my condition. I was glad to leave."*

The adults believed that the teachers had not met their schooling needs or had been unsympathetic towards them (75%), nevertheless, some had gone on to take university degrees with great success. However the parents of the younger, school age, component expressed that in every case some positive effort had been made, and in 55% of the cases they were very pleased with what had been done. Of course some felt that they needed no extra help and were coping very well indeed, though this was a small minority.

One measure of the response of the education system to the needs of the learner is the issuing of a Statement of Special Education Need (or its Scottish/Irish equivalent). Although not new, this Statement has become more widespread in recent years. 20% of the adults had a statement, typically issued around 10 years of age; this contrasts with 55% of the school age children typically issued around 5 to 7 years. Some found the process extremely easy whilst others have had to fight all the way. The experience of those without a statement should be explored - there are regional variations in the criteria demanded by LEAs that require investigation. The sadness in all this is the heartache and lost potential of those who clearly should have been given help that was denied to them.

What went well?

Strength in curriculum areas revealed wide variation, no single subject stood out as being exceptionally good or bad, however some seem more likely to stand out in the majority of cases:

Memory: Some reported an outstanding ability to remember facts, faces and, in particular, journeys and routes after just one visit.

Sport: With some noteable exceptions, contact sports were loathed and many felt they were poor at them. However non-contact sports (snooker, bowls, etc.) were extremely popular and many were very skilled along this line. Watching sport on TV was extremely popular, football was frequently named - this is hardly a revelation!

Handwriting: A small proportion claimed to have very good handwriting; this masked the majority who were generally quite poor.

What helped?

This answer requires much further investigation, but some strategies stood out. Firstly it was felt that early diagnosis and intervention were essential, this gave focus to the development of strategies, though few teachers and EPs had sufficient information to formulate effective plans. The assessment process must begin early to identify the specific needs of the individual and implement them before he becomes discouraged and develops low self-esteem. Secondly, 1 to 1 learning assists concentration and keeps an appropriate pace, this was regarded as the best possible help, though many parents had to pay for this privately. Some had attended private schools where the smaller class sizes and better parental support had proved beneficial. The topic of Private v State schools has been the subject of considerable debate; many state schools have excellent support units and a wealth of resources. There is no guarantee that a privately funded school will prove better for the children than state schools.

Most felt that the stress and anxiety of the school years would be greatly eased if there were simple guidelines for meeting the learning needs of KS boys. However virtually all the

characteristics and learning needs identified are commonly found in the learning population and strategies for addressing them are well documented. What seems more important than a universal pattern for meeting the needs of an average KS boy is guidance for teachers and EPs indicating the range of characteristics that might be investigated and suggestions for ways that these might be addressed if present. Some of the boys had similar symptoms to ADD, ADHD and/or Aspergers Syndrome, much of the superbly documented resource base for these groups could be applied to the KS boy where the characteristics overlap. Plan for us should be to put together a comprehensive resource for teachers and EPs so they might use their highly skilled professional judgment in partnership with the parents in selecting the best answers for each unique boy.

PERSONALITY

If we understand our personality we are often more able to make the right choices for work, living style and leisure. This research showed no dominant pattern, though some features were manifestly more common than others. The following words/phrases were easy to relate to around half, or more, of the 47XXY subjects:

- Kind/caring
- Poor concentration
- Happy
- Misses social cues
- Fewer friends than siblings
- Poor self esteem
- Sense of humour
- Sensitive (78%)
- Easily led astray
- Loves fun.

Hobbies

The most enjoyable set of data to analyse was in the section where respondents were asked what hobbies and pastimes had brought most pleasure. The similarities among the responses were astounding; it is hard to say that they are unique to KS, but they certainly give great pointers toward the most successful Christmas presents! Many were solo hobbies suitable for the less gregarious among us.

- **Computers:** almost every reply! Some had gone on to carve out a career in the industry, but most were less specific or mentioned the ubiquitous Nintendo/Playstation!
- **Lego:** along with other construction toys and kits - these boys (and a good few of the men) were competent engineers.
- **TV & Video:** films were identified, but general viewing seemed popular.
- **Art and Craft:** Line drawings, copying, scissors & glue, graphics, cartoons.
- **Non contact sport:** Bowls, 10-pin bowling, badminton, snooker/pool.
- **Fitness:** Cycling and swimming, roller-blading among the youngsters, walking & hiking among the more mature. Horse riding among the 8-11s

- **Music:** listening to CDs, some learned an instrument and became good quickly. Several mothers said their sons had wonderful singing voices. Many had the ability when young to hear a long musical phrase and repeat it.
- **Reading:** very popular, and a proportion were extremely strong readers, others admitted to being very weak readers.
- **Cars:** Models, toys, Grand Prix, DIY - for some a single-minded preoccupation.
- **Church:** offer a diversity of activities, acceptance, encouragement, gentle social interaction, non-judgemental.
- **Misc:** Jig-saws, clubs and societies, board games (esp. Scrabble), cooking, dancing

Skills & Character

Several OUTSTANDING skills were mentioned. Memory has been discussed already; exceptional long-term memory was singled out in over 20% of cases. Art frequently cropped up as showing exceptional talent in certain responses, though others commented on their own weaknesses in this line. Where it was a strength, artistic ability was clearly extremely impressive. Others were outstanding poets or creative writers. Throughout it was clear that most were very caring people who were kind and friendly to small children and/or the elderly, this had paved the way to satisfying employment (though poorly paid).

Aggression is frequently mentioned in the literature in connection with KS, in 42% of the responses this was reiterated. Outbursts of temper/anger were common but generally short lived and often followed by intense contrition. Some suggested outbursts were more likely with tiredness. The debate suggests that this eases when endocrine control settles down, though one mother stated that they withdrew treatment as it made the aggression worse. I suggest that if this is a problem in your household you should seek professional advice quickly as there is a suggestion that it can be extremely damaging to families and relationships. One mother suggested that aromatherapy helped to calm her son - the tenor of most mother's responses suggested that it was the mums that needed the relaxation, massage and calm! Many linked the aggression to low self-esteem and sibling rivalry, others to frustration and loss of concentration, whichever way it has pushed some families toward a crisis. Several mothers were at their wits end, we must not forget that they need support as much as the boys with KS, the comments were often a crie-de-coeur, moving and resolved, resigned yet loving.

It was suggested that we look for evidence of obsessive behaviour. Just under half indicated that this was an issue, although in almost every case this took the form of adherence to strict routines, fear of change and a desire for precise order. In some children this was lining up toy cars right across the room, in some adults it became a regular locking and checking routine before leaving the house. All the above could be classed as "control", again if you feel this is a problem it may be worth seeking professional advice, however most seemed to be at ease with the situation.

EMPLOYMENT

The following professions were the most common (remember that many of the responses were from parents of school-age boys.

- Engineering
- Computers & IT
- Caring (esp. elderly & sick) generally not as health care professionals
- Art & Design

- [There was a suggestion that Computer Aided Design held much promise, but this could not be substantiated. Several of the boys certainly seem to pick up on this topic when it was introduced at school].

Sadly some of the adults expressed disappointment at not being able to hold down a job for long, others had found their niche and were thriving. Many admitted to being loners and this influenced their vocational choice.

MEDICAL AND FURTHER RESEARCH

Few comments were passed on the experience of taking the various endocrine treatments, those that were given were so varied that it became clear that it is a matter of personal experimentation and preference in conjunction with your doctor. Generally these treatments were seen as a positive help, both medically and in terms of self esteem.

Other treatments that proved beneficial were: Counselling (KS and family), social skills training, physiotherapy for back pain, occupational therapy for motor control and balance, Horse-riding speech-therapy (mixed reaction), home learning and supplementary education, Dietician advice, losing or gaining weight, gynaecomastia, aromatherapy, early diagnosis, lots of information.

Some associated medical conditions seemed common. Among them were migraines/headaches, chest infections and asthma (around half of all school age children). My wife has pointed out that there is a possible link between babies with poor muscle-tone being poor breast feeders and the significant increased incidence of asthma in bottle-fed children.

THE FUTURE

Future research suggestions covered just about every possibility (separate list available), however some stand out as being suitable to investigate entirely within the KSA, for instance: KS and the elderly or starting a pen-pal scheme. Perhaps the experienced members should produce a booklet answering "Frequently Asked Questions." There are plenty of sources of information spread across the globe, should we collect together an extensive Resources Directory, top web pages, research abstracts...?

It is intended that the next stage is to interview volunteers to gain a better and clearer understanding of your experiences. This will then be written up for publication in the education journals, without it there is unlikely to be much further (funded) research - the aim is to stimulate awareness. It is hoped that a series of information booklets can be produced, tailored for specific readers: teachers, EPs, doctors, parents of young children, teenagers, prospective parents, older men, etc. None of this will be possible without your help.

