Clinical psychologists' attitudes towards the biology and "new genetics" of intellectual and developmental disabilities: A Q-methodology study

Dougal Julian Hare
Catherine Vahey
Samantha Walker
Anja Wittkowski

Correspondence address: Dr Dougal Julian Hare, School of Psychological Sciences, Zochonis Building, University of Manchester, Brunswick Street, Manchester M13 9PL, UK (dougal.hare@manchester.ac.uk) Tel. +44 (0)161 3060400

Introduction

Recent work in molecular genetics, the so-called "New Genetics" has advanced the biological bases of intellectual and developmental disorder syndromes (Ellison, Rosenfeld, & Shaffer, 2013). A range of techniques including molecular cytogenetics (Muir, 2000), fluorescent in situ hybridisation (as used to identify the micro-deletion on chromosome 15q11-q13 in Prader-Willi syndrome), comparative genomic hybridization and transgenic animal models (Muir 2000; Shaw-Smith, Redon, Rickman, Rio, Willatt, Fiegler et al., 2004; Slavotinek, 2008; Malan et al., 2009). As a consequence of these technological advances, a range of new concepts to explain genetic aetiology have been developed, including, expanding mutations, uni-parental disomy and genomic imprinting (Muir, 2000). The latter process, where one inherited gene from either parent in a gene pair is repressed or inactive through an epigenetic mechanism, has been found to underpin the related Prader-Willi and Angelman syndromes (Nichols & Knepper 2001). In the former, a micro-deletion on chromosome 15 occurs on the paternally inherited gene in the gene pair, while in the latter a micro-deletion on the same chromosome pair but on the maternally inherited gene occurs. Similarly, dynamic or expanding mutation was first identified in fragile X syndrome (Verkerk et al., 1991) and then in other conditions such as Friedreich's ataxia (Sakamoto, Ohshima, Montermini, Pandolfo & Wells, 2001). As current genetic technology also allows for the identification and elucidation of many new syndromes the proportion of unknown aetiology in IDD continues to reduce. Also genetic causes of mild and moderate IDD can be identified whereas traditionally this degree of IDD was thought to have an environmental cause (Gostason, Wahlstrom, Johannisson & Holmqvist, 1991; Matalainen, Airaksinen, Mononen, Launiala & Kaarianen, 1995; Rutter, Sinonoff & Plomin, 1996). These identifications are supported by research on *de novo* mutations, where neither parent possesses or transmits the mutation leading to an IDD (Vissers et al., 2010; Veltman & Brunner, 2012; Ellison et al., 2013).

The identification of specific genetic aetiology (i.e. genotype) facilitates the mapping of the corresponding behavioural phenotypes (Nyhan, 1972; Dykens, Hodapp & Finucane, 2000). Dykens (1995) proposed a probabilistic definition of behavioural phenotype, in which a behaviour reliably occurring in most cases of a syndrome can be considered part of the behavioural phenotype. The science of behavioural phenotyping has grown exponentially with the growth of the genetic technologies (Oliver & Hagerman, 2007), with behavioural phenotypes being regarded as information giving devices that explain why a syndrome has occurred, how it will affect development and explain associated problematic behaviours. Tunnicliffe and Oliver (2011) showed that such syndromic behaviour is influenced by the environment and that phenotypic behaviour can be subject to change via environmental adjustments. Hence, syndromic behaviour is operantly reinforced by the environment and that early intervention, including provision of information to services regarding the phenotype, can improve quality of life and challenge deterministic views of diagnoses. Understanding behavioural phenotypes also facilitates the development of tailored interventions (Courtenay, Soni, Strydom & Turk, 2009). Two well documented examples of this are self-injurious behaviour in intellectual disabilities (Oliver & Richards, 2010) and early-onset dementia in people with Down syndrome (Kozma, 2008). For professionals working with people with IDDs, engaging with a known behavioural phenotype has the potential to inform the design and planning of interventions and thus genetic research may have significant potential to affect the lives of people with IDDs for the good.

People with IDDs, their parents and wider family members welcome greater understanding of the genetics of the diagnosed behavioural syndrome (Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005; Statham, Ponder, Richards, Hallowell, & Raymond, 2010; Costain, Chow, Ray, & Bassett, 2012; Trottier et al., 2013). In particular, parent support groups are a key driving force in behavioural phenotyping research (Harris, 2010) and an important connecting link between the two previously described professional cultures in IDD (Finucane, Haas-Givler & Simon, 2003). A diagnosis is thought to result in greater understanding and perceived control by providing a probable trajectory for the condition and to facilitate access to services and better managed care (Klein-Tasman, Gallo, Phillips, & Fine, 2008; Lopez-Rangel, Mickelson, & Lewis, 2008; Costain et al, 2012; Trottier et al., 2013). A diagnosis of a behavioural syndrome can also help to alleviate parent guilt and for an adult with an IDD, a diagnosis can be validating of difficulties experienced due to the diagnosis (Costain et al, 2012; Trottier et al., 2013). However, behavioural phenotyping has signalled to some a re-emergence of the medical model of disability, which affects the integration of such research findings into clinical practice (Kuna, 2001). Many professional groups, including clinical psychologists, adhere to and have been trained within a generic social model of disability, which also informs recent service provision and policies for people with IDDs (Valuing People 2001, 2009).

Clinical psychology initially gained a foothold in services for people with IDD through its success with IQ testing that primarily served to further the segregation of people with IDDs but via the subsequent application of behaviourist approaches, clinical psychologists developed a more positive relationship with people with IDDs. As a result, clinical psychology in the last century progressed from its subservient relationship with psychiatry to a position of relative professional independence largely through adopting both behaviourism and the social model of disability. If recent advances in the genetics of IDD are to be effectively applied, the support of clinical professionals, such as clinical psychologists, is essential, a process that would be facilitated by understanding the views and opinions of such professional groups on this topic.

When little is known about a topic an exploratory research method is indicated. The topic of this study, clinical psychologists' attitudes to research developments in genetics is little understood with no previous research available. Q methodology, the systematic study of subjective opinions, attitudes and beliefs (Stephenson, 1935; Brown, 1993), is recommended for exploratory research and research that seeks to understand subjectivity (Wigger & Mrtek, 1994; Thomas & Watson, 2002; Watts & Stenner, 2005). The decision to use Q methodology over more traditional exploratory research approaches such as interviews and subsequent qualitative analysis was based on the aim of delineating the multiple viewpoints that clinical psychologists might be expected to hold regarding genetic research in IDD . Q methodology has been used to successfully assess staff attitudes (Dick, Gleeson, Johnstone, & Weston, 2010; Westbrook, McIntosh, Sheldrick, Surr, & Hare, 2013; Wastell et al., 2014) and has been recommended by the National Institute of Health and Clinical Excellence (NICE, 2004) to assess staff attitudes in relation to certain topics.

The initial stage of a Q methodology study is to define the topic of interest and gather the existent views held about it; in Q terminology this is termed the Q-concourse. The Q-concourse then forms the Q-set or Q-sample, which are a list of items representing all the varying viewpoints. Participants whose views are sought regarding the topic of interest (the P-set or P-sample) are asked to sort the items according to a specific condition of instruction in a process called Q-sorting. A Q-sort entails the participant sorting and ranking the items according to their level of agreement or disagreement with them (Brown, 1996). The individual participant Q-sorts are correlated and factor analysed and the emerging factors interpreted to understand the overall group's views as well as their similarities and differences (van Exel & de Graaf, 2005).

Method

An initial Q concourse developed by the researchers using a hybrid method of interviews and items drawn from relevant literature relating to behavioural genetics, phenotyping and genetic screening with regard to IDD. Relevant literature included books and journals that were reviewed to identify themes of the impact of genetics on development, impact of environment on development, use of genetic screening or testing, impact of receiving a behavioural diagnosis, use of behavioural phenotyping and developments in ID services. The principal researcher (CV) extracted material that could be construed as opinion items about research and theory on these themes. This was supplemented by four informal interviews with experienced clinical psychologists working in ID services who discussed the aforementioned themes in an open-ended style ("*What are your thoughts and views on genetic screening?*").

A Q-set representing the identified themes was then developed (van Exel & de Graaf, 2005) and reviewed by the principal researcher (CV) and supervisor (DJH). This resulted in a preliminary organisation of the items under six emerging themes of *Intelligence/intellectual functioning, Genes [nature] versus environment [nurture], Diagnosis of IDDs arguments for and against, Diagnosis and service provision/intervention for people with IDDs, Services and implementation of research* and *Socio-political influences on spread of genetics research*. Following a final scrutiny and review of the Q-set to remove identical or overlapping items and to ensure that all items were similarly phrased to increase the cohesion of the Q-set (Donner, 2001), a Q-set of 81 items grouped as above was developed in line with the recommended Q-set size of 40-90 items (Dennis, 1986; Kerlinger, 1986). Following a pilot Q-sort with four final year trainee clinical psychologists (3 female, 1 male) 16 items were re-worded or re-phrased. A forced choice quasi-normal ranking of the Q-set items was used in line with recommended practice (Prasad, 2001; Cross, 2005) and previous studies (Wastell et al., 2014). The study was peer-reviewed by the Division of Clinical Psychology Research Sub-Committee and approved by the University of Manchester Research Ethics Committee.

Participants

Qualified clinical psychologists working in ID service and trainee clinical psychologists completing or who had completed an ID training placement no more than 12 months prior to the study were eligible to participate As Q methodology studies relate to participant views rather than comparing the representativeness of participant character traits to a specific population, a large sample is not required (Smith, 2001), with participants selected based on their relevance to the study's aims rather than on whether they are representative of a wider population (Chinnis, Debra & Stephen, 2001; Cordingley,

Webb, & Hillier, 1997). A ratio of one participant per three items is recommended (Webler, Danielson & Tuler, 2007) and 27-30 participants were considered sufficient for the present study using an 81 item Q-set. Participants were instructed to sort the Q-set items according to the following condition of instruction (Cordingley et al., 1997): "*To what extent do you agree or disagree with the viewpoint expressed in each item?"* The initial sorting involved placing sorting items into *agree*, *disagree* or *neutral* category, with a re-sorting of the items on a 7 point scale from -4 to +4. Within the forced-choice quasi-normal sorting, participants were restricted to four item choices for columns +4 and -4, six item choices for columns +3 and -3, 10 item choices for columns +2 and -2, 13 item choices for columns +1 and -1 and 15 item choices for column 0 Upon completion participants were asked to reflect on their experience of the Q-sort process and to give a reason for each item choice made in the -4 and +4 columns.

Results

A total of 47 Q-sorts were completed by 31 qualified clinical psychologists (11 female, 4 male) and 16 trainee clinical psychologists (14 female, 2 male) and analysed using PQMethod 2.33 (Schmolck & Atkinson, 2012), PQMethod inverts traditional factor analysis by representing participants in columns and the items represented in rows. A correlation matrix is produced that correlates each participant's Q-sort with all the other Q-sorts available in the study and demonstrates how similar or dissimilar pairs of participant Q-sorts are. The data were subject to principal components analysis with a varimax rotation and the extracted factors were interpreted in conjunction with 'exemplar' participants' qualitative feedback regarding the items placed in the extremes of their quasi-normal distribution score grid, 'exemplar' participants being those whose Q-sorts loaded strongly on to a factor. The principal components analysis initially yielded eight factors, but only factors with an Eigen value > 1 were returned, resulting in a three factor solution, which was then subjected to varimax rotation. Factor 1 (N=14 participants) accounted for 32% of the total variance, with Factors 2 (N=12 participants) and 3 (N=1 participant) accounting for 26% and 7% of the variance respectively. The four participants who failed to load significantly on to any factor had mixed loadings (i.e. very similar scores on more than one factor). Participants who were significantly associated with a given factor were assumed to share a viewpoint (McKeown & Thomas, 1988). In Q methodology an item is considered distinguishing for a factor if there is a statistically significant difference between its score on the factor and its scores on other factors and an item is considered a consensus item if it does not distinguish between any factor (van Exel & de Graaf, 2005). Exemplary items that were distinguishing in this study were items 1 and 25 for Factor 1, items 14 and 20 for Factor 2 and items 23 and 28 for Factor 3. Items 9, 43 and 70 were negative exemplary consensus items and item 21 was a positive exemplary consensus item.

There was little difference in the amount of overall work experience with people with IDDs for qualified clinical psychologists loading on Factors 1 and 2, but participants loading on Factor 2 had about four times the number of years experience in a qualified role as participants on Factor 1. Participants on both factors had overall work experience means close to the mean for all qualified clinical participants in the P-set (10.9 years). In the trainee clinical psychologist group, the mean amount of work experience of those loading on to Factor 2 was almost double that of their counterparts on Factor 1.The participant who loaded on to Factor 3 had more overall and qualified work experience with an IDD population than the mean overall and qualified experience of qualified clinical psychologists in the P-set.

Factor 1: Integration of social and medical models of disability.

Factor 1 accounted for 32% of the variance and represented the view of nearly half the participants. The overarching theme associated with this factor was the importance of both the medical and social models of disability and that their integration was the most appropriate response when working with people with ID.

Positive exemplary items.

Item 21: Challenging behaviour needs to be considered in the wider context of family and socioeconomic background, it is unethical to work with people with challenging behaviour and ignore this context. Factor 1 participants who agreed with item 21 thought that understanding the wider context in which a behaviour occurs is necessary to understand the cause, *"Ignore context, assumes behaviour is just about person and not a reasonable response to environment"*, *"We don't exist in a vacuum."* This was also thought important for comprehensive formulations, *"Can't formulate on diagnosis alone"* and for intervention, *"Always have to know about family and wider system to effect any change regardless of whether it is a phenotypic behaviour."* One participant highlighted a nature-nurture interaction, *"I do believe environment shapes behaviour but within confines of what is inherent to the individual,"* whilst another described challenging behaviour as a *"social construction*". ***Item 31: The medical and social models of disability can and should be integrated to enhance the lives of people with intellectual and developmental disabilities***. Factor 1 participants agreeing with item 31 recognised a complementary role for the social and medical models in working with people with IDs, with both of value, *"Maximum benefit can be derived if both models are taken into account."* Some participants considered conflict between these perspectives that could be overcome, *"The strengths of the medical and social models should be integrated to benefit the lives of individuals rather than a continued battle between the models."* One participant commented that integration of these models was required as a psychologist, *"If you're not doing this you're not doing your job."* ***Item 30: Behavioural phenotyping can make a positive impact on quality of life for people with intellectual and developmental disabilities if the information is used appropriately***.

The potential benefits of behavioural phenotyping in terms of formulation and intervention were recognised by Factor 1 participants agreeing with item 30, *"Phenotyping has the potential to enable us to understand the individual needs of clients leading to better informed formulations and intervention plans."* ***Item 15: Understanding the diagnostic label informs idiosyncratic formulations, interventions and treatment plans***. Participants on Factor 1 agreeing with item 15 considered diagnosis of value in informing the formulation, *"Understanding diagnostic label gives you an idea why somebody behaves or responds in a certain way"* and that it was important to understand a diagnosis when designing interventions as, *"If you don't you might use an intervention that is doomed to failure."* Diagnosis seemed to be viewed as a helpful heuristic or adjunct when working with people with IDDs rather than a dominant factor, *"Key question is to inform not dictate."* One participant also stated that having a diagnosis helped when working with staff teams indicating the possible dominance of or preference for a medical model among other staff groups. Factor 1 participants disagreed with item 32 (-3, Diagnosing intellectual and developmental disabilities/behavioural syndromes can hinder and create barriers to therapeutic work).

Factor 1: Negative exemplary items.

Item 1: Diagnosing different intellectual and developmental disabilities does not lead to greater understanding or change. Factor 1 participants disagreeing with this item thought that a diagnosis offered insight into prognosis, *"If you're able to identify syndrome then gives you a realistic picture of what you can change"* and that there was evidence to disprove this item, *"I think there's evidence to say that's not true, in forensic and mental health stream, in medical model, in family unit."* Item 1 was a distinguishing item for Factor 1, meaning that there was a significant difference between Factor 1 participants' views of the premise of this item and the views of other participants in the P-set**.** ***Item 52: Genetic screening and behavioural phenotyping are akin to modern day eugenics***. Disagreement with this item centred on Factor 1 participants viewing the aims of genetic screening and eugenics as being different, *"Genetic screening is about information for preparation to ensure person is helped in right way and not trying to reduce social value like eugenics did."* Time was thought to have changed cultural beliefs for the better, *"Culture has moved to the individual, intentions are sound"* and that not allowing people access to genetic screening this was a "disservice." One participant however felt that there remained a residual negative threat with genetic screening *"It has potential to be abused."* ***Item 25: It is difficult to hold both a medical and a social model of intellectual and developmental disability***. Comments by Factor 1 participants on this item related to this being part of a clinical psychologist's role and not doing this meant that this role was not being fulfilled adequately, *"Clinically neglectful not to hold both in mind," "That's formulation and that's what we're supposed to do. No reason why two can't be integrated."* Item 25 was another distinguishing item for Factor 1.

Item 70: The diagnosis is more meaningful than the presenting behaviour. Some participants disagreeing with this item appeared to see a more equitable role for diagnosis and presenting behaviour, *"I think the two are equally important. If you ignore presenting behaviour you are not going to get very far."* Others seemed to consider presenting behaviour as more relevant, for example, *"A diagnosis without a presenting problem would not be seen (in services)."* Participants seemed to consider that a diagnosis could be helpful but that it was necessary to look beyond a diagnostic *"label."* Item 70 was a consensus item.

Factor 2: Social model of disability is more helpful.

Factor 2 accounted for 26% of the variance and represented views of 12 participants and was another primary factor. The main theme associated with this factor was that a social model of disability was more helpful and relevant to working with people with IDs. Opinions about the utility of a diagnosis were relatively negative among Factor 2 participants. In comparison to Factor 1's theme of equal importance of medical [biological] and social models, Factor 2's main theme was that presenting behaviour and environmental factors are more important than information yielded from a diagnosis.

Factor 2: Positive exemplary items.

Item 14: Understanding the meaning or function of an idiosyncratic behaviour is more important than understanding the diagnostic label. Factor 2 participants agreeing with item 14 considered a diagnostic label to be unhelpful in understanding the personal meaning and the function of behaviour, "*Label tells you nothing about a person," "In some ways diagnosis can be helpful but understanding the function is more meaningful. That's what you would be looking for without a diagnosis."* A diagnosis was seen to add little value to clinical work by some participants, *"Whilst I do acknowledge that individual behaviour can have a genetic influence it doesn't tell you very much regarding what to do,"* while other participants were concerned that a diagnosis was detrimental to therapeutic progress, *"Focusing on diagnosis distracts from supporting people." "Some information is more dangerous than no information if you go of the diagnostic label."* One participant stated that families often want to know about a diagnosis but considered this misguided as she thought that the most important work was *"not diagnosis related."* Item 14 was a distinguishing item for Factor 2. ***Item 20: Service provision should be provided primarily on the basis of need not diagnosis*** .Participants agreeing with item 20 considered the presenting needs of a client as more relevant than a diagnosis with regard to accessing services. This was due to a perceived variation of need within diagnostic categories, *"Need to look at individuals when assessing them as there is differentiation within a diagnosis,"* and that sometimes there was a diagnosis in the absence of a clinical need and vice versa, *"You generate delusions of need based on diagnosis"* and *"People on fringes (of diagnostic criteria) miss out."* Overall, participants agreeing with this item considered individual needs more important than

diagnosis but also that having a diagnosis made access to services easier "*This is a far cry from reality"* and *"You have to know diagnosis to access certain services."* One participant identified autistic spectrum disorders as a possible exception with need being more closely linked to diagnosis *"There are usually some connecting factors."* Item 20 was another distinguishing item for Factor 2. ***Item 13: The social model of disability is more helpful than the medical model of disability in intervening with people with intellectual and developmental disabilities***. Factor 2 participants who agreed that the social model was more helpful in intervening with people with IDDs considered it more useful as it was seen to place more emphasis on wider contextual factors, which were considered of greater relevance than the diagnostic label in working with people with IDDs, *"You need to understand history and experience. You then have a better formulation, intervention and outcome when treating the diagnosis."* The view that the social model has broader scope in interventions for people with IDDs was apparent from comments about perceived negative characteristics of the medical model, for example, one participant called this a *"pharmacological straitjacket"* and another thought that homogenous diagnostic labels were *"unhelpful."* ***Item 21: Challenging behaviour needs to be considered in the wider context of family and socioeconomic background, it is unethical to work with people with challenging behaviour and ignore this context***. Participants on Factor 2 agreed with both the premise of this item and that personal experience and other evidence showed an undoubted link between environmental influences and challenging behaviour, *"Much more compelling evidence about the environment"* and "*If we ignore context we are not going to be able to understand function of behaviour or the formulation."* Item 21 was a consensus item.

Factor 2: Negative exemplary items.

Item 43: What happens in the womb influences intelligence more than anything that happens after birth. Factor 2 participants disagreeing with this item considered intelligence to be affected by much more than prenatal influences, *"Intelligence is influenced by a range of factors, this is life-long"* and thought that acknowledging a biological influence on intelligence only was blaming of mothers, *"It's a rod to beat women with."* . ***Item 9: Genetically inherited traits are fixed and non-modifiable***. This item was disagreed with by participants on Factor 2 who thought that inherited traits are subject to adaptation by environmental factors such as opportunity, *"People can change given opportunities and support"* and *"Social modelling."* Other participants considered the interaction between genetics and environmental factors and epigenetic factors to be of importance, *"Traits are highly modifiable with lifestyle."* Item 9 was another consensus item. ***Item 2: The medical model of disability is more helpful than the social model of disability in intervening with people with intellectual and developmental disabilities***. Item 2 is the direct opposite of item 13, an item placed in the polar opposite (+4) area of the Factor 2 array. Considering they are opposites of each other, it might have been expected that they would have had an equal number of

participants placing them in their respective ranks on the Factor 2 array. However, this was not the case as more participants on Factor 2 placed item 2 in the -4 column than the number of participants who placed item 13 in the +4 column (10 versus 4 participants). Thus, whilst the medical [biological] model was not seen as more helpful than the social model, the extent to which the latter was seen as more helpful did not match the antipathy towards the medical [biological] model, indicating that participants loading on Factor 2 took a nuanced with the balance in favour of the social model. The reflective comments about this item were similar to those for item 13 "*Medical model little more than descriptive, it doesn't tell you what to do"*, *"Tells you nothing regarding diagnosis, put them in a bin."* Some participants based their opinions on personal clinical experience or other evidence, *"Clinical experience is indicative that it is pertinent to consider systemic factors"*, *"More evidence for social model of disability being relevant and meaningful."* One participant commented on the presumed dominance of the medical [biological] model *"Medical model is more dominant but not more helpful."* ***Item 70: The diagnosis is more meaningful than the presenting behaviour***. All participants on Factor 2 disagreed with this consensus item at the -4 level. Reasons for disagreement included a perceived inability to understand individual difference using diagnoses, *"Heterogeneity and complexity, hard to capture that accurately in one label"* and the greater value placed on understanding behaviour *"We can understand an individual more effectively by analysing the function of their behaviour."* Reasons why presenting behaviour was more meaningful were tangibility *"If a person is angry then what's happening now,"* being subject to modification *"Can't change genetic diagnosis but you can modify the behaviour"* and relevance to clinical work, *"Looking at meaning behind the behaviour is more important to inform how we work."*. Participants associated with Factor 2 expressed negative views about the relevance of a diagnosis and its contribution to clinical work including the derisive comment, *"A load of rubbish, ridiculous item."* Another participant commented that a diagnosis *"Gets in way of work you do"* and another that diagnoses did not have *"Much scientific validity."* A slightly positive view about diagnoses was held by some participants, for example, a comment that in *"rare"* circumstances a diagnosis can help predict behaviour.

Factor 3: Genetic advances are positive but can create conflict with recognising the value of people with IDDs.

Factor 3 accounted for 7% of the rotated variance. The factor represented one participant's views but to account for this proportion of the variance indicated that this pattern of sorting was present in some form in the Q-sorts of other participants. This illustrates how all of the Q-sorts can contribute to the emergence of factors (Stainton Rogers, 1991). Factor 3 therefore represented a secondary viewpoint of those participants who loaded on to other factors. One of the main themes emerging from this factor was the need for caution when applying recent advances in genetics in ID so as not to undermine human rights and diminish the

inherent value of people with IDDs. Another theme was Factor 3's relatively positive views of the medical [biological] model of disability in terms of diagnoses and thoughtful genetic testing. This was in conflict with a further opinion that the social model of disability was more important than the medical model of disability but risked negative consequences by advances in the latter. To summarise, Factor 3 could be described as nature – proceed with caution.

Factor 3: Positive exemplary items.

Item 11: What's not important is genetic screening but the information it yields and how that is used. The Factor 3 participant's reflective comments about this item related to the ethics and use of genetic screening. She stated that the *"Most important thing to grapple with is ethics of genetic screening. (If it is) used to have a baby or not then it is not useful, is immoral. (If it is) used to increase understanding then the better I feel about it."* ***Item 17: Impact of genetic screening on the individual and society should be considered before it is used***. The participant again highlighted ethical values in the use of genetic screening, particularly in relation to decisions regarding childbirth, fearing that genetic screening was not being used ethically in all countries. Her comments were, *"(This is) most important thing, should be considered before it is used. Genetic screening used to some degree and it's not considered, what it means to people, especially in some countries. Every human being has rights. Genetic screening is fine as long as no decisions are made regarding child birth; take unborn child's life without medical intervention."* ***Item 23: Associating genetics with people with intellectual and developmental disabilities can undermine the progress of the social model of*** disability. The participant had strong views regarding the importance of people with IDDs to society and regarded the medical model as undermining their value through its focus on the intellectual, *"I think people with learning disabilities have a huge amount to offer society. Society isn't created by just intelligence. Other things are important – characteristics like being loving, caring, funny, strong, love for gardens etc. carry as much value for society. Intelligence isn't important. Social rather than medical/intellectual models – not always the happiest."* Item 23 was a distinguishing item for Factor 3.

Item 28: Genetic screening can lead to negative social engineering with the creation of 'designer' societies where people with disabilities are undervalued and social/environmental influences on disability undermined. The participant reflected on how society could be affected if genetic screening were used in this way, *"I think this is so true. 'Designer' societies occur if genetic screening goes wrong - used to reduce learning disability rather than understand it. End up with a flawed society."* Item 28 was another distinguishing item for Factor 3.

Factor 3: Negative exemplary items.

Item 43: What happens in the womb influences intelligence more than anything that happens after birth. The participant described a personal example to demonstrate why she had placed this item in the -4 column. Item 43 was a consensus item. ***Item 9: Genetically inherited traits are fixed and non-modifiable***. The Factor 3 participant disagreed with this consensus item for the same reason as participants on Factor 2, *"Inherit but environment impacts on life."* The Factor 3 participant also slightly agreed with item 47 (+1, No one knows what the non-genetic causes of individuality are), which was further indicative of their view of the importance of environmental factors in shaping individuality. ***Item 70: The diagnosis is more meaningful than the presenting behaviour***. The Factor 3 participant disagreed with this consensus item because she thought *"Both important, both are meaningful."* The Factor 3 participant showed agreement for item 40 (+3, A diagnostic label is more helpful to an individual than it is unhelpful). They also showed slight disagreement for items 14 and 22 (-1, Understanding the meaning or function of an idiosyncratic behaviour is more important than understanding the diagnostic label; -1, Focusing on the individual's expressed difficulties is more helpful than looking at the difficulties in the context of a diagnosis or conflicting diagnoses). These views show the value the Factor 3 participant afforded diagnosis, although they considered presenting behaviour more important. Factor 3 ratings on these items were different to those of participants on the other two factors, in particular, participants on Factor 2. The Factor 3 participant also disagreed with item 20 (-3, Service provision should be provided primarily on the basis of need not diagnosis). Again, participants on the other two factors had contrasting views about this item and the contrast between Factors 3 and 2 was greater than the contrast between Factors 3 and 1.

Item 2: The medical model of disability is more helpful than the social model of disability in intervening with people with intellectual and developmental disabilities. As with participants on Factor 2 the participant on Factor 3 disagreed with this item, commenting, *"Not true – social model is hugely important."* Whilst the participant considered the social model more important, she also identified some positives of the medical model, *"Some benefit to defining cause – families feel less pressure, less responsibility as they see it as part of phenotype."* The participant also highlighted a tug of war type dynamic between the medical and social models and gave her view that the medical model was beginning to regain sway, "*What happened in society is that the medical model has existed for 100 years and social model only since 1970s, we're just beginning to have social model but pendulum might swing back to medical model."* Unlike participants on Factors 1 and 2, the Factor 3 participant agreed with item 25 (+3, It is difficult to hold both a medical and a social model of intellectual and developmental disability) but they also strongly agreed with item 31 (+3, The medical and social models of disability can and should be integrated to enhance the lives of people with intellectual and developmental disabilities).

Discussion

Understanding clinical psychologists' attitudes towards and beliefs about genetic research provides insight as how they may or may not incorporate such findings in their clinical work. Application of genetic information in the form of genetic screening and behavioural phenotyping has greatly advanced in the past number of decades and more rapidly since the completion of the Human Genome Project, but clinical services appear to have been slow to utilise this information. The present study examined the views of clinical psychologists with an active interest in clinical work with people with ID and several issues appeared to be of importance, notably amount of experience being associated with a different pattern of response to the Q-set. More experienced clinical psychologists, both in terms of level of qualification and number of years' qualified experience, held views that were *less* favourable towards genetic research. In contrast, trainee and more newly qualified clinical psychologists were more receptive towards such ideas. Several factors could account for this difference, as it may reflect timing and training with more recently trained cohorts having more knowledge about genetic research and IDD. More experienced psychologists who trained at a time when normalisation and social role valorisation theories dominated the field may not necessarily endorse genetic research in the same way. Secondly, these differences may be pragmatic in that the more experienced psychologists are aware of what works and is useful with interventions embedded in a behavioural and social model of disability being more effective than using phenotypic information. The majority of Factor One participants were associated with a clinical training programme that emphasised the role of genetic and syndrome-specific research and practice in work with people with ID. This suggests that issues relating to both curriculum and clinical requirement and competencies are important if the uptake of genetic research in ID is to become more widespread and uniform. Personal experience of genetic diagnoses appeared to have been a further factor, particularly in the case of Factor Three where the participant that defined this factor intimated a history of genetic disorder in her family, which was associated with a more favourable attitude towards diagnosis. This was congruent with research discussed in the introduction chapter regarding the value bestowed on a diagnosis by people with IDDs and their family members. Although this was of concern to all participants, it was given greater relevance on Factor Three.

It is unclear a this stage how such differences in viewpoints regarding genetic research might affect individual practice with the possibility, for example, that services for people with IDDs that was employed" Factor One" staff might function differently to a service staffed by "Factor Two" staff. Such possible links between knowledge and beliefs and service delivery merit further research, a need highlighted by the observation that during the Q-sorting process, several participants referred to so-called

"political correctness" of the clinical psychology profession, as though there was a perception or idea as to how a clinical psychologist should respond, with an implicit presumption that clinical psychologists working in IDD services would take a particular stance with regard to the "medical model". This would seem to echo Smith's (1994) assertion that professionals working within IDD population seek to distance themselves from the medical [biological] model. This may constitute a barrier to the implementation of genetic research but one that may change as new cohorts with different values enter the profession.

Awareness of the ethical issues surrounding genetic research was evident in the responses of all of the participants. Whilst this was particularly more prescient for Factor Three, participants on the other two factors also showed this awareness. For example, Factor Two participants highlighted the importance of contextual variables, which they felt should not be overshadowed by genetics and Factor One participants' engagement with the debates regarding genetics was illustrated by some of their exemplary statements. As previously noted, there was an apparent need among psychologists to protect people with IDDs from discrimination and this may have affected their engagement with advances in genetics. This concern may have some basis with regards to the pace of developments in genetic screening, which has not been matched in the development of policy, guidance and regulation. However it could be argued that, although well intentioned, this concern is not as appropriate in relation to the *diagnoses* of specific genetic syndromes, a process which appears to generally be welcomed by people with IDDs and their families. In this instance, taking a stance against a diagnosis may appear over-paternalistic, implying that the psychologist knows best.

The current study has a number of limitations and strengths, not least of which that during the Q-sort process, several participants reported some items to be confusing and ambiguous, particularly those using negative and complicated terminology. A frequently cited limitation of Q methodology is its lack of generalisability. However, as there is no intention to assess stable attributes, reliability and generalisability are of less importance than validity in Q methodology (Stenner & Marshall, 1995). However, it would be useful to determine whether the viewpoints that emerged in this study are common among the wider population of clinical psychologists, as well as with other professional groups and opinion leaders working with people with IDD. An advantage of this study was the engagement of the participants, with the majority commenting that the process had interested them and that the topic had been thought provoking.

Conclusions

Using a Q methodology design this study identified three viewpoints among clinical psychologists about research from the "New Genetics" that have implications for people with IDDs. These viewpoints indicated varying levels of support and acceptance of this research. One strong viewpoint advocated for the integration of this research in clinical practice, another was showed more scepticism towards what it could offer in practical terms. A third viewpoint, advocated by fewer participants showed appreciation for the research but also caution towards its application. Factors associated with this variability were level and amount of clinical psychology experience, place of training and personal experiences in relation to aspects of the study topic. Suggestions for future research include replicating the study with a wider sample and exploring ways of sharing the findings of genetic research.

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Appendix One - Q-sort Arrays for all Factors

Items		F1	F2	F3
1	Diagnosing different intellectual and developmental disabilities does not lead to greater understanding or change	-4	-1	1
2	The medical model of disability is more helpful than the social model of disability in intervening with people with intellectual and developmental disabilities	-2	-4	-4
3	Socio-cultural factors such as socioeconomic status and family background are more important than behavioural phenotyping in explaining behaviour	0	3	-1
4	Growing up in the same family has no discernible or marked effect on the IQs of siblings	-2	-3	-3
5	Intellectual ability is affected more by nature than by nurture	-1	-1	0
6	Humans are not born with innate tendencies; experience in the environment shapes all learning	-3	-1	-3
7	Behavioural syndromes rarely occur	-2	-1	-1
8	The cause of intellectual disability can be of equal or greater importance than the immediate and broader environment as a determinant of well-being	-2	-3	-2
9	Genetically inherited traits are fixed and non-modifiable	-3	-4	-4
10	Genetic screening/testing causes negative attitudes towards disability to pervade and continue	-2	1	0
11	What's not important is genetic screening but the information it yields and how that is used	3	0	4
12	Awareness of behavioural phenotyping and its developments is generally of a low level among staff	2	1	1
13	The social model of disability is more helpful than the medical model of disability in intervening with people with intellectual and developmental disabilities	1	4	1
15	Understanding the diagnostic label informs idiosyncratic formulations, interventions and treatment plans	4	0	2
16	The pathway to the same behaviour may be different for individuals with different genetic disorders	2	1	2
17	Impact of genetic screening on the individual and society should be considered before it is used	3	1	4
18	Many professionals working with individuals with intellectual and developmental disabilities are unconcerned with why someone has the impairment	1	1	-2
19	Diagnostic labels can serve to deny people access to services	1	2	2
20	Service provision should be provided primarily on the basis of need not diagnosis	3	4	-3
21	Challenging behaviour needs to be considered in the wider context of family and socioeconomic background, it is unethical to work with people with challenging behaviour and ignore this context	4	4	3

22	Focusing on the individual's expressed difficulties is more helpful than looking at the difficulties in the context of a diagnosis or conflicting diagnoses	1	3	-1
23	Associating genetics with people with intellectual and developmental disabilities can undermine the progress of the social model of disability	-1	1	4
24	The environment that a child experiences is as much a consequence of the child's genes as it is of external factors: the child seeks out or creates his or her own environment	-1	-2	0
25	It is difficult to hold both a medical and a social model of intellectual and developmental disability	-4	-2	3
26	Diagnosis specific services presume specialisation which fits with a medical model	-1	1	1
27	Heterogeneity of presentations within diagnostic categories can render the diagnosis meaningless	-1	2	-3
28	Genetic screening can lead to negative social engineering with the creation of 'designer' societies where people with disabilities are undervalued and social/environmental influences on disability undermined	0	1	4
29	Inclusion in society can be enhanced by understanding individual difference that can be traced to a specific genetic disorder	1	-3	-1
30	Behavioural phenotyping can make a positive impact on quality of life for people with intellectual and developmental disabilities if the information is used appropriately	4	0	3
32	Diagnosing intellectual and developmental disabilities/behavioural syndromes can hinder and create barriers to therapeutic work	-3	0	-2
33	The cause of the intellectual and developmental disability is unknown in most cases	1	0	-1
34	Genetic disorders lead to different behavioural outcomes	2	-1	2
35	Families usually want to know the cause of their child's intellectual and developmental disability	2	2	2
36	Health and social care resources should be directed towards understanding and improving social and environmental factors affecting people with intellectual and developmental disabilities	2	3	0
37	Health and social care resources should be directed towards disseminating and applying research, originating from all fields of relevance, affecting people with intellectual and developmental disabilities	2	1	1
38	The environment has less of an impact in an equal society than it does in a more unequal society	1	-1	0
39	Genetic screening may reduce complex behaviour to genes, ignoring the impact of other factors on behaviour	0	3	2
40	A diagnostic label is more helpful to an individual than it is unhelpful	0	-2	3
41	For disorder-specific services to be effective for the individual there must be no doubt in the accuracy of their diagnosis	-2	-1	-1
42	Genetic screening, and its consequences, masks and denies the individuality and opportunity in people with intellectual and developmental disabilities	-2	1	0
43	What happens in the womb influences intelligence more than anything that happens after birth	-2	-4	-4

44	Genetic screening creates a battle between innate social instinct versus human rights	0	0	0
45	Defining services by diagnostic labels means better, more individually tailored services are delivered	0	-3	-2
46	Geneticists have a moral and ethical responsibility to the today not the tomorrow	-1	-1	-2
47	No one knows what the non-genetic causes of individuality are	-2	-3	1
48	Innate abilities allow children to develop typically, absence of such abilities affects development	1	-2	2
49	Genetic testing would not add to the quality of life for a person with an intellectual or developmental disability	-3	0	-3
53	The non-shared environment, such as individual school experiences, account for more differences in siblings than genes	0	0	-1
54	Genetic screening/testing should be available to all as people have a right to information about their genetic make-up	0	0	0
55	The shared environment has a greater influence on sibling similarities and differences than genes	0	2	-1
56	Genetically inherited traits/characteristics can be subject to change and adaptation by the environment - Heritability does not mean immutability	2	2	2
57	Degree of intellectual disability (mild, moderate, severe, profound) is a better predictor of behavioural outcomes than behavioural syndrome diagnosis	-3	-2	-2
58	Genetics and behavioural phenotyping represent a shift backwards to the medical model of disability	-3	1	0
59	Genetic aspects of a condition may be viewed as irrelevant or potentially negative by professionals/staff members	0	0	0
60	The science of intelligence testing is flawed	3	2	1
61	Genetic screening, if used in an appropriate, responsible way, has the potential to positively affect lives	3	0	3
62	Genes have a greater influence on sibling similarities and differences than the shared environment	-1	-3	-1
63	Understanding the causal pathway to an individual difference can have a positive influence on well-being	1	-1	2
64	Culture is the product of individual psychological make-up rather than vice versa – a person does not inherit cultural knowledge, they acquire it through experience	1	2	1
65	Genes have a continuing influence on individuals as they develop	2	0	2
66	Focusing on how genetics influences behaviour downplays the role of more important social influences	-1	2	0
67	Diagnosing different intellectual and developmental disabilities/behavioural syndromes provide unnecessary labels and can create stigma	-1	0	-2
68	As people get older their environment has a stronger influence on their behaviour	-1	-2	-2
69	The social environment is the product of individuals innate social instincts	-1	-2	-1
70	The diagnosis is more meaningful than the presenting behaviour	-4	-4	-4
71	Generic services beneficial to all is the ideal but if this is unattainable disorder-specific services should be preferred	0	-2	-1

Items		F1	F2	F3
72	People with different behavioural syndromes have more similar than dissimilar behaviours	0	-2	1
73	Behavioural phenotyping is beneficial in understanding some syndromes such as Down syndrome but this is an exception, behavioural phenotyping does not generally aid understanding as much as other factors	-2	-1	-3
74	Current knowledge and understanding of different disorders is too limited to make disorder-specific services worthwhile	-1	-1	1
75	There are no direct genes for intelligence but an inherited resistance to stressors e.g. resistance to toxins which then enhances the ability to develop intelligence	0	-2	0
76	Robustness of the conceptualisation of disorders/disabilities needs to be improved e.g. autism, otherwise the science (phenotyping) on which it is based is flawed and any predictions made on this basis are flawed and potentially destructive	1	-1	1
77	The voice of people with intellectual and developmental disabilities in the genetic testing debate is unheard	3	3	-2
78	In clinical practice it is difficult to keep up to date on new research developments due to time and service pressures	1	1	1
79	Research of relevance to people with intellectual and developmental disabilities is often difficult to access by services which affects the application of new research	0	0	0
80	Social instincts may mean it is natural to exclude people with intellectual and developmental disabilities (IDDs) from the group; however, our human side and social responsibility should cause us to fight against this and recognise the value to the world of people with IDDs and diversity in general	2	2	0
81	A partially inherited low IQ might be subject to extensive improvement through education	0	1	0