Nature Nevers Draws A Line Without Smudging It

Reflections on the life and work of Dr Lorna Wing

Dr Judith Gould
Consultant Clinical Psychologist
• History of ideas
• Some other interests
• Work at the Lorna Wing Centre
• Personal
History of Ideas
Setting the Scene

• We now recognise how important it is to understand Autism by talking to the people themselves
• This was Lorna’s advantage in having a daughter with autism, she lived and observed the condition
• Her interest therefore began in 1956 when Susie, who had classic autism, was born
• These were dark times – theories were that the children were potentially normal but had withdrawn due to cold, over intellectual parents
• Diagnosis was difficult to obtain and no help was given to parents
• The children were excluded from education
Changes in attitude

1940 – 1950’s
• Predominance of the theories of emotional causes of autism due to the strong influence of psychoanalysis especially in the USA

1960’s onwards
Gradual change to biological theories of causes due to:
• Development of objective, scientific studies
• Influence of voluntary associations of parents and professionals
• 1966 Lorna and John wrote their first book on autism
• 1971 Lorna wrote her book ‘Autistic Children, a guide for parents’ which was revised in 1996 ‘The Autistic Spectrum’ which is still the book parents find most helpful

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1969 Lorna wrote her paper on the ‘Handicaps of Autistic Children’ she compared children with:

- Autism (speaking and non-speaking)
- Downs Syndrome
- Receptive Aphasia
- Executive Aphasia
- Those who were partially blind/deaf
- Typically developing children

She produced the first interview schedule to tease out the differences in each group and concluded ‘Autistic children are multiply handicapped, combining problems experienced by the other groups

- The idea that autistic children had multiple impairments that vary in severity with other groups became the focus of Lorna’s thinking
- Autism was not a unique and separate syndrome
In Lorna’s paper 1971 – Multiple Impairments in Early Childhood having read Van Krevelin’s paper comparing the differences between Kanner’s and Asperger’s children she speculated possibly Asperger’s Autistic Psychopathy was due to the presence of the autistic impairments in very mild or partial form.

To quote “It was sufficient to prevent the person from understanding subtle social cues which depended on non-verbal communications – making the child appear naïve and eccentric”.

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At this stage Lorna thought the behaviour problems of autistic children could be explained as secondary to the underlying impairments i.e. poverty of social contact resulted from impairment in the development of all forms of language.

In 1977 the relationship of symbolic play and development of language became her area of interest.

One of the clinical features of early childhood autism was poverty or absence of symbolic play. She hypothesised the central problem was a severe impairment of the ability to abstract concepts from experience, to give these abstractions symbolic labels and draw from them for relevant associations when thinking of the past, reacting the present and planning for the future.
A lack of symbolic play was the outward sign of this central problem.

In the 1977 study there were 3 groups, these were:

• No symbolic play
• Stereotyped repetitive copying play – which began her thinking beyond and absence of symbolic play
• Flexible varied symbolic play
In 1978 she designed the First Edition of the Children’s Handicaps Behaviour and Skills (HBS) structured interview scheduled, which was used in the Camberwell Study.

The HBS was the pre-cursor of the Diagnostic Interview for Social and Communication Disorders (DISCO)
Development of the Concept of the Autism Spectrum
Wing & Gould 1979

Lotter (1960) in his Middlesex prevalence study, used Kanner’s criteria very strictly applied in a total population of children of all levels of ability.

Wing and Gould in their Camberwell study, looked for any kind of strange behaviour in a total population of children identified as having any kind of special need. This group was selected because virtually all the children Lotter identified were known to have special needs.

A group fitting Kanner’s criteria were identified, with the same prevalence as found by Lotter.
A few children fitting Asperger’s criteria were also identified. This group was very small because the mainstream children in the area were not screened.
There were many more children who did not fit Kanner’s or Asperger’s criteria but who had all kinds of mixtures of features of these “syndromes”.

It was found that impairments of social interaction, communication and imagination could occur in a very wide range of manifestations. But, however they were manifested, there was a strong tendency for them to cluster together and to be associated with a narrow, repetitive pattern of activities. It was very difficult to draw neat boundaries between the named “syndromes” and those with the triad of impairments who did not fit into a “syndrome”.

The concept of a spectrum of autistic disorders fitted the findings better than the categorical approach. This does not imply a smooth continuum from the most to the least severe. All kinds of combinations of features are possible.
Evidence For A Spectrum

• Many people show mixtures of features of different sub-groups
• One person can show different features in different environments
• One person can show different features at different ages
• Members of the same family can show different features
• Identical twins or triplets can show different features
• The same basic principles underlie methods of education and care for whole spectrum
Dimensions Versus Categories

In clinical practice, it is extremely difficult to define the boundaries between different diagnostic categories, whatever the criteria used.

The clinical pictures found in those with autistic spectrum disorders fit better with the concept of multiple dimensions than with the concept of separate, definable categories.

Individual needs are more accurately assessed from the profile of levels on different dimensions than from assigning a categorical diagnosis.
The Importance of the Social Impairment

We now feel that social impairment due to the absence or impairment of the social instinct is the most fundamental problem of all.

**Leo Kanner 1943 said**
- Present from birth
- Genetic:
  
  “We must assume that the children have come into the world with innate inability to form the usual, biologically provided affective contact with people”

**Lorna Wing 1964 said**

“Social withdrawal is an important characteristic of autistic children which perhaps is related to the inability to communicate in speech. A mother often senses this in her child almost from birth. Later the mother notices that the child does not attract her attention to things going on around – indeed her child appears oblivious of them”

This is now referred to as lack of joint-referencing which is key in the diagnosis of young children.
The Social Impairment is the Key to Diagnosis

In children and adults with severe or profound learning disabilities the level of development may be too low for communication and imagination. But, interest in other human beings is present virtually from the beginning of life.

Children and adults with extremely high levels of cognitive ability may be verbally articulate with good imagination but have learned social skills through their intellect rather than by social intuition.
Revision of the TRIAD

Since the 1970’s our thinking has evolved. All people in the spectrum have core difficulties. These are:
- Difficulties in **social** interaction
- Difficulties in **social** communication
- Difficulties in **social** imagination
Problems in these areas are usually associated with a repetitive, rigid style of functioning
Problems of Classification

• Apart from the lack of social instinct untypical behaviours are found to varying degrees in all diagnostic subgroups, in all developmental disorders and to some extent in typical development

• So called syndromes into which autism spectrum disorders have been divided are not unique and separate syndromes

• They are best understood in the context of the full range of developmental disorders right up to the borderline of normality

• The categories have not been helpful in prescribing type of education, behaviour management and treatment
As a result - new DSM 5

No Subgroups

Autism Spectrum Disorder

A neurodevelopmental disorder which must be present from infancy or early childhood but may not be detected until later because of minimal social demands and support from parents or carers in early years.
Why Change?

The distinctions between the subgroups were inconsistent

- Over time
- Variable in interpretation across different sites
- Dependent on associated features e.g. severity, language level and intelligence
- People show mixtures of features of different subgroups

• It is difficult to draw neat dividing lines between the subgroups

• The concept of a spectrum of autism fits better than specific subgroups

• Research evidence shows that it is difficult to separate social and communication symptoms as they overlap e.g. eye-contact, gesture, facial expression are both social and communicative
Removal of the subgroups – Asperger Syndrome

In 1981 Lorna Wing published a paper linking the pattern of behaviour described by Asperger as part of the autism spectrum.

In the early 1990’s DSM-IV and ICD-10 included Asperger’s description in their classification systems as a separate subgroup.

Recognition of the pattern of behaviour is useful clinically and should remain as a description which can be specified by diagnosticians.
At the Lorna Wing Centre, in our diagnostic formulation we state

“A has an autism spectrum disorder and best fits the pattern of behaviour described by Asperger known as Asperger’s syndrome.” We then describe the individual’s pattern of skills and difficulties.
Other Special Interests
Women & Girls

• The first conference on women and girls in 2009 facilitated by Research Autism, chaired by Lorna and Richard Mills
• NAS Lorna Wing Centre increasing number of girls and women referred for diagnosis
• Historically there has been a strong gender bias of more males than females
• Autism presents differently in females
• Females mask symptoms better than males
• As a result professionals are less likely to diagnose girls / women even when symptoms and behaviours are evident
• Autism in Pink project learning about women with autism

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Women & Girls The Diagnostic Criteria

• The current systems do not give examples of types of difficulties shown in girls and women and are not good at recognising autism symptoms in girls and women

• The methods used to diagnose are still skewed to the male presentation of the condition

• There is a need for a wider perspective regarding social, communication and imaginative dimensions in addition to special interests and rigidity of behaviour

• The DISCO enables clinicians to ask the right questions and make appropriate observations
Catatonia

In 2000, based on the clinical referrals to the Lorna Wing Centre, Lorna and her colleague Amitta Shah recognised the overlap of some catatonic behaviours in adolescents and young adults with autism.

They concluded that catatonia can be a complication of autism spectrum disorders which has major implications for management and support.
Treatments - A question of Judgement (1986)

As a parent and professional Lorna was frequently asked about “treatments” for autism. In 1986 she set out guidelines as to why proper evaluations were essential.

“Parents of young children with autism are vulnerable to false theories of causes and to claims of quick fix solutions “

“Scientific evaluation of treatments is essential, but can be difficult, time consuming and expensive”

Since Lorna’s guidelines these have been followed up notably by Research Autism who have published:

- A book “Choosing Autism Interventions” A research based guide
- A website dedicated to high quality research into autism treatments, therapies and other approaches
One of Lorna’s special interests was animals.

A golden retriever called Candy had helped overcome Susie’s extreme fear of dogs.

Lorna and Richard Mills, linked with Dogs for the Disabled set up the PAWS project. Consequently various papers have been published on pet dogs and autism.

Results showed:
• A positive significant impact on reducing parental stress and on problematic behaviours of the children again reducing stress
• Parental reports indicating a calmer child and bonding of the child and dog
• Positive experiences from the children's own reports

Another interest, relating to Susie, was research on excessive drinking of fluids in children and adults on the autism spectrum. This will be published in Advances in Autism this November.
Work at the Lorna Wing Centre
The NAS Centre for Social and Communication Disorders was set up in 1991 which was the very first centre in the country to provide a complete diagnostic and assessment service for children, adolescents and adults.

In 2008 the Centre was renamed The NAS Lorna Wing Centre in recognition of her pioneering work.
The multi-dimensional diagnostic formulation carried out at the Centre is based on the Diagnostic Interview for Social and Communication Disorders (DISCO) 2002.
Understanding autism as a spectrum

Working to develop measurement of the autism spectrum 1991-2015

Diagnostic Interview for Social and Communication Disorders

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# Measuring autism as a spectrum

## The DISCO

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<tr>
<th>Reliability and validity</th>
<th>DISCO (320 items) is reliable (Wing, Leekam et al., 2002). Algorithms are valid (Leekam et al., 2002; Kent, Carrington et al., 2013) for ICD-10, Wing &amp; Gould ASD and DSM-5</th>
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<td><strong>Comparison with ADI-R and ADOS</strong></td>
<td>Strong agreement with ADI and ADOS outcomes (Nygren et al. 2009, Maljaars et al., 2012)</td>
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<tr>
<td><strong>Subgroups and support for spectrum approach</strong></td>
<td>No clear subgroups emerge based on behaviour or ICD-10 clinical diagnostic criteria (Prior et al., 1998; Eisenmajar et al., 1996; Leekam et al., 2000)</td>
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Training courses are offered for professionals involved in diagnosis and assessment of needs to understand the autism spectrum using the DISCO Framework.

Contact the Lorna Wing Centre for more details.

lornawingcentre@nas.org.uk
Lorna Wing Research Network

– Linked with Cardiff University and other International Partnerships
– Many publications using the DISCO
– Large DISCO dataset of individuals at different ages
– New questionnaires using DISCO items give insight into repetitive behaviours, sensory features, PDA

New Plans
• Broaden network to other researchers internationally
• Further validation of the DISCO
  • Age appropriate versions (and gender items)
  • DSM5 and ICD-11
  • Comparisons of full and abbreviated versions with ADOS and 3di
  • Signposting items to validate
• New training for researchers
• New research using a dimensional approach
  • e.g. study of social impairment subtypes, imagination, maladaptive behaviours and research on adults

Publications – see http://sites.cardiff.ac.uk/warc/research

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Personal
Lorna’s love of gardening was a well-deserved hobby in her very busy life.

“She nurtured her colleagues like she nurtured her seedlings and plants”

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She loved detective stories particularly Sherlock Holmes, she herself was the detective, always curious about everything, fascinated by the complex way people behaved, an eye for detail, passion for knowing the truth and fairness to all. Once she had an idea she would pursue it to the bitter end. She would investigate, chivvy and query and never give up on a clue to make the lives of autistic people and their families better.
She received many awards throughout her life.

She was one of the supreme authorities in the world today of autism. She showed us how to combine academic rigour and fidelity to the scientific method with a deep humanity. She never sought accolades, was modest and always ahead of her time in thinking.

On a personal note she was my mentor and inspiration in all my work. She instilled in me the fascination for autism in our lifetime of working together.
To conclude to go back to the beginning where I mentioned we have learned most about autism from individuals themselves. A quote from a woman with Asperger Syndrome, Olley Edwards 2015.

“The autism spectrum is vast and beautifully complex, some individuals are easily identified, but for others their autism is a prism, it is present, but yet it remains transparent until the appropriately trained clinician shines their knowledge and light onto it, it is only then that the colours and complexities can be seen and understood.
Nature never draws a line without smudging it