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# DSQ

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# DSQ

## Down Syndrome Quarterly 2011

The aim of the Down Syndrome Quarterly (DSQ) is to provide easy access to research papers and evaluated results for clinicians, professionals, and families. The journal will have a broad focus and cover a wide range of topics relating to Down syndrome. It will include relevant research abstracts, commentaries relating to practice, peer reviewed research papers, literature reviews, and regional reports. It will include reports and international work, especially encouraging submissions from developing countries. There will be the opportunity to exchange ideas, and discussion papers on key issues will be included.

The small editorial board will ensure that the journal achieves its mandate and goals. An international and widely knowledgeable review board will act as reviewers and commentators. Contact will be developed with regional representatives to encourage participation from all areas.

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# Inside this Issue

This Volume of Down Syndrome Quarterly has two separate Issues. Issue 1 is concerned with social, psychological and educational articles and Issue 2 deals with health and medical issues. In both issues it is important to recognize the biological nature of humans and the interactive nature of inheritance and genetic propensities and their interplay with physical, social, educational and psychological aspects of life.

The first issue deals with critical issues of child and adult development and discusses aspects of behaviour which often both interest and concern parents and educators. The article by Cunningham and Glenn is a reassuring document stressing the natural unfolding of behaviour and some aspects, which are affected by social issues relating to opportunity in the environment. Some behaviour, which at times looks strange, and sometimes worrying, is learning in slow motion and often experienced by people with Down syndrome- behaviours which reflect how people develop and mature. A further article by Rødevand and Hellman take up the issues of interactive technology and how it can enhance life for people with Down syndrome and other disabilities if used appropriately and geared to their level and pace of learning. Riches uses individual case studies to examine the effects of isolation, and social support amongst persons with Down syndrome and underscores the need to understand the social issues involved and the resulting psychological consequences. The area of social engagement is further examined by Cuskelly and Gordon in a research study which also looks at aspects of depression. A fifth and final article in this Issue is by Joosa concerning visual art in a girl with Down syndrome. The article explores meaning through drawings and discussion with the artist raising a number of interesting ideas relating to methodology and outcome.

The second issue focuses on challenges relating to health including parent reaction and awareness to Down syndrome. The first article by Biasotto, Quartino and Baccichetti takes up the important issue of communicating the birth of a child with Down syndrome to parents and understanding better ways of improving parent experience. Gavin, Patti, & Andiloro consider the importance of recognizing the signs and symptoms of celiac disease and study aspects of the condition through parents and carers of adults with Down syndrome. Practical recommendations are provided. The article by Tenenbaum and her colleagues deals with obesity in Down syndrome and the importance of early intervention and ongoing diet. A final article by Hurley, Martin, and Marder explores three cases of hypercarotenaemia where there are complications relating to the thyroid and indicates the importance of specific signs suggesting further examination.

In preparing these 2 Issues I would like to acknowledge the help of Joan Murphy who, at the World Down Syndrome Congress in Dublin, helped and encouraged presenters to write for DSQ. I also wish to recognize the technical support we have had from Heidi Flores from McGill University in Montreal who has looked after many of the finer points of checking and formatting of the articles.

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# Age, Social and Developmental Appropriateness: Has the Pendulum Swung Too Far?

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## **Abstract**

The current emphasis on understanding and planning education and treatment for adults with Down syndrome is strongly influenced by the idea of age and social appropriateness and ideology of equal civil rights. This has improved the opportunities and life-styles for many adults with Down syndrome but this paper argues that developmental appropriateness is at risk of being neglected and requires equal attention. This opinion is illustrated with studies from three areas: self-talk, routines and compulsive-like behavior; and self-awareness and self-esteem. The results confirm that knowledge of typical developmental processes is applicable to older children and adults with Down syndrome and should be an essential part of training those responsible for their care and management.

Keywords: Down syndrome, self-talk, routines and compulsive-like behavior; self-esteem; self-awareness

A massive shift in our understanding of intellectual disability began half a century ago. The belief took hold that people with disability could learn and achieve far more than previously thought, and that much of the behavior seen was due to a lack of expectations and commitment of resources.

Such concepts were captured in the phrases age appropriate behavior and socially acceptable behavior. These ideas rejected the prevailing view that people with intellectual disabilities had the minds of children – ‘the unfinished child’ – and hence could be treated like children, including the way they were dressed and how their lives were organized. As expectations changed and opportunities opened up, so more people with intellectual disability achieved their potential and led more interesting lives.

We will argue however, that this shift, as with most major ideological shifts, has swung so far that there is a danger we might lose the importance of understanding intellectual disability from a developmental perspective. The term developmental delay is often used synonymously with intellectual disability but without detailed knowledge of child development; for example, by merely using developmental milestones in teaching programmes to define progress and the next step. Development theory is also used to explore how people with intellectual disability differ from typical developing people. What is often missing are questions about developmental appropriateness – specifically whether the behavior is appropriate for someone at that level of development or intellectual maturity, and whether it has a positive function for the person.

We illustrate our concerns with three of our recent research projects. \*

## **Self-talk**

Talking to oneself is common in young children between the age of 2 and 6 years (e.g., Berk, 1994), and for many people when concentrating on a task. It has many positive functions, most often as externalized self-instruction when engaged in complex tasks when it helps to focus attention. It can provide practice in the use of language and, for example when having an imaginary conversation or with someone not present, a means of rehearsal and construction. Children use self-talk in sophisticated imaginary games, exploring different roles and social engagements. Some invent imaginary friends, animals and complex scenarios. It is generally agreed that talking out loud in young children is developmentally appropriate, especially at the time in developmental when their experiences and understandings are limited and their inhibitory control is still maturing.

In typically developing children self-talk decreases between the ages of 6 to 8 years, often beginning with whispers and then small mouth movements that reflect silent inner speech, which we all use. The shift to inner speech also reflects the child’s growing understanding that talking out loud is seen as strange by others, and indicates growing maturation and the ability to inhibit and regulate behavior. At this age children have also learnt more about privacy and secrets and are less inclined to speak about these out loud.

From older childhood onwards talking to oneself is generally viewed as a sign of mental health problems or social isolation. We met several parents of adolescents with Down syndrome who were unhappy about self-talk, seeing it as socially inappropriate and a sign of illness and had tried unsuccessfully to stop it, with much stress, and others who had got medical help and treatment for their child. The limited literature available tended to see self-talk in older individuals with Down syndrome as inappropriate or signs of

isolation. We embarked, therefore, on a study of self-talk in young adults with Down syndrome (Glenn and Cunningham, 2000) who were part of our cohort (Cunningham, 1996).

The aim was to explore the number of young people who self-talked; the characteristics of those who did and did not; the circumstances in which the self-talk occurred and the content of the self-talk. The method was a semi-structured interview with 77 parents of young adults with Down syndrome (45 male).

Ninety one percent were reported as having self-talked in childhood, or who were still talking to self; 9% had never self-talked and had developmental age equivalent scores under three years and very little language; 5% no longer self-talked and all had developmental age equivalents above eight years. Fifty three percent talked in front of others and 33% only when they were alone. The former had a mean developmental score of 5.8 years and the latter 7 years. These results were predicted from the typical developmental model.

No association was found between self-talk and behavior problems, or between fantasy self talk and communication difficulties, social isolation or behavior problems. Eleven of the young people had imaginary friends, and while they tended to be in the 'fantasy self-talk' group, only three had behavioral or emotional difficulties, which, as a percentage, is similar to such problems for the whole group.

Overall therefore, the results support the view that talking out loud to self by young people with Down syndrome should be seen as developmentally appropriate and adaptive, and, in the absence of other symptoms, should not be viewed as an indication of pathology. Recent studies have also concluded that self-talk is common in children and adults with Down syndrome, and is not associated with psychiatric problems for most (McGuire and Chicoine, 2006; Patti, Andiloro and Gavin, 2009)

Self-talk, however, is socially inappropriate and may interfere with the social life of older children and adults. Developmental theory suggests that instead of trying to stop the young people talking to themselves, which can become a frustrating and negative experience for all involved, it is probably better to teach them to do it more quietly and then in private. Where the young person has a restricted social life and is thought to use self-talk and fantasy to compensate, this indicates the need to provide a more active and stimulating life-style. Less frequently self-talk and imaginary friends (or hallucinations) will be associated with psychological problems; usually the behavior suddenly starts or becomes much more intense than previously, and the content can be quite different. There are also other changes, such as withdrawal or becoming aggressive and in such cases specialist help is needed.

### **Routinised behaviors**

Between the ages of 2 to 6 years many typically developing children show strong preferences for sameness and things in the right place (e.g., Gesell, Ames and Ilg, 1974); such behaviors have recently been studied as routinised and

compulsive-like behaviors (RCBs) (e.g., Evans, Leckman, Carter et al., 1997). At this age children can be quite rigid in terms of the food they like and dislike; their play can be very repetitive and ritualised, and others are expected to do things in exactly the right way. The children are often very observant of tiny details in toys and clothes and the slightest imperfection can cause an outburst. Tantrums may also occur if a plan of action is thwarted. Between 6 and 8 years there is a significant decline in these behaviors although a minority still show relatively high levels of RCBs up to 11 years or so (Glenn and Cunningham, 2008)

RCB's are believed to be useful strategies at a time in development when children are beginning to learn about and master their environment and behavior; they provide repetition and a feeling of control and understanding. Routines help to reduce and master anxiety and can simplify events, such as in bedtime routines involving familiar sequences of actions on the part of the parent and child (e.g., Leonard et al., 1990). As cognitive abilities mature there is less dependence on external organisational factors. However, most people have routines, for example sportsmen prior to big occasions, which are not just superstitions, but small steps in preparation and the maintenance of focus and calmness.

Dependence on routines and repetitive behavior is regularly reported as a characteristic of Down syndrome. Such behavior and inflexibility often become concerns for parents, teachers and other professionals. The behaviors can appear similar to those characteristic of obsessive-compulsive disorder (OCD), which is reported as slightly more frequent in adults with Down syndrome than the typical population (Prasher, 1995). As with young children, routines can help people with Down syndrome to feel confident and in control. For people who have some difficulties making sense of the world and thinking quickly and flexibly, it takes less effort and cognitive capacity if things stay much the same.

We were interested in the question as to whether the RCBs seen in children and adults with Down syndrome are developmentally appropriate or related to pathological behaviors.

We established a sample of 118 children and adults with Down syndrome aged 5 to 30 years (53 males). We assessed their developmental level and matched 50 individuals with Down syndrome to 50 typically developing children for developmental age and gender. Parents reported on RCBs, behavior problems, adaptive behavior and OCD behaviors. As expected from the literature we found that RCBs were more intense than in the typically developing children, although not more frequent. Whilst this suggests that such behaviors appear as characteristic of individuals with Down syndrome (or of people with slower mental processing), the behaviors may be more noticeable in individuals who have restricted behavioral repertoires. As with self-talk, such behaviors are not generally expected in older children or adults.

We found that the children and adults with Down syndrome whose developmental level score was under 5 years and who had higher intensity RCB ratings also had higher social adaptation scores. This implies that RCBs are associated

with some positive function at this developmental period. However in the adults and more developmentally advanced children, higher scores for repetitive behavior did not show this association and therefore the function of RCBs for these individuals requires further research.

We concluded that certain levels of routinised behavior appear to be developmentally appropriate for many children and adults with Down syndrome. An aspect of intellectual disability is problems with information processing and understanding the everyday environment. Hence daily living is a challenge and people need to feel they have control and can act with confidence. Before attempting to change RCB type behavior in older children and adults with Down syndrome, the function of such behavior for the individual needs to be examined; it may be developmentally appropriate at that time. As with the shift to inner speech, maturation brings internal control and the ability to consider options and so reduces the need for repetition and sameness. However, adaptability and flexibility can be facilitated with careful planning, small and controlled challenges, and patient teaching that offers appropriate developmental choices and encourages decision making. If there is an increase in RCBs and they interfere with everyday functioning then careful assessment of possible reasons is indicated.

### **Social comparison, self-esteem and awareness.**

Comparing oneself to others is the way we begin to understand the social world, who we are and how people differ. The developmental sequence of this has been described in many studies (e.g., Harter, 1999) and is reported in terms of average age bands as a convenient way of signposting a complex process.

Around 12 to 18 months infants recognize themselves and know if something has changed (e.g., a red spot on their face). They recognize other significant people and physical differences. By 2 to 3 years children are noting physical characteristics such as hair colour and gender differences, and in their fourth year are very aware of observable differences such as age, size, hair and skin colour. They are beginning to understand social groups such as family members, relatives and friends, and talk about me and mine. Comparison with and of others, and categorization becomes increasingly noticeable in mid-childhood with others being classified as taller, darker, fast runners, good readers, speak a different language and come from a different nationality. With this process comes the understanding of groups of people who cannot walk or talk or look very different and by 6 years children are beginning to understand that some characteristics like ethnicity and gender are permanent. Most 6- to 7-year-olds understand that not being able to walk is permanent but around 75% believe that intellectual disability is like being ill and the person can get better (Lewis, 1995).

Around eight years there are major changes in intellectual abilities. Children begin to make judgments about desirable and undesirable characteristics of others and hence themselves. These comparisons take place within their social experience and reflect the beliefs and values of their

community. It is around this age that such comparisons may have a major impact on their self-evaluation and self-esteem. They start to recognize that some characteristics, like intellectual disability or athleticism, are permanent and begin to see their future in a more tangible way. From 9 to 10 years they begin to use more abstract concepts in their comparisons and appraisals that reflect personal beliefs and values, and moral standards (e.g., Harter, 1999).

Using interviews with 77 young adults with Down syndrome in our cohort and their parents, we assessed their self-esteem (e.g., Glenn and Cunningham, 2001), and asked them if they had heard of 'Down syndrome', 'disability', 'handicap' or 'special needs'? Did they have Down syndrome and disability? Did their friends have Down syndrome or disability? What was it? We also asked their parents if and how they told their child they had Down syndrome and what the reaction was. To see if the young people recognized the facial features of Down syndrome we used a set of photographs of young men and women with and without Down syndrome. If they recognised the facial features we then asked them to place their own photograph on one of the piles (Cunningham & Glenn, 2004).

We found that about 40 to 50% of young people with a developmental age equivalent score of less than 4.5 - 5 years were rated as having no recognition and awareness of Down syndrome or disability. About 10% of these seemed to be gaining some awareness, but it was not easy to determine and it had no obvious impact on their lives. There were a few young people with higher developmental scores who had no apparent awareness. From the parental interviews we concluded their parents had protected them from learning and knowing about the disability. However, some of these young people did not have strong facial features of Down syndrome. Parents reported that facial features, which are likely to be identified by typically developing children at 4 to 5 years, are often the triggers of first awareness and self-identification for individuals with Down syndrome. However, recognition of the characteristic facial features of Down syndrome did not automatically predict that the young people placed their photograph in that group or themselves in the social category of Down syndrome.

The interviews with parents asked how they told their offspring about Down syndrome or disability. The majority reported an open system of discussion in the family. Six percent indicated that they had deliberately avoided the issue and 43% had not tried to tell explicitly - most of these felt the young person would not understand. The majority of these young people had developmental scores of less than six years and no demonstrated awareness of Down syndrome or disability (Cunningham, Glenn & Fitzpatrick, 2000). Again this follows the typical developmental pathway of which most parents were intuitively aware.

The group who were aware, but whose development scores fell below 7 to 8 years, generally described Down syndrome and disability in terms of physical or sensory characteristics in a manner similar to most children of the same age. Some described disability as not being able to do academic things or learning slowly. This reflected the most common explanation of disability that parents used.

We had examples of young people feeling they would grow out of Down syndrome and learn to do lots of things like anybody else – a view that largely mirrors that reported for children generally. Some would talk about being disabled because of their heart problem, and then say that they were not handicapped because they were good at reading; others defined Down syndrome in terms of specific things, like being able to go horse riding or bowling, and others in terms of not being allowed to drive a car, going to the pub on their own, and getting a boy or girl friend. Again these explanations are similar to those reported for understanding of disability by young typical children.

Comparisons to others appeared in those with developmental scores above 5 or 6 years. At this level, comparisons in terms of disability were about people worse off because they could not walk or talk. It was only those with higher developmental levels who indicated an understanding of permanence and consequences. The self-esteem scores were largely very positive and again it was only those with higher developmental scores (over 8 to 9 years) who were realistic about their competencies, but still generally had high feelings of self worth. As with typical people these young adults readily shifted their reference or comparison group depending on what was being discussed and usually to seek a positive self-appraisal.

These results support the notion that the process of social comparison and the development of self-identity and self-esteem are similar to that expected from the typical developmental process. However, when we asked parents to recall how frequent their child with Down syndrome made social comparisons compared to their other children, the general response was less often. We also found it quite difficult to get the young people to make comparisons or tell us about things they did not like in other people. Generally, they focused on positive things.

One indicator of recognizing a social group and the value given to it by society is the extent to which people wish to be included in that group. We found 13% of the young people in our sample indicated negative reactions to Down syndrome. And this was more likely in the men with 25% indicating negativity, most of whom had higher developmental scores. They often refused to talk about Down syndrome with us; they recognized the features but would not put their photograph in that group and several expressed strong negative feelings about Down syndrome when sorting the photographs. The parent interviews confirmed these reactions. The young women were less likely to deny and avoid discussion and more likely to describe practical implications of Down syndrome and how they tried to understand them, often in terms of marriage, motherhood or careers.

We concluded that knowledge of typical developmental model of developing identity and self-evaluation and the process of social comparison is appropriate for children and adults with Down syndrome. It can be used as a starting point to understand how they might react to events, the sort of salient information they may be using in their social engagements and understanding, what reference points for social comparison are significant and how we might help their growing sense of identity. The results also indicate

that a large number of adults with Down syndrome will not benefit from efforts to teach them awareness of Down syndrome and issues related to social stigma and attempts to teach them about such matters as a preparation for future life needs to be carefully considered.

### Conclusions

We believe the studies above illustrate how knowledge of typical developmental pathways and theory enhances our understanding for all individuals with intellectual disability. This approach is not based on a search for differences or weaknesses but as part of building up an understanding of an individual's intellectual maturity and appropriate methods of instruction and provision. We believe such work is worthwhile but has been neglected. Our search for recent literature on the areas above failed to find more than is cited.

This is not to deny the importance of taking into account age and social appropriateness, nor ignore the hard won understanding of people's rights, when planning educational curricula and making decisions on life-style support. We are certainly not advocating a return to equating capacity, aspirations and provision to a 'mental age' and so denying the importance of experience. We are arguing that in recent years developmental understanding has been supplanted in many situations by age and social appropriateness and ideologies based on rights, that lead to actions that are not in the interests of the individual with intellectual disability, or as we prefer to think about it, individuals at different levels of intellectual maturity. Beyond the scope of this paper are issues concerned with such areas as sex education – clearly a right for all citizens – but when and level of self-determination of life-style remain interesting challenges.

We believe more research is needed on how to develop an integrated model using developmental maturity, age and social appropriateness which should be clearly embedded in rights-base understanding that leads to more appropriate action plans for individuals. We also think that this approach should become a basic training module for all professionals responsible for the care of children and adults with Down syndrome.

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# "Young and Enthusiastic": ICT-Based IADL-Training

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## **Abstract**

In the research and development project "Young and enthusiastic", undertaken in Norway in 2009, areas of IADL-skills beneficial to mastering education and work situations were identified. Literature studies, informant interviews and meetings with the external expert group were used for information inquiry. We also investigated available ICT-based learning material. A national survey of available ICT-based programs in the identified areas of IADL was conducted. Finally, a web-based study on IADL-related needs was conducted. The web-based study revealed a set of major challenges for IADL-learning and -training, and pointed to areas in which there is a clear need for more IADL-training. One of the most consistent findings from the informant interviews and a group interview of young persons with intellectual disability is that youths with intellectual disability are highly motivated to use PCs and mobile phones, and that they manage to use ICT-based tools.

Keywords: Down syndrome, IADL, daily living, education, ICT, mobile phone

## **Introduction**

The complex activities of daily living are called IADL (Instrumental Activities of Daily Living). Youths with intellectual disabilities need to be trained in IADL-skills to a much greater extent than other persons of the same age in order to develop mastery of their daily lives and to be independent. Individual learning plans should be made for school-aged pupils receiving special education. According to guidelines from Norwegian educational authorities (Norwegian Directorate for Education and Training, 2004), such plans should be made on the basis of the capabilities and qualifications of the pupil and the content of the curriculum for mainstream education for the relevant school level. It is mentioned that for some pupils the targets in special education could be related to basic skills in areas like self-care, communication, social roles and practical skills.

In the project "Young and enthusiastic" areas of IADL (Instrumental ADL) skills beneficial to mastering education and work situations were identified. Instrumental in this context refers to being complex. Training in specific work situations is not usually included in IADL (Tuntland, 2008), but many IADL-skills are important for mastering a broad range of school and work situations. Early training in such skills is beneficial for the feeling of success and her/his capability to perform work tasks, in supported or open employment work (after school/education).

Youths are in general enthusiastic about ICT, and we wanted to find out to what extent this also applies to youths with intellectual disability. Common ICTs, such as PCs, mobile phones and digital cameras, are widely used in Norway (Ministry of Government Administration, Reform and Church Affairs, 2006). In 2006 an education reform called

Knowledge Promotion introduced digital skills as the fifth basic skill in addition to reading, writing, oral presentation and mathematics (Ministry of Education and Research, 2006).

The first question we wanted to clarify was for which school- and work-related areas there is a need for training in IADL-skills. We also wanted to investigate what can be done on common technology platforms, such as PC or mobile phone, and to specify requirements for IADL-training programs on these platforms. The point of departure for the requirements specifications was how these technology platforms could be utilized to develop IADL-skills in particular, and to create better learning conditions in general. Before specifying the requirements, we also interviewed persons involved in teaching and caring of persons with intellectual disability and a group of young persons with such disability. We asked to what extent and in what ways young people with intellectual disability are interested in using new information and education technologies.

## **Methods**

The important IADL-topics to train in our context were identified through literature (Tuntland, 2006), semi-structured informant interviews and the expert group of the project. The project leader also had experience from her son, a young man with Down syndrome, and his friends. Most topics were identified before the interviews started, but the informants were asked if they had topics to add to our list. A literature study of reports of electronic learning material for persons with intellectual disability was performed.

**Interviews:** Ten interviews were conducted with informants

who had daily experience with persons with intellectual disabilities. The informants included teachers from schools at three levels (6-13, 13-16, 16-18 years), a mother, a folk school (kind of boarding school without any academic degree that many Norwegian youths attend for one year after secondary education), sheltered workshops and flats for people with intellectual disabilities. They provided information about what is trained, where the training is performed, and how the training in IADL is done within specific topics. We also asked which laws and regulations were followed when IADL-training was conducted in different places. The use of ICTs was of special interest in the interviews, particularly how young persons with intellectual disability learned to use it and how ICT-programs were used for education in other topics. Finally we examined to what extent young people with intellectual disability were interested in using ICTs such as PC and/or mobile phone.

**Survey of Available ICT Programs:** For our focus areas a survey of available ICT-programs in Norwegian for training children and youths with intellectual disability in IADL was conducted. The sources for this survey were first of all electronic databases for mainstream education and special education. Web-sites for producers and importers of special education software, the web-site for the Norwegian Institute for Adult Learning, the web-site for the Association for Persons with Developmental Disabilities, databases for technical aids, exhibition stands at conferences, and retailers selling electronic games etc. were also screened.

**Focus Group Interview:** A group interview of 6 young persons with mild to moderate intellectual disability was performed. They could all communicate orally and were asked to what extent they used ICTs, such as PCs, mobile phones, digital cameras, MP3-players and TV-games. They explained in detail what they used to do on PCs, such as using the internet (and what they used the internet for), playing games and using learning and other programs.

**Web-based Survey of Key Informants:** Based on the identified focus areas for IADL-training, a web-based survey was performed. This survey covered both challenges in IADL-training and the need for training in specific activities. Both parents and professionals working with education services, caring and work services for persons with intellectual disability were invited to participate. Brief information about the study was given on web-sites for professionals working with persons with intellectual disability and web-sites for interest organizations whose members were mainly persons with intellectual disability and their parents. From these sites there were links to the survey itself. One of the interest organizations was a Down syndrome association consisting of both parents and professionals supporting persons with Down syndrome. Since e-mail information about the study was sent to parents in the Oslo-region, it is reasonable to assume that a large number of the parents who participated in the survey have a child with Down syndrome.

The respondents were asked about their relationship to persons with intellectual disability in order to know how many respondents were close relatives. Sub analyses were done for respondents who were parents/other relatives as well as respondents who were professionals, but these

results are not presented in this paper. All participants were also asked if they worked with people with intellectual disability, and if so, what kind of workplace this was (kind of school, working arrangement, activity centre etc.). They were also asked to indicate whether they had experience from one or more persons with such disability. Further, they were asked to estimate the level of intellectual disability of the persons of whom they had experience (mild, moderate, severe, unknown, mixed). We also asked what the persons with intellectual disability were doing during the daytime (attending what kind of school, working arrangement, activity centre etc.).

Before the interviews, focus areas of IADL-activities were identified and discussed with the expert group of the project. Some topics, for example, socially acceptable behavior and personal hygiene were added. A detailed interview guide with both general and specific questions was developed for the interviews of professionals (teachers, work-leaders etc.) and of a parent. In the interview material, we looked for main trends and information about where IADL-activities were trained. For instance, training in the use of mobile phones was done at the interviewed secondary level school and in adult education, but in no other organization we contacted. Based on the results from the interviews, specific questions about the need for training in specified activities were developed for the web-survey. Some activities, such as using GPS, were not included in the web-survey as they did not seem to be considered as important IADL-activities by the informants.

### Results

According to our investigations, the following focus areas within IADL are important for the schooling and work of persons with intellectual disability:

1. Management of time (both being able to know the time, handling time and appointments, and even delays and using a calendar).
2. Money/personal economy (both knowing the value of coins and notes, estimate the value of products and services, reasonable use of money, methods of payment and budget knowledge).
3. Transportation/mobility (using taxi and public transportation, finding the correct walking route, mastering traffic rules when walking, using maps, planning a travel).
4. Advanced communication (ways of contacting other persons, using mobile phones, using e-mail, storing details for contacting others, knowing who to contact for different reasons).
5. Media (other uses of PC and mobile phones in addition to contacting others, use of newspapers and magazines, radio, TV, digital cameras, MP3-players).
6. Household activities (preparing and doing cooking, setting the table, cleaning, washing clothes, tidying up, handling garbage). These activities are included as many persons with intellectual disability are doing such tasks in their work situation.

7. Mastering school and work situations (remembering to bring required items to and from school/home/workplace, communicating with parents and support personnel when needed, especially when problems occur, taking responsibility for work, being able to arrive on time, walking or using public transportation to school/work/activity centre, knowing and complying with regulations for school and work).
8. Social behaviour (including, but not limited to tackling delays, knowing when it is appropriate to contact others, knowing what to talk about in different situations, relationship to others, socially acceptable behaviour, acceptable hygiene).

The results from the interviews can be summarized in the following way:

1. Work leaders in sheltered workshops think many skills could have been trained earlier. Especially important is the development of socially acceptable behaviour and hygiene (including both personal hygiene and for clothing).
2. There is no standard for IADL-training for children and young persons with intellectual disability. There is no curriculum or checklist for what is important to learn if the potential for learning such activities seems to be present.
3. IADL-training (subjects and amount) is not only dependent on pupils and parents, but on experience, views and traditions of schools and individual teachers.
4. At schools and other institutions there is little training of young persons with intellectual disability in ICT apart from basic PC-skills. Only two of the informants said they were offering training in the use of mobile phones (at the lower secondary school and adult education). Furthermore, there was minimal interest in teaching pupils how to use digital cameras.
5. Children and youths with intellectual disability like to use PCs and mobile phones. Typically, the sessions using PC-programs last until the teacher stops them; the pupils themselves like to continue as long as possible. Mobile phones are usually not used in classes, but teachers and work leaders note that youths with intellectual disability use them often when permitted (in breaks etc.).

## RESULTS FROM THE ICT-SURVEY

### **Programs developed for pupils with intellectual disability**

In the survey, we found very few programs focusing on IADL and developed particularly for pupils with intellectual disabilities. Most of these programs were at a beginner's level. An example of this is time training just in hours, half hours, quarters and 5- minutes, but not minutes and seconds. Often, such programs had rather childish graphics.

These programs were often only available on CDs, and had a much higher cost per pupil than online programs.

The fact that we only found a few programs in ADL-topics is consistent with the findings from a report published in 2008 (Directorate of Education and Training) about the need for specially adapted learning resources in Norway. This report was commissioned by the Directorate for Education and Training. It was based on informant interviews of persons involved in special education. It stated that most young persons with intellectual disability need specially adapted learning material. Many of them will have a need for training in basic skills and knowledge in secondary school in order to master daily life and society. They need wide multifunctional learning resources that could be adapted individually to the needs of each pupil. There is a need for digital learning aids that combine text, sound, picture and video.

### **Programs for mainstream pupils**

Some of the identified IADL-activities were included in programs for mainstream subjects such as mathematics. There were many programs for children aged 6 to 10 years that included IADL-subjects such as time, date, money and basic PC-skills. Typically there was not very much focus on each IADL-activity, like telling the time, knowledge of money and shopping.

Interestingly, programs for mainstream schooling were in general not as childish as programs for special education. This seems to be due to a deliberate development from the national education authority after the introduction of the education reform in autumn 2006. Programs for special education were often older than this. Online programs were most often used for mainstream students together with text books. At the time that the survey was conducted, these programs were typically available free of charge.

Very often programs developed for mainstream education were not suitable for persons with intellectual disability. Most often literacy was assumed. Moreover, the older the target students, the more complex language and less motivating factors were used.

### **Web-based survey**

There were 75 respondents in total. More than half of them were parents. Many parents were also professionals within relevant areas. 95 % of the respondents thought there were challenges with IADL-training and pointed out what kind of challenges they had experienced. 87 % of the respondents thought there was a need for more IADL-training than they had experienced so far.

Figure 1 shows the number of respondents who had experienced the different challenges. The figure shows the total number of persons who have ticked this issue, not percent of respondents (N=70).

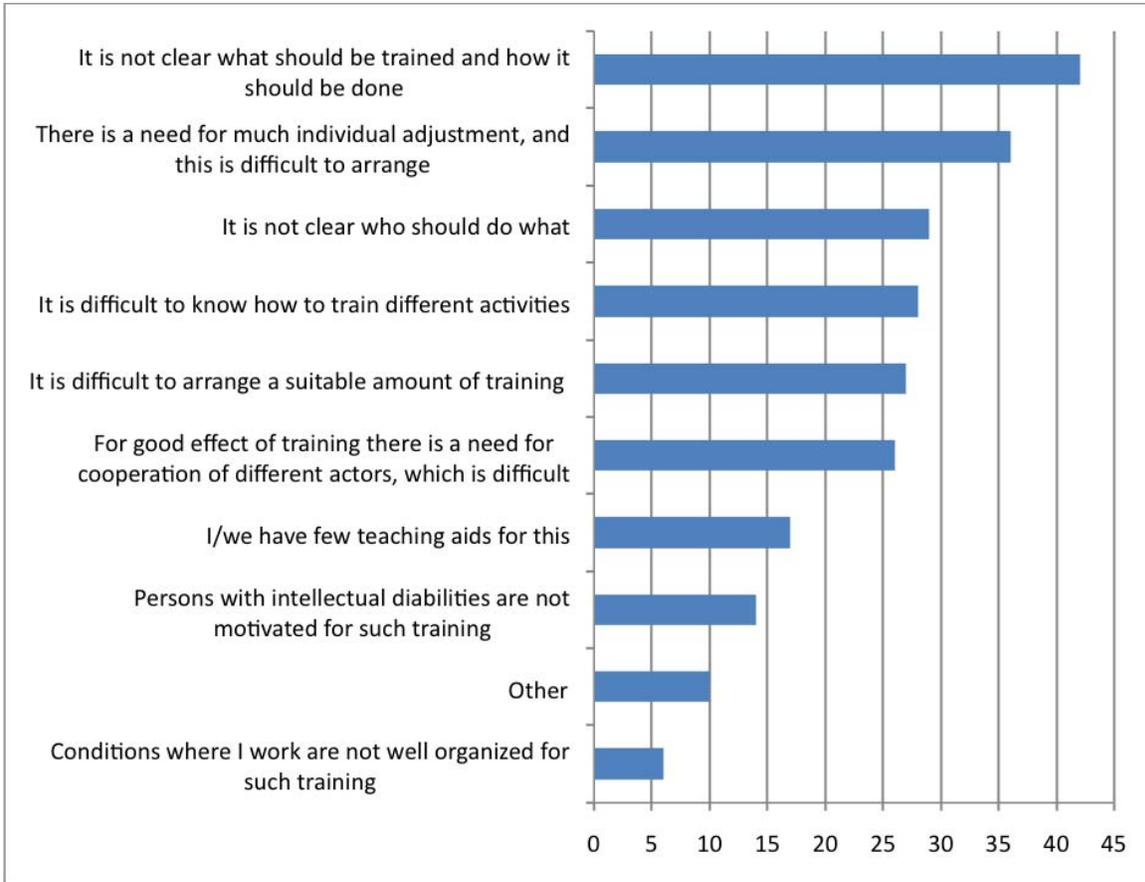


Figure 1. Number of Respondents Experiencing Specific Challenges with IADL.

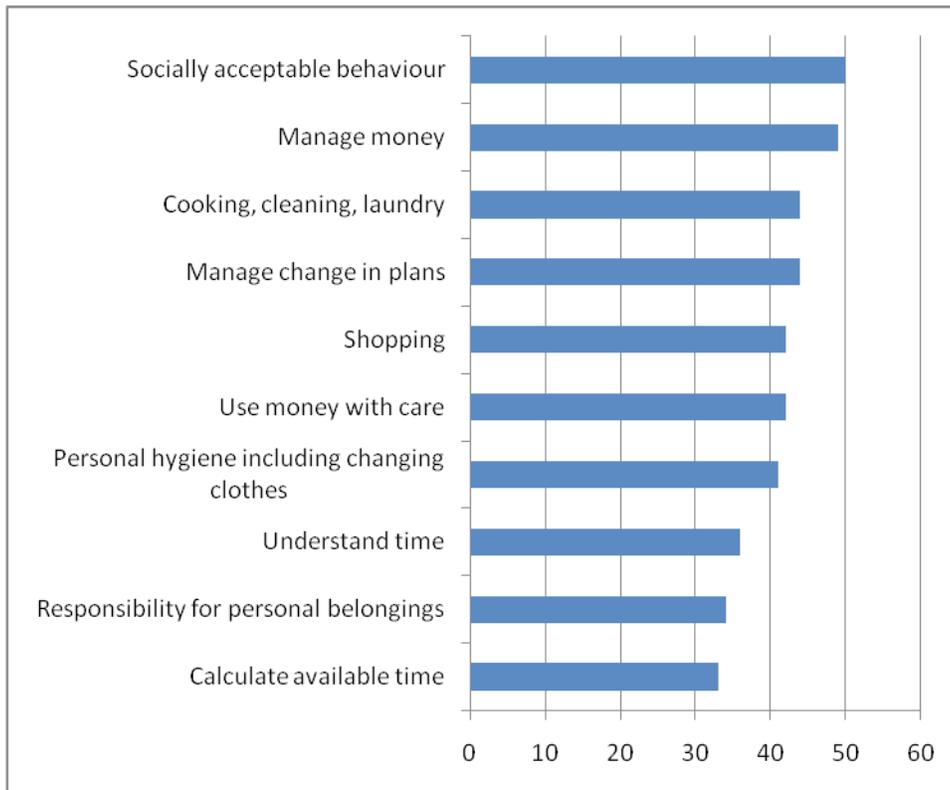


Figure 2. Number of Respondents Identifying Need for further Training in Specific IADL Activities.

The main issue seems to be that it is not clear what should be trained and how it should be done. This was experienced by 42 persons, or more than half of the respondents. Another important issue seems to be that many individual adjustments are needed in IADL-training (as pupils in special classes often are at different levels and have quite different needs), and this is difficult to arrange. Unclear responsibilities for who should do what kind of training also gets a high score, followed by "It is difficult to know in detail how to train different activities". Many of the respondents had not experienced a suitable amount of training. Typically there are some favorite activities such as baking Norwegian waffles. This is not very difficult, and it is often performed repetitively. Other training which is important for future life is often done very briefly.

With regard to the need for more training in IADL-activities related to education and work, 50 persons or 67 % thought socially acceptable behavior was important. Almost the same number of persons indicated the need for more training in handling money. Third in importance was household activities like cooking, cleaning and laundry. The same number of respondents thought there was a need for more training in managing changes in plans without being frustrated or otherwise unable to cope with it. Shopping and the use of money with care and personal hygiene, including changing clothes, were rated equally. This is followed by telling the time, taking responsibility for personal belongings and calculating available time.

The activities in figure 3 seem to be even more related to self-reliance and the basic use of mobile phones and PCs.

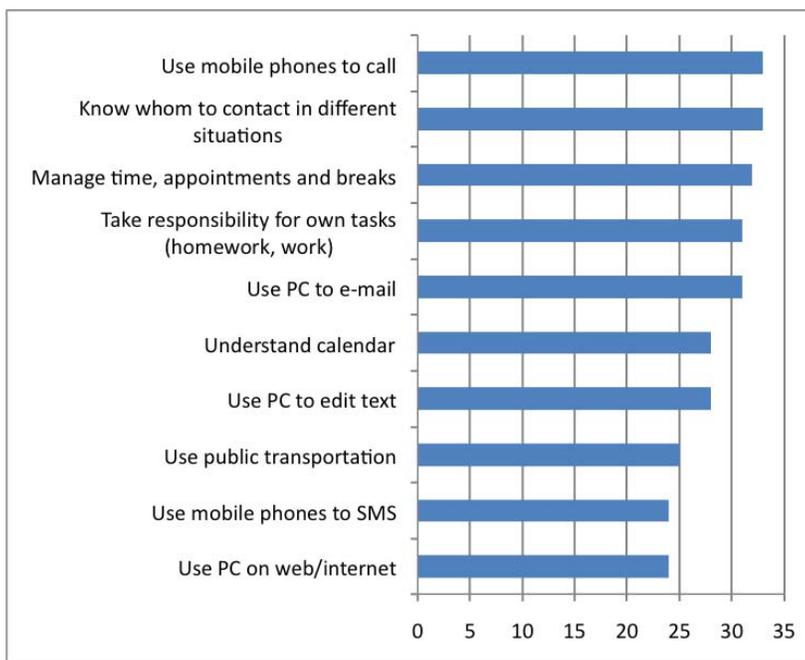


Figure 3. Number of Respondents indicating needs for IADL and related Training in Self-reliance and use of Hardware.

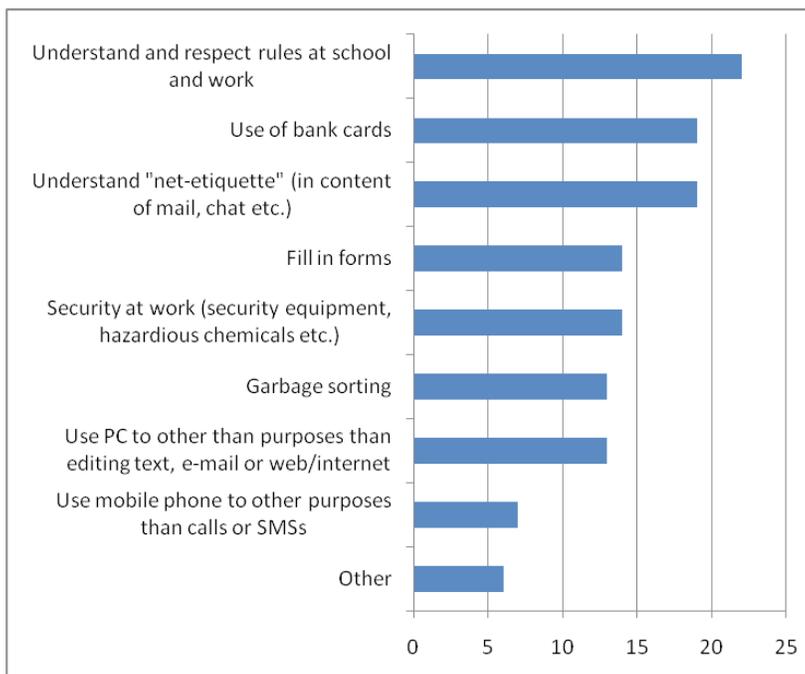


Figure 4. Advanced Activities believed to be Unrealistic for Many Persons with Moderate and Severe Intellectual Disabilities.

More than half of the respondents indicated that they had experience with persons with moderate intellectual disability, 12 % had experience with mild, 8 % severe and 23 % mixed groups. For many persons with intellectual disability of moderate degree the activities in Figure 4 are so advanced that they are not realistic to master.

### Conclusions

IADL-training in Norway is not particularly well-structured, and there are many challenges related to such training. There is a clear need for more IADL-training in very many topics. The web-survey revealed alarming results with regard to IADL-training with three major challenges: 1) it is not clear what should be trained and how it should be done, 2) many individual adjustments are needed in IADL-training and this is difficult to arrange, and 3) it is not clear who should teach the youth what.

Youths with intellectual disability are highly motivated to use PCs and mobile phones and are often mastering the use of such information technology surprisingly well. There are few ICT-based programs within IADL that are suitable for youths with intellectual disability. Not any programs using mobile phone technology was found even if our target group is very enthusiastic about using such devices. The researchers believe that for youths with mild to moderate intellectual disability almost all IADL-activities mentioned in this paper can be trained by using such technology, supported by real life training. More research is needed to establish the learning effect of using communication technology to scaffold learning and independent living.

### Recommendations

We recommend a more structured IADL-training for reaching the individuals potential for independent/self-dependent living. To obtain this the development of age- and capability-adjusted PC and mobile phone programs for IADL-training would be desirable. The training should be both theoretical and connected to real situations with real objects. The incorporation of self-produced material (such as photos, videos taken by teachers, pupils themselves and/or parents) seems very useful. This could easily make the youth understand how to do tasks in usual situations in his/her daily life. For example, photos of the different objects to be placed in the school bag or rucksack could help the youth to take responsibility for doing the packing himself/herself. Another example is a video describing how to buy a bus ticket at the local bus stop. The pupil could bring the bus ticket to school, register on the PC or mobile phone each time this is done, and a specific number of such registrations could lead to a diploma. For most people mastering activities of daily living and reducing dependency on others help to increase the quality of life. Many of the activities mentioned in the context of the web-survey may increase social inclusion.

### Future work

As a result of the study presented in this paper, we have produced rather detailed requirement specifications for ICT-based programs for IADL-training, and are currently

proceeding to the development of such software for PCs and mobile phones. The project team is currently developing prototypes of mobile phone software to support IADL training. In connection with this software development it is important to develop guidelines for using the software, both for the pupils themselves, as well as their teachers, parents (and other family members), carers and work leaders. This is in line with the findings in the report by Directorate of Education and Training (2008), concluding that more teachers' material for using software in the teaching was highly wanted.

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# Preventing Social Isolation in Adulthood: A Discussion Around Four Vignettes

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## **Abstract**

While adulthood has many positive features, referrals to a psychology clinic over the past ten years reveal that a number of men with Down syndrome become increasingly socially isolated once they leave school and this can result in depressive symptoms and poorer quality of life. In contrast, the presence of social networks and social supports are known contributors to emotional and psychological resilience and well-being. Four clinical case studies are shared to highlight the challenge that men with Down syndrome may face with respect to their social relationships after leaving school and when family dynamics change. They highlight the need to ensure preventative strategies and appropriate supports are cultivated to foster friendships and relationships, particularly at key transition points throughout adult life

Keywords: Social isolation, Relationships, Networks, Socio-emotional support, Down syndrome

## **Introduction**

There are many types of human relationships and interactions that can involve both joy and pain. Not all relationships are positive or supportive, especially when there is conflict, breakdown or betrayal of trust involved (Hall & Wellman, 1985; McVilly, 2006; Knox & Parmenter, 1993; Wellman, 1981, 1982). However, social networks involving friendships and relationships have been found to be essential for the experience of overall well-being, better physical and mental health in a number of contexts, better quality of life, greater resilience, and an increased sense of satisfaction with social support (Brown, 1997; 2009a; Dangan, 2007; Duck, 1991; Filary & Pernice, 2006; Hatton, 2002; Hensel, Kroese & Rose, 2007; Knox & Parmenter, 1993; McVilly, 2000, 2006; Renblad, 2002; World Health Organization, 2001).

Friendships are important throughout our lifetime, and it is critical friendships continue to be fostered and sustained in adulthood. This paper presents four vignettes from the author's own clinical work that indicate that this has not been the experience for a number of men with Down syndrome.

## **Friendship and Family Changes**

Jim was one of a number of men with Down syndrome referred to a psychologist in Sydney, Australia over the past 10 years. While issues for women may be similar, Jim's story and the other vignettes shared here reveal that men with Down syndrome can become increasingly socially isolated once they leave school, and this can have serious consequences such as depressive symptoms and poorer quality of life, as it did in Jim's case.

## **Jim's story**

*Jim's parents were worried. Jim was spending more and more time in his room alone. Over the past months his communication and interactions had gradually reduced, and he was even refusing to go for his normally beloved daily walk to the local shop. He was still attending a weekly gym with his Dad and working three days a week in the community, with support from a local Disability Service. But Jim had lost interest in work and staff reported his productivity had reduced dramatically. Jim was only 23 years old. Jim lives with his Mum and Dad in a country community where he is well integrated. He has Down syndrome. A trip to the family Doctor resulted in a diagnosis of depression and a referral to a Specialist Disability Clinic located 300 kilometers away.*

*At an initial appointment, Jim's Dad explained that he and his wife were now retired and looking forward to enjoying a quieter and more relaxed lifestyle, as the other children had moved out to marry and/or complete further study. He expressed concern that a family friend had died recently and perhaps this was affecting Jim. However, talking with Jim himself, a different picture emerged. Jim failed to establish eye contact, spoke in monosyllables, waited for others to talk and failed to engage in conversation at all in a group setting. He appeared withdrawn and sad. When interviewed on his own, he nodded he was not happy and rated his current happiness at 2/10. He was adamant that the death of the family friend was not worrying him, nor did he want to make new friends or go out. Instead, he was desperately missing his siblings who had moved to other cities and towns to establish their own careers and families. The once busy, active home and social life that he enjoyed when his siblings were around and that Jim had thrived in was gone. The house was quiet and peaceful – not at all the environment this young man wanted or enjoyed. He felt very sad and alone. Jim had not felt able to tell his parents that*

*he was missing the very noise and activity and social chaos they were happy to have a break from.*

*Jim was assisted to share his feelings and the reason for this with his parents, and together they worked on plans to increase and maintain regular contact with his siblings, including visits to stay with them, return visits and increased telephone contact. This resulted in an immediate improvement in Jim's mood, and with additional strategies in place, Jim recommenced his regular walks. He is now communicating and interacting more with family and others in the community, and has been assisted to join a new sports club where he is meeting new people and learning a new sport. In a session with the psychologist four months later, Jim made regular eye contact, spoke in full sentences, and even volunteered some information about his life, including plans about an upcoming overseas holiday. He rated his happiness at 8/10.*

To be effective and satisfying, relationships require work and some reciprocity and mutuality, with opportunity to participate and influence or exert social power. Adults with intellectual disabilities can and do develop friendships based on mutuality and reciprocity, and documented examples exist of friendships marked by mutual exchanges involving shared emotional support, practical assistance, companionship and acceptance (Knox & Hickson, 2001; McVilly, 2001, 2006; Nunkoosing & John 1997). However, there is also ample evidence demonstrating that mere physical presence in inclusive settings does not necessarily lead to social integration and meaningful relationships for people with intellectual disabilities (Amado, 1993; Hagner, 1992; Knox & Parmenter, 1993; Shafer, Rice & Metzler, 1989; Van Dam & Cameron-McGill, 1995). Social networks for many adults with Down syndrome are often fewer than those enjoyed by other members of society and tend to consist of staff and family. This can result in less opportunity for friendships and communication, a limited number of activities and roles available and an unequal balance of power operating, such that people with intellectual disability can easily become passive, dependent and acquiescent (Emerson & McVilly, 2004; McVilly, 2001; Knox & Parmenter, 1993; Nunkoosing, 1997; Rapley & Beyer, 1996; Renblad, 2002).

Van Dam and Cameron-McGill (1995) expected that, once liberated from the restrictive environment of an institutional setting, people with intellectual disabilities would "go forth" and socialize. Instead, they found that these individuals had non-existent social networks, and the service system itself contained attitudes and practices that hindered friendships forming, such as concentration on the person and not relationships. They also discovered social networking did not occur naturally, but required a planned and concerted effort. These findings applied to people coming from institutional settings, but it now appears that similar circumstances can develop for adults with intellectual disabilities living in community settings and family homes. Not only are social bonds with school friends often severed or weakened once formal schooling ends, but key siblings without disabilities usually leave home to establish their own lives of study, work,

and relationships. For the adult with disability who remains at home, this can result in reduced social activities and social connections, and a sense they have missed out. They too usually long for greater independence, as well as intimate relationships, marriage and children. At the same time, aging parents tend to relax to enjoy some well-earned personal time and families assume that all is fine and relationships will continue naturally. But opportunities for creating new friendships and relationships tend to dwindle. This was Jim's experience. Strain and relationship breakdowns can also occur, further isolating individuals. These changes appear cumulative and their effects may go unrecognized until a crisis occurs. The implication is that planned and purposeful social networking needs to be sustained over time and the individual's satisfaction with their social networks reviewed regularly.

### **Loneliness and loss**

Deficits in a person's social relationships can lead to loneliness, which is a subjective experience that is more dependent on quality than quantity of relationships (Cutrona, 1982; Peplau & Perlman, 1982). Although loneliness and social dissatisfaction are not pervasive, several studies have reported significant loneliness among some adults with intellectual disabilities across a range of settings, including integrated study and work settings (Chadsey Rusch, DeStepahano, O'Reilly, Gonzalez & Collet-Klingenberg, 1992; McVilly, 2001, 2006). Parents and relatives may assume that because someone has a job or is integrated into the community that they have social support, but early studies such as that by Knox and Parmenter (1993) revealed that support in the workplace for adults with intellectual disability can be restricted, lack complexity and may not provide a sense of fulfillment. Furthermore, the interconnections that do occur still tend to be brought about consistently by the person's family or an organization with whom the person is involved. Clique analysis was used to investigate the relative frequency, reciprocity and the "who-with-whom" of interactions for a person with severe disability in an inclusive work setting. This woman was found to be a typical member of the network of people that greeted each other and shared daily small talk, as well as being a participant in social interactions related to work conversations. However, she was less involved in the personal conversations network and this did not extend beyond the workplace (Yan, Mank, Sandow, Rhodes & Olson, 1993). Such findings are common (Riches & Green, 2003) and it appears that while workplaces may provide instrumental support, they do not necessarily provide companionship or emotional support -these are generally provided by family or staff and friendships need to be fostered for lifelong inclusion (Brown, 2009a; 2009b).

Loss can also contribute to changes in social contact and increased loneliness. Loss and grief are a natural part of life. McBride (1996, p.2) stated:

*"It is a natural part of human life that we form attachments or bonds to other people in our lives and also to places, things, and ideas that have meaning for us; for example, attachments to people in our lives, to stages such as childhood, to our possessions*

*and homes, and to our ideas about work and career. Generally, we have a small number of people in our lives to whom we are very strongly attached, and if this attachment is broken a loss occurs and a grief reaction follows.”*

Many individuals underestimate the amount of loss in their lives including loss of friends and family, changes in living arrangements that can disrupt relationships, ageing and bereavement. Parents and carers have often failed to recognise the impact such losses have on those with intellectual disability, including significant long-term effects on quality of life, mental and physical health and well-being (Allen, 1996; Ballin & Balandin, 2007; Bonell-Pascual et al, 1999; Hollins & Esterhuyzen 1997; Hollins & Sireling, 1991; Knox & Hickson, 2001; Riches, 2008). Such a combination was found occurring for Mark.

### **Mark's story**

*Mark was in his mid thirties when he was brought to counseling by his mother. Mark has Down syndrome and had been diagnosed with depression by a psychiatrist two years earlier. He was also on psychotropic medication because he talked to imaginary people and engaged in a great deal of self-talk. He was heavily medicated, so much so that when first seen, he was falling asleep at 9 o'clock in the morning.*

*Mark lived at home with his mother and was working several days per week at a local McDonald's store where he cleaned tables, bathrooms and handled the garbage. He traveled independently to work and was supported by a Disability Employment Service. His productivity level had dropped dramatically and he was tired, lethargic, anxious and no longer living the active social life that he had enjoyed several years previously. He reluctantly attended occasional social functions, including a Down syndrome network, but contact with previous school friends and siblings had ceased. He had no social contact with anyone from his workplace.*

*Mark's mother reported Mark had been un-well two years previously with a viral infection and she thought his depression had started around that time. However, it was later found that Mark's grandmother had died of cancer two years previously. The grandmother had lived with Mark and his mother for many years and Mark had been very attached to her. Sadly, there had been an argument between the mother and grandmother immediately before her death over medical treatment, and although he did not talk about it, Mark had witnessed this angry outburst. His grief over the grandmother's death and the anger surrounding it had never been recognized or acknowledged.*

*Additional investigation revealed that Mark's father had died when Mark was a small child. His father had left a wonderful tape recording for Mark, telling him how much he loved him, and how proud he was of him. He also asked Mark to look after his mother. Over time, it became apparent that Mark could not express any anger towards his mother whom he was "looking after" and that any anger or frustration was consequently re-directed towards neighbors –the "imaginary people" he shouted at. When Mark was asked who else he*

*talked to, he drew a picture and said it was his father.*

*Mark was assisted with grief and anger work, and his mother worked hard to ensure important social networks were re-established. A brother returned from overseas and re-established regular contact with Mark, taking him out once a week to dinner, clubs and music concerts. Mark's medication was subsequently decreased as anxiety and depressive symptoms disappeared.*

### **Anger and anxiety**

Lack of social and/or practical skills, poor self esteem and fear of rejection are other powerful factors that can inhibit social contact and contribute to social isolation and loneliness among adults with disabilities. This has been experienced as the absence and/or loss of a close intimate attachment and/or the absence of a social network of friends with whom to share interests and activities (Nunkoosing & John, 1997). Other relationships can be ambivalent or conflicted, providing some aspects that enhance well-being, yet overall, resulting in considerable distress or social strain (Lunsky & Benson, 2001; Rook, 1984). This was the situation for Sheldon who wanted desperately to prove his competence and gain greater independence, but whose dependence on his mother and lack of contact from extended family resulted in a continuing spiral of anger, rejection, fear of rejection and self rejection.

### **Sheldon's story**

*Sheldon is a 31 year old man who lives at home with his mother and works in supported employment in the community. His father died when he was 14 years old, and his two elder siblings have left home. He has a fiancée who also has a mild intellectual disability. Both families are supportive of this relationship and Sheldon and his fiancée plan to marry in several years time. Parents assist them to go on regular weekly social outings and enjoy occasional family holidays together. However, Sheldon was referred to a psychologist because arguments with his mother were increasing. These arguments had sometimes lasted an hour at a time, and had involved property damage.*

*Sheldon would shout, swear, and throw small objects such as money, watches and phones when frustrated, upset or angry. He had also punched several holes in the wall. No physical aggression had ever been directed at his mother. Often, the trigger for these outbursts was considered small by Sheldon's mother, but not Sheldon, who admitted he would get cranky, anxious and stressed. His anger was fuelled by feelings of incompetence and self rejection. Sheldon has poor monetary skills and arguments often revolved around Sheldon wanting greater independence with his money and budgeting, even though he knew he often spent unwisely. Arguments also occurred when Sheldon refused to tell his mother where he was going or what he was doing time wise. He understood his mother did not trust his judgment and decision making, yet he saw himself as the man in the family who was about to take on new responsibilities and roles as*

he transitioned into marriage.

Sheldon also experienced significant anxiety. Worry that he would miss his bus to work each morning frequently resulted in arguments around his leaving for work way too early. But significant tension, worry and distress also related to expectations that extended family members would contact him by telephone. Sheldon often became agitated and angry as he waited for promised weekly phone calls that failed to eventuate.

Sheldon was assisted to develop better strategies for managing his anxiety, frustration and anger, his fear of rejection and self rejection. He began to communicate and negotiate more with his mother who was also supported to manage her emotions as Sheldon asserted greater independence and control.

### **Establishing and maintaining friendships**

Relationships are constantly changing and evolving, particularly at key transition points that affect the whole family such as leaving school, moving house or job, marriage, retirement etc. Family and staff have been found to play a critical role in assisting adults with disabilities to negotiate these transitions, and to establish, reestablish or maintain relationships with family and friends. Typically the focus has been upon the practicalities of social contacts, such as opportunities to choose activities, the frequency and range of contacts and activities available and support to physically participate in social encounters. Van Dam and Cameron-McGill (1995) effectively demonstrated the power of social networking that used a planned approach by skilled people to initiate friendships. Important steps in this process comprised establishing the person's interest, researching the interest, contacting a potential group, visiting the group, going with the person, actively facilitating interaction, then gradually fading or withdrawing as the person was accepted and actively participating. Brown (2009a; 2009b) recommended a number of strategies and tactics for widening social experiences, providing support, allowing the expression and discussion of choices and supporting and respecting these.

Maintaining friendships is just as critical. A number of friendships involve others with disabilities that emanate from school days or long-term relationships, and maintenance of these requires support and encouragement (Knox & Hickson, 2001). Indeed, adults with mild intellectual disabilities who participated in several focus groups about their friendships reported they were missing people from school and from places they used to live. Practical help with friendships is often wanted and needed for things such as transport to meet and go out with friends, to find a private place to talk, to invite friends to their place for meals or visits, to allow friends to pay when going shopping, to reciprocate and initiate contact using various means including internet or the telephone to contact friends, to buy presents for special occasions and to be notified if their friend was sick or in hospital and to visit friends in hospital (Brown, 2009a; 2009b; McVilly, 2006; Nunkoosing & John, 1997). For individuals living in supported settings Emerson and

McVilly (2004) also suggest that intervention at a systems level would appear critical to the promotion and support of friendship for people with intellectual disabilities, rather than simply to focus on the development of social skills of individuals. Emotional support may also be required.

### **Darren's story**

Darren presents as an outgoing and friendly young man, who wants to be friends with everyone. He is in his early 20s, lives with his parents and one younger sibling, and works in the community in a supported employment setting. Darren has a large family network comprised of his immediate family, grandparents, uncles and aunts. He loves to socialize and his favourite activities include visiting and going out for dinner with immediate and extended family members, having a drink with the men at the local football club and attending football and cricket matches with his uncles.

Darren has Down syndrome. He has very rigid thinking patterns and can easily become upset or offended when he misinterprets information. He does not like interacting with others who have intellectual disability and is particularly distressed when he meets or sees others who have Down syndrome. Unfortunately, Darren often gets upset and angry with key members of his family network, usually taking offence at some seemingly insignificant word or action that he interprets as rejection or being "put down". When this happens, he refuses to speak or interact with the person, obsesses on the "fault" or offence and cannot think about anything but the problem. Darren usually has a long list of people he is currently not talking to, because they have upset him. As well as family, this typically includes various people from his workplace, and local shopkeepers.

Darren needs regular support from immediate family and an external person to talk through these problems and incidents when he is upset. Only with this support is he able to let go of the problem and forgive the offending party. Without this regular support, Darren would quickly become isolated and totally cut himself off from the very people he likes and interacts well with. This would prevent him from engaging in his favourite activities and interests.

Little research has been undertaken regarding the emotional support required for maintaining satisfying relationships in this population. Yet teasing, rejection, misunderstandings, anger, conflict and jealousy are prevalent in relationships, causing considerable distress and contributing to relationship strain and breakdown (Riches, 1998). The lived experience of Sheldon and Darren demonstrate that attention to and support for these emotional components can be as essential for maintaining relationships as practical support.

### **Conclusion**

The presence of social networks and social supports are known contributors to emotional and psychological resilience and well-being. Yet changes over time, particularly at key transition points throughout adult life can result in diminishing social networks and social contact. Loss of

important contacts and relationships can lead to loneliness, depression, anger and grief reactions, as exemplified in several of these men's lives. The complexity of relationships, however, means that support is also required to negotiate those more difficult and painful aspects that are also part of friendships and connections, including misunderstandings, conflict, rejection and even betrayal. Failure to address these areas can also result in isolation and loneliness. These cases have been shared to highlight some of the challenges and stimulate efforts to ensure preventative and supportive strategies are cultivated. Further research and development is recommended in this critical area, and to determine whether the issues are the same for women as they are for men with Down syndrome.

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# Social Comparisons: Associations With Psychosocial Functioning In Individuals With Down Syndrome

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## **Abstract**

The importance of social comparison in the development of understanding of self is

well recognized in typically developing individuals but has been relatively neglected in the examination of constructs related to self-understanding in individuals with an intellectual disability. Social comparison has also been found to be associated with depressed mood, something to which individuals with Down syndrome may be prone. Using an interview procedure, 40 individuals (aged between 12 and 51 years) with Down syndrome completed a range of adapted questionnaires related to social comparison, self-concept, and mood. The data from 34 participants were included in analyses as others were judged to be responding acquiescently and thus excluded. Parents also completed a questionnaire about mood and provided information about the social engagement of their daughter or son. Social comparison was correlated positively with self-concept, and negatively with mood. There was a significant negative correlation between social engagement and social comparison with those who were more active in their communities reporting more negative social comparisons. The implications of these findings are explored and the difficulty of measuring these self-related constructs in individuals with an intellectual disability are discussed.

Keywords: Down syndrome, social comparison, self-concept, depression, social engagement, measurement

## **Introduction**

Individuals with Down syndrome have been identified as being vulnerable to depression in early adulthood (Collacott, Cooper, & McGrother, 1992; McCarthy & Boyd, 2001) although the contributors to this vulnerability are uncertain. One possible mechanism is social comparison, which is the process of comparing oneself to others. If this comparison is unfavourable, then poor self-concept and even depression may follow. The study reported here is an examination of the associations among social comparison, self-concept and mood in adolescents and adults with Down syndrome. In addition, social activity was considered as it may be a protective factor against lowered mood.

Social comparison is one of the processes by which individuals come to an understanding of their position in their social environment. Individuals may make downward comparisons by comparing their performance against that of others who are less competent or may choose to measure themselves against those who display more competence (upward comparison) (Delelis & Desombre, 2005). This latter is also referred to as negative social comparison. Individuals with an intellectual disability may be more likely than many others to use social comparison as a means of thinking about self. Weary, Marsh and McCormick (1994) identified uncertainty about one's own judgements and opinions as increasing interest in making social comparison, and Gibbons and Buunk (1999) found that those whose sense of control over their own lives was more limited were also more likely to use social comparison. Both of these attributes have been identified as aspects of the lives of many individuals with an

intellectual disability (see, for example, Bennett-Gates & Zigler, 1999; Zigler, Bennett-Gates, Hodapp & Henrich, 2002).

There are a very limited number of studies of social comparison by individuals with Down syndrome in the published literature. Social comparison generally begins to occur at around seven years of age in those who are developing typically (Harter, 1987). Glenn and Cunningham (2001) suggested that the results of their study of self-perceptions of individuals with Down syndrome indicated that those with a verbal mental age below 6 to 7 years were not making social comparisons. Most individuals with Down syndrome are unlikely to attain a mental age of this level before adolescence (see, Crombie & Gunn, 1998) with perhaps, the majority never reaching this developmental age (Carr, 2005). This may account for the neglect of this topic in the research on Down syndrome. Recent evidence suggests, however, that the process of social comparison begins earlier than previously thought (see, for example, Wilson, Hoshino-Browne & Ross, 2002) and the assumption that a particular level of ability is a requirement for social comparison is likely to be incorrect, although the form of social comparison and how it is expressed may well become more accessible as children age.

In a recent study, Glenn and Cunningham (2004) found that 65% of parents of a group of young adults with Down syndrome reported that their adult child compared him/herself to others, although 16% of this group were said to do so rarely. The majority were reported to make lateral comparisons (i.e. saw themselves as similar to), with only

small numbers making upward, downward or both upward and downward comparisons.

A smaller group was observed to make social comparisons during an interview designed to elicit information about self-perceptions. Of the group who made social comparisons during the interview, 17% made upward comparisons only, 27% made downward comparisons only and 41% made both upward and downward comparisons.

Social comparison has also been associated with self-concept, both in those who are developing typically (Butzer & Kuiper, 2006; Renick & Harter, 1989) and in those with an intellectual disability (Dagnan & Sandhu, 1999). Downward comparison is likely to improve self-concept whereas upward comparison is likely to result in poorer self-concept (Bailis, Chipperfield & Perry, 2005). Two studies of self-concept in those with Down syndrome found very positive concepts of self (Cuskelly & de Jong, 1996; Glenn & Cunningham, 2001). It is possible that individuals with Down syndrome are more likely to use downward social comparison. Crocker and Major (1989) suggested that stigmatised groups, including those with an intellectual disability, develop strategies to protect a positive sense of self, such as the use of downward comparisons. Crabtree and Rutland (2001) found that individuals with intellectual disabilities used this strategy, attending less to upward comparisons and placing more emphasis on downward comparisons. An alternative explanation is that the individuals in the Cuskelly and de Jong and the Glenn and Cunningham studies were not yet using social comparison and so their ratings reflected the high self-concepts typically seen in very young children.

Social comparisons have been related to the experience of negative mood in those who are developing typically, with those who make more upward comparisons being more likely to report increased negative affect (Bäzner, Brömer, Hammelstein & Meyer, 2006)

and to be more vulnerable to depression (Swallow & Kuiper, 1988). This association has been demonstrated also in individuals with an intellectual disability. MacMahon and Jahoda (2008) compared two groups of individuals with an intellectual disability; one group comprised individuals who had been diagnosed with depression. The groups differed significantly on social comparison, with the depressed group reporting significantly more negative (upward) social comparisons. McGillvray and McCabe (2007) also examined the association between depression in individuals with an intellectual disability and social comparison. Their study included 151 adults with an intellectual disability (described as moderate/mild on the basis of files held by their employment agency) who were able to complete an extensive interview. The participants were divided into a depressed group, an at-risk group and a non-depressed group. The three groups were found to be significantly different in their social comparison scores: the depressed group had the most negative social comparisons scores, the at-risk group had the next lowest, and the non-depressed group had the highest (most positive) scores. Social comparison did not, however, contribute significantly to the depression measure when included in a multiple regression with other predictors.

Social engagement not only provides opportunity for social comparisons but also allows other people to influence individuals' self-concepts (Banaji & Prentice, 1994; Renick & Harter, 1989) through the information and feedback provided (Harter, 1999). The association between social support and self-concept has been well researched in those developing typically. Parents' acceptance and approval has been found to be positively

associated with high self-concept in children (Harter, 1996); however, as adolescents get older, peers become much more influential on a person's self-concept, in comparison to parents (Hay & Ashman, 2003). The association of social activity with social comparison, self-concept or mood has not been extensively investigated in those with Down syndrome, although this group is vulnerable to social isolation.

In general, individuals with Down syndrome have limited opportunities for social contact with peers, particularly after their involvement in formal schooling ends. Fujiura, Fitzsimons, Marks and Chicoine (1997) conducted a study with 49 adolescents and adults with Down syndrome. Among many other variables, the authors measured the average level of social activity and found around 49% of the participants were involved in one or less than one social activities per week. It was also found that around a third did not have a close friend. Jobling and Cuskelly's (2002) study on the lifestyles of adults with Down syndrome found that a substantial proportion were reported to have no friends outside their immediate family.

The current study examined the associations among social comparison, self-concept and depression. We hypothesized that individuals who made more negative (i.e. upward) social comparisons would have poorer self-concepts and more depressed mood and that these latter would be positively correlated.

## METHOD

### Participants

Forty individuals with Down syndrome and their parents agreed to participate in the study. These comprised 19 adolescents with Down syndrome (11 females) aged between 12 and 17 years ( $M = 15$  yrs 0 mths,  $SD = 1.52$  yrs) and 21 adults (8 females) who ranged in aged from 25 to 51 years ( $M = 34$  yrs, 9 mths,  $SD = 7.53$  yrs). We had decided to recruit both adolescent and adult samples in order to increase the spread of developmental level, as this aspect has been identified as important in the use of social comparisons. The mean age of the entire sample was ( $M = 24$  yrs 6 mths,  $SD = 10.49$  yrs).

The most recent form of schooling for the majority of participants was provided in a segregated setting (61%). Five adult participants were attending post-school educational programs. Thirty-nine participants were living in the family home; one was living in supported accommodation. The majority (70%) of participants were identified as having no or only minor health problems; 30% were reported to have

several or serious health problems. Only one participant was reported to have a diagnosed psychological problem, which was depression.

### **Instruments**

One of the most substantial issues when collecting information about self-perceptions from individuals with an intellectual disability is the level of understanding of the respondents. An additional issue that must be considered is the propensity to acquiescent responding that has been identified as an attribute of individuals with an intellectual disability (Bybee & Zigler, 1998; Finlay & Lyons, 2002), possibly in response to poor understanding of the material presented to them. Despite these difficulties, self-report is clearly to be preferred when the matter under investigation is psychological and subjective states (Finlay & Lyons, 2001). Most studies that have examined the issues which are the focus of this study have been conducted with individuals whose intellectual level is above that generally attained by individuals with Down syndrome (e.g., Crabtree & Rutland, 2001; MacMahon & Jahoda, 2008); therefore some modifications were made to the methods and instruments used in this study, following the advice provided by Finlay and Lyons (2001). These are described below.

### **Instruments Completed by the Individuals with Down syndrome**

Social Comparison Scale (SCS; Allan & Gilbert, 1995) is designed to measure the types of comparisons a person makes between him/herself and other people. The version used in this study was modelled on Dagnan and Sandhu's (1999) adaptation of the original version in that it adopted simplified wording of items and a shorter response scale than the original. Unlike the shortened version used by Dagnan and Sandhu, which comprised 6 items, this study included all original 11 items. Each item consists of two opposing responses, for example, "when I am with other people I feel worse than other people" or "I feel better than other people". In contrast to the original scale, the order of positive and negative response options was varied to minimise and detect response biases. The total score is calculated by reversing the scores of the negatively

phrased items and then summing all items. The higher the score the more positively a person compares him or herself with others; that is, the more downward comparisons are used. Dagnan and Sandhu used their amended version with a group of adults with an intellectual disability and reported an internal consistency of .56 and a test-retest reliability of .84. Internal consistency is a property of the interaction between the scale and the sample with which it is being used and is also affected by the length of the scale, with longer scales generally producing higher reliability. Based on these considerations and the relatively poor internal consistency reported by Dagnan and Sandhu we decided to use the complete scale in this study.

**Self-Perception Profile for Children** (SPPC; Harter, 1985) measures self-concept using self-report. The SPPC was considered most relevant for this study as it provides a measure of global self-worth. The SPPC comprises 36 items

that contribute to 6 subscales (Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Behavioural Conduct and Global Self-Worth). Small adjustments were made to the wording of the items in order to make them easier to understand and more relevant to the participants, e.g., the phrase "some kids" was changed to "some people". For adult participants, items that contribute to the Scholastic Competence subscale were reworded to make them work rather than school related. The question set used depended on whether the participant was studying or had a job. Each item is scored on a 4-point scale (1-4). After reversing negatively worded items, mean scores are calculated. Higher scores represent more positive self-concept. Crabtree and Rutland (2001) reported internal consistencies of .73 for Global Self-Worth and a range from .56 to .78 on the others subscales for a group with moderate intellectual disabilities.

**Zung Self-Rating Depression Scale** (Zung, 1965) is a self-report measure of depressive symptoms. The version used in this study was modified by Reiss and Benson (1985) for use with participants with intellectual disabilities. This modified version omits one question of the original 20. This question asks about enjoyment of sex and was omitted by Reiss and Benson on the assumption that lack of enjoyment of sex may not be related to mood in this population. Dagnan and Sandhu (1999) simplified the response format from a 10-point rating scale to a dichotomous (yes, no) scale for their study and this adaptation was adopted in the current study. The order of positively and negatively worded statements was balanced to minimise response bias. The total score is calculated by reversing the scoring for the positively phrased items and then summing all items. Higher scores indicate more depressive symptoms. Powell (2003) examined the internal consistency of the Zung in a sample of people with Down syndrome and found it to be moderately reliable ( $\alpha = .58$ ) and Dagnan and Sandhu reported the test-retest reliability of their short form SCS to be .75 for their sample.

**Peabody Picture Vocabulary Test, Third Edition** (PPVT-III, Form B; Dunn & Dunn, 1997) is a measure of receptive vocabulary. It can be administered to individuals from 2 ½ to 90 years of age. Age equivalent scores were used in this study.

### **Instruments Completed by the Parents of the Individuals with Down syndrome**

**Mood, Interest and Pleasure Questionnaire** (MIPQ; Ross & Oliver, 2003) measures the frequency of behavioural correlates of depression as observed by someone who knows the person well. The measure consists of 25 items, with a 5-point Likert scale response format. The 25 question items comprise two subscales, Mood and Interest and Pleasure. Parents are asked to recall the presence and frequency of certain behaviours in their child over the past two weeks. Higher scores indicate positive mood, and increased interest and pleasure. Ross and Oliver (2003) derived reliability and validity scores for the MIPQ on a sample of adults with severe and profound learning disabilities, with a key worker as the informant. The MIPQ was reported to have a respectable test-retest reliability of .86 and a high internal consistency

of .94.

**A Social Activity Diary** was constructed for the parents to record the social activities of their child over a one-week period. The page was divided into six columns for day, activity, number of family members present, number of friends present, number of staff present and length of time of the activity. Printed at the top of the first page were the words: "for the purposes of this diary, social activity is defined as activity that involves interaction with other people". There was space in the diary for parents to record other comments if desired.

### **Procedure**

Ethical clearance for this study was provided by the ethics committee of the School of Psychology at The University of Queensland.

### **Recruitment**

This study recruited participants from several different sources within South-East Queensland, Australia including a database, held by the Down Syndrome Research Project at The University of Queensland, which included families who had indicated their interest in being involved in research. Others were recruited through adult services for adults with an intellectual disability. Five individuals were introduced to the researchers by already recruited participants. In total, 179 invitations were mailed; 40 families met the criteria of having an individual with Down syndrome between 12 to 17 years or 25+ years and agreed to participate. Parents returned consent forms by mail and informed, voluntary consent was obtained from the adolescents and adult participants prior to conducting the interview. The majority of parents completed the questionnaires and returned them by post. Several preferred to respond to the items over the telephone. Parents provided all demographic details including health information.

### **Presentation of questionnaires**

Each of the items of the SCS, SPCC and the Zung were read to the participants with Down syndrome simultaneous with the presentation of the item in printed form. The researcher pointed to the appropriate words as they were read. Each item was on a separate page, printed in Times New Roman 36 point font in landscape-format on A4 paper. The most salient words in each response pair were printed in bold, in the case of the SRC and the SPPC; for the Zung, the most salient word in the item was highlighted.

The SRC and the SPPC followed the format developed by Harter (1982) for use with young children. Two circles were drawn below each response; one large with "a lot like me" printed underneath and one small with "a little bit like me" printed underneath. Below each statement of the Zung was printed the words "yes" and "no".

To assess acquiescent responding, three items were added to the end of the Zung. These items were directly opposite in meaning to the original items 4, 11, and 12.

A pilot test was carried out on two individuals with Down syndrome aged 18 and 22 years, for the purpose of identifying any potential areas of difficulty and to ensure that the interview delivery method was standardised. The pilot study highlighted areas requiring adjustment, which included the response scale for the Zung and the order in which the measures were delivered. The pilot test also indicated that a short break was needed in the middle of the session. These changes were made for the subsequent data collection.

For the purpose of maintaining consistency, all of the interviews were conducted by the second author. They were conducted at the place most convenient for the participant. The participant and the interviewer became acquainted with each other through an informal conversation upon first meeting. The purpose of the study as well as confidentiality and the participant's right to withdraw from the study were then explained to the participant. Both the participant and a witness signed a consent form prior to the interview being conducted.

The PPVT-III was administered followed by the Zung. After a short snack and exercise break, the interview resumed with the administration of the SPPF followed by the SCS.

## **RESULTS**

### **Preliminary Data Analysis**

Five parents did not return their questionnaire pack and therefore their data are missing from the analyses. An additional four parents did not return the social activity diary with their other questionnaires, or returned it blank; therefore these data are also missing. In addition, six respondents with Down syndrome were judged to be answering acquiescently, based on their response to the identified questions, and all data from these respondents and their parents were removed from the data set. Thus, data from 34 participants with Down syndrome were used in analyses.

Responses on the Mood and Interest subscales of the MIPQ were found to be highly correlated ( $r = .78$ ) and so were combined. Only this combined total score was used in subsequent analyses. Checks were performed for missing data and normality. The MIPQ was found to be negatively skewed. As only one participant reported a diagnosis of clinical depression, this disproportionate reporting of positive mood scores was to be expected. Logarithmic and square-root transformations did not improve the skewness of the data. On the basis of this lack of improvement and for simplicity of interpretation, it was decided to use the untransformed scale in subsequent analyses. Missing data from the other instruments were deemed to be unsystematic. Data missing from any of the scales were replaced by the mean of the participant's answers on the same scale.

Internal consistencies of all scales were investigated and the results of these analyses are summarized in Table 1. All six subscales of the SPPC had unacceptably low alphas, and as our interest was primarily in the rating of global self-concept only this subscale was considered further. Negatively worded items appeared to be particularly difficult for these participants so Cronbach's alpha was calculated

using positively worded items only. The resultant alpha level of .63 was deemed acceptable. The data used in analyses comprised the modified scales as described in Table 1.

Chronological age (CA) was not normally distributed as a result of our recruitment strategy, so Spearman correlations were used to examine the associations between CA and the other variables of interest. CA was not associated with the

age equivalent score of the PPVT-III ( $\rho = .10$ ), nor with any other variables in the study. Age was also considered as a group variable and with one exception, described below in the section on social activity, there were no differences between the adolescent and adult groups with respect to the variables used in the study so the two groups were combined for all further analyses.

Table 1. Cronbach's alphas, modifications to instruments, and range, means and standard deviations of measures

Measures	Original Alpha	Modification	New Alpha	Possible Range	Study Range	Mean	Standard Deviation
<b>Social Comparison Scale</b>	.60	Removed items 4 & 11 <sup>d</sup>	.67	9-36	18-36	28.74	5.43
<b>Global Self-concept<sup>ac</sup></b>	.38	Only +ve items included	.63	1-4	1-4	3.20	0.85
<b>Zung Self-rated depression<sup>a</sup></b>	.56	Removed items 8 & 17 <sup>e</sup>	.62	0-17	1-11	5.38	2.83
<b>Mood, interest &amp; Pleasure Q'airre<sup>b</sup></b>	.94	Nil	.94	25-125	68-123	97.68	12.73
<b>PPVT III Verbal Age Equivalent<sup>a</sup></b>					21-124	60.97	23.09

<sup>a</sup>n = 34 <sup>b</sup>n = 30 <sup>c</sup> from the Self-Perception Profile for Children

<sup>d</sup> "When I am with other people I feel alone/not alone" & "When I am with other people I feel more left out/not as left out"

<sup>e</sup> "Sometimes I can feel my heart beating fast" & "My life is busy"

Table 2. Correlational table of psychosocial variables (n = 34)

	SCS	Global Self-concept	Zung Depression	MIPQ	Social Activity	No. of friends	PPVT VAE
<b>SCS</b>	1						
<b>Global Self-concept<sup>ac</sup></b>	.35*	1					
<b>Zung Self-rated depression<sup>a</sup></b>	-.41**	-.25	1				
<b>MIPQ</b>	.28	.11	-.30 <sup>d</sup>	1			
<b>Social Activity (n=26)</b>	-.53**	.08	.31	-.12	1		
<b>No. of friends<sup>b</sup></b>	-.06	.11	.01	.32*	-.12	1	
<b>PPVT VAE</b>	.29 <sup>c</sup>	.07	-.42**	.25	-.24	.03	1

One tailed\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

<sup>a</sup> from the Self-Perception Profile of Children <sup>b</sup> Spearman correlations

<sup>c</sup>  $p = .051$  <sup>d</sup>  $p = .052$

### **Social comparison**

Twenty-two participants (11 adolescents, 11 adults) were reported by parents to make social comparisons. Of those making social comparisons, 14 made positive (downward) comparisons, 3 made negative (upward) comparisons, 3 made neutral (lateral) comparisons and 2 made both positive and negative comparisons. These comparisons were made most often with siblings (33%), other people with Down syndrome (25%), people of the same age (22%), other people with a disability (14%), and television personalities (6%). There was no significant difference in PPVT-III AE scores of those who were reported to be making social comparisons compared to those who were not.

The means for the measures used in this study are reported in Table 1. As a group, the participants in this study viewed themselves positively in comparison to others, had a positive global self-concept, had a mean score virtually at the first third of the self-report measure of depression, indicating healthy functioning, and were reported by their parents to be positive in their expression of their mood.

Correlations between the measures of interest were run. See Table 2. As hypotheses about the direction of these associations had been made, one tailed tests were used. Social comparison was positively correlated with global self-concept and negatively with self-reported mood. Those who made positive social comparisons were more likely to be happy with themselves and to report better mood. Verbal ability was significantly associated with self-reported mood with those with better ability reporting more negative mood.

### **Social activity**

Data from the social activity diaries were analysed. Due to the structure of this diary, a broad range of information was reported. Some parents/guardians were meticulous in filling every space with details of activities, others were less so. The total number of activities recorded for adolescents ( $M = 15.17$ ,  $SD = 4.57$ ) was significantly higher than that for adults ( $M = 10.85$ ,  $SD = 5.39$ ),  $t(29) = 2.41$ ,  $p = .02$ . When school and/or work was excluded from the total, however, there was no difference in the number of social activities for adolescents ( $M = 6.22$ ,  $SD = 2.39$ ) and adults ( $M = 5.77$ ,  $SD = 5.60$ ),  $t(29) = .31$ , ns. The most common type of activities recorded were interaction with family (64%), sport (18%), interaction with friends (11%) and watching television at home (7%).

A negative correlation was found between scores on the SCS and the number of social activities reported by parents. The measure of social activity used in these analyses was that of social activities with school and work related activities removed. Those who were

more socially active made fewer positive social comparisons. No significant correlation was found between the number of social activities and total MIPQ scores.

### **Friendship**

The average number of close friends parents/guardians reported for their child was 2.15 ( $SD = 2.52$ ). A total of

fourteen respondents reported the individual with Down syndrome had no close friends. One parent reported 10 close friends of their child. No difference was found in level of self-concept or any of the other variables of interest when the data were coded for the presence of at least one friend or having no close friend. Number of friends was unrelated to all measures except parental report of mood. Parents who reported their child had a higher number of friends reported better mood.

### **Discussion**

Almost all participants in this study were able to respond to the questionnaires in their modified form, although a small number appeared to be acquiescent in their responses. Internal consistencies were only barely adequate for some instruments so caution must be exercised in interpreting the results of this study. There was also a discrepancy

between the data collected: the data collected from the individuals with Down syndrome suggested that all but the six participants who were acquiescent in their responding were able to make social comparisons; however, only a little over 50% were reported to do so by parents. This discrepancy may reflect differences in spontaneous social comparisons and those produced when prompted to do so, for example as occurred in this study. Individuals may be capable of making these comparisons but may not do so unless prompted; or may make them but not share them with others unless asked about them directly. Clearly, more work needs to be done on both instrument development and on establishing effective data collection techniques with this population if we are to be confident that we have a solid base for understanding the internal processes of this group.

The mean score for the group on the social comparison measure suggests that most individuals made positive social comparisons; that is, they regarded themselves as doing better than others with respect to the attributes contained in the questionnaire. Nevertheless, there were some individuals for whom this was not the case, and there were also some items that were scored negatively (at the group level), indicating that some discrimination was applied to responses. The group mean was at the first third of the Zung scale suggesting they were not depressed, but also were not completely carefree.

Social comparison in this group of individuals with Down syndrome was associated with measures of self-concept and with self-reported mood as anticipated - those who made more positive social comparisons reported higher self-concept and better mood. The individuals who participated in this study were, as a group, less intellectually able than those in both the MacMahon and Jahoda (2008) and the McGillvray and McCabe (2007) studies; nevertheless, a similar association was found between upward social comparison and depression.

While in the same direction, the association with parental reported mood did not reach significance. Self-reported mood and parental report of mood just failed to reach the level of significance but, again, was in the expected direction. The very modest size of the correlation underlines

the importance of developing methods that provide reliable and valid measures of the self-perceptions of individual with intellectual disability – relying on proxy measures is a poor substitute.

The strongest correlation found in this study was between engagement in social activities and social comparison. Those who were more involved in activities outside school or their workplace were those who made the most negative (i.e. upward) social comparisons. This is not surprising as these individuals will have the most exposure to others with whom to make comparisons, many of whom will be more competent. It is also possible that those who are more engaged with their community are also those who are more capable and may therefore be more aware of differences, and/or of their own difficulties. This latter possibility is not supported by the results with respect to the measure of receptive language ability as it was unrelated to social activity in this study.

The small sample size may have contributed to the failure to find a significant association.

The age equivalent score of the PPVT III was negatively correlated with self-reported mood – those with higher VAEs reported better mood. The association between receptive vocabulary and social comparison almost reached significance, with higher scorers reporting more positive social comparison. One possibility to be considered is that those with higher receptive language abilities were better able to understand the questionnaires used in the study and to answer them more consistently, and did so positively. There was no relationship between performance on the PPVT III and parental report of the use of social comparison. While VAE was associated with scores on the instrument measuring social comparison there was no significant association with chronological age, indicating that the accumulation of experience alone does not determine the direction of social comparisons.

The correlations between social engagement and social comparison should not be used to argue that inclusion leads to negative social comparisons and thus should be avoided. The group, as a whole, made positive social comparisons. Involvement with a broader range of people may assist individuals to attain a more realistic understanding of self and thus to recognize some areas in which they might focus efforts of self-improvement. This exposure is also likely to provide them with experiences that enhance their view of themselves in contrast to others.

While measurement issues are the most important for immediate attention, there are a number of aspects of psychosocial functioning of those with Down syndrome that require further investigation. For example, there is evidence that situational factors affect social comparison (Buunk, 1995). This, in concert with our finding of more negative social comparison in those who have more social activity, suggests that examination of the conditions under which those with Down syndrome are likely to make upward or downward comparisons would be worthwhile.

The limitations of this study mean that the findings must be treated with some caution; however, the results do suggest that this is an area that requires further exploration

and that there are methods that may be able to be further developed to allow more rigorous scrutiny of the area. The limitations include the low internal consistency of the instruments, the incomplete data set from parents and the likelihood that those who agreed to participate in the study differ systematically from those who did not respond to our invitation. In addition, the sample does not represent those individuals who live away from their family home. It seems very probable that some of the associations identified in this study are mediated by other factors; however, the small sample size did not allow investigations of these.

The results do suggest an area that may have some utility for therapists working with individuals with Down syndrome or intellectual disability. Negative social comparisons may be making a contribution to mood disturbances, and intervening to assist individuals to reduce upward (negative) social comparisons may prove helpful for these

individuals. Cognitive therapies are being used successfully with some individuals with an intellectual disability and so social comparison may be a process amenable to intervention for this group. Collaboration between therapists skilled in working with individuals with an intellectual disability and researchers may also provide the most effective way to establish valid measurement approaches relevant to psychosocial processes for those with Down syndrome and others with an intellectual disability.

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# Beyond the Surface: The Context of Meaning-making through Visual Art of a Young Girl with Down Syndrome

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## **Abstract**

This study describes the construction of meaning-making through a drawing by a young girl with Down syndrome. The objective is to foreground the purpose and intent behind this young child's visual representation. Based on video observation and with the use of ethnographic content analysis, this investigation brings forward the richness and depth beyond the surface of an artwork, which, at first glance, resembles a 'mere scribble'. The findings reveal an intricate relationship and connection between graphic and narrative interplay, reality and make-believe, and influences from the social world. The nature of this investigation does not allow for generalizations, but instead emphasizes the unique nature of thought and action. The discussion points further at the possibilities of image-based research to gain a deeper understanding how individuals with Down syndrome experience life.

Keywords: Down syndrome, ethnographic content analysis, meaning-making, drawing, image-based research

## **Introduction**

In recent years there has been a growing interest in exploring the nature of young children's drawing and making tangible the complex process of construction of meaning-making (Brooks, 2009; Coates & Coates, 2006; Freeman & Mathison, 2009; Haas Dyson, 1997; Narey, 2009; Wright, 2003, 2007). Despite exciting new possibilities in research and changed understandings of young children as capable meaning-makers, there are few studies available on how individuals with Down syndrome express their experiences through art (Taylor, 2005). Personal investigations show that, when given the opportunity, individuals with Down syndrome are able and eager to use art to convey their intent (Joosa, 2008). Based on video-observations in a naturalistic setting this study explores the representational process of Julie, a seven-year-old girl with Down syndrome. The dialogue reflects an intricate process of how, through drawing and interaction, Julie shapes her understanding of the world in relation to the practices of her everyday life. It makes visible that Julie, just as most children her age, brings into this process her own knowledge and experiences. The qualitative nature of this study does not allow for generalizations. It provides opportunities to evaluate new foci in research and to consider how changing perspectives on representation can give new insights into the lives of individuals with Down syndrome.

When looking at Julie's drawing it shows an array of messy scribbles, lines and unidentified shapes. Without any background information, one would barely recognize that there could be a storyline behind her artwork. For many, this picture would hardly be worth a display or even a second glance and one might, perhaps, even question her expressive abilities. I often witness how art of individuals with a cognitive disability is labeled as "very special art"

(Wilson, 2004), thereby treating their art and its concomitant communication of meaning, as being different from the art of others or not meeting normalized standards. Without doubt, the developmental delays associated with her disability can easily be assumed as a cause of, or provide a plausible explanation for, the lack of maturity of her artwork. Some studies show that there are indeed quantitative differences between individuals with Down syndrome as compared to typical developing norms in art making (Cox & Maynard, 1998; Laws & Lawrence, 2001).

The last two decades have witnessed a significant shift in definitions and references to young children and researchers have given alternative understandings of their art-making. Researchers no longer seek generalizations but instead point at the intricate nature of visual representation and its role in construction of knowledge and socio-cultural-contextual influences (Gadsen, 2008). Matthews (1994, 1999) has provided strong arguments to look beyond the restrictions of developmental norms or "stage theories" and to consider the many additional influences on the artistic process of children. Matthews suggests that microanalysis allows for investigating and revealing of intricate networks of sensory channels that give evidence of the structure of events and objects.

Investigations show mounting evidence of children as competent meaning-makers, informants and participants who often use visual representation to express important events. Despite their sometimes unidentifiable images, investigations give evidence of their ability to use drawing as powerful tools for transformation of ideas and communication of intent (Anning, 2002; Anning & Ring, 2004; Brooks, 2004, 2009; Wright, 2003).

Meaning is an emergent process and not restricted to

drawing or another single modality. Young children often combine modalities and use their newly created signs as a means to make explicit the implicit dynamic aspects of intended meaning (Van Oers, 1997; Wright, 2007). Kress (1997, 2000, 2003) notes that meaning, mode, action, interaction and form are an indistinguishable whole and cannot be separated. He argues not to focus solely on the product but to expand our views and look into intentions and processes. The communicative nature of the drawing process gives evidence of children's knowledge and understanding of particular topics and the many layers of representational resources available to them (Kendrick & McKay, 2002, 2009).

The construction of meaning and use of resources does not take place in a vacuum, but is a process illuminated by a variety of influences, such as adult expectations, cultural beliefs, community and personal experiences and the relation of utterances on the drawing process (Cox, 2005; Coates, & Coates, 2006). Wright (2007, 2010) points at the need to include the intricate role of the interlocutor, who is often the adult in the communicative relationships with the child and to take into account the importance of sensitive responses.

The many additional dimensions in researching young children such as, intent of the researcher, the process of thought and action, the relation to contextual experiences and the variety and uniqueness of interactions, have directed researchers to explore different forms of qualitative enquiry (Leavy, 2009; Thomson, 2008). The number of participants in these explorations tends to vary, but seldom move beyond a selected group. A single participant is not uncommon in qualitative research, for example Matthews (1999) tracked the artistic development of his own son. Video technologies are an added force to reexamine established practices with young children. They offer new and exciting possibilities for the inclusion and understanding of the interactions between different modalities during drawing, such as the use of gestures and sounds (Flewitt, 2006; Norris, 2002; Wright, 2010). New and changing perspectives mark a significant shift towards the role of the child as a participant rather than subject in the research process and the importance of including children's original voices (Moss, 2008; Thomson, 2008).

In this qualitative study the drawing of a young girl with Down syndrome is explored. This study examines the emerging process of meaning-making with the aim to discover the development and construction of content and form, and to identify relationships and interplay between the narrative, context and other aspects.

### **Method**

Central to this study is seven-year old Julie's (pseudonym) drawing, both as a process as well as a product. As an art-educator, I have worked with Julie for a number of years, mainly in one-to-one situations, and am extremely familiar with her interests and work. Julie is a talkative, inquisitive and willing participant, who has been part of previous investigations on art and Down syndrome (Joosa, 2008). She

lives with her parents and older sister in Singapore. Just as so many other children with Down syndrome, Julie was born with severe heart problems. However, there is little evidence of the traumatic start she made early in life. Julie's situation is quite unique in Singapore, where there is a strong focus on academic excellence. Her parents made the decision to home-school both her and her elder sister as they preferred their children not to worry about rigid school schedules but to enjoy a "world" filled with books, pretend-play and family-life. It is hard to gauge Julie's mental age as her parents do not believe in testing, but her reasoning and language level could, however be regarded as on par with typical developing peers. Her parents' educational focus is on Julie's expressive communicative skills and self-determination, rather than on traditional pen and paper literacy activities. Julie's parents' view on Down syndrome is that one needs to bear in mind the characteristics of her disability, but as her mother highlights, "not everything needs to be attributed to Down syndrome".

The study uses Ethnographic Content Analysis (ECA) to investigate a video observation of Julie's representational process. ECA is an integrated qualitative method that allows for locating, identifying, retrieving, and analyzing documents and is often used to understand the product of a social action such as modes of exchange within media studies (Altheide, 1987, 1996). Altheide highlights that in contrast with the conventional mode of quantitative content analysis, ECA is an emergent process aimed at discovery of meaning through analyzing content, form, action, and narrative to reflect on the context and other nuances. Data were collected through in situ observations during one of our regular art sessions. Julie is familiar with me conducting video observations and a strategically positioned video camera captured the 45 minute art session. The analysis is based on a 10 minute segment, which was selected based on the richness of the data. The conversation was transcribed verbatim and details of gestures and other observations were added.

In my work as an art educator and researcher I focus on bringing out voice as a right to speak and to be represented (Thomson, 2008). Yet, children, with and without disability are vulnerable in research and care needs to be taken to respect the participant's privacy. To ensure the authenticity of personal information her parents have read this paper beforehand. As an acknowledgement to Julie, as well as her family's contributions and consent, this study is dedicated to Julie and her parents.

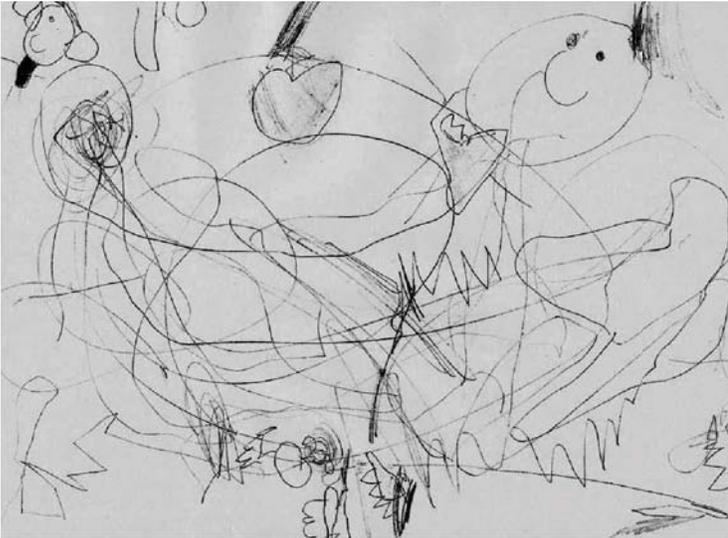
### **Findings**

This section reports on Julie's drawing (Figure 1) and the sequence of her actions in the drawing process. It presents various segments of the transcript, which were selected on their value in understanding the process. These segments provide insights into Julie's intentions, decisions, the use of materials, interactions and interplay between the graphic (e.g., form, line), the narrative (e.g. fictional, non-fictional) and the embodied (e.g., gesture, position) (Wright, 2010). Within the transcript the narrative is represented in normal script, while the embodied is represented in italics. Inferences and other explanations are placed in brackets.

## Meaning-making through visual art

For this art session, Julie brought along one of her favorite storybooks, "Strawberry Shortcake's world of friends" (Bryant, 2006). Julie positions herself on the floor and before starting she makes sure she has easy access to the art materials. Sitting next to me, she starts by drawing a simple human image and after some prompting introduces her story characters:

Figure 1. Julie's drawing.



Julie (J): Draws a person in the top center...This is Strawberry Shortcake (A fictional book character).

Esther (E): So this is Strawberry and who is this friend of Strawberry?

Although I know she can hear me Julie does not respond and continues drawing with her face close to the paper...What is the name Strawberry's friend?

J: Points at drawing this is Ginger Snack.

E: Uh? (It takes me some time to recollect the other book characters).

J: **This is Ginger snack!** Louder and with emphasis.

As we continue, Julie sets her expectations for me in regards to how, what and when to draw. She is particular about adherence and specifies our roles and positions. As the person in charge, Julie comments, assigns gender roles and assesses my contributions:

E: While helping Julie to look for pink crayons... So, Strawberry Shortcake likes pink. I wonder why Strawberry Shortcake likes pink.

J: Because she is having a baby... draws on the bottom of the picture and instructs you have to colour.

E: Ok, now I colour with pink... I take on role as participant and colour Strawberry Shortcake...Did I do this alright teacher?

J: Yes! She looks up while colouring her part and takes on the role of instructor you did a very good one! Well done!

The intensity on mark-making increases and Julie appears to become more and more involved. With a pencil she draws lines for actions, and her story emerges. Trying to indicate time and space, she rapidly moves her pencil around her paper to describe her trips to the hospital and home, while only stopping to mark some events that are in a locality, such as going to bed. She explains:

J: This is a baby... points at what she drew...She has a baby ...draws a line from Strawberry Shortcake... with her hand she points at her stomach indicating a rotating action... inside her tummy.

E: Inside her tummy? I indicate surprise... Ooh!

J: Draws circles... Hospital... draws lines... home... continues with the line... over here...and go back to bed.

E: Yeah. (Acknowledgement)

J: And back to bed ...continues with the line.

E: And what happens in the hospital... what happens in the hospital with the baby?

J: They take the baby out and then they bring it home... makes moving action with the pencil... put the baby here and back to bed!

E: And is Strawberry Shortcake very happy with the baby??

J: Yeah... Julie nods and draws circles with pencil on paper.

By now Julie is completely involved in her role. Fantasy and reality are taking on a complex role. Her picture shows a gradual transformation of meaning. It may seem that, with her scribbles at the bottom of her drawing that Julie is not responding accurately but sickness, time and action are difficult concepts to portray in a still picture and she is happy to provide details when asked:

E: I wonder what that is and point at the scribbled closures at the bottom of the paper.

J: This belongs to baby... the baby is not well and keeps on drawing

E: What happened?

J: He had to stay in bed ... while she speaks she stays focused on drawing task.

E: **Emphatic Oh, is the baby a little bit sick?**

J: Yes... Julie concentrates on her drawing ... he ate garbage...like this and makes gestures to the mouth.

E: I exclaim in shock the baby ate garbage things? How come the baby ate garbage things?

For a while Julie stops. I can see that she thinks about what is happening in her environment and how to further use the artistic resources. My role as co-participant becomes now an important story character. When she continues, she clarifies my role:

- J:** You are Esther, I am the baby. You always go the hospital *and points at direction of the hospital on the paper in the top left hand corner.*
- E:** So how many babies did I have?
- J:** One.
- E:** What am I going to call the baby...*I pause and get closer to Julie...*What would be a good name for my baby? What is a nice name for my baby? Shall we think of a nice name for my baby?
- J:** *Softly* Julie ...*and writes her name on the paper in the left-hand top corner.*
- E:** *I exclaim happily* Julie, ooh, I call my baby Julie! I think that is the most beautiful name for a baby ... Tell me what clothes shall I get for my baby?

### Analysis

In her drawing Julie enacts various characters and events and her story is a mixture of reality and fantasy. It illustrates a sophisticated narrative structure within her story, which includes a beginning, middle and end, as well as, an elaboration of characters and definitions of roles. By using the third-person narrative (Strawberry Shortcake as the pregnant mother, followed by me taking over the role of mother), Julie's story is almost similar to that of a documentary (Wright, 2010). Her many actions, explanations and comments indicate that she values her independence and negotiates her power both as initiator and controller (Matthews, 1999). The interactions highlight the position of the interlocutor. Indeed, this demonstrates the need to be sensitive in responses, such as to shift position or to take on multiple roles, ranging from participant, to student, to facilitator in order to bring about Julie's story.

Julie's artistic representation together with the dialogic interchange gives evidence to the unique and holistic nature of the contextual relationship and interaction between her drawing, thinking and meaning-making (Brooks, 2009; Wright, 2007, 2010). It may appear that Julie does not care about the aesthetic appeal nor has understanding of reality or form. However, an explanation from her parents reveals the meaning behind the many action lines and "scribbled garbage". It gives unique insights of Julie's involvement and thought in order to explain what could be the cause of the baby's illness. Recently the family revisited photo albums of Julie's birth in which she was pictured in the intensive care unit of the hospital awaiting heart surgery. At the same time, a family friend's baby is hospitalized and Julie's family is greatly concerned about this baby's recovery. This information from her parents illustrates the role of the social context and highlights the circumstances in relation to the development of text as well as Julie's position in this story. Indeed, when seen together with the interactions of accompanying narratives, gestures and contextual information, Julie's picture comes to life and shows the richness of this young girl's representation.

### Discussion

Solely relying on the surface of Julie's artwork could have created a false impression of her being artistically or communicatively limited. By taking the time to listen and look beyond the surface, it was possible to discover the deeper meaning embedded in her drawing. Moving reflexively between data and analysis gave the opportunity to increase the understanding of Julie's meaning-making process. Small details, such as the interplay between the many spontaneous and non-verbal exchanges, are often invaluable and allow deeper insight into individual intent and meaning-making (Deacon, Pickering, Golding, & Murdock, 2007; Flewitt, 2006; Norris, 2002). Definitely, the qualitative nature of this study, the focus on a single participant and the unique circumstances of Julie's art-making do not allow the findings to be generalized to the community of individuals with Down syndrome at large. Furthermore, the use of ECA and video observation is a subjective process, in particular, the mapping out and selection of examples. Despite these limitations, this study creates awareness of this young girl's sensitivity and how she is emotionally attuned to her social world. It draws attention to the focus of socio-cultural perspectives in understanding learning and behavior, which move beyond representation according to ages and stages. Indeed, it points at the need to critically re-examine the navigation that people do between social spheres and illustrates that communication, in whatever form, cannot be seen as context-free information processing, but is embedded in social relationships (Gee, 2008; Lewis, 2007; Lewis & Lindsay, 2000). It further foregrounds how art-based practices may provide additional tools to mediate and transform thought processes. It is with these insights and changing research perspectives that it will be possible to renegotiate previously held assumptions about self-expression and representation of individuals with Down syndrome.

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# Book Review

Rhonda Faragher, PhD

**Title:**

***Down Syndrome: When to worry about mental health and what to do about it!  
A Guide for Parents and Care-Givers***

**Authors & Affiliations:**

Robin Friedlander, Psychiatrist, University of British Columbia, Canada

Peter Johnson, Psychologist (retired), Canada

**Publisher:** NADD Press

**Country of Publication:** USA

**ISBN** 1-57256-068-1

**Reviewer:** Rhonda Faragher (PhD)

Senior Lecturer, Australian Catholic University.

**Rhonda Faragher is an academic, predominantly working in the areas of education, disability and quality of life. She is the mother of a child with Down syndrome and has other close family members living with mental illness.**

This small book (68 pages) ably lives up to the cover claim as a book written in a straightforward manner for care-givers of people with Down syndrome. Indeed, its use of plain language throughout is a defining and refreshing feature for a book tackling a complex subject.

The authors have organised the book into four main sections, following a beginning focussing on staying mentally well. These sections are: dealing with life events, challenging behaviours, personality problems and finally, mental illness. Each section of the book features simple descriptions of the topic, strategies for dealing with the situation (often with summary tables) and lists of references for further reading. These are very useful features of the book and considerably aid in the readability of the text. In a book with no diagrams or other visual prompts, the tables provide a concise summary of the text and would be a useful support for readers.

The opening chapter presents clear guidelines to establish habits that can assist people with Down syndrome, and indeed anyone, to prevent mental health disorders. This would have been a useful place to discuss what mental health might look like for people with Down syndrome. Also, there is value in assisting all people, including those with Down syndrome, to develop ways to express feelings.

Chapter 2 begins the move to areas of concern, discussing the effects of life events. Here was an example of one of the considerable strengths of this book – the case stories. In this chapter, readers are introduced to Naomi, a woman who has had to deal with more than her fair share of life's challenges. The power of this story is perhaps in sharing a rarely heard life experience for a person with DS. Fortunately, most of us don't have to cope with drug abuse and prostitution, however, this vignette reminds us that people with Down syndrome can experience the full range of life experiences and can also overcome considerable difficulties, as well.

Challenging behaviours are dealt with in chapter 3 from the

perspective of inappropriate ways developed to meet needs. The challenging behaviours discussed are: aggression, eating disorders, emotional abuse, conduct disorder, self-injury, and sexual behaviours. As for the rest of this book, these behaviours were considered in a straightforward, non-judgmental way. In particular, the discussion of sexual behaviour was sensitively raised and would be of considerable reassurance to parents dealing with this issue. Of less assistance would be the section on aggression. The only strategy suggested for dealing with this very troubling behaviour was 'time-out'. This approach was explained for a young child, an age where it may be successful. However, aggression is much more troubling in adolescents and adults. As I was reading this section, I had in mind the 15-year-old son of a friend of mine. This young man with DS was reacting to considerable tension in the family home with violence towards his mother. There would be no way the mother would have been in a position to put her son in 'time-out'. I cannot see this section being of assistance to her. Likewise, the mother who asked me for help with her 13-year-old daughter who had pulled a knife on her, needs more age-appropriate 'first aid' suggestions prior to seeking professional help.

In dealing with the complex area of personality problems addressed in chapter 4, the authors take the view that there is a range from normal to aberrant behaviour. This is a helpful approach in allowing readers to be reassured that most behaviours do not need professional help, while offering suggestions for those that do. Unfortunately, the authors have attempted to distil this complex area into a short chapter, and this has not been particularly successful. For example, the spectrum of tidiness is reduced to: overly tidy could be obsessive-compulsive disorder, overly untidy could be schizophrenia. It would have been more helpful to acknowledge extreme untidiness can be an indicator of many mental health disorders, including schizophrenia. There are more obvious indicators of schizophrenia than untidiness,

## Book Review

including hallucinations (as described in the chapter 5).

This book provides few in-text references, which does aid the readability of the material. It is therefore somewhat surprising that one of the few references is to an extended exposition of a contentious theory espoused by Jaynes (1976) to explain inner voices. Far more helpful would have been to discuss the difference between normal metacognitive activity where language is used to moderate behaviour and abnormal auditory hallucinations. A very common, normal behaviour of many adults with DS is 'self-talk' (Glenn & Cunningham, 2000). Unfortunately, parents and carers can become concerned about this behaviour and some health professionals have regarded the behaviour as pathological, even prescribing medication. The authors do deal with this behaviour but not until the end of the book and as part of a description of what is not schizophrenia. It is my view that many carers will pick up this book for reassurance about self-talk behaviour. The normality of talking out loud even to imaginary friends could have been raised here to reassure readers.

The final chapter deals with serious mental illnesses and provides a useful summary of key features of three common disorders: major depressive disorder, bipolar disorder and schizophrenia. This chapter provides a succinct discussion of these disorders, providing advice about possible treatments and how to obtain them. There is a passing reference to the challenges of distinguishing Alzheimer's disease from mental illness, particularly depression.

This small book is likely to find its way onto the bookshelves of parents and other carers of people with Down syndrome, providing reassurance as well as ways to obtain the correct treatment when needed. The authors have taken obvious care to present a highly readable book with international relevance.

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# Submitting a Paper to Down Syndrome Quarterly

DSQ will publish papers that advance the understanding of Down syndrome in all areas of science, education, health care and practice. Articles must be comprehensible to a broad audience, including researchers, practitioners, and families of children with Down syndrome.

**Three categories will be considered for publication:**

## **1. Research**

Articles reporting original clinical, educational, psychological, or basic science findings and contributing to the international literature in their respective disciplines. Manuscripts should contain a clearly written abstract, including background, methods, results and interpretation (summarized in tabular format where possible), and discussion concerning application of the findings as they apply to Down syndrome. Suggested length is 2500 words, excluding the abstract, figures, tables, and references.

## **2. Practice**

Articles directed at practicing clinicians and educators. These may include case reports on teachings, brief educational reviews of a focused problem, or short descriptions of innovative programs and preliminary findings. Suggested length is 2500 words.

## **3. Review**

a. Scholarly evidence-based reviews of topics relevant to practice. Systematic reviews should attempt to answer a focused question. Suggested length is 2500 words, excluding abstract, tables, figures and references.

b. Narrative reviews provide readers with a synthesis of the existing literature in a particular field and are prepared by experts with a comprehensive understanding of the research area. Authors should discuss the application of existing evidence to practice. Suggested length is 3000 words, excluding abstracts, tables, figures and references.

Manuscripts should be prepared either according to the standards set out by the International Committee of Medical Journal Editors (ICMJE), found in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication, or according to the format specified in the Publication Manual of the American Psychological Association (APA) (5th Ed. 2001). All information regarding ethical considerations and manuscript preparation and submission can be found at the ICMJE website: <http://www.icmje.org/> or at the APA website: <http://www.apa.org/>.

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