

NORBERT WAS ASKED TO DO
A POWERPOINT PRESENTATION.



*Fluency treatment
from the client's perspective*

Norbert Lieckfeldt
British Stammering Association

About me



Person who stammers

Only one therapy episode

Started as a volunteer with the British Stammering Association in 1993

Chief Executive since 2000



About the BSA



The British
Stammering
Association

The UK's national organisation on all aspects of stammering

Information and Support Service – wide range of resources

www.stammering.org

www.stammeringineducation.net

www.stammeringineducation.net/expertparent

Membership of 1,250, 80% of whom are adults who stammer

Runs Information and Advocacy campaigns

Lobbies for better and more appropriate services for adults and children who stammer



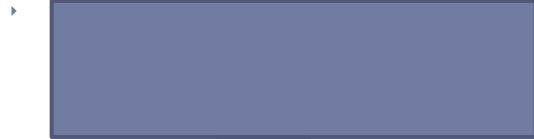
The NHS



Speech and Language Therapy in the NHS

▶ SHEFFIELD PRIMARY HEALTH TRUST

▶ Referrals: Open referral to Isabel O'Leary, Kate Williams contact details as for Lesley Cogher



▶ Telephone: 0114 [REDACTED]

▶ Fax: 0114 [REDACTED]

▶ Stammering Specialists: (both part time and together making one full time post): Ms. Isabel O'Leary and Ms. Kate Williams,

▶ **REFERRALS ADULTS AND CHILDREN:** Individuals or parents/carers who live in Sheffield can contact the service directly by letter, email or telephone. For those living outside Sheffield a referral from their GP is required. Anyone wishing to discuss their stammer or that of their child can contact Kate Williams or Isabel O'Leary at the Speech and Language Therapy Department (contact details above) email [REDACTED]

▶ Sheffield is fortunate in having a specialist service for people of any age who stammer. Qualified NHS speech and language therapists work in partnership with each individual and/or family to come up with an action plan aimed at reducing the impact of stammering for the person contacting the service. Sheffield Speech and Language Therapy Service has links with a local self-help group for adults. It also has links with a newly launched social group for families of children/teenagers and adults who stammer.

▶ **PROVISION FOR ADULTS:** Seen by specialist therapists, adults are offered weekly individual therapy appointments and/or the possibility of attending a group which may run on a weekly, or intensive basis, according to demand/need. The service provides a weekly evening clinic for adults who may find attending during the day difficult due to work/family/study commitments.

▶ **PROVISION FOR YOUNG ADULTS (16-19 yrs)** Seen by specialist therapists, young adults are offered weekly individual therapy appointments and/or the possibility of attending a group which may run on a weekly, or intensive basis, according to demand/need. The service provides a weekly evening clinic for young adults who may find attending during the day difficult due to work/family/study commitments

▶ CHILDREN'S SERVICES

▶ **PROVISION FOR PRE-SCHOOL CHILDREN:** Children are seen in the local clinic (as far as possible) for assessment with their parents/carers, An individualised package of therapy is offered to meet identified client and family needs. This may include offering general advice and monitoring, parent/child interaction therapy, Lidcombe programme. It is hoped, in the near future, to offer an information/support group to parents/carers of young children who stammer

▶ **PROVISION FOR SCHOOL-AGED CHILDREN:** Children receive clinic based therapy on an individual basis with a specialist therapist. Intensive group therapy is available during some school holidays. There are some evening follow up sessions and parents meet as part of an intensive course. Training workshops for school staff are offered twice yearly and individual school liaison visits are arranged as appropriate.

▶ **PROVISION FOR TEENAGERS (13-16 yrs):** Teenagers are offered an individualised therapy programme that may comprise weekly individual appointments as well as intensive group therapy during some school holidays either in Sheffield or part of a residential course involving PCT's from across the North of England. Therapy is provided by specialist therapists. There is close and timely liaison with schools. Training workshops for school staff are offered twice yearly. The service provides a weekly evening clinic for teenagers who may find attending appointments during the day difficult due to study commitments.

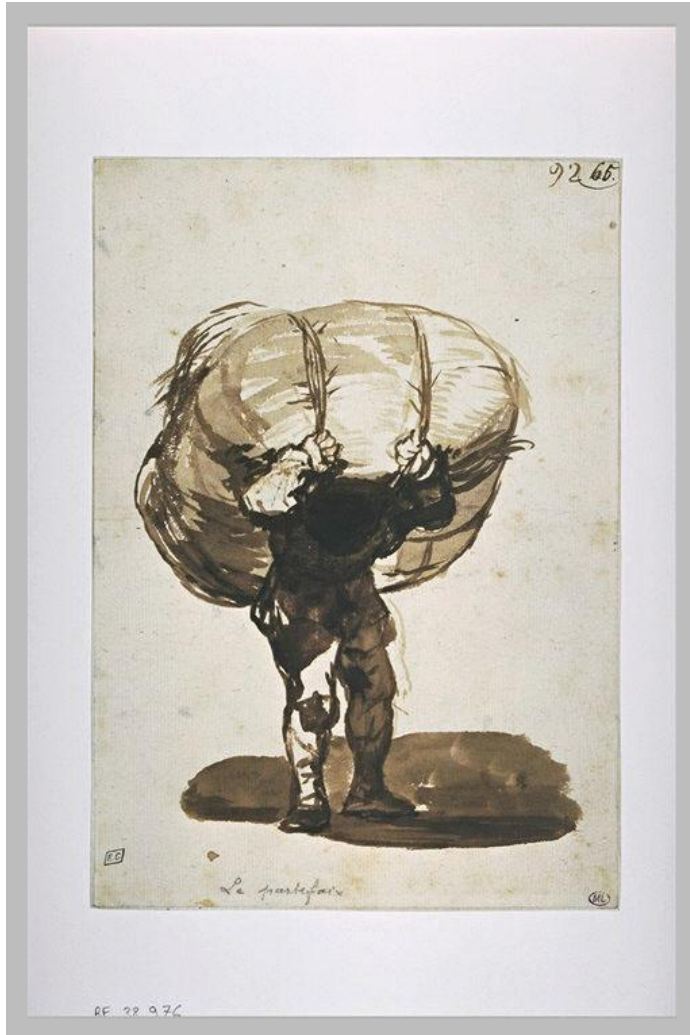
Speech and Language Therapy in the NHS

- ▶ **GREENWICH PRIMARY CARE TRUST**
SOUTH EAST LONDON STRATEGIC HEALTH AUTHORITY
- ▶ [REDACTED]
**Clinical Manager of SLT services for
Pre School / Clinic
Memorial Hospital
Shooter's Hill ,Woolwich
London SE18 3RZ**
- ▶ [REDACTED]
**Clinical Team Leader (ADULTS)
Speech and Language Therapy
Queen Elizabeth Hospital
Stadium Road
WOOLWICH SE18 4QH**
- ▶ [REDACTED]
- ▶ **PROVISION FOR ADULTS :**
No provision
- ▶ **PROVISION FOR CHILDREN (up to 16yrs) : individual and/or group therapy is available in local clinics. Referrals may be made to City University or to the Michael Palin Centre. There is currently no designated specialist in stammering. Resources for training and support of a specialist are being actively sought.**

What will I talk about

- ▶ Findings from the Better Communication Research Programme (not yet published)
- ▶ Findings from two (non-scientific) surveys conducted by the British Stammering Association, asking adults who stammer and parents of stammering children about their therapy experiences

What is stammering to a person who stammers?



What is stammering to a person who stammers?



Fluency treatment from the client's perspective

- ▶ First rule – ask us!

- ▶ Is it an overwhelming burden? Perhaps it's just an itch?



Better Communication Research Programme

The Better Communications Research Programme is part of the government's response to the Bercow Review of provision for children and young people with speech, language and communication needs, published in July 2008.

The government published its response “*Better Communication, the speech, language and communications needs (SLCN) action plan*” in December 2008, which committed to a series of initiatives to improve services for children and young people with SLCN, culminating in the National Year of Speech, Language and Communication in 2011.

Research amongst others on
Preferred Outcomes: Survey of Children’s and Parents’ Views

Summary of Children's Perspective

- ▶ Younger children have a clearer focus on SLCN
- ▶ Older children have a less evident focus on difficulty with talking even though they may still receive SLT or be viewed by others as having SLCN
- ▶ they expressed concerns in terms of behaviour (keeping calm, not doing secondary behaviours etc), specific aspects of school work, being organised and concentrated.
- ▶ It is possible that once a certain level of communication has been reached, particular SLCN are less likely to be perceived as the central issues for the child. Other needs such as literacy, behaviour, emotional, attentional or memory difficulties are then perceived as more critical



Children's Perspective

“several common themes emerged that are important for children and young people: (i) time for fun and laughter both in terms of social activities and in relationship with teachers and family; (ii) feeling supported and listened to; (iii) dealing with emotions, particularly [...] frustration, anger and sadness; and (iv) improving other people's behaviour towards them in terms of listening more and interrupting less...”

What are the desired outcomes for children?

Every Child Matters definition

- ▶ to be healthy
 - ▶ to stay safe
 - ▶ to enjoy and achieve
 - ▶ to make a positive contribution
- and, eventually,
- ▶ to achieve economic well-being.

Fluency treatment from the client's perspective

- ▶ Parents' wishes for outcomes for their child:
- ▶ “what was apparent was that few of the parents the Inquiry met seemed to have been encouraged to have a discussion about the outcomes they expected, or aspired to, for their child or how best these outcomes might be achieved.”

(p. 20, Report, Lamb Enquiry into special educational needs and parental confidence (2009))

Fluency treatment from the client's perspective

- ▶ Parents
- ▶ BCRP research identified two overarching themes
- ▶ *To be included* – to play, and to make friends
- ▶ *To achieve independence* – to stay safe, avoid risk, avoid bullying, be competent and confident, gain qualifications, asserts rights

Parental Perspective

Not yet published, check
<http://www2.warwick.ac.uk/fac/soc/cedar/better/> for details

Fluency treatment from the client's perspective

▶ BCRP findings

Not yet published, check <http://www2.warwick.ac.uk/fac/soc/cedar/better/> for details



Parents Perspective

▶ “ [redacted] for their
[redacted] e children
[redacted] s position
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Not yet published, check <http://www2.warwick.ac.uk/fac/soc/cedar/better/> for details



BSA Questionnaire – Parents of children who stammer

- ▶ Started surveys: 32; completed surveys: 27
- ▶ 71.9% male, 28.1% female (n=32)
- ▶ Average current age: 133 months (11;1) (n=32)
- ▶ Average age at last therapy: 98 months (8;2) (n=32)
- ▶ Stammering in family? 55% yes, 45% no (n=29)

BSA Questionnaire – Parents of children who stammer

- ▶ Did you feel you had enough knowledge about stammering before the start of therapy, on a scale of 1 to 5 (1 = no previous knowledge, 5 = expert knowledge)

1 = **50.0%** (15)

2 = **13.3%** (4)

3 = 33.3% (10)

4 = 3.3% (1)

5 = 0.0% (0)

BSA Questionnaire – Parents of children who stammer

- ▶ Did you feel the information provided by the therapist was helpful? (on a scale of 1 to 5, where 1 = not helpful at all and 5 = extremely helpful)

1 = 10.0% (3)

2 = 23.3% (7)

3 = 30.0% (9)

4 = 16.7% (5)

5 = 20.0% (6)

BSA Questionnaire – Parents of children who stammer

- ▶ Stammering made it hard for my child to make friends (on a scale of 1 to 5, where 1 = not a problem, and 5 = always a problem)

1 = 28.6% (8)

2 = 28.6% (8)

3 = 28.6% (8)

4 = 7.1% (2)

5 = 7.1% (2)

BSA Questionnaire – Parents of children who stammer

- ▶ How did therapy address the problem of making friends?
(on a scale of 1 to 5, where 1 = not at all, and 5 = resolved the problem)

1 = 56.0% (14)

2 = 28.0% (7)

3 = 12.0% (3)

4 = 0.0% (0)

5 = 4.0% (1)

BSA Questionnaire – Parents of children who stammer

- ▶ Does stammering make it hard for your child to play with other children? (on a scale of 1 to 5, where 1 = never a problem and 5 = always a problem)

1 = 21.4% (6)

2 = 32.1% (9)

3 = 25.0% (7)

4 = 14.3% (4)

5 = 7.1% (2)

BSA Questionnaire – Parents of children who stammer

- ▶ How well were problems with play addressed in therapy?
(On a scale of 1 to 5, where 1 = not at all, and 5 =
problem was resolved)

1 = 61.5% (16)

2 = 19.2% (5)

3 = 11.5% (3)

4 = 3.8% (1)

5 = 3.8% (1)

BSA Questionnaire – Parents of children who stammer

- ▶ I felt my child withdrawing, and ceasing to communicate (on a scale of 1 to 5, where 1 = not at all, and 5 = all the time)

1 = 14.8% (4)

2 = 29.6% (8)

3 = 29.6% (8)

4 = 25.9% (7)

5 = 0.0% (0)

BSA Questionnaire – Parents of children who stammer

- ▶ My child's withdrawal and failure to communicate was addressed through therapy, on a scale of 1 to 5 where 1 = not at all and 5 = was resolved

1 = 44.0% (11)

2 = 16.0% (4)

3 = 16.0% (4)

4 = 12.0% (3)

5 = 12.0% (3)

BSA Questionnaire – Parents of children who stammer

- ▶ Stammering makes my child frustrated or upset (on a scale of 1 to 5, where 1 = not an issue and 5 = all the time)

1 = 7.7% (2)

2 = 15.4% (4)

3 = 30.8% (8)

4 = **38.5%** (10)

5 = **7.7%** (2)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Issues around frustration and being upset were addressed in therapy (1 = not at all, 5 = were resolved)

1 = 29.6% (8)

2 = 25.9% (7)

3 = 22.2% (6)

4 = 7.4% (2)

5 = 14.8% (4)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ My child's stammer impacted negatively on communication in the family (1 = not at all, 5 = very serious impact)

1 = 37.0% (10)

2 = 33.3% (9)

3 = 11.1% (3)

4 = 14.8% (4)

5 = 3.7% (1)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Issues around family communication were addressed during therapy (1 = not at all, 5 = were resolved)

1 = 25.9% (7)

2 = 22.2% (6)

3 = 11.1% (3)

4 = 33.3% (9)

5 = 7.4% (2)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Do you feel that the notion of 'talking is fun' was central to your child's therapy? (1 = not at all, 5 = was central to therapy)

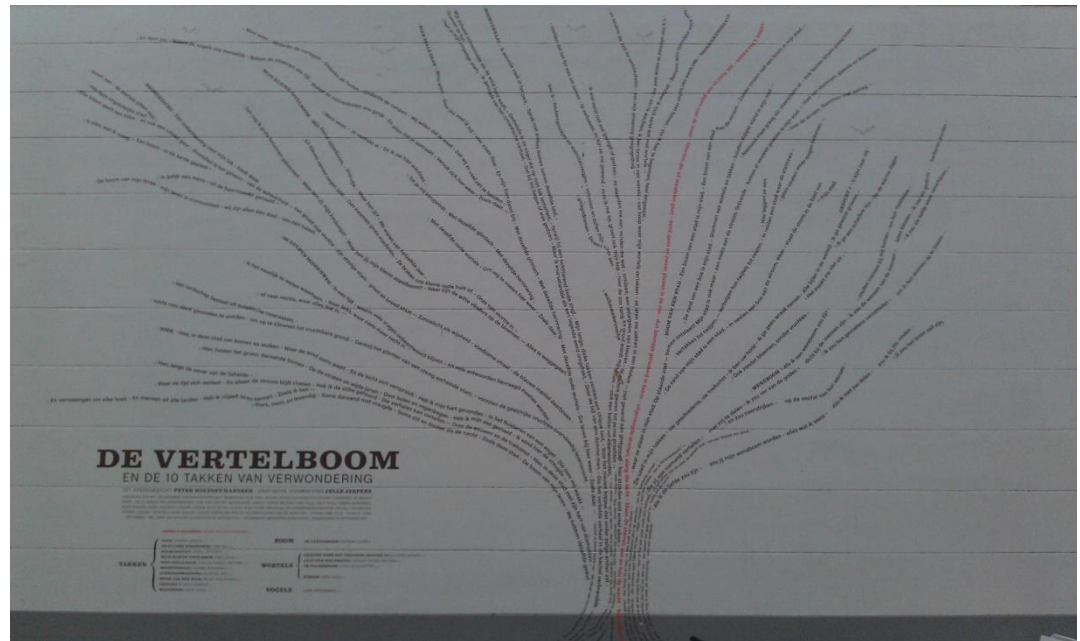
1 = **50.0%** (13)

2 = **15.4%** (4)

3 = **11.5%** (3)

4 = **11.5%** (3)

5 = **11.5%** (3)



BSA Questionnaire – Parents of children who stammer

- ▶ Aims of therapy - what do you think as a parent that therapy for your child should primarily achieve?
- ▶ Therapy should enable fluent talking 30.4%
- ▶ Therapy should address any problems caused by stammering. 39.1%
- ▶ Therapy should instil the concept that 'talking is fun'. 30.4%

BSA Questionnaire – Parents of children who stammer

- ▶ As a parent, I struggled with my own feelings and concerns about my child's stammer.
(1 = not at all, 5 = overwhelmingly)

- ▶ 1 = 0.0% (0)
- ▶ 2 = 22.2% (6)
- ▶ 3 = 11.1% (3)
- ▶ 4 = **25.9%** (7)
- ▶ 5 = **40.7%** (11)

BSA Questionnaire – Parents of children who stammer

- ▶ My own concerns and emotions were addressed in therapy.
(1 = not at all, 5 = were resolved)

- ▶ 1 = 44.4% (12)
- ▶ 2 = 22.2% (6)
- ▶ 3 = 11.1% (3)
- ▶ 4 = 14.8% (4)
- ▶ 5 = 7.4% (2)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Surveys started: 155; survey completed: 127
- ▶ Male: 73.5%, Female: 26.5%
- ▶ Average current age: 45;5 yrs
- ▶ Average age at most recent therapy: 34:4

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Meeting new people and making new friends is difficult
(1 = not at all, 5 = all the time)

1 = 6.1% (8)

2 = 18.2% (24)

3 = 36.4% (48)

4 = 25.0% (33)

5 = 14.4% (19)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ How did therapy address any problems with meeting new people and making friends? (1 = not at all, 5 = resolved the problem)

1 = 21.4% (28)

2 = 29.0% (38)

3 = 22.1% (29)

4 = 26.0% (34)

5 = 1.5% (2)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Talking to strangers in a non-social setting (shop, counter etc) is hard (1 = not at all, 5 = all the time)

- ▶ 1 = 9.0% (12)
- ▶ 2 = 16.5% (22)
- ▶ 3 = 39.1% (52)
- ▶ 4 = 26.3% (35)
- ▶ 5 = 9.0% (12)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ How did therapy address any problems in talking to strangers? (1 = not at all, 5 = resolved the problem)

1 = 15.2% (20)

2 = 24.2% (32)

3 = 31.1% (41)

4 = 27.3% (36)

5 = 2.3% (3)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ I find talking to people I find attractive difficult
(1 = not at all, 5 = all the time)

1 = 8.5% (11)

2 = 24.0% (31)

3 = 26.4% (34)

4 = 25.6% (33)

5 = 15.5% (20)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ How did therapy address any problems you may have with talking to people you find attractive?
(1 = not at all, 5 = resolved the problem)

1 = 45.3% (58)

2 = 26.6% (34)

3 = 18.0% (23)

4 = 8.6% (11)

5 = 1.6% (2)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Did you feel you were offered enough information about stammering as therapy progressed?
(1 = was given no info, 5 = was given enough information)

- ▶ 1 = 6.5% (8)
- ▶ 2 = 12.2% (15)
- ▶ 3 = 13.0% (16)
- ▶ 4 = 22.0% (27)
- ▶ 5 = 46.3% (57)



BSA Questionnaire – Adult Expectations of Therapy

- ▶ Did you feel the information provided by the therapist was helpful?
(1 = not helpful at all, 5 = was extremely helpful)

1 = 4.1% (5)

2 = 22.8% (28)

3 = 22.8% (28)

4 = 24.4% (30)

5 = 26.0% (32)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Do secondary behaviours cause a problem with your life and/or your communication?
(1 = not at all, 5 = very severely)

- ▶ 1 = 29.8% (37)
- ▶ 2 = 33.1% (41)
- ▶ 3 = 15.3% (19)
- ▶ 4 = 14.5% (18)
- ▶ 5 = 7.3% (9)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Were any problems with secondary behaviours addressed in therapy?
(1 = not at all, 5 = were resolved)

- ▶ 1 = 35.0% (42)
- ▶ 2 = 13.3% (16)
- ▶ 3 = 22.5% (27)
- ▶ 4 = 26.7% (32)
- ▶ 5 = 2.5% (3)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ I feel I needed help to enable me to speak with a reasonable degree of fluency (1 = not at all, 5 = quite a lot)

- ▶ 1 = 13.3% (16)
- ▶ 2 = 20.0% (24)
- ▶ 3 = 19.2% (23)
- ▶ 4 = 30.8% (37)
- ▶ 5 = 16.7% (20)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ How did therapy address your problems with establishing more fluent speech?
(1 = not at all, 5 = resolved the problem)

- ▶ 1 = 8.5% (10)
- ▶ 2 = 23.9% (28)
- ▶ 3 = 33.3% (39)
- ▶ 4 = 30.8% (36)
- ▶ 5 = 3.4% (4)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ I have had problems beyond fluency in communicating with people (body language, appropriateness etc) (1 = not at all, 5 = all the time)

- ▶ 1 = 35.0% (43)
- ▶ 2 = 25.2% (31)
- ▶ 3 = 18.7% (23)
- ▶ 4 = 15.4% (19)
- ▶ 5 = 5.7% (7)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Therapy has addressed these additional communication problems
(1 = not at all, 5 = were resolved)

- ▶ 1 = 29.9% (35)
- ▶ 2 = 30.8% (36)
- ▶ 3 = 13.7% (16)
- ▶ 4 = 23.1% (27)
- ▶ 5 = 2.6% (3)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Avoiding words and/or situations has been a problem for me
(1 = not at all, 5 = all the time)

- ▶ 1 = 4.0% (5)
- ▶ 2 = 8.9% (11)
- ▶ 3 = 24.2% (30)
- ▶ 4 = 41.9% (52)
- ▶ 5 = 21.0% (26)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Therapy has addressed my problems with word or situation avoidance
(1 = not at all, 5 = resolved the problem)

1 = 12.1% (15)

2 = 33.1% (41)

3 = 22.6% (28)

4 = 27.4% (34)

5 = 4.8% (6)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ I have problems with communicating my skills and experiences in a job interview
(1 = not at all, 5 = all the time)

1 = 9.3% (11)

2 = 17.8% (21)

3 = 36.4% (43)

4 = 25.4% (30)

5 = 11.0% (13)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ My problems with job interviews were addressed in therapy
(1 = not at all, 5 = were resolved)

- ▶ 1 = 27.6% (32)
- ▶ 2 = 25.0% (29)
- ▶ 3 = 24.1% (28)
- ▶ 4 = 18.1% (21)
- ▶ 5 = 5.2% (6)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Problems with assertiveness - being able to communicate your own wishes, skills and knowledge, asking for support when needed, dealing with unhelpful colleagues
(1 = not at all, 5 = all the time)

- ▶ 1 = 12.9% (15)
- ▶ 2 = 18.1% (21)
- ▶ 3 = 40.5% (47)
- ▶ 4 = 22.4% (26)
- ▶ 5 = 6.0% (7)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ My problems with asserting myself at work have been addressed in therapy
(1 = not at all, 5 = have been resolved)

- ▶ 1 = 33.9% (39)
- ▶ 2 = 27.8% (32)
- ▶ 3 = 20.0% (23)
- ▶ 4 = 13.9% (16)
- ▶ 5 = 4.3% (5)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ I am worried about how others perceive me because of my stammer
(1 = not at all, 5 = all the time)

- ▶ 1 = 4.2% (5)
- ▶ 2 = 7.5% (9)
- ▶ 3 = 30.0% (36)
- ▶ 4 = 32.5% (39)
- ▶ 5 = 25.8% (31)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ How were any problems with how you feel about others and their reaction to your speech addressed in therapy?
(1 = not at all, 5 = were resolved)

- ▶ 1 = 12.5% (15)
- ▶ 2 = 21.7% (26)
- ▶ 3 = 25.0% (30)
- ▶ 4 = 35.0% (42)
- ▶ 5 = 5.8% (7)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Stammering makes me feel depressed
(1 = not at all, 5 = all the time)

- ▶ 1 = 8.4% (10)
- ▶ 2 = 29.4% (35)
- ▶ 3 = 35.3% (42)
- ▶ 5 = 19.3% (23)
- ▶ 6 = 7.6% (9)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ How did therapy address any problems with depression?
(1 = not at all, 5 = resolved the problem)

- ▶ 1 = 36.7% (44)
- ▶ 2 = 23.3% (28)
- ▶ 3 = 14.2% (17)
- ▶ 4 = 19.2% (23)
- ▶ 5 = 6.7% (8)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Accepting myself as a person who stammers has been a problem for me
(1 = not at all, 5 = all the time)

- ▶ 1 = 6.7% (8)
- ▶ 2 = 9.2% (11)
- ▶ 3 = 34.2% (41)
- ▶ 4 = 29.2% (35)
- ▶ 5 = 20.8% (25)

BSA Questionnaire – Adult Expectations of Therapy

- ▶ Has your therapy addressed the problem of self-acceptance?
(1 = not at all, 5 = has resolved the issue)

- ▶ 1 = 20.3% (24)
- ▶ 2 = 24.6% (29)
- ▶ 3 = 22.0% (26)
- ▶ 4 = 25.4% (30)
- ▶ 5 = 7.6% (9)

So, what do we want?



versus



So, what do we want?



versus



▶ nl@stammering.org

