From Cookies to a Communication Community

Changing Attitudes and Belief Systems to Allow for Development of Functional Communication in a Specialist Autism Setting.

Haylee Parfett
Speech Pathologist, Consultant and Trainer
Haylee Parfett Speech Pathology

"Communication is the essence of human life" (ASHA, 1991, p.9)

Communication allows us to

- make contact with other people

- establish relationships

- express our personality

- demonstrate and share our knowledge

- ensure that our needs are met and our wishes are considered. (Gayle Porter, 1997; Light, 1988.)

Communication is more than making requests and rejecting (Mirenda, 1998)

"Requesting and rejecting often constitute both the beginning and end of AAC for many individuals with ASD." (Mirenda, 2008, p.225)

'Preponderance… on teaching individuals with ASD to use AAC symbols… to either request, terminate or avoid items, activities or events.' (Mirenda, 2003a)

"There's more to life than cookies!"

(Light, Parsons, & Drager, 2002, p. 187)

Communication Functions

greet   manipulate   relate information

agree / disagree   answer   ask questions

instruct others   ask for things   joke

express an opinion share information

express feelings   **protest**   **describe**

discuss interest   ''MAKE SOCIAL CONTACT''   bargain

comment   request / attract attention   **complain**

Functional Communication

The National Research Council stated in its 2001 landmark publication, 'Educating Children with Autism:'

'Functional spontaneous communication is a critical skill that must be addressed in all interventions for children with ASD.'

But what is Functional Communication?

- Forms of behavior that express needs, wants, opinions, complaints, protests, feelings, and preferences
- Communication which is easily understood by both familiar and unfamiliar communication partners (Mirenda & Erickson, 2000)
- Communication which the individual uses in a generalised manner (i.e., across people and settings) over time (Mirenda, 2003)
- Expressing themselves without resorting to problem behavior or experiencing **communication** breakdown.

http://www.asha.org/NJC/faqs-comm-dev.htm

Autonomous Communication

Being able to say

what I want to say,

to whoever I want to say it to,

whenever I want to say it.

(Porter, 1997)

Autism and AAC: What is a valued outcome?

"… why do persons with complex communication needs… as well as individuals with autism spectrum disorders, continue to struggle to achieve **successful interaction** and the pursuit of **valued outcomes** (Johnson, Douglas, Bigby, & Iacono, 2009; Mirenda, 2014)?

Essentially the challenge is two-fold: There is a need to re-think both AAC intervention and research in order to transform these outcomes."
(Light & McNaughton, 2015, p. 2-3)

Cookies to a Communication Community

The cookies: EHG

EGH is an independent provider of specialist early-years, primary and secondary day schools for children and young people with ASD.

- **Two Provisions:**
  - Primary School
    - between 44-65 students aged 4-12 years
  - Secondary School
    - between 65-80 students aged 13-19 years

- Between 50-65 % of students have 'complex communication needs' (varies each year)

School-wide Challenges

Highly complex population of students representing all aspects of the Autism Spectrum

- Staff faced with severe and challenging behaviours on a daily basis
  - The aim for some staff was to get through each day without getting physically hurt
- Knowledge deficits
  - Poor understanding of Autism
  - Weak teaching methodologies and practices
- Attitudinal barriers
- Systemic issues
  - Weak Senior Management Teams
  - Lack of policies and little accountability

Approach to Communication

- 'Total' communication approach that included:
  - Manual Signing
  - Presence of receptive visual tools such as visual timetables, first/then cards, visual cue cards, reward systems
  - Widgit symbol support for literacy
  - PECS used at snack and lunch time

- TEACCH approach used within some classes

Approach to Communication

- Several limitations to existing approach
  - Multiple symbol sets and photo's used
  - Little consistency in how symbols were taught and used
  - Staff viewed visual or AAC strategies as "patronising," "a step backwards," "make the student lazy"

The BIG Challenge…

- Staff believed that communication for students with complex communication needs started and stopped with informal modes and picture exchange, ie. requesting.

- 'Communication' was an activity that occurred between 9-9.30 on Wednesday mornings!

But there were **BIG** problems with this approach:
- Frequent communication breakdowns
- Frustration
- Anxiety
- Learned helplessness
- Passivity
- Challenging behaviours

Ahhhhh!!!!!!!

Helping people to see other possibilities

"I think we need to question what we think we know about people with ASD in general and how we support those individuals whose speech does not develop to communicate through AAC in particular."

- Mirenda, 2008, p. 229

Do we really know what we know?

Cookies to Communication…

2011	2012	2013	2014

Use of Aided Language Strategies

Started small but planned BIG!!!

Plan for the long term.

THINK BIG
You can achieve much more than you THINK you can.

imaginearea.piczo.com

Use of Aided Language Strategies

Communication Community = 1 (Me!)

Small steps…

1. Developed 'new' communication and literacy resources
2. Started modelling aided language strategies within structured class-based sessions
3. Started *talking* about *functional communication*
4. Observed, noted and recorded students' responses to this input (video)
5. Discussed achievements with Teachers and Support Assistants

Developing a Case Study

- Identified *one* student who had been attending to and starting to use the aided language displays

- Discussed the idea of trialing a comprehensive communication book

- Teacher and Support Assistants agreed!

- Collected further baseline data and video

Developing a Case Study

Step 1: 'Engineered' the classroom environments for aided language learning

1. Customised single communication boards for breakfast routine, literacy lessons, cooking and choice making activities

2. Problem solved how to integrate the teaching of aided symbols into the wider curriculum

Developing a Case Study

Step 2: Focused on providing 'real-life' aided language stimulation throughout naturally occurring situations

Developing a Case Study

- 3 Months later, introduced a PODD communication book
    - One page opening, 20 symbols per page

- Adam quickly 'outgrew' his communication system
- 5 months later introduced a new PODD
    - Two page opening with side panel, 36 symbols per page

Collaborative Planning and Joint Working

- Met regularly with the class team to discuss and highlight the improvements in Adam's:
  - Attention
  - Engagement
  - Anxiety
  - Behaviour
  - Initiation
  - Participation
  - Expressive Communication
  - Understanding of language

Me!!

1 Class team

Cookies to Communication…

ALS in sessions

Case Study

| 2011 | 2012 | 2013 | 2014 |
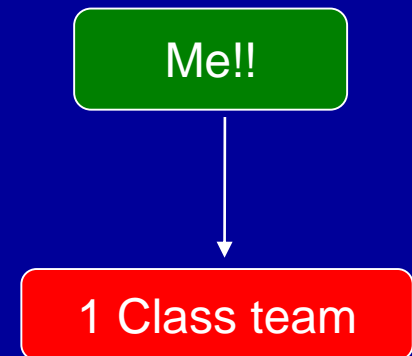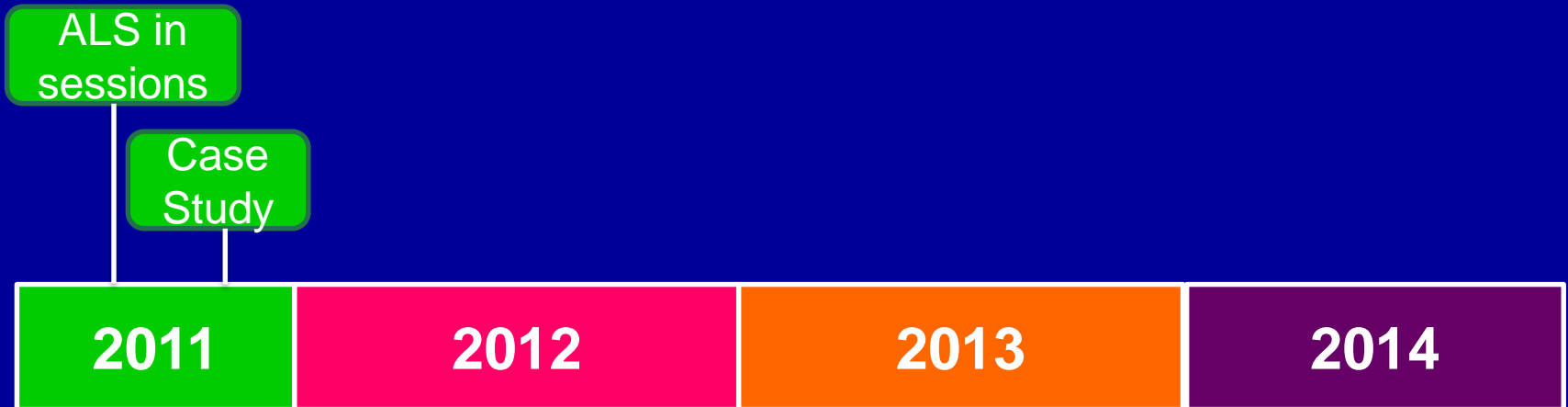
Overcoming Knowledge and Skill Barriers

- Identified 4 enthusiastic people across the two schools

- Pleaded with the *Senior Management Team* to allow them to attend an upcoming 5 Day PODD Workshop!
  - Talked about the evidence base for AAC and ASD
  - Showed Adam's case study
  - Outlined the range of observed improvements
  - Detailed the possible benefits from a business perspective

Cookies to Communication…

ALS in sessions

4 staff attended training

Case Study

| 2011 | 2012 | 2013 | 2014 |
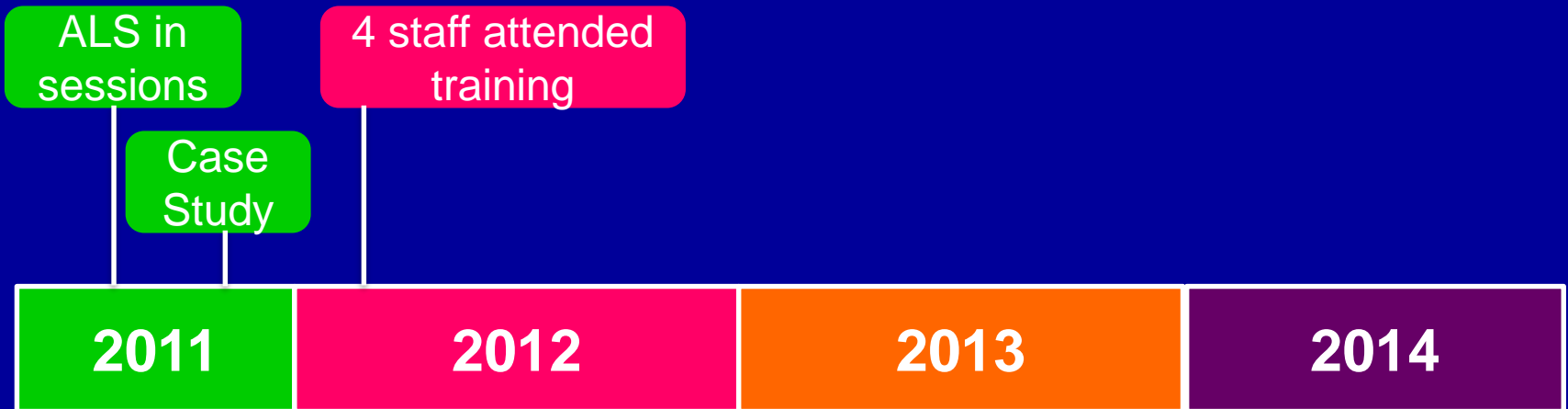
Changing Attitudes of Senior Management

- We needed the Senior Management Team (SMT) to understand communication, AAC and PODD to:
  - Support us on a senior, group-wide level
  - Provide financial backing
  - Develop an implementation strategy
  - Assist with changing the ethos and culture of the schools

Changing Attitudes of Senior Management

- Delivered a formal presentation to the SMT:
    - De-bunked myths around AAC and ASD
    - Helped them to see the need for *functional, spontaneous and autonomous communication*
    - Outlined the evidence base for prioritising these skills for students with Autism
    - Shared strategies to enable and develop functional spontaneous communication skills through aided language stimulation
        - Showed video of Adam communicating
    - Proposed PODD as a possible new resource in the 'AAC tool box'

Open expectations and new possibilities!

Implementation Strategy

Dates	Aims	Haylee	SLT	Resources	Training
11.6.12 – 20.7.12	•Introduce PODD to Senior Administrative Team •Introduce PODD to key parents •Introduce PODD to all staff members at Mitcham •Continue PODD trial with small number of students (5) •Purchase equipment and develop PODD resources •To identify key students across school	•Seek input from all trained PODD staff on customising PODD templates •Customise all 1 page opening PODD books (x6) Develop and present •Introductory PODD presentation to Senior Team •Continue working with students participating in PODD trial •Continue to collect video of PODD use, analyse. •Contact parent of child in Sutton PODD trial to seek permission and background information •Meet with parents to introduce PODD and share video •Make and introduce 2 page book with Sutton student in PODD trial •Develop and present PODD Twilight and Parents workshop •Work with L to organise Parent Workshop •Customise all one page opening PODD books	•Identify key students for PODD trial •Make group PODD's •Informally introduce PODD to class teams •Contact parents to seek permission and background information •Model PODD within classes and sessions •Collect video •Support HP to customize templates	• Customise PODD templates for UK and EHG (HP) • Source and cost equipment for making books • Order Equipment • Customise and create simple group books for CA Team and classroom staff • Purchase 'I've got something to say' bands (£20) • Make 2 sample books in each format (20) •Make 15 practice PODD books for trainings – 'Training Kit.' •Make individual books for students in PODD trial and any other identified key students •Start making class books for Robin and Owl	•Presentation for Twilight Session 5.7.12 •Parents workshop 28.6.12 •HP to meet with SLT's on fortnightly basis to monitor progress with PODD •HP and LT to meet with parent 16.7.12
Summer Holidays	•To complete PODD 'Training Kit' of books •To finish making a full set of sample books in	•Continue to customise all one page opening PODD books •Support the making of PODD training kit and sample books		• Continue creating PODD 'Training Kit' • One Page Kit- 8 completed, need another 11 finished	• PODD Overview/ Inspiration Session to School Business Office and other Senior Staff

Changing attitudes, knowledge and skills of teaching staff

- Knowledge and skills needed to be broadened in order to change attitudes and practices
- Interactive training sessions for all staff were developed:

  1. Basic characteristics of ASD and communication
  2. Introduction to AAC for young people with ASD
     - Different modes and approaches
     - The evidence and clinical base
     - Myths and realities

  3. What is Aided Language Stimulation?
     - how do you do it?
     - how does it work in a classroom?
  4. What is PODD?
     - Intro to one page opening PODD books
     - Features of PODD
     - Using PODD

Changing attitudes, knowledge and skills of teaching staff

Most Importantly:

We needed to create an INSIGHT into what was possible,

and INSPIRE people to try!!
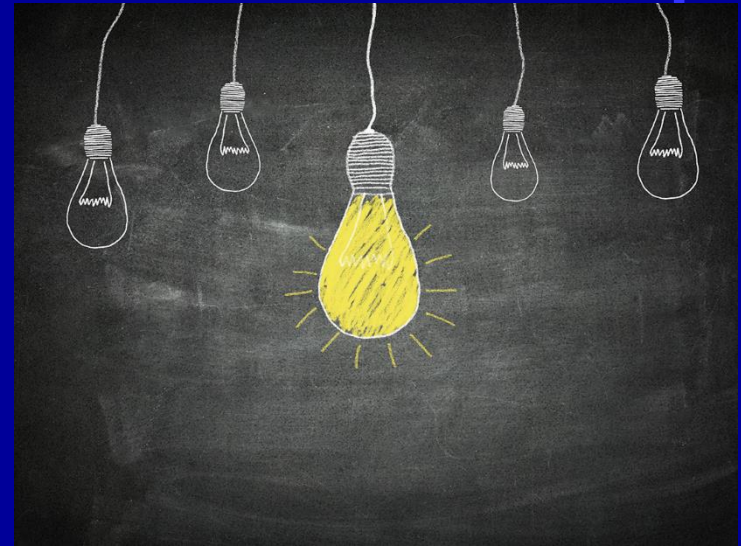
Changing attitudes, knowledge and skills of parents

- Parent Workshops were written and delivered over multiple 2-3 hour sessions from June 2012

- Individual meetings with parents were also carried out

- **25** Parents attended one or more workshops and/or meetings across the two schools

Phase 1- Introduction to AAC and PODD

- Included:
  - 1. Brief overview of Autism and Communication
  - 2. Rationale behind introducing Pragmatic Organisation Dynamic Display (PODD) Communication books
  - 3. Case study of PODD Trial
  - 4. Discussion and Q&A sessions

Changing attitudes, knowledge and skills of parents

Phase 2 – Using Aided Language around the Home

- Included:
  - Overview of features of PODD
  - Conventions for modelling aided language
  - Hands on activities to practice using PODD
  - VIDEO of their children communicating
  - Simple prompts and cues to increase attention and engagement
  - Commonly asked questions
  - Time to PRACTICE!!!

Feedback from Parents
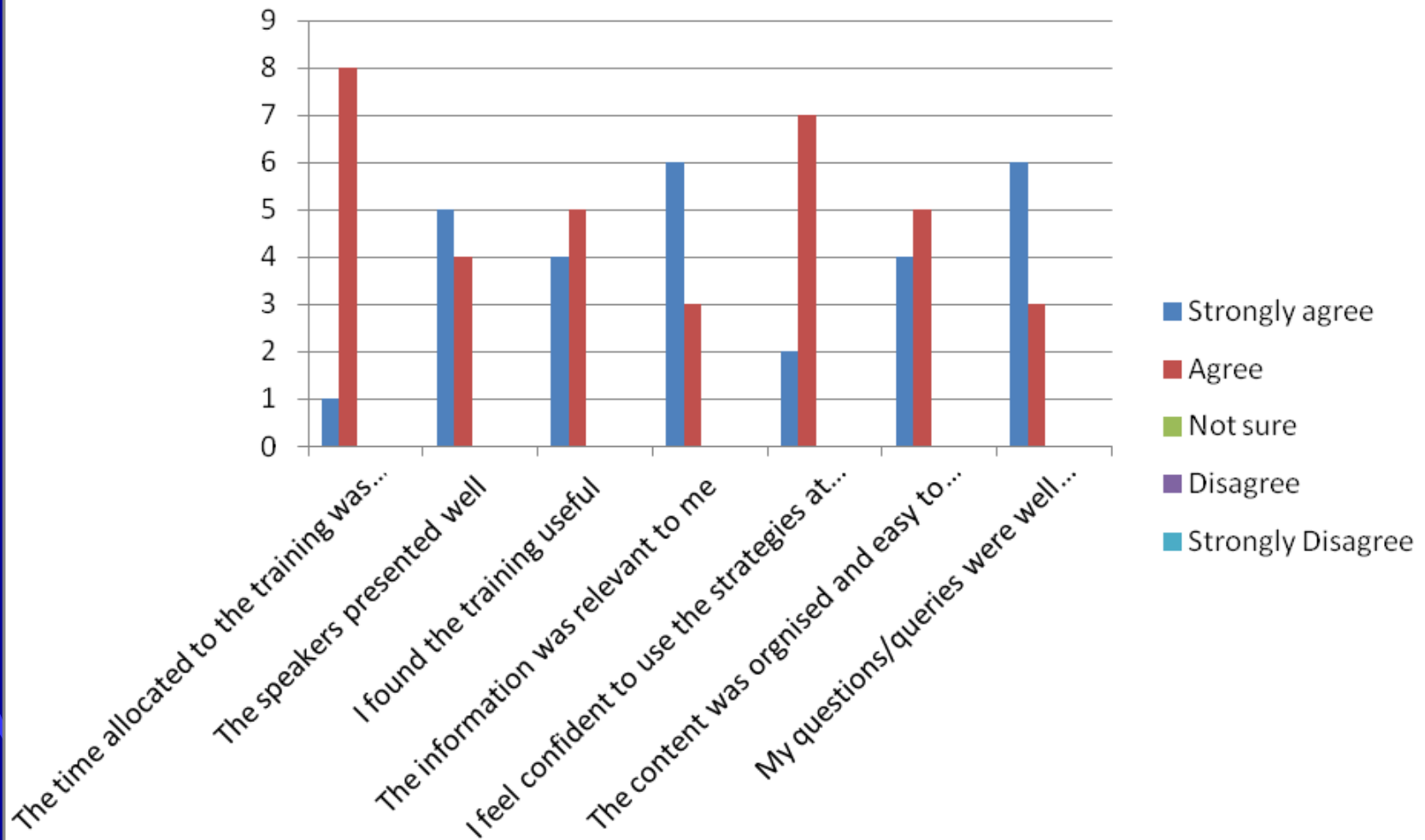
What our parents taught us!

We needed to:

- **Allow more time!**
  - Only 11% strongly agreed that the time allocated to the training was sufficient
- **Be practical with 'real life' examples**
  - 67% strongly agreed that the training was relevant to them
- **Needed lots of hands-on practice using strategies**
  - 78% agreed that they felt confident to use the strategies at home
- **Needed to allow time for questions and discussions**
  - 67% strongly agreed that their questions/queries were well answered

Cookies to Communication…

ALS in sessions	4 staff attended training	Parent Workshops	
Case Study	Development Plan		

2011	**2012**	**2013**	**2014**

Staff Workshops

Presentation to Senior Team
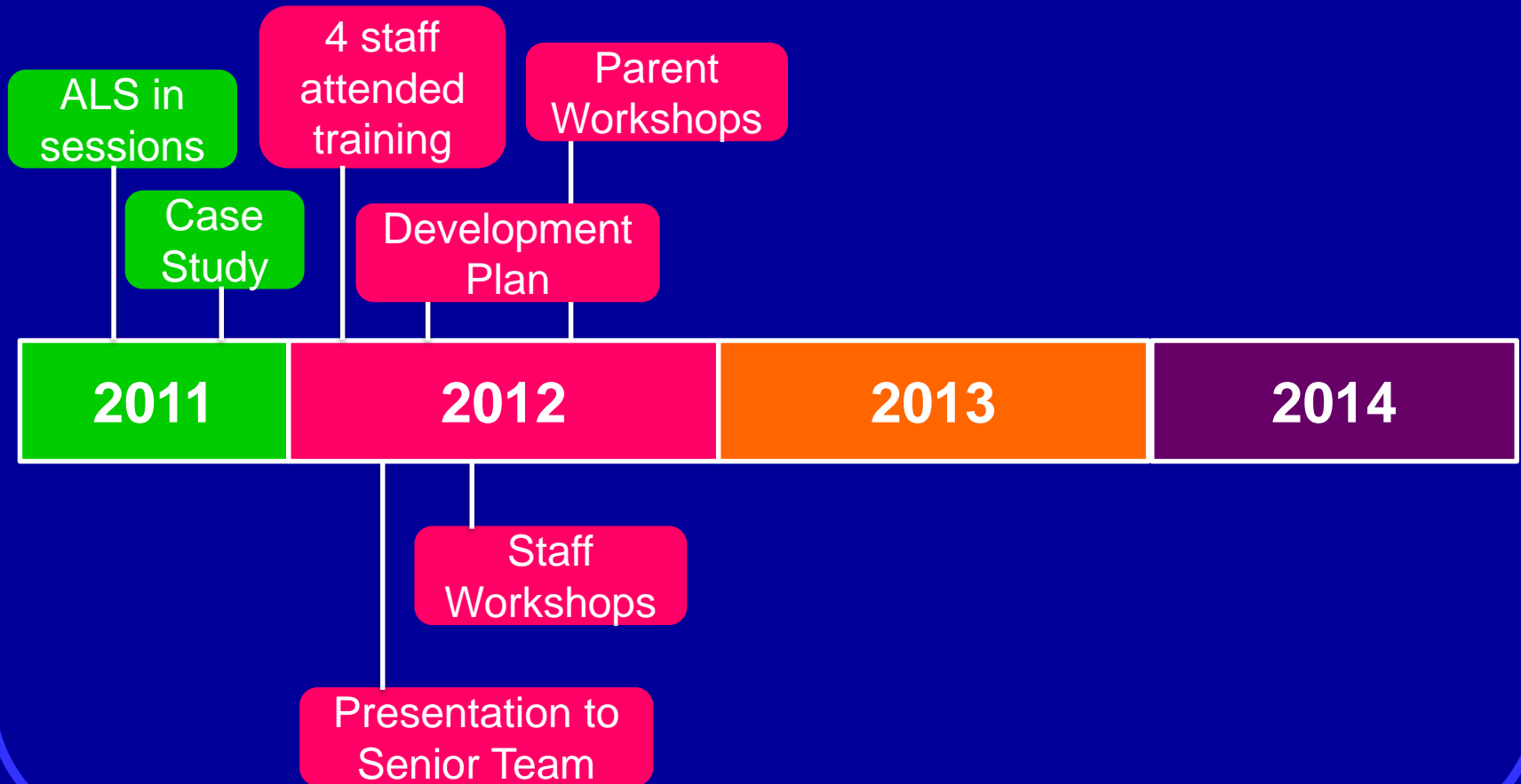
'PODD Facilitator' Role

- 'PODD Facilitator' worked across both provisions to:
  - develop the group wide implementation strategy
  - integrate aided language into the classroom curriculum
  - model and support staff to provide aided language stimulation in class and the wider school environment
  - co-ordinate the customising and making of AAC supports for general within class use
    - eg. aided language displays, PODD communication books
  - co-ordinate and deliver staff and parent training
  - collect and analyse video and written data
  - feedback progress to staff and SMT on a regular basis

Establishment of a Referral and Evaluation Process

- Needed to collect 'pre-PODD' data
- Wanted staff and parents to reflect on:
  - the students' presenting difficulties
  - strategies that had previously been implemented
  - their goals of implementing a comprehensive communication system
- Determine current level of functioning in expressive communication
- Degree of attention, engagement, self-esteem and behaviour regulation

Request no.

Eagle House School, Sutton
PODD Request for Input Form

Name of Student/Child: .... Date: ....

Form completed by: ....

Presenting Difficulties: ....
....
....
....

Please outline any approaches or strategies which have been used with the student/child:
....
....
....

Please outline how the student/young person currently communicates: ....
....
....
....

What do you hope to achieve by implementing PODD: (this could be related to communication, language, anxiety, behavior, independence, self-esteem in home, school or community environments)
....
....
....

Please rate your students/child's ability in the following areas: (please circle and tick as necessary)

Expressive Communication:

Approximate size of vocabulary of spoken words, signing or symbols:								
1-10	11-30	31-50	51-70	71-90	91-100	100+	200+	300+

Range of functions expressed using speech, signing or symbols								
1	2	3	4	5	6	7	8	9	10

Requesting for object ☐   Giving information ☐   Commenting ☐
Requesting for action ☐   Expressing emotions ☐   Asking questions ☐
Requesting for help ☐   Sharing an opinion ☐   Answering questions ☐
Requesting for more ☐   Naming/labelling ☐
Greeting ☐   Rejecting/protesting ☐

Average number of spoken words, signs or symbols in a sentence:								
1	2	3	4	5	6	7	8	9	10

Number of different types of words (spoken, signed or symbols) used:								
1	2	3	4	5	6	7	8	9	10

Noun ☐   Preposition ☐   Adjective ☐
Pronoun ☐   Interjection (e.g. Ah!) ☐   Adverb ☐
Verb ☐   Article (eg the, a, an) ☐
Pronoun ☐   Conjunction (eg and, but) ☐

Attention, Engagement, Self-esteem and Behaviour

	All the time	Usually	Sometimes	Rarely	Never
Student participates in all aspects of school life	5	4	3	2	1
Student is actively engaged in all academic lessons	5	4	3	2	1
Student attends to written and spoken information with minimal prompting	5	4	3	2	1
Student understands and follows instructions	5	4	3	2	1
Student remains calm throughout the school day	5	4	3	2	1
Student is able to effectively self regulate	5	4	3	2	1
Student uses words/signs/symbols to express anxiety or distress	5	4	3	2	1
Student is able to calmly transition between locations within the school	5	4	3	2	1
Student is able to calmly transition between school and community locations	5	4	3	2	1
Student is able to effectively communicate with familiar people	5	4	3	2	1
Student is able to communicate effectively with unfamiliar people	5	4	3	2	1
Student will initiate communication with adults	5	4	3	2	1
Student will initiate communication with peers	5	4	3	2	1
Student initiates social activities easily	5	4	3	2	1

Social Networks:

How many people can the student effectively communicate with:									
1-5	6-10	11-15	16-20	21-30	31-40	41-50	50-99	100+	200+

Any additional comments: ....
....
....
....
....
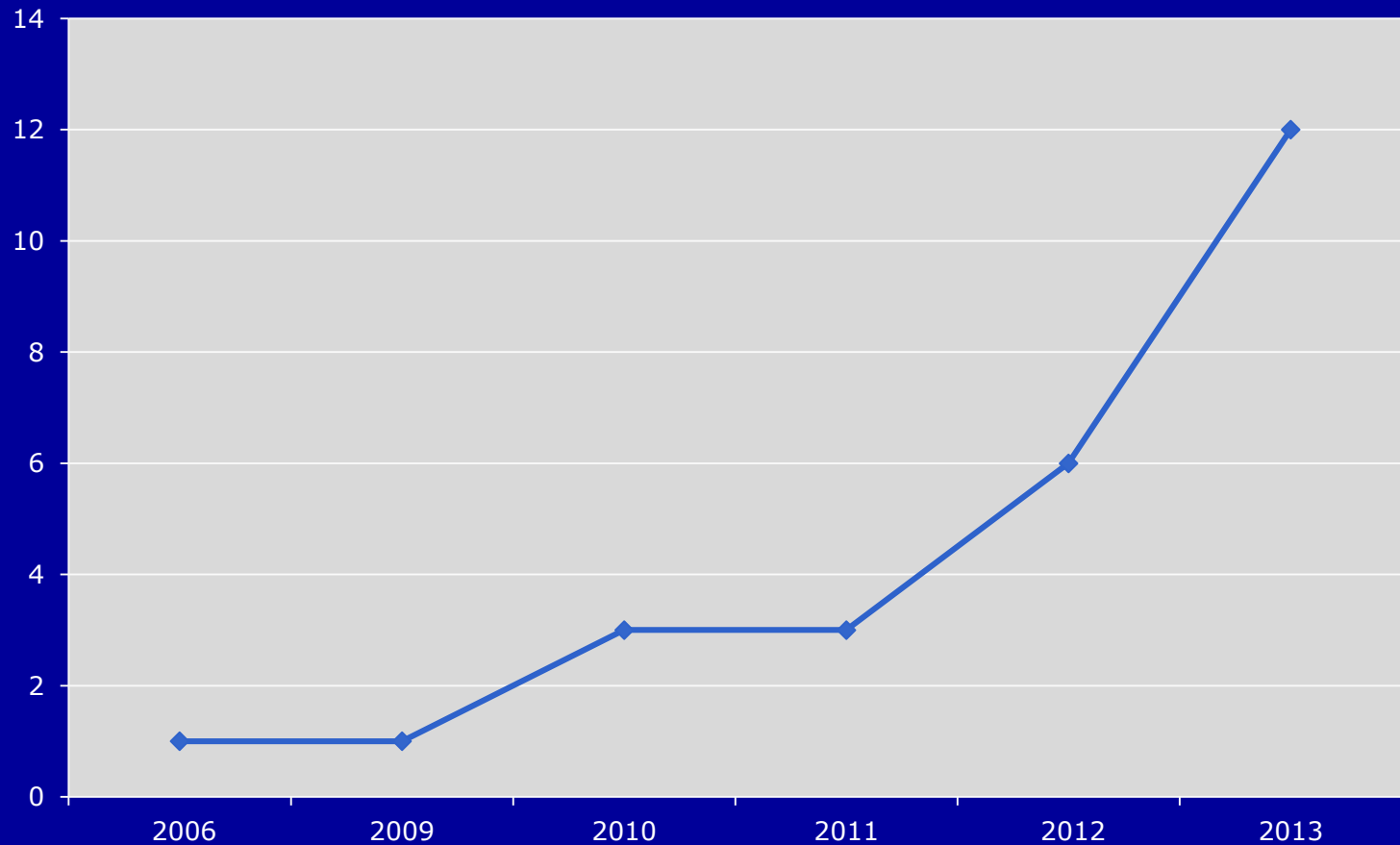
Thankyou! Please hand to the Speech and Language Therapist working with your class. ☺
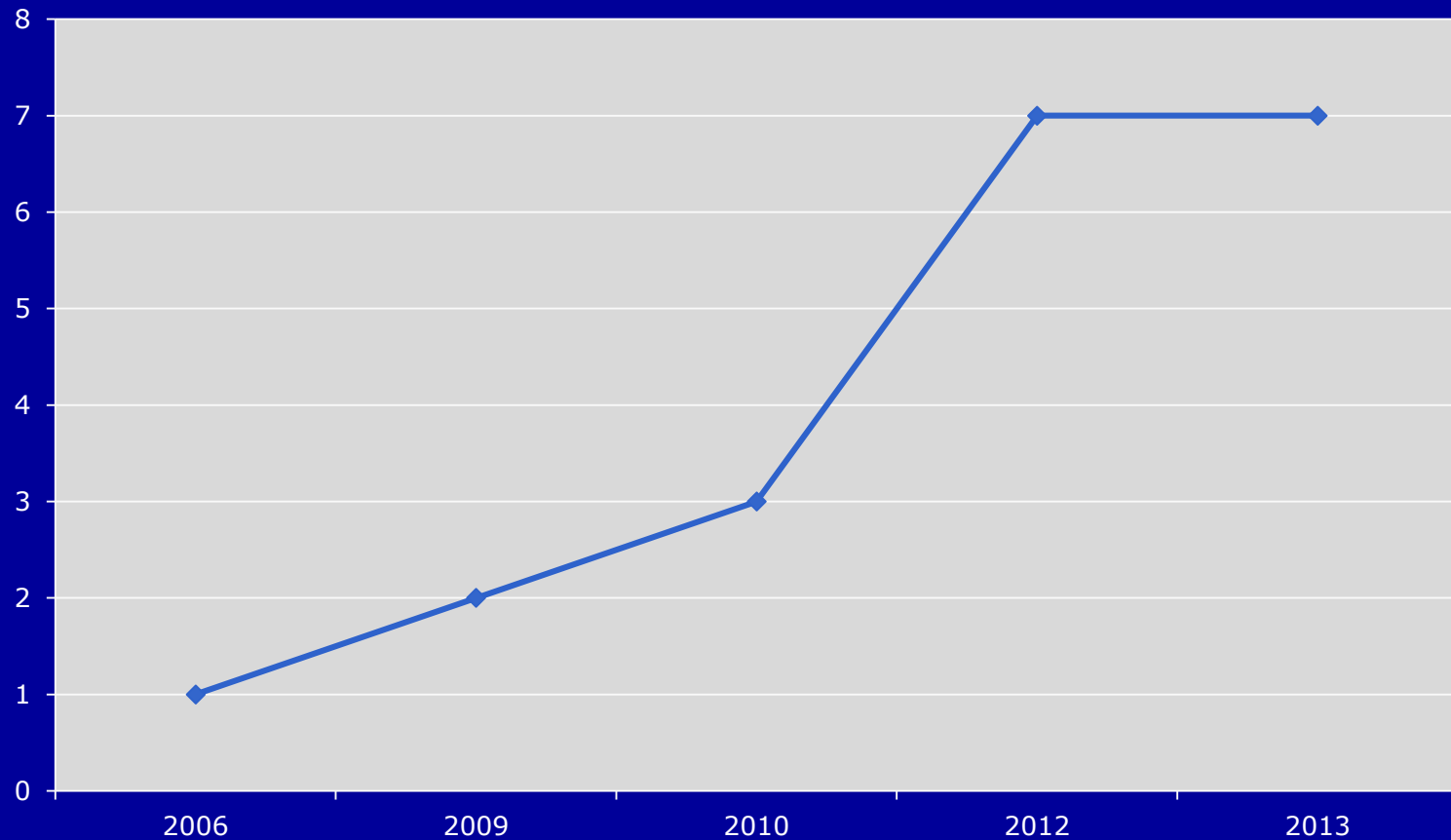
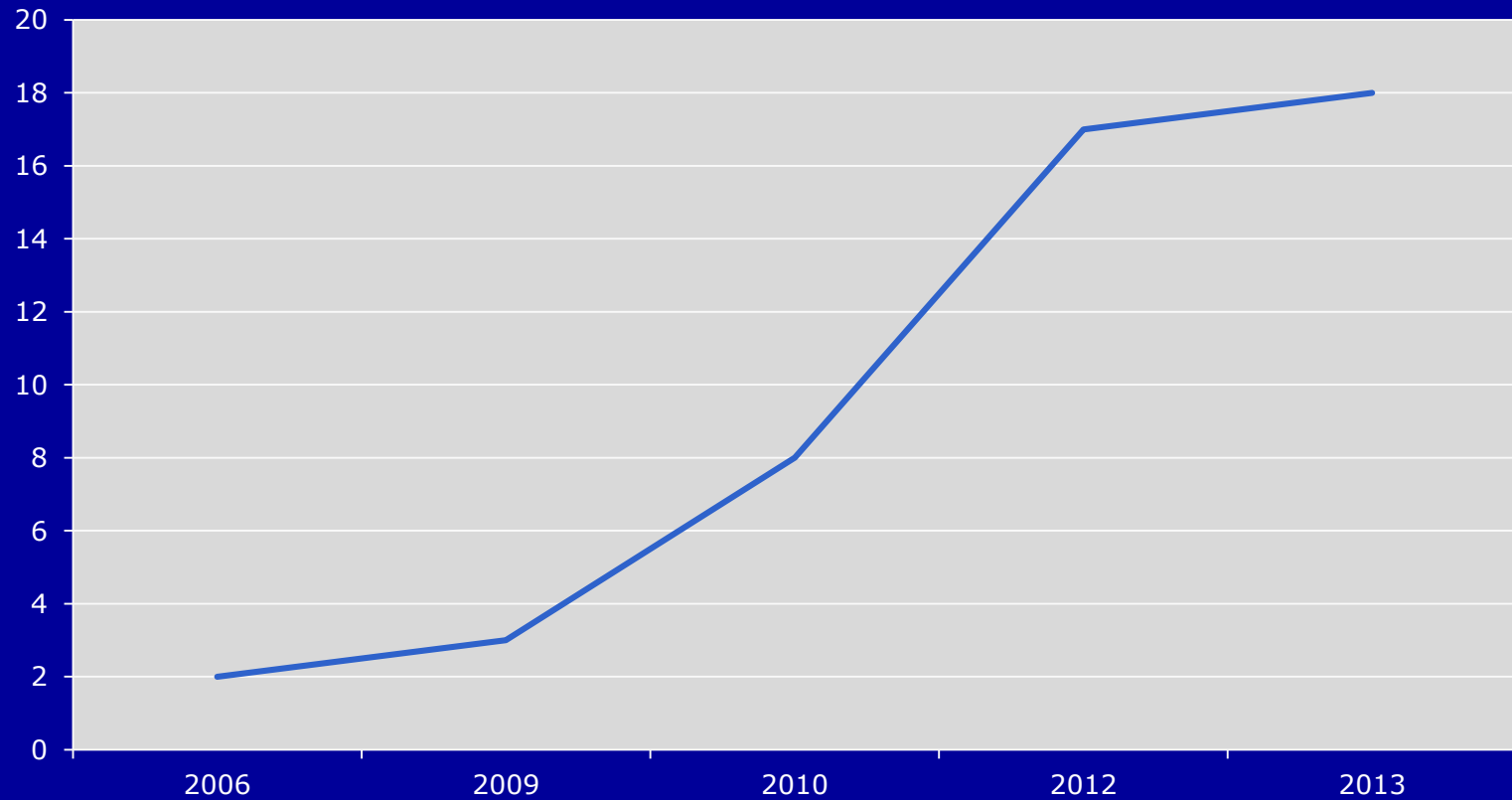# Data Collection and Outcomes

Length of Utterance

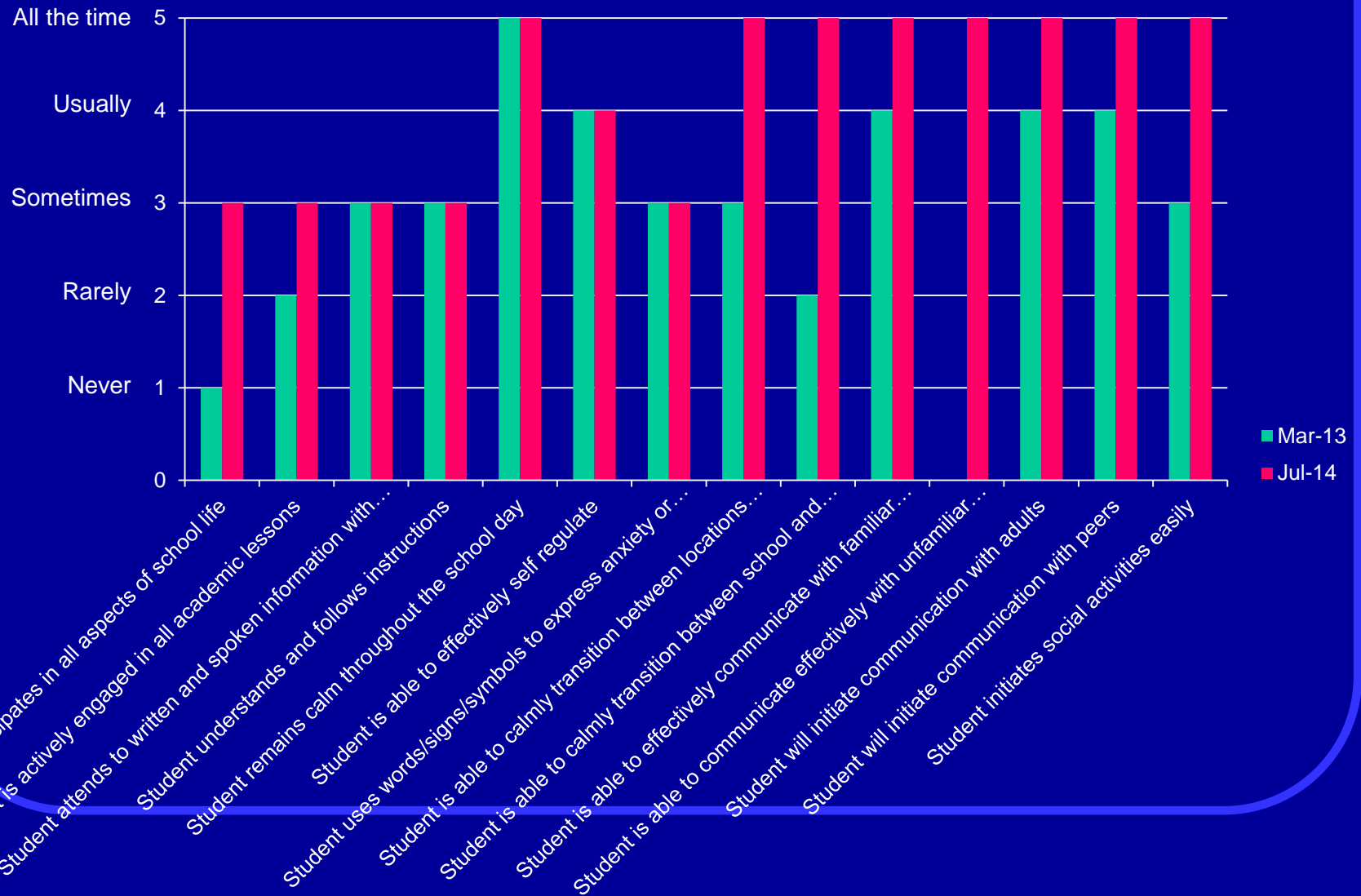# Data Collection and Outcomes

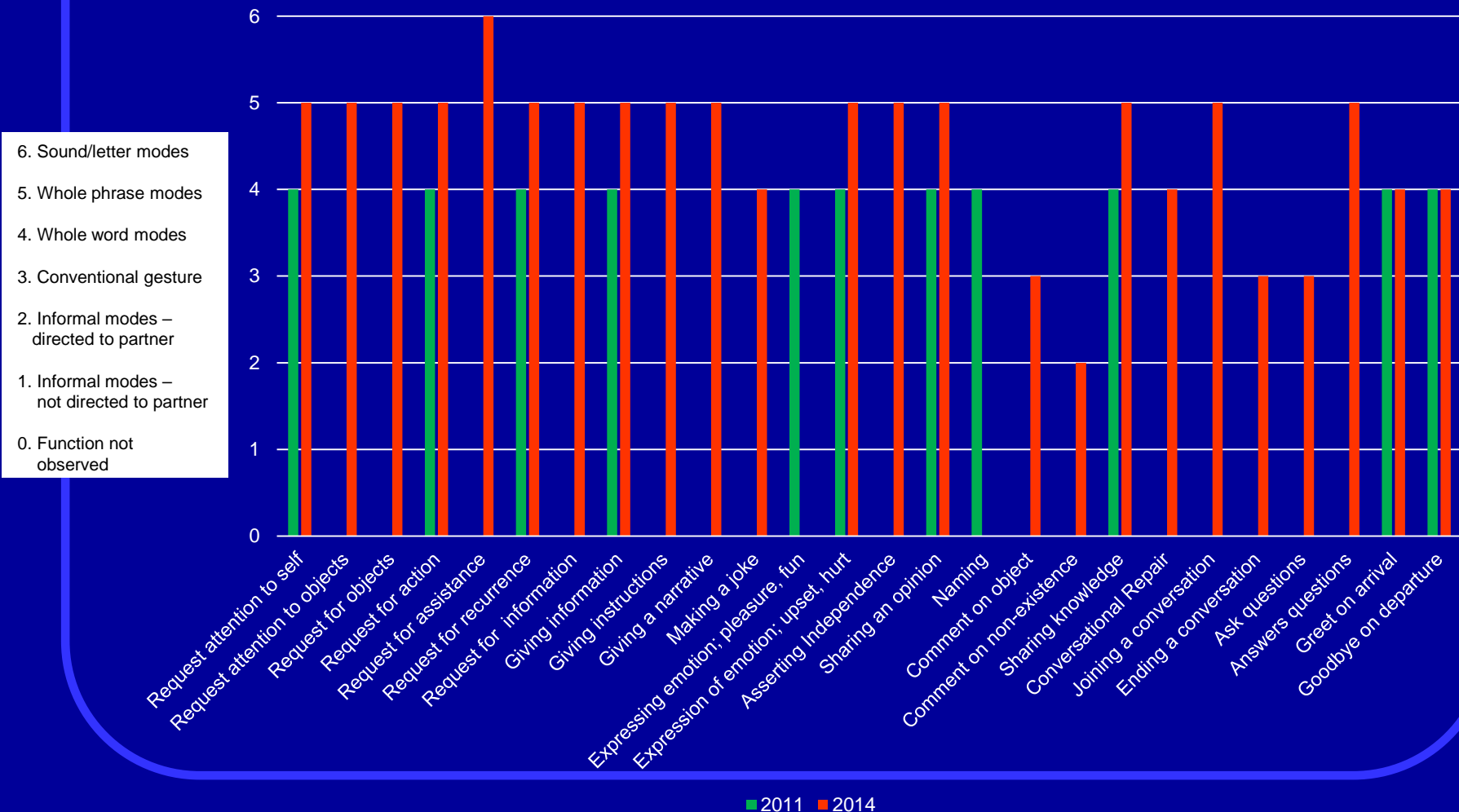**Number of Parts of Speech**

Data Collection and Outcomes

Range of Communicative Functions

Data Collection and Outcomes- Pragmatics Profile

6. Sound/letter modes

5. Whole phrase modes

4. Whole word modes

3. Conventional gesture

2. Informal modes – directed to partner

1. Informal modes – not directed to partner

0. Function not observed

Legend: ■ 2011 ■ 2014

Data Collection and Outcomes- Testimonies from the Community

'A'

Learning Support Assistant:

- "When asked how he feels about 'his words', 'A' said **"I feel excited and pleased."** I feel that 'A''s statement shows exactly how life changing this journey has been. Compared to when I first met 'A', he is now unrecognisable. PODD has given him a voice that he never had before."

"He can finally 'say' what

he wants using the words he thinks with."

Data Collection and Outcomes- Testimonies from the Community

R.C. (teacher)

- "Now he uses a PODD book at home and school and he responds very well to it. Since he started using it, his behaviour has improved." - 17.1.13

- "T's behaviour has improved dramatically since starting PODD- he used to run around the room or scream, now he will point to 'I don't understand."

- 1.3.2013

Data Collection and Outcomes-Testimonies from the Community

O.A. (mother)

- "He is talking a lot more now and is easier to understand. He is attempting to say more new words, I think it's because he is becoming more confident with his speech as he has a back-up."
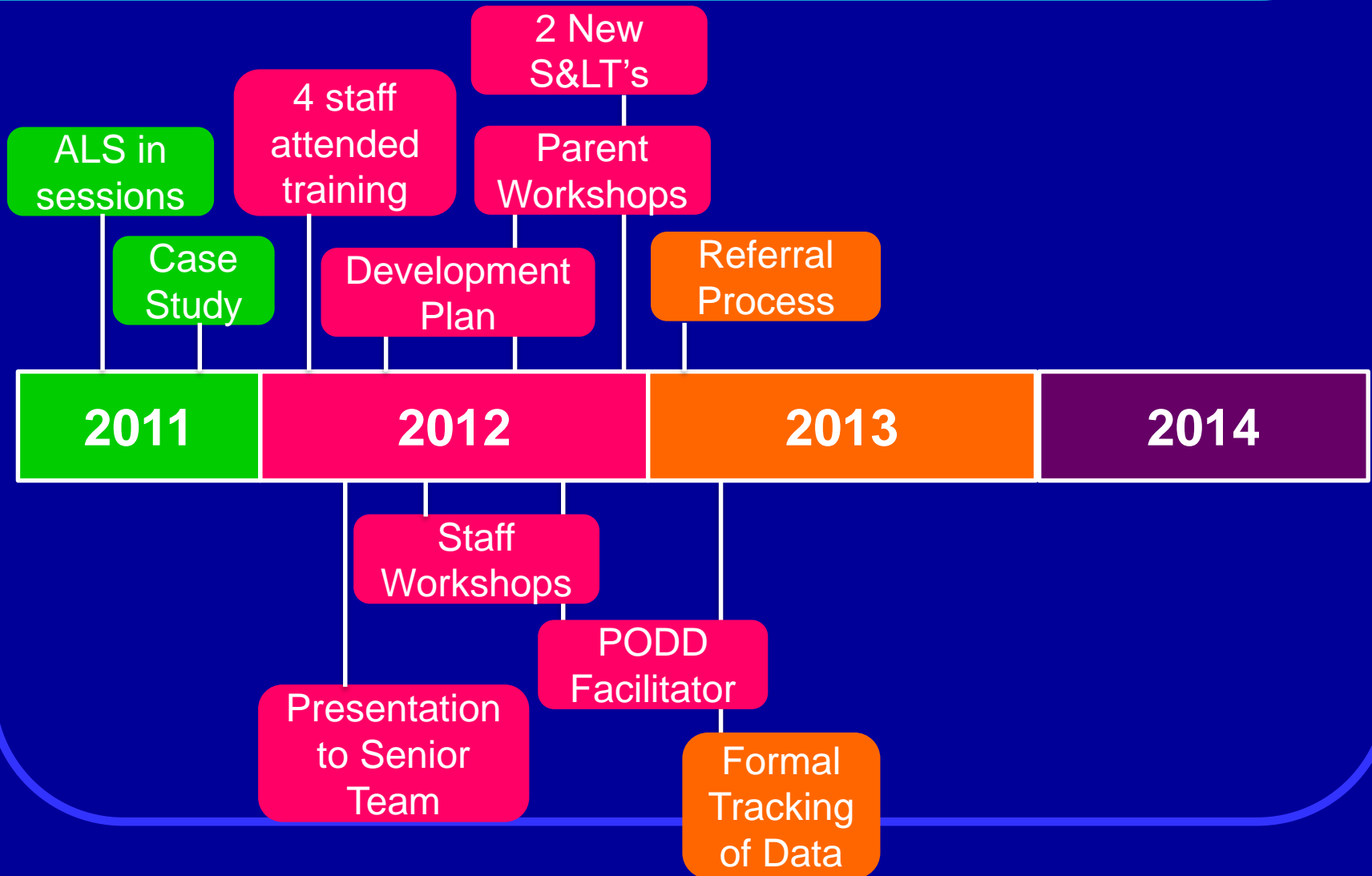
Data Collection and Outcomes- Testimonies from the Community

E.H,

(Speech and Language Therapist, Sutton)

- 'I've noticed that in X the communication boards and PODD books are really beneficial to support the students in following instructions and transitioning, for example, T was asked to wash her dishes verbally several times - I have seen before that she has required adult physical prompts to complete this. She was then shown visually and she spontaneously (and) independently completed this, showing an impact on her understanding and independence skills.' - 1.3.2013

Cookies to Communication…

2 New S&LT's

4 staff attended training

ALS in sessions

Parent Workshops

Case Study

Development Plan

Referral Process

2011	2012	2013	2014

Staff Workshops

PODD Facilitator

Presentation to Senior Team

Formal Tracking of Data

Bumps in the Road!

Difficulties reported around:

1. knowledge of Senior Management Team

- difficulties attending training

- school inspections (and assessment) taking priority!

- prioritising service delivery models which enable 'natural' in-class communication support

2. training of new staff and re-inspiring 'old' staff

- sustaining knowledge and skills in the classroom

3. support to maintain resources

- time to make communication displays and books

- funding to support ongoing resource development

Cookies to Communication…

2 New S&LT's

2 Formal PODD Workshops

Parent Workshops

4 staff attended training

Parent Workshops

ALS in sessions

Development Plan

Referral Process

1 New S&LT

Parent Coffee Mornings

Case Study

2011	2012	2013	2014

Staff Workshops

Interim SMT

Playground Engineered

PODD Facilitator

I leave EHS!

Interim SMT

Presentation to Senior Team

Formal Tracking of Data

Parent & Staff Workshops

Our Communication Community

- **13** classrooms currently using aided language stimulation and PODD within their curriculum
- **22** students have customised communication systems which travel between home and school (13 primary, 9 secondary)

- ***All*** staff have attended at least two trainings on AAC, Aided Language Stimulation and PODD
- **46** staff have completed PODD Introductory Workshop
- **25** Parents have attended Phase 1 and/or Phase 2 Communication Training
  - 16 additional individual parent meetings

The Communication Community

1 Operations Director, 2 Head Teachers, 2 Deputy Head Teachers

Clinical Psychologist, 4 Assistant Psychologists, 2 Occupational Therapists

2 Speech and Language Therapists

2 Speech and Language Therapists

Diver

Crane

Barn Owl

Woodpecker

Robin

Kingfisher

Egret

Falcon

Phoenix

Penguin

Starling

2 Learning Support Assistant

2 Learning Support Assistant

2 Learning Support Assistant

2 Learning Support Assistant

3 Learning Support Assistant

1 Learning Support Assistant

2 Learning Support Assistant

2 Learning Support Assistant

2 Learning Support Assistant

2 Learning Support Assistant

2 Learning Support Assistant

3 Parents

2 Parents

1 Parent

3 Parents

1 Parent

3 Parents

2 Parents

3 Parents

3 Parents

3 Parents

73 Teachers, Therapist, Assistants and Parents around 25 students

Communicating in the Community

- March 2013
  - A confidently accesses the community using his communication book
  - A worked with his LSA to customise his third PODD Book

- July 2014
  - A now uses a 48 key word expanded two page opening PODD with side panel
  - Communicates for a wide range of functions using full sentences and morphology

" I am feeling happy & excited. I am going to supermarket, OK Magazine!"

Please get in touch!

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