

# **1<sup>st</sup> Seattle Club Conference on Research in Intellectual Disabilities**

17-18 December 2001

University of Birmingham

## **ABSTRACTS**

## Welcome

Welcome to the first Seattle Club Conference on Research in Intellectual Disabilities. The idea of a conference for UK researchers in the field has been around for some time and was crystallised at the IASSID conference in Seattle in August 2000. For this first conference, we have used the rather exclusive label of Seattle Club for want of a better name and to ground the establishment of this meeting in the context of those earlier discussions. The idea was to replicate aspects of the Gatlinburg annual conference in the USA by focusing on papers and posters that include research data, by establishing a theme, and by involving current and recent students as well as established researchers.

The conference theme for 2001 is **Cognitive, Behavioural, and Emotional Functioning in Intellectual Disability**. Many of the papers in the programme address this theme, but there is also space for presentations that do not.

We hope that you enjoy the conference, and will take the opportunity to contribute to open discussions about whether, how, and under what name such a conference might continue in the future.

Our thanks go to the team at Birmingham who have done a great job in getting this conference off the ground at such short notice, especially *Sharon Siviter* and *Jane Petty*. Thanks also to all contributors who have also worked to tight deadlines. We hope that you feel it's been worth the effort!

Ad-hoc organising committee:

<b>David Felce</b>	(Welsh Centre for Learning Disabilities, University of Wales College of Medicine, Cardiff)
<b>Richard Hastings</b>	(Centre for Behavioural Research Analysis and Intervention in Developmental Disabilities, University of Southampton)
<b>Chris Hatton</b>	(Institute for Health Research, Lancaster University)
<b>Chris Oliver</b>	(School of Psychology, University of Birmingham)



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**Tuesday 18 December**

*Session 4.* Chair: Steve Beyer

09.30 - 09.55	01-21 Beail	Brief Symptom Inventory
09.55 - 10.20	01-31 Oliver	Depression and SIB
10.20 - 10.45	01-25 Sequeria	Sexual abuse and psychological problems
10.45 - 11.10	01-22 Dagnan	Social-cognitive model for ID

11.10 - 11.30           COFFEE

*Session 5.* Chair: Dave Dagnan

11.30 - 11.55	01-14 Perry	Quality of life assessment
11.55 - 12.20	01-07 Felce	Active support training
12.20 - 12.45	01-24 Beyer	Supported employment

12.45 - 14.15           LUNCH (followed by discussion about future meetings)

*Session 6.* Chair: Biza Kroese

14.15 - 14.40	01-08 Carr	Auditory-visual exclusion in autism
14.40 - 15.05	01-17 Jones	Memory for spatial location
15.05 - 15.30	01-15 Dye	Capacity to consent to research

15.30 - 15.45   Closing remarks           Professor David Felce

15.45           CONFERENCE ENDS.

***NB. Numbers 01-XX are the numbers of abstracts in this book.***

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**Poster Presentations**

17.05 – 18.30 Monday 17 December

<b>Abstract Number</b>	<b>Presenter</b>	<b>Abbreviated Title</b>
01-01	Alexandra Beck	Mothers' expressed emotion toward children with LD
01-06	Corinna Grindle	Discrete trial training for children with autism
01-11	Gail Thomas	Students with MLD: Reactions to participating in sexuality research
01-12	John Rose	Evaluation of group treatment for men who sexually offend
01-19	Steve Noone	Attributional style in staff explanations about challenging behaviour
01-23	Dave McDowell	Carers' and service users' cognitive-emotional responses to challenging behaviours
01-28	Debbie Forman	Descriptive analysis of self-restraint and SIB
01-29	Jenny Sloneem	SIB in Cornelia de Lange syndrome
01-30	Kate Arron	Pro-social communicative behaviours in Cornelia de Lange syndrome
01-32	Michael Hearn	Social proximity and challenging behaviour

**01-01 Mothers' Expressed Emotion Towards Their Children With And Without Learning Disabilities.**

*Alexandra Beck* (University of Southampton)

Co authors: David Daley, Richard Hastings, Jim Stevenson

Objectives: To identify which factors may be associated with maternal expressed emotion (EE) towards their child with learning disabilities.

Design and Methods: 33 mothers who have a child with learning disabilities and at least one child without disabilities between the ages of 4 and 14 years participated in the study. Mothers completed self-assessment questionnaires which addressed their sense of parenting competence, beliefs about child-rearing practices and their reports of behavioural and emotional problems of their child with learning disabilities. Telephone interviews were conducted to assess maternal EE using the Five Minute Speech Sample (FMSS, Magana et al., 1986) and to assess the adaptive behaviour of the child with learning disabilities using the Vineland Adaptive Behaviour Scale (VABS, Sparrow, Balla & Cicchetti, 1984).

Results: Mothers with high EE towards their child with learning disabilities were more satisfied with their parenting ability, and their children had more behaviour problems. Analysis of differential maternal parenting, through comparisons of EE towards their two children, showed that mothers are more negative towards their child with learning disabilities for all domains of the FMSS except Dissatisfaction.

Conclusions: A small number of factors associated with maternal EE towards children with learning disabilities were identified. Differences in maternal EE towards their child with learning disabilities and their other child suggest that EE is child-driven rather than a stable maternal characteristic. Implications of the data for future research will be discussed.

**01-02 Frequent Aggression and Perspective Taking: A lack of Insight or The School of Hard Knocks?**

*Andrew Jahoda* (Glasgow University)

Co-authors: Carol Pert, Peter Trower

Objectives: This paper sets out to examine the assumption that cognitive deficits, such as a lack of perspective taking ability, result in difficulties with inter-personal understanding or problem solving, thereby making conflict and aggression more likely.

Design: This is a controlled study, examining the perspective taking abilities of aggressive and non-aggressive individuals. Forty three frequently aggressive individuals and 46 non-aggressive peers, with mild to moderate intellectual disabilities, were selected for participation from a survey of Day and Employment services.

Methods: Participants were shown sets of video scenes about an angry and a calm character. The characters were depicted facing situations: i) where there was provocation by protagonists, and ii) where it was unclear whether the protagonists were acting with hostile intent or not. Participants were asked to describe the emotions, behaviour and attributions of the characters in these situations.

Results: Role taking skills were analysed by determining the participants' ability to distinguish between the reactions of the characters, depicted as angry and calm. Both groups had some success recognising that the angry character would feel angrier and behave more aggressively than the calm character. However, only the aggressive participants thought that the angry character would be more likely to attribute hostile intent to the protagonists than the calm character.

Conclusions: These findings suggest that role-taking, and social understanding in general, cannot be assumed to be causal or maintaining factors of frequent aggression. This has practical implications for the assessment and treatment of aggression, which need to be based on more elaborate psychological models.

**01-03 Social Support Networks and Psychological Well-being of Mothers with Intellectual Disabilities**

*Biza Stenfert Kroese* (University of Birmingham)

Co-authors: Hannan Hussein, Clair Gifford, Nazia Ahmed

Objectives: To investigate the impact of social support networks of mothers with intellectual disabilities on their psychological well-being and their views of parenting.

Design: A sample of 15 mothers with intellectual disabilities were included in a study which used a descriptive as well as a correlational design.

Methods: Through semi-structured interview mothers were asked about the social support they received and the benefits, burdens and future expectations of parenthood. Qualitative measures of affect, assertiveness and self-esteem were also included.

Results: Significant associations were found between the number of reported social contacts and positive affect, the recency of reported social contacts and self-esteem, and lack of self-esteem and reported burdens of parenting.

Conclusions: Size and quality of social support networks do appear to be relevant to parental psychological well-being. Experiences of parenting are similar to parents who do not have intellectual disabilities.

**01-04 Factors Associated with the Physical and Mental Health of South Asian Carers of a Child with Severe Learning Disabilities**

*Chris Hatton* (Lancaster University)

Co-authors: Yasmeen Akram, Janet Robertson, Robina Shah, Eric Emerson

Objectives: This study aimed to describe the physical and mental health of South Asian carers of a child with severe learning disabilities, and investigate factors associated with carer physical and mental health.

Design: The study consisted of a quantitative cross-sectional survey of 136 South Asian carers, and a qualitative survey of 26 carers repeated at two time points.

Methods: For the qualitative study, Time 1 semi-structured interviews concerned various aspects of carers' lives. Time 2 semi-structured interviews fed back the researchers' interpretations of the earlier qualitative and quantitative data for verification. All interviews were audio-taped, translated and transcribed into English, and analysed. For the quantitative study, structured interviews were translated into Urdu, Hindi, Gujarati and Bengali. Information concerned family circumstances, child characteristics, child and carer social life, the disclosure process, formal and informal supports, family needs, carer coping strategies, future plans for the family, and carer physical and mental health.

Results: Very high rates of physical health problems, distress and mental health problems were reported by South Asian carers compared to general UK populations of South Asian adults or White parents of a child with learning disabilities. Using logistic regressions, anxiety and distress, but not depression, were associated with physical health problems. Carer physical health problems were also associated with struggles for family services. Carer depression was associated with restricted home leisure, carers not seeking social support and carers not having a collaborative relationship with professionals. Carer anxiety and distress were associated with greater unmet family needs, unsuitable housing and greater problems supervising the child. Qualitative findings from semi-structured interviews endorsed the quantitative findings.

Conclusions: The very high rates of physical and mental health problems amongst South Asian carers are a source of urgent concern. Interventions to improve carer health must involve comprehensive family support.

**01-05 Psychopathology in People with Epilepsy and Intellectual Disability: An Investigation of Potential Explanatory Variables**

*Colin Espie* (Glasgow University)

Co-authors: Jessamy Watkins, Lisa Curtice, Audrey Espie, Roderick Duncan, Jennifer Ryan, Martin Brodie, Mark Sterrick

Objectives: There are few studies on epilepsy and psychopathology in people with intellectual disability, despite epilepsy prevalence thirty times higher than the general population. To identify reliable, epilepsy-specific predictors of psychiatric and behavioural disorder, and reliable predictors of carer stress.

Design: Correlational.

Methods: A database of 685 was compiled from which 250 were randomly selected. Structured interviews on 186 (74%) [108 men, 78 women; mean age 35.5 (sd 10.1)] comprised descriptive, clinical and functional components and validated measures of psychopathology for which normative data were available. Logistic and linear regression was used to identify predictors.

Results: One-third satisfied criteria for possible psychiatric disorder, particularly affective/ neurotic disorder, twice normative rates for disability alone. Behavioural problems were lower than population norms. Half the carers reported significant stress. Regression models explaining modest amounts of variance ( $R^2 \leq 24\%$ ) suggested seizure phenomena as risk factors for psychiatric disorder. General disability contributed more to explaining behaviour. Medication side-effects predicted aberrant behaviour and contributed to carer stress.

Conclusions: Psychiatric disorder and behaviour should be considered separately because different factors are associated with predictive models in this population.

**01-06 Discrete-Trial Training for Autistic Children when Reward is Delayed: A Comparison of Conditioned Cue Value and Response Marking.**

*Corinna Grindle* (University of Southampton)

Co-author: Bob Remington

Objectives: Although classical conditioning is often thought to be the process through which the cue value of conditioned reinforcers is determined, animal research has shown that other processes may additionally be involved. For example, previous research has shown that a response-marking procedure, in which stimuli that contingently follow a choice response regardless of whether it is correct or incorrect, can facilitate the development of accurate performance when primary reinforcement is delayed. These findings cannot be easily explained by the cue value account of conditioned reinforcement. The aim of this research was to compare cue value and response marking procedures in the context of receptive labelling tasks with delayed reinforcement, using children with autism as participants.

Design: The effects of training receptive labels to 3 children with autism were compared across cue value and response marking procedures using an alternating treatments design.

Methods: In the cue value condition, a stimulus occurred immediately after correct responses and again when a reinforcer was delivered after a 5-s delay; in the response marking condition a second stimulus occurred after both correct and incorrect responses, but was not paired with a primary reinforcer.

Results: All three children acquired the first three receptive labels trained in the cue value condition faster than in the response marking condition. The mean trials to criterion in the value and marking conditions respectively were: Andrew: 72, 314; Steven: 109, 253; Claire: 72, 123. Given the strength of this effect, the procedure was modified so that the last three labels assigned to the response marking condition were taught using the value procedure. Under the revised procedure, mean trials to criterion of cue value and marking switched to value were very similar. Multiple probe data for each child showed that the acquisition of labelling was a function of the training procedure used. For every label in both conditions, correct responding was at chance level before training but at 100% after training. Taken together, the results indicated that participants can learn in both conditions but that acquisition is faster in the cue value condition (mean interobserver reliability: 98%).

Conclusions: Although the cue value condition was superior, acquisition still occurred in the response marking condition. The data suggests the possibility that the marking cue, may have an effect on acquisition over delayed reinforcement alone. Consequently, the development of response marking procedures may have important implications for future practice.

**01-07 Differential Response to Active Support Training: Evaluating the Impact of Individual Characteristics**

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*David Felce* (Welsh Centre for Learning Disabilities, Cardiff)

Co-authors: Clare Smith, Edwin Jones, Kathy Lowe

Objectives: The aim was to analyse the responsiveness of people with intellectual disabilities with different personal characteristics to the change in staff support arising from Active Support training.

Design: Active Support training was replicated in 38 community houses accommodating 106 participants (Group 1). In a further 36 houses accommodating 82 participants (Group 2), the activity planning element of Active Support training was conducted but the in situ training on how to provide effective assistance was omitted.

Methods: Staff:participant interaction and participant engagement in activity were observed before and after Active Support training. Change in Yule's Q statistics, indicating the likelihood that participant engagement in activity followed verbal instruction or non-verbal assistance from staff, were compared for the two groups. Changes were also compared for participants within Group 1: (a) with Adaptive Behaviour Scale scores above and below 180, and (b) with and without severe challenging behaviour, the triad of social impairments, and mental illness.

Results: Yule's Q for engagement given non-verbal assistance significantly increased post training among Group 1 but not among Group 2. Similar significant increases were found among Group 1 participants with ABS scores below 180, without challenging behaviour, with and without the triad of social impairments and without mental illness, but not with ABS scores above 180, with challenging behaviour or with mental illness.

Conclusions: Findings reinforce previous studies on the effectiveness of Active Support training for adults with more severe intellectual disabilities. Active Support is equally applicable to people with or without the triad of social impairments.

**01-08 Auditory-Visual Exclusion with Autistic Children: Exemplar Training, Transfer of Exclusion Responding and Improved Learning Outcomes with Undefined Nouns**

*Deborah Carr* (Welsh Centre for Learning Disabilities, Cardiff)

Objectives: 1. To investigate whether children with severe linguistic disabilities and autism demonstrated exclusion-based receptive vocabulary learning (i.e. fast mapping). 2. To determine whether exclusion-based learning with undefined words could be facilitated by multiple exemplar teaching, with children failing to demonstrate it in initial tests.

Design: The series of single-case studies with seven children used a multiple baseline design, in accordance with the current receptive vocabulary content and the preferred mode of representation (i.e. picture or object) for each child.

Methods: In the first study, seven children with autism and severe language disabilities participated. A set of 2 receptively defined and 8 receptively undefined items (pictures or objects) was identified for each child. An initial test for matching-to-sample by exclusion was administered by presenting each of four of the undefined items with each of the two defined items over a series of 40 exclusion trials (10 trials per item). In the second study, the six children who failed to demonstrate reliable exclusion-based learning received reinforced exclusion trials using the first four items, mixed in trial blocks with non-reinforced exclusion trials using the second four items. Learning outcome tests for vocabulary learning were given subsequent to the exclusion test.

Results: Five of the six children demonstrated reliable exclusion performances using a binomial test. Four of these children also demonstrated stable learning outcomes for receptive vocabulary with the tested items, subsequent to the exclusion test.

Conclusions: It was concluded that although performances varied from child to child, reinforced examples of exclusion with multiple exemplars minimised their errors with new undefined items in exclusion test and resulted in stable exclusion performances. This facilitated demonstration of stable learning outcomes in four of the children. Therefore it was concluded that a multiple exemplar method of teaching exclusion can be effective in teaching receptive vocabulary to children with autism and severe language disabilities.

**01-09 A Large-scale Study of the Significance of the Site of Self-injurious Behaviour in People with Learning Disabilities**

*Dougal Hare* (University of Manchester)

Co-authors: Julie Wisely, Louisa Fernandez-Ford, Kelsey Healy, Michelle Perkins, Jan Kilroy

Objectives: To examine the extent to which self-injurious behaviour (SIB) is significantly associated with specific bodily sites and whether there is a significant association between SIB and body sites associated with acupuncture analgesia (AA) to provide an indirect examination of the role endogenous opiates in SIB.

Design: Structured interviews with keyworkers were carried out in two learning disabilities services in cities in the UK to maximise numbers of participants and generalisability of research outcomes.

Methods: Data on 241 people with moderate to severe learning disabilities was collected, with data on the site of SIB being collated using a standard 2cm<sup>2</sup> body map grid procedure and classified as AA / non-AA site.

Results: 53 participants (22%) currently displayed SIB, with the number of sites of SIB per person varying 1 to 13. SIB sites were unevenly distributed across the body's surface area, with 20.8% corresponding wholly with AA sites, 41.5% corresponding with no AA and 37.75% corresponding with both AA and non-AA sites. The difference between the frequency of self - injury locations on AA and non AA sites was statistically significant at the .001 level.

Conclusions: Findings from the study confirm those of previous studies in that the SIB sites were found to be unevenly distributed over the body surface area with a significant correlation with AA sites, which cover less than 8% of the body surface area.

**01-10 Mothers of Children And Adolescents With Intellectual Disabilities: Social and Economic Situation, Mental Health Status and Self-Assessed Social and Psychological Impact of Child's Difficulties**

*Eric Emerson* (Lancaster University)

Objectives: To describe the social and economic situation and mental health status of mothers of children with intellectual disabilities. To identify variables associated with variation in the mental health status of mothers.

Design: Survey.

Methods: Secondary analysis of the 1999 ONS survey of the *Mental Health of Children and Adolescents in Great Britain*. This survey collected information on a multi-stage stratified random sample of 10,438 children between 5 and 15 years old across 475 postal code sectors in England, Scotland and Wales. Secondary analysis was undertaken of the social and economic circumstances and stress reported by 245 mothers of children with intellectual disabilities and a comparison group of 9,481 mothers of children who did not have intellectual disabilities. Children were identified as having intellectual disability on the basis of parental report, type of school attended and teacher report.

Results: On all indicators of socio-economic position families where the sampled child had intellectual disabilities were significantly more disadvantaged than families where the sampled child did not have intellectual disabilities. Logistic regression identified a number of direct associations between the assessed mental health status of the sampled child's mother and (1) indicators of socio-economic deprivation; (2) the number of potentially stressful life events experienced by the child (and presumably the family); (3) the mother's self-assessed social impact of the sampled child's difficulties; (4) family functioning; and (5) the gender of the sampled child.

Conclusions: The results highlight some of the social and economic adversities faced by mothers of children with intellectual disabilities. They also point to some variables that are associated with increased rates of psychological distress among mothers.

**01-11 An Investigation of Students' with Mild Learning Disabilities Reactions to Participating in Sexuality Research**

*Gail Thomas* (Services for Adults with Learning Disabilities, Telford)

Co-author: Biza Stenfert Kroese

Objectives: To investigate 35 students' with mild learning disabilities reactions to participating in a research project exploring their sexual knowledge, attitudes and behaviour.

Design: Observational study.

Methods: All students completed an informed consent procedure prior to their participation in the sexuality research project and were interviewed using a confidential interview procedure. Research interviewers observed participants' reactions during interviews. Researchers were provided with instructions for observing, recording, and responding to students' reactions. Students were aware their reactions would be observed, and it was explained that any signs of distress would result in interviewers checking that they still wished to continue. After the interviews, all students consented to discussing the experience of participation with their college tutor. They were made aware that their reactions would be fed back to researchers. Tutors met the students in private. Tutors were provided with instructions for post-interview discussions and asked to record their observations on an anonymised questionnaire.

Results: Researchers observed that although some students were embarrassed discussing certain sexual topics, none chose to stop their interviews when invited. Ten students requested additional information from researchers about the issues discussed. Tutors reported that no students were anxious or distressed following participation and no inappropriate sexualised behaviour or talk was observed. They also reported that several students appeared to have been positively affected by their participation. No tutors expressed concern about their students participating in similar research in the future.

Conclusions: A number of methodological and participant factors may have accounted for the positive outcomes reported. The implications of these findings and recommendations for future research are discussed.

**01-12 The Evaluation of a Group Treatment for Men who Sexually Offend or Abuse**

*John Rose* (University of Birmingham)

Co-authors: Rosemary Jenkins, Chris O'Connor, Catherine Jones

Objectives: This presentation describes an intervention and evaluation of a group for men with an Intellectual disability who have sexually offended or abused others.

Design: A simple pre, post assessment and follow up of participants. Unfortunately it was not possible to run a control group due to difficulties with recruitment.

Methods: A variety of assessments including: attitude towards offending, locus of control, sexual knowledge and victim empathy, were done with participants prior to the group, immediately after the group and at 3 and 6 month follow up.

Results: Attitudes consistent with offending reduced after participation for most participants however these tended to revert to pre group levels over time. Locus of control became more external and knowledge tended to increase after the group treatment. No further incidents of sexual abuse have been recorded by any of the five men who completed the sessions, since the start of the group (a period of one year to date).

Conclusions: This group should be seen as a pilot project. However, initial results are generally promising and further therapeutic work is indicated. The increase in locus of control scores is contrary to the result expected and is of some concern, non Intellectual disabled sex offenders frequently blame their offending on external circumstances. In this instance education about external consequences leading to a greater external locus of control may be an entirely appropriate outcome.

### **01-13 Anger Treatment for Offenders with Learning Disability: Results of a Controlled Study**

*John Taylor* (Northgate Hospital)

Objectives: Aggression is the primary reason for people with learning disabilities to be admitted or re-admitted to institutions. It is also the main reason for this client group to be prescribed anti-psychotic and behaviour control drugs. Anger is a significant predictor and activator of aggressive behaviour. There is some limited evidence for the value of cognitive-behavioural treatments for anger problems with people with intellectual disabilities. However, no controlled studies of anger treatment involving intellectually disabled offenders living in secure settings have been conducted to date.

Design and Methods: In this study 40 detained patients with intellectual disabilities and histories of offending were allocated to specially modified cognitive-behavioural anger treatment (AT group) or to routine care waiting-list control (RC group) conditions. Eighteen sessions of individual treatment were delivered over a period of 12 weeks. The AT and RC groups were assessed simultaneously at 4 time points: screen, pre- and post-treatment, and at 4-months follow-up (all before the AT group entered treatment). Assessment measures used included the State-Trait Anger Expression Inventory (Spielberger, 1996), the Novaco Anger Scale (Novaco, 1994), the Provocation Inventory (Novaco, 1988) and the Ward Anger Rating Scales (Novaco, 1994). The effectiveness of the treatment was evaluated by linear trend analyses of group differences on the main outcome measures using repeated measures mixed design ANOVAs.

Results: Patients' self-report of anger using several reliable and validated measures of anger was significantly lower following intervention in the treatment condition, compared to the wait-list condition. Limited evidence for the effectiveness of treatment was provided by staffs' ratings of patient behaviour post-treatment.

Conclusions: Detained offenders with intellectual disabilities can benefit from intensive individual cognitive-behavioural anger treatment. Further research is required to examine the mechanisms for change and their sustainability.

**01-14 Subjective and Objective Quality of Life Assessment: Responsiveness, Response Bias and Agreement Between the Responses of People Being Supported and Those of Staff Responding on Their Behalf**

*Jonathan Perry* (Welsh Centre for Learning Disabilities, Cardiff)

Co-author: David Felce

Objectives: Quality of life assessment should take account of objective life conditions and individuals' satisfaction with these conditions. However, subjective data is difficult to elicit from people who have low language ability and is susceptible to contamination from response bias. In cases of non-response or response bias, the substitution of the respondent with a person who responds on their behalf has been proposed as an alternative method of gathering subjective data. The objectives of this study were to investigate the characteristics of people with learning disabilities who were able to self-report without bias and those of people who exhibited response bias. It also aimed to investigate the extent to which the responses of people with learning disabilities correlated with those of people who responded on their behalf.

Method and Results: Structured interviews with a random sample of 154 people with mental retardation showed that around two thirds of respondents were either unable to respond or exhibited response bias. Ability to respond without bias correlated significantly with scores on the Adaptive Behavior Scale, a measure of ability. Concordance between individuals' responses and those of proxies was found to be low on a subjective measure and high on an objective scale.

Conclusions: The importance of facilitating the direct involvement people with learning disabilities in the quality assurance process is beyond doubt. However, it is equally important to exercise caution when interpreting or acting upon subjective data because of the distinct possibility of invalid results.

## **01-15 Capacity of People with Learning Disabilities to Consent to Take Part in a Research Study**

*Linda Dye* (Building Bridges, Liverpool)

Objectives: To examine the capacity of people with learning disabilities to consent to take part in a research study and the effect of different forms of information provision on this capacity.

Design: A questionnaire measure of participants' ability to consent to take part in this research study was administered individually to participants. The questionnaire was devised for this study, but closely modelled ability to consent measures used in previous research. It consisted of open and closed questions related to the various aspects of consent e.g. understanding of procedure, understanding of choices, understanding of consequences.

Methods: 102 participants with learning disabilities were selected from 3 day services for adults with learning disabilities. The consent information relevant to the study was presented to the participants, and their capacity assessed using a questionnaire. Three experimental conditions were used: Control (n = 34) -consent information was presented followed by the questionnaire. Section (n = 34) -consent information was broken into sections and the appropriate questions were asked following each section. Photograph (n = 34) -consent information was accompanied by 6 colour photographs, followed by the questionnaire. Participants also completed measures of memory ability, verbal ability and non-verbal problem solving ability.

Results: 17 participants withdrew from the study at some point. Of the remaining 85 participants, no significant differences in ability to consent scores were found between the experimental conditions. Using this measure only 5 participants (5.9%) were deemed able to consent, i.e. scored the minimum required on each aspect of consent. Participants' ability to consent scores were positively correlated with their scores on the psychometric measures of memory, verbal and problem solving ability.

Conclusions: This study proposes a measure to allow systematic assessment of participants' capacity to consent to take part in a research study. The small proportion of participants who were deemed able to consent challenges the validity and usefulness of the current dichotomous concept of consent.

**01-16 Behaviour Problems in Adult Women with Rett Syndrome**

*Richard Hastings* (University of Southampton)

Co-authors: Rebecca Mount, Sheen Reilly, Hilary Cass, Tony Charman

Objectives: Despite considerable interest in genetic, physical, and neurological aspects of Rett syndrome (RS), there have been few studies of associated behavioural and emotional features. Furthermore, few case studies or surveys have included adult women with RS. The main aim of the present study was to compare behaviour problems in a sample of RS women against data from normative samples.

Design: A cross-sectional survey was used.

Methods: Primary carers of 50 women with RS completed the Aberrant Behavior Checklist - Community version along with a demographic and medical history questionnaire.

Results: Women with RS were rated as having lower levels of irritability, hyperactivity and inappropriate speech behaviours than normative samples of adults with intellectual disabilities. No reliable correlates of behaviour problems in the sample were found.

Conclusions: A number of factors may affect the presentation of behaviour problems in women with RS (e.g., cognitive impairments, physical disabilities). Therefore, more research is needed in order to generate information about the behavioural phenotype of RS. The implications of the present data for future research are also discussed.

**01-17 Memory for Spatial Locations in People with Intellectual Disabilities**

*Robert Jones* (University of Wales, Bangor)

Co-author: Frances Vaughan

Objectives: Memory for spatial location has been investigated in several studies of people with intellectual disabilities. However, it is not clear that persons with intellectual disabilities possess the same spatial memory skills as their non-disabled peers as the results of previous research have been mixed. The objectives of the present study were to examine the hypothesis that, under the right conditions, people with intellectual disabilities could learn spatial information as well as their non-disabled peers.

Design: The design corresponded to a 2 (disabled vs non-disabled) x 2 (intentional vs. incidental learning) factor design. Both factors were between-participants

Methods: We compared thirty persons with intellectual disabilities with thirty non-disabled individuals. Following either intentional or incidental learning, participants recalled and then re-located sixteen objects on a matrix.

Results: The non-disabled participants recalled more intentionally learned material than incidentally learned material. The persons with intellectual disabilities performed both tasks better after incidental learning than after intentional learning, and scored as highly as the controls on incidental spatial memory.

Conclusions: The results support the suggestion that memory for spatial location is an automatic process and, to some extent at least, is not directly affected by the individual's level of intelligence. The results also confirm that, under specific conditions, persons with intellectual disability are able to learn new material as well as their non-disabled peers.

**01-18 Headteacher Perspectives on the Reasons Pupils Presenting Behavioural Challenges are Permanently Excluded from Special Schools for Children with Severe Learning Difficulties**

*Roger Norgate* (Hampshire Educational Psychology Service)

Objectives: This study sought to determine: 1. How many pupils are excluded from SLD schools? 2. What factors prompt headteachers to decide a pupil should cease to attend? 3. Why permanent exclusion is used?

Design: A mixed-method (qualitative/quantitative) design was used. This involved a postal survey and semi-structured interviews with headteachers (to determine how variables actually present in the life of the school). This presentation will focus on the survey findings.

Methods: A questionnaire went to all SLD schools in England and obtained a 72% response. Returns were subjected to a factor analysis and the relationship between exclusion and other variables was explored.

Results: Approximately 25 pupils are excluded from SLD schools each year. The diversity of need currently being met within SLD schools, was perceived to increase the difficulties in managing behavioural challenges. The analysis identified three main factors associated with exclusion: Physical protection of staff and pupils; Staff confidence; Breaking deadlocks perceived to inhibit behaviour change. This was linked to whether consistency of approach could be achieved and whether such needs might be better met elsewhere. Permanent exclusion was typically prompted by an unanticipated increase in the level of challenge, administrative procrastination and parental opposition to a residential school placement.

Conclusions: LEAs need to be clearer about the role of special schools, the type of need that can be met locally and those needs which require alternative provision. Local authorities need to develop a corporate approach to funding residential placement and providing local support services.

## 01-19 Investigation into the Concept of Attributional Style in Staff Explanations About Challenging Behaviour

*Steve Noone* (University of Wales, Bangor)

Objectives: The present study investigates whether care staff use an attributional style when explaining challenging behaviour. A common paradigm in a number of recent studies have involved presenting participants with a scenario of challenging behaviour together with an adapted version of the Attributional Style Questionnaire to measure the staff explain behaviour. This makes the assumption that participants will draw upon some form of style of explaining challenging behaviour. The present study investigates whether staff use the same attributions to explain challenging behaviour of similar topography by different residents. A second part of the study investigates how the same group of staff explain the same topography of behaviour shown on a specially made video using actors, to depict the build up of aggressive behaviour by a resident towards two staff members. The hypothesis that care staff possess a style in explaining challenging behaviour would predict that staff would use the same kind of explanations for the same topography of behaviour.

Design: A within-participant design was used to test this prediction. The sample was taken from a large hospital for people with learning disabilities and all participants had personal knowledge and direct care experience of two residents who both presented with similar challenging behaviour. The behaviour was similar in topography but differed in function.

Methods: 23 care staff completed an adapted version of the Attributional Style Questionnaire ASQ for two known clients, who both presented with aggressive behaviour. Each participant was also shown a video role play that depicted an example of aggression by a resident behaviour and asked to complete an ASQ for what they had witnessed

Results: Differences were found in some of the attributional dimensions between the known clients and between the known clients and the invented scenario.

Conclusions: The results challenge the assumption that care staff maintain a style about the cause of specific topographies of challenging behaviour. There is evidence to suggest that staff form explanations about individual clients based on their own experience. Furthermore any attempt to understand staff explanation within a paradigm that assumes some form of style of thinking may be ultimately be flawed.

**01-20 Looking Forwards and Back at the Same Time: the Shifting Perspectives of Mothers During the Middle Years of Parenting**

*Stuart Todd* (Welsh Centre for Learning Disabilities, Cardiff)

Objectives: This paper explores the changes taking place in the lives of mothers of people with learning disabilities during the transitional years. It is based upon a view that although research suggests that the transitional years are critical ones, our understanding of these years is partial and one-sided. That is, it is restricted to the changes taking place in the lives of young people with learning disabilities. This paper examines the lives of mothers during these years and seeks to explore, through narrative analysis, their life changes and the impact of these upon self-identity.

Methods: In-depth interviews were held with 38 mothers of adolescent children with learning disabilities. Interviews were taped and transcribed. Data were analysed using an inductive iterative process.

Results: In the early years of parenting mothers viewed their lives as having much in common with those of mothers more generally. However, the transitional years usher in a series of events which alter this perspective. The results describe and locate these events, and mothers' interpretations of them within a biographical context.

Conclusions: The transitional years are as critical for mothers as they are for young people with learning disabilities. It is during these years that they become the mothers of disabled children in as much as they adopt a different perspective of their lives. The research reveals the value and strength of narratives to reveal some of the personal, temporal and cultural struggles associated with being the parent of a child with learning disabilities. The paper argues for the need for support which is biographically sensitive.

**01-21 The Reliability and Validity of the Brief Symptom Inventory for People with Mild Intellectual Disabilities**

*Nigel Beail* (Psychological Health Care, Barnsley)

Co-author: David Newman

Objectives: To evaluate the utility of the Brief Symptom Inventory (BSI) to reliably index psychological distress in people with intellectual disabilities.

Design: Reliability analyses were performed on the nine symptom scales of the BSI completed with 200 adults with mild intellectual disabilities. Further analyses of discriminative validity were then carried out.

Methods: Two hundred participants with mild intellectual disabilities were administered the BSI in an assisted completion format. This involves administration in an interview where wording can be modified and using modified response sheets containing three formats: pictorial, numerical, and using words. Participants were recruited from community, clinical and forensic groups.

Results: The Brief Symptom Inventory's nine symptom scales were found to have comparable reliability coefficients to those reported for non disabled groups using a self-completion format. High discriminative validity was also found between clinical and community groups. Despite this however, a concerning level of psychological distress was detected in community participants.

Conclusions: The BSI was found to have good reliability and validity. The measure when used in an assisted completion format may assist in the assessment of psychological distress. The use of the BSI as an outcome measure in treatment evaluations was endorsed.

**01-22 Stigma, Self-Evaluation and Social Comparison: Evaluating a Social-Cognitive Model for People with Learning Disabilities**

*Dave Dagnan* (West Cumberland Hospital)

Co-authors: Martina Wearing, Erica Clayton

Objectives: This paper describes a model that integrates the social experiences of people with learning disabilities with a cognitive model of psychological distress. The model identifies that people with learning disabilities experience negative social construction and/or structural discrimination as stigma. Constructional social models do not often consider the psychological impact of such processes; indeed some social models would reject psychological explanation as incorrectly identifying the cause of disability as within the person. Here we present a model that suggests that continued exposure to stigmatisation affects core self-evaluations, which in turn affects active social comparison and subsequent emotional experience. In this paper we present data that tests the core process linking the perception of stigma to social comparison via the mediating role of self-evaluation.

Design: The study has a cross sectional design.

Methods: Thirty-nine adults with learning disabilities completed adapted measures of perceived stigma, evaluative beliefs, self-esteem and social comparison. Analysis used a regression approach to explore the mediating function of self-evaluation in the relationship between stigma, self-esteem and social comparison.

Results: Participants who are more aware of being stigmatised are more likely to have negative evaluative beliefs, low self-esteem and to engage in negative social comparisons. The relationship between perceived stigma and social comparison, and perceived stigma and self-esteem was mediated by self-evaluative beliefs

Conclusions: Self-evaluations have a fundamental role in mediating the effect the experience of stigma on cognitive processes such as self-esteem and social comparison. The model describes the impact of social experience on cognitive processes and thus encourages formulations that suggest parallel interventions in social and cognitive domains.

**01-23 A Comparison of the Cognitive-Emotional Responses of Carers and Service Users to People with Learning Disabilities and Challenging Behaviour**

*David McDowell* (West Cumberland Hospital)

Co-author: Dave Dagnan

Objectives: To compare the cognitive-emotional responses of carers and service users to the challenging behaviour of people with learning disabilities.

Design: A between groups analysis of self-report data.

Methods: Participants were 23 day-service carers and 34 people with learning disabilities who attend day-services. Three examples of challenging behaviour were presented to participants (self injury, stereotypy and physical aggression) who were asked to give a probable cause and to rate the cause on attributions of internality; stability; globality and controllability; their emotional response to the behaviour; their optimism for potential change in challenging behaviour; and their willingness to put extra effort into changing the behaviour. Participants were also asked to suggest likely interventions for these behaviours.

Results: Service users were more likely than carers to attribute a higher level of internality to challenging behaviour; whereas staff attributed a higher level of controllability to challenging behaviour. Carers reported generally higher levels of happiness, were more optimistic for change and more willing to put effort into helping than service users. Carers made more external and specific attributions for physical aggression and self-injury than for stereotypy. Carers were angrier about aggression than other behaviours, happier and less sad about stereotypy than other behaviours, and more frightened about physical aggression and self-injury. Carers were less optimistic and less willing to put effort into helping in response to stereotypic behaviour. People with learning disabilities discriminated between behaviours less than carers, however they were more frightened and sad in response to physical aggression and self-injury than to stereotypy. Both carers and people with learning disabilities use the same categories to describe the causes of challenging behaviour and to discuss potential interventions.

Conclusions: This study highlights the differences in the way carers and people with learning disabilities understand and feel about challenging behaviour. The findings inform discussion of the impacts of living and working with people with learning disabilities who challenge.

**01-24 The Cost:Effectiveness of Supported Employment for People with Multiple Disabilities**

*Stephen Beyer* (Welsh Centre for Learning Disabilities, Cardiff)

Co-authors: Julia Shearn, James Thomas

Objectives: A project was set up to deliver paid employment for a number of learning disabled adults with high support needs among the last to be resettled from a long-stay hospital between July 1998 and July 2000. The project worked with 7 people, 4 of who obtained jobs. The study evaluated whether percentage of time observed engaged in meaningful activity; challenging behaviour; task assistance; and social contact, were greater through supported employment, and whether greater outcomes per unit cost were achieved, than through alternative day activities.

Design: A group comparison design with matched controls was used. Ten hours observations were taken for people referred to the project and matched controls, before employment was found, when first in employment, and after 3 months

Methods: Engagement was recorded continuously during observation sessions and using Psion palm top computers. Percentage engagement levels were divided by the hourly cost of supporting the person, to produce a cost:effectiveness measure.

Results: Employment provided higher levels of engagement in 9 out of 11 engagement areas when compared to the control group. Engagement was higher in employment than day activities in total non-social engagement by a factor of 3; in total assistance by a factor of 5; and was lower for challenging behaviour and "Other" engagement. Employment had higher social, non-social engagement, and unpaid assistance, and lower interaction with other clients, than controls. Average cost per hour of employment was double that of day activity for the control group. Engagement outcomes per £1 of support for employment were 2 to 6 times more effective than day activity in non-social engagement, interaction with the public, assistance and unpaid assistance from co-workers or supervisors.

Conclusions: Complex needs are a barrier to employment, but should not exclude people from employment. Supported Employment can be cost effective in delivering key outcomes. Positive planning, effective joint working can provide the platform for safe and effective job placement. Employers are supportive, but risk assessment procedures and an agreed approach to disclosure of information is required. The cost:effectiveness approach does appear to offer a way of comparing services on a level playing field.

**01-25 Psychological Disturbance in Sexual Abuse Survivors who have Intellectual Disabilities: A Controlled Study**

*Heather Sequeira* (St Georges Hospital Medical School)

Objective: To identify the psychological sequelae to sexual abuse in people with intellectual disabilities. Hypothesis: A group of adults with intellectual disabilities who have experienced sexual abuse will score significantly higher on specific measures of aberrant behaviour, PTSD and symptoms of psychopathology compared with a comparison group who are not known to have experienced sexual abuse.

Design: The study employed a matched pairs design (matched on degree of ID, sex, development of speech and age). This design was employed to reduce the possible confounding effects of the variables stated. Samples were selected from a non-referral population of adults living in the community to reduce potential sampling bias. Formal assessments were used to document symptomatology in a systematic and reliable way.

Methods: Mental health needs and behavioural disturbance were compared in 54 matched pairs who were known or not known to have experienced abuse. Known abuse cases were selected if they met with the criteria for Proven / highly probable sexual abuse or Probable sexual abuse, (Brown & Turk, 1992). Unsubstantiated cases were excluded. Individuals were examined by means of a structured interview (PASADD-10 respondent and informant interviews), the Aberrant Behaviour Checklist (ABC), the sexual behaviour domain (ABS:RC2) and trauma symptom measures.

Results: Higher depression and anxiety symptoms scores were reported in the sexually abused group compared with the non-abused group. In addition, significantly higher levels of disturbed behaviour such as self-injury and inappropriate masturbation were identified using validated measures. Appropriate statistical methods were applied to address the hypothesis stated.

Conclusions: Although a causal relationship between sexual abuse and psychological disturbance remains inconclusive, the findings suggest that survivors of sexual abuse are more symptomatic than their non-abused counterparts. No other controlled studies are known to have addressed this question, yet intellectual disability professionals are frequently presented with clients who have experienced sexual abuse. It is not sufficient to apply the established findings from child abuse literature, as factors associated with cognitive impairment will undoubtedly mediate the impact of sexual trauma. This represents an important area for continuing research.

**01-27 When do Judges Intervene to Help People with Intellectual Disabilities?**

*Caitriona O'Kelly* (University of Birmingham)

Co-authors: Mark Kebbell, Chris Hatton, Shane Johnson

Objectives: This paper aims to outline how Judges control court cases involving witnesses with intellectual disabilities and witnesses from the general population.

Design: Court transcripts were obtained from a total of 32 witnesses, 16 from people with intellectual disabilities and 16 people from the general population.

Methods: Each intervention made by a Judge was documented and coded into one of three categories: interactions with witnesses, interactions with counsel and interactions with the jury.

Results: The most frequent interventions concerned clarifying an issue with the witness, questioning counsel to clarify a witness's comments and difficulty hearing the witness. No significant differences were found between the Judge's interactions with witnesses with intellectual disabilities and those from the general population, indicating that the needs of witnesses with intellectual disabilities was not being taken into account

Conclusions: The implications of this work are that both Judges and lawyers need advice concerning the strengths and vulnerabilities of witnesses with intellectual disabilities to ensure fair and appropriate questioning. Judges have a crucial role in ensuring that fair examination of witnesses in general occurs but this role is particularly important for witnesses with intellectual disabilities.

**01-28 On the Relationship Between Self-injurious Behaviour and Self-restraint**

*Debbie Forman* (University of Birmingham)

Co-authors: Chris Oliver, Scott Hall

Full abstract to be available at conference.

**01-29 Multiple Topographies of Self-injurious Behaviours in Individuals with Cornelia de Lange Syndrome: the Influence of Environmental Events.**

*Jenny Sloneem* (University of Birmingham)

Co-authors: Kate Arron, Scott Hall, Chris Oliver

Objectives: Self-injurious behaviour (SIB) is commonly reported to be part of the behavioural phenotype of individuals with Cornelia de Lange syndrome (CdLS). Few studies, however, have investigated the environmental factors which may maintain these behaviours. The present study aims to investigate the influence of social interaction on the exhibition of such behaviour.

Design: 32 individuals diagnosed with CdLS were reported by teachers or carers to have engaged in self injury in the month prior to interview (mean age 15.5 years, mean Vineland Adaptive Behaviour Scale standard score 27.3). Each participant was observed for approximately four in his/her typical day care setting.

Methods: Different topographies of self-injury were carefully coded, as well as the environmental events of interaction (verbal and/or physical interaction with staff and peers) and non-interaction. Inter-observer reliability was collected for at least 20% of the video recordings for each participant. Kappa values were calculated and ranged from 0.61 – 0.81. Unconditional probabilities were calculated together with conditional probabilities of the behaviours occurring given the environmental events (Lerman & Iwata, 1993) and the Yule's Q statistic was used to determine the strength of the association between the injurious behaviours and environmental events.

Results: Results suggested that 85% of the self-injurious behaviours exhibited by participants were unrelated to environmental events whereas 15% of the topographies analysed appeared to be associated with interaction or non-interaction.

Conclusions: These findings indicate that specific topographies of SIB in some individuals with CdLS may have a social function and suggest therefore that SIB may not be determined simply by abnormal neuroanatomy. Further analysis, will determine the nature of the function. The data also support the need for an analysis of separate topographies of SIB when conducting functional assessments.

**01-30 Investigating the Expression of Pro-social Communicative and Challenging Behaviours in Children with Cornelia de Lange Syndrome**

*Kate Arron* (University of Birmingham)

Co-authors: Chris Oliver, Scott Hall, Jenny Sloneem

Objectives: Few studies have examined the effect of antecedent attention on problem and communicative behaviours. Individuals with Cornelia de Lange Syndrome are known for their apparent disinterest in social interaction and physical contact. In this study, the effect of antecedent attention on communicative and challenging behaviour in children with Cornelia de Lange Syndrome was examined.

Design: The participants were exposed to two analogue conditions in which levels of social contact were systematically manipulated using a reversal design. All analogue sessions were videotaped and specific communicative and problem behaviours were operationally defined and coded using a real time data capture system.

Methods: Recruitment took place at a Cornelia de Lange Syndrome Foundation Family Conference. Posters and information sheets were presented to all families who registered at the conference. Participants were sixteen children (nine male, seven female) diagnosed with Cornelia de Lange Syndrome. Participants were aged 1.67 – 16.08 years ( $M = 7.61$ ,  $SD = 3.68$ ).

Results and Conclusions: Inter-observer reliability was calculated on a 10-second interval by interval basis and Cohen's Kappa was satisfactory for all codes. Results indicated that, contrary to expectations, individuals with CdLS exhibited a number of pro-social communicative behaviours in order to elicit social interaction from others. Both challenging and communicative behaviours showed variation in levels of expression with the degree of social contact.

**01-31 The Association Between Depression and Self-injurious Behaviour in People with Severe Intellectual Disability**

*Chris Oliver* (University of Birmingham)

Co-author: Elaine Ross

Objective: Research into affective disorders in adults with severe intellectual disability suggests that “atypical symptoms” of depression, such as self-injury, aggression and irritability, might be included in diagnostic criteria. However, studies assessing an association between depression and atypical symptoms evidence threats to validity, primarily due to measurement and design issues. In this study an informant based measure of mood, interest and pleasure (MIPQ) was developed and the association between low mood and atypical symptomatology was assessed.

Design and Methods: A 25 item scale with two subscales (Mood; Interest and Pleasure) was developed. Test-retest, inter-rater reliability and internal consistency indices were all good. The total score was also significantly correlated with the Lethargy and Social Withdrawal subscale of the ABC ( $r(48)=-.59, p<.001$ ). From a pool of 53 non or partly verbal participants the 12 highest and lowest scorers on the MIPQ were compared on the Challenging Behaviour Interview to establish rates of atypical symptoms.

Results: The two groups showed no difference in terms of self-injury, aggression and disrupting the environment. However, a secondary analysis indicated that participants who showed challenging behaviour scored significantly lower on the MIPQ than a comparison group ( $t(21)=2.87, p<.01$ ).

Conclusions: The preliminary analysis of the psychometric properties of the MIPQ is encouraging and the potential utility of the measure might extend beyond the appraisal of depression. There was no evidence that ‘atypical symptoms’ were more prevalent when low mood was reported. However, those showing challenging behaviour did evidence lower mood. These results are discussed with reference to the appraisal of depression, the possible links between low mood and self-injury and the potentially confounding variable of autistic spectrum disorders in this area of research.

**01-32 The Effects of Social Proximity on the High Frequency Challenging Behaviour of a Boy with a Severe Learning Disability**

*Michael Hearn* (University of Birmingham)

Co-authors: Scott Hall, Chris Oliver

Objectives: To examine the effect of the absence of social proximity of the participants on challenging behaviour. To present data which suggest strong evocative effects on challenging and communicative responses by the participant, occasioned by his mother withdrawing from view. To consider how these data might be informative for the interpretation of data derived from analogue approaches (particularly with reference to the test for automatic reinforcement).

Design: Single-case study, using naturalistic observations.

Methods: Eleven hours of video recording were undertaken in the participant's family home. The tapes were previewed to identify 1) topographies of challenging responses, 2) communicative responses and 3) environmental variables. The material was then coded using real-time observational software. Acceptable inter-observer agreement was attained.

Results: During the periods when the participant's mother was absent, there was an associated increase in the likelihood of challenging responses and particular communicative responses (indicated by a measure of association, Yule's Q). Similarly, challenging responses and interactions were positively associated, suggesting a social positive reinforcement hypothesis. However, lag analysis indicated that at the point in time when the participant's mother left the room, there was a burst in both challenging responses and a vocal communicative response (that would usually be associated with positive reinforcement).

Conclusions: The results can be discussed in the light of data derived from analogue assessments. That is, given a finding that challenging behaviour is positively socially reinforced, could it be that an increased rate of responding during the 'alone' condition is related to responding maintained by a thin schedule of positive reinforcement, rather than automatic reinforcement?

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