The participation of children with multi-sensory impairment in person-centred planning

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Consultation with pupils with learning disabilities through the use of person-centred planning methods is becoming increasingly common. However, little research has focused on pupils with multi-sensory impairment (MSI). Kim Taylor has taught children with special educational needs for over 25 years and holds a post-graduate diploma in multi-sensory impairment. In this article, she suggests that the characteristics of MSI affect the capacity of some pupils to participate in person-centred planning. Kim Taylor presents case studies in which she investigates the impact that the characteristics of MSI have upon adults’ abilities to elicit the views of children with MSI about their experiences in the classroom. The article provides an analysis of the factors that maximised the children’s involvement and participation and a commentary on the trustworthiness of the outcomes of the consultation processes described. At the end of her article, Kim Taylor commits herself to implementing improved approaches in the classroom and calls upon other practitioners to follow her example.

Key words: learning disabilities, hearing impairments, visual impairments, planning, participation.

Introduction
Enabling children’s participation in their own reviews, and allowing them to express their views, has become an important feature of government legislation in all services for children, including schools (DfES, 2001, 2004). Annual reviews for students with Statements of special educational needs must seek to take account of the students’ views. Many schools are developing reviews based on person-centred planning models (O’Brien & O’Brien, 2002); however, little attention has been paid to how these models can be meaningfully applied to students who have significant and multiple disabilities, such as multi-sensory impairment (MSI). Therefore, this study addresses two specific questions, namely:

- How can children with MSI participate in person-centred planning reviews?

- How do the characteristics of MSI impact on this process?

Person-centred planning
Person-centred planning is a process that uses a variety of different methods to include the views of people with severe disabilities and plan with that person how they wish to live and be supported both now and in the future (Kincaid, 1996; O’Brien, 2004). It places individuals with learning disabilities at the centre of the planning process and seeks to enable them to identify their needs and aspirations with the support of others who are important to them, and to generate creative solutions in order to deliver individualised services (Routledge, Sanderson & Greig, 2002).

Person-centred planning has been developed in services for adults with learning disabilities and is supported by governmental guidance and legislation in this area, such as Valuing People (DoH, 2001), which requires that this approach is made available within England and Wales. It is increasingly being used in school settings within reviews, particularly with regard to transition planning. Sanderson (2004) describes different methods that may be used both to gather information prior to a transition meeting and to elicit information and produce an action plan at the review. These include involving the family and other ‘circles of support’ in order to identify what would be a good or bad day for the focus person, and keeping a written record of what is working or not working from the person’s perspective, the school’s perspective and the family’s perspective. Sanderson suggests that this can enable those at the review to see the focus person differently with the result that a clearer picture will emerge of what he/she wants.

Consulting disabled children
A variety of methods have been developed to attempt to elicit the views of young people with disabilities. These include the use of cue cards (Lewis, 2002), graphic facilitation (Hayes, 2004) and ‘Talking Mats’ (Brewster, 2004; Cameron & Murphy, 2002; Germain, 2004), where participants move symbols about on mats as a means of indicating their preferences. All of these approaches can – for people for whom pictures and symbols are meaningful, and who can understand the options and process – be powerful and useful tools.
Other researchers have specifically investigated how the views of students with profound and multiple learning disabilities (PMLD) may be elicited, and some of the issues and difficulties that can arise have been identified. Porter, Ouvry, Morgan and Downs (2001) discuss how the early levels of communication of such students, involving reflexes, actions, sounds and facial expression need to be correctly interpreted and validated by the different people living and working with that student. Wheadon (2003, 2004), while welcoming the development of consulting with people with intellectual disabilities, questions if it is realistic for students with PMLD to participate in consultation processes. She further identifies that though simple preferences might be expressed in the ‘here and now’, this cannot be taken to be an expression of views for the future, and that the interpretation of such students’ behaviour is highly inferential. This last point is supported by Thurman, Jones and Tarleton (2005) who point to the: ‘inevitable ambiguity in ascribing meaning to people’s communication’ (Thurman et al., 2005).

Reid and Green (2002) found that carers and workers working with people with severe learning disabilities were not always accurate in identifying preferences and conclude that considerable research is required on how to identify accurately preferences that affect comprehensive aspects of the lives of individuals with severe multiple disabilities. An investigation into consultation with children with autism spectrum disorder (ASD) (Preece, 2002) shows how characteristics of ASD such as inflexible thought processes, lack of personal insight and dislike of change impacted on the ability of children with ASD to participate in meaningful consultation. This points to similar problems that learners with MSI might have, where the difficulties involved with accessing information, communication, sensory impairment, mobility and relationships might inhibit the process of meaningful consultation with such learners.

It can therefore be seen that the literature regarding consultation with children with disabilities raises more questions than answers. What of the literature focusing more specifically on individuals with MSI?

**Consultation and MSI**

Multi-sensory impairment is the term used for a spectrum of conditions, including – but not limited to – individuals who are deafblind or have hearing and visual impairments as well as physical impairments and learning disabilities (Aitken, 2000). Individuals with MSI experience numerous difficulties in many areas of daily life. The literature (McInnes & Trefry, 1982; McInnes, 1999; Aitken, 2000) suggests that the characteristic areas of difficulty in MSI can be broadly summarised and grouped as follows:

- communication;
- accessing and finding out information;
- relationships;
- mobility and orientation;
- use of senses;
- cognitive abilities.

Aitken and Millar (2002) identify the deleterious effects that a visual impairment as well as additional difficulties can have on ability of affected individuals to communicate. These include: a reduced and confused experience of the world, becoming passive and isolated, and the tendency to be echolalic or repeating the last word said to them, all of which limit their ability to make choices. Aitken and Millar (2002) also highlight the effects of hearing impairment on individuals’ communication, including isolation from information and from other people. A physical impairment in association with communication difficulties will also present additional challenges. The child with MSI has all these difficulties compounded.

Granger and Rose (2003) discuss what consultation with people with MSI means and entails and they raise important issues. Even where a person with MSI can use speech, it is important to know how to present questions to them and to establish whether their responses have been correctly understood. At the other end of the communication spectrum, although an individual person may be able to express likes and dislikes relating to what is happening at a particular moment, these forms of consultation will need to be repeated in order to make sure that their responses consistently relate to an activity or experience and not to general feelings on the day. Grainger and Rose (2003) recognise the importance of place, environmental factors and relationships with others who can validate the communication of the person with MSI.

A small number of authors have focused on the use of person-centred planning with individuals with MSI. Morgan, Bixler and McNamara (2002) focus on adolescents with MSI and their rights to self-determination. They state that parents and educators may limit opportunities for people with MSI by restricting independence in choice-making and making all decisions for them in an atmosphere of ‘knowing best’. Morgan et al. (2002) recommend the use of person-centred planning approaches and curricula that teach self-determination skills – such as independent choice-making – to young people. Unfortunately, they do not suggest how the preferences of these young people are identified, just that they should be.

Wiley (2004), Bellah (2004) and Nelson (2005) all consider the use of person-centred planning in this area. They describe the outcomes of such planning with young adults with MSI, with the parents, intervenors (specialist workers whose role is to enable the child to learn compensatory means of accessing information from the environment that would normally be gained through hearing and vision (Sense, 2004)), teachers and service providers and other members of the family being asked to contribute to the process of determining the young person’s preferences. However, these authors do not indicate if or how the young people themselves communicated their preferences. Todd (2002) discusses how person-centred planning is being adopted as an ideology by Sense (the UK organisation for people with MSI) and suggests that for those people with no formal means of communication, the close observation...
of what such people enjoy or dislike is the starting point for planning a more person-centred lifestyle.

The literature to date is unclear as to how individuals with MSI can participate in person-centred planning. In the main, the results of third party observation, carried out by those who have a close relationship with the person with MSI, are presented as representing that individual’s views. In this study I investigated whether more direct methods could be used in conjunction with observation to identify whether meaningful information can be obtained, and how the characteristics of MSI impacted on the process.

**Methodology**

The research questions of this study were addressed by studying three linked cases.

**Choice of sample**

The study was undertaken using three students from my class. They were not randomly selected, as I wished to include students who were illustrative of the range of pupils described as having MSI, and who communicated in very different ways, so that a variety of consultation methods could be investigated.

**Ann**

Ann was 14 years old. She had cortical visual impairment (CVI) and epilepsy. Ann had a functional hearing impairment due to her difficulties in interpreting sound. She had no speech but had limited intentional communication through facial expression, happy or crying vocalisations, and gesture such as reaching for objects. She had an intervenor to facilitate access to her environment.

**Bill**

Bill, also aged 14, had quadriplegic cerebral palsy, which caused weakness in all limbs, and epilepsy. His left arm and hand had some useful function for picking up objects, signing and gesturing. He had bilateral optic atrophy and was registered blind, with some useful vision in his left eye. He also had a conductive hearing loss. Other people communicated with him mainly through speech, objects and signing on the body, and expressively through sign, gesture, and vocalisation. He used a voice output communication aid (VOCA) to relay messages from home to school and to make some choices.

**Charles**

Charles, aged 12, had bilateral optic atrophy and was registered blind. He presented as highly sensitive to normal sounds and exhibited distress and head-banged in response to some sounds. He was verbal with a good memory and would talk to and ask questions of any adult in the room.

**The consultation process**

The first stage in designing the consultation process was to identify what questions to ask. Person-centred planning can involve all aspects of the individual’s life; in this study however, I concentrated on the area in which I was involved through my work as the children’s teacher – their experience of the school day.

The areas of questioning were identified through reference to the literature concerning person-centred planning, including *Listen to Me* (USARC/PACE, 1996); Smull and Sanderson (2005); and the Sense assessment framework (Sense, undated). This identified six areas of questioning, which I used in this study:

- What do I/don’t I like to do at school?
- What do I/don’t I like to eat at school?
- What is my day (morning/afternoon) like at school?
- Who is important to me at school?
- What are good things about me?
- What would I like to change at school?

Having identified what to ask, the next stage was to establish how the students would be asked. In each case, the consultation process was individualised.

**Ann**

The literature suggests that for a student such as Ann the most appropriate consultation method would be to use third party evidence from significant people in her school life. A questionnaire was designed, with the questions worded for the third party to answer as if from the student’s own perspective – that is, the third party had to try and put themselves in the student’s place and write the answers from their point of view. This was completed by her class teacher, other teachers, her intervenor, other classroom assistants and her lunchtime supervisor.

This research tool was also used to collect third party evidence from significant others regarding Bill and Charles. The use of multiple methods of data collection is important to facilitate triangulation, thus maximising validity and reliability (Detheridge, 2000).

**Bill**

To consult directly with Bill, I employed a variation on the Talking Mats concept (Cameron & Murphy, 2002) to enable him to express his likes and dislikes. Bill did this (loudly and forcefully) when participating in activities. I wanted to identify whether he could express his views when not engaged in the actual activity. While he had some residual vision and seemed to recognise functional objects, he had not shown any recognition of pictures or symbols. I therefore decided to use real objects and the objects of reference for the lessons to ascertain whether he could express his likes or dislikes. I used two Big Mack Communication Aids programmed with a response:

- ‘I like it, mmm.’
- ‘I don’t like it, yuk.’

In the first consultation, different food items were used; in the second, the objects of reference for the different lessons/activities were used, and Bill was asked what he thought about them. I presented him with one object at a time,
together with the two Big Macks. Two trays, rather than mats, were used to put the objects into, as this facilitated his placement of the objects. The consultation was carried out in the classroom when the other staff and students had gone to the sensory room. Bill was asked whether he wanted to go to the sensory room, or ‘work with Kim’: he chose to ‘work’. Consultation was undertaken on two separate occasions, for about half an hour each time.

Charles
I consulted with Charles by interviewing him verbally. This took place in the classroom in order to be in the natural setting and to ensure that Charles was comfortable. The consultation sessions were recorded on a cassette recorder. The interviews were semi-structured and covered the same six general areas as used in the staff questionnaires, but with freedom to sequence and word the questions as appropriate. After the first consultation session the wording of the questions was restated and a second consultation session was carried out three weeks later.

Consent
Informed consent was obtained from the parents of the three students. Permission to carry out this study was also obtained from the headteacher of the school. In addition, Bill and Charles, the two students participating directly in the research, were asked at each consultation if they would answer some questions about school. Their consent was treated as an ongoing process (Marchant, Jones, Julyan & Giles, 1999) thus giving them control over when the sessions ended. Bill was able to put up his hand to sign ‘stop’ whenever he wanted to stop answering questions by using the Big Macks and objects. In practice, he appeared to enjoy the activity and it tended to be me who drew each session to a close. Charles was able to say when he wanted to stop the interviews. In practice, a natural conclusion happened after about 20 minutes of conversation. Ann participated only by being observed.

Results
Data were collected in all three case studies regarding the consultation process and its effectiveness and each student’s daily experience in school. These were examined in the light of the characteristic areas of difficulty in MSI, namely:

- communication;
- accessing and finding out information;
- relationships;
- mobility and orientation;
- use of senses;
- cognitive abilities.

The findings are summarised below.

How do the characteristics of MSI impact on our ability to involve people with MSI in person-centred planning?

Communication difficulties
Difficulties in communication affected the consultation process for all three students. Ann, being non-verbal and lacking any formal or symbolic means of communication, was most obviously affected, as all consultation was carried out through third party observation of her behaviour which can be highly inferential and potentially inaccurate (Ware, 2003; 2004).

Bill had some signs, gestures and vocalisation and understood simple language. He could participate to a limited extent in the consultation process and provided information in two of the six question areas. He was limited to answering closed questions – ‘yes/no, like/don’t like’ – and was unable to explain his answers or provide more abstract responses.

Charles responded verbally to some questions but the consultation process highlighted several communication difficulties. Although he could speak in sentences and phrases in the classroom, much of his conversation seemed to be linked to routine activities, with the same phrases being repeated whenever the activity occurred, for example, ‘stick Peter and the Wolf on’. Within the consultation process, his responses were often limited to ‘yeah’ or single or two words responses, with some short phrases. Sometimes he gave appropriate reasons for disliking activities; at other times he gave the same answer as a reason for both liking and disliking something, not seeming to understand the question. Charles’ grammar was sometimes immature, for example, he remarked: ‘Thursday, I done the balloon song’, and some answers were factually inaccurate, such as talking about people ‘in the classroom’ that were actually from his primary school.

In the second interview, when Charles was asked about what he liked about the curriculum area personal and social development, he began to give the same answer he had given before – ‘cleaning teeth’ – which at the time of the first interview was the most recent activity he had done in that lesson. However, he changed his response to ‘the foot spa’, which was the last thing he had done in his personal and social development lesson before this interview. This raises the question of whether Charles tended to simply identify the most recent activity as the one he liked most, thus highlighting the importance of triangulation of responses with other sources in order to ensure accuracy.

He also tended to refer to himself as ‘you’ and ‘Charles’, although he did sometimes say ‘I’. This tendency to confuse the use of personal pronouns and one’s own name is identified by Strickling (2003) when discussing the delayed development of self-concept in blind children.

Accessing and finding out information
Students with MSI have limited experience of the world owing to the reduced and possibly distorted visual and auditory information they receive (Aitken, 2000). Charles demonstrated a lack of understanding about the microphone being used to record his interviews. He was familiar with microphones being employed to amplify sound in
the school hall for the Harvest Festival and creating ‘feedback’: the presence of the microphone on the table was distracting, as he seemed to expect it to cause feedback. Both Charles and Bill were most likely to be able to express preferences with regard to concrete subjects, such as food.

Social relationships
Developing close, stable relationships can be problematic for children with sensory impairments and their difficulties are compounded by the additional disabilities they may have. Mclnnes and Treffry (1982) discuss such children: ‘extreme difficulty in establishing and maintaining interpersonal relationships’ (Mclnnes & Treffry, 1982).

Best (1998) suggests that children with MSI should have a limited number of contacts in order to learn to understand through a consistent approach. Ann had an intervenor with whom she mainly worked at school. Third party opinion might differ depending upon whether Ann was observed undertaking an activity with her intervenor or with another staff member.

Bill seemed to associate different people with particular activities and he allowed certain people to undertake particular procedures if he felt safe with them. This could make it difficult to ask him about liking or disliking particular people at school using the ‘Talking Mats’ approach described above. Furthermore, having carried out two consultation sessions with me in the classroom, he might only have wanted to undertake this activity with me in the future.

It is possible that Charles’ most important relationships were those made at his primary school and that is why he frequently answered questions with reference to people and activities from this school. He also had difficulty recognising his emotions and saying how he felt.

Mobility and orientation
Charles’ recurrent references to people and activities from his primary school (two years earlier) raised the possibility that – being blind – he did not realise that they were two different schools, separated by some miles. Travelling to and from school on school transport may impact on his understanding.

Use of senses
Bill would feel and smell items such as food and feel the objects of reference as well as look at them before answering questions about them. This did, however, restrict the consultation process to concrete subjects. Charles was very distracted by extraneous noises during the interviews, including doors closing, people talking in a different classroom and the computer. Being blind, he received most of his information through his hearing; his over-sensitivity and inability to ‘switch off’ any background noise seemed to impact adversely on his learning.

Cognitive abilities
Structure and routine are frequently used with people with MSI as tools to aid anticipation and understanding and provide a safe and predictable learning environment (Hodges, 2000; Porter, Miller & Pease, 1997). Charles, a week after the second interview, was overheard ‘role-playing’ another interview – saying: ‘I’m just going to ask you a few questions’, and then giving the same answers as before. This suggested that he had internalised and remembered the questions and answers and that he would be likely to anticipate them again. It seemed that he had made a routine out of the process, that he would always expect the same sequence to be followed, and that it would be unlikely that any more meaningful information would be elicited through further interviews at this time. Conversely, the fact that routines provide a safe environment to learn in could have meant that Charles might feel more secure in the interview and provide more information. If the research had been carried out over a longer period of time, this could have been put to the test. However, based on my experience of Charles’ tendency to become ‘stuck’ in a routine, I felt the former, unhelpful outcome was the most likely.

Discussion
Can we meaningfully elicit information about the experiences of young people with MSI from their perspectives – and how?
As the literature review identified, third party observation is the general tool used to elicit the views of children such as those in this study. However, I believe that the results and analysis reported here not only identify the limitations of reliance on proxy information but also show that – in some cases – children with MSI can meaningfully contribute in consultation processes and that we can gain insights into their experience from their contributions. I will now move on to consider what I learned through the process of consulting with these children.

Increased understanding of children as individuals
I had taught in this class for over a year and felt I knew the students well. However, the change of perspective required by the person-centred approach that was used to carry out this study, and having to focus in depth on these three students, taught me a lot about them as individuals; and I was surprised by much that I learnt.

Bill
During this study it became clear that Bill, who had not previously shown any recognition of photographs, was able to use his residual vision to recognise some two-dimensional images when they were presented as ‘true object-based icons’ (Stokes, 2001) created by cutting around the shape of an object in a photograph. I was also surprised by his ability to answer questions outside their direct context and by his ability to press the Big Macks to say whether he liked activities or not and to put objects in a tray to express his opinions.

As well as finding out information about Bill’s ability to participate in consultation, I also broadened my understanding of his likes and dislikes, gaining knowledge that would not have been obtained using only proxy responses.
Bill identified strongly that he enjoyed teeth cleaning and cooking, neither of which were identified by any staff as preferred activities. This supports Reid, Everson and Green’s warning (1999) regarding the potential dangers of relying solely on third party data.

**Charles**

The data I obtained from Charles was in part limited by my inexperience as an interviewer and my uncertainty in knowing how to phrase the questions to him. At times I asked questions in a more complicated way than necessary, causing misunderstanding. It might have been helpful to have had a different person from the class asking the questions, or to have obtained the support of a speech and language therapist to advise on phrasing questions in a relevant way. The second interview did not elicit much new information and succeeded only in getting the same answers. The use of a wider range of communication supports, such as objects of reference, with Charles might help to focus his attention on different activities.

**Ann**

Thurman et al. (2005) warn of the responsibility that we all have in interpreting the responses of people with high individual communication needs. The use of third party observations for Ann showed that proxy reports could only be considered as being from her own perspective when sufficiently evidenced. The staff completing the questionnaires were often inferential or voiced their own opinions, especially in the section ‘What would I like to change at school?’ This reflected previous similar findings by Ware (2003, 2004).

**What supported effective consultation?**

Though there are clear limitations to this study, I feel that meaningful consultation did occur. The factors that helped maximise effectiveness are similar to those identified by Granger and Rose (2003) and are outlined below.

**Individualisation**

All three students had a Statement of special educational needs highlighting their multi-sensory impairment. However, all three students were very different in their communicative, cognitive and social abilities and it was necessary to assess each student’s strengths and weaknesses in order to individualise the consultation process for them, as no single method was suitable for all the students.

**Use of appropriate communication supports**

Real objects, objects of reference and true object-based icons all proved to be useful and appropriate communication supports for one of the students. The use of VOCAs was also helpful and motivating. I did not include a Big Mack and symbol to indicate ‘I don’t mind’ as is used with the Talking Mats approach (Cameron & Murphy, 2002) as I felt this would be too confusing for Bill.

The provision of an intervenor was highlighted by all staff as benefiting Ann. The intervenor gave more evidence-supported information in her response to the questionnaire about Ann than any other member of staff. Finally, appropriate and effective phrasing of questions was important for both Charles and Bill.

**Prior knowledge of the children**

It was important that the people carrying out the third party questionnaires, and the person carrying out the interviews had prior knowledge of the students. This was necessary in terms of:

- putting the students at ease;
- understanding the students’ communication;
- interpreting the students’ moods and responses.

During consultation, Bill had a habitual tendency to throw objects and this overrode his ability to use them to identify whether he liked the activities to which they referred. This prolonged the process, as each time this happened the object of reference was returned to him and he was asked the question again. It was helpful that someone who knew Bill was carrying out the consultation – someone unfamiliar with his habits might have concluded that he did not like these activities, rather than that this was a habitual behaviour. Equally, the interviews with Charles would have been more difficult had an unfamiliar person interviewed him. It was useful that, as Charles’ teacher, I knew what he was talking about during the interviews. An interviewer unfamiliar with Charles would not have recognised factual inaccuracies in his responses.

**Environmental factors**

It was also important that the interviews took place in an environment where the students felt comfortable, which in this case was their classroom. Issues of distractibility were reduced for Bill by him being interviewed on his own when the rest of the class had gone elsewhere. He was aware of where they had gone and was happy to stay behind in the class. For Charles, other noises in the classroom proved quite distracting, both from other students and noises from outside the classroom. This would need to be addressed in future consultations for his annual reviews.

**Triangulation**

The information obtained directly from Charles and Bill was limited and sometimes inaccurate. Triangulation through third party questionnaires and other school records and observations is essential. However, even if a student cannot give answers in all the different areas of person-centred planning, this does not mean they cannot express views in some areas. Partial participation is still significant and valid and worth the investment of time and effort required.

**Time and resources**

Finally, it must be acknowledged that consulting with children with MSI is complex and time consuming. Sufficient time needs to be given both to carry out the consultation and to develop appropriate individualised resources – if the process is to be more than a token gesture.

**Limitations of the study**

It is not suggested that generalisations can be drawn from this study. The sample group of three students was small,
and they were not necessarily representative of students with MSI, which can encompass a very broad spectrum of needs. Indeed, due to the highly individualised nature both of individuals with MSI and of case study research, it might be difficult to draw valid generalisations even with a larger sample.

Further limitations include the brevity of the study. A longer research period would have allowed more fine tuning of the questions asked and the methods used. For Bill in particular, there would need to be a period of learning new skills associated with the consultation process, in order to extend consultation into the other question areas.

The study took place in the last half of the summer term, when individual holidays interrupted the consultation process for two of the students and end-of-term activities resulted in disruption of the normal timetable. It was also not possible to go back to the staff respondents to clarify anything they had written down on the questionnaires. Carrying out the study at a different time of year might have been helpful.

Finally, the study is limited by my own individual, personal perspective and by my own individual limitations as a researcher and in engaging with these children. Further research needs to be carried out to ascertain whether the conclusions drawn from this study would hold for research undertaken by other researchers, in different settings and with children at different points on the MSI spectrum.

Conclusions
This study was undertaken to answer the research questions:

- How can children with MSI participate in person-centred planning reviews?
- How do the characteristics of MSI impact on this process?

A number of factors that affect the ability of the children with MSI within the sample group to participate within person-centred planning processes are identified. However, from the analysis of the data collected, I also suggest strategies and tools that might enable the wishes, views and opinions of children with MSI to be better understood. I will be using these approaches within my own practice and setting and would welcome feedback and comment from other practitioners in the field.

It is clear from this study that using these strategies and tools is time-consuming, requires resources and can be difficult. However, if person-centred planning is truly to enable people with MSI more fully to lead the lives that they want, as Todd (2002) suggests, then these efforts are necessary.

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Manuscript submitted: December 2006
Accepted for publication: August 2007